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Eli V. Latta
HIV-serodiscordant couples, Pre-
Exposure Prophylaxis, and
Relationship Satisfaction

ABSTRACT

This mixed-methods study explored the use of post-exposure prophylaxis (PrEP) and relationship satisfaction in HIV-serodiscordant couples. “Serodiscordant” refers to couples in which one partner is living with Human Immunodeficiency Virus (HIV) and one is not. PrEP is a daily dose of the antiretroviral medication Truvada, taken as a prevention measure by HIV-negative individuals at substantial risk for contracting the virus. This study was conducted via an anonymous online survey with both quantitative and open-ended questions to determine whether there is any relationship between the use of PrEP and relationship satisfaction in HIV-serodiscordant couples. Data was analyzed by comparing people in serodiscordant couples in which the HIV-negative partner is using PrEP with people in serodiscordant couples in which PrEP is not used. No statistically significant results were found. A thematic analysis was conducted of the answers to the qualitative questions. Participants who were using PrEP (either taking PrEP themselves or partnered with someone taking PrEP) were more likely to name Sexual and Physical Connection as a way that their partner provided emotional support and as one of the best things about their relationship. Respondents from this group were also more likely to cite the theme of Comfort, Safety, and Trust as one of the best things about their relationship, although this theme was reported by both groups. Participants from the non-PrEP-using group were unique in reporting Closeness as one of the best things about their relationship

and in reporting the themes of Age/Time/Future and Communication as things they would like to change about their relationship.

**HIV-SERODISCORDANT COUPLES, PRE-EXPOSURE PROPHYLAXIS, AND
RELATIONSHIP SATISFACTION**

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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2016

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Dedicated to my Grandma Roz, who didn't know a lot about HIV but who always supported my education – both in institutions of higher learning and in life. May her memory be a blessing.

I could not have made it this far without my family of origin, chosen family (especially Laura, Jesse, Robin, and Myla), and friends. Thank you to my Smithie community – you are all so compassionate and brilliant. Shoutouts in particular to Liz for teaching me how to use Qualtrics, Bianca for all the work dates, and Nathalie for the encouragement when I was on the verge of giving up.

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Bless this mess!

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CHAPTER I

Introduction

Human Immunodeficiency Virus (HIV) is a virus that weakens the immune system and can eventually lead to Acquired Immune Deficiency Syndrome (AIDS). In the 35 years since HIV was first discovered, the landscape of treatment and prevention has shifted dramatically, yet there are still an estimated 1.2 million people living with HIV in the U.S., with as many as 50,000 new infections each year (Pereira, Goschin, & Ashley, 2016; Centers for Disease Control and Prevention, 2015b; Krakower & Mayer, 2015).

Newman et al. (2015) note that “All biomedical technologies are also social interventions.” Perhaps nowhere is this truer than the HIV field, in which interventions must be designed to address not only the medical needs of people living with HIV and AIDS, but the complex biopsychosocial factors at play when it comes to engaging marginalized communities, increasing access to care, improving treatment adherence, and preventing new infections. Couples interventions are increasingly being used for HIV prevention and treatment (Gamarel & Golub, 2015; McMahon et al, 2014).

Globally, half of all HIV-positive people in long-term relationships have a partner who is HIV-negative; these relationships are referred to as “serodiscordant” (Mavhandu-Mudzusi & Sandy, 2015). One of the newest HIV prevention tools available is pre-exposure prophylaxis (PrEP), a daily dose of the antiretroviral drug Truvada (TDF/FTC), approved in 2012 by the Food and Drug Administration for HIV-negative individuals. PrEP is currently recommended for people at substantial risk for acquiring HIV, including those in serodiscordant relationships (Centers for Disease Control and Prevention, 2014).

The purpose of this study is to explore the following question: In HIV-serodiscordant couples, is there a relationship between the use of PrEP and relationship satisfaction? I used a mixed-methods research design, specifically an anonymous online survey with both quantitative and open-ended questions. In analyzing the data, I compared people in serodiscordant couples in which the HIV-negative partner is using PrEP with people in serodiscordant couples in which PrEP is not used.

CHAPTER II

Literature Review

HIV/AIDS

Human Immunodeficiency Virus (HIV) is a virus that weakens the immune system and can eventually lead to Acquired Immune Deficiency Syndrome (AIDS). It is transmitted through bodily fluids including blood, semen, breast milk, and vagina secretions, and can be spread through sexual contact, intravenous drug use, or mother-to-child transmission. There is currently no cure for HIV, although research to that end is being conducted (World Health Organization, 2015).

An estimated 1.2 million people in the United States are currently living with HIV (Centers for Disease Control and Prevention, 2015b). As treatment for HIV advances, HIV-positive people are living longer and longer (Centers for Disease Control and Prevention, 2015b). However, there are still as many as 50,000 new HIV infections every year in the U.S., and two million globally (Krakower & Mayer, 2015). In the U.S., the highest rate of new infections is occurring among young black men who have sex with men, or MSM (Centers for Disease Control and Prevention, 2015a).

The global percentage of women living with HIV has also increased; in the U.S., this is particularly true among black and Latina women. For many, AIDS is no longer seen as the death sentence it once was. However, it is still one of the top five causes of death for African-American women ages 25-44. The majority of HIV infections in women are sexually acquired (McMahon et al., 2014).

Historical context. In 1980, gay men in the U.S. began falling ill with a mysterious terminal disease, initially termed “Gay-Related Immune Deficiency” (GRID) by the medical community. For the first five years of the HIV/AIDS epidemic, there was silence from the Reagan administration and from the mainstream media. Institutionalized homophobia resulted in a lack of research and funding to treat HIV/AIDS, which was seen as a “gay” disease. Due to the failure of medical, political, scientific, and media institutions to respond to a major public health issue, AIDS spread throughout the U.S., killing nearly 12,000 and taking an enormous toll on the gay male community in particular. In 1985, the death of actor Rock Hudson from AIDS ushered in a new era of public awareness and response (Shilts, 2007). Although HIV-positive people today can live long and healthy lives, there remains a culture of stigma and silencing.

Treatment. Today, highly active anti-retroviral therapy (known as HAART or ART) can control the virus, reduce the risk of transmission, and prolong the progression of HIV into AIDS (World Health Organization, 2015). According to guidelines set by both the Centers for Disease Control and Prevention (2015b) and the World Health Organization (2015), starting ART is now recommended to all people living with HIV when they are initially diagnosed. Consistent adherence to an ART regimen can lower the viral load in a person’s blood to undetectable levels, making it virtually impossible to transmit the virus to sexual partners (Safren, Perry, Blashill, O’Cleirigh, & Mayer, 2015).

Psychosocial needs. In the treatment of HIV, Safren et al. (2015) emphasize that psychosocial as well as behavioral interventions must be utilized. Looking at HIV-positive MSM at the highest risk of infecting others, Safren et al. (2015) found that these men had complex mental health and psychosocial needs that got in the way of medication adherence, including substance abuse, depression, domestic violence, and history of childhood sexual abuse.

Prevention. HIV testing is available at community health centers, primary care doctor's offices, and various outreach settings; more recently, at-home HIV test kits are available in drugstores (Hoff, Chakravarty, Beougher, Neilands, & Darbes, 2012). Condoms have long been considered a first-line HIV prevention strategy; they were first approved by the FDA to prevent HIV in 1986 (Pereira, Goschin, & Ashley, 2016). When used correctly, condoms are very effective at preventing HIV infection. However, in the U.S., gay men's use of condoms has been decreasing for over a decade; the only group of MSM in which condom use has increased has been among 18-24-year-olds, who comprise a high risk group (Paz-Bailey et al., cited in Pebody, 2016). Some of the major reasons for not using condoms are intimacy and sexual pleasure (Hoff et al., 2012).

Treatment as prevention. Treatment as prevention (TasP) refers to the use of ART to sufficiently suppress an HIV-positive individual's viral load so as to make transmission unlikely. In addition to prevention at the individual level, TasP is used as an intervention to reduce the community viral load, or aggregated viral loads of HIV-positive people in a specific community (Newman et al., 2015). In a study of HIV-positive individuals not taking ART, Newman et al. (2015) found tensions regarding the beneficiary of TasP, and whether it was intended for the individual or the greater community. Concerns cited by respondents included side effects, adherence, lifelong reliance on meds, and accidental disclosure; however, some participants reported that being on TasP would make them less anxious about disclosure (Newman et al., 2015).

Post-exposure prophylaxis. Post-exposure prophylaxis (PEP) is a course of ART taken for 28 days following a potential exposure to HIV. It is both in healthcare settings (i.e. in response to a needle stick) and is also available to individuals who have had an unprotected

sexual encounter or had a possible exposure through injection drug use. In addition, PEP is given to infants who have been exposed to HIV during birth and/or breastfeeding in order to prevent mother-to-child transmission. PEP must be administered within 72 hours of exposure in order to be effective (Centers for Disease Control and Prevention, 2014).

