


“Reclaiming Control” Patient Acceptance and Adherence to HIV Post-Exposure Prophylaxis Following Sexual Assault

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Abstract

Sexual assault is an irrefutable trauma; an insult to the autonomy of the person forced into sexual acts. Sexual assault sequelae range from physical injury and acute traumatic stress, to pregnancy and sexually transmitted infections, including human immunodeficiency virus (HIV). HIV post-exposure prophylaxis (HIV PEP) following sexual assault may decrease the likelihood of HIV transmission. Many patients seeking healthcare post-sexual assault either do not initiate HIV PEP or do not complete the 28-day medication regimen. In this qualitative interpretive description, we interviewed sexual assault patients (N=11) about HIV PEP discussions/reactions, attitudes and understanding related to HIV and PEP, and barriers and facilitators of HIV PEP acceptance and adherence. Participants described a process of losing and reclaiming control throughout post-assault care and follow-up; and how this affected HIV PEP-related decision-making. Most HIV PEP decisions were described as a process of reclaiming control over one outcome while simultaneously losing control of another.

Keywords

Sexual assault, forensic nursing, HIV PEP, post-exposure prophylaxis, Mid-Atlantic Region USA, Appalachian Region USA

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Globally, 30% of women have been physically or sexually assaulted by an intimate partner, while 7% of women report being sexually assaulted by someone other than a partner (World Health Organization, 2013). Due to the observational nature of studies examining sexual assault, there are no data explicitly determining HIV transmission risk in the context of sexual assault. There have been documented cases of HIV transmission following sexual assault in countries with lower HIV prevalence (Albert et al., 1994; Murphy et al., 1989) and higher HIV prevalence (Claydon et al., 1991; Meel, 2005). HIV post-exposure prophylaxis (HIV PEP) is a 4-week course of anti-retroviral medications that may decrease the chance of HIV infection if initiated within 72 hours of an exposure (Centers for Disease Control and Prevention, 2016). The effectiveness of HIV PEP following sexual assault is inferred from other populations including occupational exposures, consensual sex exposures, and animal studies (Centers for Disease Control and Prevention, 2016).

The prevalence of HIV and whether HIV is considered a general or concentrated epidemic varies between jurisdictions. This is reflected in the corresponding HIV PEP guidelines. The World Health Organization PEP guidelines, which are often geared towards lower and middle income countries where HIV prevalence is generally higher, recommend provision of HIV PEP to sexual assault patients irrespective of whether the source person's HIV status is known, with the caveat to discontinue PEP if the source is

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later found to be HIV negative (Ford et al., 2015). In lower prevalence, more industrialized countries, such as Canada (Tan et al., 2017), the United Kingdom (UK) (Creswell et al., 2017), and the United States (US) greater emphasis is placed on the mode of exposure and whether the source person's HIV status is known or suspected (Centers for Disease Control and Prevention, 2016). In the US, the CDC only recommends HIV PEP for "high-risk" sexual assault exposures: contact of the "vagina, rectum, eye, mouth, or other mucous membrane... with blood, semen, vaginal secretions, rectal secretions... when the source is *known to be HIV-infected*" (emphasis added; Centers for Disease Control and Prevention, 2005, 2016). If the source person's HIV status is unknown—as is common in sexual assault cases—the CDC recommends a case-by-case determination but provides no added guidance for the treating nurses and clinicians (Centers for Disease Control and Prevention, 2005, 2016).

Post-sexual assault care in the US is often provided by Sexual Assault Nurse Examiners (SANEs) or Forensic Nurse Examiners (FNEs)—registered nurses with additional training in responding to and working with patients who have experienced interpersonal violence. Per national guidelines (Littel, 2013) and international sexual assault training guidelines (Lechner et al., 2018), post-sexual assault care should include (a) a forensic medical exam; (b) evidence collection; (c) sexually transmitted infection (STI) and HIV testing; (d) STI/HIV/pregnancy prophylaxis; (e) referrals; and (f) safety planning if there is risk of future harm (Campbell et al., 2006; Linden, 2011). In a survey of SANE/FNE program coordinators located throughout the world, less than half reported their programs routinely offered HIV PEP to post-sexual assault patients (Draughon et al., 2014). Sexual assault program coordinators cited medication costs and lack of patient compliance as barriers to routine HIV PEP provision (Campbell et al., 2006; Draughon et al., 2014). Providers have been shown to closely comply with clinical site protocols in determining whether patients are offered HIV PEP post-sexual assault (Draughon et al., 2015). Providers' HIV PEP provision has also been associated with patient age, patient and perpetrator race, anogenital injuries or head injuries noted at the time of exam, lack of condom use during the sexual assault, and a "stranger" or "unknown" assailant (Djelaj et al., 2017; Draughon et al., 2014, 2015).

Approximately half of post-sexual assault patients offered HIV PEP initiate the medication regimen (Scannell et al., 2018). Factors positively associated with patients' starting HIV PEP post-sexual assault in the US (Draughon Moret et al., 2016), and Canada (Loutfy et al., 2008) include having a known high-risk exposure (per CDC or program-specific guidelines) or an assailant known to have HIV. One's mental state has been reported to impact South African post-sexual assault patients' understanding of HIV PEP (Vetten & Haffeejee, 2005). In addition, being uninsured or having financial concerns surrounding HIV PEP negatively influenced

a San Francisco sample of post-sexual assault patients' decisions to start treatment (Myles et al., 2000).

In the US, about one-quarter of post-sexual assault patients complete the HIV PEP medication regimen (Scannell et al., 2018). Globally, rates of HIV PEP completion are lower in the sexual assault population than in occupational, or other non-occupational routes of exposure (Ford et al., 2014). Factors associated with increased HIV PEP completion post-sexual assault globally include: high-risk exposures in Brazil, Spain, and the UK (Garcia et al., 2005; Inciarte et al., 2020; Morgan et al., 2015, respectively); anxiety (as perceived by the health care provider) (Loutfy et al., 2008); knowing the assailant less than 24 hours (Inciarte et al., 2020; Loutfy et al., 2008); and absence of a concomitant physical assault (Loutfy et al., 2008). Fear of HIV has been reported by patients as both positively and negatively impacting HIV PEP continuance (Vetten & Haffeejee, 2005, 2008). Reported barriers to HIV PEP completion include medication side effects (Garcia et al., 2005; Inciarte et al., 2020; Krause et al., 2014; Vetten & Haffeejee, 2005, 2008) and financial barriers (Diniz et al., 2007; Malinverni et al., 2018).

