

UC Davis

UC Davis Previously Published Works

Title

Patient and Provider Decision Making About HIV Postexposure Prophylaxis Following Sexual Violence: A Qualitative Analysis.

Permalink

<https://escholarship.org/uc/item/82m5f4vw>

Journal

Journal of the Association of Nurses in AIDS Care, 34(6)

Authors

Anderson, Jocelyn

Boakye, Michelle

Draughon Moret, Jessica

et al.

Publication Date

2023-11-01

DOI

10.1097/JNC.0000000000000430

Peer reviewed



HHS Public Access

Author manuscript

J Assoc Nurses AIDS Care. Author manuscript; available in PMC 2024 September 28.

Published in final edited form as:

J Assoc Nurses AIDS Care. 2023 ; 34(6): 566–581. doi:10.1097/JNC.0000000000000430.

Patient and provider decision making about HIV postexposure prophylaxis (PEP) following sexual violence: A qualitative analysis

Jocelyn C. Anderson, PhD, RN, SANE-A [assistant professor],

Ross and Carol Nese College of Nursing, Pennsylvania State University, University Park, Pennsylvania, USA

Michelle D.S. Boakye, PhD, MPH, RN [postdoctoral fellow],

Fitzpatrick College of Nursing, Villanova University, Villanova, Pennsylvania, USA

Jessica Draughon Moret, PhD, RN [associate clinical professor]

Betty Irene Moore School of Nursing at UC Davis.

Abstract

Purpose: To explore patient and healthcare provider HIV postexposure prophylaxis (PEP) decision making following sexual assault.

Methods: Semi-structured interviews regarding HIV PEP provision with 15 patients and 10 healthcare providers were conducted. A qualitative descriptive thematic analysis approach was used.

Results: Four themes were derived: 1) medical concerns; 2) emotional, trauma and support factors; 3) daily medication management; and 4) ensuring access to HIV PEP. How participants described these themes and the *importance* placed on factors within each theme varied between the two groups.

Conclusions: Altering provider communication so that HIV PEP discussions better align with patient decision making factors (e.g., trauma and ability to take in information, how to manage side effects) could facilitate improvement in the HIV PEP decision making following sexual assault for patients. High level policy changes would improve HIV PEP access for sexual assault patients without necessitating the extraordinary efforts individual providers currently undertake.

*Corresponding author: Jocelyn C. Anderson; jocelyna@psu.edu.

Author contributions:

All authors on this paper meet the four criteria for authorship as identified by the International Committee of Medical Journal Editors; all authors have contributed to the drafting or been involved in revising it, reviewed the final version of this manuscript before submission, and agree to be accountable for all aspects of the work.

Specifically, using the CRediT taxonomy, the contributions of each author is as follows:

Conceptualization: J. Anderson, J.D. Moret; Methodology: J. Anderson, J.D. Moret; Formal Analysis: M. Boakye, J. Anderson, J.D. Moret; Supervision: J. Anderson; Writing – original draft: J. Anderson, M. Boakye, J.D. Moret; Writing – review & editing: J. Anderson, M. Boakye, J.D. Moret; Funding acquisition: J. Anderson.

Disclosures:

The authors have no conflicts of interest to report. The authors confirm that the research presented in this article met the ethical guidelines, including adherence to the legal requirements, of the United States of America and received approval from the Institutional Review Board of the Pennsylvania State University.

Keywords

HIV PEP; decision making; sexual assault; post-exposure prophylaxis

Background

People who experience sexual violence are at risk of contracting sexually transmitted infections (STIs) such as HIV, chlamydia, and gonorrhea (Inciarte et al., 2020; McCormack & Koons, 2019). While there are relatively few published reports of cases of HIV infection following sexual assault, a recent California state-level report estimated the single year incidence of HIV infection due to sexual assault to be 192 unique cases (Miller et al., 2018). In the United States, the Centers for Disease Control and Prevention (CDC) provides evidence-based recommendations for clinicians regarding post-exposure prophylaxis for STIs. One set of recommendations is specific to HIV post-exposure prophylaxis (HIV PEP) following non-occupational exposures such as sexual assault. HIV PEP is typically a three drug combination of antiretroviral medications (most commonly recommended tenofovir DF 300 mg / emtricitabine 200 mg once daily with raltegravir 400 mg twice daily or dolutegravir 50 mg once daily) which if initiated within 72 hours of HIV exposure and taken daily for 28 days decreases the likelihood of an HIV infection following an exposure (Centers for Disease Control and Prevention, 2016; Otten et al., 2000; Tsai et al., 1995). HIV PEP can decrease the likelihood of HIV infection by 80% in occupational exposures (Cardo et al., 1997). Observational studies have shown HIV PEP to be 99.5% effective when HIV risk-taking is minimized (Centers for Disease Control and Prevention, 2016; Otten et al., 2000; Tsai et al., 1995).

