THE AMBIGUITY OF HIV RISK IN PRE-EXPOSURE PROPHYLAXIS (PREP) ADMINISTRATION IN NEW YORK

By

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ABSTRACT

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"Risk" has become a ubiquitous concept in American healthcare settings, drawing both on objective biostatistics and on subjective, morally-charged interpretations. In particular, past epidemiological categorizations of a patient's identity or behavior—like their race or sexual practices—as "risk factors" for contracting HIV has promoted the sociocultural interpretation of HIV risk and stigmatized individuals in those groups. Nonetheless, with the advent of the pharmacologic Pre-Exposure Prophylaxis (PrEP) to prevent HIV transmission, such epidemiological categories of HIV risk are being even more broadly applied. The first medication used for PrEP was Truvada (emtricitabine and tenofovir disoproxil fumarate), an antiretroviral manufactured by the pharmaceutical giant Gilead Sciences that was first approved by the FDA in 2004 to *treat* HIV-positive patients and then approved again in 2012 as PrEP to *prevent* HIV infection in HIV-negative patients. Currently, the indications for PrEP prescription are impressively broad and vague, allowing much room for interpretation. Given how past identifications of HIV risk factors negatively implicated entire groups of people, there is a significant need to better understand how HIV risk has been conceptualized, how these concepts may be influenced by the interests of public health agencies and healthcare corporations, and how they play out for health professionals and patients in the clinical setting.

In this dissertation, I examine the concepts of HIV risk that come into play in the administration of PrEP, considering how these concepts are understood by individual health professionals and patients alike and how such representations may align with the goals of healthcare corporations and public health agencies. Using ethnographic research techniques, I contrast the perspectives of HIV-negative patients identified as candidates for PrEP, HIV-positive patients, and health professionals administering PrEP to capture how they may understand HIV "risk" and PrEP's role in treating it. I conducted the fieldwork for this dissertation in a New York community health center network that provides PrEP and HIV services to diverse patient populations. I interviewed patients, clinic administrators, social workers, public health workers, and pharmaceutical industry members; observed clinical interactions; reviewed medical charts; and analyzed HIV prevention advertisements, publications, and guidelines. Based upon these collected data, I found that the discourse surrounding HIV risk is ambiguous, PrEP distorts and crystallizes this ambiguity, and structural risk (embedded healthcare structures identifying certain people as "at risk") is a reflective "model *of*" and constructive "model *for*" this process in a top-down direction. In doing so, I draw attention to the social significance of the pharmaceuticalization of risk by showing how pharmaceutical marketing can impact how risk is conceptualized, communicated, and experienced.

In loving memory of my strong and forthright grandmothers, Patricia Ann Andreas, who encouraged me, as a 7-year old, to "kick ass," and Christine Arndt, who said "those poor people," when I told her I wanted to be a doctor.

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KEY TO ABBREVIATIONS

ACT UP	AIDS Coalition to Unleash Power (ACT UP)
AIDS	Acquired Immunodeficiency Syndrome
AIRS NY	New York State Department of Health AIDS Institute Reporting System
ARV	Antiretroviral medications
ART	Antiretroviral treatments
AZT	Azidothymidine [an antiretroviral medication]
CDC	Centers for Disease Control and Prevention
CD4	CD4 immune T cells
CMA	Critical medical anthropology
CNICS	Centers for AIDS Research Network of Integrated Clinical Systems
DTC	Direct-to-consumer
EMR	Electronic medical record
FDA	United States Food and Drug Administration
FTC–TDF	Emtricitabine and tenofovir disoproxil fumarate [the generic of the drug Truvada]
HHS	United States Department of Health and Human Services
HIV	Human Immunodeficiency Virus
HOPWA	Housing Opportunities for Persons with AIDS
HPV	Human Papilloma Virus
ICD-10	International Classification of Diseases, Revision 10
MoCA	Montreal Cognitive Assessment
MSM	Men who have sex with men
NIH	National Institutes of Health

NIAID	National Institute of Allergy and Infectious Diseases
NYC	New York City
NYCHC	New York Community Health Center [a pseudonym for the research site]
NYSDOH	New York State Department of Health
PEP	Post-Exposure Prophylaxis
PrEP	Pre-Exposure Prophylaxis
PrEP-AP	Pre-Exposure Prophylaxis Assistance Program
STD	Sexually-transmitted disease
STI	Sexually-transmitted infection
TAG	Treatment Action Group
TAF	Tenofovir alafenamide [a component of the antiretroviral drug Descovy]
TDF	Tenofovir disoproxil fumarate [a component of the antiretroviral drug Truvada]
USPSTF	United States Prevention Services Task Force
WHO	World Health Organization

Introduction

In current healthcare settings, patients' wellbeing is thought to be constantly attenuated by a continuum of risk (Beck 1992; Lupton 1993). Based upon their characteristics, they are "at risk" of having a heart attack, are "at risk" of developing a certain cancer, and are "at risk" of contracting certain infections, such as HIV. Though defining these "risks" is often rooted in quantitative epidemiologic data of disease prevalence and incidence, their regular use in medical vernacular has allowed room for subjective interpretation of what being "at risk" actually *means* both to individual patients as well as the healthcare providers caring for them (Kreiner and Hunt 2014). While there are many ways of identifying "risk," ambiguous cultural constructions of "risk" have the potential to do great harm to patients by implying a causative relationship between a patient's characteristics—their "risk factors"—and their healthcare outcome (Finerman and Bennett 1994). In particular, past epidemiologically-based categorizations of a patient's identity or behavior—like their race or sexual practices—as "risk factors" for contracting an infectious disease like HIV allowed the sociocultural interpretation of that risk, potentially stigmatizing individuals categorized into those groups (Schiller 1992). A noteworthy example is what happened after the CDC's 1983 Morbidity and Mortality Weekly report stating that those at "risk" for developing AIDS were "homosexuals," "Haitians," "persons with hemophilia," and "intravenous drug users" (CDC 1983). The negative impact on people bearing these identities in the U.S. still reverberate to this day (Spieldenner 2016; Romain and Courtwright 2016).

These concepts of "risk" are not born in a vacuum, however (Beck 1992; Chamberlain 2012; Dean 1998). Rather, a multitude of sociocultural and political economic factors contribute to their construction; factors which are incorporated into models disseminated by public health agencies seeking to reduce disease morbidity and mortality rates and healthcare corporations seeking to turn a profit (Greene 2007, Dumit 2012, Crosswell and Porter 2016). In the context of HIV, the goals of public health agencies and healthcare corporations contribute to the current models of what it means to be "at risk" for the virus, and are incorporated into guidelines for prescribing pharmacologic Pre-Exposure Prophylaxis, or PrEP. The first medication used for PrEP was Truvada (emtricitabine and tenofovir disoproxil fumarate), an antiretroviral manufactured by the pharmaceutical giant Gilead Sciences that was first approved by the FDA in 2004 to *treat* HIV-positive patients and then approved again in 2012 as PrEP to *prevent* HIV infection in HIV-negative patients (Drugs.com 2020) following a series of pharmaceutical trials whose results now serve as the "basis" of public health agencies' recommendations for the use of PrEP (CDC 2018b:14). Currently, the CDC's (2018b) recommendations for PrEP prescription are vague and all-encompassing, being indicated for any patient "whose sexual or injection behaviors and epidemiologic context place them at substantial risk of acquiring HIV infection" (p.14). What is more, the U.S. Prevention Services Task Force (USPSTF) (2019) gave their highest grade, "A," to PrEP in preventing HIV, citing "adequate epidemiologic data on risk factors that can be used to identify persons at high risk of acquiring HIV infection," while at the same time finding "inadequate evidence that specific risk assessment tools can accurately identify persons at high risk of HIV acquisition" (USPSTF p.2204). In other words, though there is sufficient epidemiological data to identify HIV risk factors on the population level, there is little data on how these epidemiological risk factors might be used to accurately identify individuals at risk for HIV, allowing much room for interpretation. Given how the identification of HIV risk factors negatively implicated entire groups of people in the past, there is a significant need to better understand how HIV risk is currently being conceptualized, how these concepts may be influenced by the interests of public health agencies and healthcare corporations, and how they play out for health professionals and individual patients in the clinical setting.

In order to address this need, I use HIV risk in the administration of PrEP as a lens to examine how individual health professionals and patients perceive HIV risk and PrEP. I also consider how these perceptions may align with those of healthcare corporations and public health agencies. Applying ethnographic research techniques, this dissertation contrasts the perspectives of HIV-negative patients identified as candidates for PrEP, HIV-positive patients, and health professionals administering PrEP to capture how they may differentially understand HIV "risk" and PrEP's role in treating it. I conducted the study in a New York community health center network that provides PrEP and HIV services to diverse patient populations. I also interviewed clinic administrators, social workers, public health workers, and pharmaceutical industry members; observed clinical interactions; reviewed medical charts; and analyzed advertisements, publications, and guidelines regarding HIV prevention. By exploring the similarities and differences between perceptions of what it means to be "at risk" for HIV and the role PrEP may play in treating it, I hope to elucidate the ways HIV risk may be culturally constructed and how medication guidelines may reflect and contribute to this.

Summary of Dissertation Chapters

In Chapter 1, "A Critical Medical Anthropology Approach to HIV," I contextualize this research within critical medical anthropological (CMA) literature on the meaning and management of health and disease, specifically HIV, in contemporary biomedical practices. Applying Merrill Singer's contention that "critical medical anthropology is concerned with synthesizing the macrolevel understandings of political-economy with the microlevel sensitively and awareness of conventional anthropology," I accomplish this by examining the significance of biomedical constructions management of HIV on the individual "microlevel" as well as the social and political economic "macrolevel[s]" (Singer 1990:181). By considering CMA perspectives on HIV, this chapter provides background and significance for this research study for an anthropological analysis of how HIV risk is constructed and treated using PrEP.

In Chapter 2, "Deconstructing Constructions of Risk: How HIV Risk is Biomedicalized, Individualized, and Laden with Moral Values," I examine the anthropological perspectives of risk in health and illness, exploring the ways in which "risk" is a cultural construct that reflects collective ideologies defining what is and what is not a threat to societies' values, including bio-social values within the field of medicine (Lupton 1993). Specifically, I focus on how cultural constructs of HIV risk are actualized through processes of biomedicalization, individualization, and moralization with bio-social values and the implications this has for patients, namely those "at risk" for HIV.

In Chapter 3, "Research Design and Methods: Situating HIV Risk and PrEP Administration in New York," I discuss the setting of the research in New York, exploring the historical context of the HIV epidemic in the state and examining the current political and social campaigns to address it. After situating the research within its geographic context, I introduce the research site's location at a community health center network in New York, as well as the researcher's experiences both as a volunteer prior to dissertation research and when returning for this research as a dual medical and anthropology student. Following this, I review the research methods, which include participant observation, semi-structured, open-ended interviews, and analysis of medical records and HIV prevention publications and guidelines. I then explain how the data collected from these methods are analyzed using an iterative, "grounded-theory approach" (Bernard 2006:492) to allow for a more in-depth analysis of HIV "risk" and PrEP's role in treating it.

In Chapter 4, "The Ambiguity of HIV Risk," I examine how patients and health professionals construct and communicate HIV risk. Based upon observations and interviews with patients and health professionals, I break down the discourse of HIV risk into its constituent frames. In particular, I explore the following questions: *What* is HIV risk? *Who* is at risk for HIV? *Where* is HIV risk situated? *When* are persons at risk for HIV? And, perhaps most significant of all, *why* are certain people at risk for HIV? For each of these questions, I develop various themes, such as the pharmaceutical creation of the "Undetectable" HIV status and how deception may affect one's agency in determining HIV risk.

In Chapter 5, "PrEP's Crystallization and Distortion of HIV Risk's Ambiguity," I further investigate how these patient and health professionals situate PrEP address HIV risk. In an echoing response of their ambiguous discourse surrounding HIV risk, I break down their perceptions of PrEP into its materiality (*what*), identity (*who*), location (*where*), timing (*when*), and agency (*why*) to both reinforce and distort HIV risk's narrative components. Notably, I further explore the role of PrEP plays in "risk compensation," the paradoxical phenomenon by which certain harm reduction measures result in some individuals increasing their "risky" behaviors.

In Chapter 6, "Structural Risk," I address the final narrative element of *how* HIV risk's ambiguity is constructed. I propose the concept of "structural risk" to describe *how* ambiguous concepts of "risk" are built, top-down, into the structure of society, specifically health care systems, and how these concepts manifest as an ever-narrowing definition of health and ever-diminishing power of individual health professionals and patients to influence it. More specifically, I investigate *how* HIV risk's ambiguity is constructed in healthcare guidelines, codified in electronic medical records (EMRs), and perpetuated by HIV prevention advertisements. Significantly, I argue that these examples of structural risk enable PrEP use to distort and crystallize HIV risk's ambiguity by serving both as reflective "models *of*" as well an constructive "models *for*" its ambiguous conceptualization (Geertz 1973:93; emphasis in original).

In Chapter 7, "Conclusion," following a summary of the major points of the dissertation, I discuss the implications this study might have for future anthropological research, PrEP administration, and our society as a whole. More specifically, I elaborate upon how this research reflects the pharmaceuticalization of society, calls for more anthropological research to illuminate and disentangle the increasingly intertwined interests of public health agencies and healthcare corporations, and suggests how PrEP administration might be improved upon to better treat the structural factors of HIV risk.

Chapter 1: A Critical Medical Anthropology Approach to HIV

HIV is a virus that not only infects human cells on the microscopic level, but also affects and is affected by individuals' experiences and relationships, sociocultural processes, and political economic structures. Though biomedicine's approach to HIV centers on its molecular mechanisms and interpersonal routes of transmission, it still impacts these broader social and political levels.

In this chapter, I will review critical medical anthropological (CMA) approaches that assess the meaning and management of health and disease, specifically HIV, in contemporary biomedical practices. Applying Merrill Singer's (1990) contention that "critical medical anthropology is concerned with synthesizing the macrolevel understandings of political-economy with the microlevel sensitivity and awareness of conventional anthropology," I will accomplish this by examining the significance of biomedical constructions management of HIV on the individual microlevel as well as the social and political economic macrolevels (p.181). More specifically, I will consider how CMA perspectives unveil the ways biomedicine's constructions and management of HIV implicate HIV-positive and HIV-negative individuals, their sociocultural interactions, and the political economic structures in which they take part. By exploring this anthropological approach to understanding biomedical constructions of HIV, I will show how CMA's perspective is ideally positioned to analyze how such constructions may influence understandings of HIV "risk" as well.

The Impact of Biomedical Constructions of HIV on Individuals

Regarding the significance of HIV on the individual level, the CMA approach shows how biomedicine's construction of HIV and its management shapes individuals' experiences of being

"HIV-positive" and the way this label affects how they see themselves—their very sense of identity.

While biomedical research prioritizes the scientific discovery of the mechanistic processes by which HIV enters the human body and embeds its DNA within the human genome (Martin 1990), it has neglected, to a great extent, the cultural processes by which HIV becomes entwined with an individual's identity and experiences. Arthur Kleinman (1995) discusses how biomedical practices "discount the moral reality of suffering—the experience of bearing and enduring pain as a coming to terms with that which is most at stake, that which is of ultimate meaning, in living—while affirming objective bodily indices of morbidity" (p.32). Several anthropologists have challenged how biomedical constructions of HIV, too, deny the "moral reality" of HIV-positive individuals' suffering. For example, in his autoethnography as an HIV-positive gay man, Andrew Spieldenner (2014) discusses the repercussions his HIV-positive diagnosis has had on his personal and professional relationships. To Spieldenner, the HIV-positive diagnosis is a critical moment at which one's own "body becomes the enemy" (p.23). How it exactly "becomes the enemy," he maintains, may vary by cultural setting; in the gay community, for example, he feels as if being HIV-positive renders him a "point of vulnerability and the infectious agent" with a profound sense of shame at being so "inconvenient and messy" (p.22-3). Disclosure of one's positive HIV status, which he says is often compulsory by public health institutional mandates, complicates this "potent stigmatizing identity" (p.23), and revealing it to others has become "another level of 'coming out,'" which, like sexuality, "can alter an individual's support network, professional life, dating, and goals" (p.17). In other words, to Spieldenner, an HIV-positive status is not merely a facet of his identity limited to one context, but rather is an integral component of his sense of self with the potential to affect every aspect of his life. Given this, how HIV "risk" may also affect individuals' identities then becomes an area of concern.

Though a biomedical perspective of HIV only allows room for a binary serostatus—an individual can only be HIV-positive or HIV-negative—how HIV-positive individuals identify with their serostatus does not necessarily fit neatly into such rigid constructions (Spieldenner 2014). Yelena Tsarenko and Michael Jay Polonsky's (2011) narrative analysis of HIV-positive people in Australia sheds further light on how having an HIV-positive diagnosis does not readily lend itself to an individual's HIV-positive identity. Referring to their study participants' HIV-positive diagnosis as the acquisition of an "undesired possession," they contend that each person underwent an identity transition upon discovering their positive serostatus (p.466). Moreover, they maintain that the extent to which each person reconstructed their identity reflects the degree of their "ownership" of their "undesired possession," which, in turn, determine "if people perceive themselves to be in control, or powerless" (p.478). Without consideration of each individual's unique socioeconomic barriers that might make doing so difficult, they argue that an individual must "own" their HIV status in order to "liv[e] positive" with their HIV illness (p.475). This dissertation will further explore how HIV risk creates an entirely new HIV status and the extent to which individuals may identify with that or not.

Additionally, the biomedical perspective of an individual's experience being HIV-positive often focuses on the viral infection exclusively instead of considering the personal loss the serostatus might signify for patients (p.466). Andrew Irving's (2011) innovative research combining participant-led ethnography and photography explores this sense of loss by capturing how HIV has affected the "inner life worlds" of HIV-positive Ugandan women and how, in turn, these "inner expressions" interface with their external environments. He documents their narratives as they physically re-walk their journeys from the clinics where they first received their diagnoses to their respective homes, including the photographs they take to capture the locations, exteriorizing significant emotions they had felt along the way. Based upon the women's physically contextualized narratives and photographs this technique elicited, Irving identifies a "strange distance" between the women's imagined lives if they had remained HIV-negative and the true events they endured since becoming HIV-positive. Irving says when analyzing one of the women's narratives,

> "The strange distance between the material conditions of the present and the imagined, alternative lifestyle creates an ongoing, comparative moral framework for interpreting her daily practices and current life circumstances, suggesting that to understand people's lives and experiences it is necessary not only to consider people's immediate situations and material conditions but also the other lives they could have, and do, live through their inner voice, fantasies, and imagination, while negotiating the emergence and closure of different possible life paths" (p.36-7).

Irving's findings convey that biomedicine's binary of HIV-positive and HIV-negative statuses is mirrored by an interlaced division of an individuals' inner narratives into a what could have been and what is. More importantly, however, Irving suggests that considering both of these "life paths"—the fantasized and the realized alike—is critical to understand not only how HIV has contributed to individuals' lives, but also what it might have taken away from them. Another path that has yet to be considered, however, is how HIV "risk" might create yet another life path entirely, which this dissertation will take up.

While biomedicine's construction of a binary HIV serostatus has been shown to profoundly influence how individuals view themselves and interact with the world around them, biomedical treatment for HIV, particularly in the form of pharmaceuticals, also profoundly shapes how HIV-positive individuals experience their disease. Though these improved medications have extended the lives of many HIV-positive individuals, they are not without consequences (Spieldenner 2014:19). Spieldenner describes his experience starting treatment, saying that, for him, “taking medication is a clear sign of downward mobility. Over a decade of publicity on the side effects of medication has encouraged a fear of the pills: I have no desire for uncontrollable diarrhea or lypodystrophy (a condition that causes fat to shift in the body, leaving unsightly lumps on the face, back and gut)” (p.19). For Spieldenner, starting medication signifies “downward mobility” not just because of the adverse side effects the medications may cause, but also because biomedical guidelines at the time recommended an HIV-positive person has to continue taking medication for the rest of their life once they begin treatment. In this way, the adverse side effects of antiretroviral medications extend beyond the physical as HIV-positive individuals must keep regular medical appointments so that their health may be continuously monitored and their medication adherence evaluated. Spieldenner explains that this exacts a toll on HIV-positive individuals because “healthcare is difficult to incorporate into a regular routine, especially if the individual is not accustomed to medical visits, clinic staff, blood draws and adherence to daily medication regimens” (p.19).

Though biomedicine emphasizes individual adherence to antiretroviral regimens as the key for treatment efficacy (Tsarenko and Jay 2011:473), even strict adherence does not guarantee an individual’s health, whether from the development of viral resistance to that medication or deleterious long-term side effects caused by it. Spieldenner (2014) experienced this personally, leaving him “cautious about treatment” and disillusioned of his previous belief that his medication could be a “static process” fixed to his daily routine (p.22). When recounting the impression the experience made on him, he says, “I am part of a dynamic partnership with my doctor and pharmaceutical companies, [and] that I have to pay attention to little changes in my body” (p.22). As Spieldenner infers, his medication is not merely a pill that he takes every day: it symbolizes a complex and changing relationship between himself and his body, his doctor prescribing the medication, and the pharmaceutical companies that produce it. As of yet, however, there is little research on how the new medication to treat HIV risk may affect individuals' perceptions of themselves. This dissertation will help fill that gap.

Though Spieldenner (2014) notes that "living with HIV is not as simple as taking a pill," his personal experiences taking antiretroviral medications are framed by his socioeconomic status as a professional man living in a high-income country with ready access to food and clean water (p.19). Other HIV-positive individuals living in low-income countries do not necessarily have such access, and their experience taking antiretroviral medications is drastically different because of it. Ippolytos Kalofonos' (2010) research on the effects AIDS treatment programs have had in Central Mozambique raises ethical concerns about the provision of antiretroviral medications (ARVs) to populations who have little food with which to take them. In contrast to the lifesaving medications AIDS treatment programs claim to provide, Kalofonos argues that the "unrelenting hunger" many Mozambicans suffer as a side effect of taking these medications without food has "paradoxica[l]," "dehumanizing effects" undermining the truth of such claims (p.364). As one patient exclaimed in an interview with Kalofonos, "I have nothing to eat. All I eat is ARVs!" (p.364). To expand upon the moral connotations "hunger" has, Kalofonos maintains that the "idiom of hunger represents one of the ways that many expressed their disappointment as the new interventions reinforced contemporary realities of diminishing public and social supports" (p.367). In this way, the hunger Kalofonos' informants feel is twofold: resulting both from the lack of physical nourishment and from the lack of the socioeconomic infrastructures to make food accessible.

This injustice is compounded by biomedicine's evolving label of HIV from being an "acute" illness to a "chronic" disease reflecting improvements in the biological efficacy of antiretroviral treatments. As Janet McGarth et al (2014) contend in their research on HIV-positive individuals in Uganda being treated for HIV, this epistemological shift reflects biomedical biases and assumptions that patients have socioeconomic support systems which are not universally present. In contrast to the "sick role" a patient may assume while suffering from an acute disease, McGarth et al maintain that

> "The chronic disease paradigm requires patients to actively manage disease through self-monitoring and ongoing engagement with biomedical care. Therefore, the chronic disease management model explicitly includes the responsibility to self-manage. This requires transition to a role in which one simultaneously has both a 'normal' life and an ongoing disease" (p.306).

What this chronic disease paradigm does not consider, however, is the social and economic hardships that many HIV-positive patients face when trying to self-manage their disease, such as "drug stock outs, lengthy and frequent trips to the clinic," and, consistent with Kalofonos' study, "food insecurity" (p.214). As a result of this, McGarth et al observe that HIV-positive individuals in low-resource settings often are "unable to claim either the sick role or their 'normal' role," instead "occupy[ing] a state of 'social in-between,' compounding their social and economic vulnerability" (p.314).

To summarize, CMA perspectives reveal how biomedical constructions and management of HIV—particularly its neglect of HIV-patients' "moral reality," its reductionist binary of HIV serostatus, and its treatment regimens' lack of consideration of HIV-positive individuals' socioeconomic backgrounds—implicate the personal suffering and experiences of individuals living with HIV every day. This dissertation will expand upon this by analyzing how such biomedical constructions are extended to target the "risk" of HIV for treatment and implicate patients and health professionals alike.

The Social Significance of Biomedical Constructions of HIV

While CMA can elucidate how biomedicine's construction of HIV shapes HIV-positive individuals' experiences, it reaches beyond the individual level to expose how these experiences fit within broader social relationships. To better understand these relationships, I will now consider CMA perspectives revealing the significance of biomedicine's construction and management of HIV on the social level in order to show how CMA is positioned to analyze HIV risk on the this level as well.

One of the main ways biomedical constructions of HIV operate on the social level is through its reinforcement of the social stigma associated with an HIV-positive diagnosis. As Spieldenner (2014) observes, while he confronts stigma in his relationships with his family, friends, romantic partners, and coworkers, he maintains that "stigma is a phenomenon at the structural and social level, so there are some limits to an individual's capacity to mitigate the entire social structure" (p.21). Alternatively put, an HIV-positive individual may experience stigma through her daily interactions at a personal level, but these encounters are part of a larger web of social relationships revealing broader cultural patterns. To analyze the specific patterns of social stigmas associated with HIV, Judgeo and Moalusi (2014) have shown through their research how HIV-positive individuals are made to feel like they are "irresponsible, filthy and immoral" social "'deviants'" in comparison to HIV-negative, moral "'normals'" (p.79-81). Their portrayal of HIV stigma not as a static characteristic assigned to an individual but rather as dynamic language is significant. As a dynamic language, stigma may reflect changing societal values and reinforce the power differentials between individuals' various roles, whether HIV-positive or those who are HIV-negative and are at "risk" for HIV. Judgeo and Moalusi's description of language, though in a different context, is consistent with Chantel Tetreault's

(2015) research on how French teenagers of North African descent use the Arabic speech act *Hashek* to “publicly mark peers as inappropriate or rude” (p.285). Expanding upon this notion, Spieldenner (2014) describes how moral value assignations to serostatus are communicated within the gay community through use of the terms “‘clean’” and “‘dirty’” on online dating profiles “to indicate HIV-status where being HIV-negative is ‘clean’ and HIV-positive is ‘dirty,’ assignations that are obviously value-laden” (p.22). This dissertation will further explore how such labels are applied to those at “risk” for HIV and how pharmaceutical treatment of that risk contributes to such label constructions.

Notably, the social stigma that many HIV-positive individuals feel is often a magnification of biomedicine’s microscopic constructions of HIV as a violent threat to and in violation of the body’s defenses. In her research decoding biomedical scientific texts on HIV and the immune system, Emily Martin (1990) analyzes the use of nation-state warfare analogies to describe the “total war between ruthless invaders” like HIV and other antigens and the “determined defenders” of the body’s immune system (p.411). Many HIV-positive individuals like Spieldenner (2014) seem to internalize this violent imagery, as demonstrated by his feeling that being “HIV-positive presents a *threat* to the personal and communal identities. In the former, having HIV means that you can transmit it. In the latter, having HIV shows that not all gay men are successful and accepted in mainstream society” (p.17; emphasis added). Here Spieldenner conveys how the biomedical construction of HIV as a physical threat extends beyond personal bodies to reveal the vulnerability of social bodies as well. Such threats spanning both biological and social boundaries warrant aggressive responses, as demonstrated President Donald Trump’s use of nation-state warfare connotations when describing his plan “to end” the HIV epidemic by 2030 in his 2019 State of the Union Address, avowing, “Together, we will defeat AIDS in America and beyond" (Goldstein 2019). How such combatant public health plans extend to include the treatment of HIV risk will be further explored in this study.

In spite of such social reverberations of biomedicine's construction of HIV as a biological threat, its perspective remains fixed on microscopic and interpersonal routes of transmission instead of considering the larger, social processes that facilitate them. As Alan Goodman and Thomas Letterman (1998) assert, "[P]eople don't just end up rich or poor, sick or healthy, landed or landless. These all happen for reasons, and those reasons frequently lie upstream" (p.33). Applying this "upstream" view toward HIV transmission, even the social patterns determining sexual interactions may be drawn into question. "With whom one has sex, in what ways, under what circumstances, and with what specific outcomes are not simply random questions," anthropologist Richard Parker (2001) maintains (p.69). Rather, sexual practices are determined by "issues such as 'class,' 'race,' or 'ethnicity' and the other multiple forms" that "structure the possibilities for social interactions across lines of social difference" (p.169). Adding historical depth to this argument, medical anthropologist Daniel Halperin and journalist Craig Timberg (2012) examine how colonialism "structure[d] the possibilities for social interactions" facilitating HIV's spread from Africa. They contextualized this perspective within current scientific research, such as the mapping HIV's phylogenic tree to pinpoint its origins in the Cameroonian jungle via the practice of hunting and consuming chimpanzees (Sharp et al 2001), HIV's extension from Cameroon to Kinshasa via colonial trade and porter routes (Faria et al 2014), its dissemination within Kinshasa facilitated by the colonialism-driven industrial population boom (Worobey et al 2008), and its exportation beyond Kinshasa to other parts of the world, like Haiti and then to the U.S. (Gilbert et al 2007) by the political unrest the fall of colonialism left in its wake (Timberg and Halperin 2012). However, they delve deeper into these scientific claims by analyzing the specific social practices during colonial rule in the Belgian Congo, such as the inhumane treatment of the Congolese men and women, whom the Belgians called "*basenji*," meaning "'savages'" (Timberg and Halperin 2012:58; emphasis in original). For example, Craig and Timberg scrutinize how HIV was quickly spread by Belgians' enslavement of African male laborers in order to build Kinshasa's industrial infrastructures, separating them from their wives, potential partners, and families and limiting their opportunities for sexual interactions exclusively to prostitutes (p.58; emphasis in original).

Timberg and Halperin also discuss the social processes that facilitated HIV's spread within the United States in the 1970s and 1980s, looking more closely at the sexual practices that possibly explain the disproportionate HIV rates among gay and bisexual men. They convey how penetrative anal intercourse between two men is more "efficient" at transmitting HIV than vaginal intercourse because the tearing of rectal tissues allows direct transmission of the virus into the bloodstream (p.80-1). In city centers with larger populations of gay men like San Francisco and New York, they maintain that this increased "risk was multiplied over time when men frequented bars and bathhouses where it was easy to have scores or even hundreds of sexual partners a year" (p.81). However, Timber and Halperin do not consider the social reasons *why* bars and bathhouses were such focused locations for gay men to express their sexual preferences, namely the pervasive prejudice in the U.S. during this time towards those not strictly heterosexual and monogamous. In particular, as Allan Bérubé (2003) conveys in his historical analysis of gay bathhouses in the U.S., he suggests they operated as "safety zones" for many gay and bisexual men, places where they could "overcome isolation and develop a sense of community and pride in their sexuality, to gain their right to sexual privacy, to win their right to associate with each other in public" and "be sexual and affectionate with each other with a minimal threat of violence, blackmail, loss of employment, arrest, imprisonment, and humiliation" (p.34). In essence, the fact that gay bathhouses were one of the few places for gay and bisexual men to openly, and safely, express their sexuality says less about their individual lifestyles than it does about the heteronormative violence in other public spaces at the time. Given this history, understanding how the current treatment of HIV risk may propagate stereotypes against the gay community is of particular importance and will be considered in this dissertation.

Altogether, CMA analyses reveal how biomedical constructs of HIV on the social level contribute to the stigmatization of HIV-positive individuals by framing them as "threats" using nation-state warfare terminologies and offering management plans that neglect their continued victimization by sociocultural phenomena like colonialism and heteronormativity. This dissertation will further expand upon this by showing how such biomedical constructs may extend to affect HIV-negative individuals on the social level through the treatment of HIV "risk."