Little is known about patients' decision-making regarding starting or stopping HIV PEP post-sexual assault. Most data on factors associated with acceptance or adherence stem from chart reviews while other evidence is from provider perceptions (e.g., patients perceived by providers as anxious were more likely to complete) (Draughon & Sheridan, 2012). Few studies regarding HIV PEP post-sexual assault include self-report data from patients (Abrahams & Jewkes, 2010; Vetten & Haffeejee, 2005, 2008).

The literature reporting on HIV PEP post-sexual assault is further limited by variations in the way HIV PEP "adherence" is operationalized: for example, whether patient self-report of HIV PEP completion is sufficient, or—as is the case in many studies—whether sexual assault patients returned to the initial treating hospital/program for all of their remaining HIV PEP prescription doses and/or HIV testing which can range up to 6-months post-assault (Chacko et al., 2012; Draughon & Sheridan, 2011, 2012). An international meta-analysis examining HIV PEP adherence, across all forms of exposure (including but not limited to sexual assault) found higher HIV PEP completion rates when patients were given a full 28-day supply of HIV PEP medication (Ford et al., 2015). In a South African study included in the review specific to sexual assault patients, Kim et al. (2009) found higher rates of HIV PEP completion in those given the full course of medications versus those given a starter pack (71% vs. 29%) as reported by the post-sexual assault patient.

Despite a growing body of research, there remains limited patient-reported data of the experience of decision-making regarding HIV PEP uptake and adherence in the context of sexual assault. To address this limitation, the goal of our study was to explore post-sexual assault patients' care and experiences related to HIV PEP, including decisions to initiate and complete HIV PEP.

Methodology

Interpretive description-guided qualitative data collection and analysis in a two-part multi methods study in which data was triangulated from quantitative sources and qualitative interviews collected continuously throughout the study to garner a more complete picture of post-sexual assault patients' experience of HIV PEP (Draughon et al., 2015; Draughon Moret et al., 2016). The multi methods study was guided by the theory of reasoned action and planned behavior (TRA/TPB) as a framework for understanding patient perceptions of experiences influencing HIV PEP adherence post-sexual assault. The TRA/TPB has been used extensively in routine medication adherence literature (Becker & Maiman, 1975; Charach et al., 2008) and in patient healthcare decision-making contexts (Mirkuzie et al., 2011). The TRA/TPB was adapted, based on both HIV PEP post-sexual assault adherence and anti-retroviral therapy (ART) adherence literature, to provide a framework for this study including social, personal, and cognitive factors (Charach et al., 2008), health habits, (Reach, 2005) and how these influence accepting and adhering to HIV PEP post-sexual assault.

Applicable to clinical problems (Thorne, 2008), interpretive description takes into account "what is known, whether by virtue of formal research or of clinical interpretation" (Thorne et al., 1997, p. 173). The first author's emergency, trauma, and forensic nursing experience served as a platform upon which the qualitative portion of the study was designed (Hunt, 2009) to explore patients' experience of post-sexual assault care related to HIV PEP including reactions to and understanding of HIV and PEP and barriers and facilitators to HIV PEP acceptance and adherence.

Setting and Sample

Recruitment took place at three FNE programs in the mid-Atlantic/Appalachian regions of the US between February 2012 and February 2013. These sites were the primary post-sexual assault forensic nursing programs for each of their respective cities/counties and were chosen because they routinely offer HIV PEP according to site-specific HIV risk assessment algorithms as part of post-sexual assault care. All sites provided baseline HIV testing and a 3-day starter pack of HIV PEP with prescriptions for the remaining doses. Patients were referred out for the remaining HIV prevention related follow-up (e.g., recommended follow-up testing). Potential patients accessed all three sites by presenting for care at the associated emergency room.

Post-sexual assault care related to HIV prevention in the US was guided at the time of data collection by the 2005 CDC guidelines (Centers for Disease Control and Prevention, 2005) which were updated in 2016 (Centers for Disease Control and Prevention, 2016) to reflect changes in the recommended medication regimens to use for non-occupational

post-exposure prophylaxis. Forensic nursing practice was similarly guided by the 2004 National Protocol for Sexual Assault Medical Forensic Examinations (Littel, 2004), with the second edition released the summer after data collection for the present study was completed (Littel, 2013). There are no meaningful differences in the recommendations regarding HIV PEP provision in the 2004 versus the 2013 (Littel, 2004, 2013) National Protocols. Thus, despite the length of time since data collection, the practice contexts both then and now are grossly congruent for forensic nurses providing post-sexual assault care related to HIV prevention.

Patients were eligible for qualitative interviewing if they (a) presented to the FNE program within 72-hours of the assault; (b) were offered HIV PEP according to site-specific guidelines; (c) were over the age of 18; (d) able to speak and read English; (e) had completed at least one quantitative study survey; (f) consented to be recontacted for interview, and (g) scheduled the qualitative interview within 6-months of the sexual assault. Exclusion criteria included (a) health care decisions made by proxy, (b) previous diagnosis of HIV, and (c) pregnancy, as there are different HIV treatment and prevention guidelines for each of these populations. During the recruitment period, 48% ($n=71$) of 148 screened patients were eligible for the quantitative portion of study, 45% ($n=32$) consented to participate in the study; however, one declined to be recontacted for interviewing. Sixty-five percent of study participants (20/31) completed at least one quantitative survey, making them eligible for interviewing. Eleven (55%) participated in the qualitative portion of the study. These response rates are consistent with prior studies recruiting participants at their initial help-seeking post-sexual assault visit (Campbell et al., 2011).

Recruitment and Enrollment

The treating FNE screened patients for eligibility; eligible patients were then recruited by the FNE or a trained research assistant. All FNEs and research assistants were trained by the first author, with monthly face-to-face meetings and phone calls as needed. All members of the study team who had participant contact identified as female. Participants provided voluntary informed written consent. Eligible participants were then contacted by phone by the first author and offered an interview. Of the 20 eligible participants, 11 completed an interview, four participants did not respond to the request for an interview, and five were not contacted for interview participation due to attainment of study aims prior to their window of eligibility for interview participation. No one reached via phone at this phase of the study declined to be interviewed. As data collection and analysis continued simultaneously, the decision was made by the study team to purposively capture the three primary HIV PEP decision states (Oliver, 2012; Thorne, 2008): (a) those who declined ($n=4$); (b) those who initiated but did not complete ($n=3$); and (c) those who completed ($n=4$).

Although one participant in the quantitative portion of the study did identify as male, all interview participants identified as women. Nine were between the ages of 18 and 25 years and two were older. Six identified as white; three as Black; one as Hispanic White; and one did not identify race or ethnicity. All interview participants received a list of national and local resources related to trauma, sexual assault, and mental health along with a US\$35 gift card.