President's Emergency Plan for AIDS Relief. The President's Emergency Plan for AIDS Relief (PEPFAR) was implemented in 2003; it currently targets 150 countries, primarily in Sub-Saharan Africa, Asia, Central America, and the Caribbean (Doucleff, 2016). Initially, PEPFAR stipulated that one-third of the funding was earmarked for abstinence-only programs; in many African countries, a common prevention slogan used is "ABC: Abstain, Be Faithful, Condomise" (Doucleff, 2016). This requirement was removed in 2008. Recently, a study in 22 different African countries showed that PEPFAR had no effect on young people's choices regarding sex. Other research has shown that PEPFAR has been able to increase access to treatment and prevent AIDS-related deaths; however, it has been unsuccessful in preventing new infections (Doucleff, 2016).

Couples interventions. Couples interventions are increasingly being used for HIV prevention and treatment (Gamarel & Golub, 2015; McMahon et al., 2014). Within couples, each partner's perception of relationship quality is "an important and independent predictor of optimal coping efforts & positive health outcomes" (Gamarel et al., 2014, p.172). Starks, Gamarel, & Johnson (2013) also found that "diminished relationship functions may serve as a barrier to implementing harm-reduction strategies" (p.145).

Gamarel & Golub (2015) use interdependence theory in their research, positing that partners are more likely to participate in health-enhancing behaviors when they perceive a health threat such as HIV as affecting their partner and their relationship as well as themselves. In

addition, couples who are able to feel a “we” orientation may have better health outcomes due to their desires to put their partner’s safety above their personal interests and consider the long-term interest of the couple (Gamarel et al., 2014). However, prioritizing the needs of a relationship above one’s own individual needs could also have negative consequences, particularly in terms of negotiating sexual agreements regarding outside partners and how to proceed when these agreements are broken (Hoff et al., 2012).

Pre-exposure prophylaxis. Pre-exposure prophylaxis, or PrEP, is a daily dose of the antiretroviral drug Truvada (the brand name of tenofovir/emtricitabine, also known as TDF/FTC). PrEP was approved in 2012 by the Food and Drug Administration for HIV-negative individuals. As an intervention, its goal is to reduce the spread of HIV along with its mortality rate and its individual and societal costs. PrEP is currently recommended for people at substantial risk for acquiring HIV (Centers for Disease Control and Prevention, 2014). PrEP has been shown to decrease risk of HIV infection in serodiscordant couples (couples in which only one partner is living with HIV), MSM, heterosexuals in areas with high HIV incidence, and injection drug users (Karris, Beekmann, Mehta, Anderson, & Polgreen, 2014). It has been tested and found to be safe for MSM, transgender women who have sex with men, serodiscordant couples, intravenous drug users, and straight men and women living in areas with a generalized HIV epidemic (Krakower & Mayer, 2015). As of May 2016, PrEP is approved in seven countries: the U.S., Canada, South Africa, Kenya, France, Israel, and most recently Australia.

In initial research on PrEP, the iPrEx study focused on MSM and transgender women, while the Centers for Disease Control and Prevention’s TDF2 study focused on heterosexual men and women, and the Partners PrEP study specifically on straight men and women in serodiscordant relationships (Brooks et al., 2012). The Partners PrEP study showed that younger

HIV-negative women had higher rates of adherence to PrEP when they were in a serodiscordant relationship (McMahon et al., 2014).

Barriers. Despite the favorable results of PrEP trials, it is still not widely used (McMahon et al., 2014). Structural and individual barriers to PrEP use include a low awareness of PrEP among at-risk populations, not enough knowledge among healthcare providers, stigma, little data on long-term side effects, and adherence – PrEP must be taken at the same time every day in order to be effective (Krakower & Mayer, 2015). For some, taking a pill every day may be an uncomfortable reminder of the risk of contracting HIV (Grant, 2010, cited in Pereira, Goschin, & Ashley, 2016). The “reminder” factor may also be a barrier to adherence to retention in care for HIV-positive people; taking ART daily is a reminder for some of being infected.

Provider knowledge. In a 2014 survey of adult infectious disease doctors, Karris et al. found that although 74% of doctors supported the use of PrEP, only 9% had prescribed it. Concerns cited by the participants included adherence, including the risk of future drug resistance if a patient was to eventually contract HIV; not wanting to give potentially toxic medication to healthy patients; and not enough evidence that PrEP is effective. Some participants also expressed the view that they work with HIV-positive, not HIV-negative patients; some cited beliefs that the most at-risk individuals do not present for care and the greater importance of retaining HIV-positive people in treatment. Many participants were unclear on or disagreed with the CDC guidelines on PrEP, and one of the respondents likened PrEP to “an expensive condom” (Karris et al., 2014). Pereira, Goschin, & Ashley (2016) note that there is a continuum of views in regards to PrEP: from a hopeful end to the HIV epidemic enabling sexual liberation without anxiety; to one tool among many; to a potential danger that could lead to more risky behavior, more HIV and STI infections, and unknown long-term side effects.

Cost. Cost was the number one concern cited by doctors in regards to PrEP (Karris et al., 2014). Most state AIDS Drug Assistance Programs and some insurances do not cover PrEP; however, its manufacturer, Gilead, does have a drug assistance program of its own (Krakower & Mayer, 2015). Some healthcare providers view the CDC guidelines on PrEP as including too many groups of people, and are concerned about the costliness (Pereira, Goschin, & Ashley, 2016); Safren et al. (2015) noted that behavioral interventions are often viewed as expensive and ineffective. However, a study by these authors (2015) estimated that the cost of even the most expensive behavioral interventions was less than the cost of treatment for all those who would have contracted HIV.

Risk compensation. Risk compensation is another concern impeding access to PrEP: the idea that HIV-negative people on PrEP may perceive themselves as being at reduced risk for HIV and thus engage in more risk behavior, neutralizing the efficacy of PrEP as an intervention (Calabrese & Underhill, 2015; McMahon et al., 2014). McMahon et al. (2014) notes the phenomenon of “treatment-related optimism”: that in the general population, people take more sexual risks after new breakthroughs in HIV treatment. The gay and bisexual male community, in particular, has been stigmatized by the label “Truvada whore,” a term for men on PrEP that assumes they are engaging in sexual promiscuity due to the perceived protection of PrEP (Calabrese & Underhill, 2015). This label has also been reclaimed by some men who take PrEP, as evidenced by “Truvada whore” T-shirts.

The risk compensation theory, however, has not been widely proven. In a review of eight PrEP trials, only one trial found a suggestion of risk compensation and there was no increase in sexually transmitted infections (Pereira, Goschin, & Ashley, 2016). Data from the Partners PrEP Study indicates that PrEP use in serodiscordant heterosexual couples may not actually lead to

more sexual risk taking, especially when part of a comprehensive prevention package (Mugwanya et al., 2013). In fact, some studies have shown that PrEP use actually reduces risky behavior (Calabrese & Underhill, 2015). Additionally, condom use has been on the decline since before PrEP was approved, and the decrease cannot be attributed to PrEP (Pebody, 2016).

A study of medical students by Calabrese, Earnshaw, Underhill, Hansen, & Dovidio (2014) showed risk compensation to be a concern among participants; moreover, participants were more likely to perceive risk compensation among black patients than among white patients. Because of their perceptions of black MSM having more unprotected sex, participants were less likely to prescribe PrEP to this group. However, these respondents, who were primarily white, reported that they had no bias towards black patients. Racism in healthcare settings is often implicit and institutionalized rather than overt. These findings are consistent with stereotypes of black men as irresponsible, uninhibited, and likely to engage in risky behavior on the “Down Low” (i.e. having sex with men unbeknownst to a female partner). Healthcare providers have also been more likely to provide birth control and safer sex counseling to black patients, as well as more likely to advise them to limit the number of children they have. However, in opposition to these stereotypes, black MSM have actually reported fewer partners and more condom use than white MSM (Calabrese et al., 2014).

Relationships

People in relationships, including same-sex pairings, have been found to have higher levels of social support (Kurdeck & Schmidt, 1987, cited in Darbes & Lewis, 2005). In addition to the benefits of romantic relationships, MSM and others are also more likely to engage in risky behavior such as unprotected anal sex within the context of a primary or long-term relationship (Palmer & Bor, 2001; Starks, Gamarel, & Johnson, 2013; Darbes & Lewis, 2005; Hoff et al.,

2012). Young gay men in particular are more likely to contract HIV from a primary partner, defined as a sexual partner with whom one is committed to above anyone else. Male couples have found various ways to mitigate HIV risk, such as serosorting (having sex with people of the same HIV status) and negotiated safety (HIV-negative couples agreeing to monogamy) (Darbes & Lewis, 2005). While general social support is not a consistent predictor of HIV risk behavior, such as unprotected anal intercourse, HIV-specific support has been found to predict a decrease in HIV risk behavior. (Darbes & Lewis, 2005; Hoff et al., 2012).