The Political Economic Implications of Biomedical Constructions of HIV

Having established how CMA perspectives can illuminate the meaning and management of biomedical constructions of HIV on the individual and social levels, I will now examine how it does so on the political economic level as well. In particular, I will adopt a CMA approach to analyze how biomedical constructions of HIV reveal certain power differentials, specifically institutionalized racism, sexism, and homophobia, which facilitate HIV's disproportionate transmission amongst certain groups in the U.S.

One way that biomedicine reveals power differentials facilitating HIV's spread on a political economic level is through its "epidemiological construction of 'risk groups' and 'risk behaviors'" (Singer 1994:937). As Jehan El-Bayoimi and Soheir Morsy (1993) contend, these "ahistoric and desocialized formulations...distance ill health from the social context of its production, logically lead to blaming the victim" (p.5). In order to understand how these "social contexts" influence HIV's spread, Merrill Singer (2004) suggests HIV be viewed as a "syndemic," a term he coined to convey how socioeconomic conditions, such as those relating to opioid addiction, might facilitate the synergistic spread of two or more diseases, such as HIV and Hepatitis C (p.27). More specifically, Singer (1994) uses "syndemics" as a lens to analyze how structures of inequity, namely racism and poverty in urban centers, have led to the disproportionate spread of HIV amongst US urban poor and minority populations. He maintains, "*AIDS itself emerges as an opportunistic disease*, a disease of compromised health and social conditions, a disease of poverty" because the HIV transmission disparities between these low income minority and high income white groups in urban centers are "tied to" their race and income statuses (p.937; emphasis in original). In contrast to biomedicine's epidemiological "risk groups" and "risky behaviors," Singer argues that syndemic analyses of HIV draw attention to the "particular historic and political conditions" facilitating its spread—such as institutionalized racism and economic elitism—that risk group analyses neglect (p.937). This dissertation will explore how the treatment of HIV "risk" may neglect such historic and political conditions by focusing on the treatment individuals' HIV "risk" instead of the socioeconomic determinants of it.

As syndemic analyses reveal, these forms of discrimination are not necessarily distinct, but rather intersect to augment one another. Peter Smit et al's (2011) metanalysis of existing literature on HIV/AIDS and stigma shows how HIV-positive diagnoses are associated with “multiple layers of stigma” based on race and ethnicity, age, physique, and even timing of HIV diagnosis (p.409). Adding to these claims, Kenneth Mayer et al’s (2014) research explores the socioeconomic reasons why HIV incidence is highest among black men who have sex with men (MSM) and transgender women in the US. They interviewed 1,553 HIV-positive black homosexual and bisexual men and transgender women across the country and found that that they were more likely to be unemployed, an aspect they suspect helps facilitate HIV’s spread by delaying them from “seeking health care services because of low income and lack of health insurance” (p.8). Almost half of their informants also reported experiencing symptoms of severe depression and internalized homophobia, which Meyer et al contend is connected to the “multiple manifestations of stigma and discrimination” their informants experience on a daily basis, especially for those who grew up in “non-affirming communities” (p.8). Building upon previous research showing that internalized homophobia “has been linked to increased sexual risk taking behaviors,” they argue that this discrimination is directly associated with the disproportionate HIV transmission among gay and bisexual black men and transgender women. How the treatment of HIV “risk” may likewise neglect, or even reaffirm, such discrimination will be a topic of this dissertation.

While Singer’s syndemic paradigm reveals how numerous sociocultural and political economic factors contribute to HIV’s disproportionate spread amongst certain groups, CMA’s analytical motif of “structural violence” more deeply investigates the extent to which such harmful factors are embedded within social institutions, including that of biomedicine. Johan Galtung (1969) first used the term “structural violence” to describe how “violence” is “built into the structure” of society and “shows up as unequal power and consequently unequal life chances" (p.170-1). With regards to HIV transmission, Arachu Castro and Paul Farmer (2005) adopt this perspective in their qualitative analysis of HIV patient care and outcomes in Haiti. They contend that,

> "Structural violence predisposes the human body to pathogenic vulnerability by shaping risk of infection and also rate of disease progression. Structural violence also determines who has access to counseling, diagnostics, and effective therapy for HIV disease. Finally, structural violence determines, in large part, who suffers from AIDS-related stigma and discrimination" (p.55)

Applying Castro and Farmer's lens of structural violence to Allan Bérubé's claim that gay bathhouses were "'safety zones'" for gay and bisexual men in the U.S. in the 1980s further elucidates the institutional violence against gay and bisexual men in other public spaces at the time. Laws against sodomy, which remained in various states' constitutions until as late as 2003 (Eskridge 2005) sanctioned police brutality against gay men, most notably culminating in the Stonewall Riots of 1969 (Timberg and Halperin 2012:81). Biomedicine played an important part in contributing to this institutionalized homophobia by pathologizing homosexuality as various forms of psychiatric illnesses (Drescher 2015). In perennial editions and revisions of the American Psychiatric Association's Diagnostic and Statistical Manual (DSM), the canonical encyclopedia of all psychiatric diagnoses in the U.S. first published in 1952, homosexuality was long pathologized as the following: "Sociopathic Personality Disturbance," "Sexual Deviation," "Sexual Orientation Disturbance," and, until 1987, "Ego Dystonic Homosexuality" (p.569-571). This dissertation will expand upon the concept of structural violence to explore how "structural risk" is built into society, specifically healthcare, to produce an ever-narrowing definition of health and ever-diminishing power of individual health professionals and patients to influence it.

The last way CMA might evaluate biomedical constructions of HIV on a political economic level is its attention to power. By contextualizing individuals' and social groups' experiences of HIV within broader political economic structures of power, several anthropologists have shown how HIV is spread along power differentials between them. Phillipe Bourgois (2009), for example, discusses how public health HIV prevention campaigns' neglect of broader structures of injustices attenuates the agencies of the clients they seek to serve. His ethnographic research on the HIV transmission risk practices among heroin users experiencing homelessness in San Francisco shows how individuals' heroin use is framed by "moral economies" of power consisting of "income-generating strategies and the social symbolic hierarchies of respect, identity, and mutual dependence shap[ing] risky behavior" (p.2323). Though these "moral economies" of power shaping HIV transmission risk play out on the individual level, they are extensions of broader structures of power, such as "the criminal justice system and laws governing controlled substance and paraphernalia; the ideological and social structural enforcement of social marginalization by institutions and mainstream discourses; or the structuring of networks and identities/practices of risk by race, class, gender, sexuality, and geography" (p.2344). Moreover, Bourgois says that public health researchers' "psychological behaviorist paradigm of 'individual health risk behavior'" focuses on "changing individual behavior in a vacuum," which only "obscure[s] and ultimately reinforce[s] the power dynamics that shape risk" (p.2344). This dissertation will expand upon this to examine how constructions of HIV risk are extensions of public health agencies and pharmaceutical organizations structures of power.

To review, CMA perspectives of HIV on the political economic level—such as analyses of syndemics between HIV and socioeconomic determinants of health, structural violence within sociopolitical institutions, and the playing out of broader structures of power play on personal levels—reveals how biomedical constructions of HIV may amplify the power differentials by which it spreads. This dissertation will further explore how such power dynamics on the political economic level may contribute to the construction of HIV “risk” and further embed it within structures of healthcare.

Conclusion

HIV is a disease without political or figurative boundaries, passing between individual bodies, impacting social relationships, and reinforcing and reflecting political economic institutions in power. As this chapter has shown, though biomedical perspectives favor HIV’s molecular dynamics and behaviorist interventions, a critical medical anthropological analysis is ideal for showing how biomedical constructions and management of HIV have cultural ramifications on the individual, social, and political economic levels. Significantly, by attending to the personal suffering and individual experiences of HIV, the sociocultural patterns and relationships it implicates, and the broader power differentials by which it spreads, critical medical anthropology shows how HIV is not a just a disease that infects bodies but one that affects *people*. This dissertation will expand on this anthropological perspective to consider how constructions and treatment HIV “risk” may likewise affect individuals, implicate social relationships, and reflect broader power structures.

Chapter 2: Deconstructing Constructions of Risk: How HIV Risk is Biomedicalized, Individualized, and Laden with Moral Values

As French historian and philosopher François Ewald (2009) has said, “Nothing is a risk in itself; there is no risk in reality. But on the other hand, anything can be a risk; it all depends on how one analyses the danger, considers the event” (p.1999). In other words, “risk” is a cultural construct that reflects collective ideologies defining what is and what is not a threat to societies’ values, including bio-social values within the field of medicine (Lupton 1993).

How patients are identified as at “risk” for HIV is not exempt from this cultural construction of risk. When HIV was first identified in the early 1980s, the Centers for Disease Control and Prevention (CDC) released a Morbidity and Mortality Weekly Report identifying Haitian immigrants, heroin and intravenous drug users, hemophiliacs, and homosexuals as groups of people posing a “risk for transmitting AIDS” (CDC 1983). Over time, the CDC’s definitions of HIV risk have become more ambiguous, more obscurely delineating “some groups of people in the United States” to be “more likely to get HIV than others because of many factors, including their sex partners, their risk behaviors, and where they live” (CDC 2018a). With the recent introduction of the pharmacologic Pre-Exposure Prophylaxis (PrEP) to prevent HIV transmission, these definitions HIV risk have become further reified, if more obscure. According to the CDC’s 2017 clinical guidelines for PrEP administration, high risk groups indicated for PrEP are “Men Who Have Sex with Men,” “Heterosexual Women and Men,” and “Persons Who Inject Drugs” with one or more of the following indications for “substantial risk of acquiring HIV infection”: having a “HIV-positive sex partner,” “recent bacterial STI,” “high number of sex partners,” “history of inconsistent or no condom use,” involvement in “commercial sex work,” “HIV positive injecting partner,” or practice of “sharing injection equipment,” with the additional specific provision for heterosexual women and men of living “in a high HIV prevalence area or network” (CDC 2018b:11).

In contrast to Ewald's assertion that "there is no risk in reality," the CDC's constructions of HIV risk—both past and present—have profoundly shaped the reality of many individuals. In this chapter, I will discuss how cultural constructs of HIV risk are actualized through processes of biomedicalization, individualization, and moralization with bio-social values and the implications this has for patients, specifically those "at risk" for HIV transmission. First, I will begin with a brief critical analysis of how risk may be defined and deconstructed to more closely examine its power on the political economic level. I will then discuss how these abstract concepts of risk may be biomedicalized into more concrete ones, such as numerical delineations and monetary values, and how these biomedical forms of risk may implicate HIV patients' views of themselves. After this, I will consider how HIV risk may further shape patients' realities through processes of individualization, which not only neglect broader socioeconomic issues facilitating HIV transmission, but also maintain them. I will conclude by examining how these individualized constructions of HIV risk may be moralized with bio-social values, impacting patients by associating their risk for HIV with immorality and blame.

Deconstructing Constructions of Risk

Before analyzing how HIV risk may affect patients on the personal level, I will first consider how constructions of risk signify power over patients on the broader, political economic one.

Against the backdrop of advancing scientific technologies and modernization, concepts of risk, too, have evolved over time. Etymologically, the word "risk" is derived from the Greek words "*rhizikon, rhiza*" meaning "root, stone, cut of the firm land," which served as navigational metaphors to describe a "difficulty to avoid in the sea" (Skjong 2005). According to the

Merriam-Webster Dictionary, the noun risk has many definitions based upon the field in which it is used. More generally, it can be "possibility of loss or injury" or "someone or something that creates or suggests a hazard" (Merriam-Webster Dictionary 2019). In insurance and financial terms, it can be the "chance of loss or the perils to the subject matter of an insurance contract," the "degree of probability of such loss, a "person or thing that is a specified hazard to an insurer," "an insurance hazard from a specified cause or source," or the "chance that an investment (such as a stock or commodity) will lose value" (Merriam-Webster Dictionary 2019).

However, in more functionalist terms, German sociologist Ulrich Beck discusses how the permeation of risk throughout society is a product of its "reflexive modernization," a process that occurs when postmodernism's questioning of scientific authority collides with industrial modernism's compliance with its claims and assumptions (Lash and Wynne 1992). The result of such a collision is the reflexively modern society's production of intangible "'bads'"—risks—in contrast to previous industrial society's production of material "goods" (p.3). In more complex terms, Beck (1992) defines risk to be a "*systematic way of dealing with hazards and insecurities induced and introduced by modernization itself*" (p.21; emphasis in original). In other words, the potential benefits of advancing scientific technologies and innovations (such as the instant global connectivity afforded by the internet) are reciprocated by the possible societal vulnerabilities—risks—these advances exacerbate, introduce, or reveal (such as cyber attacks and identity theft).

This "systematic way" risk is identified, however, signifies an asymmetrical consolidation of power within select social institutions to create such risk constructions (Chamberlain 2012:9). Sociologist Mitchell Dean (1998) contends that paradigms of risk, specifically individualized and privatized versions of it, have emerged as "new forms of governing in contemporary liberal-democratic states" (p.26). Expanding upon Beck's definition of risk, Dean defines “risk” to be “a way—or rather, a set of different ways—of ordering reality” that consists “of diverse forms of calculative rationality for governing the conduct of individuals, collectivities and populations” (p.25). In other words, paradigms of risk both reflect social mores within a population as well as legitimize the governing structures that enforce them.

Key to governing systems of risk is the expansion of population-wide systems of surveillance, a phenomenon that has become increasingly prevalent within the medical setting in the form of electronic medical records and quality improvement systems. Medical sociologist John Chamberlain (2012) connects Anthony Giddens’ “surveillance society” to Ulrich Beck’s concept of “risk society” by contending the former’s necessity in establishing the latter since “surveillance is essential to the task of identifying and managing and controlling risk” (p.9). More specific to the field of biomedicine, Chamberlain attributes the ability of the medical elite to survey the health of masses to their Foucauldian “panoptic” biopower, which in turn authorizes their intervening on its behalf through recommended medical treatments and preventions (p.11). As a result of this, biomedicine operates in “tension” between its assumed roles both as the “solver of risk” through medical treatments as well as the “creator (and masker) of risk” through its surveillance (p.42). In other words, biomedicine constructs risk in ways that call for its own interventions to address it.

Overall, this political economic deconstruction of “risk” suggests that it is a cultural construct by which social and political institutions, including that of biomedicine, exercise power over individuals. In this light, this dissertation will further explore how HIV “risk” may implicate patients not only by suggesting their susceptibility to a virus, but also to the structures of power poised to identify, and monitor, that susceptibility, most notably public health agencies and healthcare corporations.

Biomedical Constructions of HIV Risk

In many ways, the biomedicalization of risk is a distortion of time and space: it distorts time by foregrounding *possible* anticipated negative health outcomes in the immediate future, requiring immediate treatment, and it distorts space by suggesting a hypothetical, immaterial disease outcome is currently near, if not already within, an individual's body (Armstrong 2005). According to medical sociologist David Armstrong (2005), risk is able to distort time and space like this because it has neither "fixed nor necessary relationship with future illness, it simply opens up a space of possibility" suggesting "future illness potential" in which the lines separating "normal" from "pathological" and the "individual" from the "population" are blurred (p.400). In this new "space of possibility," a risk factor is not a "symptom or sign pointing tantalizingly at the hidden pathological truth of disease," but rather occupies an "extracorporeal space" represented by numerical markers and designators of "'lifestyle'" to "identify the precursors of future illness" (p.400).

Specifically, the use of numerical markers of risk based upon population health data has played an important role in the creation of concrete forms against which individual patients may be measured, and more often than not, found wanting (Greene 2007:7). French philosopher George Canguilhem (1991) attributes this to biostatistics' numerical equivalence of "normal" with "average" from a population perspective, rendering each and every individual abnormal because "real individuals whom we meet diverge more or less and this is precisely in what their individuality consists" (p.154). Expanding upon this sentiment, Canguillhem says, "The sick man is not abnormal because of the absence of a norm but because of his incapacity to be normative" (p.186). In other words, biostatistics transforms "health" into population-based "normativity" and places individuals in a constant state of risk for never being able to achieve it.

In contrast to David Armstrong's perspective of risk as an extracorporeal space of possibility in which an individual might suffer future disease, normativity describes a paradoxical space of *impossibility* in which an individual may never experience health in such numerical terms.

What is more, though these numerical markers of risk occupy an "extracorporeal space" indicating potential disease, patients labeled as "at risk" for disease are often made to feel as if they already have it. As Meta Kreiner and Linda Hunt (2014) show in their research on hypertension and diabetes, the clinicians they interviewed treat patients equivalently, whether they have with borderline lab results classifying them as "at risk" for these diseases, or lab results "clearly above diagnostic thresholds" for the diseases. As a result, the "borderline" patients "believ[ed] they had a serious illness" (p.878). Effectively, this not only results in the "conflation of risk and disease" (p.870), but also turns the entire premise of a clinical visit on its head. Instead of a patient presenting to a clinician with a subjective complaint exteriorized by the clinician's objective analysis, tests, diagnosis, and treatment, the clinician's objective identification of numerical markers of risk, determined by lab tests, is being internalized as patients' subjective experience of disease.

In regard to HIV, numerical markers of risk have also caused many HIV-positive patients to embody these numeric constructions of disease in new ways (Sangaramoorthy 2012:293). Thurka Sangaramoorthy's (2012) ethnographic research on HIV sheds further light on how HIV-positive individuals may subjectively internalize quantifications of HIV risk based upon HIV virus and CD4 immune T cells counts (p.293). Sangaramoorthy recounts how one HIV-positive black woman stood up at a public lecture hosted by the clinic and introduced herself to the group by saying, "I am 400 CD4 count and 250 viral load" (p.293). The woman's use of these numbers to label herself rather than using her own name is as an example of the "numerical subjectivities'' by which many HIV-positive patients intertwine their identities and narratives with biomedical numerations of HIV/AIDs (p.293). As Sangaramoorthy contemds, "Through cellular statistics and hematological and virological calculations [the HIV-positive patients and their healthcare providers she interviewed] communicate ways of being and belonging, imagining bodies as objects of medical knowledge and numbers as markers of suffering, personal triumph, and achievement" (p.293). However, she also maintains that public health officials and HIV care providers who interpret HIV/AIDS epidemic data on HIV prevalence and incidence rates are not exempt from such "numerical subjectivity." On this, Sangaramoorthy says, "By formulating a so-called portrait of the epidemic and by forecasting future trajectories of HIV/AIDS, these statistics prompt providers (and the general public) to infer that numbers are rising because certain kinds of people have inadequate education and unprotected sex" (p.297). Put more simply, numeric biostatistic representations of HIV transmission risk data are subjective because they "allow for the moral readings of people" (p.297). In other words, these "objective" quantifications of risk and HIV have not only caused patients to subjectively internalize these numerical delineations, but allow for others to subjectively evaluate them, too.

The biomedicalization of risk is further advanced by pharmaceutical companies' manipulation of these numerical delineations in order to expand their marketplaces (Green 2007). In many ways, such healthcare corporations' use of biostatistics and public health data is part of the broader, sociocultural trend by which the "scientization of risks" is inherently tied to a "commerce of risk" that "*profits* from the abuses it produces" (Beck 1992:56; emphasis in original). In the specific context of biomedicine, medical historian Jeremy Greene (2007) calls this practice the "pharmacopoeia of risk reduction," the linking of epidemiolocal numerical delineations of risk factors from a public health perspective and the development of drugs to treat them from the pharmaceutical one (p.3). Echoing Armstrong's notion of risk as an "extracorporeal," "space of possibility" for "future illness," Greene maintains that the numerical delineations of risk factors allow them to "float free from the individual body into the broader logics of bureaucratic systems and the marketplace" (p.219). In other words, the same "space of possibility" that risk creates for potential disease is also a "space of possibility" for potential pharmaceutical profit.

The phenomenon of linking public health constructions of risk to pharmaceutical profits (Dumit 2012:5) did not occur immediately in the U.S. HIV/AIDS epidemic. By the time HIV/AIDS first began gaining public recognition in the 1980s, thousands of gay men across the U.S. were already dying, and the Food and Drug Administration's (FDA) was slow to fund, develop, and release antiretroviral treatments (ART) (France, Richman, and Walk 2013). What is more, when the first drug azidothymidine (AZT) was finally released in 1987, it cost over $10,000 annually, well beyond the affordability of most HIV-positive men and women in the U.S. at the time and still too toxic for many who could afford it to even take (France, Richman, and Walk 2013). As David France's documentary *How to Survive a Plague* (2013) conveys, the life-saving antiretroviral treatments become readily accessible to HIV-positive people because of the pressure exerted on the FDA by the protests, marches, and demonstrations of AIDS activist groups like AIDS Coalition to Unleash Power (ACT UP) and Treatment Action Group (TAG) (France, Richman, and Walk 2013). As Larry Kramer, one of the founding organizers of ACT UP, claimed, "Every single drug that's out there is because of ACT UP, I am convinced. It is the proudest achievement that the gay population of this world can ever claim" (France, Richman, and Walk 2013).

However, as Cindy Patton (2011) notes, HIV-positive men and women's advocacy for the development of treatments out of respect for their lives as human beings has been usurped over time by pharmaceutical-driven public health campaigns' recasting of HIV-positive men and women as "'bodies to be protected against'" (p.263). Pivotal to this evolution, Patton maintains, was the introduction of "treatment-as-prevention" programs based upon the "cost-effectiveness" of providing HIV antiretroviral treatments to prevent the "high direct medical costs associated with the disease" as well as reduce transmission to further limit the HIV's "economic burden" (p.252). In contrast to ACT-UP and TAG's fight for human rights to gain access to treatment, these treatment programs "dehumanize" HIV-positive men and women as "potential transmission points associated with cost units" and necessitates they be on treatment whether they want to or not. Patton argues, "When the individual is subsumed into the population in which aggregate viral load is to be reduced by the suppression of virus through drugs, we should be very clear about whose bodies will come under scrutiny, both as potentially HIV positive, and if positive, as the vessels of requisite treatment-for-life" (p.263).

In essence, the biomedicalization of HIV risk solidifies abstract notions of illness into more concrete forms of numerical markers and monetary values which can be assigned to pharmaceuticals. By creating a "space of possibility" for potential disease and pharmaceutical profits, these biomedical constructions of risk may attenuate HIV-positive individuals' experiences of health and wellbeing. To expand upon this concept, this dissertation will illuminate how the marketing and administration of PrEP may contribute to the construction of HIV risk as a "space of possibility" for HIV protection and profit alike.

The Individualization of HIV Risk

Perhaps in overly simple terms, the individualization of risk is just a remapping of political economic inequalities on the personal level (Beck 1992). As Ulrich Bick (1992) asserts, population-wide social inequalities may be "redefined" in terms of "individualiz[ed]" social risks such that "[s]ocial crises appear as individual crises, which are no longer (or are only very indirectly) perceived in terms of their rootedness in the social realm" (p.100). By placing individuals into risk groups based upon their characteristics and behaviors, such as their race, ethnicity, gender, age, sexual orientation, and lifestyle preferences, the "problems of the system are lessened politically and transformed into personal failure" (p.89). Not only is this depiction of risk distorted, but it is also inaccurate. As epidemiologist Geoffrey Rose (1985) maintains, these risk factors are determined by probabilities based upon population trends and thus cannot be directly applied to individuals. This is because the "determinants of incidence for a population are not necessarily the same as the causes of cases" as individuals' exposure to the causal agent may or may not be equally distributed within a population (p.34). Epidemiologist Beverly Rockhill (2001) describes this phenomenon as the "privatization of risk," a process reflecting a "value system now underlying much of public health and preventive medicine in the United States" that gives "primacy to personal autonomy and action and seeks to induce personal behavior change rather than to promote social interventions that often must confront powerful opposing interests" (p.365).

In a similar manner, public health institutions have also individualized the risk HIV poses to the public by individualizing its transmission through the epidemiological concept of "network theory" (Danon et al 2011). Per network theory, infectious diseases are spread along the "connections between individuals (or groups of individuals)" to "naturally define a network" between them based upon the “frequency and types of risk behavior” (p.1-3). In this light, diseases like typhoid are spread by individuals like Mary Mallon, the Irish cook whom The Journal of the American Medical Association gave the moniker of “Typhoid Mary” in 1908 and the New York City Sanitary Police quarantined against her will in 1915 until she died twenty-three years later (Markel 2014).

A historical examination of the HIV/AIDS epidemic within the U.S. demonstrates how the inaccuracy and bias of network theory’s myopic focus on individuals and their behavior led to the misidentification of the “Typhoid Mary” believed to bring HIV to the U.S.—the French-Canadian flight attendant Gaétan Dugas (McKay 2017). In 1981, a CDC task force investigated a cluster of HIV-related opportunistic diseases in California and used network theory based on the patients’ contacts to identify Dugas as the link between them and another cluster of patients in New York. They labeled Dugas as “Patient-O” for “Out[side]-of-California,” but this moniker evolved to the numeric “Patient 0” within the CDC in reflection of CDC epidemiologists’ belief he was “ground zero” of the epidemic (McKay 2014:170-1). When the investigative journalist Randy Shilts learned of Dugas from several interviews with the CDC (McNeil 2016), his portrayal of Dugas as a “repulsive,” sexually irresponsible criminal who “should be locked up” for knowingly spreading “gay cancer” within the U.S. (Shilts 2000:200) led to Dugas’ instant villainization as “The Man Who Gave Us AIDS” (*New York Post* 1987:1). However, as evolutionary biologist Michael Worobey et al’s (2016) recent research tracing the phylogenic mapping of HIV strains within the U.S. demonstrates, Gaétan Dugas was *not* the first person to bring HIV to the United States. Using molecular genomics, Worobey compared the HIV strain in preserved samples of Dugas’ blood to the HIV strains from more recently infected people in the

U.S. and found that Dugas' strain of HIV was "not basal to the U.S. diversity" of HIV, meaning he was not the source of the U.S. epidemic (p.3).

In spite of this revelation, however, network theory's individualization of HIV risk has continued to shape how public health HIV prevention campaigns prioritize the management of individual's "risky behaviors" over the socioeconomic determinants of health that conscript them. Basing her research on HIV prevention programs in Poland, Jill Owczarzak (2009) shows how HIV prevention campaigns are still primarily "concern[ed] with 'fixing the individual,' rather than the social context that shapes risk" (p.431). Comparing one HIV prevention program's behaviorist construction of HIV risk as "the product of individual decisions and altered through instantaneous behavior change, if one self-reflexively makes the right choices" to another program's construction of HIV risk as a "complex, socially determined quality" that individuals may know about" but "lack the ability to act on or manage," Owczarzak shows how both programs still place the individual at the "locus of HIV prevention intervention" (p.429).

However, this individualization of risk—whether by epidemiological network theory or HIV prevention programs' behaviorist approaches—does more than *neglect* the "upstream" structural inequalities facilitating unequal distributions of disease, it helps *maintain* them as well (Aronowitz 2006:153-4). In some instances, as epidemiologists Y G. Doyle, A. Furey, and J. Flowers (2006) contend, the individualist risk factor paradigm may "widen" social inequalities, an argument supported by Hannah Bell et al's (2018) ethnographic research showing how risk factors may be "racialized" in the context of diabetes in the U.S. Their study at diabetes and weight loss clinics reveal how black patients are disproportionately "marked" as "risky bod[ies], which nee[d] to be consistently checked, monitored, labeled, and treated for illness, reinforcing structural power and inequity along racial lines" (p.12). What is more, they found that "racially marked" patients were more likely to "internalize" this risk, "undermining their agency in managing their disease and casting blame and stigma on them" (2018:12).

Like Bell et al's research on racialized risk in diabetes, Nina Schiller (1992) has shown how the association of "culture" with HIV transmission effectively "otherizes" certain populations based upon their assumed shared traits (p.239). Her contention is further supported by the racially reductionist language used to convey HIV transmission disparities in recent scientific research publications. While several researchers from the NIH noted a "higher likelihood of black race being associated with a detectable viral load compared with other racial groups" (Marston et al 2018:411), others from the Centers for AIDS Research Network of Integrated Clinical Systems (CNICS) attributed this to the "the need for culturally tailored interventions to encourage ART use, enhance medication adherence, and improve viral suppression and other outcomes" (Nance et al 2018:381). Building upon Bell et al and Schiller's arguments, these examples demonstrate how HIV transmission risk is "racialized" by associating higher transmissibility with the "black race" and attributing it to assumed "cultural" reasons precluding individuals' medication adherence rather than structural ones, like institutionalized racism in healthcare and medical research settings.

Currently, epidemiological categories of HIV transmission risk seem to have shifted from "risk groups" *assigned to* individuals based upon their shared characteristics to "risky behaviors" individuals *assign themselves to* based upon their lifestyle choices, and as a result, the individualization of risk seems to be more pronounced (Watney 1996). As historian Simon Watney (1996) maintains, this shift implies that the "risk for HIV comes not from who you are, but from what you do" while ignoring the fact that HIV is "not an 'equal opportunity' disease" (p.431-2). Jehan El-Bayoumi and Soheir Morsy's (1993) anthropological analysis of the HIV epidemic in the United States describe how this new focus on "risky behaviors" is a "basic recipe for desocialization" that "distance[s] ill health from the social context of its production, logically lead[ing] to blaming the victim" (p.5-6). By its very nature, the individualization of risk through focus on behaviors is a process of "desocialization" because it separates an individual from the socioeconomic factors shaping their choices.

In summary, by focusing on individuals instead of social and political institutions, individualized constructions of HIV risk may neglect and maintain the broader socioeconomic issues facilitating the spread of HIV. To explore this issue further, this dissertation seeks to better understand the ways patients are identified to be "at risk" for HIV and how that may influence their treatment responsibility.

Moralizing Risk with Bio-Social Values

Just as the individualization of HIV risk may be attributed to biomedical institutions' focus on the spread of the virus between individuals, the moralization of HIV risk with bio-social values may attributed to institutions' attempts to explain why *those* individuals were infected with HIV in the first place (Finerman and Bennett 1994). In broader terms, the moralization of risk is a product of its emergence as a functionalist explanatory model for disease in which "onset and outcome are directly ascribed to the afflicted themselves" (Finerman and Bennett 1994:1). As sociologist Dorothy Nelkin and historian Sander Gilman (1988) convey in their analysis of risk and blame in public health, the explanatory model of risk linking individuals' lifestyles and behaviors with their health, or lack thereof, "defines the normal, establishes the boundaries of healthy behavior and appropriate social relationships, and distinguishes the observer from the cause of fear" (p.363). They contend that, because biomedical risk is used to reinforce social mores and create order, disease becomes a "public sign" of an individual's "violation of socially defined boundaries" (p.368).

With regards to HIV, Jan Grover (1987) also argues that biomedical constructions of risk have "been used to stereotype and stigmatize people already seen as outside the moral and economic parameters of 'the general population'" (p.27). More specifically, Steven Epstein (1996) discusses how the HIV/AIDS epidemic's labeling as the "gay disease" was a reflection of how the concurrent gay liberation movement threatened entrenched social pillars of puritanical heterosexuality. Reviewing medical literature on HIV during the beginning of the epidemic in the 1980s, Epstein notes how medical researchers assumed HIV's "link to gay men meant that the epidemic was related to gay men's sexuality; that if gay men (by this view) were 'promiscuous,' then the illness must be a consequence of their promiscuity" (p.52-53). As Brook Schoepf (2001) discerns, the medical researchers' use of the term "promiscuous" to explain HIV transmission among gay men is a "a notion so imprecise and value-laden it cannot be used scientifically" (p.340). Effectively, their morally-charged explanatory link between gay men's "promiscuity" and HIV transmission risk served not only to reinforce social mores of sexuality, but simultaneously blamed gay men for becoming HIV-positive while distancing themselves from the threat HIV posed to their own health.