The current CDC guidelines for HIV PEP has three primary recommendations for those who present within 72 hours of a potential nonoccupational exposure (Centers for Disease Control and Prevention, 2016). The first recommendation summarizes that for patients whose exposure to HIV is via oral contact only (e.g., kissing, penile-oral, vulvar-oral contact) or in which the perpetrator is *known* to be HIV negative that HIV PEP is not recommended due to the nearly zero rate of transmission via these routes. The second recommendation is that HIV PEP be initiated for patients who have penile-vaginal or penile-anal contact with a perpetrator who is *known* to be HIV positive. The third recommendation, and perhaps the greatest challenge to patients and providers alike in the post-sexual assault context: It states that for patients who have a penile-vaginal or penile-anal exposure with a perpetrator whose HIV serostatus is *unknown*, a “case-by-case” determination should be made regarding whether HIV PEP is initiated.

As it is rare for patients and health care providers to definitively know the HIV serostatus of a sexual assault perpetrator, the vast majority of clinical cases are determined individually by providers and patients. This translates into variations in clinical practice. Studies examining providers’ behavior in offering HIV PEP to patients following sexual assault indicate that they are influenced by factors such as pre-existing relationship between patient and the perpetrator, patient age, patient and perpetrator race, and anticipated patient financial burden (Djelaj et al., 2017; Draughon et al., 2014, 2015). A survey of Sexual Assault Nurse

Examiner (SANE) program coordinators reported a perception that patients “don’t, won’t, or can’t follow-up” as a key reason for not offering HIV PEP routinely (Draughon et al., 2014). Individual hospitals and health systems have undertaken work to create further risk stratification tools based on perpetrator, patient, and assault characteristics (Draughon et al., 2014; Wieczorek, 2010), and prior work demonstrates that providers are highly likely to follow a local protocol when one is in place (Draughon et al., 2015). Factors that may be included in local protocols or risk stratification tools typically include those that may increase the risk of HIV transmission such as presence of genital ulcers and injuries as observed during the medicoforensic post-sexual assault exam, presence of other STIs, reported multi-perpetrator assault, and reported exposure to blood (Draughon, 2012; Edinburgh et al., 2014).

There are few studies of post-sexual assault HIV PEP provision and uptake exploring the elements of decision-making for patients during the acute treatment phase following sexual violence (Abrahams & Jewkes, 2010; Draughon Moret et al., 2021, Vetten & Haffejee, 2005, 2008). These qualitative studies found patients reported several common issues impacting HIV PEP decision making including: being able to pay for the HIV PEP medications (Draughon Moret et al., 2021), fear of HIV PEP side effects (Draughon Moret et al., 2021), interference with daily routine (Abrahams & Jewkes, 2010; Draughon Moret et al., 2021), and that the medications were a daily reminder of the assault (Abrahams & Jewkes, 2010; Draughon Moret et al., 2021; Vetten & Haffejee, 2005, 2008). Perhaps most important for post-sexual assault providers, patients report how difficult it is to make a decision about HIV PEP uptake in the stressful acute post-assault period (Draughon Moret et al., 2021; Vetten & Haffejee, 2008). Patients report discussions regarding potential HIV exposure following sexual assault can cause an emotional response and asked providers to “do more” regarding explaining the realities of daily HIV PEP (Draughon Moret et al., 2021; Vetten & Haffejee, 2008).

HIV PEP for the prevention of HIV transmission is often the only HIV prevention strategy available to people who have experienced sexual violence, and thus must be a top public health priority. However, the inability to ethically conduct randomized controlled trials of HIV PEP efficacy in the context of sexual assault, and the resultant current CDC guidelines, leaves patients and providers without a clear path forward. The purpose of this qualitative descriptive study was to compare information gathered from patients and health care providers regarding their HIV PEP decision making process and priorities to inform future interventions.