In terms of reasons for engaging in unprotected anal sex, the couples in Hoff et al.'s 2012 study cited intimacy, pleasure, establishing trust, knowledge of their partner's status, condom fatigue, the perception of low risk associated with an undetectable viral load, and sexual agreements (i.e. whether partners were having sex with people outside the relationship or not). Forty-five percent of respondents reported being in a closed or monogamous relationship, with 55% in an open or non-monogamous relationship. A higher commitment to their sexual agreement was associated with less unprotected anal sex with outside partners, regardless of what the agreement was (Hoff et al., 2012).

Serodiscordant couples. In many countries, the number of serodiscordant relationships – couples in which one partner has HIV and the other does not – are increasing (Mendelsohn et al., 2015). Other words used for these partnerships are “serodifferent,” “mixed-status,” and “magnetic.” Globally, half of all HIV-positive people in long-term relationships have a serodiscordant partner (Mavhandu-Mudzusi & Sandy, 2015). There are currently about 200,000 HIV-serodiscordant heterosexual couples in the US (McMahon et al., 2014). HIV-negative individuals in mixed-status relationships are considered to be at substantial risk for HIV infection, and the CDC (2014) recommends PrEP for this demographic. In Pereira, Goschin, &

Ashley's study (2016), a major reason medical students cited for prescribing PrEP to an HIV-negative patient was being in a serodiscordant relationship.

Sexual issues. Multiple studies found that some serodiscordant couples experienced a period of celibacy after diagnosis, after which they usually resumed having sex (Palmer & Bor, 2001; Nieto-Andrade, 2010). Some couples took sexual risks (such as unprotected anal sex) to maintain the "status quo" of their relationship or to maintain intimacy and closeness; negative partners were more likely to initiate risky sexual behavior (Palmer & Bor, 2001; Nieto-Andrade, 2010). This may be attributed to "prevention altruism" in which the HIV-positive individual wants to protect their partner (Starks, Gamarel, & Johnson, 2013). Palmer & Bor (2001) note that couples' sexual satisfaction may be negatively affected by the fact that sex is a constant reminder of the reality of HIV.

Many mixed-status male couples do not consistently use condoms for anal sex, though they may practice harm reduction in other ways, such taking the positive partner's viral load into account when making sexual decisions, or having the negative partner penetrate the positive partner, which is known as seropositioning (Starks, Gamarel, & Johnson, 2013). Only 10-30% of serodiscordant couples in the U.S. are using condoms consistently (McMahon et al., 2014). Reasons that may factor into this include intimacy, sexual pleasure, and in heterosexual couples, a desire to conceive children (Gamarel & Golub, 2015). The CDC guidelines (2014), however, encourage PrEP users to also use other forms of prevention such as condoms.

Underhill (2015) points out that protected sex using condoms and protected sex using PrEP may have different meanings to couples. For some couples, using condoms may actually be a reminder of the risk of HIV transmission (Gamarel et al., 2014). Intimacy motivations to have sex without condoms may be associated with intentions to take PrEP (Gamarel & Golub, 2015).

Brooks et al. (2012) found that among HIV-negative MSM in Los Angeles in serodiscordant relationships, being able to have sex without condoms was a major motivator for the acceptability of PrEP, along with protection from HIV and the ability to have sex with their positive partner without fear. Starks, Gamarel, & Johnson (2013) found that sexual satisfaction was negatively associated with risk taking for HIV-negative partners but positively associated with risk taking for HIV-positive partners.

Hoff et al. (2012) found that 47% of serodiscordant couples in their sample had unprotected anal intercourse with each other, and 19% with outside partners. For mixed-status couples, more HIV-specific social support and longer relationships were correlated with lower odds of having condomless anal sex with each other, while feeling a greater attachment was correlated with higher odds of this. HIV-positive partners in serodiscordant relationships were two point five times as likely as negative partners to have unprotected anal sex outside of the primary relationship (Hoff et al., 2012).

Emotional issues. Research on serodiscordant couples shows that there is often an imbalance created by the divide in HIV status (Palmer & Bor, 2001; Mendelsohn et al., 2015). In Palmer & Bor's study of serodiscordant male couples living in London (2001) a diagnosis of HIV served the function of blurring boundaries between partners. In the majority of the couples interviewed, the negative partner served as the primary caregiver for the positive partner. HIV/AIDS is still highly stigmatized, so in addition to the stress associated with illness and caregiving, many serodiscordant couples are also coping with societal and political oppression. This may be even more present for male couples due to homophobia and heterosexism (Palmer & Bor, 2001).

Fear and anxiety emerged as a common theme in the literature about serodiscordant couples, across gender and sexual orientation (Mendelsohn et al., 2015; Underhill, 2015; Ware et al., 2012; Beckerman, Letteney, & Lorber, 2000; Mavhandu-Mudzusi & Sandy, 2015; Brooks et al., 2012; Pereira, Goschin, & Ashley, 2016). HIV-positive individuals often fear transmitting the virus their negative partners, while their partners fear becoming infected and both members of the dyad fear discrimination, disease progression and death. For many serodiscordant couples, there is an initial period of fear, panic, and urgency following diagnosis that eventually dissipated as time went on (Palmer & Bor, 2001). For both positive and negative partners, their views on time and the future changed after diagnosis. Time seemed like a luxury to some couples, particularly for positive partners, who often felt left out of future planning (Palmer & Bor, 2001).

Research Gaps and Research Directions

Transgender people. One demographic that has been excluded from much of the research on PrEP is transgender people. In particular, transgender women in the U.S. have extremely high rates of HIV, with up to 22% of trans women living with the virus (Highleyman, 2016). Trans women in HIV research have often been included in the MSM category, which erases their identities as well as the unique psychosocial barriers they may face such as discrimination, poverty, survival sex work, unstable housing, and inconsistent healthcare (Highleyman, 2016; Gallagher, 2015). The iPrEx study did include trans women, after researchers advocated for it, but to date there have been no trans men included in PrEP studies (Gallagher, 2015). Clear estimates of the trans male population living with HIV are also lacking (Highleyman, 2016). One recommendation for further study is to include trans people in HIV research based on what types of sex they are having (Gallagher, 2015). Recently, three new

studies on PrEP and trans people were launched, one specifically for trans women of color. One aspect the researchers will look at is potential interactions between PrEP and hormones, which many trans people take as part of gender transition (Highleyman, 2016).

Other research gaps. Mendelsohn et al. (2015) note that there is a lack of research on sociostructural factors that contribute to whether serodiscordant couples disclose their status and to whom, such as HIV criminalization. Other research gaps include community attitudes towards PrEP; social & behavioral factors leading to PrEP use; whether PrEP use will change sexual and drug risk behaviors; gender-related factors in male-positive versus female-positive heterosexual couples; and best practices for outreach, uptake, clinical monitoring, and adherence to PrEP (McMahon et al., 2014; Brooks et al., 2012). On the healthcare side, there is also a need for more research on ethical concerns in prescribing PrEP, the long-term safety of PrEP use, and cost effectiveness (McMahon et al., 2014; Pereira, Goschin, & Ashley, 2016). Additionally, Karris et al. (2014) note that there is a lack of knowledge on how effective PrEP is in serodiscordant relationships when the HIV-positive partner is virally suppressed due to ART.

CHAPTER III

Methodology

Study Purpose and Research Question

In this chapter, I will describe the purpose of this study and the methodology used to conduct this research. This is a mixed-methods study, the purpose of which is to explore the use of post-exposure prophylaxis (PrEP) and relationship satisfaction in HIV-serodiscordant couples. “Serodiscordant” means that one partner is living with HIV while the other is not. Other terms that are used by people in this type of relationship include “mixed-status,” “serodifferent” and “magnetic.” For my research design, I used an anonymous online survey with both quantitative and open-ended questions. This study explored the following question: In HIV-serodiscordant couples, is there a relationship between the use of Pre-Exposure Prophylaxis (PrEP) and relationship satisfaction? I hypothesized that couples in which the HIV-negative partner was taking PrEP would experience higher levels of relationship satisfaction.

Research Method and Design

I used a mixed-methods survey made up primarily of closed-ended questions, with four open-ended questions at the end. The survey was anonymous and hosted online by Qualtrics. Using primarily closed-ended quantitative questions allowed me to explore relationships in the data and to compare the groups: serodiscordant couples in which PrEP was used versus serodiscordant couples in which PrEP was not used. I included open-ended questions because these issues have still not been researched extensively – PrEP was approved only in 2012 (Centers for Disease Control and Prevention, 2014). Using open-ended questions allowed me to gather more in-depth information on the participants’ experiences.