Data Collection

A semi-structured interview guide was developed from domains identified through prior study, the extant literature, and clinical knowledge (Draughon & Sheridan, 2011, 2012; Hunt, 2009; Oliver, 2012). It was reviewed and revised with input from all authors and other faculty. Interviews were designed to explore patient perceptions of barriers and facilitators to starting and completing HIV PEP post-sexual assault including reactions to discussing PEP; attitudes and understanding related to HIV and the PEP medications. As concurrent data collection and analysis continued, it became apparent that the central theme most salient to participants' post-sexual assault HIV PEP experience was a push-pull dynamic between losing control and reclaiming control over their circumstances post-sexual assault as opposed to the anticipated adherence framing used to structure data collection. In discussing this shift, the authors determined no major revisions to the interview guide were needed although some probes were refined. See [Supplementary file 1](#) for the interview guide.

Each participant was interviewed once between June 2012 and March 2013. The first author conducted all 11 interviews either in-person ($n=5$) or by telephone ($n=6$). Interviews were scheduled as early as approximately 4–5 weeks post-assault (to capture experiences after PEP completion) and could be completed up to a maximum of 6-months post-recruitment to minimize recall bias. Interviews took place an average 70 days post-sexual assault (range 34–154 days), the majority ($n=6$) in the second month post-sexual assault, three in the third month, and one each in the fourth and fifth months post-sexual assault. The previously signed written consent form—including information about the study purpose—was reviewed at the agreed upon interview time by the first author and the participant. All participant questions were answered prior to beginning the interview.

Interviews ranged from approximately 20 minutes to 2 hours; four interviews were less than 30 minutes, six lasted between 45 and 60 minutes, and one interview lasted slightly less than 2 hours. Our interview approach was guided by the tenets of trauma informed care (Campbell et al., 2019; Substance Abuse and Mental Health Services Administration, 2014). This means that participants were provided with maximum agency and choice regarding how, where, and when they were interviewed. Participants selected their preferred modality of interview participation: either in-person

or via phone. To ensure privacy, in-person and phone interviews were conducted at a time and location of the participant's choosing with no others present. Participants chose diverse interview settings: their home, a park, outside a library, a community center, and a counseling center. The quantity and quality of information was reviewed and was similar across the in-person and phone interviews in that some participants in either modality were concise while others chose to share more of their story. Consistent with tenets of voluntary research participation and trauma informed care, participants were encouraged to skip questions or stop the interview as per their own personal comfort level. Due to the potential retraumatization associated with being asked to relive an assaultive experience and the recency of their index sexual assault, none of the interview questions asked explicitly about participants' sexual assault experience (see [Supplementary File 1](#)). The interview questions were focused specifically on post-sexual assault care related to HIV PEP. Some interview participants spoke very succinctly about their care experience as it related to HIV PEP—resulting in shorter interview lengths. In the longest interview, the participant chose to discuss their assault, and post-assault experiences with multiple different service sectors in-depth. The first author did not press participants to expand upon their initial responses beyond appropriate attempts at probing in order to respect participant boundaries for disclosure. Similarly, the first author did not cut participants off when their responses expanded beyond content related to HIV PEP. Therefore, the range in interview length was primarily due to the participant-centered trauma informed approach (Campbell et al., 2019). As sexual assault patients are a vulnerable population, we chose not to contact participants following their interview except to provide remuneration or resources.

All interviews were audio recorded except one (in accordance with the participant's request), and field notes were used to collect preliminary perceptions of data and to maintain connectedness (Hunt, 2009). Recorded interviews were transcribed verbatim and double-checked for correctness and completeness. For the participant who chose not to be recorded, extensive notes were taken and verified with the participant immediately post-interview. These notes were then typed and included in the analysis. Saturation was achieved after eight interviews in the form of informational redundancy (Saunders et al., 2018) meaning that the primary factors participants across the HIV PEP decision states considered in their HIV PEP decision-making (e.g., medication costs and side effects) were repeating across interviews. The additional three interviews were conducted for confirmation and to round out the three HIV PEP decision states. Our final sample of 11 qualitative interviews is consistent with purposive sampling in interpretive projects with narrow research aims (Sim et al., 2018; Thorne et al., 2004).

study, control is conceptualized as having the power to influence the course of events. Exerting control over one potential outcome (i.e., making a decision), often meant losing control over another outcome. Declining HIV PEP was seen as a way of reclaiming control over daily routine but resulted in a loss of control over HIV prevention. Accepting HIV PEP was seen as a way of reclaiming control over HIV risk but resulted in a loss of control over funds used to pay for the medications, or whether side effects were experienced. Deciding to stop taking HIV PEP was described as a way to stop the experience of medication side effects (reclaiming control) but meant a loss of control over HIV prevention. Deciding to continue taking the HIV PEP medications on a daily basis until completing the 28-day HIV PEP regimen was perceived as reclaiming control over HIV prevention but meant a loss of control over experiencing medication side effects for the 28-day medication regimen period.

Losing and Reclaiming Control

This push-pull dynamic is presented as two main themes—*losing control* and *reclaiming control*. The first insult to participants' sense of control was the assault itself. Sexual assault is “not something anyone asks to happen to them.” (10) The first theme, *losing control* began with the sexual assault and was experienced repeatedly: finding out about HIV and HIV PEP (*coping with HIV risk, being able to pay for the medications*), and the potential for debilitating side effects (*feeling sick*). *Losing control* alternated with participants' efforts to *reclaim control* of their lives and circumstances. The second theme, *reclaiming control* occurred when participants exerted control over the assault consequences through the decisions they made post-assault: addressing the physical injury (*getting checked out*) and managing HIV risk (*coping with HIV, being able to pay for the medications*) or HIV PEP side effects (*creating new habits*) and finally *getting back to a daily routine*. Table 2 contains a summary of the themes and sub-themes affecting HIV PEP decision-making.

We present the findings in narrative order from *getting checked out* through to *getting back to a daily routine*. Figure 1 provides a visual representation of this narrative including differences in whether a given sub-theme was experienced as an additional loss of control, or an opportunity for reclaiming control. Within each sub-theme we present the three HIV PEP decision states in order as applicable: (a) those who declined, (b) those who initiated but did not complete, and (c) those who completed HIV PEP.