Methods

A qualitative descriptive approach with semi-structured individual interviews was used to explore decision making around HIV PEP following sexual violence. All study procedures were approved by the Institutional Review Board of Pennsylvania State University.

Sample

We purposively recruited both patients and providers for this study because their decision-making interacts to influence the other. Providers take into account exam findings, and

sexual assault history to best determine whether the patient is eligible for HIV PEP. Patients' ability to make a decision about HIV PEP uptake is dependent on the providers' decision of whether to offer HIV PEP, (Draughon et al., 2015; Draughon Moret et al., 2021) and if so, how HIV PEP is offered. A sample size of 15 patients who had previously been offered HIV PEP following sexual violence and 9 providers who deliver HIV PEP to patients following sexual violence were recruited for this study. Participants were recruited from June 2019 to August 2021. Participants were recruited via online social media advertising, paper flyers, and emails to community-based sexual violence, HIV, and nursing organizations. Interested people were directed to a preliminary online screening questionnaire that was answered anonymously. The screening determined if the participant was eligible for the study. Eligibility criteria included: age 18 years or older, currently living in the United States, and ability to consent and participate in English. Additionally, providers needed to be currently involved with seeing or consulting with patients in the immediate (<72 hours) post-sexual assault window. Eligible patients needed to have been offered HIV PEP following a sexual assault. No time limitation was put on how long ago the assault and care could have happened for participation in this study. If eligible, participants were asked to provide contact information, review the study consent form, and contacted to schedule the video interview.

Data Collection

Semi-structured in-depth individual interviews were conducted via online video interviews. Interviews were conducted by trained members of the research team; specifically, two nurses and one undergraduate research assistant. During the interviews, participants first reviewed consent materials and had an opportunity to ask questions before data collection began. All participants answered demographic questions including age, sex assigned at birth, gender, and race/ethnicity (Table 1). Providers answered items regarding their training and position within their healthcare facility. Patients were asked about insurance and employment status. The semi-structured interview guide was developed by the first author (JCA) and reviewed by the senior author (JDM). The primary focus of the interview was discussion of sexual assault medical care and HIV PEP provision. Interviews were audio recorded, professionally transcribed through an HIPAA-complaint service, and then further de-identified to prepare for analysis. Considering the infinite complexity and variations in human experience, a comprehensive representation of all possible experiences of HIV PEP provision and uptake is unattainable (Thorne, 2008). Instead, we halted recruitment for study participants once content saturation was achieved, in other words when no new information was heard from already identified (by the researchers or the participants) categories (Saunders et al., 2018). Participants were compensated \$50 for their time participating in the study and provided with a national resource list via email.

Data Analysis

The qualitative analysis software Dedoose Version 9 was used for data analysis (Dedoose, 2021). Thematic analysis approaches as described by Guest and colleagues (2011) were used to analyze the data (Guest et al., 2011). *A priori* questions otherwise known as structural codes were developed prior to data analysis (Saldana, 2021). Data analysis began with one research assistant reading and reviewing all of the transcripts and creating the initial code

book. The code book included a combination of *a priori* and inductive codes. The coders continued to code each unit of meaning with a subsample of interviews from both patients and providers using inductive coding, allowing for new codes to be included in the codebook as they emerged. Once the coders agreed that all codes were identified, they finalized the codebook. Two additional research assistants then checked all transcripts to ensure that all applicable codes were applied. Any discrepancies were discussed at regular weekly team meetings to achieve consensus. Codes were then examined for patterns and relationships and grouped into categories accordingly. Categories were clustered into themes (Cohen et al., 2000). Working together, final themes were compared and contrasted across the two participant groups.

Measures to ensure trustworthiness of the study

Here we summarize the strategies used to ensure the validity of the study using the elements outlined by Guest, MacQueen and Namey (Guest et al., 2011): a) team based interview guide development; b) trained interviewers; c) monitoring of data as they came in; d) transcription of data followed a specific protocol both with the professional transcription service, and subsequent cleaning/deidentification; e) the codebook was developed collaboratively and iteratively; f) multiple coders and assessment of subjective agreement with consensus on final codes; g) external review of coding and themes by the lead and senior authors; h) triangulation between patients and providers; i) and results supported by exemplars from the data to describe the HIV PEP decision making experiences of patient and provider to support transferability of findings. From an ethical perspective, the research was voluntary, and participants had to initiate contact with the research team to ensure that only participants who were willing to participate in the study were interviewed.