The overall research took place over nine months. The Human Subjects Review (HSR) Committee at Smith College School for Social Work approved the methodology of this study prior to beginning this research. Participants were recruited via cluster and snowball sampling. Data collection took place during March and April of 2016.

At the beginning of the survey, respondents were asked the following four screening questions: “Are you 18 years of age or older?”, “Are you currently in a relationship that has lasted at least six months?”, “Do you know your HIV status?”, and “Do you know your partner’s HIV status?” If participants’ responses indicated that they were at least 18 and in an HIV-serodiscordant relationship lasting at least six months, they were then taken to the informed consent page. They were informed that it would take 15-20 minutes to complete. They were also given resources to access if the survey caused them any distress, and were informed that they could skip questions or withdraw their participation from the study at any time. The survey measured relationship satisfaction using questions from Funk & Rogge (2007); McKibbin, Bates, Shackelford, Hafen, & LaMunyon (2010); and Moorman, Carr, & Boerner (2014).

Recruitment

I reached out first to HIV/AIDS organizations in Boston, MA, New York City, NY, and San Francisco, CA via email. I picked these three locations because of my own professional and personal connections in Boston and the San Francisco Bay Area, and the knowledge that New York, as well as San Francisco, has long been an epicenter of HIV treatment, activism, and research.

In my email, I attached a print flyer (with the survey link on tear-off strips) as well as a social media flyer. I made two specific asks of each organization: to post the flyers in areas their members/clients would see (such as waiting rooms), and to post my online flyer and recruitment

announcement on their social media accounts. I also asked each one for additional contacts in the HIV/AIDS field that may be helpful, in an effort to increase my sample size.

In the announcement, I included the criteria for participation: that participants be 18 or older, in a relationship, know their HIV status, and know that their partner's status differs from their own. I also included information about the purpose of the research, the fact that the study had been approved by the Smith College HSR committee, and my contact information.

The initial organizations and clinics I reached out to were Fenway Health (Boston), AIDS Action Committee (AAC, Boston), Boston Living Center (BLC), Massachusetts General Hospital (MGH), Cambridge Health Alliance (CHA, Massachusetts), Asian and Pacific Islander Wellness Center (APIWC, San Francisco), Shanti (San Francisco), University of California San Francisco Alliance Health Project (UCSF-AHP), San Francisco LGBT Center, San Francisco AIDS Foundation (SFAF), Ward 86 (part of the San Francisco Department of Public Health), AIDS Healthcare Foundation (AHF, San Francisco and various locations), Gay Men's Health Crisis (GMHC, New York), Housing Works (New York), and Mt. Sinai Adolescent Health (New York).

The researcher at Fenway Health who I emailed did not write back. I then talked to one of the medical providers there, who told me that since Fenway does so much of its own HIV research, it is usually not feasible for them to assist in recruitment for other studies. However, she asked me to forward the information to her to pass on to some of her patients, which I did. The original email address I had for AAC was defunct, so I emailed two different people I know who work with AAC who put me in touch with colleagues of theirs. The staff person that I ended up making contact with told me he had approval to post my flyer at both AAC's Boston and

Cambridge sites, although he was not able to post it online. He also expressed interest in seeing the results of my research.

At BLC, the staff person I got in touch with said she would also post the flyer, and that she did not control BLC's social media accounts but would forward to my request to those who do. She also told me that Justice Resource Institute (JRI) has a group for serodiscordant couples in their peer support program, and suggested that I reach out to them, which I did. JRI required my study to get approval from their RIB committee, which I obtained. My initial contact there put me in touch with someone who worked directly with the serodiscordant couples group, but I did not get a specific commitment on which of my recruitment asks they would be able to do.

A personal contact who works at Massachusetts General Hospital said he would post the flyer in the waiting room at their HIV-specific program. At Cambridge Health Alliance, my contact passed along my recruitment information to their colleagues. The staff I talked to at APIWC, my first year field placement, said they would post my print and online flyers and gave me a contact at Housing Works. That person put me in touch with various other coworkers, but I did not get a response as to whether they would post my materials.

My contact at Shanti agreed to post my print flyer but said he was not able to post anything on their social media accounts. An HIV medical provider who I worked with at APIWC committed to putting the flyer up at Ward 86 and Tom Waddell Urban Health Center. He also suggested that I reach out to City Clinic, but I was not able to get contact information for them. Additionally, he told me that Magnet, a clinic which is now part of the San Francisco AIDS Foundation, prescribes PrEP. I discovered that Magnet is now called Strut, and I contacted them through their Twitter account with no response.

A personal contact who had interned at UCSF-AHP said she would forward my materials to her colleagues there if I emailed them to her, which I did. The staff person I emailed at the San Francisco LGBT Center told me that the Center was currently undergoing a renovation and did not have a space to post my flyer. I also asked him for contacts at Strut and the Department of Public Health, and he replied that he was unable to share individual contact information but he linked me to their websites. San Francisco AIDS Foundation committed to posting my link on their social media accounts and also expressed interest in seeing the results of my study. I filled out a form on AIDS Healthcare Foundation's website to contact them and a representative replied to me via email, but did not respond to my subsequent email about recruitment. I found a lot of overlap in San Francisco HIV/AIDS services in terms of funding and locations.

The person I emailed at GMHC reported that he would post the flyer in their reception areas but was unable to post it on their social media accounts or websites. A chance conversation with a community member who works at Whittier Street Health Center (Boston) led me to email her my recruitment materials. She told me that her workplace was unlikely to assist with recruitment but that she would pass it on to other colleagues of hers in the HIV field. My contact at Mt. Sinai Adolescent Health told me he would forward my materials to his colleagues. I also posted the announcement on Boston's Queer Agenda: The List (an email listserv for the LGBTQ community in the Boston area).

In addition to email recruitment, I posted the announcement on my Facebook page and asked people to share the announcement with people they know who were either personally or professionally connected to HIV/AIDS. Thirty-one people shared the post. I also posted it in relevant Facebook groups and pages, including Queer Exchange Boston, Queer Exchange: Western Mass, Bay Area Queer Exchange, Smith Social Workers Speakeasy, Smith Class of

A'16, Transcending Boundaries Conference, Radical Social Work Group, Western Mass Trans Social Network, HIV Alliance, Rise Above HIV, Trans MSM, HIV is Not a Crime Conference, and PrEP Facts (a group with over 12,000 members). Other Facebook contacts shared my post in the groups Outshine NW and LGBTQIA+ Clinical Case Group. I also sent the link to personal contacts living with HIV via Facebook message.

Additionally, I tweeted the survey link several times from my personal Twitter account. I used the hashtags #HIV, #AIDS, #PrEP, #PrEPworks, #PrEP4love, #knowyourstatus, #gettingtozero, #catchdesire, #transmitlove, #lgbthealth, #starttalkinghiv, #bethegeneration, and #serodiscordant. I got these hashtags from a post in the PrEP Facts Facebook group. I also tweeted it directly at self-identified HIV activists and the following HIV/AIDS organizations: AIDS United, Black AIDS Institute, Greater Than AIDS, Talk HIV, PrEPare LA, Get PrEP LA, Strut SF (part of the San Francisco AIDS Foundation), HelpFightHIV (a program of BridgeHIV, part of the San Francisco Department of Public Health), La Clínica, The HIV League, Meet PrEPpies, Young Men's Affiliation Project (YMAP) Chicago, HIVE (part of University of California San Francisco), AIDS Drug Assistance Program (ADAP) Advocacy, A Day With HIV, Pos Aware, Stronger Together (a research study for men in serodiscordant same-sex relationships in Atlanta, Boston, and Chicago), AIDS Accountability International (AAI), 30 for 30 Campaign, Nurx, and Project Inform. I found many of these accounts on Greater Than AIDS' list "Greater Than AIDS Community." My tweets were retweeted twelve times; however, three of those retweets happened after I had already closed my survey. AAI also tweeted at me apologizing for not seeing my tweet until the survey link was closed.

After reaching out to the first group of organizations, I expanded my recruitment to HIV/AIDS organizations in Los Angeles, CA and Miami, FL. I had picked these locations based

on the high incidences of HIV in these areas (Reynolds, 2014). I had also planned to contact organizations in the Atlanta, GA area but did not do so due to time constraints. The agencies that I did reach out to were AIDS Project Los Angeles (APLA), University of California at Los Angeles (UCLA) CARE Center, To Help Everyone (THE) Health and Wellness Center (Los Angeles), C.A.R.E. Program (Long Beach, CA), Jeffrey Goodman Clinic (part of the Los Angeles LGBT Center), Care Resource (Miami/Broward County, FL), Empower “U” (Miami), and AIDS Help (Key West, FL). I found some of these organizations on a list of where to get PrEP in the areas I was targeting.