The moralization of risk by blaming individuals for diseases like HIV based on their lifestyles and characteristics also reinforces social structures of racism and ethnocentrism. In American politics, psychologist William Ryan (1986) refers to this as the "blaming the victim" explanatory model in in which victims of social injustice, specifically black Americans, are blamed as the cause of their own misfortunes by the merits of their lower socioeconomic status. Within the HIV epidemic, the "blaming the victim" explanatory model is made most apparent in the CDC’s 1983 delineation of “Haitians” as a “risk group” for HIV, the only one framed by racial or ethnic identity. Based upon his ethnographic research in the Haitian village Do Kay in the 1980s, Paul Farmer (2006) traces the “fault lines of economic structures long in the making” by which Haitians came to be blamed for bringing HIV to the United States (p.6). Referring to William’s argument, he contends that the blaming of Haitians for bringing HIV to America, and the significant discriminatory repercussions it had for Haitian populations both in the U.S. and Haiti, is a reflection of the institutionalized racism Haitians have faced since becoming a liberated slave colony and still today via Atlantic trade practices and U.S. immigration policies (Farmer 2006). Though Farmer reflects rather than discredits the placement of this blame by suggesting that “gay tourists” were actually responsible for bringing HIV from America to Haiti (p.146-7), a contention that has since been disproven (Gilbert et al 2007), his argument about how moral constructions of HIV risk reveal “fault lines” of racism and ethnocentrism is still valid.

And while these “fault lines” of HIV risk are rooted in historical and economic structures of discrimination of the past, current constructions of HIV risk continue to redraw them into the present (Schoepf 2001). In a similar manner to Farmer, anthropologist Brook Schoepf (2001) has also discerned how HIV transmission in the U.S. is facilitated by “fault lines of society” that are repeatedly “drawn” at power fault lines between “people of high moral repute” and “stigmatized ‘others’” at risk for HIV (p.344). Notably, the effect the CDC’s latest PrEP guidelines has had on those considered at risk for HIV demonstrates how they might further reinforce, if not extend, these fault lines. Sarit Golub, Kristi Gamarel, and Anthony Surace’s (2015) study on PrEP-related stereotypes among men who have sex with men (MSM) reveals that over 80% of the study participants associated at least one negative stereotype with the drug. The most common of these stereotypes associated with PrEP were that PrEP consumers' being promiscuous, really HIV-positive (and lying about their status), irresponsible, and contributing to gay-related stigma (p.1232-3). Perhaps an amalgamation of all of these stereotypes is the slur "PrEP whore," a term increasingly being used in social media forums to designate those taking PrEP (Spieldenner 2016). Spieldenner (2016) reflects on the implications of "PrEP whore" use in these public fora, discussing how it is a "form of slut shaming" conveying that "those who use PrEP are somehow taking a prevention shortcut, a copout from the responsible use of condoms" (p.1691). Spieldenner maintains, "The irony of this construction is that gay men living with HIV are usually stigmatized as sluts. Therefore, both health outcomes—the use of PrEP to prevent HIV acquisition and an HIV infection—lead to the label 'whore'" (p.1691). Like Kreiner and Hunt's (2014) contention that the equivalent treatment of "at risk" and definitively diagnosed patients results in the "conflation of risk and disease," Spieldenner shows how the equivalent medical treatment of HIV and HIV risk results in the moral conflation of the stigma associated with being HIV-positive and HIV-prophylactic.

Altogether, the biomedical use of risk to explain why certain individuals get infected with HIV has led to its moralization with bio-social values, impacting patients by associating their risk for HIV with immorality and blame. Though an HIV-positive test result may once have indicated an individual's immorality while an HIV-negative one confirmed their innocence (Lupton 1993:430), with the advent of PrEP, even an HIV-negative test result may no longer be exonerating. To further explore these issues, this dissertation explores how PrEP's administration may contribute to the moralization of HIV risk with bio-social values and the obligations such values impose on health professionals and patients to treat it with PrEP.

Conclusion

As this chapter has demonstrated, risk is a cultural construct that may not exist in reality but is tethered to it by processes of biomedicalization, individualization, and moralization. While these tethers may serve to reinforce the safety and health of some members of society who are not “at risk” for certain diseases like HIV, they significantly impact those who are “at risk” by imposing bio-social values on their characteristics and activities and influencing moral constructs of their identities. In this light, this dissertation will explore how the labeling of individuals as “at risk” for HIV in the hopes of protecting them from a microscopic virus may potentially reinforce their susceptibility to the very macroscopic structures of inequality by which the virus spreads.

Chapter 3: Research Design and Methods: Situating HIV Risk and PrEP Administration in New York

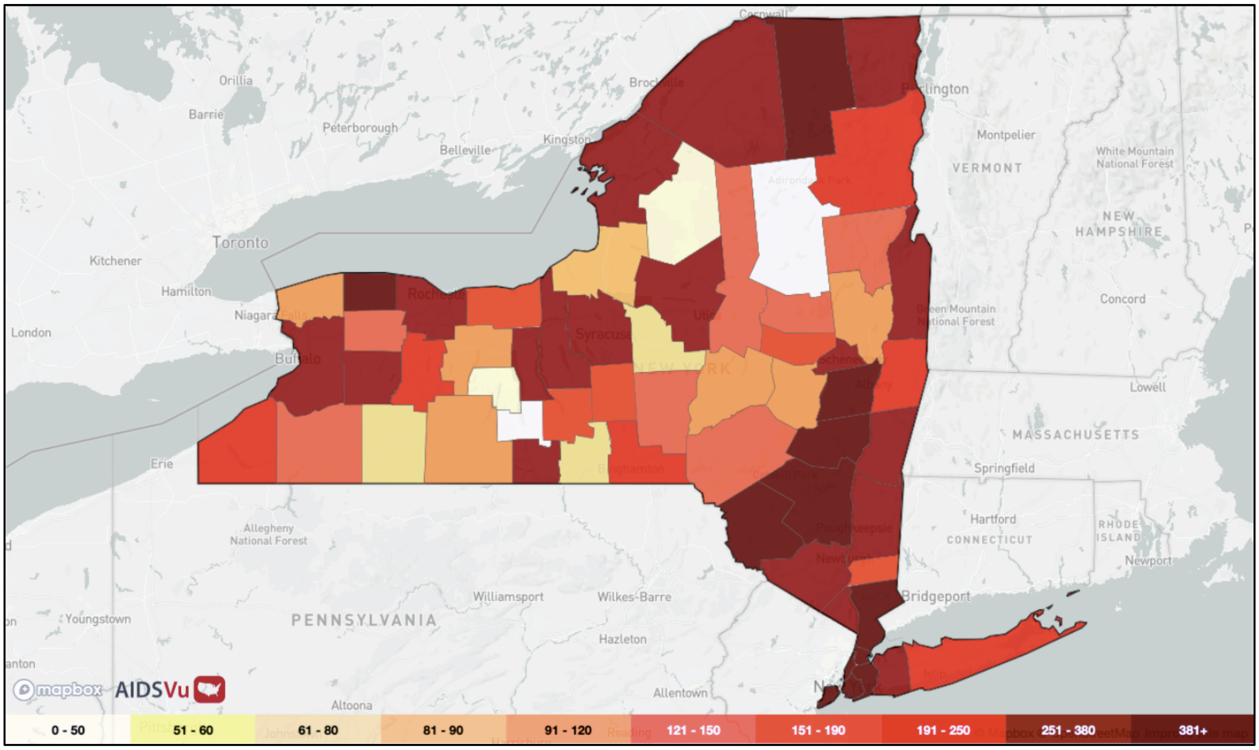
In this chapter, I will discuss the setting of the research in New York, exploring the historical context of the HIV epidemic in the state and examining the current political and social campaigns to address it. After situating the research within its geographic context, I explain the reasons for choosing to conduct the research at a community health center network in New York, as well as my experiences as a volunteer prior to graduate school and when I returned for this research as a dual medical and anthropology graduate student. Following this, I will review the research methods and then discuss my data analysis for examining of HIV "risk" and PrEP's role in treating it.

Setting

New York State consists of 19.8 million people, 8.6 of which live in New York City (AIDSVu 2019). Though originally colonized by the Dutch in the early 1600s (The New York State Senate 2019), New York has now come to be a diverse state, with 55.7% of its population being white, 19.0% Hispanic/Latinx, 14.6% black, 8.7% Asian, 1.7% multiple races, and 0.3% American Indian/Alaskan native (AIDSVu 2019). Historically speaking, New York has always been an international destination: from 1892-1924 New York City's Ellis Island was the largest and most active U.S. immigration station, processing more than 12 million immigrants (National Park Service 2019).

According to a recent scientific study, New York City was one of the first places that HIV arrived in the United States, serving as "the crucial hub of early US HIV/AIDS diversification" (Worobey et al 2016:98). By the end of 2016, New York had 127,934 people living with HIV in the state, the highest prevalence in the entire country (AIDSVu 2020). After Florida, California, and Texas, it also had the fourth highest number of new cases of HIV in 2017 at 2,768 people (AIDSVu 2020). Though the counties in New York City have the highest rate of persons living with HIV in the state, other New York counties throughout the state also have a high prevalence of HIV as shown in Figure 1 below:

Figure 1. Map of New York State Counties by Rate of Persons Living with HIV in 2016 (AIDSVu 2020)



Color key: Number of people with HIV per 100,000 people in the population, by county, with darker shades indicating a higher number and lighter shades indicating a smaller one.

New York State also leads the nation in HIV prevention efforts, including the use of Pre-Exposure Prophylaxis, or PrEP, the daily medication to prevent HIV. In 2018, it had the highest number of people using PrEP, with approximately 27,409 people taking the drug to prevent HIV in 2018 (AIDSVu 2020). This is in large part due to the state's early adoption of the drug as part its "Ending the Epidemic" campaign established on June 29, 2014 with the goal of "reducing new HIV infections from 3,000 to 750 per year by the end of 2020," which "would result in saving medical costs of $804.4 million from averting 2,250 HIV infections" (New York State Department of Health 2015:14). Given its high rate of HIV and PrEP use, New York served as an ideal location to conduct this study and meet its aims of illuminating how HIV risk has been conceptualized.

The community health center network in New York where this study was conducted provides both HIV treatment and preventative services, including the administration of Pre-Exposure Prophylaxis (PrEP). To protect the health center professionals who participated in the study, I refer to the health center by the generic pseudonym New York Community Health Center (NYCHC). Though NYCHC has a large number of clinics its network, my research focused on three health centers, each in New York cities ranging in population from 14,000-30,000 people and with a 2016 HIV prevalence of 153-441 persons living with HIV per 100,000 people (AIDSVu 2020).

Currently, NYCHC serves over 225,000 patients within its network, most of whom are on public insurance. Its PrEP program began shortly after the June 2014 announcement of New York's "Ending the Epidemic" campaign, and since that time it has served over 1,200 PrEP patients. In the specific region where this research took place, the community health center network actively serves approximately 600 HIV patients and 150 PrEP patients as of August 2019.

Prior Experience at NYCHC

Prior to beginning graduate school, I volunteered at NYCHC between 2013-2015, accumulating over 3200 hours of volunteer experience there. As a volunteer, I was a part of the health center's HIV Treatment and Prevention team. In additional to providing patient services, such as the administration of HIV tests and serial Montreal Cognitive Assessment (MoCA) tests, I assisted in developing and implementing quality improvement projects. I also generated the monthly HIV viral load and CD4 immune helper T-cell reports on all of the patients for the interprofessional teams to review, participated in the activities of the health center's HIV Consumer Advisory Committee, and attended New York AIDS Institute meetings and trainings.

Importantly, during this time, I formed professional relationships with a variety of primary care and infectious disease clinicians, nurses, case managers, and administrators. Significantly, these relationships offered me insight into health professionals' perspectives on HIV risk and PrEP administration, helping me better understand their commitment to prevent further HIV transmission. Additionally, the previous relationships I formed with patients who were members of the HIV consumer advisory committee also gave me insight as to what many HIV-positive individuals think of PrEP and the role they believe it plays in the HIV epidemic. For my dissertation research, these insights helped me further explore health professionals' and patients' perceptions on HIV transmission and PrEP.

I returned twice to the health center for preliminary 3-4 day research trips. I returned once in May 2016 and again in March 2017, meeting with members of the health professionals and the HIV consumer advisory committee to learn more about their PrEP program. On both occasions, the health center's clinicians and administrators were enthusiastic about the possibility of my returning to conduct my dissertation research at the health center, and continued to offer support during the IRB application process. During my first trip, I met with the Director of Research at the health center, the Administrative Director of HIV Services, and the Clinical Director of Infectious Disease and Specialty Services in addition to attending an HIV Consumer Advisory Committee meeting. During my second trip, I met with the health center's Administrative

Director of HIV Services, new PrEP Case Manager, and a member on NY State's "Ending the Epidemic" Task Force. I was also able attend the annual Reunion Latina in Albany, NY, a two day-long conference attended by NY AIDS Institute officials, HIV health professionals, and HIV-positive consumers.

After these two trips, I worked with the health center's Director of Research and Clinical Director of Infectious Disease and Specialty Services to receive IRB approval to conduct my research at the health center and ensure my research access.

Research Design and Methods

This study consisted of a variety of data collection strategies that are overlapping and mutually informing, and resulted in a rich body of interrelated data sets to allow for in-depth examination of clinician and patient perspectives and experiences and comparative analysis. I used participant observation; semi-structured, open-ended interviews; and analysis of medical records and HIV prevention publications and guidelines. Prior to beginning the research, I received approval from Michigan State University's Institutional Review Board in addition to the approval by the research department officials at the New York Community Health Center (NYCHC) where this research was located.

Participant Observation

Participant observation is a research method by which a researcher experiences and notes the same phenomena as the subjects of her study in order to get as close as possible to understanding their subjective experiences while maintaining her objective perspective. This approach allowed me to glimpse how both patients and health professionals interpret and communicate what it means to be “at risk” for HIV transmission within the context of the clinical setting. After finalizing my research approach with appropriate clinic officials, I began my participant observation in the form of clinical shadowing, following health professionals at the health center and observing any interactions they had with patients as well as other health professionals. Over one month I conducted 104 hours of observation. Prior to shadowing each health professional and observing each patient, I introduced myself as a researcher and obtained their consent for me to be in the room with them. Though no health professionals declined my requests to shadow them, several patients declined my request to observe their visit with the health professional and were not included in my observation notes. At the end of each day, I typed up my hand-written notes and impressions, focusing on the clinical environment, generalized descriptions of the consenting health professionals and patients, and how health professionals and patients communicated HIV risk. All subject information was kept secure in password-protected files on the computer or in a locked file container or cabinet.

Interviews

I also conduct semi-structured, open-ended interviews, asking each subject the same series of non-leading questions, allowing them to answer as expansively as they wish. Because each subject is asked the same set of questions, this enabled me to compare their answers. However, because each question is open-ended, the subjects also have the freedom to answer as they wish. It was ideal for this study because it allowed me to not only delve further into patients’ and health professionals’ understandings of HIV transmission, but it also allowed me to compare the similarities and differences between and among their understandings. I conducted a total of 38 interviews of 11 HIV-negative patients indicated for PrEP, 13 HIV-positive patients, and 14 health professionals. Each interview lasted approximately 10 minutes to over 1 hour depending upon the depth of the interviewee's answers, averaging around an estimated 25 minutes. Patients and health professionals to be interviewed were recruited from those I observed while shadowing health professionals at the clinic. After observing the patients interacting with the health professionals, I would ask them if they would like to participate in an interview, and if they agreed, we would leave the exam room to conduct the interview in an empty room, such as an unused clinical exam room, office, or consultation room. Several patients declined to participate in the interviews due to lack of time or not wanting to participate, and 2 patients declined to participate in the interview but still wanted to my observations of their interactions with the health professionals to be included in the study. Of the 24 patients that agreed to be interviewed, all but one allowed me to audio record the interview, and for that one interview I recorded their answers by hand. Perhaps because my previous experience as a volunteer at the health center afforded me a certain rapport with many of the health professionals, all of the 14 whom I asked to interview agreed. I interviewed the health professionals during their breaks or at the end of the clinical day, usually in their office or an empty exam or consultation room. All of the interviews with the health professionals were audio recorded and done individually except for the one with the pharmaceutical industry members, who told me their company prohibited their being recorded and asked to be interviewed at the same time. For that interview, I interviewed them both together and recorded their interview answers by hand.

Table 1 below shows the demographic breakdown of the 24 interviewed patients, and Table 2 shows the demographics of the 14 interviewed health professionals involved with patient care at NYCHC.

Table 1. Interviewed Patients' Demographics

	Total[1]	
	n	%
Participants[2]	24	
Sex[3]		
Male	15	63%
Female	8	33%
Non-binary	1	4%
HIV Positive Status		
Negative	11	46%
Positive	13	54%
Age (range: 23-78, median: 46)		
20-29	3	13%
30-39	5	21%
40-49	4	17%
50-59	6	25%
60-69	4	17%
70-80	1	4%
Declined to answer	1	4%
Race/Ethnicity[3]		
Non-Hispanic White	10	42%
Black or African American	8	33%
Hispanic or Latinx	6	25%
Highest Education		
< High school diploma	5	21%
High school diploma	6	25%
Trade school	1	4%
Some college/Associate's Degree	4	17%
Bachelor's degree	4	17%
Graduate education or higher	4	17%
Annual Household Income		
< $10,000	4	17%
$10,000-$20,000	3	13%
$20,001-$50,000	7	29%
$50,001-$70,000	2	8%
$70,001-$90,000	4	17%
> $90,000	2	8%
Missing[4]	2	8%

[1] Note: Percentages are rounded and may not always add up to 100%

[2] One HIV-negative patient and one HIV-positive patient also worked at the health center as Peer Educators and chose to be interviewed as patients, so they are counted as such.

[3] Both "Sex" and "Race/Ethnicity" demographic categories were self-identified

[4] One patient declined to answer the annual household income question and another patient's annual household income was excluded due to recorder error.

Table 2. Interviewed Health Professionals' Demographics

	Total[1]	
	n	**%**
Participants	14	
Role at Health Center		
Program administrator	3	21%
Medical doctor	4	29%
Nurse	3	21%
Case manager	2	14%
Pharmaceutical industry member[2]	2	14%
Sex[3]		
Male	3	21%
Female	11	79%
Age (range: 27-59, median: 41.5)		
20-29	1	7%
30-39	5	36%
40-49	4	29%
50-59	4	29%
Race/Ethnicity[3]		
Non-Hispanic White	6	43%
Black or African American	3	21%
Hispanic or Latinx	4	29%
Asian	1	7%

[1] Note: Percentages are rounded and may not always add up to 100%
[2] The "pharmaceutical industry members" asked for their profession to be identified as such.
[3] Both "Sex" and "Race/Ethnicity" demographic categories were self-identified

Medical Record Review

In addition to observing and interviewing patients and health professionals, I also reviewed patient medical records. After undergoing the required training at the health center, I accessed medical records for patients, who had agreed to allowing me access and had signed HIPAA Authorization. In addition to this, they also signed an "Authorization for Release of Health Information AIDS Institute and Confidential HIV-Related Information." A total of 7 patients declined my accessing their medical records. I collected records from 19 patients, 7 HIV-negative indicated for PrEP and 12 HIV-positive patients. In order to receive the records most relevant to the aims of this study, I requested records starting from January 1, 2012—the year PrEP was approved by the FDA, to August 7, 2019—the end of the data collection period.

Furthermore, for HIV-negative patients indicated for PrEP, the following records were included for analysis: the patient summary, PrEP Assessment encounter, 2 encounters before PrEP Assessment, the first 3 PrEP follow up visits, the last 3 PrEP follow up visits, and HIV/STI Testing or STI Testing. For HIV-positive patients, their patient summary, first 3 HIV program encounters, last 3 HIV program encounters, and STI testing were included for analysis. Altogether, these medical records further illuminated how health professionals perceive HIV risk and contribute to the codification of that risk within the clinical setting.

HIV Prevention Publications and Guidelines Review

I also obtained HIV prevention publications and guidelines from a variety of sources throughout my observations at the clinic, during interviews with health professionals, and through additional literature reviews. These varied extensively, from guidelines that the health professionals reported they followed to HIV prevention advertisements I observed hanging in the public spaces and exam rooms of the clinics. These publications and guidelines further elucidated how messages from public health agencies and healthcare corporations represent HIV risk, and allowed me to examine the extent to which health professionals and patients may or may not align with these conceptions.

Data Analysis

I thus generated four sets of data for this study to be analyzed: observational field notes, interview transcriptions, patient medical records, and HIV prevention publications and guidelines. I analyzed these using triangulated, iterative "grounded-theory approach" allowing for an in-depth analysis of HIV "risk" and PrEP's role in treating it (Bernard 2006).

After enlisting a transcription services to confidentially transcribe all of the interviews, I carefully reviewed them for accuracy. Next, I reviewed them and my typed observational fieldnotes for impressions and themes using the process of “memoing.” As anthropologist H. Russell Bernard describes, memoing is “the method for recording relations among themes” in which you “continually write down your thoughts about what you’re reading” in order “to develop theory” (2006:494). Then, I input all of the interviewees’ answers into an excel table in order develop an initial set of common themes, comparing and contrasting the interviewees’ answers to each question. I then thematically coded the transcripts, typed fieldnotes, and scanned materials from the field site using NVivo, a software system for analyzing qualitative data. I continuously developed these codes as the project progressed to reflect the themes and concepts either based upon the study aims or those that emerged from the data. Examples of themes include the construction of HIV risk, assignment of HIV risk to the individual vs. social level, the agency of HIV risk, impressions of PrEP, and how PrEP affects HIV risk. I analyzed subjects’ responses by subgroup of health professionals, HIV-positive patients, and HIV-negative patients indicated for PrEP. As new codes emerged, I was vigilant to continuously contrast these study subgroups to see if they yielded any variation in thematic occurrence.

After deidentifying all of the medical records, I summarized each record into an Excel spreadsheet noting the purpose of the visit/encounter and the context of any mention of PrEP or HIV risk. I then input this spreadsheet into NVivo for thematic analysis, looking specifically at how health professionals codified HIV risk in the electronic health record (EHR), documented discussions with patient about HIV risk, identified patients for PrEP administration, and identified patients for the cessation of PrEP. I then integrated these thematic analyses with that of the fieldnotes and subject interviews to offer greater insight into how HIV risk is constructed in the administration of PrEP and how these concepts play out in the clinical setting.

I also scanned and uploaded the HIV prevention publications and guidelines into NVivo, generating codes to capture how the messages of public health agencies and healthcare corporations construct risk. In particular, I closely examined what they understand to be the sources of risk, where they place that risk, whom they identify as responsible for addressing that risk, and why they convey the need to address this risk. By combining this analysis with my fieldnotes and subject interviews, I hoped to better understand how public health agencies and healthcare corporations conceptualize risk and the ways in which their goals may become aligned in doing so. I present my results of my data analyses in the following chapters.

Chapter 4: The Ambiguity of HIV Risk

"When you hear that someone might be at risk for HIV, what does that mean to you?" I asked Trudy.[1] She is a 49-year-old Pre-Exposure Prophylaxis (PrEP) administrator at New York Community Health Center (NYCHC) who is tasked with identifying individuals as candidates for PrEP. It was a hot July afternoon and we were sitting in a slightly cramped, windowless yet airconditioned office at one of the branches NYCHC. After mulling over my question for several moments, she answers[2],

> "When I feel that they're at risk for HIV, I just feel like they're, they're not taking—that they're—there are sort of—now, I'm not saying that they're not being careless because when people are at risk for HIV, I feel like, you know, they're at their harm.
> I don't know how to answer this question.....
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> Can I skip your question?.... Because I sound silly. I don't want to sound silly, but I just feel like for at risk for HIV, I, I feel like they are at—they need intervention. I feel like we really need to—when I feel that someone's at risk that they are—they're—not necessarily they're being careless, but they're being, like, whether they really don't know or they don't know where—what they're—what's up ahead and they feel that they need to be spoken to, I feel like I feel fearful for HIV. It's a big change in someone's life. And I want—I like to—for my position is now where I could try to prevent them from doing so and educate them. I just feel it's a hard—It is a hard question for me because I feel like I'm not answering it correctly. But I feel like when I feel like someone's at risk for HIV, I feel that they're—I don't know. I—I'm so sorry.....
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> I guess I don't know what it is for me. I think it's hard for me to put things into words. I struggle with how to describe it and put it—make it sound—like, how to put it into words. But I think HIV to me is, is life changing. And it's life changing....Because they feel like HIV is the end of their life sentence. And they, they see no life after HIV. So I feel like someone's at risk for getting HIV, I feel like I have to—I guess that's where the screening comes in....
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> And so I don't know. When I feel like someone's at risk for HIV, I just feel like they need—they need extra love and they need extra care and extra spoken to and extra just....When it comes to sex and sexual pleasures, they are really just going off the pleasure; they really don't know what lies behind or what can it cause and, and the damage that certain things can do to your body."

Trudy, whose job it is to determine if individuals are at risk for HIV when identifying candidates for PrEP, cannot readily answer this key question. Significantly, however, Trudy's inability to define HIV risk was *not* due to a problem of ignorance or any shortcoming on her part. Though

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[1] The names and personal details of all people involved in this study have been changed to protect their identities and privacy.

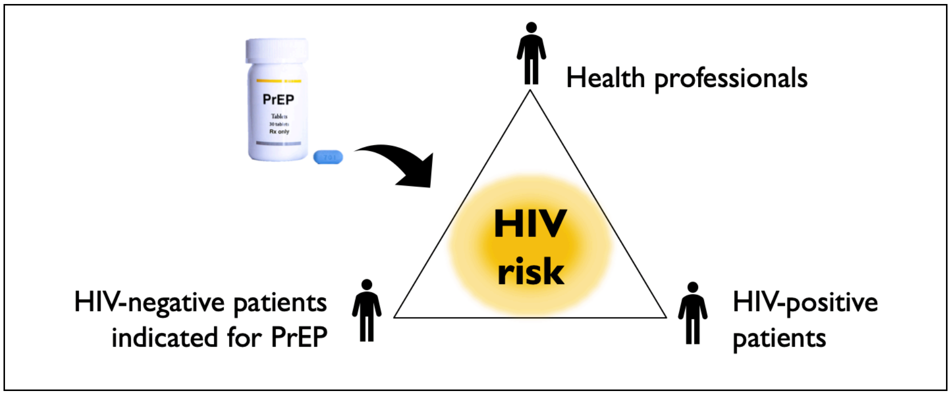
[2] This excerpt of an interviewee's response, and several other excepts in the following chapters, have been shortened to exclude the interviewer's remarks and brief exchanges for the purpose of brevity, clarity, and readability.

seemingly such a simple question, her circuitous answer speaks to how defining HIV risk is anything *but* simple.

Nonetheless, though her answer reflects the complexity of defining risk, Trudy's answer did reveal a certain pattern. Per Laury Oaks and Barbara Harthorn's (2003) discussion on how people perceive risk through different "frames" which "reflect their values, world views, and concepts of social order" (p.viii), Trudy navigated several of these frames of HIV risk. The first frame she navigated is one of agency—*why* people are at risk for HIV—first placing the responsibility of HIV risk at the feet of those deemed at risk and then retracting that sentiment to contend that they are not being careless, but perhaps just unaware and in need of intervention. The second and third frames she navigated are time and space—*where* and *when* people are at risk for HIV—contending that those at risk for HIV simply don't know where or what's up ahead, and some living with the virus see no life after HIV. The fourth frame she navigated is the tangibility of HIV risk—*what* HIV risk is, discussing how HIV is a life changing event that physically can cause damage to the body but mentally affects everyone differently. And the fifth frame she touched on is identity—*who* is at risk for HIV, alluding that those at risk are without the education of HIV and STIs or those who are really just going off the pleasure of sexual experiences.

Taken together, these five shifting-yet-interdependent frames of HIV risk show how HIV risk is difficult to boil down to a straightforward answer. This challenges the assumptions I had at the beginning of the study. I had expected I would be able to neatly triangulate HIV risk and understand PrEP's role in treating it by interviewing HIV-negative patients indicated for PrEP, HIV-positive patients, and health professionals, as demonstrated by Figure 2 below.

Figure 2. Original Research Aim to Triangulate HIV Risk



Instead of this neat triangulation of HIV risk, what I instead found was the existence of shifting frames of HIV risk constituting an ambiguous discourse. Based upon my interviews and observations, I will break down the "semiotic entanglements" of the discourse surrounding HIV risk into their constituent frames of *who*, *what*, *where*, *when*, and *why* to reflect how the interviewed patients and health professionals alike translated HIV risk from such uncertain terms (Carr 2011:2). In particular, in the following chapter, I will explore the narrative frames: *What* is HIV risk? *Who* is at risk for HIV? *Where* is HIV risk situated? *When* are persons at risk for HIV? And, perhaps most significant of all, *why* are certain people at risk for HIV? By showing that individuals navigate multiple frames for HIV risk, I argue that the discourse surrounding HIV risk is ambiguous, which raises the question: Is such an ambiguous concept really a suitable object for pharmaceutical treatment with PrEP?

***What* is HIV Risk? The Tangibility of HIV Risk Perceptions**

In this section, I argue that both the patients and health professionals interviewed for this study navigated multiple ambiguous frames when answering the question, "*What* is HIV risk?"

Several of the HIV-positive patients used a variety of metaphors to frame the tangibility, or lack thereof, of HIV risk. As Nancy Scheper-Hughes and Margaret Lock (1986) contend, metaphors are "the most 'truthful' way of regarding illness" serving as "messages in the bottle through which patients, and society at large, express their horror, their repugnance (and their protest) at suffering, illness, and decay" (p.138). While some patients used more concrete metaphors to describe what HIV meant to them, referring to it as a "monster," others framed HIV risk in less tangible terms, such as a "beautiful nightmare." For example, Mike, a 54-year-old computer technician and HIV-positive patient at NYCHC, said,

> "There's no face to the virus. There's no face to any kind of STD. So you think you're looking at a drug user or a prostitute or somebody who's not had clean habits. You know? You may look at them and say, oh, they could be infested. But the one person who's clean, well dressed, well mannered, not into IV drugs could be the one who's carrying the virus and you would never know. A disease doesn't have a face."

Mike's saying that "there is no face to the virus," has multiple layers of meaning. In the biomedical sense, the virus itself doesn't physically have a face, but rather is a spherical capsid containing strands of RNA. However, more consistent with what Mike said, HIV's transmission transcends associations with any specific physical signs or identities. This sentiment was echoed by a 54-year-old nurse named Ava, who relayed the following story about a young man who asked her what she thought of HIV,

> "And when he look at me, this very young, handsome fellow, he says to me, 'Can I ask you a question?' I said, 'Of course.' And he said to me in Spanish—he asked me in Spanish, the equivalent in English is something along these lines, 'When somebody is diagnosed with HIV, are you disgusted by it?' And I said 'Well absolutely not!' And I told him, 'I don't know what you're talking about. I don't see HIV anywhere. Do you see it? I don't see it. I see a person in front of me that has been diagnosed with a chronic disease that needs help."