Getting checked out. Per study inclusion criteria, all participants sought care at an FNE program. Seeking care appeared to be a way participants reclaimed control over possible sexual assault consequences. The women stated a variety of reasons for *getting checked out* including to allay concerns about pregnancy, STIs, and physical injury. For example, one woman explained that she wanted to know “That I didn't contract anything.... Any damage that was

caused from the assault I could control that...That was my biggest concern... knowing that I was physically OK” (7)

Coping with HIV risk. After *getting checked out* to *reclaim control* over physical consequences of the assault, many experienced a *loss of control* when made aware of unforeseen consequences—HIV risk. Reactions ranged from overwhelm, to fear, frustration, and anger. One participant who was not previously aware of her HIV risk expressed this *loss of control* as follows:

So when they started bringing up the STDs, ... I was just like so frustrated that I had to be in this situation where I had to take medication and like... it's like really not my fault I have to like be in a situation where I had to worry about it [HIV]. (10)

For the two participants who already knew about HIV risk, confirming and validating their concerns, coupled with timely treatment and initiation of HIV PEP, facilitated their sense of control. Deciding to take HIV PEP proactively addressed participants' concerns about HIV and, subsequently, their ability to move on from the assault:

[It] made me feel relieved just because that was the one thing [HIV] I was worried about from the get go ... Like everyone always says like getting treatment as soon as possible will help prevent anything or STDs ... So that was my top priority so I just wanted to get it. Like I wanted that information the most. So once I got it I felt better. (8)

Deciding to start or stop HIV PEP did not appear to be solely a knowledge issue. Instead, there was a deep consideration of how initiating the HIV prevention medications might impact them. For example, a participant who declined HIV PEP in order to avoid side effects and the “*negativity*” of being sick for a month, when asked “What was your understanding of why these medications were being offered?” clearly described how HIV PEP works: “Because there's a risk of getting HIV, there's a stage that it doesn't show up for X number of days. My understanding is that the [HIV PEP] medications keep that stage from manifesting” (4).

Being able to pay for the medications. HIV PEP medications are expensive and can present an insurmountable structural barrier. Participants in all three of the HIV PEP decision-making categories described feelings of frustration, surprise, and hopelessness when confronted with the monetary cost of HIV PEP. This suggests the need to pay for the 28-day course of HIV PEP medications represented a further *loss of control*. Thus, the cost of obtaining HIV PEP was a barrier to *reclaiming control*. For two participants, cost was the only factor in declining HIV PEP; one stated:

When they told me about the medicine and told me the range of prices of how much it cost it was kind of discouraging... If I did have a high chance of catching it then it's not like I can afford the medicine. So what am I supposed to do? (2)

Table 2. Theme and Sub-Theme Summaries of Losing Control/Reclaiming Control in Post-Sexual Assault HIV Post-Exposure Prophylaxis (HIV PEP) Decision-Making.

		Theme: Losing Control/Reclaiming Control	
<i>Losing control</i> began with the sexual assault and was experienced repeatedly, alternating with participants' efforts to <i>reclaim control</i> of their lives and circumstances		<i>Reclaiming control</i> occurred when participants exerted control over sexual assault consequences: physical injury, HIV risk, and side effects	
Sub-theme	Summary	Sub-theme	Summary
Sexual Assault	Sexual assault was the initial <i>loss of control</i>	Getting Checked Out	Seeking health care to address potential physical sexual assault consequences
Coping with HIV risk	Some experienced being offered HIV PEP as a new loss of control, because they had not considered HIV a sexual assault consequence	Coping with HIV risk	Those who had already considered HIV risk, experienced an offer of HIV PEP as reclaiming some control over possible consequences of the assault
Paying for the medications	<i>Loss of control</i> if unable to afford HIV PEP	Creating new habits	Participants created new habits to assist them in managing HIV PEP side effects
Feeling sick	Potential or actual experience of side effects	Getting back to a daily routine	The decisions participants made were focused on <i>getting back to a daily routine</i> post-sexual assault in the context of controlling the consequences of the assault
Post-sexual assault HIV PEP decision-making			
Declining	Seen as a way of <i>reclaiming control</i> over daily routine, but <i>loss of control</i> over HIV prevention		
Accepting	Seen as a way of <i>reclaiming control</i> over HIV risk, but <i>loss of control</i> over paying for the medications or experience of side effects		
Stopping	Some chose to discontinue HIV PEP to reduce side effects (<i>reclaiming control</i>) which meant <i>loss of control</i> over HIV risk		
Completing	Preventing HIV by completing HIV PEP meant <i>loss of control</i> over side effects		

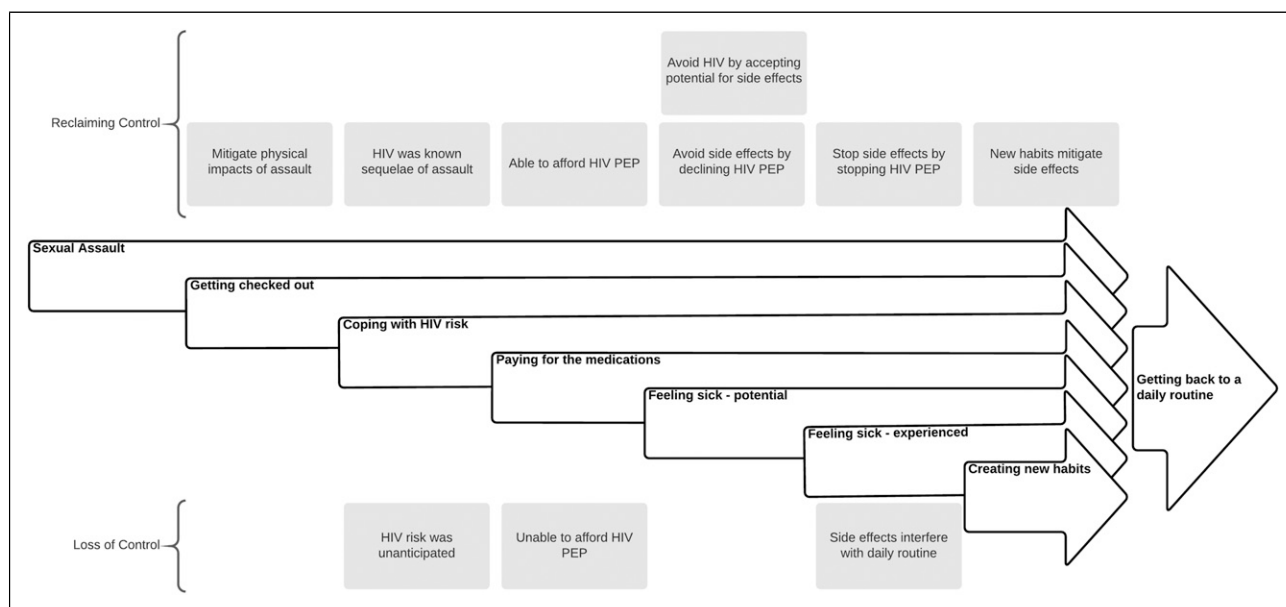


Figure 1. Post-sexual assault participant experiences of losing and reclaiming control with HIV post-exposure prophylaxis.