The person I contacted at APLA was the coordinator for a program called R3VNG (Reshaping 3 Letters through the Voice of the Now Generation) and reported that he would post my recruitment materials on R3VNG’s Facebook and Instagram accounts as well as distribute them to the youth who attend their meetings. A staff member from UCLA Care Center asked if my study had been approved by the UCLA Institutional Review Board and did not respond to my subsequent emails. I did not get a response from THE, C.A.R.E. Program, Jeffrey Goodman Clinic, Care Resource, Empower “U”, or AIDS Help. Additionally, I got an email from someone who reported that his son had sent him a link to my survey and that he was interested in taking it, but the link was inactive. This was after I had already closed the survey, so I thanked him for his interest and let him know my data collection period had ended.

Sample

The inclusion criteria for the survey required that participants be adults (18 or older), in a relationship of at least six months, and either HIV-positive with an HIV-negative partner or vice versa. Due to the limited scope of this project, participants were required to be able to read and write English. Data was coded by and processed with the support of Marjorie Postal, Smith

College School of Social Work. The study was open to people of all genders and sexual orientations.

Ethics and Safeguards

This study had low risks associated with it, although it is possible that participants may have experienced strong feelings from being asked questions about their HIV status and their relationship. The following list of resources was provided to them at the beginning of the survey:

- National HIV/AIDS hotline: 1-800-CDC-INFO
- State specific HIV/AIDS hotlines: <http://hab.hrsa.gov/gethelp/statehotlines.html>
- Crisis Text Line: Text “GO” to 74141, <http://www.crisistextline.org>
- Suicide Prevention Lifeline: 1-800-273-TALK (8255),
www.suicidepreventionlifeline.org

This was an anonymous survey. Informed consent was obtained via a page at the beginning of the study after participants answered affirmatively to the four criteria questions. The consent form explained the purpose of the study, a description of study procedures, and potential risks and benefits of the study. Participants were informed of their right to skip questions and to stop taking the survey at any time. They gave consent by clicking a button marked “Yes, I agree to participate.”

All of the respondents were 18 or over. As required by federal guidelines, all data will be kept in a secure location for three years. Data stored electronically will also be encrypted and password-protected through the use of a password and encryption. Since the survey was anonymous, there was no identifying information attached to the data during presentation or

publication. However, some of the potential respondents commented on my Facebook posts asking questions about the study, which compromised their anonymity.

Limitations

Because the survey was administered online in English, it required that respondents have access to the internet and enough familiarity with technology to take the survey. This may exclude people of lower socioeconomic status, people who are not fluent in English, and potentially people of older generations.

Additionally, many HIV studies have incentives in the form of cash or gift cards. Due to the limited scope of my research project, I was not able to offer any compensation. This may have caused some potential participants to decide against participating in the study.

Data Analysis

Data was coded with the support of Marjorie Postal from Smith College School for Social Work. A t-test was performed to measure difference in responses to the three final quantitative questions that specifically named satisfaction: “How emotionally satisfied are you with your partner?”, “How sexually satisfied are you with your partner?”, and “Overall, how satisfied are you with your partner?”. The variable of PrEP use was coded by combining the “yes” responses to either taking PrEP or having a partner on PrEP.

There were eight Likert-type questions in the survey. A scale was created by combining the responses to these questions and taking the mean. Another t-test was run to determine whether there was a difference in overall agreement with these questions by PrEP use.

At the end of the survey, there were four qualitative questions: “In what ways does your partner provide emotional support to you?”, “In what ways does your partner provide other types

of support to you (i.e. financial, medical)?”, “What are the best things about your relationship?”, and “If you could change anything about your relationship, what would it be?”. I then did a thematic analysis of the answers to these questions, divided into two groups by PrEP use. In the following chapter, I will present the findings from this survey.

CHAPTER IV

Findings

In the following chapter, I will summarize the results of my study. This was a mixed-methods study conducted via an online survey to determine whether there is any relationship between the use of Pre-Exposure Prophylaxis (PrEP) and relationship satisfaction in HIV-serodiscordant couples. There were no statistically significant results. For the purpose of these findings, I will use the phrase “using PrEP” to mean either an HIV-negative person taking PrEP, or an HIV-positive person with a negative partner taking PrEP.

Participant Demographics

Forty-six people started the survey and 28 completed it. The data from these 28 respondents was used for this study. To meet criteria for the study, participants had to be 18 or older and in an HIV-serodiscordant relationship that had lasted for at least six months. Thirty-two point three percent of respondents indicated that they were HIV-positive with a negative partner, and 67.7% HIV-negative with a positive partner. Of the HIV-negative respondents, 35.5% reported that they were taking PrEP. Of the HIV-positive respondents, 19.4% reported that their partner was taking PrEP. HIV-negative individuals in serodiscordant relationships are considered a high-risk group for HIV infection, and may choose to take PrEP to prevent contracting the virus and to be able to have condomless sex with their partners.

This study was open to people of all genders and sexual orientations. The majority of participants (51.6%) identified their gender as cisgender (non-trans) male. Nine point seven percent identified as cisgender female, 9.7% as genderqueer/non-binary, 3.2% as transgender male/transmasculine, and 3.2% as transgender female/transfeminine. One person (3.2%) chose to fill in the blank with “female,” and 19.4% of participants did not answer the question.

As for sexual orientation, the majority of respondents (54.8%) identified as gay/lesbian. 16.1% identified as bisexual/pansexual/queer, 9.7% identified as straight/heterosexual, and 19.4% did not answer the question.

In terms of race/ethnicity, the majority of participants (64.5%) identified as white/European descent. 9.7% identified as Latin@/Hispanic, 6.5% as Black/African descent, and one person filled in the blank with “uncomfortable with category: i'm an argentine of european descent [sic].” No one identified as Asian/Pacific Islander or Native American/Indigenous.

Age distribution was as follows: 32.3% of respondents were in the 40-55 range, 25.8% in the 30-39 range, 12.9% in the 25-29 range, 6.5% in the 18-24 range, and 3.2% were 56 or older. 19.4% did not answer the question.

Since I was targeting the Boston area, New York City area, and San Francisco Bay Area in my recruitment, I included those three locations as possible answers with an option to fill in the blank. Twelve point nine percent of people were from the San Francisco Bay Area; there were no valid responses from the Boston or New York City metro areas. The majority of participants filled in the blank. U.S. locations included Atlanta, GA; Austin, TX; Charlotte, NC metro area; Chicago, IL; Los Angeles, CA metro area; Minneapolis, MN; Philadelphia, PA metro area; Portland (one person specified Portland, OR and a second did not specify a state); rural Western Massachusetts; Santa Fe, NM; Wichita, KS; Washington, DC; and “east coast.” International locations included Lima, Peru; Munich, Germany; Toronto, Ontario; Vancouver, British Columbia; and the U.K.

The distribution of education was as follows: 29% had a 4-year college degree, 25.8% had a graduate degree, 12.9% had a 2-year college degree, 9.7% had some college, and 3.2% had a high school diploma or GED. Nineteen point four percent did not answer the question.

Length of relationships varied, with 29% having been with their partner for 1-3 years, 16.1% for six months to one year, 16.1% for 5-10 years, 16.1% for over 10 years, and 6.5% for 3-5 years. Sixteen point one percent did not answer the question. Respondents were fairly evenly split between monogamous and non-monogamous relationships, with 38.7% reporting monogamy and 45.2% reporting non-monogamy. Sixteen point one percent of participants did not answer this question.

Overall, the demographics were skewed heavily in favor of the following categories: cisgender male, gay/lesbian, white/European descent, and highly educated. Therefore, these results should not be generalized to the population as a whole.

Quantitative Findings

Data was coded with the support of Marjorie Postal from Smith College School for Social Work. A t-test was performed to measure difference in responses to my three final quantitative questions that specifically named satisfaction: “How emotionally satisfied are you with your partner?”, “How sexually satisfied are you with your partner?”, and “Overall, how satisfied are you with your partner?”. The variable of using PrEP was coded by combining the “yes” responses to taking PrEP and having a partner on PrEP. There was no statistically significant difference between the PrEP-using group and non-PrEP-using group.

I also included eight Likert-type questions asking about specific aspects of relationships. These questions were borrowed from Funk & Rogge (2007); McKibbin, Bates, Shackelford,

Hafen, & LaMunyon (2010); and Moorman, Carr, & Boerner (2014). I accidentally included a repeat of one of the questions: “My partner encourages me to do things that are important to me.” These questions were combined into a scale by creating a mean of the responses. Another t-test was then run to determine whether there was any difference in overall agreement with these questions by PrEP use. Again, no statistically significant difference was found in the way that the PrEP-using and non-PrEP-using groups answered these questions.