Ava's insistence that she doesn't see HIV anywhere is a powerful assertion that, like Mike's contention that the disease doesn't have a face, also navigates multiple frames and layers of meaning. Literally speaking, HIV is microscopic, and thus cannot be seen without the assistance of a high-powered microscope. However, as Ava said, she doesn't see the stigma associated with those who are HIV-positive. Though HIV stigma itself is an incorporeal cultural construction on the social level (Spieldenner 2014:21), for many HIV-positive patients, the stigma of being HIV-positive manifests in more palpable terms on the individual level. Echoing Yelena Tsarenko and Michael Jay Polonsky's (2011) narrative analysis on how HIV-positive individuals feel like their virus is an "undesired possession" (p.466), the 47-year-old HIV-positive patient, Peter, said he felt like he was "damaged goods" and that he had taken "on somebody else's burden." Other HIV-positive patients reported feeling "dirty," reiterating Judgeo and Moalusi's (2014) findings on how HIV-positive individuals are made to feel like they are "irresponsible, filthy and immoral" social "'deviants'" in comparison to HIV-negative, moral "'normals'" (p.79-81). In this way, HIV risk itself is framed as the possibility of a tangible acquisition of a "burden" or "dirt."

Framing HIV risk as a punishable offense was another commonality between many of the HIV-positive patients and interviewed health professionals. Recalling how he was first notified of his positive status, the 39-year-old salesman, Chris, described how a health professional, one not associated with NYCHC, interrogated him. He said,

> "It was kind of scary, actually. She took me over to some building. It was… She, she called me up and went to this building. And I remember being in a small, tiny room, like an interview room. And she starts grilling me on who you've slept with in the last six months. And where have you been and where do you live? Who do you hang out with? Who are your friends? So, eventually I was like, Jesus Christ, lady, what is going on here? I feel like I broke the law here. So, she's like, well, you know, you are at risk of spreading the disease to someone else.

In this example, Chris relays how a health professional made him feel as if he "broke the law" by being HIV-positive and "at risk of spreading the disease." Expanding upon this, others also framed HIV and the risk of HIV transmission as punishment, and those with HIV as the punishable. One of the case managers, a 31-year-old named Irene, said this sentiment was common among many of her HIV-positive patients, especially women. She said,

> "A lot of times, well I know for some women, they feel guilty that there's that taboo that 'oh, I'm a whore because I have HIV'' or you know, 'Oh, I slept with that guy and he gave me HIV and that's just like my punishment for sleeping around'.... People carry guilt that way. I mean, we even have some of our ladies who are older who say they haven't had sex since their diagnosis. And we're talking like 15 or 20 years. And it's ... that guilt, I think. Guilt and fear."

As Irene conveys, these women feel as if their acquisition of HIV is a punishment for being sexually active, and because of their guilt they feel as if they must now remain chaste. This sentiment was echoed by Gina, a 54-year-old HIV-positive transwoman who conveyed that many HIV-negative women who don't like to use condoms and don't know their partner's history are playing Russian Roulette. In this frame, HIV risk is equated with a dangerous act actively undertaken by someone, and the acquisition of HIV as the inevitable harm resulting from such an act.

In addition to these frames used to describe HIV and its risk of transmission, many of the patients and health professionals in this study framed HIV risk using biomedical metaphors, often highlighting pharmaceuticals. As the nurse Ava demonstrates when asked how she explains the risk of HIV transmission, pharmaceuticals frame the discussions. She said,

> "Well, I just tell them, again, I have a diagram that one of the pharmaceutical reps gave us a long time ago, and it's a diagram—very simple, very plain. It has illustrations and very simple explanations on how the virus gets into the body and how it gets transmitted—how it replicates... And how these medications stop that viral replication at different stages in the CD4s, in the cell. And I tell them—if they were going to stop taking the medication or didn't take it properly, the viral load will come back and, yes, they will be at risk for passing HIV to other people."

As Ava conveyed, patients' risk for HIV transmission is often framed as directly proportional to their viral load, which is kept in check by pharmaceuticals, specifically HIV antiretroviral medications. This example reiterates Thurka Sangaramoorthy's research on how numerical markers can frame HIV risk for HIV-positive patients. Recounting how one HIV-positive woman stood up at a public lecture and introduced herself by saying, "I am 400 CD4 count and 250 viral load," Sangaramoorthy discusses how the woman's use these of numbers to label herself over her own name is as an example of the "numerical subjectivities'' by which many

HIV-positive patients “frame and portray themselves through numbers and statistical calculations” (Sangaramoorthy 2012:293). Significantly, by framing HIV risk in such numerical terms, HIV-positive patients are held responsible for continuously taking their antiretrovirals to reduce their risk for transmitting the virus.

In addition to framing HIV risk in numerical terms, pharmaceuticals also create the entirely new HIV status of “undetectable” to frame HIV risk. Neither wholly positive nor wholly negative, the liminal HIV “undetectable” virus status has slowly emerged over time as HIV antiretrovirals improved and laboratory viral load quantification tests gradually became more sensitive. Today, according to the CDC, an undetectable viral load is defined when a person has less than 40 copies of the virus per milliliter of blood, with a “virally suppressed” status being achieved at less than 200 copies of the virus (CDC 2019b). What is more, as promoted by the Prevention Access Campaign’s slogan “Undetectable = Untransmittable” or “U=U,” when HIV-positive individuals have an undetectable viral load as achieved by taking their antiretrovirals, they cannot transmit this virus (Prevention Action Campaign 2019). In this study, this “undetectable” status was referenced by 61% of the individuals interviewed (73%, 8/11 PrEP patients; 46%, 6/13 HIV-positive patients; and 64%, 9/14 health professionals). Amongst the HIV-positive patients, several specified that being undetectable was a significant health goal because of the reduced risk of HIV transmission. As the 47-year-old HIV-positive patient Peter told me, when he was diagnosed with HIV, one of his first questions to his case manager was “‘What does it take for me to be undetectable?’” To which he was told, “You just got to take your medicine. Kept that in my head. Take your medicine. Take your medicine. Go check your viral-, go check your viral loads and your numbers. If it goes down, you’re good.” In this example, Peter's repetition of "take your medicine" illustrates how HIV antiretrovirals and the viral load quantifications may frame a patient's sense of wellbeing and HIV transmission risk.

In summary, from monsters, to social deviance, to undetectable viral loads, the patients and health professionals in this study navigated multiple frames when answering the question, "*What* is HIV risk?" This raises the question, how can such an intangible concept be the object of medical treatment and targeted by PrEP?

***Who* is at Risk for HIV? The Identities Associated with HIV Risk**

Just as patients and health professionals continuously navigated various frames for *what* HIV risk is, so too did they traverse multiple frames of identities when answering the question "*Who* is at risk for HIV?" to illustrate HIV risk's ambiguity.

Many ascribed HIV risk to certain groups based upon their behaviors. Most prominently, 92% of those interviewed (91%, 10/11 HIV-negative patients indicated for PrEP; 100%, 13/13 HIV-positive patients; and 86%, 12/14 health professionals) attributed HIV risk to people who have multiple sexual partners and/or those who do not use condoms. To characterize this behavior, some used specific phrases, sometimes with derogatory connotations, such as "sex addicts" and "promiscuous people" while others used more generalized descriptions such as "anyone who's having sex." Additionally, all of the health professionals (100%, 14/14) associated drug users as those at risk for HIV, in contrast to only roughly half of the patients doing so (55%, 6/11 HIV-negative patients indicated for PrEP and 54%, 7/13 HIV-positive patients). One possible reason for this difference is that the health professionals may be more familiar with the CDC's epidemiologic categories of HIV risk and the biomedical science behind the blood-to-blood transmission risk of HIV associated with intravenous drug use.

The frame of *who* is at risk becomes more ambiguous when stereotyped behavior is conflated with profession. For example, some of the patients identified cross-country truck drivers as being at risk for HIV because they believed they are more likely to elicit the services of prostitutes at truck stops. Alternatively, several PrEP patients and a health professional considered first responders and healthcare workers as being at risk for HIV, namely because of the possibility they come into contact with infected blood. What these risk groupings speak to is how identities and behaviors become intertwined with framing who is at risk for HIV. This is similar to a behaviorist approach to HIV risk like that which was the focus of Jill Owczarazak's research on HIV prevention programs in post-socialist Poland (Owczarazak 2009). Significantly, as Owczarazak contends, when HIV prevention programs focus on managing individual's "risky behaviors," it reveals their primary "concern with 'fixing the individual,' rather than the social context that shapes risk" (2009:431).

In contrast to this behaviorist frame, most of the HIV-positive patients broadly ascribed HIV risk to the younger generation, with 70% (9/13) of the HIV-positive patients doing so in comparison to only 9% (1/11) HIV-negative patients indicated for PrEP and 21% (3/14) health professionals. This is perhaps due to the HIV-patients' older age, providing them a greater retrospection than the younger PrEP patients and health professionals (the median age of the HIV-positive patients was 57 in contrast to the median ages of the PrEP patients being 39 and the health professionals being 41.5). As one 65-year-old HIV-positive man, Paul, said,

> "People don't seem to be using protection anymore, especially younger people. The people that are my age, that lived through it are still conscious about protection or even not having sexual relationships at all anymore. But the young kids don't know it because they didn't live through it, and they just think that they're invins--indispensable, and it's not going to happen. But I notice a lot of the young kids think that it's just a free-for-all. Anybody and everybody."

For Paul, the younger generation is at risk for HIV because have not been scared into protecting themselves by the death and stigma that AIDS once portended in the eighties and nineties. This identification of the younger generation was echoed by several of the other HIV-positive patients, like the 47-year-old Peter, who said that the people at risk for HIV are the “fast people,” the “ones that want to grow up fast and want to turn into adults so quick, but don’t have the knowledge of life.” Or Gina, a 54-year-old HIV-positive transwoman who said, “You know, the juveniles, the really young people that party. They need to wise up. They really do. They’re kids and they just think, oh, I look good. I’m 20 years old. I’m untouchable.” Echoing Paul and Gina, Elaine, a 57-year-old HIV case manager, said that she feels many of the teenagers have “‘it’s not going to happen to me’ syndrome.” Paul’s use of the term “indispensable,” Gina’s use of “untouchable,” and Elaine’s use of “‘it’s not going to happen to me’ syndrome” in describing the younger generation speak to how they frame this demographic as at risk for HIV for the very reason that they don’t believe themselves to be at risk for HIV.

Significantly, a majority of the health professionals (10/14 of those interviewed) used cultural identities to frame those at risk for HIV, such as minority communities or “MSM,” or Men who have Sex with Men. When asked who is at risk for HIV and why, Cat, a 37-year-old nurse, answered,

> Cat: Young MSM, both Latino and black…Because I think most of my new positives lately have been young MSM with color. We need to get to them people … We got to educate them and help them out. Why is there a barrier for them, you know, to get the safeties that others get or why they don’t feel comfortable enough to come in before this happens, get the condoms and get on PrEP or something like that?
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> Researcher: What kind of barriers do you think are out there?
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> Cat: Well, cultural, definitely. Financial, probably. Family stigma, period. It’s not as accepted in, I want to say, people of color as like, cultural. You know, black people and Latinos, to be MSM, to be gay is not… Not everybody has it where they can just be open about it. So, it’s a lot of hidden stuff. And when you live in secret, you know, you do a lot of other stupid shit in secret.

To Cat, young Latino and black MSM are at greater risk because of the intersectionalism of their identities both as gay and as minorities. This is consistent with the research of Kenneth Mayer et al, who found such identities may manifest as multiple inequities, be it racism, financial hardships, community homophobia, and a lack of freedom of expression (Mayer et al 2014).

Other health professionals framed not only minority MSM patients as at greater risk for HIV, but all minority patients. Within the Latinx communities specifically, several health professionals went further to identify women as at higher risk because of "machismo." As the PrEP administrator Trudy described it, Latina women "lack the education" of HIV prevention and "they just trust and believe in their man." Likewise, the HIV care administrator Selena contended that some HIV-positive Latina women were at greater risk for HIV "because it was cultural, meaning that you don't ask who your man is with. He's paying the bills." This cultural placement of HIV risk reiterates Nina Schiller's critical analysis of the hegemonic construction of culture and risk in the context of AIDS research in the United States. She argues that the hegemonic processes identifying "culture" among certain "risk groups" for the transmission of HIV not only "otherizes" certain populations based upon their assumed shared traits (Schiller 1992:239), but may neglect the structural reasons, in this case structural sexism, that might perpetuate the disease's spread (1992:246). In a similar line of reasoning, Hannah Bell et al have argued how the medical "racialization of risk" reinforces embedded social structures of racism (Bell et al 2018). They show how black patients are disproportionately "marked" as "risky bod[ies], which nee[d] to be consistently checked, monitored, labeled, and treated for illness, reinforcing structural power and inequity along racial lines" (2018:12). By identifying minority patients as being "at risk" for diabetes based upon their minority status, they argue that clinicians are not empowering them to "take control" over their diagnosis, but rather are "channeling blame toward minority patients for developing health problems and exhorting them to shoulder an increased burden of responsibility for managing disease" facilitated by structural inequalities beyond any individual's control (2018:11). Contrast to this, I was continuously impressed by the sense of social justice with which NYCHC health professionals spoke when describing the mission of NYCHC to serve the underserved. Their mention of cultural reasons for HIV risk was not presented in a way to "channel blame" toward any one cultural group. Instead, they were interested in drawing attention to existing structures making such groups more vulnerable to HIV.

In contrast to the behaviorist and cultural groupings often invoked by the health professionals, when asked who is at risk for HIV, a frequent answer amongst the HIV-negative PrEP patients and HIV-positive patients alike was "everybody." "I think HIV is not exclusive to a particular race, a particular group, a particular person," said, Quinn, a 29-year-old nonbinary hair stylist and PrEP patient. Or, as Cesar, a 26-year-old school counselor and PrEP patient said, "HIV doesn't discriminate." Similarly, when asked if some groups of people are more likely to get HIV than others, Jack, a 43-year-old waiter and HIV-positive patient, responded,

> Jack: I think that people who say, "Oh, well the minority groups are, are more susceptible to getting HIV," I think it's bullshit, to be honest. I think it doesn't know any race or gender or class or anything. I think anyone can get it at any time. It does-, knowing how much money you have or little money you have or what neighborhood you grew up in or whatever. That's my view on that.
> Researcher: All right. Do you think that's changed over time at all, or it's always been like that?
> Jack: I think it's always been that way.

To Jack, HIV is an equal opportunity disease, and the risk for its transmission knows no race, class, or gender. His belief demonstrates Jehan El-Bayoumi and Soheir Morsy's contention that "official" groupings of HIV risk only "len[d] justification to the assertion that the disease is one of marginal persons, whether local 'deviants' or alien Other" (El-Bayoumi and Morsy 1993:2). In other words, to HIV-positive patients like Jack, his sense of equality in becoming infected with HIV is inherently tied to his sense of equality as a person in society.

In summary, the patients and health professionals painted a diverse picture of identities associated with HIV risk, from people who have multiple sexual partners, to "young MSM of color," to everyone. This shifting frame of "*Who* is at risk for HIV?" further illustrates the ambiguity of its amorphous narrative.

***Where* is HIV Risk Situated? The Location of HIV Risk**

What HIV risk is and *who* is more associated with it are only two aspects of the ambiguous discourse surrounding HIV risk, however. *Where* that risk is located was yet another frame used by the patients and health professionals in their descriptions of how HIV risk is differentially situated.

Of those interviewed, several patients and health professionals specifically framed HIV risk as being located within an individual's blood. As Iris, a 66-year-old HIV-positive woman, explained, "Because once you get it in your blood, it's in there." This permanence of HIV, and its risk, being located in the blood was often a topic of rumination for another HIV-positive patient, the 47-year-old man named Peter. He wondered aloud, "If I just get a blood transfusion and just get all cleaned up, would I still be HIV-positive? To wipe out all the blood and then new blood comes in." To Peter, his HIV-positive status is located in his blood, and if he were to wholly replace his blood, he may no longer carry that status with him. While per biomedical beliefs, there are other reservoirs of the virus in the body, such as the cerebrospinal fluid, but to Peter, his blood is the location of his HIV.

Other patients were less specific in their framing of HIV risk's location. When asked why they[3] were able to stay HIV negative until now, Quinn, the 29-year-old nonbinary hair stylist and

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[3] "They/them" pronouns are used for the patient, Quinn, who identified as non-binary.

PrEP patient said, “Because I stay in the house. I don’t go outside. I really don’t. I don’t go outside.” For Quinn, they have been able to stay HIV-negative because they stay inside, situating the risk of HIV beyond the walls of their house and the safety from its transmission within them. Gina, a 54-year-old HIV-positive transwoman, reiterated this sentiment of inherent danger beyond walls, saying, “This is New York. It’s a jungle out there.”

To others, HIV risk was framed as more differentially spread out than just being “out there.” To Selena, a 41-year-old HIV care administrator, her past experience once led her to believe that HIV risk was more closely associated with “an area, a population, a region, whatever you want to call it, that was highly engaging in meth parties and drugs use and prostitution.” She expanded upon this, saying that, in that region, “we were testing a lot of positive because there was a lot of barriers there as well, of course, homelessness, social determinants of health.” In particular, Selena went on to explain that, when it came to HIV care,

> “Housing is the number one barrier that we have because, unfortunately, when you don't have a place to lay your head, the last thing you're thinking of is taking this pill. Because, where are you going to keep that pill? What if someone finds the pill? What if you lose the pill? So, housing has presented to be a number one barrier.”

As previously discussed, HIV transmission risk is much higher when patients are not able to take their medications to suppress their viral load, and, according to Selena, housing is imperative to this. In complement to Quinn, who placed HIV risk as outside their house, Selena in this instance is ascribing HIV risk to a *lack* of housing altogether.

Overall, HIV risk was differentially framed in various locations by the patients and health professionals, being situated in blood, outside protective walls, and within certain neighborhoods to further demonstrate the ambiguity of HIV risk.

When **are People at Risk for HIV? The Timing of HIV Risk**

Thus far, I have explored how the patients and health professionals have navigated multiple frames of *what*, *who*, and *where* HIV risk is. In this section, I will further examine the multiple timings of HIV risk, or *when* they believed people are at greatest risk for HIV and its impact on their lives.

Several of the patients framed HIV risk as being in the past. Specifically, they portrayed the eighties and nineties to be an era of HIV risk, evoking images of the "fear, hysteria, and outright bigotry that was all too common at the epidemic's onset" (Parmet 2008). Contrasting today's current views of HIV risk with those in the past, Paul, a 65-year-old HIV-positive man, said, "I don't think it's scared anybody at all, especially nowadays. Like I said, back in the '80s, it scared a lot of people, but it's been so many years that—and then with all the medications and things, people think that it's not there anymore, but it's actually still there." This sentiment was shared by the 37-year-old nurse Cat, who said, "You know, I'm an eighties baby. So, early nineties, late-eighties. It was like, you got [HIV], you're going to die."

Alternatively, instead of placing HIV risk in the past, several HIV positive patients framed HIV risk within the future, specifically attributing it to a "lack of vision" or "focus" on what the future might hold. When asked how he may have been at risk for HIV, Mike, a 54-year-old computer technician and HIV-positive patient, said:

> "Very simple. Thought I was invincible. Party. Lack of vision. Because as a young person, we get caught up into the scene of … Almost like we have to satisfy our peers instead of satisfying ourselves. So, we lose the focus. And especially these young kids today. Everything is social media, status, and all that."

To Mike, he was at risk for HIV because, as a youth, he had lost his "vision," or "focus," and was beholden to "satisfying [his] peers" instead of protecting his own future. Diego, a 28-year-old barista and HIV-positive patient, said that becoming HIV-positive was a "lifechanging alert," that prompted him to “stop[p] partying” and “star[t] focusing,” reiterating Mike’s portrayal of HIV risk as a lack of focus on the future. Several other patients mentioned drugs as a risk for HIV because of their mind-altering properties affecting individuals’ ability to focus. As Dot, a 54-year-old HIV-positive woman explained, “You know, drugs. I was taking drugs. My lifestyle at the time, you know? But, you know, when people are on drugs and they're getting high and doing this and that, they don't think about that kind of stuff.” Gina, a 54-year-old HIV-positive transwoman echoed Dot, saying that, “Smoking pot. Doing blow. Etcetera, etcetera. The mind changes...You know? Especially at nighttime. Especially when there’s a lot of people, strangers in the same club. But your only attention is that man, guy you like.” In these instances, these patients frame HIV risk as a lack of focus on their future protection, whether because of drugs or because of seemingly competing priorities like social status or intimate connections.

In addition to how many of the HIV patients frame their risk of HIV as a lack of focus on their future, several of them also described how their vision of that future drastically changed once they found out they were infected. The 47-year-old patient Peter told me that right after the healthcare visit when he found out he was HIV-positive, he almost jumped off of a bridge because, as he said, “I didn’t want to feel like I wanted to pass this onto somebody else. And somebody else’s family is going to go through what I’m going through or my family’s going through with me. So, it’s just like, I didn’t want to do that. I was going to end the cycle right there.” Fortunately, Peter was able to get the support he needed from his family, but his tortuous desire to “end the cycle right there” speaks to how HIV can eclipse many patients’ hope for any sort of future. As one of the physicians, a 32-year-old named Dr. Gabriel, described, many of these newly diagnosed HIV-positive patients often lose sight of their future. He told me,

> “I had one patient in his 60s and newly diagnosed. And he was trying to piece together dates. And I felt like I was being a detective more than being a doctor at that point, in terms of trying to piece together when the window was, potentially, that he got it. And I was able to try to narrow it down

> a bit for him. But eventually I had to kind of refocus him on what's going on. The fact that since he is positive we, and what we have to do about it."

As Dr. Gabriel relates, he had to "refocus" the patient, reorienting him away from the past, when he became infected with HIV, toward a present and future in which he must learn to manage and live with that HIV.

On the whole, the patients and health professionals in this study associated different timings with HIV risk, whether placing that risk in the past or eclipsing any focus on what the future may hold.

Why **are Some at Risk for HIV? The Agency of HIV Risk**

Though the ambiguous discourse surrounding HIV risk navigates multiple frames of *what* HIV risk is, *who* is at risk, *where* they are at risk, and *when* they are at risk, perhaps the most important frame it traverses is *why* some are at greater risk for HIV than others. In other words, according to the various accounts of the patients and health professionals interviewed, the agency of HIV risk is drawn into question. In this section, I will discuss how this agency of HIV risk was framed in terms of lifestyle choices, circumstance, and deception.

Overwhelmingly, most of the interviewees (82%, 9/11 of the HIV-negative patients indicated for PrEP; 77%, 10/13 HIV-positive patients; and 93%, 13/14 health professionals) framed HIV risk as a matter of lifestyle choices, whether those be involving sex, drugs, or any other forms of "unsafe play" as a 44-year retail manager and PrEP patient, Luke, described it, saying,

> "It just depends on what your lifestyle is. So, it's all lifestyle. So, if you're a person that's going to have multiple sex partners, then obviously? You're going to be at more risk. If you're taking drugs, then you're at a risk. But I know plenty of people that don't do any of that stuff. So, it's really just a matter of the person's lifestyle that, that puts you in that category. Because for me, I'd never had an STD until… I was not married. I married my high school sweetheart. I was with

> her since 16 years old. And she was my only partner up until I hit, you know, my forties. So… Never had an STI until that ended."

In this excerpt, Luke directly ascribes HIV risk to a person's lifestyle, indirectly blaming HIV acquisition on that lifestyle.

However, for others, framing HIV risk in terms of one's "lifestyle" is much more nuanced than that, especially when one does not necessarily have complete agency over their lifestyle choices. Selena, a 41-year-old HIV care administrator, demonstrates this complexity when answering the question, "When you hear that someone is at risk of HIV, what does that mean to you?" She said,

> "That means that the person is experiencing behaviors that can lead to acquiring the HIV virus. So, whether it's through injection drugs, so whether it is through transactional sex, like sex workers, whether it is multiple partners without condoms, non-condom use, whether it is the lack of education, not understanding what HIV is itself. "

Selena's use of the phrase "is experiencing behaviors" is interesting in that is neither active nor passive. To experience a behavior, a person can actively engage in that behavior, be passively forced into that behavior, or an infinite combination of the two. A good example of this neither-wholly-active-nor-passive phenomenon in framing HIV risk is the question of condom use. In this study, a majority of those interviewed (100%, 11/11 HIV-negative patients indicated for PrEP; 77%, 10/13 HIV-positive patients; and 79%, 11/14 health professionals) framed HIV risk in terms of a lack of condom use or unprotected sex. While some patients attributed HIV risk to "not using condoms," or "wearing raincoats" in the active sense, placing the agency for using the protection within an individual's capacity, others pointed to how it is more complex than that. As Irene, the 31-year-old HIV case manager, described it, "someone at risk for HIV would be someone who has multiple partners, who has trouble negotiating condom use or prefers not to use condoms." Irene's use of the phrase "negotiating condom use" points to the power dynamic at play when condoms are, or are not, used during sex. Describing the extreme end of this active-passive spectrum, Selena reported that she “had young ladies come to me saying that the pimp will beat them up if they were using condoms” because “condom use doesn't pay the bills.” But individuals need not be transactional sex workers to have mitigated agency of their HIV risk. As several health professionals noted, women in domestic violence situations, in any form, are also at risk for HIV. As the 37-year-old nurse, Cat, explained,

> “I want to point out women too that are in these situations where they don’t have control. They don’t have the control in their sex or their life, period. And when they get dominated by these men… And God knows what they’re doing. You know? Because half the time, while they’re beating the fuck out of them, they have another woman that they’re having sex with, or a man, who knows? And they can be at risk also.”

In this way, these health professionals speak to how HIV risk might be framed in terms of a *lack* of agency, or control, over one’s lifestyle and choices.

Tangentially, several of the subjects interviewed also framed HIV risk in terms of an individual’s life circumstance. As the 39-year-old physician Dr. Wanda described this circumstance of HIV risk, some people are simply “born in the wrong place at the wrong time.” When I asked Cesar, a 26-year-old school counselor and HIV-negative PrEP patient, “Why do you think you’ve been able to stay HIV-negative until now?” He responded with one word: “Luck.” He went on to explain, “Honestly, I haven’t always followed proper precautions. As far as like in my sexual life, I have had encounters where I wasn’t protecting myself, or I wasn’t caring about my own health and I had multiple partners at a point, you know. So, I have been at risk for it.” While Cesar framed his HIV risk in terms of circumstances that worked in his favor, others framed HIV risk in less favorable terms. For example, the 38-year-old physician Dr. Alexandra discussed how several of her patients who were perinatally infected with HIV “didn’t even have a choice,” further supporting the frame of HIV risk in terms of a lack of agency. But this vulnerability to HIV risk extends well past pregnancy. Describing his friend’s HIV risk, the 47-year-old HIV-positive patient Peter said,

> "Well, my friend got kicked out of his house at 14. His mom didn't accept that he was gay. So, at 14 you have to use what you got to get what you want...He had to use what he got to get what he want. And that's what he used. He used his body to get everything that he wanted."

Unlike Cesar who attributed his HIV-negative status to "luck," Peter attributed his friend's HIV-positive status to the fact that he lacked any form of social, emotional, and financial support at an extremely vulnerable age. This demonstrates Merrell Singer's use of syndemic theory to describe how health disparities are "tied to" other disparities in the U.S. such that "*AIDS itself emerges as an opportunistic disease*, a disease of compromised health and social conditions, a disease of poverty" (Singer 1994:937; emphasis in original).

Additionally, under this purview of individual circumstance, multiple patients and health professionals referenced a "lack of education" in framing the agency of HIV risk. As the 39-year old salesman and HIV-positive patient Chris said, "Everyone's at risk. So, the best way to protect yourself is to educate yourself against it and go from there." As Dr. Alexandra maintained, part of that education is helping patients make the connections between their behaviors and possible outcomes, overcoming the distance they put between themselves and the idea of HIV. She said,

> "Like somebody comes in with an STI and I say, 'Okay, like, have you had STIs before?' And they give me that answer of yes or no. And then I say, 'What else do you think you could potentially have gotten from this?' And then they'll be like, 'Well, I don't know. I mean I think it just happened rand—this was just an STI.' They kind of think of it as isolated events and then when you talk about sexual networks, then they start thinking about HIV. And then when you mention the word HIV, they're like, 'Oh, not me, that can't happen to me.' And then, then you have to kind of counsel them about how they're potentially at risk. So, I don't think patients sometimes realize their risk really."

This echoes Beverly Sibthorpe's research on intravenous drug user's perceptions of HIV transmission risk sheds further light how education targeting "personal behaviors alone" instead of social issues make the "risk of HIV easy to depersonalize as something 'out there,' not personally relevant" (Sibthorpe 1992:267). Expanding upon this, Dr. Wanda said, "I think in a lot of people's heads, there's sort of a scale of risk, and HIV is at the end, and I think that's not the case. It could be the very first thing that you acquire." In both scenarios, what Dr. Wanda and Dr. Alexandra are trying to impress upon patients is that HIV is neither an isolated event nor is it at the end of a scale of risk. Rather, HIV risk is not as distant from them as they believe it to be, requiring further education to see how close it actually is.

Significantly, in contrast to lifestyle and circumstance framing why some are more likely to get HIV than others, another frequently discussed frame of HIV risk was deception. When asked the question, "Did any health professional ever tell you were at risk for HIV?" the 51-year-old teacher and HIV-positive patient, Miranda, said,

> "No. It was never discussed. And I wasn't at risk...I was married to the same man....You know, he was my first boyfriend and everything. So, I wasn't at risk. To me, it was like, oh, I'm safe because I've only been with one partner....Not knowing he was positive. But, no. When I took the test I was like, I know I'm negative. I've never been with anyone else. Yeah."

As this excerpt demonstrates, Miranda did not feel she was at risk for HIV because she herself was not engaging in any risky behaviors. It also demonstrates my own bias as an interviewer by assuming that, because she was HIV-positive, she must have been at risk in some way. The juxtaposition of these two interpretations—Miranda believing she was not at risk for HIV and my assumption she had been based upon her positive status—points to how inaccurate such assumptions about HIV risk may be. They also point to the deception at play—Miranda's husband's not telling her he was positive—that led to Miranda's ultimate serostatus conversion. Miranda was not alone in feeling this way. Another HIV-positive patient, a 56-year-old woman named Patricia, also believed she was not at risk for HIV. She just "happened to have the wrong partner." Describing her own HIV risk, Patricia said, "Housewife. Person that went to work. Person that took care of their kids. That's—what kind of risky behavior was that?"

This deception leading to these HIV-positive statuses for these women was replicated in a lack of trust felt by several other patients and health professionals in framing HIV risk. The 57-year-old case manager Elaine described how she conveys this lack of trust to patients, saying,

> "I've said, 'I'm not trying to tell you your partners cheating on you or whatever, but you're not around that person 24 hours a day. You don't know—' 'But yet, my husband went to work today.' 'Well, something could have happened during work time. Might know somebody on the job. You know?'"

As Elaine demonstrates, by its very nature, deception is unpredictable and can happen to anyone, thereby rendering everyone as at risk for HIV and in need of protecting themselves. In contrast to Elaine, who placed responsibility for HIV risk with the person *being* deceived by their partner, others placed the responsibility with the person *doing* the deceiving. As the 44-year HIV-negative PrEP patient, Luke, averred, it "should, you know, be a real crime" to have the HIV virus and not disclose it to your sexual partners. Peter, a 47-year-old HIV-positive man, agreed with Luke, saying about the person who infected him, "Somebody should have went to jail for me for attempted murder because I didn't know that this person was HIV positive. He didn't disclose anything of that nature. And I asked him." And while this deception seems black-and-white, other patients depicted such acts in less straightforward terms. Ivin, a 32-year-old HIV-negative patient taking PrEP, expanded upon this, saying, "I think there are people who might lie about their status to not feel bad about themselves." In other words, self-deception is a way some people may protect themselves from the truth, and its impact, of their status.