Difficulty *being able to pay for the medications* in order to *reclaim control* over HIV risk was experienced by another participant who chose to initiate HIV PEP expecting her insurance would pay for the medications. She received a 3-day starter pack. At the pharmacy, she was informed her insurance was not covering the medications costs and she would have to pay over US\$1000 for the remaining 25 doses. By the time she and the FNE program coordinator developed an alternate affordable option, the patient had missed 2 days of medications, rendering HIV PEP no longer effective. Despite her efforts, the structural barriers (the FNE program only providing a starter pack and insurance company reimbursement policies) resulted in an inability to pay for HIV PEP in a timely fashion.

One participant stated she was willing to “figure out a way to pay for it,” because she adamantly wanted HIV PEP (*reclaiming control*). She contacted a friend and developed a plan to pay for the medications if her insurance would not pay (8). Another participant explained:

The medicine is extremely expensive... I did have the money, but that wasn't money I planned to spend on medication. So that was stressful....When I found out how much it costs I was like no wonder people don't get this medicine because it's a ridiculous amount of money...I would hate for that to be a reason for someone not to take it. (11)

Feeling sick—potential. The next consideration for participants regarding HIV PEP was fear of experiencing debilitating medication side effects. This decision was framed as avoiding yet another negative experience. If the participant chose to initiate HIV PEP, the often-unpleasant symptoms

could be minimized but not entirely controlled. Some participants perceived the risk of *feeling sick* as disruptive to their ability to *reclaim control* and declined HIV PEP. One stated: “They offered it to me, explained like a month and sick off it and...I just didn't want to go through that.” (4)

Participants who decided to take HIV PEP also expressed serious concerns related to side effects and their impact on *getting back to a daily routine*:

Matter fact I was kinda hesitant...about takin' the pills...Once they started tellin' me about the side effects and how long I had to take it that kinda – kinda draw me back. Like do I really wanna go through the entire four weeks bein' nauseas and feelin' dizzy and stuff? (5)

Feeling sick—experienced. Two of the three participants who initiated but did not complete HIV PEP reported they decided to stop taking the medications due to side effects. We interpreted this as an attempt to *reclaim control* over their daily routine; although notably *losing control* over their ability to prevent HIV in the process. These participants described major disruptions to their day-to-day functioning, including feeling trapped at home due to gastrointestinal symptoms, feeling too fatigued to care for their children, and discomfort with returning to work while dealing with the side effects.

A main difference between participants who completed HIV PEP and those who did not appeared to be perceptions about how to reassert control over the assault consequences. Those who discontinued HIV PEP did not feel able to control how side effects were dictating their daily lives. This suggests they *reclaimed control* by deciding to stop taking HIV PEP;

ending their exposure to side effects and losing control of HIV prevention. Conversely, participants who completed HIV PEP-related statements consistent with *reclaiming control* by doing everything they could to *cope with HIV risk*:

I mean, is thirty days a long ass time to feel like crap? Yeah it is. But you know, thirty days of feelin' like crap versus dying of AIDS...I'll take thirty days of feelin' like crap any day if that's ... my choice. (9)

Creating new habits. The four participants who completed HIV PEP all experienced side effects at some point during the HIV PEP regimen. Two reported relatively mild side effects, while the other two reported more frequent and severe side effects. The creation of new health habits to manage HIV PEP side effects was critical for HIV PEP completion. These new habits included adjusting when they took the medications (at night vs. in the morning), and how they took the medications (e.g., on a full stomach). The two participants who experienced more severe side effects also shared strategies for managing nausea like drinking carbonated beverages.

Participants explained how the purpose of HIV PEP was both a help and a hindrance in creating new habits around taking the pills. On the one hand it improved adherence:

That was probably like the only medicine that I was able to take on a consistent basis based on you know why I was taking it... even though it was making me sick and I couldn't stand to take it the only reason I continued to take it on a regular basis consistently was because I wanted to take whatever measure possible to prevent um, to prevent from getting HIV. (11)

On the other hand, participants explained the medications reminded them daily of the assault. "It was really, really, really hard to take the specifically the HIV medications because it's over such a long period of time um... and I felt like it was just like a constant reminder of what had happened." (10) This participant also stated she was frequently traveling and, "consciously not wanting to take it and so I would leave it places." She took all the pills over a longer period of time and reported that it took her longer to get "back like in my life."

Despite these symptoms of both emotional and physical discomfort associated with taking HIV PEP, decreasing the chances of contracting HIV was still more important than avoiding unpleasant emotions or reminders of the assault. As one participant said,

I didn't feel bad if I couldn't take 'em all at one time. Like if it took me like forty-five minutes to take the pills... To actually swallow because I mean, every time I swallowed I thought about it. You know, I thought about when it happened. (9)

Deciding to take the medications was described by one participant as an active response to avoid an unpleasant

outcome: "But I did everything that I could do and I handled it and I got the help I needed. I got the right medication I needed and I did everything that I could possibly do to remedy it" (8).

Getting back to a daily routine. As part of the recovery process, participants perceived re-establishing a daily routine as tantamount to *reclaiming control* over their lives. One participant expressed a desire to "get over" the assault, defining "getting over it" as:

Being able to go back to my daily routine... not having to take anxiety medication. Being able to go out and not have to worry about someone putting something in my drink ... just not being able to think about it. (7)

Discussion

This foundational study presents important gains in understanding post-sexual assault patient's HIV PEP decision-making especially as it relates to their sense of control. The decisions participants made related to HIV PEP were the primary way they reclaimed control in the post-sexual assault period. The study adds to the limited amount of literature exploring patient-level data regarding HIV PEP in the post-sexual assault context (Abrahams & Jewkes, 2010; Vetten & Haffejee, 2005, 2008). All of the participants were making efforts to *reclaim control* after experiencing sexual assault. Along the way to *getting back to a daily routine*, participants experienced challenges and situations which represented an additional *loss of control* (e.g., *being able to pay for the medications*), which then impacted decision-making with respect to HIV PEP. Choosing to *reclaim control* over HIV risk, meant *losing control* over the potential or actual experience of side effects. Declining or deciding to discontinue HIV PEP meant *getting back to a daily routine* sooner but *losing control* over HIV prevention. The clinically useful narrative we describe can be used as a guide for nurses and other clinicians providing post-sexual assault HIV PEP-related care. Each sub-theme represents a potential leverage point for situating tailored interventions, especially when considering the different ways patients may experience each decision point (whether loss of, or reclaiming control).