Qualitative Findings

At the end of the survey, I included four open-ended qualitative questions: “In what ways does your partner provide emotional support to you?”, “In what ways does your partner provide other types of support to you (i.e. financial, medical)?”, “What are the best things about your relationship?”, and “If you could change anything about your relationship, what would it be?”. I then did a thematic analysis of the answers.

The two most common themes in answers to the first question were Verbal Communication/Listening and Help in Hard Times. These themes were common both for respondents using and not using PrEP. Two different participants using PrEP stated “he is always there for me in whatever I may be struggling with” and “I experience occasional social anxiety, so he often speaks for me in public settings.” A respondent in the non-PrEP-using group reported that their partner “...helps me feel my way through my emotions when I'm struggling. When I'm having a hard time emotionally my partner asks what I need and goes out of the way to be sweet to me and support me.” Eleven of the respondents used the word “listen” in their answer. Three of the subjects using PrEP also reported the theme of Sexual and Physical Connection when discussing emotional support.

Another theme that came up either once or twice for both groups was Encouragement. One PrEP-using subject responded “He encourages me to put my best foot forward and actively pursue good things in life,” while a subject from the other group cited that their partner “celebrates my successes.”

Both groups reported themes of Material Support (such as cooking and helping with housework), and HIV-Specific Support. Under the latter theme, one participant using PrEP reported, “He help me through my transition on to taking pills” [sic] and one HIV-negative participant whose partner was not on PrEP reported “showing me that my status does not matter to him.” Only one subject (who was using PrEP) answered the question with “He doesn’t [provide emotional support].”

In the second open-ended question, participants both using and not using PrEP reported Financial Support from their partner. Those using PrEP were more likely to report that their partner’s financial support allowed them to pursue goals such as going back to school or making “smart financial moves as a unit.” Those not using PrEP were more likely to mention their partner paying bills. At least one respondent in each group reported that although their partner had financial limitations, they still contributed when possible: “My partner is disabled, so he contributes what he can whenever he can;” “When he works he pays bills.”

Both groups also reported the theme of Medical/HIV-Specific Support when answering this question, including providing insurance, helping their partner to navigate insurance and make appointments, and providing money for medication. One respondent not using PrEP also reported that their partner was using Treatment as Prevention (TasP). Transportation was a theme in both groups, including driving one’s partner around and providing car maintenance.

A theme reported by three of the respondents who were using PrEP was Financial Interdependence, including the comments “we live together and share finances” and “we make roughly the same salary and love better because of it” [sic].

Two of the participants who were not using PrEP reported the theme of Emotional Support in their answer to this question, with one responding “My partner helps me grow spiritually and emotionally... My partner helps me be my best self and live into my values and intentions.”

Other themes reported by subjects not on PrEP were Childcare and Gender Identity Support. Three of the respondents not using PrEP reported that their partner either did not provide other types of support or that it was not needed.

In the answers to the third question, “What are the best things about your relationship?”, the most common theme across the board was Comfort, Safety, and Trust. One PrEP-using respondent cited “total comfort being together and alone with each other,” while a member of the other group reflected on “our complete trust in each other...the fact that we honor each other's triggers and trauma.”

Three members of the PrEP-using group cited “open communication” as a best thing about their relationship, with one more reporting Communication as a theme as well. Members of both groups responded “sex” to this question, as well as other types of physical affection such as “cuddles” and “we are affectionate and playful.” Overall, participants using PrEP were more likely to report the themes of Communication and Sexual and Physical Connection.

Love and Friendship was also a theme that came up for both groups. Themes reported by only one participant each in the PrEP-using group were Compatibility, Past Orientation (“we

have created so many wonderful memories together”), Sense of Humor, and Non-Monogamy. One person in each group reported the theme of Future Orientation (“I get excited thinking about sharing our lives and growing together.”). Three of the non-PrEP-using respondents reported the theme of Closeness, and two reported Self-Actualization. One also reported an External Orientation: “the fact that we do work together to make the world a better place.”

For the final question, “If you could change anything about your relationship, what would it be?”, the most common themes in the PrEP-using group were Sexual and Physical Connection and Jealousy/Possessiveness. These themes also came up for respondents who were not using PrEP, although to a lesser extent. Although this group was likely to report Sexual and Physical Connection as one of the best things about their relationship, they were also likely to describe this theme as something they would like to change about their relationship, responding “How we engage in sex” and “more active sex life together” as changes they would like to see. One respondent who was not using PrEP also cited “sexual compatibility.”

In terms of Jealousy/Possessiveness, some PrEP-using respondents described this in terms of non-monogamy, with different participants stating both “i'd feel less jealousy about the open thing” [sic] and “for him to feel less anxious about non monogamy.” Others discussed it without referencing their relationship structure, reporting “I'd like my partner to be a little less jealous and possessive of me in certain environments” and “[I] wish we felt more independent from each other.” The two non-PrEP-using respondents who cited this theme did not mention non-monogamy, but stated, “Allowing for more freedom, less control issues on his part” and “I wish he were more independent.”

The most common theme for the non-PrEP-using group was Age/Time/Future, with three respondents describing this theme. One of these participants discussed issues around having an

older partner living with HIV, in particular not being able to take for granted “growing old together.” Another discussed issues around having a younger partner, and a third stated “I wish I would have found him sooner.”

One person in the PrEP-using group cited “His temper” as the thing they would most like to change, and another responded “Societies expectations” [sic]. Another member of this group answered “being more financially stable.” Two respondents who were not using PrEP also reported the theme of Communication as something they would change, with one noting “There are cultural differences that can get in the way of some communication.” One member of this group stated “Wish he could be more emotionally available to meet my needs,” while another responded “probably live together.” Multiple participants in each group reported that they would not change anything, or much of anything, about their relationship.

Summary

The quantitative findings from this mixed-methods study did not actually determine whether there is any relationship between the use of Pre-Exposure Prophylaxis (PrEP) and relationship satisfaction in HIV-serodiscordant couples. However, there were some differences by group in the qualitative responses.

Participants who were using PrEP were more likely to name Sexual and Physical Connection as a way that their partner provided emotional support. They were also more likely to cite this theme as one of the best things about their relationship. A smaller number of non-PrEP-using respondents also named Sexual and Physical Connection as one of the best things about their relationship, but none of them mentioned it when discussing emotional support.

Respondents from the PrEP-using group were also more likely to cite the theme of Comfort, Safety, and Trust as one of the best things about their relationship, although this theme was reported by both groups. Two PrEP users also brought up non-monogamy when discussing the theme of Jealousy/Possessiveness. Although this theme was also reported by non-PrEP-users, this group did not mention non-monogamy.

Participants not using PrEP were unique in citing emotional support when discussing the ways in which their partner provided other types of support. Multiple respondents from this group described the theme of Closeness when listing the best things about their relationship. This group also differed from the PrEP-using group in that they reported themes of Age/Time/Future and Communication as things they would like to change about their relationship.

CHAPTER V

Discussion

The intent of this mixed-methods, survey-based study is to explore whether there is a relationship between the use of Pre-Exposure Prophylaxis (PrEP) and relationship satisfaction in HIV-serodiscordant couples. There were no statistically significant results to this study. In this chapter I will discuss some potential explanations for why the findings were not significant, explore the limitations of recruitment and of the study design, and provide suggestions for future research.

Recruitment Limitations

In order to achieve a large enough sample to draw statistically significant conclusions, I aimed for at least 50 participants. Of the 46 people who started the survey, only 28 completed it with valid responses.

The sample skewed heavily in favor of people from the following identity groups: cisgender male (51.6%), gay/lesbian (54.8%), and white/European descent (64.5%). It was also a highly educated sample, with 64.5% of respondents possessing a 4-year-college degree or higher. A significant percentage of the sample – approximately one in five – did not answer these demographic questions.

The snowball method of sampling may have contributed to the lack of diversity in the sample. I am white, and posting my recruitment announcement on my Facebook page means the results were biased towards my personal networks, many of whom are also white. I also posted it in Facebook groups where I did not know any of the members, and on my Twitter account,

which is public. On Facebook, potential respondents could click on my profile and see that I am white by my pictures, while on Twitter, I explicitly name whiteness in my biography.

There is a history of distrust in communities of color towards researchers, and with valid reason. African-American men, Puerto Rican and Central American women, and other racially oppressed groups have been subject to exploitative and unethical medical research from the dominant U.S. culture. Many white researchers have pathologized communities of color and co-opted their voices. Given that my study focused on a medical issue – HIV/AIDS – it makes sense that people of color might feel uncomfortable or wary of taking my survey. The intersection of racism and homophobia is also relevant: in the HIV field in particular, providers have been shown to hold biased views of black men who have sex with men as irresponsible and more likely to engage in risky behavior, although this is statistically untrue (Calabrese et al., 2014).