In summary, the patients and health professionals interviewed in this study navigated multiple frames for *why* individuals are at risk for HIV, including their lifestyle choices, circumstance, and deception. Significantly, this attenuation of the agency associated with HIV risk, or *why* some individuals are at risk for HIV when others are not, further begets the question, why should some take PrEP over others?

Conclusion

Returning to Trudy’s long, circuitous response to my question “What does being at risk for HIV mean to you?” at the beginning of this section, her seemingly lack of an answer in admitting “I guess I don’t know what it is for me. I think it's hard for me to put things into words” shows she perhaps understands the complexity of HIV risk best of all. As my interviews with the health professionals and patients have shown, “HIV risk” has an ambiguous discourse all by itself. And with that ambiguous discourse comes a constituent, if amorphous, framework concerning *what* is risk, *who* is at risk, *where* risk is located, *when* individuals are at risk, and *why* some individuals are at risk while others are not. In contrast to my original expectation of neatly triangulating HIV risk and understanding PrEP’s role in treating it as demonstrated by Figure 2 below, this study points to an ambiguity of HIV risk more aptly demonstrated by Figure 3.

Figure 2. Original Research Aim to Triangulate HIV Risk

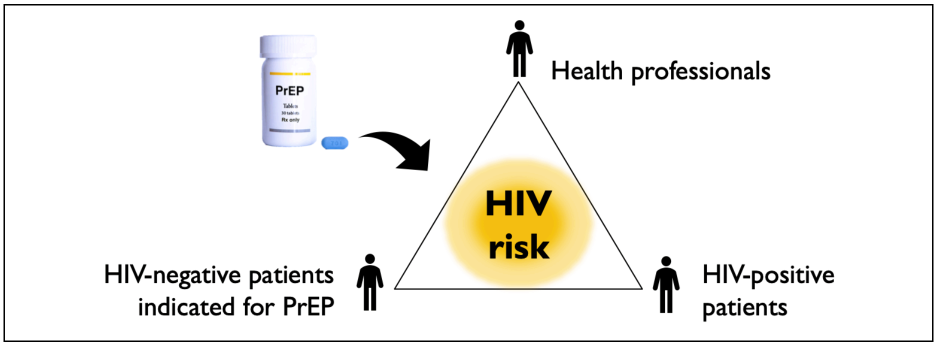
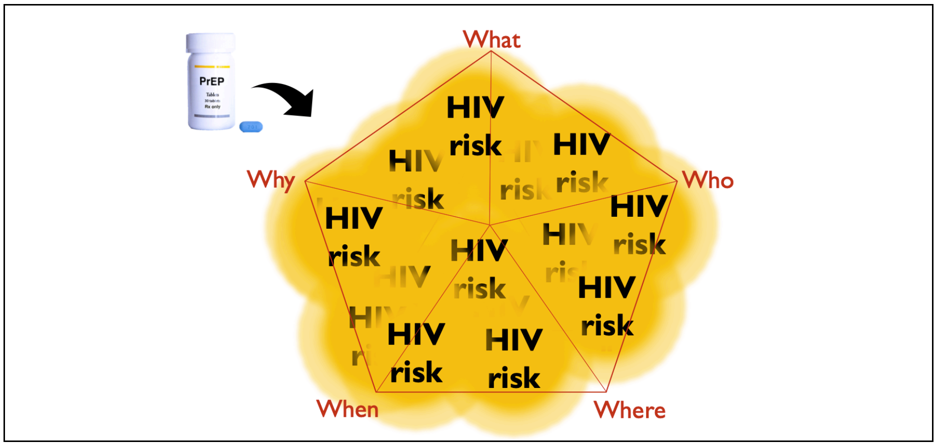


Figure 3. The Ambiguity of HIV Risk



In other words, HIV risk cannot be put “into words” because its ambiguous usage allows it to navigate so many words at once. Significantly, as the next chapter will explore, if HIV risk cannot be put into words, in what ways might it be manipulated to be an object of pharmaceutical treatment with PrEP?

Chapter 5: PrEP’s Crystallization and Distortion of HIV Risk’s Ambiguity

It's early Saturday one July morning, and I am in an empty exam room at New York Community Health Center (NYCH) interviewing the HIV-negative patient, Luke. Luke is an amicable 44-year-old retail manager with a heavy New York accent who is currently taking PrEP and is here for a follow-up visit. “Well, what do you think about PrEP?” I ask him. He responds,

> “I think it allows people to be a little bit more risky than they would have been if they weren’t on PrEP. Because even myself, I’ve always played safe. Okay? And since I was on PrEP, there are moments of weakness. It’s like that devil and angel on the shoulder. Where the devil’s like, ‘Yeah, you’re on PrEP. You can do it. You can be unsafe.’ Where you’re going to do some kind of penetrative without a condom. And, the angel’s kind of like, ‘Don’t do it.’ Which I always had… I always say before PrEP, I always had two angels on my shoulders. And that PrEP is like my devil. That’s personal, my belief. But I think people that are less inclined to have safer sex practices, that PrEP will be two devils on their shoulders. Where they are going to be more risky. And I’ve heard this. I mean, it’s not where I’m just making it up. Where it’s a theory. I’ve heard this from playmates. That, they’re like, oh, everything else is curable. It’s like chlamydia, gonorrhea, minus other stuff that may, viral stuff that’s not curable. But they feel that, okay, as long as I’m safe from HIV, that everything else doesn’t matter.”

In contrast to the ambiguity of HIV risk, as discussed in the previous chapter, PrEP, a daily pill, has a very tangible form with very tangible consequences. For Luke, PrEP is like a devil on his shoulder that is telling him “You can be unsafe.” Never having had an STI before starting PrEP, he now has had two. This speaks of the complexity of risk: though PrEP is supposed to reduce HIV risk, for Luke, it has actually increased his risk for other STIs. As this “devil on the shoulder” image demonstrates, multiple new frames of meaning emerge when the ambiguity of HIV risk clashes with the tangibility of PrEP. *What* PrEP is, *who* should take it, *where* it works, *when* it should be taken, and *why* individuals should it take it all contribute to a discourse conceptualizing HIV risk.

In this chapter, I will argue that this pill’s collision with the ambiguous discourse surrounding HIV risk crystallizes and warps certain aspects of that discourse. In contrast to the ambiguity of HIV risk established in the previous chapter illustrated by Figure 3, this chapter will show how PrEP both reinforces and distorts certain aspects of that ambiguous discourse, as illustrated by Figure 4.

Figure 3. The Ambiguity of HIV Risk

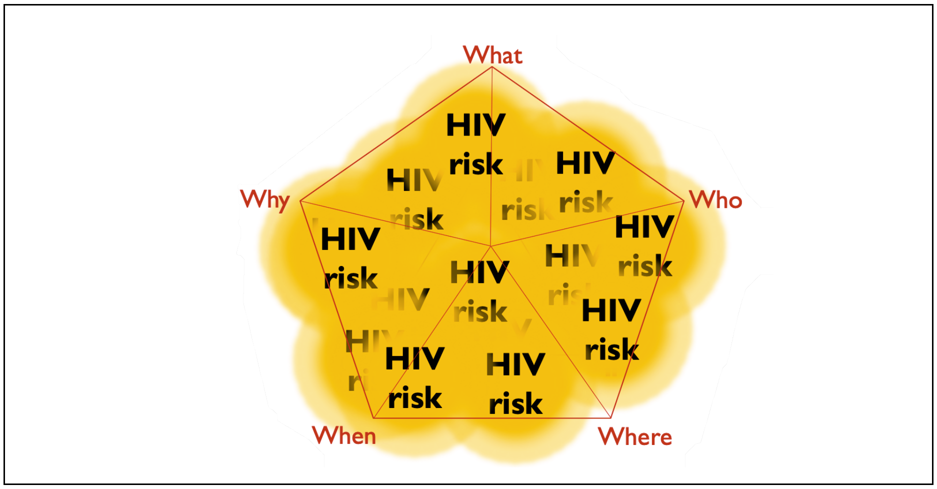
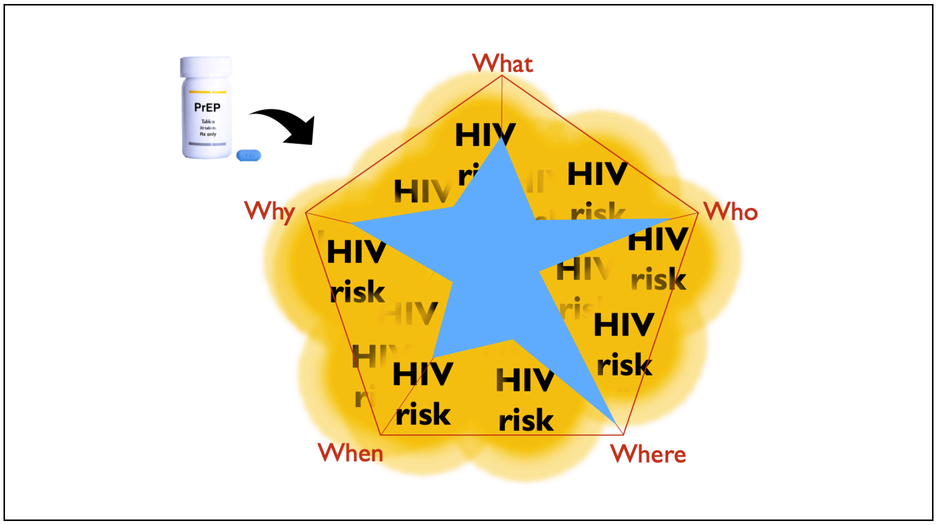


Figure 4. How PrEP Distorts and Reinforces HIV Risk's Ambiguity



For each section of this chapter, the patients and health professionals' perceptions of PrEP is broken down into the frames of *what* (materiality), *who* (identity), *where* (location), *when* (timing), and *why* (agency) to both reinforce and distort HIV risk's narrative components.

Specifically, for each section, I will ask: *What* is PrEP? *Who* should take it? *Where* is it located? *When* does it work? And lastly, *why* do people take it? By showing how PrEP's use transforms the ambiguity of HIV risk, I raise the broader question of what effects this drug might have on our society as a whole.

***What* is PrEP? The Materiality of a Pharmaceutical Intervention for HIV Risk**

As Henry, a 25-year-old artist starting PrEP, said, "[PrEP]'s almost a slang word at this point. Like saying 'LOL'. Everybody's on PrEP." The pervasiveness of PrEP in some communities has allowed for its interpretation through several different frames of perspective. In this section, I will discuss how the tangibility of PrEP—or *what* PrEP is—is framed, and how this tangibility reinforces the tangibility of HIV risk, too.

Several of the patients framed PrEP in terms of physical protection. One HIV-negative patient, a 54-year-old mechanic named Gus, said, he thinks of it as an "added protection" analogous to another "seatbelt." Another patient taking PrEP who previously worked in IT described it as a "backup to a worst-case scenario," like a computer in case it crashes. To the 28-year-old barista and HIV-positive patient, Diego, PrEP is like a "shield" protecting one from HIV. This tangibility of PrEP was also expressed by Dr. Alexandra, a 38-year-old physician at NYCHC. When asked, "Does PrEP change the way you feel about your patients' risk for HIV?" She said, "Yes. Because I think PrEP is protective so I feel that they have a blanket around them. I feel safer when they're on PrEP of not getting HIV." Using terms like seatbelts, backups, shields, and blankets, PrEP was often framed in tangible terms to solidify the tangibility of HIV risk. This demonstrates what Whyte, Geest, and Hardon's (2002) described in the "Social Lives of Medicines" in which they remind us that "*material medica*," Latin for "medical material," means that “medicines are material things” (p.3). They argue, “When medicinal objects with such meaningful associations are applied to ailing bodies, they concretize the problem and thus make it accessible to therapeutic action of a fitting symbolic nature. Suggesting connections and making disorder and its correction tangible is the symbolic and very practical work of medicines” (2002:15). In these terms, by applying PrEP to at risk bodies instead of ailing ones, the medicine further concretizes HIV risk and thus makes it accessible to therapeutic action.

Interestingly, several of the HIV-negative patients used the biomedical frame of medication to frame PrEP. Val, a 57-year-old insurance agent and HIV-negative patient who was indicated for PrEP, said she’d “rather take a pill” than use a condom. When asked to elaborate, she said,

> “I mean, I don't have a problem with taking medication. I'm very good about my own medication that I take and—this might sound silly, but condoms are kind of a nuisance, so if you can take a pill and—that's changing your whatever is in your immune system in your body. I mean, the condom is just a material. It's a barrier. So, if there's something that you can take that improves your immunity to HIV, that, to me, seems more healthy and less risky. I mean, the condom can break, can slip off, you know.”

To Val, taking PrEP is “more healthy” and “less risky” than using a condom because, in her mind, it “improves your immunity” inside the body unlike the untrustworthy condom which works outside the body and can malfunction. In biomedical terms, PrEP is an antiretroviral that prevents HIV by building to certain levels in the blood and various tissues to prevent the virus from replicating and taking hold (San Francisco AIDS Foundation 2020). However, to Val, the medication is enhancing her body’s immune system, suggesting an inherent need for that immune system to be strengthened by a medication like PrEP. Samuel, a 39-year-old landscaper and HIV-negative patient taking PrEP, thinks the medication does even more than that. He said, “I had chlamydia. And so I take that pill... When I go to lab they tell me that I’m clean.” To Samuel, PrEP, “cleans” his body of all STIs, including chlamydia, a sexually transmitted bacterial infection that is usually treated with antibiotics, not PrEP. This framing of PrEP as "cleaning" his body is concerning because it paints a picture of the human body at risk for HIV as a dirty receptacle needing pharmaceutical intervention to rid it of that dirt.

To other patients, PrEP is superior to condoms because of its regularity as a medication. As Cesar, a 26-year-old school counselor and HIV-negative patient taking PrEP, said, "It's like taking a vitamin every morning. You know, drinking your coffee." Jack, a 43-year-old waiter and HIV-positive patient, echoed Cesar, saying, "It's not like it's a big deal. I take one pill a day, and I have [HIV]. So, to take one pill a day is nothing. You take a vitamin every day, don't you? What's the big deal?" Framing PrEP as a vitamin reinforces Val's belief that PrEP is "more healthy," working with the body. In contrast, to the 37-year-old nurse, Cat, thinking of PrEP as a vitamin is useful because of its familiarity. On this she said,

> "You can take it as if you're taking a vitamin. Nobody needs to really know what the hell that medication is. You just like, I've got to take my vitamin today and pop that in your mouth. And keep it moving. You know what I mean? Nobody's going to look twice at you for taking a pill. Everybody takes some kind of medication nowadays."

To Cat, since everybody takes some kind of medication nowadays, taking PrEP fits into the status quo. This speaks of what Simon Williams, Paul Martin, and Jonathan Gabe (2011) describe as the "pharmaceuticalization of society" as the dynamic and complex process by which "human conditions, capabilities, and capacities" are transformed "into opportunities for pharmaceutical intervention" (p.711). In this scenario, the human condition of potentially being at risk for HIV has been transformed into an opportunity for pharmaceutical intervention with PrEP. Given that 55% of all American adults take at least one medication, with the average number of pills each person takes being four, taking another pill to prevent HIV is, as Jack said, no big deal (Consumer Reports 2017).

In summary, when answering the question, “*What* is PrEP?” the patients and health professionals framed PrEP in terms of protection and medication, concretizing HIV risk and thus its treatability as an object of pharmaceutical intervention. In other words, the treatment of an ambiguous concept of HIV risk with the tangible pill of PrEP, in turn, transforms that HIV risk into something more concrete, too.

Who **Should take PrEP? The Identities Targeted for HIV Prevention**

Just as the patients and healthcare professionals employed several frames of HIV risk’s tangibility when describing *what* PrEP is, they likewise enlist several frames of identity when describing *who* should take PrEP. In the previous chapter, the patients and health professionals painted a diverse picture of identities associated with HIV risk when asked *who* is at risk for HIV, from people who have multiple sexual partners, to “young MSM of color,” to “everyone.” Now, when describing *who* should take PrEP, they drew on several of those frames and added another in the form of participants of “social sex” applications like Grindr.

Echoing who they thought were at risk for HIV, most of those interviewed (64%, 7/11 HIV-negative patients indicated for PrEP; 77%, 10/13 HIV-positive patients; and 79%, 11/14 health professionals) said PrEP should be taken by those who exhibit the behaviors of an active sex life, whether or not they are using protection. However, in contrast to how in the last chapter all of the health professionals associated drug/alcohol use with HIV risk, only 1 of them explicitly said that PrEP should be taken by drug users or those who drink alcohol. This difference suggests that the subjects associated PrEP with groups engaged in risky sexual behavior more than other groups they considered at risk for HIV. More specifically, the subjects in this study indicated PrEP should target the gay community. Quinn, a 29-year-old hair stylist and PrEP patient said, “And I think it’s much like pregnancy pills. It’s for everybody, but mainly it’s targeted against gay people. Because, unfortunately, gay people have unprotected sex. That’s the fact of the matter.” Their[4] perspective on this was echoed by several of the health providers, like Irene, a 31-year-old case manager who said that PrEP should be taken by “young MSM who have multiple partners, or anyone with multiple partners, but particularly young MSM. Someone who’s a sex worker, for sure.” When asked to elaborate, Irene went on, “They’re just at risk. They have more partners. There’s more opportunity for them to be exposed.” By reinforcing these frames of who should take PrEP, this shows how PrEP crystallizes certain aspects of HIV risk, specifically concerning groups associated with sexual risk, making its targets less ambiguous and more tangible.

On a different note, one health provider, the 35-year-old PrEP Administrator, Savannah, maintained that PrEP should be indicated for minority communities, drawing upon that frame that minority communities are at greater risk for HIV. According to her, black and Latinx communities are at greater risk for HIV given that they have some of “the highest rates of [HIV] acquisition and contraction.” When asked why she thinks that may be, she responded, “I think there's a few things. I think there’s definitely some deep-rooted cultural things that cause a barrier for the uptake of PrEP.” This reiterates what Sanders et al (2019) discovered in their study on health care providers’ views of PrEP. They note that “notions of risk and race become mutually constitutive through the practice of PrEP” by “racializ[ing]” that risk (p.269). According to the health providers in Sanders et al’s study, “if you’re African American and living in the [inner city], then you should be taking PrEP” (p.268). They argue this is worrying, not only because it “distracts from broader structural factors that underlie disproportionately HIV

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[4] “They/their” pronouns are used for the patient, Quinn, who identified as nonbinary.

prevalence in impoverished urban communities," but worse, it might actually *reinforce* such structural factors, specifically structural racism (p.270). Additionally, building on Hannah Bell et al's (2018) research on how black patients are marked to be "risky bod[ies]" in U.S. healthcare, this points to how they may also be targeted as "bodies" for pharmaceutical intervention. Though I did not witness any specific instances of racial targeting of patients during my time at NYCHC, it is important to draw attention to the possibility of that PrEP might contribute to the racialization of HIV risk in other settings.

In contrast to such targeting, and in reflection of how many of the patients believed that "everybody" is at risk for HIV in the last chapter, several of those interviewed (36%, 4/11 of the HIV-negative patients indicated for PrEP and 31%, 4/13 of the HIV-positive patients) believed that "everybody" should take PrEP. When asked who should take PrEP, Albert, a 74-year-old HIV positive patient said, "I think everyone should, really. You really should. Who the hell wants this?" To Albert, who lives with HIV, everybody who doesn't have the virus should take PrEP so that they won't also have to live with it. Similarly, Cesar, a 26-year-old HIV-negative patient taking PrEP, said,

> "If enough people start taking the medication and start taking care of themselves, and being safe, we could get rid of this terrible, terrible virus that has ruined so many lives and so many families, and has taken so many people's lives. I feel like if society starts taking these precautions, that we could stop this. So, yeah, I feel like everybody could benefit from [PrEP]."

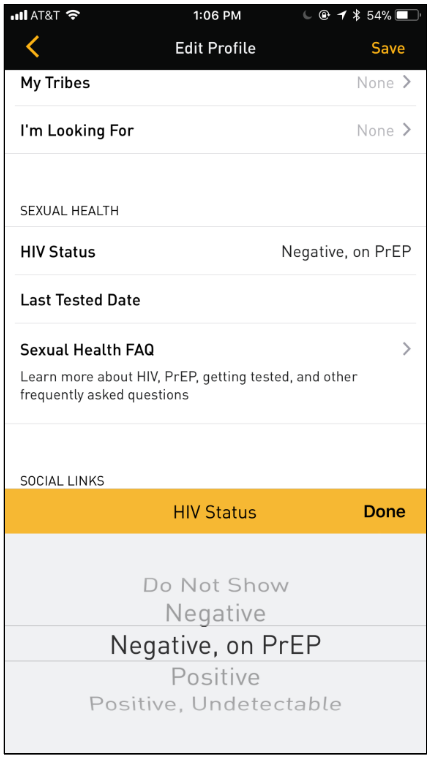
While Albert thinks individuals should take PrEP so that they won't have to live with the virus on the personal level, Cesar thinks "society" should embrace PrEP as a "precaution[n]" to "get rid" of this virus on the population level. As Jeremy Greene (2007) argued, such coupling of public health population-level goals of risk reduction with pharmaceutical agents lends to a "pharmacopeia of risk reduction." This is concerning for several reasons, perhaps most of all because, as he contends, "in the treatment of risk, where there are no symptoms except for the numbers themselves," and in the case of HIV risk, no numbers at all, "the prospects for therapeutic expansion appear limitless" all the while the parameters of health become obsolete (2007:229).

In addition to these reiterated frames of HIV risk when discussing *who* should take PrEP, the patients and health professionals offered another frame: the participants of "social sex" sites like Grindr. Grindr is a "geosocial-networking smartphone applicatio[n]" that "use[s] global positioning system technology to form connections between users," often other MSM, "based on their current geographic locations" (Geodel et al 2016). As the 29-year-old HIV-negative patient Quinn described the practice,

> "I know a lot who take PrEP. I know there are a lot of them that are sexually active and a lot of them live on Grinder, unfortunately. I call it the F website because that's all it does. It's not a dating website. Originally created as a dating website, but everybody meets up that has sex. Let's meet right here, right now. And they come over and next thing they're boom, boom, boom, boom."

Significantly, as several interviews indicated, Grindr may have been pivotal in the PrEP movement in multiple ways. First, it seems to serve as a platform for users to educate one another about PrEP and its role in preventing HIV. As the 44-year-old HIV-negative patient, Luke, related, he actually first learned about PrEP when talking to another user on Grindr. Secondly, in a more structured way, it allows users to actually indicate in their profile whether they are using PrEP, as shown in the screenshot of the Grindr app profile set-up in Figure 5 below.

Figure 5: Grindr Profile Set-Up Showing HIV Status Listings (Warner et al 2018)



My Tribes None

I'm Looking For None

SEXUAL HEALTH

HIV Status Negative, on PrEP

Last Tested Date

Sexual Health FAQ

Learn more about HIV, PrEP, getting tested, and other frequently asked questions

SOCIAL LINKS

Do Not Show
Negative
Negative, on PrEP
Positive
Positive, Undetectable

Notably, in this drop down menu for users' "HIV status," they have multiple options for how to describe their HIV status, from "Negative," "Negative, on PrEP," "Positive," to "Positive, Undetectable." Just as antiretrovirals taken by HIV-positive patients have created the new social status of HIV-Positive "Undetectable" as discussed in the previous chapter, PrEP has created a new "Negative, on PrEP" HIV social status with which users can identify on Grindr. When asked what he thinks about this practice of listing one's PrEP status on Grindr, the PrEP patient Luke said,

> "I mean, it's good. I mean, it gives you an illusion that it's safer to play with this person. But it's only as good as—are they taking their medications regularly? Or some people might be making it up. And two, it's still not safe. Right? Because it only protects you against HIV and hence, you know, my issues that I've had with other STI's...."

Irene, an HIV case manager, expanded upon this illusion of safety that listing PrEP on Grindr creates, saying,

> “Apparently there's like a whole code system for how people can determine whether or not they're positive or whether or not they're on PrEP. And, a lot of times they're like... deception. It's just wild because I feel like that's a whole ‘nother world that a lot of people aren't aware of, but that's how our patients are getting out there.”

According to Irene, indicating PrEP use on Grindr creates more than an illusion, but an entire world of code and deception that individuals must navigate in order to form intimate connections. Importantly, what this symbolic world illustrates is how PrEP might distort patients’ reality of HIV risk and the role electronic apps like Grindr might play in that distortion.

All in all, the patients and health professionals framed *who* should take PrEP in a variety of ways both similar and different to how they framed HIV risk. They identified people who have multiple sexual partners, MSM, minority communities, and “everyone” as those who should take PrEP, and added participants of “social sex” sites like Grindr. Significantly, by reinforcing and adding to the frame of *who* is at risk for HIV, these perceptions speak to how PrEP use transforms identities associated with HIV risk into objects of treatment to further solidify its market.

***Where* is PrEP Situated? The Location of PrEP’s Efficacy**

Though PrEP crystalizes certain narrative components of *what* and *who* is at risk for HIV, perhaps one of its greater distortions of HIV risk is *where* it situates that risk. In the previous chapter, the subjects located HIV risk both inside and outside the body, including in certain neighborhoods and communities. However, as this chapter will reveal, many of the subjects see PrEP as operating *inside* the body, thus firmly situating HIV risk within human bodies instead of the external circumstances by which such bodies are shaped.

Unlike condoms, which mechanically prevent HIV externally, PrEP is a consumed medication that works internally, treating the risk of HIV within the body itself. This difference was important to several of the subjects interviewed. When asked how he thought PrEP differs from past ways of preventing HIV, like condom use, the 74-year-old HIV-positive patient Albert said,

> Albert: It’s probably better.
> Researcher: And why do you say that?
> Albert: Well, it’s taken internally, really.
> Researcher: Okay. So, versus external things, why do you think that’s important?
> Albert: I don’t trust external.

Albert’s preference for “internal” measures of prevention was echoed by several other patients, including the 39-year-old salesman and HIV-positive patient Chris. Chris answered the same question with, “Well, I think [PrEP] affects you internally, right? So, doesn’t it stop the spread altogether from cell to cell? I think PrEP puts a block up there somewhere.” Though Chris went on to say that condoms should be used to prevent other STDs, he maintained that PrEP is superior to condoms because it “affects you internally.” Paul, a 65-year-old HIV-positive patient, reiterated this, saying that PrEP is “better because it's proven to stop HIV from getting hold in your body.” In a similar vein, the 54-year-old nurse Ava said that PrEP is superior to condoms because it builds up in the blood. When asked to elaborate why she thought PrEP was superior to condoms, she said,

> “Because if somebody takes this one tablet once a day, they remember to take it, then also, that medication will be in the blood. Sometimes, if they might not have a condom with them, they might get too caught in the moment and they might not want to use a condom, their partner or whoever they are having relations with might say, ‘Well, that's ridiculous. I don't have that.’ So, there's all these series of things. But you take one tablet, it's already there, you don't need to do anything at any other time, other than to take it the following day.”

To Ava, PrEP’s being in the blood makes it superior to condoms because, in case people get too caught up in the moment and don’t use that form of external protection, they still carry that internal protection from HIV *within* them. Significantly, what these accounts point to is how PrEP distorts HIV risk as being situated within the body, neglecting any external factors that might contribute to that risk.

PrEP's internal location also means that it can incur some negative side effects within the same body it is protecting from HIV. Notably, several (45%, 5/11 HIV-negative patients indicated for PrEP; 38%, 5/13 HIV-positive patients; and 43%, 6/14 health professionals) mentioned these side effects as a reason someone may *not* take PrEP. But what are these side effects? The literature reports some serious possible side effects of PrEP, namely bone density loss and kidney toxicity (Mugwanya and Baeten 2016). Dot, a 54-year-old HIV-positive patient, had some concerns about these. She said,

> "It should be a vaccine-type thing for that. A pill and how often do you have to take that pill? Once a day, that ain't good, because you don't know what that pill is doing to the rest of your body. You understand?... And then in the long run, oh, remember the pill you had on so-and-so? Because you hear it with a whole lot of other stuff. Oh, the pill they had out with so-and-so-and-so, well, they had to put a hold on it, they didn't try to change it, blah, blah, blah, blah, blah, because it's messing with people's kidneys or it's causing such-and-such-and-such. But it takes a while for them to even know those things, so why not just make a vaccine and give the shot?"

Dot's insistence that PrEP should be a vaccine instead of a pill is significant. In contrast to a vaccine, which boosts your body's own immune system to fend off certain bacteria and viruses, a pill taken every day to fight against a possible virus may also fight against one's own body. Historically, pharmaceutical companies do not profit as much from vaccines in comparison to a pill that must be taken every day because "drugs that cure people or stop the spread of disease, like vaccines are supposed to do, reduce revenue" (Dumit 2012:177). What is more, there have been some class-action lawsuits against Truvada (emtricitabine and tenofovir disoproxil fumarate), the medication used for PrEP, concerning its side effects of bone loss and kidney toxicity in treating HIV-positive patients (Peterson 2018). Tony, a 63-year-old HIV-negative patient taking PrEP, saw a commercial advertising one of these lawsuits and asked Dr. Alexandra about it. Their exchange was captured in my fieldnotes as follows,

> *Dr. Alexandra tells Tony, "I understand where the lawyers are coming from, as well as where Gilead [Truvada's maker] is coming from. My advice to you is to have some filters and to take the commercials with a pinch of salt." She then admits, "It's kind of complex and I don't know*

> *what the answer is. In the PrEP world, TAF [a newer medication with fewer side effects] will likely be approved for PrEP. It's like how driving a car puts you at risk, and older cars are at greater risk." Tony adds, "and you need to wear a seatbelt...I'd rather have bone loss than HIV." He then continues, "If you're happy with it doc..." to which Dr. Alexandra says, "Yeah I'm happy with it."*

This weighing of risks—the risk of PrEP's side effects of PrEP versus that of contracting HIV—was on the minds of several other patients taking PrEP, including the 44-year-old accountant Stuart. Stuart said,

> "My only concern is that there's a lot going on in the news right now about PrEP, and there's been concerns about people having bone issues, which makes me a little bit nervous myself, because I also feel like I'm taking something that I don't really need to be on, because I don't have a disease. But if it's something that's going to potentially harm you in the future, I'm not sure which outweighs the other"

To Stuart, who feels as if he is taking something he doesn't need to be on because he doesn't have a disease, he must weigh the possibilities of the side effects versus the possible outcome of "something that's going to potentially harm you in the future," HIV. In regard to hypertensive drugs, Jeremy Greene (2007) asks the pertinent question underlying Stuart's concern: "when did the unknowable future danger of a patient's elevated blood pressure validate the risk of the treatment at hand?" (p.59). In the PrEP scenario, however, the question is instead, when did the unknowable future danger of the mere *possibility* of HIV validate the risk of side effects from PrEP?

In sum, though in the previous chapter the patients and health professionals framed HIV risk both inside and outside the body, PrEP's use distorts this risk by exclusively situating it within the body where is also can incur deleterious side effects. By situating the risk inside the body, PrEP's use makes bodies out to be inherently "risky" and values the treatment of that risk to be greater than any side effects incurred.

When Should People Take PrEP? The Timing of PrEP

In the previous chapter, the patients and health professionals associated different timings when framing HIV risk, whether placing that risk in the past or eclipsing any focus on what the future may hold. Now, in this chapter, how those interviewed believe PrEP affects the timing of HIV risk, specifically *when* should individuals take PrEP, will be explored.