Participant perceptions of control have not previously been linked to post-sexual assault HIV PEP decision-making or adherence and, thus, were not an explicit component of our interview guide. In this study, all participants demonstrated attempts to reclaim control over their lives in the aftermath of the assault. As part of an *a posteriori* examination of control in the context of sexual assault we found several studies highlighting its importance in post-sexual assault recovery. Similar to results of a metasynthesis examining the essence of healing from sexual trauma (Draucker et al., 2009), participants in our study all sought to rid themselves of the consequences of the sexual assault by seeking care at the FNE programs. In prior grounded theory studies of female sexual assault survivors, Duma et al., 2007a, 2007b) identified two

recovery process themes similar to this study's theme of *reclaiming control*. They first described the "turning point" in the recovery process as when women began to retake control of their healing; and second, they identified a "returning to self" stage which is similar to the sub-theme of *getting back to a daily routine* described by our study participants. In a quantitative study with sexually assaulted patients, higher perceptions of control over recovery were associated with more constructive coping post-assault (Frazier et al., 2004) and lower levels of mental health symptoms (Frazier et al., 2012). Similarly, people who felt they had control over their sexual assault recovery experienced lower levels of post-traumatic stress and depression (Walsh & Bruce, 2011). Finally, SANEs interviewed by Djelaj et al. (2017) conceptualized HIV PEP post-sexual assault as a way for their patients to take back control.

The Department of Justice national protocol for sexual assault medico-legal examinations (Littel, 2013) and numerous studies encourage clinicians to empower patients with choices during the acute post-assault exam (Djelaj et al., 2017; Du Mont et al., 2009; Ericksen et al., 2002; Fehler-Cabral et al., 2011; Frazier et al., 2004). In three qualitative studies, facilitating sexual assault patients' sense of control and allowing them to determine their post-assault care, was shown to improve satisfaction with forensic nursing care (Du Mont et al., 2009; Ericksen et al., 2002; Fehler-Cabral et al., 2011). Patients reclaiming control over their lives in the weeks post assault can take many forms and manifest as different decisions as noted by study participants. Patients may reassert control by declining the medications, limiting the effect of the assault in the days and weeks following. Conversely, patients may decide to take the medications and reassert control by lessening their chances of HIV infection. The treating nurse or clinician should support patient autonomy to choose how to handle the repercussions of the sexual assault by ensuring that patients have adequate information through which to make informed decisions. At the time of post-sexual assault care, being able to make informed decisions about different interventions, including HIV prophylaxis, is crucial.

It is apparent from this *a posteriori* examination of the sexual assault literature related to control that decision-making is deeply enmeshed in facilitating a sense of control in post-sexual assault patients. While we initially approached this study from the perspective of understanding factors impacting patient adherence to HIV PEP post-sexual assault, the issue most salient to participants was their sense of control over their experience of HIV PEP care provision and related decision-making. Both researchers and nurses engaged in HIV PEP care provision post-sexual assault may benefit from incorporating a decision-making framework into their practice. The Ottawa Decision Support Framework has 20 years of research supporting its use in assisting patients in making difficult health care decisions (Stacey et al., 2020). The decisional needs (Stacey et al., 2020) related to choosing

whether to initiate or decline HIV PEP post-sexual assault are high: (a) difficult timing—the decision must be made within 72 hours of the exposure (Centers for Disease Control and Prevention, 2016); (b) uncertainty—since the HIV transmission rate from sexual assault is unquantifiable, treating providers cannot readily ease HIV-related fears with facts (Han, 2013); and (c) emotionally charged—a sexual assault is an undeniable trauma which can impact patients' ability to make decisions, as well as their confidence in their decisions (Lipkus, 2007; Stacey et al., 2020). The Ottawa Decision Support Framework can guide clinicians in selecting, and researchers in creating, decision support interventions which may improve the quality of post-sexual assault HIV PEP decision-making through helping patients to feel better informed about the choice, and ensuring that their choice matches what matters most to them in the post-sexual assault recovery period.

Coping with HIV risk. Nine of the 11 participants reported never imagining they would be exposed to HIV. They did not have control over the fact that they may have been exposed to HIV and experienced this as an additional *loss of control*. Although participants in our study knew sexual assault could lead to injuries, STIs, and pregnancies, HIV was often not considered until the FNE discussed HIV transmission risks. Similarly, in Resnick et al. (2002) classic US study of 68 recently sexually assaulted women, 26% reported not being fearful of HIV *during* the assault, while 71% were extremely concerned about HIV risk *afterward*. This is in contrast to a community sample of Kenyan men and women who were aware of HIV as a post-sexual assault sequelae, but did not know that HIV PEP was a prevention option (Kilonzo et al., 2008). Recognizing that discussing HIV risk might be a shock to some post-sexual assault patients, the SANEs interviewed by Djelaj et al. (2017) recommend starting the HIV risk conversation after rapport is established, for example, after completing the forensic history portion of the exam. Due to the ethical impossibility of determining the HIV transmission rate specifically from a sexual assault exposure, treating nurses and clinicians cannot address HIV-related fears with evidence-based facts. In other research fields, lack of facts to estimate risks has been shown to affect patients' decisions, as well as confidence in their decisions (Han, 2013). Further, emotional responses to risk can impact decision-making (Lipkus, 2007). In the context of sexual assault trauma, given the time-bound nature of HIV PEP treatment, and the range of emotions described by participants, the decision to start or stop HIV PEP is particularly fraught and can be further complicated when HIV risk is not well quantified within the context of sexual assault. Although we did not measure sexual assault patients' confidence in their decision to accept HIV PEP, it is highly likely the degree of uncertainty of an individual patient's risk may have impacted their decision to initiate or decline HIV PEP as well as their intent and ability to complete the medication regimen (Stacey et al., 2020).