In trying to obtain a diverse sample, I specifically reached out to organizations serving people of color, women, transgender people, and youth, such as Asian and Pacific Islander Wellness Center, Mt. Sinai Adolescent Health, Black AIDS Institute, To Help Everyone Health and Wellness Center, R3VNG (Reshaping 3 Letters through the Voice of the Now Generation – a program of AIDS Project LA), Young Men’s Affiliation Project Chicago, HIVE, La Clínica, and 30 for 30 Campaign. Some of these contacts were made over email, and others on social media.

However, it became clear in analyzing the data that social media had been a more lucrative source of recruiting participants than organizations. After sharing my recruitment post in the “PrEP Facts” Facebook group, the number of responses to my survey increased significantly. On the survey, the possible answers to the question “Where are you located?” were as follows: Boston metro area; New York City metro area; San Francisco Bay Area; or Other (fill

in the blank). I delineated these responses based on my recruitment to organizations in these three cities. However, there were no respondents from any of these areas, although there was one who reported their location more generally as “east coast.” There were also two participants located in Los Angeles, which along with Miami was one of the secondary locations I targeted. All other respondents filled in the blank with various locations around the U.S. as well as Canada, U.K., Germany, and Peru. This leads me to believe that the vast majority of my sample was recruited not from organizations they were connected to but from social media. In addition, some of the organizations that I anticipated being the most helpful in recruitment were actually not able to post my materials.

I hypothesized that it would be easier to recruit HIV-positive individuals than HIV-negative individuals in serodiscordant relationships. There is an established network of medical, psychosocial, and legal services for people living with HIV, while there are far fewer supports for HIV-negative people with positive partners. However, 67.7% of my sample was HIV-negative. This may have been because a large number of them were recruited via the “PrEP Facts” Facebook group. Stigma may also have played a role in HIV-positive people feeling wary of identifying themselves, even in an anonymous survey (Palmer & Bor, 2001; Krakower & Mayer, 2015).

The language that I used in this study may also have affected the low turnout. In my recruitment materials, I used the word “serodiscordant” to describe couples with a differing HIV status. In personal communication with me, people identified their relationships as “magnetic” and “serodifferent.” These words may be less stigmatizing than “serodiscordant,” which can carry a connotation of “discord” among partners.

Study Limitations

One limitation to this study is the lack of information regarding each participant's partner. While we do know whether or not the HIV-positive respondents' partners were taking PrEP, we do not know whether the HIV-negative respondents' partners were taking antiretroviral therapy (ART). Since ART decreases the viral load of HIV in one's bloodstream and thus decreases the chances of transmitting HIV to sexual partners (World Health Organization, 2015), it may follow that having a partner on ART could decrease anxiety about sex. Anxiety was found to be a major emotional issue for people in serodiscordant relationships (Mendelsohn et al., 2015; Underhill, 2015; Ware et al., 2012; Beckerman, Letteney, & Lorber, 2000; Mavhandu-Mudzusi & Sandy, 2015; Brooks et al., 2012; Pereira, Goschin, & Ashley, 2016); I also did not ask specifically about anxiety in my survey.

There are also other factors I did not ask about that could have an impact on this data. I did not include questions about length of time on PrEP and adherence to PrEP for those taking it. I also did not ask about whether the positive partner was diagnosed before or after beginning the relationship, or about any of their health information such as viral load or CD4 count.

Additionally, I had a limited amount of time during which to conduct research. The overall project took place over nine months, with data collected during a two-month period. Given a longer time frame, I would likely have been able to recruit more participants.

Quantitative Results

Why were there no statistically significant results? This could be attributed to my small sample size (N=28) and lack of statistical power. Ideally, I would be able to recruit larger numbers of people from each group: HIV-negative and on PrEP; HIV-negative and not on PrEP; HIV-positive with a partner on PrEP; and HIV-positive with a partner not on PrEP.

I unintentionally included a repeat of one of the questions in my survey, “My partner encourages me to do things that are important to me.” In the first iteration of this question, 6.5% of respondents answered with “Disagree somewhat,” 6.5% with “Disagree slightly,” 6.5% with “Agree slightly,” 16.1% with “Agree somewhat,” and 51.6% with “Agree completely.” Twelve point nine percent of participants did not answer the question. The second time the question was asked, no participants responded with “Disagree somewhat,” and the percentage of “Agree completely” answers went up to 58.1%. This calls into question the validity of these results, and by extension, the validity of the other Likert-type questions as well. It could also be that the answers these types of questions had little to do with PrEP use and more to do with other individual and societal factors.

I had hypothesized that couples who were using PrEP would experience higher sexual satisfaction. This is partly because of decreased anxiety with regard to sexual transmission of HIV. Additionally, being able to stop using condoms has been a major factor in PrEP acceptability (Brooks et al., 2012; Gamarel & Golub, 2015). Not using condoms has been associated with greater sexual pleasure as well as intimacy and attachment (Hoff et al., 2012). However, there were no statistically significant differences in sexual, emotional, or overall satisfaction between PrEP users and non-PrEP users. Again, this is likely due to the lack of statistical power.

Qualitative Results

There were a few key differences in the ways that PrEP-using and non-PrEP-using respondents answered the four qualitative questions: “In what ways does your partner provide emotional support to you?”, “In what ways does your partner provide other types of support to

you (i.e. financial, medical)?”, “What are the best things about your relationship?”, and “If you could change anything about your relationship, what would it be?”.

Three members of the PrEP-using group talked about their sexual and physical connection to the partner as part of their partner providing emotional support, including the answer “He fucks me when I’m anxious.” These participants may be experiencing decreased anxiety about contracting or transmitting HIV due to their use of PrEP.

The two different groups described financial support in slightly different ways – those using PrEP were more likely to describe their partner’s financial support as allowing them to pursue goals, or financial interdependence, while non-PrEP users talked more about their partner helping to pay bills. However, this difference was based only on two to three respondents in each category, so it does not appear to be significant.

In describing the best things about their relationship, respondents who were using PrEP were slightly more likely to cite the theme of Communication; although, again, this was only a difference of a few participants. Four PrEP-using subjects named Sexual and Physical Connection as one of the best things about the relationship versus one non-PrEP-using subject. However, this group was equally as likely to cite Sexual and Physical Connection as an answer to the last question (“If you could change anything about your relationship, what would it be?”). It is worth noting that these responses primarily described a desire for more frequent sex with their partner, including one participant who answered, “I am hopeful as we move forward together that more sexual activities are in our future.” Having more information about how long the couple had been using PrEP, as well as a larger sample size, would have been helpful in this instance. Perhaps couples who had been using PrEP for a longer time would be more likely to

name sex as one of the best parts of their relationship, due to decreased sexual anxiety and potentially due to a lesser perceived need for condoms (Brooks et al., 2012).

Four PrEP users named Jealousy/Possessiveness as something they would like to change about their relationship, as compared to two non-PrEP users. Of these four, one mentioned their partner's jealousy about non-monogamy, while another named their own anxiety about it. (Two members of the other group also cited Jealousy/Possessiveness without commenting on monogamy or non-monogamy.) It is impossible to draw any conclusions from these two respondents, but an area for further research could be how couples' decisions regarding PrEP and non-monogamy influence each other, and/or how non-monogamous couples navigate their relationship agreements when using PrEP.

Were I to do further research on this topic, I would do qualitative interviews with both members of a couple, which might be more effective than a mixed-methods survey. Since PrEP is still a relatively new prevention method, a qualitative study would allow me to learn more in-depth information about the emotional and sexual lives of serodiscordant couples who do and do not use PrEP. I would ask questions about when the positive partner had been diagnosed, what it was like to make the decision to start taking PrEP (and whether negative partners made that decision on their own or in tandem with their positive partners), PrEP adherence, non-monogamous agreements, and whether each person saw their relationship differently since beginning PrEP.

Implications for Social Work

Given the recent emergence of PrEP as a form of HIV prevention, more knowledge is needed among clinicians who work with communities at risk for HIV, as well as clinicians working with HIV-positive clients who may have negative partners. Social workers should be

aware of their potential biases around race and sexuality and working to change these within themselves and the agencies in which they work. Clinicians may encounter the stigmatized label “Truvada whore”— a stereotype of PrEP users, specifically gay men, as promiscuous, engaging in risky behaviors, and increasing the spread of other sexually transmitted infections. They should be able to educate clients on PrEP and explore with them whether PrEP is a good choice for them and how it may affect their romantic and sexual relationships.