In contrast to how the subjects framed those at risk for HIV as having lost “focus” on their futures in the previous chapter, they framed PrEP as reorienting patients to think about protecting their present. As Mike, a 54-year-old computer technician and HIV-positive patient, said, “The benefit of PrEP is it gives focus back on the virus.” Based on these interviews, it seems PrEP is able to refocus individuals to this present because of its own timing as a daily medication. As Cesar, a 25-year-old school counselor HIV-negative patient taking PrEP described it, “[PrEP’s] a daily protection. It’s not just when you’re going to have sex.” Tony, a 63-year-old HIV-negative patient taking PrEP, expanded upon this saying that, “Well, I think as a daily preventative it's much easier than last minute, oh I got to stop at the drug store or something.” To both Cesar and Tony, PrEP’s timing of taking it every day makes more convenient than that of condoms, which can interrupt the “moment” during sex.

However, having to take a pill every day, though preferred to both Cesar and Tony, is no small task, and seems to firmly place onus of prevention onto the patient. As Olivia, a 55-year-old HIV-negative patient taking PrEP said, “The only time [PrEP] don’t work is if you don’t take it.” Quinn, a 29-year-old hair stylist and HIV-negative patient taking PrEP, reiterated this sentiment. They said, “if you take [PrEP] every single day—And I don’t mean you have sex and then you stop. You just take it that day. Be like, ‘Oh, I just had sex, let me go pop this pill.’ No. You have to take that shit every single day.” To Quinn and Olivia, the onus is on the patient to take PrEP every single day in order to prevent HIV. This builds upon what Beverly Sibthorpe (1992) has called HIV education programs' exclusive focus on the individualistic, "personal responsibility model of risk in their risk-reduction messages" surrounding HIV such that "if individuals participate in certain behaviors, they put themselves at risk of contracting HIV and getting AIDS" (p.257). Now, however, with PrEP, if individuals participate in certain behaviors that put themselves at risk for HIV, they can also participate in a behavior that mitigates this risk by taking prophylactic medication.

Selena, a 41-year-old HIV administrator at NYCHC, said the fact that PrEP has to be taken every day concerns her. She identified this as one of the "cons" of PrEP, saying,

> "what if you forget to take it every day. It would be nice to have an injectable maybe, because we do have that population that doesn't take it every day. We do have that population that uses it as a weekend pill. We do have that population that doesn't understand that every day you miss that pill is less and less. So, again, the, the con is that it is something that the patient has to take and remember to take every day."

To Selena, she worries that the timing of PrEP, having to take it every day, is too much responsibility for some patients. Selena was not alone in her fear. As the 32-year-old physician, Dr. Gabriel, told me while I was shadowing him one morning, he felt one of the patients on his schedule was the "worst candidate for PrEP. I don't think she is compliant with her medications." In this light, PrEP candidacy is equated with medication compliance. And, as the 28-year-old barista and HIV-positive patient, Diego, conveyed, if a patient doesn't take PrEP and becomes infected with HIV, it is now that patient's fault. He described this possibility, saying,

> "lately in the news I've been seeing that PrEP has not been working. There's some people who's been getting infected even though they are on PrEP. But then again, it could be the news is probably fake. They can probably miss a dose or two, or—and it was their fault. But overall, from what I've heard and from what I've seen of studies, what they showed me, PrEP is really good."

To Diego, the only possibility that PrEP does not work is if the patient forgot to take it, turning the blame on the patient for the acquisition of HIV and away from any other factors that could influence it.

Additionally, PrEP affects the timing of HIV risk in more ways than by forcing patients to take a pill everyday: at NYCHC as at many other health centers, the PrEP program requires patients come into the clinic every three months for STI screens and bloodwork. To Dr. Gabriel, this is a benefit of the medication. On this, he said,

> "The benefit with that, I think, is the fact that you're prescribing a medication, they have to come in now for routine testing. Particularly for places like here where you have grants that you have to maintain, so you have to maintain quarterly visits for the PrEP program that we run here. It forces them to have to come in. And the more that they come in, you make sure that their STDs are negative. Their HIVs are negative."

According to Dr. Gabriel, the fact that the NYCHC's PrEP program is grant-based and requires the patient comes in for quarterly visits is a good thing because it provides more opportunity to pinpoint any positive STD screen, including HIV. This brings to mind Foucault's (1984) comparing of health care clinics to penitentiary systems: both are "fixing [individuals] in space; classifying them; extracting from them the maximum in time and forces; training their bodies; coding their continuous behavior; maintaining them in perfect visibility; forming around them an apparatus of observation, registration, and recording; constituting on them a body of knowledge that is accumulated and centralized" (p.214). To no surprise then, what to Dr. Gabriel is a boon is a barrier to PrEP patients like Tony, who said, "The only, the one thing that I don't like about [PrEP] is that every three months you got to come here and you have to do the tests, the blood tests and stuff."

In summary, PrEP distorts the timing of HIV risk by exclusively placing that risk in the present, resulting in a shift of responsibility onto the patient not only to take a daily medication but also comply with the mandatory lab tests and visits.

Why Take PrEP? PrEP's Effect on Agency and Risk Compensation

As discussed in the last chapter, the patients and health professionals in this study navigated multiple frames for *why* individuals are at risk for HIV, including their lifestyle choices, circumstance, and deception. In this chapter, PrEP's reframing of *why* individuals are at risk for HIV will be explored, including how those interviewed view PrEP as an individual's choice that increases their sense of control, liberation, and practices of risk compensation.

In contrast to how the subjects framed HIV risk in terms of both a lack of and a result of an individual's agency, many framed the use of PrEP as an individual's choice. When asked if he thought there were certain groups of people that should take PrEP, the 44-year old HIV-negative patient Luke responded, "No...I mean it's a personal decision." In response to the same question, the 66-year-old HIV-positive patient Iris said, "They just need to get [PrEP] out there, so people can have choices to make." Significantly, this framing of PrEP as an individual's choice, in turn, reinforces the framing of HIV risk in terms of an individual's lifestyle choices. What is more, to several of the health professionals, a patient's choice to take PrEP is a means for them to increase their agency. A handful of those interviewed (21%, 3/14 health professionals and 0 patients) maintained that PrEP has the potential to "empower" individuals. As Selena, a 41-year-old HIV care administrator, said,

> "I think PrEP has really empowered so many young patients, including MSM, including Latinos, all these populations that have had this taboo...They're coming in with gonorrhea and syphilis, but they're not coming in with HIV, which shows me that all along you weren't using the condom regardless of the education that we were giving you. But, it's so nice to see that I can give you an antibiotic for a syphilis or a chlamydia and that I don't have to give you the news that you're HIV-positive. So, I think it's such an amazing, revolutionary, empowering medication"

Though Selena frames PrEP as empowering for the patients, increasing their options of protecting themselves from HIV, it seems to also be empowering to the health professionals by helping them protect their patients in ways they were previously unable to. Given that none of the patients described PrEP as “empowering,” perhaps the empowerment of PrEP lies more in its prescription rather than its consumption. This is further demonstrated by Trudy, a 49-year-old PrEP Administrator, in describing how she recommends patients take PrEP, saying,

> “I’m not going to tell you need to stop living the life that you're living because who am I to tell you that? You know, that's a choice that you as an individual have to make. But I have to tell you the risk factors and what—if you continue to live this life without protecting yourself correctly, without using condoms, without taking this pill [PrEP], you can get HIV. You are in high risk category.’”

As Trudy related, she cannot tell people to stop living the life they are living, but she *can* recommend that people choose to take PrEP.

However, as Gina, a 54-year-old HIV-positive transwoman, conveyed, there really is no choice at all in taking PrEP. She said,

> “If [PrEP]’s going to prevent you from getting some disease that’s going to kill you, you have no other choice but take it. If you don’t take it, what happens? You’re going to get sick. And you’re going to have to start taking medication to live.”

Gina’s framing of PrEP as something an individual *must* take to prevent HIV suggests that HIV risk is not only inherent, but also the transmission of HIV, and its treatment with antiretrovirals, inevitable. This demonstrates the phenomenon Joseph Dumit (2015) describes, “For more and more Americans, health is a sign of concern, something they must see a doctor for in order to ward off the invisible risk they have been taught to worry about. Treatment is neither an imposition nor a choice: it is increasingly ordinary and the action one must take” (p.85). Olivia, a 55-year-old HIV-negative patient, expressed such lack of choice when taking PrEP, saying that “The only negativity about that is if you don’t take [PrEP] because you put yourself at risk and it shows you don’t respect yourself or your partner.” Like Gina, Olivia believes there is no choice to taking PrEP, but instead of framing it in terms of survival, she frames it in terms of respect for oneself and one’s partner.

In contrast to lack of choice some patients described in taking PrEP, other patients framed PrEP in terms of sexual liberation. As Jack, a 43-year-old waiter and HIV-positive patient, said,

> “And [PrEP] is giving back to the people that sexual freedom again, the experience in the '70s. And then when HIV/AIDS came about, it kind of just squashed it. But now, it's starting to come back, that sexual liberation, because we're protected again in a way.”

To Jack, PrEP is a means of returning to the sexual freedom of the 70’s that was fettered by the fear of HIV/AIDS (Cruikshank 1992). Trudy, the PrEP administrator, echoed this sense of liberation, saying that she thinks PrEP is a “lifesaver” to “many people who live that life who, who are being very free right now with their bodies.”

What seems to be a key aspect of this sexual freedom is the simultaneous sense of “control” PrEP provided the patients over their health, just as birth control served as a symbol of women’s sexual liberation of the 1960s (May 2010:71). In relation to this, patients and health professionals alike compared PrEP to birth control. As the HIV administrator Selena described it,

> “It's like a plan, a birth control pill I could take just to prevent pregnancy. I can definitely take this to prevent HIV, and, looking at the population that I work with, especially my college students, it's more okay. This is what they're doing. They've been doing it.”

The likening of PrEP to birth control is significant for several reasons. First, birth control in the 1960s was revolutionary in that it gave women not only “the ability to choose whether and when to have children,” but also “a way to separate the act of contraception from the act of sexual intercourse, allowing women secure and total control over their fertility without the knowledge, participation, or approval of their sexual partners” (Watkins 2016:50). In this way, PrEP, too, allows individuals control over their health, allowing them to choose to protect themselves from HIV without having to involve their partner in condom negotiation. The 39-year-old physician Dr. Wanda demonstrated this sense of control conferred by PrEP when she said, “Maybe because you're making the choice to be on PrEP, whereas you're often asking somebody to use condoms, so there's more of an interaction with somebody else." Secondly, the birth control pill also contributed to the normalization of daily medication consumption by healthy bodies, spreading from pharmaceutical companies' laboratories to the medicine cabinets of women not only across the country, but worldwide (Watkins 2016). By treating healthy bodies to prevent HIV, PrEP, too, has this two-fold limitless potential: it expands the definition of disease to include the risk of disease as grounds for pharmaceutical treatment and it expands its market to include healthy bodies as grounds for prophylactic intervention.

Also, like birth control pills, PrEP doesn't prevent other sexually transmitted infections (STIs) aside from HIV. Of the 14 health professionals interviewed, 7 noted that, since the advent of PrEP, they have observed an increase in STIs. When asked if she thought there were any consequences of PrEP, the 54-year-old nurse, Ava, said, "I think there's a consequence that the people become carefree and just have unprotected sex like there's no tomorrow. We have seen an increase in sickness and gonorrhea, chlamydia, and all the other STIs." This increase in unprotected sex because individuals feel protected from HIV is called "risk compensation." The concept of "risk compensation" first appeared in highway safety literature in the 1960s and 1970s to describe how automobile drivers increased riskier behavior on the road after safety regulations like seatbelts began to be enforced (Hedlund 2000). Since that time, however, it has begun to be used in healthcare to describe how biomedical interventions, such as needle exchange programs, intended to reduce patients' risk of developing a disease might lead to patients' increased riskier behavior that might "consequently counteract the benefit of the prevention tool in question" (Castro, Delabre, Melina 2019:50).

And though risk compensation has been widely contested by many HIV/AIDS healthcare advocates as being inaccurate and morally-charged (Castro, Delabre, Melina 2019), other reports, like Traeger et al's (2018) systematic review of 17 open-label studies on PrEP, found that PrEP is associated with an increase in STIs amongst its users. Regardless, in this study, many of the subjects interviewed *did* associate PrEP with practices of risk compensation. For example, when asked if they thought PrEP might affect condom use, a majority of subjects (73%, 8/11 HIV-negative PrEP patients; 62%, 8/13 HIV positive patients; and 71%, 10/14 health professionals) said they believed PrEP could *decrease* condom use. As Stuart, a 44-year-old accountant and HIV-negative patient taking PrEP, said,

> "I think people use [PrEP] recklessly. For some, it's an excuse to not have to use condoms. And it's giving people a false sense of security that they're not going to get anything, which is not true. I mean, even for myself I'm more comfortable, 'Well, I don't have a condom,' and I sleep with somebody, at least I know at least I'm not going to get that. And as much as that's really good, I think it's also having opposite effect, because I truly believe that the more PrEP use, the less condom use."

Like Luke, who portrayed PrEP as having a "devil on his shoulder" telling him he doesn't need to use a condom, Stuart also feels like PrEP is detracting from condom use both personally and amongst other people. Describing condom use as a "pendulum," swinging between the decreased condom use during the sexual liberation of the 70s and 80s and increased condom use after the HIV/AIDS crisis of the later 80s, Stuart later said,

> "People were a bit more careful with who they were having sex with and how they were having sex, and I think PrEP changed that. It was like a pendulum, and I think the pendulum swung again. And now, I think PrEP kind of changed people's mindsets. And to be honest with you, I think people are having more sex like they did in the 80s now, because they feel they have this barrier. It's a protective barrier without having to physically put a condom on"

To Stuart, PrEP has pushed the "pendulum" of condom use back toward a increase in condomless sex because people are less scared of HIV since they feel protected from it with PrEP. The 54-year-old computer technician and HIV-positive patient, Mike, noticed this a similar trend, saying, "And [PrEP] also gave the gay community almost carte blanche to go crazy. That's why you saw such a large increase in the infections when they started issuing PrEP." Paul, a 65-year-old HIV-positive patient, described the same thing, caricaturizing PrEP advertisements and health professionals as saying "'Well, take this pill, and then you can just be free-for-all and just have a good time.'"

The specific phenomenon that Mike and Paul are describing brings to mind what Jeremy Greene (2007) refers to as "pharmacologic Calvinism," whereby the "decision to seek a pharmaceutical solution as a replacement for some other, more individually responsible solution (e.g., diet, exercise, existential reckoning) reflects a corrosive moral laxity, a short-circuiting between effort and result" (p.217). As Greene notes, such an argument assumes an *a priori* set of moral principles (2007:2016), which in the case of PrEP reflects a conservative attitude toward sexual partnerships and practices. Regardless of these arguments' moral origins, however, PrEP's alignment with certain aspects of pharmacologic Calvinism and risk compensation was identified by the subjects in this study, demonstrating how PrEP may challenge existing social mores regarding individuals' sexuality and risk.

In summary, in contrast to how the patients and health professionals framed *why* individuals are at risk for HIV in terms of lifestyle choices, circumstance, and deception in the last chapter, they framed *why* people should take PrEP in terms of individual choice, increasing their sense of control, liberation, and practices of risk compensation.

Conclusion

In this chapter I have argued how PrEP's collision with the ambiguous discourse surrounding HIV risk crystallizes and warps certain aspects of HIV risk's narrative framework. In asking "What is PrEP," I showed how the patients and health professionals framed the tangibility of PrEP in terms of protection and medication, concretizing HIV risk as an object of treatment. In asking "Who should take PrEP?," I discussed how PrEP reinforces HIV risk groupings in order to solidify its targets for pharmaceutical intervention. In asking, “Where is PrEP located,” I revealed how PrEP distorts HIV risk by exclusively situating it within the body where is also can incur deleterious side effects. By asking “When should individuals take PrEP?” I established how PrEP distorts the timing of HIV risk by placing that risk in the present, assigning responsibility to the patient not only to take a daily medication but also comply with the mandatory lab tests and visits. And lastly, in asking “Why should individuals take PrEP?” I showed how PrEP warps HIV risk by exclusively framing it in terms of individual choice.

This crystallization and warping of the ambiguous discourse surrounding HIV risk is of great social significance. It shows how a reliance on pharmaceuticals drastically impact not only how we, as a society, communicate risk with one another, but also how we each, as individuals, might interact with that risk. In this way, though PrEP is a pill that treats HIV risk, it is also a prism that distorts how HIV risk is conceptualized and experienced on a fundamental level.

Chapter 6: Structural Risk

It's the end of the day one July afternoon and I am sitting in one of the now-empty patient exam rooms at New York Community Health Center (NYCHC) interviewing the nurse Jade. She was nervous about being interviewed because, though she professionally promotes Pre-Exposure Prophylaxis (PrEP) for HIV prevention, she herself has many doubts about it. This was demonstrated by the following exchange after I asked her how she thinks PrEP differs from previous ways of preventing HIV.

Jade: I don't know. I just think condoms are just as effective. I just think there's a hidden agenda behind taking a medication to prevent HIV for what seems like is basically a lifetime. I don't think there was anything wrong with condoms before. I think we just needed to encourage people to use them just like we have to encourage people to take the pill every day.
Researcher: Who do you think is running the hidden agenda?
Jade: I think it's the pharmaceutical companies. It's money. Those medications are like $1200 a month. They want that money.
Researcher: Do you think PrEP will change HIV prevention in the future?
Jade: I don't know. I wish that they'd just figure out a cure. I don't think that they're—it's interesting to me that they're working on prevention and not the cure. That's probably my issue with it. There's no money in the cure. But if you tell people that they can take this pill for the rest of their life and it would prevent possibly getting HIV—people are like, "All right, fine. I guess I'll do that."

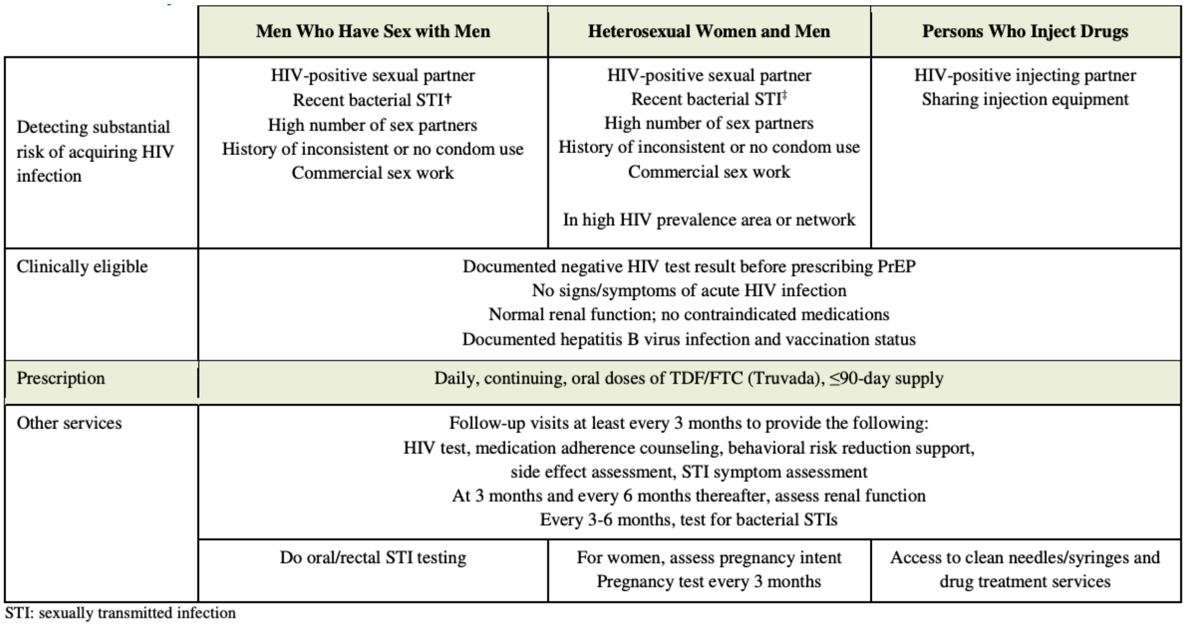
Consistent with Jade's perspective, critics note that U.S. pharmaceutical companies prioritize the production of profitable drugs to treat diseases over less profitable cures for those diseases. For example, Dumit (2012) argues that pharmaceutical companies, backed by the numbers from their clinical trials, redefine high risk, determine that individuals are "ontologically at risk" and as such both "ethically and imperatively" must be put on treatment (p.155). How these agendas, discussed in the boardrooms of healthcare corporations, trickle down to affect the patients in clinic exam rooms is of great anthropological concern. Reflecting Johan Galtung's (1969) concept of "structural violence" to describe how "violence" is "built into the structure" of society and "shows up as unequal power and consequently unequal life chances" (p.170-1), I propose the concept of "structural risk" to describe how such ambiguous constructions of "risk" are built, top-down, into the structure of society, specifically health care systems, and how these concepts manifest as an ever-narrowing definition of health and ever-diminishing power of individual health professionals and patients to influence it. Thus far, I have analyzed the *what*, *who*, *where*, *when*, and *why* aspects of HIV risk's ambiguous discourse and PrEP's effect on it. In this chapter, I use the concept of "structural risk" to analyze the final narrative element of *how* HIV risk is ambiguously conceptualized. Significantly, I argue that structural risk enables PrEP use to distort and crystallize HIV risk's ambiguity by serving both as a reflective "model *of*" as well an constructive "model *for*" its ambiguous conceptualization (Geertz 1973:93; emphasis in original). I accomplish this by investigating *how* HIV risk's ambiguity is constructed in healthcare guidelines, codified in electronic medical records (EMRs), and perpetuated by HIV prevention advertisements. By tracing how ambiguous concepts of HIV risk are built into the structures of healthcare, I hope to illuminate how they attenuate not only the concept of health and wellbeing, but also the institutions meant to uphold and protect health and wellbeing.

How **HIV Risk's Ambiguity is Constructed in Healthcare Guidelines**

In this section, I will explore *how* HIV risk's ambiguity is constructed in healthcare guidelines identifying patients as candidates for PrEP and what implications this has for patients and the health professionals treating them. By doing so, I will argue that these PrEP guidelines are examples of structural risk by serving both as reflective "models *of*" HIV risk's ambiguity and constructive "models *for*" its ambiguous conceptualization.

As noted above, clinical trials play an instrumental role in the definition of risk groups and the role of pharmaceuticals in treating that risk (Dumit 2012; Greene 2007). The same holds true for PrEP. The CDC based its 2017 guidelines for PrEP in the prevention of HIV on a series of trials showing how Truvada (emtricitabine and tenofovir disoproxil fumarate) for PrEP reduced the transmission of HIV in Men who have Sex with Men (MSM), heterosexual couples, and persons who inject drugs (CDC 2018b:14). These groups were targeted based on a series of clinical trials and studies, which were key in determining which groups are considered to be at risk for HIV. Significantly, 14/16 of the studies serving as the basis for the CDC's guidelines for PrEP disclosed receiving donated drug from Gilead, the manufacturer of Truvada for PrEP, or had investigators who received grant funding from Gilead, owned stock in company, received consulting fees, or were employees of the company. Based upon these studies' results, the CDC published its "Clinical Practice Guidelines" for PrEP, summarizing the groups indicated and their risks for HIV for the drug in the figure below.

Figure 6. CDC's 2017 Guidelines Summarizing PrEP Administration (CDC 2018b)



	Men Who Have Sex with Men	Heterosexual Women and Men	Persons Who Inject Drugs
Detecting substantial risk of acquiring HIV infection	HIV-positive sexual partner Recent bacterial STI[†] High number of sex partners History of inconsistent or no condom use Commercial sex work	HIV-positive sexual partner Recent bacterial STI[‡] High number of sex partners History of inconsistent or no condom use Commercial sex work In high HIV prevalence area or network	HIV-positive injecting partner Sharing injection equipment
Clinically eligible	Documented negative HIV test result before prescribing PrEP No signs/symptoms of acute HIV infection Normal renal function; no contraindicated medications Documented hepatitis B virus infection and vaccination status		
Prescription	Daily, continuing, oral doses of TDF/FTC (Truvada), ≤90-day supply		
Other services	Follow-up visits at least every 3 months to provide the following: HIV test, medication adherence counseling, behavioral risk reduction support, side effect assessment, STI symptom assessment At 3 months and every 6 months thereafter, assess renal function Every 3-6 months, test for bacterial STIs		
	Do oral/rectal STI testing	For women, assess pregnancy intent Pregnancy test every 3 months	Access to clean needles/syringes and drug treatment services

STI: sexually transmitted infection

Though several of the indications for PrEP prescription, such as “Recent bacterial STI,” seem straightforward enough, other indications, such as “In high HIV prevalence area or network” show how these guidelines may both reflect and construct the ambiguity of HIV risk.

Significantly, the complex financial history behind the development of these guidelines suggests how such ambiguous constructions of HIV risk may be to pharmaceutical companies’ benefit. One of the first and most pivotal studies serving as the basis of the CDC’s guidelines for PrEP was the iPREX study, a phase III clinical trial of 2,499 HIV-seronegative men or transgender women that showed daily emtricitabine and tenofovir disoproxil fumarate (FTC–TDF), the generic Truvada drug combination that became PrEP, reduced the risk of HIV transmission by 44 percent (Grant et al 2010). As was the case in most of the studies in the CDC’s guidelines for PrEP, Gilead had significant influence over the iPREX study. While the study was funded by the National Institutes of Health (NIH) and the Bill and Melinda Gates Foundation, Gilead donated the drug for the study (Grant et al 2010). What is more, in the financial disclosure of the study, several of the study investigators reported receiving grants from Gilead, being employees of Gilead, or owning stock in the company (2010:2598).

Not surprisingly, Gilead has profited dramatically from the drug, although it was the U.S. government who almost completely funded the discovery of PrEP in the iPREX study and has held four patents on the treatment since 2015 (the patent status of PrEP remains controversial, a point to which I will return later) (Rowland 2019). While PrEP only costs about $60 a year to make, Gilead has been charging up to $20,000 a year for it (Barbaro 2019). As a result of this large profit margin, Gilead has earned $3 billion from Truvada each year (McNeil & Mandavilli 2019). Though the company recently made a grand gesture of donating Truvada to over 200,000 patients in the U.S. for 11 years, whether this is a truly philanthropic move seems questionable if

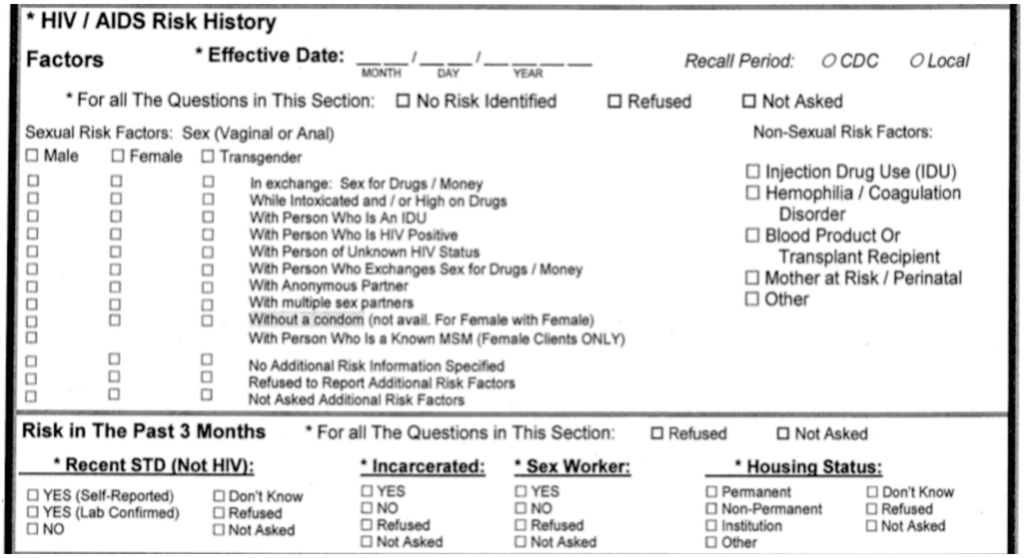
Gilead received a tax deduction for this program at retail cost of Truvada of close to $20,000 per year, instead of their actual cost of $60 per year (Barbaro 2019). What is more, through the donation program, Gilead is switching the patients' treatment to their new PrEP drug, Descovy, a slightly safer daily HIV prophylaxis pill that is patented for the next 20 years (Barbaro 2019). As Donald McNeil Jr. says, this move is "making a market for a new drug that otherwise would have cost them a lot of advertising money to create, and it's drying up the demand for generic Truvada because nobody's going to want it anymore" (Barbaro 2019). Responding to mounting public pressure by AIDS Activists, the U.S. government recently sued Gilead, seeking damages for Gilead's infringement on the four patents for PrEP owned by the U.S. Department of Health and Human Services (HHS) (HHS 2019). Of this, HHS Secretary Alex M. Azar II said, "HHS recognizes Gilead's role in selling Truvada and Descovy to patients for prevention of HIV. Communities have put these drugs to use in saving lives and reducing the spread of HIV. However, Gilead must respect the U.S. patent system, the groundbreaking work by CDC researchers, and the substantial taxpayer contributions to the development of these drugs. The complaint filed today seeks to ensure that they do" (HHS 2019). And though the outcome of the lawsuit is still unfolding, the complexity of PrEP's financial history is significant for a variety of reasons. In relation to this study, it shows how the definition of HIV risk, and the ambiguous discourse surrounding it, did not occur in a vacuum: It was shaped by a combination of public health agencies' interests in promoting HIV prevention and healthcare corporations' pursuit of financial profit.

The influence of healthcare corporations and public health agencies extends beyond the definition of HIV risk, however. It also shapes how those definitions of risk may contribute to the ambiguous discourse surrounding HIV risk through program grant requirements. At

NYCHC, the health professionals told me that the PrEP program was funded by a program grant from New York State that came with a several-page long workplan, demonstrating the top-down structuring of the clinical setting and patient experience. Specifically, at NYCHC, the health professionals conveyed to me how this program grant structured the PrEP program with its requirements of screening patients for HIV risk according to clinical guidelines, patient quarterly visits, and outcome reporting.

To screen patients for their HIV risk, the program grant gave the NYCHC health professionals a structured form from the New York State Department of Health AIDS Institute Reporting System (AIRS NY). On its website, AIRS NY describes itself as “a comprehensive client and service/encounter reporting application” that is “designed and to meet the reporting needs of AIDS Institute and its contractors” (AIRS NY 2020). It reports that it is “compliant with all CDC (Centers for Disease Control) program monitoring data requirements for both Counseling and Testing and Risk Reduction initiatives” and “generates the Ryan White Services Report client level data” (AIRS NY 2020). After using the Electronic Medical Record to generate a list of patients potentially at risk for HIV, a process I will later discuss in greater detail, the PrEP administrator would either call or meet with the patient and use the AIRS NY form to determine that patient’s HIV risk. In addition to collecting the demographic information of the patients, the form assessed the patient’s HIV risk using the following checklist the PrEP administrator showed me.