Being able to pay for the medications. Similar to previous studies, cost (a structural barrier) was described by participants in this study as a barrier to HIV PEP acceptance. In a US study of 10 pediatric/adolescent patients who were offered HIV PEP (six of whom were sexually assaulted), four patients experienced financial difficulties in obtaining the medications (three exposed via needlestick and one via sexual assault) (Babl et al., 2000). In a Brazilian study of HIV PEP use and adherence after sexual violence, 10% of women reported financial difficulties in obtaining the medications (Diniz et al., 2007). Similar to findings from a Belgian study, in which patients who had health insurance were significantly more likely to adhere to HIV PEP post sexual assault (Malinverni et al., 2018), we found in our sample that financial barriers also impacted participant adherence. In an interview study with SANEs, the nurses noted the additional work patients had to go through in order to obtain HIV PEP could be a significant barrier to both uptake and adherence (Djelaj et al., 2017).

The cost of HIV PEP post-sexual assault in the US varies by medication regimen and the payor. This in turn, varies by region, state, and even individual FNE programs. In our study, participants reported HIV PEP costs ranging from US\$1500 to US\$2500. Insurance may not cover the prescription costs, or patients may be unwilling to submit the prescription for reimbursement. For example, college students covered by parents' health insurance may be concerned their parents could learn about their assault from an insurance bill. These issues are not confined to non-single payor countries. Therefore, insurance coverage alone is not enough to surmount this barrier. If insurance does not cover the prescription costs, patients may be asked pay upfront for HIV PEP with uncertainty regarding whether local crime victims' compensation funds will reimburse them. From multiple perspectives, cost represents a large structural barrier to HIV PEP acceptance and initiation. In a Canadian study examining sustainability of providing HIV PEP medications to patients free of charge, providers raised many concerns regarding finite funds to treat patients, and how HIV PEP is allocated based on those funds (Du Mont et al., 2011).

Currently, in the US, the Victims of Crime Act will reimburse SANE/FNE programs for the initial doses of HIV PEP—usually a 3–5-day starter pack. Under the Violence Against Women Act (VAWA) the state or territory must certify that the full out-of-pocket cost of forensic medical exams is covered. However, each state and territory can interpret what services fall under the “forensic medical exam” coverage. Policy change at the federal level to VAWA explicitly stating that STI and HIV prophylaxis be considered part of the “forensic medical exam” would remove cost as a patient consideration in HIV PEP decision-making post-sexual assault. In countries with universal health care, these issues will likely not have a meaningful impact on how post-sexual assault patients make decisions about whether to initiate HIV PEP. Future research should examine the impact

HIV PEP costs, patient income level, and health insurance status have on HIV PEP decision-making in the context of sexual assault. While structural barriers like victim compensation and insurance regulations may be specific to individual countries, patient decision-making regarding side effects have global health implications.

Feeling sick—potential. Taking HIV PEP to prevent HIV was perceived by some as onerous—a month-long regimen with the potential for serious side effects. In our study, regardless of the HIV PEP regimen offered, participants could not control whether they would experience medication side effects. The impact of potential side effects on deciding to initiate or decline HIV PEP has not previously been examined from the patient perspective in the post-sexual assault context. This finding adds to those from prior studies where the provider noted that concerns about side effects may have impacted HIV PEP uptake (Du Mont et al., 2008; Loutfy et al., 2008). Deciding to start or not start HIV PEP was a way participants could control whether or not they experienced side effects, thereby exerting control over some of their circumstances (Frazier et al., 2004, 2012; Walsh & Bruce, 2011). The fact that the same issue (*reclaiming control*) could be applied to either decision (initiating or adhering to HIV PEP post-sexual assault) suggests opportunities to positively frame information provided to sexual assault patients.

Feeling sick—experienced. Our study supports prior research that HIV PEP side effects were reported by all who initiated HIV PEP and acted as a driving force when participants decided to discontinue the medications (Abrahams & Jewkes, 2010; Inciarte et al., 2020; Krause et al., 2014; Vetten & Haffeejee, 2005, 2008). Loutfy et al. (2008) found 82% of patients stopped HIV PEP because of side effects; followed by interference with daily routine (42%); and not being able to miss work or school (22%). The interference that the medications and side effects had on daily routine has been previously reported by post-sexual assault patients who chose to discontinue HIV PEP (Abrahams & Jewkes, 2010). This was reported specifically by our participants who discontinued HIV PEP because they could no longer handle the side effects. Participants perceived that discontinuing the medications would allow them to return more quickly to a daily routine than if they had completed the 28-day regimen. As the goal of our study was to understand the role of side effects in general on HIV PEP decision-making in the context of sexual assault, we did not obtain specifics related to the medications such as the number of medications in the regimens unless participants spontaneously shared that information; or the specific medications included in the regimen. While we were not attempting to tie the experience of side effects back to specific HIV PEP medication regimens or follow-up protocols, it is possible that some of our findings related to the different PEP regimens participants were provided post-sexual assault.

Since the completion of data collection, the CDC updated their preferred medication regimens for non-occupational

HIV exposures to include medications that are better tolerated with fewer side effects (2016). A recent retrospective chart-review conducted in Germany reported an almost 30% reduction in post-sexual assault patient reports of side effects after changing to a better-tolerated HIV PEP regimen (Ebert et al., 2018). Previous data suggest higher rates of HIV PEP completion post-sexual assault are associated with fewer HIV PEP drugs in a given regimen. Post-sexual assault patients prescribed with a two drug regimen were less likely to stop HIV PEP due to side effects as compared to a three drug regimen (Garcia et al., 2005) and those on either two or three drug regimens had higher rates of completion than those on a four drug regimen (Kumar et al., 2017).

There may also be value in simplifying the medication administration schedule. A study comparing a single tablet multi-formulation of HIV PEP to a multiple tablet regimen found higher HIV PEP adherence across exposure categories in the single tablet group, which may have been due to the ease of the schedule and/or better-tolerated medications with milder side effect profiles (Malinverni et al., 2020). The same study also reported lower adherence rates across both medication groups in patients who were sexually assaulted, suggesting relevant barriers in the context of sexual assault beyond the specific PEP medication regimen (Malinverni et al., 2020).

Creating new habits. Echoing Vetten and Hefjee's (2005) qualitative findings, participants in our study who completed HIV PEP shared new habits or strategies to lessen the impact of side effects and the medications themselves on their daily lives. These strategies allowed participants to reclaim some control over physical symptoms. By making these changes, participants were able to better manage HIV PEP adherence and manage further potential injury (HIV infection) related to the assault.

Similar to findings in previous qualitative work, our participants reported the medications were a daily reminder of what had happened to them (Abrahams & Jewkes, 2010; Vetten & Hefjee, 2005, 2008). It is possible that completing HIV PEP, in fact, increases post-traumatic stress symptoms, specifically avoidance symptoms. Conversely, it is also possible that those who experience post-traumatic avoidance symptoms are more likely to complete HIV PEP because they are successfully avoiding other reminders of the event. As HIV PEP adherence has not previously been examined in relation to post-traumatic stress, this finding is an important first step in understanding the complex interactions between sexual assault traumas, post-traumatic stress symptoms, and negotiating HIV PEP adherence.