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[Promotion&utm_medium=aidsmap-news&utm_campaign=aidsmap-news](http://www.aidsmap.com/page/3058699/?utm_source=NAM-Email-Promotion&utm_medium=aidsmap-news&utm_campaign=aidsmap-news)

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Appendices

Appendix A: Human Subjects Review Committee Approval



School for Social Work
Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

February 19, 2016

Eli V. Latto

Dear Eli,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.
Co-Chair, Human Subjects Review Committee

CC: Claudia Staberg, Research Advisor

Appendix B: Survey

Page 1: Screening

- Are you 18 years of age or older?
 - YES
 - NO
- Are you currently in a relationship that has lasted at least six months?
 - YES
 - NO
- Do you know your HIV status?
 - YES, I AM HIV POSITIVE
 - YES, I AM HIV NEGATIVE
 - NO, I DON'T KNOW MY STATUS
- Do you know your partner's HIV status?
 - YES, MY PARTNER IS HIV POSITIVE
 - YES, MY PARTNER IS HIV NEGATIVE
 - NO, I DON'T KNOW MY PARTNER'S STATUS

Page 2: Ineligible

Thank you for your interest in this research. At this time, you do not qualify for the survey.

[If they answered “no” to any of the screening questions, or if their HIV status was the same as their partner's HIV status]

Page 3: Informed consent and resources for support (see Appendix C)

- Yes, I agree to participate
- No, I do not agree to participate

Page 4: Personal demographics

- What is your gender identity?
 - CISGENDER (NON-TRANS) MALE
 - CISGENDER (NON-TRANS) FEMALE
 - TRANSGENDER MALE/TRANSMASCULINE
 - TRANSGENDER FEMALE/TRANSFEMININE
 - GENDERQUEER/NON-BINARY
 - OTHER: FILL IN THE BLANK _____
- How do you identify your sexual orientation?
 - STRAIGHT/HETEROSEXUAL
 - GAY/LESBIAN
 - BISEXUAL/PANSEXUAL/QUEER
 - OTHER: FILL IN THE BLANK _____
- How do you identify your race/ethnicity? (check all that apply)
 - ASIAN/PACIFIC ISLANDER
 - BLACK/AFRICAN DESCENT
 - LATIN@/HISPANIC
 - NATIVE AMERICAN/INDIGENOUS
 - WHITE/EUROPEAN DESCENT

- FILL IN THE BLANK _____
- How old are you?
 - 18-24
 - 25-29
 - 30-39
 - 40-55
 - 56 or older
- Where are you located?
 - BOSTON METRO AREA
 - NEW YORK CITY METRO AREA
 - SAN FRANCISCO BAY AREA
 - OTHER: FILL IN THE BLANK _____
- What is your highest level of education?
 - PRIMARY SCHOOL/MIDDLE SCHOOL
 - SOME HIGH SCHOOL
 - HIGH SCHOOL DIPLOMA/GED
 - SOME COLLEGE
 - 2-YEAR COLLEGE DEGREE
 - 4-YEAR COLLEGE DEGREE
 - GRADUATE DEGREE

Page 5a: For HIV-negative people

- Are you currently taking Pre-Exposure Prophylaxis (PrEP)? This is a daily dose of the antiretroviral medication Truvada, intended to prevent HIV transmission.
 - YES
 - NO

Page 5b: For HIV-positive people

- Is your partner currently taking Pre-Exposure Prophylaxis (PrEP)? This is a daily dose of the antiretroviral medication Truvada, intended to prevent HIV transmission.
 - YES
 - NO

Page 6: Relationship demographics

- How long have you been with your partner?
 - 6 MONTHS-1 YEAR
 - 1-3 YEARS
 - 3-5 YEARS
 - 5-10 YEARS
 - OVER 10 YEARS
- Some couples are monogamous, while others have sexual and romantic relationships with others as well. People may use a variety of terms to describe their non-monogamous relationships, such as polyamorous, open, or monogamish. Do you consider your relationship monogamous, or not?
 - YES, WE ARE MONOGAMOUS
 - NO, WE ARE NON-MONOGAMOUS

Page 7: Relationship satisfaction

- I feel like part of a team with my partner.
 - 0: disagree completely
 - 1: disagree somewhat
 - 2: disagree slightly
 - 3: neither agree not disagree
 - 4: agree slightly
 - 5: agree somewhat
 - 6: agree completely
- I enjoy my partner's company.
 - 0: disagree completely
 - 1: disagree somewhat
 - 2: disagree slightly
 - 3: neither agree not disagree
 - 4: agree slightly
 - 5: agree somewhat
 - 6: agree completely
- How well does your partner meet your needs?
 - 0: not at all
 - 1: not well
 - 2: not very well
 - 3: neutral
 - 4: slightly well
 - 5: somewhat well
 - 6: very well
- My partner shows love and affection toward me.
 - 0: disagree completely
 - 1: disagree somewhat
 - 2: disagree slightly
 - 3: neither agree not disagree
 - 4: agree slightly
 - 5: agree somewhat
 - 6: agree completely
- My partner encourages me to do things that are important to me.
 - 0: disagree completely
 - 1: disagree somewhat
 - 2: disagree slightly
 - 3: neither agree not disagree
 - 4: agree slightly
 - 5: agree somewhat
 - 6: agree completely
- My partner listens when I need someone to talk to.
 - 0: disagree completely
 - 1: disagree somewhat
 - 2: disagree slightly

- 3: neither agree nor disagree
- 4: agree slightly
- 5: agree somewhat
- 6: agree completely
- I can rely on my partner if I have a serious problem.
 - 0: disagree completely
 - 1: disagree somewhat
 - 2: disagree slightly
 - 3: neither agree nor disagree
 - 4: agree slightly
 - 5: agree somewhat
 - 6: agree completely
- How emotionally satisfied are you with your partner?
 - 0: very unsatisfied
 - 1: somewhat unsatisfied
 - 2: slightly unsatisfied
 - 3: neither unsatisfied nor satisfied
 - 4: slightly satisfied
 - 5: somewhat satisfied
 - 6: very satisfied
- How sexually satisfied are you with your partner?
 - 0: very unsatisfied
 - 1: somewhat unsatisfied
 - 2: slightly unsatisfied
 - 3: neither unsatisfied nor satisfied
 - 4: slightly satisfied
 - 5: somewhat satisfied
 - 6: very satisfied
- Overall, how satisfied are you with your partner?
 - 0: very unsatisfied
 - 1: somewhat unsatisfied
 - 2: slightly unsatisfied
 - 3: neither unsatisfied nor satisfied
 - 4: slightly satisfied
 - 5: somewhat satisfied
 - 6: very satisfied

Page 8: Open-ended questions

In what ways does your partner provide emotional support to you?

In what ways does your partner provide other types of support to you (i.e. financial, medical)?

What are the best things about your relationship?

If you could change anything about your relationship, what would it be?

Appendix C: Informed Consent Form



2015-2016

Consent to Participate in a Research Study
Smith College School for Social Work • Northampton, MA

.....

Title of Study: HIV-serodiscordant couples, Pre-Exposure Prophylaxis, and Relationship Satisfaction

Investigator(s): Eli V. Latta

.....

Introduction

- You are being asked to be in a research study of couples with differing HIV statuses and relationship satisfaction.
- You were selected as a possible participant because you are an adult in a relationship of at least six months who has an HIV status that is different from your partner's status.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study

- The purpose of the study is to determine whether there is a relationship between the use of Pre-Exposure Prophylaxis (PrEP) and relationship satisfaction in HIV-serodiscordant couples. I am recruiting couples who do and do not use PrEP.
- This study is being conducted as a research requirement for my master's in social work degree.
- Ultimately, this research may be published or presented at professional conferences.

Description of the Study Procedures

- If you agree to be in this study, you will be asked to you will be asked to complete the following online survey. It will take approximately 15-20 minutes of your time.

Risks/Discomforts of Being in this Study

- There is a low likelihood that some questions in this study may cause discomfort or distress. If you are feeling distressed, you can utilize the following resources:
- National HIV/AIDS hotline: 1-800-CDC-INFO
- State specific HIV/AIDS hotlines: <http://hab.hrsa.gov/gethelp/statehotlines.html>
- Crisis Text Line: Text "GO" to 74141, <http://www.crisistextline.org>
- Suicide Prevention Lifeline: 1-800-273-TALK (8255), www.suicidepreventionlifeline.org

Benefits of Being in the Study

- There are no direct benefits of participation.
- The benefits to social work/society are helping to further research on HIV and couples

interventions.

Confidentiality [*choose one of the following*]

- This study is anonymous. We will not be collecting or retaining any information about your identity.

Payments/gift

- You will not receive any financial payment for your participation.

Right to Refuse or Withdraw

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study *at any time* without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely up to the point noted below. If you choose to withdraw, I will not use any of your information collected for this study.

Right to Ask Questions and Report Concerns

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Eli V. Latto, at elatto@smith.edu. If you would like a summary of the study results, one will be sent to you once the study is completed. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974.

Consent

- Clicking “Yes” indicates that you have decided to volunteer as a research participant for this study, and that you have read and understood the information provided above.

.....