Reflexivity Statement—The authors of this study are female researchers from several disciplines interested in mitigating long-term sequelae of sexual violence through timely and evidence based acute post-sexual assault medicoforensic healthcare. We are committed to the tenets of reproductive justice, specifically the right to bodily autonomy. The authorship team is made up of nurse researchers, and team members who assisted in data collection and analysis including undergraduate students preparing for graduate programs in medicine, pharmacy, and neuroscience, and a graduate medical student. Our work is influenced by our gender, race (2 White researchers and 1 Black researcher) and diverse academic discipline experience including focused training in violence etiology, treatment, mental health, and substance use. JCA and JDM further draw upon experiences as post-sexual assault care providers who have grappled with many of the same circumstances recounted by the participants, had similar conversations with colleagues, and navigated HIV risk discussions and HIV PEP provision with our patients. An overall goal of our work is to provide comprehensive medical, emotional, and logistical support for patients following sexual violence.

Results

During the recruitment period 141 people visited the screening website. Of those 50 patients and 32 providers initiated the screening process. Of those who completed the screening, 33

patients and 19 providers were eligible (63% of those who initiated screening), 23 patients and 18 providers shared contact information, and 15 patients and 10 providers participated (61% of those who shared contact information). See Figure 1 for full recruitment details.

Participant Characteristics

Patients received post-sexual assault care in 10 different states. Two thirds of patients were cisgender women ($n= 10, 67\%$), almost a third were cisgender men ($n= 4, 27\%$) and one transgender woman participated. Most were between the ages of 20 and 29 years ($n= 9, 60\%$) and identified as White ($n=8, 60\%$) and non-Hispanic ($n=14, 93\%$). Less than half the sample identified as heterosexual ($n=6, 40\%$), with almost a third identifying as gay or lesbian ($n=4, 27\%$), a fifth identified as bisexual ($n=3, 20\%$) and the remainder identified as heteroflexible or fluid ($n=2, 13\%$). All of the patients had completed high school, with almost three quarters reporting attaining a baccalaureate degree or higher ($n= 13, 72\%$) and the majority reported working either full- ($n=10, 67\%$) or part-time ($n=3, 20\%$). All 15 patients reported having health insurance, with 10 reporting a private insurance carrier (67%), and 5 (33%) reporting a public health insurance plan such as Medicare, Tricare, or Medicaid.

The providers practiced in six different states. Over three-quarters of providers were cisgender female ($n=8, 80\%$) and over the age of 30 ($n=8, 80\%$). The majority identified as White ($n=9, 90\%$) and non-Hispanic ($n=10, 100\%$). Two were Emergency Department physicians, and 8 were Registered Nurses. Eight (80%) worked in a hospital setting, while two (worked in a community setting (e.g. child advocacy center, family justice center, mobile service provider). Most reported working as a healthcare provider for 10–19 years ($n=6, 60\%$) but fewer than 10 years working with sexual assault patients ($n=6, 60\%$). Providers reported a range of training and education specific to working with sexual assault patients. The majority reported completing a 40- hour didactic sexual assault nurse examiner (SANE) training course ($n=8, 80\%$), 9 ($n=9, 90\%$) reported completing 17 or more hours of classroom or continuing education specific to sexual assault, and one reported completing 4 or fewer hours of classroom or continuing education specific to sexual assault. Demographic characteristics of all participants ($n=25$) are summarized in Table 1.

Patient and provider HIV PEP decision making

Our results are presented as four themes reflecting the types of factors patients and providers described surrounding decision making: 1) medical concerns; 2) emotional, trauma and support factors; 3) daily medication management; and 4) ensuring HIV PEP access. While patients and providers each described ways in which each broad theme impacted their decision making, the specific ways in which decisions were made varied between patients and providers. These similarities and differences are described in the subsequent results and Table 2.