Figure 7. HIV/AIDS Risk History Section of NYCHC's AIRS NY Intake Form



*** HIV / AIDS Risk History**

Factors *** Effective Date:** __ __ / __ __ / __ __ __ __ (MONTH / DAY / YEAR) *Recall Period:* *○ CDC* *○ Local*

* For all The Questions in This Section: ☐ No Risk Identified ☐ Refused ☐ Not Asked

Sexual Risk Factors: Sex (Vaginal or Anal)

☐ Male	☐ Female	☐ Transgender	
☐	☐	☐	In exchange: Sex for Drugs / Money
☐	☐	☐	While Intoxicated and / or High on Drugs
☐	☐	☐	With Person Who Is An IDU
☐	☐	☐	With Person Who Is HIV Positive
☐	☐	☐	With Person of Unknown HIV Status
☐	☐	☐	With Person Who Exchanges Sex for Drugs / Money
☐	☐	☐	With Anonymous Partner
☐	☐	☐	With multiple sex partners
☐	☐	☐	Without a condom (not avail. For Female with Female)
☐			With Person Who Is a Known MSM (Female Clients ONLY)
☐	☐	☐	No Additional Risk Information Specified
☐	☐	☐	Refused to Report Additional Risk Factors
☐	☐	☐	Not Asked Additional Risk Factors

Non-Sexual Risk Factors:

☐ Injection Drug Use (IDU)
☐ Hemophilia / Coagulation Disorder
☐ Blood Product Or Transplant Recipient
☐ Mother at Risk / Perinatal
☐ Other

Risk in The Past 3 Months * For all The Questions in This Section: ☐ Refused ☐ Not Asked

*** Recent STD (Not HIV):**
☐ YES (Self-Reported)
☐ YES (Lab Confirmed)
☐ NO
☐ Don't Know
☐ Refused
☐ Not Asked

*** Incarcerated:**
☐ YES
☐ NO
☐ Refused
☐ Not Asked

*** Sex Worker:**
☐ YES
☐ NO
☐ Refused
☐ Not Asked

*** Housing Status:**
☐ Permanent
☐ Non-Permanent
☐ Institution
☐ Other
☐ Don't Know
☐ Refused
☐ Not Asked

If the patient's answers met any of the criteria for the "Sexual Risk Factors," "Non-Sexual Risk Factors," or "Risk in the Past 3 Months," the PrEP administrator would recommend that the patient talk to their doctor about PrEP, in addition to discussing other harm reduction measures to protect themselves from HIV. Notably, NYCHC did not create this form; it was a requirement of the state program grant funding their PrEP program. What this speaks to is how these HIV risk assessments are structured and implemented from the top-down, further evidence of how structural risk permeates every level of everyday clinical experience to contribute to the ambiguous discourse surrounding HIV risk.

In addition to requirements for screening patients for HIV risk, the state grant for NYCHC's PrEP program also requires patients to come in every three months for STI screening and bloodwork in order to be prescribed PrEP. When a patient doesn't adhere to these requirements, the reason must be documented on a "PrEP Program Case Closure Form." Trudy, one of the PrEP administrators, told me the most common reasons documented on the closure form were "Voluntary withdrawal" or "Non-compliant with program-agency requirements." If the patient feels they no longer need PrEP, the reason is documented as "Voluntary withdrawal." If the patient simply does not come in for the three-month appointments or complete the labs, the reason is documented as "Non-compliant with program/agency requirements." Notably, the form lists no reason conveying "Patient no longer at risk," with the closest reason being "Completed therapy/service." This juxtaposition between the AIRS NY form listing all the ways a patient may be at risk for HIV and the lack of an re-assessment of that HIV risk conveys how the program grant structures the PrEP program to perpetually identify patients as at risk for HIV and continually enroll them in treatment. This reiterates what Jade described in the opening quote: that patients are made to feel like they have to "take this pill for the rest of their life." Dumit (2012) has described a similar phenomenon in the field of psychiatry, quoting the psychiatrist Joseph Glenmullen in describing how "'in managed care settings, little or no effort is made to periodically assess whether a patient's dosage can be reduced or the drug stopped" (p.172-3). This contributes to the ambiguity of HIV risk because once a patient is labeled as "at risk," they seem to be indefinitely in that state of risk, and thus require indefinite treatment. It must be stressed that these guidelines for PrEP administration are coming from a higher level than NYCHC. NYCHC is only implementing them, not creating them, showing how structural risk is perpetuated again in a top-down direction.

The program grant for NYCHC's PrEP program also includes requirements for outcome reporting. During my time at NYCHC, I observed the stress and pressure this requirement put on the health professionals, from the PrEP administrators to the physicians, as demonstrated by an excerpt from my fieldnotes below.

> *I wait in the clinician's pod area to shadow Dr. Alexandra. While doing so, Trudy, the PrEP administrator comes in to talk to Dr. Alexandra about the patients she saw last Saturday. Dr. Gabriel enters and Trudy asks him about one of the patients he saw this morning who was on his schedule for a PrEP assessment. She asks, "Can I count her as an assessment for my numbers?" Dr. Gabriel says he didn't even mention PrEP because she was there for a physical exam. Trudy*

> *is dismayed because the report is due in just a few days and, since she was on vacation last week, her numbers are down. Dr. Gabriel asks, "How many do you need?" Trudy says three. Dr. Gabriel assures her he can talk to a Hep C patient tomorrow about PrEP to help her meet her numbers.*

This shows the pressures the program grant has placed on the PrEP Administrator and healthcare providers by encouraging ambiguous interpretations of HIV risk in order increase PrEP assessment and enrollments to meet its top-down number requirements. At NYCHC, the providers were constantly under pressure to meet numeric goals. In fact, in the hallways of the clinic, large TV screens were constantly projecting what provider was in which exam room, the number of patients each provider had seen, and the patients' cycle times (amount of time the patients spend alone, with staff, and with providers). When I asked one of the physicians about this, she told me, "The numbers are everywhere you look. You get used to them" and then showed me how those same metrics were listed on her patient list on her EHR screen in addition to being projected on the TVs.

In summary, HIV risk's ambiguity is constructed from the top-down via the healthcare guidelines based on clinical trials and embedded into program grant requirements, impacting patients and health professionals in a variety of ways on the clinical level. Though unseen, this structural risk has real impacts on daily life, serving both as a "model *of*" HIV risk's ambiguity by rendering patients as being perpetually at risk and in need of treatment, as well as a "model *for*" HIV risk's ambiguity by assigning health professionals the role of identifying risk with no end point.

How **HIV Risk's Ambiguity is Codified in the Electronic Medical Record**

In this section, I will explore *how* HIV risk's ambiguity is codified in the electronic medical record (EMR) to consider an important mechanism by which structural risk becomes further embedded in healthcare infrastructure. In doing so, I will examine how the EMR serves both as a reflective "model *of*" HIV risk's ambiguity as well as an constructive "model *for*" its amorphous conceptualization.

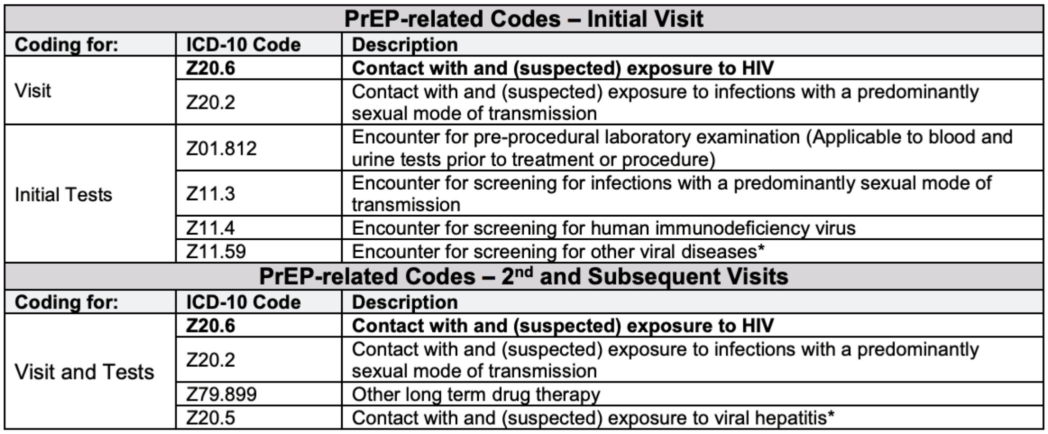
One of the most prominent ways HIV risk's ambiguity is codified in the EMR is through the implementation of the International Classification of Diseases, Revision 10, Clinical Modifications/Procedure Coding System (ICD-10 CM/PCS). The ICD-10 is a coding system continuously published and revised by the World Health Organization (WHO) that serves as the international "diagnostic classification standard for all clinical and research purposes" (WHO 2020). Every time a physician sees a patient, their assessment of that patient's health and any procedures done during the visit is coded using one or more of over 140,000 alphanumeric, 3-7 digit codes in the ICD-10 lexicon (CDC 2015). This coded information can then be extracted from the EMR and used for a variety of purposes, such as health information sharing, quality improvement, public health morbidity and mortality monitoring, research, and insurance claims (Brooks 2009). As Hunt et al (2017) have shown in their research on EMRs in the healthcare center, the ICD-10 is one facet of an EMR that reflects a "corporate logic" beholden to "billing, regulatory, and quality monitoring" and leaves little room for patients' experiences and narratives (p. 417). As such, the coding of health conditions with the ICD-10 code is another way that "Clinical goals and successes are increasingly defined in terms of quantifiable outcomes, requiring the digitization of each patient's health status to a set of data points" (2017:418).

Nowadays, EMR data is often used to determine risk for disease, and other research has shown how HIV-risk prediction models may be applied to EMR data to identify those at risk for HIV (Marcus et al 2019). This study found that the health professionals at NYCHC often relied on ICD-10 Codes to help identify those at risk for HIV. According to the HIV Care

Administrator and former PrEP Administrator, Selena, there were two main ways that patients were identified for PrEP at NYCHC outside of visits with their provider. First, patients who went to the NYCHC Urgent Care branch for STI screening may be identified by the staff, who then are supposed to send a message in the EMR to the PrEP administrator to follow up with them. The PrEP administrator then calls those patients to educate to them about PrEP and encourage them to ask their doctor about it. Second, the PrEP Administrator uses a software called COGNOS to generate a “Positive STI Visits by Location” report, which Selena referred to as the “Missed Opportunity Report.” Every 2 weeks, this report was generated by extracting the ICD-10 codes from the EMR to create a list of all of the patients who had a positive STI at NYCHC in the past 2 weeks. The PrEP Administrator then uses this list to review all of the clinical visits (called “encounters”) of those patients, looking specifically for exposures or reasons for getting STI testing. If the individual was not referred to the PrEP program during the encounter, the PrEP administrator will call them, educate them about it, and perform a risk assessment screening using the AIRS NY checklist. If the patient is interested in seeing the doctor to discuss PrEP, the PrEP administrator informs the provider through the EMR that the patient will be coming in, and either schedules them for a combined appointment or makes a separate appointment just for PrEP Assessment.

In addition to identifying patients for the PrEP program, the ICD-10 codes served as a basis for tracking the patients’ risk status over time in the program. Upon review of the EMR of the patients in the PrEP program, the healthcare providers’ assessment of HIV risk was codified as one of several Z codes, as listed in the NYSDOH and NYC Health’s ICD-10 Recommendations for Pre-Exposure-Prophylaxis (PrEP) and Post-Exposure Prophylaxis (PEP) (NYSDOH 2017).

Figure 8. New York State Department of Health and NYC Health's Recommended ICD-10 Z Codes for Pre-Exposure-Prophylaxis (NYSDOH 2017)



PrEP-related Codes – Initial Visit		
Coding for:	**ICD-10 Code**	**Description**
Visit	**Z20.6**	**Contact with and (suspected) exposure to HIV**
	Z20.2	Contact with and (suspected) exposure to infections with a predominantly sexual mode of transmission
Initial Tests	Z01.812	Encounter for pre-procedural laboratory examination (Applicable to blood and urine tests prior to treatment or procedure)
	Z11.3	Encounter for screening for infections with a predominantly sexual mode of transmission
	Z11.4	Encounter for screening for human immunodeficiency virus
	Z11.59	Encounter for screening for other viral diseases*
PrEP-related Codes – 2nd and Subsequent Visits		
Coding for:	**ICD-10 Code**	**Description**
Visit and Tests	**Z20.6**	**Contact with and (suspected) exposure to HIV**
	Z20.2	Contact with and (suspected) exposure to infections with a predominantly sexual mode of transmission
	Z79.899	Other long term drug therapy
	Z20.5	Contact with and (suspected) exposure to viral hepatitis*

Z codes codify risk in several ways. For example, in the ICD-10-CM Official Guidelines for Coding and Reporting, Z codes reflect a wide range of reasons for patient encounters to indicate "factors influencing health status and contact with health services," from socioeconomic determinants of health to screening services (HHS 2018:91). Z codes are particularly useful for population health statistics and value-based reimbursement models of care (Goar 2017). More specifically, the sub-category Z20 codes, which were most commonly used for the PrEP visits, "indicates contact with, and suspected exposure to, communicable diseases. These codes are for *patients who do not show any sign or symptom of a disease* but are suspected to have been exposed to it by close personal contact with an infected individual or are in an area where a disease is epidemic" (HHS 2018:91; emphasis added). In other words, the Z20 codes are for people who are healthy but are "at risk" for disease, demonstrating not only how HIV risk's ambiguity is codified in the EMR, but also how public health initiatives drive that codification.

Another way HIV risk's ambiguity was codified in the EMR at NYCHC was through the use of standardized templates for "PrEP Initial Assessments" and "PrEP Follow Up Visits." The "PrEP Initial Visit" template contained a wide variety of information about the patients, including a detailed sexual history, domestic violence history, drug use history, mental health status, housing status, knowledge of PrEP, reasons patients wanted PrEP, means to pay for PrEP, and perhaps most relevant to this study, “Risks Identified.” The “Risks Identified” for the PrEP patients in this study included “HIV+ partner,” “Unprotected sex,” “Transgender,” “MSM,” “Multiple partners,” and “previous STI.” Significantly, this shows how certain interpretations of HIV risk’s ambiguity may be further concretized and the role the EMR plays in that process. The health providers would also document “PrEP Education,” showing that they counseled the patient on symptoms of acute HIV, how PrEP works, the number of days PrEP should be taken for it to be effective, side effects of PrEP, long-term safety of PrEP, limitations of PrEP, and ways the patient could protect themselves from other STIs. For “PrEP Follow Up Visits,” the template showed the providers discussed acute symptoms of HIV in the last 90 days, any missed doses of PrEP, risk reduction, condom use, behavioral changes, side effects, and STI symptoms in addition to offering the patients condoms.

Missing from the template were any reasons why the patient may no longer wish to take PrEP or be considered a candidate to take PrEP. Dr. Gabriel told me, as he was about to see the PrEP patient Samuel, “I’m not sure why this patient Samuel is in the PrEP program. He isn’t MSM and doesn’t engaged in risky behavior.” He went on to explain that he inherited this patient from another provider, implying that he may not have started him on PrEP in the first place. However, when Dr. Gabriel saw Samuel, there was no discussion of possibly discontinuing PrEP. In fact, the appointment, which was less than ten minutes long, primarily focused on how Samuel needs to do his STI and blood work labs in order to remain eligible for the PrEP program because he didn’t do his labs last time. This entire patient encounter is conveyed in my fieldnotes below.

> *When he enters the room, Dr. Gabriel asks Samuel, "How have you been?" Samuel says good. Dr. Gabriel says, "Amigo, last time you didn't do your blood test for your meds." Samuel tells him, "I went, but the system [in the lab] was down." Dr. Gabriel says, "Then you have to come back to do them. You need to do them today because we need the test results for your insurance in order to send in the medication [PrEP]." Samuel nods in agreement. Dr. Gabriel continues with the visit, asking, "How many partners do you have?" Samuel tells him "Just one." Dr. Gabriel asks, "Are you using condoms?" Samuel says no. Dr. Gabriel asks, "Is she taking meds too?" Samuel, "No." Dr. Gabriel, "Just you?" Samuel, "Yeah." Dr. Gabriel says, "Okay I'll order the same labs as usual. Everything's pretty much the same since I last saw you?" "Yeah," Samuel says. Dr. Gabriel, "Have any questions?" "No," says Samuel. "Alright," Dr. Gabriel tells him, "Then let [the nurse] come in to give you the lab slips before you go to the lab." Dr. Gabriel then leaves.*

Not only does this reinforce how PrEP administration places the onus of preventing HIV on the patient by requiring them to comply with lab tests and frequent visits, but it also shows how these lab requirements are driven by insurance companies. Additionally, it demonstrates how PrEP administration contributes to the ambiguity of HIV risk by construing it as having no end point. Even though Dr. Gabriel implied Samuel shouldn't have been started on PrEP in the first place, the EMR template for PrEP doesn't offer an opportunity for him to consider stopping it for Samuel.

In summary, HIV risk's ambiguity is codified in the electronic medical record (EMR) in several ways, from ICD-10 codes to templates, demonstrating how structural risk may be both a reflective "model *of*" HIV risk's ambiguity that's embedded, and unquestioned, in healthcare infrastructure, as well as an constructive "model *for*" its amorphous conceptualization through standardized electronic documentation.

How **Risk is Perpetuated by HIV Prevention Advertisements**

In this final section, I will examine *how* ambiguous concepts of HIV risk are perpetuated by HIV prevention advertisements to demonstrate the ways in which structural risk becomes enmeshed in the fabric of everyday life. In other words, I will examine how HIV prevention advertisements serve both as "models *of*" and "models *for*" HIV risk's ambiguous construction.

At NYCHC, great care went into the design and architecture of their various health clinics around the state to make them patient-friendly. One of the clinics I went to had a wide open entrance where several health insurance agencies had tables set up to help eligible uninsured patients quickly enroll. The walls were painted with soothing blues and greens, and everywhere there crisp graphics promoting the health center's mission and personnel along with informational signs directing people where to go using simple icons for those with low literacy or different language backgrounds. At one of the branches, the walls also contained several posters provided by pharmaceutical companies, specifically Gilead. One day, when closing the door to the restroom facility, I was greeted by not one but two of these posters hanging on the back of the door. The first poster was bright blue and featured an elephant, saying "Sexual health shouldn't be the elephant in the room. Talk to a healthcare provider about your sexual health and all the ways to protect yourself." The second poster emulated an eye-exam chart, but instead of random letters for patients to read aloud, it said, "LGBTQ Your Sexual Health Matters. Talk to a healthcare provider about your sexual health and all the ways to protect yourself." Down the hallway, I was confronted by several more Gilead posters, such as the one below.

Figure 9. Example[5] of Gilead Poster for Healthysexuals.com (LGBT Life Center 2018)

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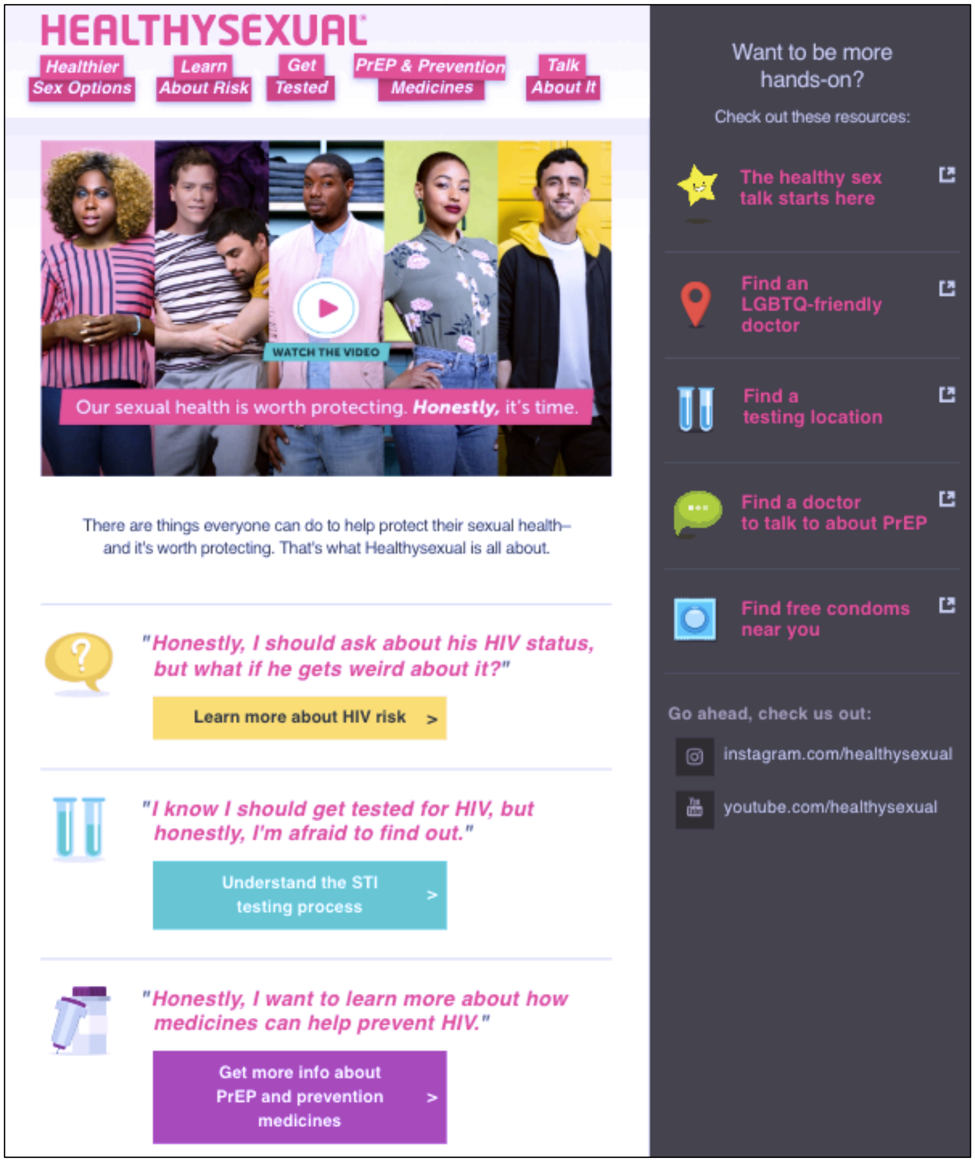
[5] Though I saw this same poster at the health center, this image was taken from another source (LGBT Life Center 2018). The Gilead name and logo appeared at the bottom of the original poster.

Further down the hall hung an infographic from Gilead, saying “Let’s talk about (Healthy) Sex,” providing information on the number of STIs diagnosed in the U.S. every year and encouraging patients to initiate the conversation with their provider about “testing and STIs, healthy sex practices, *prevention medications*, talking to partners, and living with HIV” (emphasis added). All of these posters contained the Gilead name and logo and directed the observer to visit the Gilead website healthysexuals.com below.

Figure 10. Screenshot of Gilead’s Healthsexuals.com Website (Gilead Sciences 2020b)



Our sexual health is worth protecting. ***Honestly,*** it’s time.

There are things everyone can do to help protect their sexual health–and it's worth protecting. That's what Healthysexual is all about.

"Honestly, I should ask about his HIV status, but what if he gets weird about it?"

"I know I should get tested for HIV, but honestly, I'm afraid to find out."

"Honestly, I want to learn more about how medicines can help prevent HIV."

Want to be more hands-on?

Check out these resources:

Go ahead, check us out:

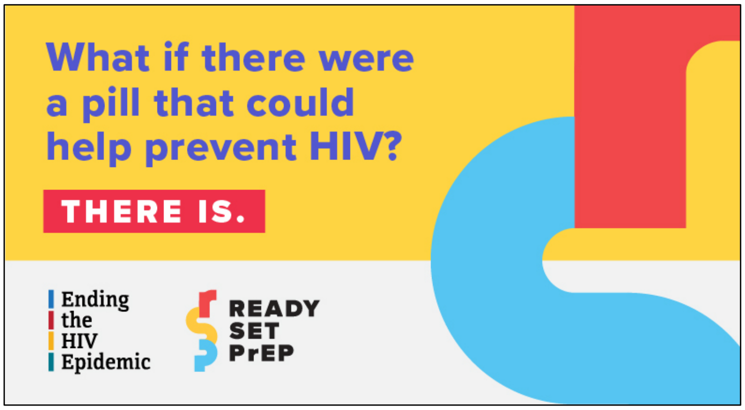
And while this Gilead website does contain a wealth of information about how individuals can connect to health care providers, broach difficult topics with their partners, and protect themselves from STIs, it also repeatedly encourages them to consider PrEP as a means to "protect" themselves (Gilead Sciences 2020b). This embedding of PrEP in messages regarding sexual health, in turn, contributes to the ambiguous discourse surrounding HIV risk by suggesting a reconstitution of that health in pharmaceutical terms, which is exactly what direct-to-consumer (DTC) pharmaceutical advertising aims to do.

Though DTC advertising has been intertwined in the fabric of American culture long before the FDA was able to regulate it (Donohue 2006), it was not until 1997 when the FDA relaxed its regulations on pharmaceutical company ads that DTC advertising took a more prominent position in American daily life (Hartgraves 2002). Notably, the only countries that allow DTC pharmaceutical advertisements are the United States and New Zealand (Ventola 2011). Today, an average American sees more than 9 pharmaceutical advertisements a day and over 16 hours of advertisements per year, much more time than they spend with their primary care physician (Ventola 2011). In comparison to the 2.1 billion (11.9% of total spending) pharmaceutical companies spent on DTC ads in 1997, they spent 9.6 billion (32.1% of total spending) on DTC ads in 2016 (Schwartz and Woloshin 2019). The growth of DTC advertisements is significant given they operate in tension on the sociopolitical level between government regulations and private sector growth as well as on the interpersonal level between the patients-as-consumers asking for medications and the healthcare providers prescribing them. For example, approximately 2/3 of patients who ask their doctors for prescriptions after seeing an ad for them have that request granted (Donohue and Berndt 2011).

As Joseph Dumit (2012) has shown, pharmaceutical companies carefully craft DTC advertisements through a series of market strategies, including awareness through education, personalizing the risk, motivation to self-diagnose, seeing and convincing a doctor, and branded compliance (p. 62). Gilead's Healthysexuals DTC advertisements for PrEP illustrate all of these steps. The website educates patients on STI and HIV risk and personalizes that risk for patients: "Multiple factors can affect the chances of being exposed to an STI, like HIV. Understanding these factors means you'll be better able to figure out which prevention options are best for you" (Gilead Sciences 2020b). It motivates them to self-diagnose: "Your sexual health is just one aspect of your overall well-being. Getting tested is no different from getting a checkup. It's regular maintenance for a healthier body" (Gilead Sciences 2020b). And it encourages them to see and convince a doctor to prescribe PrEP and continue taking the medication: "If you're HIV-negative, PrEP could be right for your situation. Talk to a healthcare provider. You two can talk about what's best for you" (Gilead Sciences 2020b). The website even contains a link to a personalized tutorial on how you can "rock the talk with a healthcare provider" by discussing HIV prevention including PrEP with them, and, in the case that the provider "isn't willing to talk or help out," it lists several links to directories of providers who are (Gilead Sciences 2020b).

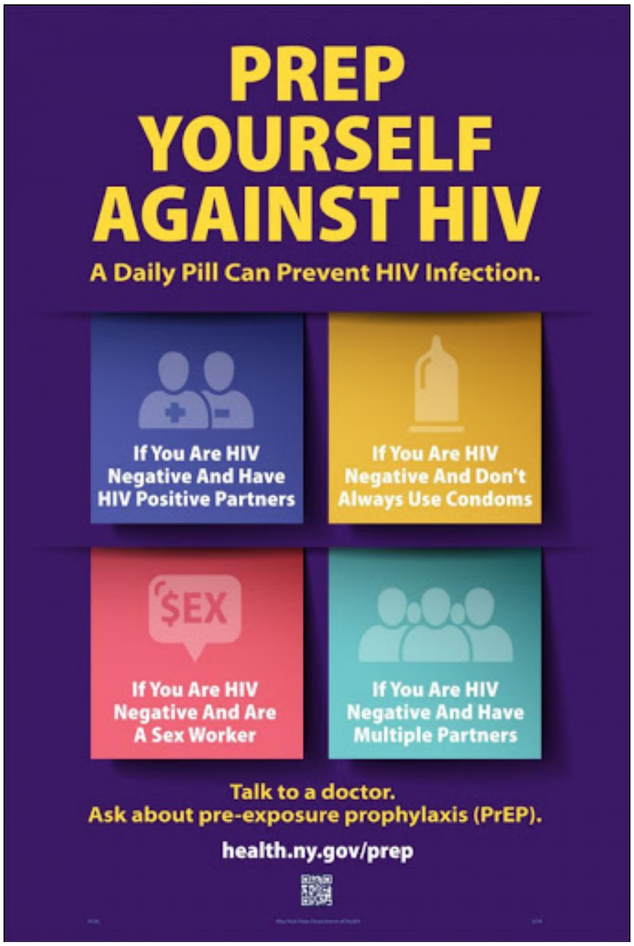
Though pharmaceutical companies seem to be driving most DTC campaigns directly, they have also benefited from the help of public health agencies to promote their products. Laura Crosswell and Lance Porter have called attention to how pharmaceutical companies have achieved a public prerogative through subsidizing the FDA and financing politicians' campaigns (Crosswell and Porter 2016). Specifically, they examined how Merck Pharmaceuticals was able to exploit these avenues in order to "commercialize" the government's public health communication promoting the Gardasil vaccination for Human Papilloma Virus (HPV) in Texas, pointing to the ethical implications of how healthcare messaging, which is supposed to protect, if not promote, public welfare, has become “increasingly vulnerable to profit-driven agendas and big business corruption” (p.217). Both reflective of and constructive to HIV risk’s ambiguity, this line between public health goals and healthcare corporations’ interests has become further blurred in the instance of PrEP. Though the this blurring is demonstrated by the patent battle of PrEP between Gilead and the U.S. Department of Health and Human Services as previously discussed, it is also evident in some of the public health campaigns and publications promoting PrEP both on the national and state level. On the national level, the United States Preventative Services Task Force (USPSTF) (2019) gave PrEP its highest recommendation, the grade A, in preventing HIV in “persons at high risk of HIV acquisition” (p.2203). Anthony Fauci (2019), Director of the National Institutes of Health's (NIH) National Institute of Allergy and Infectious Diseases (NIAID), has promoted antiretrovirals and PrEP by saying, “Theoretically, if we accessed and put on antiretrovirals everyone who has HIV and provide PrEP for all at high risk of HIV, we could rapidly end the epidemic.” Moreover, in early December 2019, the U.S. Department of Health and Human Services announced its “Ready, Set, PrEP” program, providing PrEP for over 200,000 uninsured Americans (McNeil Jr. 2019).

Figure 11. “Ready, Set, PrEP” Advertisement (HIV.gov)



Significantly, the "Ready, Set, PrEP" program does not cover the mandatory office and laboratory visits required for a PrEP prescription, which can cost a patient up to $1000 per year, and the government is reimbursing Gilead for $200 per bottle of medication when the cost for the prescription is only $60 to make an entire years' supply (McNeil Jr. 2016). On the state level in New York, PrEP has been one of the three-prongs of New York governor Andrew Cuomo's 2014 "Ending the Epidemic" plan (NYSDOH 2015).

Figure 12. New York State Department of Health's "PrEP Yourself Against HIV" Advertisement (Tompkins County 2020)



New York State has worked hard to remove as many financial barriers to patients taking PrEP as possible. In addition to its own medication assistance programs like the PrEP Assistance Program (PrEP-AP) for uninsured patients (NYSDOH 2020), it has also recently passed state legislation requiring insurance companies to cover the cost of PrEP and its maintenance visits (The New York State Senate 2020). Gilead even offers assistance cards to cover copays for PrEP for commercially-insured patients, covering up to $7,200/year (Gilead Sciences 2020a). So far, it seems to be working: In 2018, the estimated number of New Yorkers taking PrEP increased to 32,000 and the number of new cases of HIV decreased to 2,481, 38% less than in 2014 when the state began its initiative (McKinley 2019). Gilead may be reaping the financial rewards of PrEP, but epidemiological results seem to show a clear public health benefit.