Limitations

All participants in our sample chose to seek post-sexual assault care at a FNE program. This sample may differ from patients who choose to seek post-assault HIV prevention through a primary care provider, community-based or

other out-patient HIV PEP program. Only a sub-sample of people who experience sexual assault seek *any* kind of treatment post-sexual assault. Accessing a formal support source (such as emergency medical care) is in contrast to US National Crime Victimization Survey data in which only 25% of sexual assaults were reported to law enforcement in 2018 (Morgan & Oudekerk, 2019). Similarly, Starzynski et al. (2005) found 61% of women in their mail-survey study who had an unwanted sexual experience since the age of 14 reported their assault to a health care worker, police, advocacy group, or other formal support provider. Jacques-Tiura et al. (2011) found less than a quarter of the 272 women in their representative community sample reported sharing their assault with a formal support service. Thus, our sample may not be representative of the general sexual assault population. Selection bias may also have been introduced by the FNE in choosing which patients to offer HIV PEP and also whom to approach for study recruitment. While there is some research around factors which influence how healthcare providers offer HIV PEP post-sexual assault (Djelaj et al., 2017; Draughon et al., 2014, 2015; Draughon & Sheridan, 2012) future research into the ways provider attitudes may influence HIV PEP provision post-sexual assault is warranted given the number of sexual assault cases which fall under the CDC "case-by-case determination" portion of the guidelines (Centers for Disease Control and Prevention, 2016).

The total sample from which the interview participants were drawn was well educated; every participant had completed high school and all but two had completed "some college." It is possible those who chose to participate were more educated than those who declined participation. This may explain why we found declining HIV PEP was unrelated to knowledge and more an issue of control. In future research, it would be useful to systematically assess HIV PEP knowledge as well as health literacy levels to determine if there is an association with declining or accepting HIV PEP. It is also possible that participants had learned more about HIV PEP *after* making the decision to take the medications but before being interviewed for this study. Since we purposefully scheduled interviews as early as 4 weeks post-assault, but no more than 6-months post-sexual assault there is a potential for recall bias. Traumatic memories are often more persistent and more likely to encode in the brain due to the high emotional charge (Haskell & Randall, 2019). Studies which recruit patients in the immediate post-sexual assault help-seeking period often follow those patients for a year or more (Campbell et al., 2011; Duma et al., 2007a, 2007b). We are confident that the major factors our participants reported as impacting their HIV PEP decision-making (e.g., cost of the medications, potential for and experienced side effects) warrant continued investigation in the future. Certainly, future studies which could capture decision-making in the moment would be highly valuable to nurses and clinicians providing HIV PEP to patients during post-sexual assault care.

There may be additional domains influencing post-sexual assault patient decision-making regarding HIV PEP uptake and adherence which we did not uncover in our analysis. Our sample size of 11 is relatively small compared to many qualitative interview-based studies, especially considering we interviewed each participant only once. Based on our definition of saturation, and the fact that our study was tightly focused on patients' experiences with post-sexual assault HIV PEP provision, our sample size was adequate to construct a clinical useful narrative (Hunt, 2009; Oliver, 2012). Our final sample size is consistent with prior interpretive description studies described by Thorne et al. (2004), studies of medication adherence (Charach et al., 2008), SANEs (Djelaj et al., 2017), and post-sexual assault patients (Draucker et al., 2009). Regardless of the clinical adequacy of the sample, future studies should seek to replicate and build upon this foundational work to further enhance patient care related to post-sexual assault HIV PEP provision.

Male-identifying patients were eligible for the study, and the single male-identifying participant was lost-to-follow-up. This is similar to most post-sexual assault clinical samples as men have to contend with societal norms and gender stereotypes which may present barriers to seeking post-sexual assault care (Donne et al., 2018). We continue to have minimal information on men's experience with post-sexual assault care. Future research may include recruiting a community-based sample of men to purposively interview them to better understand their experiences with post-sexual assault care.

With respect to societal norms and social contexts, the US is currently experiencing significant racial upheaval. It is highly likely that racism and other forms of discrimination impact the care provided to post-sexual assault patients. These racial disparities are becoming starker in light of the current COVID-19 pandemic. Future research regarding HIV PEP decision-making post-sexual assault should systematically assess for patient's perceptions of these biases and how the experiences of patients with marginalized identities may differ.

Finally, the interviews in this study were conducted almost 8 years ago. The goal of the study was to understand post-sexual assault patients' experience of HIV PEP. The findings from the interviews, while conducted at a particular time and context, remain relevant because people continue to be sexually assaulted, and HIV PEP continues to be initiated and adhered to at less-than-optimal rates in this population. Since the interviews were completed, many countries have updated their HIV PEP guidelines to recommend better-tolerated medication regimens (Centers for Disease Control and Prevention, 2016; Creswell et al., 2017; Ford et al., 2015; Tan et al., 2017). This may decrease the number of post-sexual assault patients who discontinue HIV PEP due to side effects. However, in the study comparing a PEP regimen with fewer daily doses and better-tolerated drugs to a more complicated regimen, Malinverni et al. (2020) still found

lower rates of adherence in post-sexual assault patients across both groups.

Our study supports the importance of reclaiming control of various consequences of the sexual assault in patients' decision-making and ability to adhere to HIV PEP. This warrants further research to clarify the interrelationships between loss of control/reclaiming control and decision-making as well as recommendations for nurses and other health care providers when communicating with post-sexual assault patients to support HIV PEP initiation and adherence.

Implications and Conclusions

In the period following an acute sexual assault, patients search for ways to reclaim control over their circumstances and any consequences of the assault. Being able to make informed decisions about different interventions, including HIV prophylaxis, immediately post-assault is both necessary and potentially traumatizing. The level of control participants feel over their recovery process after a sexual assault should be assessed, clearly understood, and explicitly addressed by all professional staff. Nurses and other treating clinicians should support patient autonomy through providing as much choice over post-assault care as possible simultaneously informing post-sexual assault patients of potential opportunities to regain control as well as diminishing assault repercussions. Thus, nurses and treating clinicians may find it helpful to reframe HIV PEP discussions to assist patients in recognizing positive ways to reassert control. Approaches may include helping patients reestablish as many daily norms as possible, while incorporating HIV PEP and sharing strategies to handle side effects.

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Supplementary Material

Supplementary material for this article is available online.

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