And while these epidemiologic results are promising on a population level, the public health campaigns' ambiguous constructions of HIV risk have some potentially serious implications on the individual level. Not only are Americans paying a private drug company—whether through insurance or through assistance programs—for a medication whose research was funded by taxpayers' dollars, they are also paying a price in terms of their health. For example, at a public workshop I attended on PrEP given by the Latino Commission on AIDS, the speaker promoted PrEP as a "condom that never breaks," a pill that "allows you to take ownership of your body." In this light, patients inherently do *not* have ownership of their body and may only gain such ownership through pharmaceutical means. Similarly, New York City's "Living Sure" PrEP ad campaign also paints individuals' futures as uncertain, encouraging them to reclaim that certainty using PrEP (NYC Health 2018).

Figure 13. NYC Health's "Living Sure" Subway Advertisement (Mount Sinai IAM 2018)

ENJOY SEX WITH ONE LESS WORRY.
PrEP CAN KEEP YOU HIV NEGATIVE.

If you are HIV negative, PrEP is a safe, daily pill that protects you from HIV. PrEP will not interfere with hormonal birth control. Condoms offer additional protection against other sexually transmitted infections and unintended pregnancy.

PLAYSURE: Talk to your doctor or visit nyc.gov/health and search for "PrEP".

Though such efforts by New York State and New York City public health programs to reduce the stigma surrounding HIV and sexual practices are praiseworthy in many ways, what such messages confer to people is that, without PrEP, they do *not* have control over their bodies, their futures, and their health. And by doing so, these HIV prevention advertisements not only contribute to the ambiguous discourse surrounding HIV risk, but they also perpetuate it.

In this way, these HIV prevention advertisements are an example of structural risk serving both as a "model *of*" HIV risk's ambiguity by interweaving its amorphous constructions into American culture and daily life, as well as a "model *for*" HIV risk's ambiguity by broadcasting such constructions such far and wide.

Conclusion

In this chapter, I have used the concept of “structural risk” as a lens to analyze the final narrative element of *how* HIV risk is ambiguously conceptualized. Specifically, I examined *how* HIV risk’s ambiguity is constructed in healthcare guidelines, codified in EMRs, and perpetuated by HIV prevention advertisements. I argued that these examples of structural risk are what enable PrEP use to distort and crystallize HIV risk’s ambiguity by serving both as reflective “models *of*” and constructive “models *for*” its ambiguous conceptualization.

Though there may not be a conspiratorial “hidden agenda” behind PrEP’s use as Jade conveyed at the beginning of this chapter, nevertheless these findings show how the ambiguous discourse surrounding HIV risk has been heavily shaped by an overlap between a pharmaceutical company’s desire for profits and public health agencies’ desires to decrease HIV incidence. This overlap between public and private interests is of great anthropological concern. As public health agencies promote concepts of risk that have become increasingly more subjective and broad to reflect widening pharmaceutical markets and profit margins, the definition of health and wellness becomes increasingly narrow. And with it, the power of individual health professionals and patients to counteract these processes becomes increasingly diminished.

Chapter 7: Conclusion

Though rooted in objective, epidemiological data on disease prevalence and incidence, “risk” is a subjective, morally-charged concept. In this way, “risk” is a cultural construct shaped by social and political economic factors, such as public health campaigns and healthcare corporations’ agendas, and translated into individuals’ beliefs and experiences. The cultural construction of HIV “risk,” and the treatment of that risk with PrEP, is no exception to this. Since the beginning of the U.S. HIV epidemic in the 1980s, the CDC has defined HIV risk factors from a public health perspective based upon epidemiological network theory (MacQueen 1994) and numerical rates of HIV amongst certain groups (CDC 1983). However, these “objective” groupings of HIV “risk” have allowed for subjective, moral readings of people by “prompt[ing] providers (and the general public) to infer that numbers are rising because certain kinds of people have inadequate education and unprotected sex” (Sangaramoorthy 2012:297). Until recently, the only way to reduce the risk associated with the sexual transmission of HIV was through the use of condoms or the practice of abstinence. However, with the recent advent of PrEP, HIV-negative individuals may now also reduce their HIV risk through the use of pharmaceuticals, creating an entirely new market for healthy people to take medications in the absence of illness.

As I have shown in this dissertation, the pharmaceutical treatment of HIV risk, in turn, signifies a critical cultural shift in how individuals perceive and experience not only the risk of disease, but also health in general. I investigated the current ways HIV risk may be culturally constructed and how medication guidelines for Pre-Exposure Prophylaxis (PrEP) may reflect and contribute to that construction. By using HIV risk in the administration of PrEP as a lens to consider how individual health professionals and patients perceive risk and prophylactic medications treating it, I examined how these perceptions align with those of healthcare corporations and public health agencies.

In this final chapter, I will briefly summarize the major points of the dissertation and discuss the implications this study might have for future anthropological research, PrEP administration, and our society as a whole. More specifically, I will elaborate upon how this research reflects the pharmaceuticalization of society, calls for more anthropological research to illuminate and disentangle the increasingly intertwined interests of public health agencies and healthcare corporations, and suggests how PrEP administration might be improved to better treat the structural factors of HIV risk.

The Ambiguity of HIV Risk, Its Distortion through PrEP, and Structural Risk

Given how constructions of HIV risk have drastically impacted individuals in the past (see Chapters 1 and 2), I began this dissertation with the aims of examining how HIV risk is currently perceived by individuals in healthcare settings today, how the pharmaceutical treatment of HIV risk with PrEP impacts those perceptions, and what broader structural factors shape this process.

I first examined how patients and health professionals construct and communicate HIV risk (see Chapter 4). By showing that the patients and health professionals in this study navigated multiple frames for HIV risk, I argued that HIV risk has an ambiguous discourse. My analysis built upon Laury Oaks and Barbara Harthorn's (2003) discussion on how people perceive risk through different "frames" which "reflect their values, world views, and concepts of social order" (p.viii), in order to deconstruct their discourse surrounding HIV risk into its constituent narrative parts of *who*, *what*, *where*, *when*, *why*, and *how*. In asking, "*What* is HIV risk?" I found the study participants adopted numerous frames to define HIV risk, from monsters, to social deviance, to undetectable viral loads. In asking "*Who* is at risk for HIV?" I found that they painted a diverse picture of identities associated with HIV risk, from people who have multiple sexual partners, to "young MSM of color," to "everyone." In asking "*Where* is HIV risk situated?" I found they differentially framed HIV risk in various settings, situating it in blood, outside protective walls, and within certain neighborhoods. In asking "*When* are persons at risk for HIV?" I found they associated different timings with HIV risk, whether placing that risk in the past or eclipsing any focus on what the future may hold. And lastly, in asking "*Why* are certain people at risk for HIV?" I found they navigated multiple frames for individuals' agency over HIV risk, including their lifestyle choices, circumstance, and deception. By asking each of these questions, I showed that the discourse surrounding "HIV risk" is ambiguous, a direct contrast to my original expectation of triangulating HIV risk based on existing literature, as demonstrated by Figure 2. Instead I proposed that this ambiguous discourse of HIV risk may more aptly demonstrated by Figure 3.

Figure 2. Original Research Aim to Triangulate HIV Risk

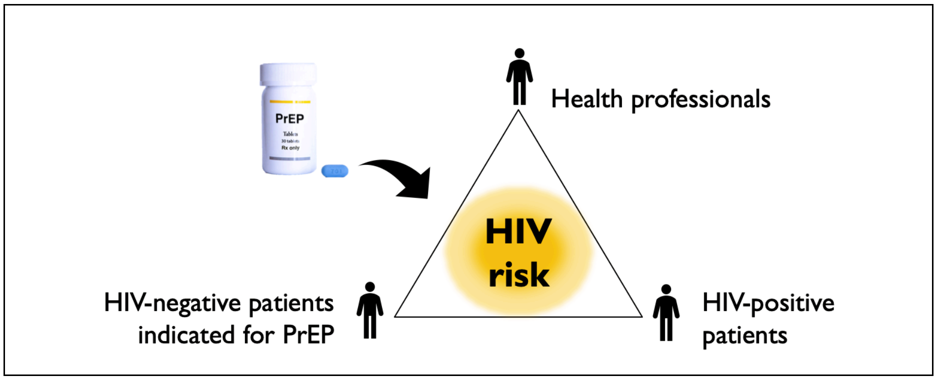
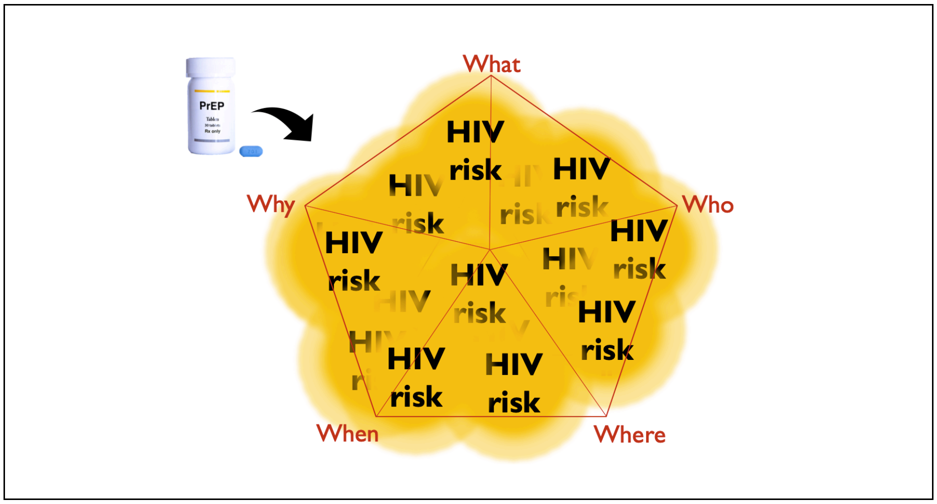
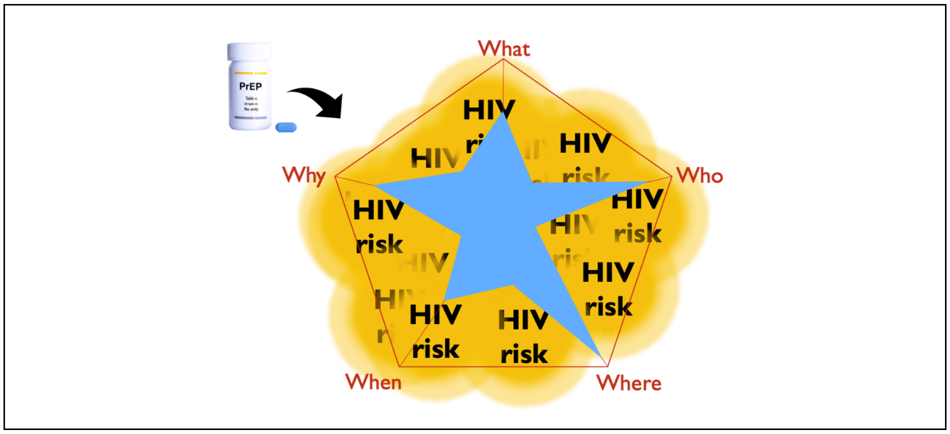


Figure 3. The Ambiguity of HIV Risk



I then investigated how the patient and health professionals in the study situate PrEP to address HIV risk (see Chapter 5). In contrast to the ambiguous discourse surrounding HIV risk established in the previous chapter, I found that PrEP both crystallizes and warps certain aspects of that discourse, as illustrated by Figure 4 below.

Figure 4. How PrEP Distorts and Reinforces HIV Risk's Ambiguity



My analysis found that the patients and health professionals' perceptions of PrEP were broken down into the frames of *what* (materiality), *who* (identity), *where* (location), *when* (timing), and *why* (agency) to both reinforce and distort the ambiguous discourse surrounding HIV risk. When answering the question, "*What* is PrEP?" they framed PrEP in terms of protection and medication, concretizing HIV risk and thus its treatability as an object of pharmaceutical intervention. When answering "*Who* should take PrEP?" they identified people who have multiple sexual partners, MSM, minority communities, and "everyone" as those who should take PrEP, and added participants of "social sex" sites like Grindr, further solidifying PrEP's market. When answering, "*Where* does PrEP function?" they exclusively situated it within the body where is also can incur deleterious side effects. When answering, "*When* does PrEP work?" they showed how PrEP distorts the timing of HIV risk by placing that risk in the present, resulting in a shift of responsibility onto the patient not only to take a daily medication but also comply with the mandatory lab tests and visits. And in answering "*Why* people should take PrEP?" they framed it in terms of individual choice, increasing individuals' sense of control, liberation, and practices of risk compensation. By considering how PrEP crystallizes and warps the ambiguous discourse surrounding HIV risk, I showed how PrEP is both a pill that treats HIV risk while also a serving as prism that distorts how HIV risk is conceptualized and experienced by both patients and the health professionals treating them.

Lastly, I addressed the final narrative element of *how* this ambiguous discourse surrounding HIV risk is influenced (see Chapter 6). I proposed the concept of "structural risk" to describe *how* ambiguous concepts of "risk" are built, top-down, into the structure of society, specifically health care systems, and how these concepts manifest as an ever-narrowing definition of health and ever-diminishing power of individual health professionals and patients to influence it. Significantly, I argued that structural risk enables PrEP use to distort and crystallize the ambiguous discourse surrounding HIV risk by serving both as a reflective "model *of*" HIV risk's ambiguity as well an constructive "model *for*" how that ambiguity is conceptualized (Geertz 1973:93; emphasis in original). First I explored *how* HIV risk's ambiguity is developed in healthcare guidelines, showing how they ambiguously construct it through clinical trials and program grant requirements to impact patients and health professionals on the clinical level. Specifically, I investigated how Gilead, the maker of PrEP, had a significant role in most of the clinical trials demonstrating the efficacy of PrEP in reducing the risk of HIV, which influenced the CDC's 2017 clinical guidelines for health professionals in determining what groups of people are at risk for HIV and should be treated with PrEP. According to these guidelines, the high risk groups indicated for PrEP are "Men Who Have Sex with Men," "Heterosexual Women and Men," and "Persons Who Inject Drugs" with one or more of the following indications for "substantial risk of acquiring HIV infection": having a "HIV-positive sex partner," "recent bacterial STI," "high number of sex partners," "history of inconsistent or no condom use," involvement in "commercial sex work," "HIV positive injecting partner," or practice of "sharing injection equipment," with the additional specific provision for heterosexual women and men of living "in a high HIV prevalence area or network" (CDC 2018b:11).

In addition to observing the CDC's guidelines, I found that the health professionals at NYCHC also had to follow protocols outlined in a program grant from New York State, which structured their PrEP program with its requirements of screening patients for HIV risk, patient quarterly visits, and outcome reporting. I then discussed how HIV risk's ambiguity is codified in the electronic medical record (EMR), looking at how public health ICD-10 codes are used both to help identify patients at risk for HIV as well as document that risk in the patient chart. Another way HIV risk's ambiguity was codified in the patient chart was through the use of standardized templates for PrEP assessments and follow-up visits, which portrayed HIV risk as having no end point. Lastly, I examined *how* HIV risk's ambiguity is perpetuated by HIV prevention advertisements, showing how they not only promote ambiguous concepts of HIV risk, but also further enmesh it into American culture and daily life. I looked specifically at Gilead's Healthysexuals advertisements and analyzed their direct-to-consumer (DTC) market strategies, including awareness through education, personalizing the risk, motivation to self-diagnose, seeing and convincing a doctor, and branded compliance (Dumit 2012). I also examined how both federal and state public health PrEP advertisements continue to blur line between public health goals and healthcare corporations' interests, placing into question any definition of sexual health that isn't pharmaceutically-mediated. By examining how these examples of structural risk regarding PrEP use are "models *of*" and "models *for*" HIV risk's ambiguous construction, I raised concerns over how the increasing overlap between public health agencies' and healthcare corporations' objectives may narrow the definition of health and diminish the power of individual health professionals and patients to influence it.

The Pharmaceuticalization of Risk Society

Though PrEP is a newer drug, the pharmaceutical treatment of risk is by no means a new practice (Greene 2007; Dumit 2012). Having explored how HIV risk is culturally constructed and distorted by PrEP, I will now discuss how my findings on PrEP's treatment of HIV risk fit within the larger pattern of society's increasing pharmaceuticalization.

The "pharmaceuticalization of society" (see Chapter 5) is the dynamic and complex process by which "human conditions, capabilities, and capacities" are transformed "into opportunities for pharmaceutical intervention" (Williams, Martin, and Gabe 2011:711). The extent of this pharmaceuticalization is readily apparent by the sheer magnitude of the role prescriptions play in Americans' daily lives: 55% of all American adults take at least one medication, with each person taking an average of four (Consumer Reports 2017).The medical treatment of risk has been an integral component of this pharmaceuticalization. As Jeremy Greene (2007) has shown, pharmaceutical companies have used clinical trials to drastically expand their marketplaces in the treatment of symptomless risk factors for chronic diseases like hypertension, hypercholesterolemia, and diabetes. Key to this process is healthcare corporations' manipulation of numerical delineations for these risk factors, numbers which may "float free from the individual body into the broader logics of bureaucratic systems and the marketplace" (p.219). As he contends, "in the treatment of risk, where there are no symptoms except for the numbers themselves, the prospects for therapeutic expansion appear limitless" (p.229). But this dissertation suggests that a significant change may be occurring in this pharmaceuticalization process: as demonstrated by the ambiguous, subjective portrayal of HIV risk, the pharmaceuticalization of risk may no longer require such numerical delineations as it previously has. Though artificial and manipulated, these numerical tethers have helped ground constructs of risk in reality. Without these tethers, the question remains: Where will definitions of risk and its treatment end? And, aside from the healthcare corporations profiting from the treatment of risk, to whose benefit?

This increasing pharmaceuticalization is of great anthropological concern and carries numerous implications on both the individual and social levels. On the individual level, it has led to a reconstitution of health in pharmaceutical terms. As discussed in this dissertation, multiple patients and health professionals used words like "seatbelts," "backups," "shields," and "blankets" to frame how PrEP conferred a sense of safety to them. One patient described how PrEP "cleaned" his body, connoting the human body at risk for HIV as a dirty receptacle needing pharmaceutical intervention to rid it of that dirt. Such images were reflected by the HIV prevention advertisements for PrEP, promoting messages that, with PrEP, people are “Living Sure” (NYC Health 2018). But what these images and advertisements imply is that, without medications like PrEP, individuals’ health statuses are *not* safe, and their futures are *not* certain. The only way to reclaim that sense of safety and certainty is to take a prophylactic medication, perhaps for the rest of their lives. And through this reclaiming of health by means of pharmaceuticals, it changes what it means to be healthy to begin with. As Joseph Dumit (2012) says,

> “On an absolute level there is a risk, and on a very obvious level we are all at risk of dying within ten years, five years, one year. What has changed is that health is no longer keyed to either an experiential sense of wellness or an absence of disease and imminent danger. Rather, our nonhealth, or risk, is defined by the fact that we can reduce it by taking a drug” (p.202).

As Dumit suggests, health is no longer defined by what it is, but rather is defined against what it is *not*—disease or the risk of disease. This is in direct contrast to the World Health Organization’s definition of “health” as “a state of complete physical, mental and social well-being and not merely the *absence* of disease or infirmity” (WHO 2020; emphasis added). What is more, pharmaceuticals are not only contributing to new definitions of health, but also to a new way of life. As Dumit (2012) has shown, “many patients consume pharmaceuticals as a means of maintaining rather than changing a lifestyle” (p.192). He quotes Paul Braverman, an individual who takes statins presumably for hypercholesterolemia, saying, “‘As a weak man without willpower or self-motivation, it’s a lot easier for me to take the pill than to eat the damn veggie burger’” (p.193). This “pharmaceutical living” (p.192) or “statins-for-steaks” (p.194) mentality echoes what many patients said in this study: When it comes to PrEP, it is much easier to take a pill than to use a condom. As the 37-year-old nurse Cat said, “Nobody’s going to look twice at you for taking a pill. Everybody takes some kind of medication nowadays.” Taking a pill has not only become part of what it means to be healthy, but has also become an unquestioned aspect of American daily life.

In many ways, this reconstitution of health and daily life in pharmaceutical terms on the individual level reflects the increasingly intertwined interests of public health agencies and healthcare corporations on the political economic level. This dissertation has explored the extensive role the pharmaceutical company Gilead played in the clinical trials and studies serving as the basis of the CDC's guidelines for PrEP and the United States Preventive Services Task Force's recommendations for it. Though the research discovering the use of Truvada (emtricitabine and tenofovir disoproxil fumarate) for PrEP was almost entirely publicly funded, Gilead is still charging over $20,000 per year for the medication. As such, Americans' payment for this overlap between public health agencies and healthcare corporations in the case of PrEP is twofold: First, they are paying a private drug company for a medication whose research was funded by taxpayers' dollars, if influenced by pharmaceutical interests. Secondly, they are paying for a price in terms of their health by as this ambiguous construction of risk reframes their wellness in terms of uncertainty.

Combining Williams, Martin, and Gabe's (2011) "pharmaceuticalization of society" with Ulrich Beck's "Risk Society" (as discussed in Chapter 2), what the findings of this dissertation point to is a pharmaceuticalization of risk society. By proposing the concept of structural risk, it has illuminated the ways that structural risk is embedded, top-down, into our healthcare system and serves as a "model *of*" and "model *for*" HIV risk's ambiguity to disempower health professionals and patients on the clinical level. However, the only examples of structural risk explored in this dissertation were healthcare guidelines including clinical trials and grants, electronic medical records, and pharmaceutical advertisements. Much more anthropological research is needed to uncover the extent to which structural risk might be further enmeshed within healthcare to further narrow definitions of health and wellness. For example, this dissertation focused on structural risk in the administration of PrEP, and other research is needed to see if similar constructs might be at play in the administration of other drugs, such as those treating hypertension and diabetes. Additionally, this dissertation discussed how a program grant circumscribed many of the definitions of HIV risk under which the health professionals were operating, and more ethnographic research is needed to better understand the broader factors that influence such grants, like federal legislation and guidelines, and the factors that determine their outcome reporting measures. While this research sought to build upon Linda Hunt et al's (2017) important findings on the ways electronic health records reflect a "corporate logic" in healthcare to impact patients and health professionals, more is still needed to disentangle the many factors driving such corporatization, such as health insurance companies' reimbursement models and the expanding conglomeration of clinics and hospitals. And lastly, given that the U.S. is one of the few countries that allows direct-to-consumer (DTC) advertisements, cross-cultural ethnographic perspectives are needed to illuminate how pharmaceutical companies' DTC advertisements might impact clinicians' relationships with patients and the power dynamics at play when prescribing medications.

Implications of this Research for PrEP Administration

Though this dissertation reveals many areas requiring further research, it also offers insight into some of the limitations of treating HIV risk with PrEP and how the administration of PrEP might be improved upon.

Most significantly, the findings of this dissertation suggest that the treatment of HIV risk with PrEP, a pill that operates on the microlevel, is limited because it does not address the structural factors, such as racism and homophobia, that operate on the macrolevel to impact HIV risk. Though the patients and health professionals in this study ascribed HIV risk both to an individual's lifestyle choices as well as to the structural circumstances beyond their control, they exclusively framed PrEP as operating within an individual's domain. Placing responsibility onto individual patients to reduce their own risk by taking PrEP not only neglects these broader socioeconomic factors, but potentially strengthens them. This is particularly concerning when it comes to the possibility for the racialization of risk in the administration of PrEP, by targeting certain groups, like black communities, for the drug (as discussed in Chapters 4 and 5). Sanders et al (2019) have shown how many health professionals' belief that black Americans living in the inner city should be on PrEP "distracts from broader structural factors that underlie disproportionate HIV prevalence in impoverished urban communities" (p.270). They draw upon Jonathan Khan's (2010) analysis to argue that, "while it is laudable to draw attention to the needs of the medically underserved, it is also important to avoid reifying assumptions of bodily or racial difference that obscures structural forces that drive health disparities" (Sanders et al 2019:269). In a different context, Dumit (2012) has shown how the pervasiveness of treating the risk for high cholesterol and heart disease has "naturalized" that risk such that "doctors no longer contemplate the causes" of these illnesses (p.195). Likewise, the treatment of HIV risk with PrEP may lead to the naturalization of racialized constructs of HIV risk such that doctors no longer question *why* certain minority groups may have a higher incidence and prevalence of HIV because they can give them a pill to treat that risk. And without continuing to question these disproportionate rates of HIV amongst certain groups, the structures that facilitate these rates, namely “racial/ethnic oppression, such as the discriminatory rates of arrest and incarceration, economic deprivation, [and] inadequate access to medical and social care” will continue to exist (Friedman, Cooper, and Osborne 2009:1004).

The same can be said of the structural factors propagating the disproportionate rates of HIV amongst the gay community, specifically heteronormative oppression and homophobia. Several of the patients in this study referred to the sexual liberation of the gay community in the 1970s and 1980s, contextualized against the backdrop of police violence against gay men leading to the Stonewall Riots of 1969 (Timberg and Halperin 2012), the medical “pathologization” of homosexuality as a psychiatric illness until 1987 (Drescher 2015:571), and the existence of laws against sodomy in the United States until 2003 (Eskridge 2005). From the beginning of the HIV epidemic, the CDC has associated HIV risk with “homosexuality” (CDC 1983), an association that has mostly persisted with its delineation of certain “Men Who Have Sex With Men” (MSM) as a risk group indicated for PrEP (CDC 2018b). In reflection of this, many of the health professionals and patients in this dissertation also believed MSM to be at risk for HIV and in need of PrEP. As the case manager Irene said, “They’re just at risk. They have more partners. There’s more opportunity for them to be exposed.” Just as PrEP might lead to the naturalization of racialized HIV risk, this statement suggests the PrEP might also contribute to the naturalization of HIV risk constructs associated with certain sexual orientations. And with that naturalization, the structures of heteronormative oppression may continue to exist unquestioned. Such processes that naturalize discrimination must continue to be challenged by society, and nothing demonstrates this better than the current treatment of transwomen in the U.S. According to a recent systemic review and meta-analysis, an estimated 14% of transwomen in the U.S. have HIV (Becasen et al 2019). In contrast to that, only an estimated 0.3% of the entire U.S.

population has HIV (CDC 2019a and United States Census Bureau 2020). While offering transwomen the option of taking PrEP may help mitigate their risk for HIV, it does nothing to address the “discrimination, violence, social and economic marginalization, and abuse” contributing to transwomen’s HIV risk (Stotzer 2017:1362). For example, according to the Office for Victims of Crime (2014), up to 66% of transwomen experience sexual assault. PrEP may protect transwomen from HIV on the microlevel, but the structures of violence making transwomen disproportionately vulnerable to its spread still remain in place.

Given such neglect of broader structural issues, one of the ways the administration of PrEP and similar HIV prevention efforts may be improved is by attending more to the power dynamics connecting individual experiences to the socioeconomic forces shaping them. On a public health policy level, Phillipe Bourgois’ (2009) research on HIV risk practices among heroin users experiencing homelessness in San Francisco corroborates the importance of considering power dynamics, but from a more nuanced perspective of how power shapes homeless heroin users’ “moral economies” of drug use, a phenomena often neglected by public health campaigns seeking to curb it (p.2331-2). On this, he says,

> “mainstream applied public health paradigms ignore power—whether it be the criminal justice system and laws governing controlled substance and paraphernalia; the ideological and social structural enforcement of social marginalization by institutions and mainstream discourses; or the structuring of networks and identities/practices of risk by race, class, gender, sexuality, and geography. By focusing on changing individual behavior in a vacuum, public health researchers obscure and ultimately reinforce the power dynamics that shape risk” (p.2344).

Applying this critique to PrEP, public policy might change to better reflect these structures of power shaping HIV risk. For example, as discussed in Chapter 4, the HIV care administrator Selena identified a lack of housing as a risk factor for HIV. New York State is extremely progressive in assisting HIV-positive individuals with housing through their Housing Opportunities for Persons with AIDS (HOPWA) and Ryan White Part A Housing Program.

Additionally, the “New York State's Blueprint to End the AIDS Epidemic” repeatedly recommends the expansion of housing assistance programs to decrease HIV progression and spread (NYSDOH 2015). However, the White House’s recent release of “Ending the HIV Epidemic: A Plan for America” does not mention housing at all, instead exclusively focusing on the expansion of PrEP programs as a means of preventing HIV (Health Resources & Services Administration 2020). For the HIV prevention efforts to comprehensively address the structural factors of HIV risk like a lack of housing, both federal and state resources must be allocated to also address them in conjunction with PrEP.

On the clinical level, Nicole Haberland’s (2015) meta-analysis demonstrates the effectiveness of sexual health education programs that specifically address power dynamics in relationships in preventing STIs and unwanted pregnancy. Her results showed that 80% of the programs that taught women and adolescent females how to negotiate power in relationships and reflect upon their personal “self-worth” reduced STIs and unwanted pregnancies in comparison to only 17% of the programs that exclusively taught them about abstinence and contraception modalities (Haberland 2015). Though NYCHC’s “PrEP Initial Assessment” EMR template did include the important screening questions “Any history of sexual abuse?” and “Any history of domestic violence?”, these brief questions did little to capture the sensitivity and compassion I observed the physicians showing their patients. This might be improved upon by allocating more resources and time to helping patients negotiate the power dynamics in the relationships. Though there is no time to spare in the 15 minute encounter the physician has with the patient, incorporating a simple, open-ended question or two, such as “What does your sexual health mean to you?” to promote patients’ critical reflection on their self-worth might be possible. What might be more feasible is if the health center also offered PrEP support groups for individuals to practice some of the exercises Haberland's research recommends, such as playing games examining gender stereotypes in the media, writing personal essays, sharing experiences in past relationships, reflecting upon power inequality in negotiations of condom use, and discussing types of intimate partner violence (Haberland 2015:37). NYCHC has already made great strides to reduce barriers between providers and patients by hiring a PrEP Peer to talk to patients about PrEP and help them address any issues they may have with it. This Peer is already in an excellent position to lead such support groups, and such Peer support models should be emulated by similar programs.

Closing Remarks

In considering how constructs of HIV risk are influenced by its treatment with PrEP, this dissertation has examined how risk and pharmaceuticals are becoming increasingly ingrained in American daily life. However, the findings of this dissertation cannot be reduced to an oversimplified deliberation of whether or not health professionals should prescribe PrEP to otherwise healthy patients or whether or not such patients should consume it. Though I question the inherent bias of pharmaceutical companies' clinical trials and studies showing PrEP's efficacy in reducing HIV transmission, questioning the science underlying their claims is beyond the scope of this study. This dissertation is also *not* a critique of the health professionals at NYCHC, all of whom were passionately dedicated to their patients' health and wellbeing and were following standards of care. Rather, by tracing how structural risk is embedded within our healthcare system, I hope to illuminate how health professionals' agency to counteract such structures might be inherently limited.

What this dissertation *does* is examine how HIV risk is currently being conceptualized, how these concepts may be influenced by the interests of public health agencies and healthcare corporations, and how they play out for health professionals and individual patients in the clinical setting. I found that the discourse surrounding HIV risk is ambiguous, PrEP distorts and crystallizes this ambiguity, and structural risk is a reflective "model *of*" and constructive "model *for*" this process in a top-down direction. By doing so, I draw attention to the social significance of the pharmaceuticalization of risk society by showing how medications impact how risk is conceptualized, communicated, and experienced by patients and the health professionals treating them. In this way, through the pharmaceutical treatment of risky bodies, healthy bodies are being reimagined as anything but.

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