Theme 1: Medical concerns—Previous experience, knowledge, and comfort with medical care—both specific to HIV, and care more generally— factored into patients' decision making. Patients' medical concerns were varied, and included side effects, taking

into account personal anecdotes in addition to information from the provider. A patient who had a friend take HIV PEP previously noted:

“I was really, really nervous about the side effects. Yeah. ‘Cause I know someone who had taken them—she was still taking them when I went into the hospital, and she was sick—sick, sick, sick every day—super sick. I was looking at conferences I had coming up and work and weighing out, can I afford to be sick, but then if I—sick for 28 days or a lifetime, potentially, of consequences, so that was it.”
(White Hispanic female)

While a second patient with liver and kidney concerns consulted with her primary care physician prior to deciding whether to initiate PEP:

“Then when it came down to the preventative measures and stuff, I think the only thing I didn’t take was the HIV prophylactic because I have liver and kidney function problems ...I mean the last time I’d done anything that had an adverse effect on my liver and kidneys, I was in liver failure in the hospital...I didn’t wanna do that unless I talked to my doctor first.” (White female)

Despite concerns, patients also noted heavily weighing the potential benefits of HIV PEP – doing everything within their control to prevent a life altering illness. This could be interpreted as taking control of their medical concerns by making the decision to take HIV PEP after not having a choice in the decision to be exposed in the event that their assailant had a current HIV infection.

“I guess I feel like, for me, it was common sense. That’s not something I would want, [HIV] especially because it wasn’t my decision for what happened that night...I wanted to get the medication as soon as possible and complete the cycle so that I would have a lot less likely of a chance of contracting it. (White female)

While patients’ medical concerns related to HIV PEP were influenced by previous life experiences, providers were more focused on routinized provision of standardized information. Providers’ medical concerns were focused on sharing appropriate medical facts related to HIV exposure risk and HIV PEP.

“...we have a decision tree and our documentation packet that looks just like what you’d see, pretty basically, on the CDC website. We talk about the fact that there’s medicine available, what their risk is nationally, and what their risk is locally.”
(White female SANE)

Providers also described a tension between sharing appropriate medical knowledge necessary to make an informed decision about PEP with the desire to not cause patients additional harm or mental burden. In some instances, this can result in a paternalistic desire to shield patients from the detailed risk assessments as described by the provider participant below.

“I’ll go through the risk assessment with them at discharge. Sometimes, it’s just so overwhelming because it is—the risk assessment’s lengthy. It looks scary. I always tell nurses, ‘If someone does not fall within the risk assessment like, you don’t—if you look at that CDC algorithm, and they don’t fall in that, then do not show them

that risk assessment ‘cause it just opens up a whole can of worms.’” (Asian female SANE)

The way providers shared information and patients received information was noted to influence decision making. The decision to take or not take HIV PEP included being presented with new and complicated information; this information could also be presented in ways that increased feelings of fear, guilt, and anxiety. Or perhaps eliminated patients’ ability to feel like taking HIV PEP was a decision they were able to make as highlighted by one provider who noted they had never had a patient decline HIV PEP. One participant who had experienced more than one assault shared two contrasting encounters with providers:

“Even still, as a highly educated upper middle-class person, I was still misguided and felt judged and pushed. It makes me wonder in cases where there’s a language barrier or in cases where maybe they can’t read the handout so well or cases where there’s not the ability to ask questions and to really think critically about it—I felt snowballed. I felt pushed into these interventions and guilted and judged and—and I consider myself fairly lucky. That part also needs to change. Accessibility of information. Because the three-sentence synopsis I got that was in hopes of swaying me one way or another, I was lucky enough to comprehend it and be like, that sounds scary, but also was with it enough and able to think critically about it in the coming days.” (White female)

The patient recalls another discussion where the information was presented in a way that empowered her to make a decision recalling the provider stating:

“You could take them. You could not take them. You’re gonna be okay.” The you’re gonna be okay either way’ was really what struck me” (White female)

Theme 2: Emotional, Trauma, and Support Factors—Patients highlighted factors such as social support, re-traumatization, and stigma as important to their decision making, both initially and in their ability to follow through on a 28-day course of medications. Some providers also recognized the impact of trauma on decision making and the need for structured support for their patients.

The impact of the acute traumatic event and the way information was provided made it difficult for some participants to understand all the information trying to be communicated. This eventually affected their HIV PEP decision. One patient described:

“All of that information just goes in one ear and out the other and “m sure the people that were taking care of me that night meant no harm with trying to be fast paced, with trying to explain everything and get in and get out. That’s just what they have to do in a hospital, but unfortunately, I didn’t remember anything that was told to me afterwards and so, that was definitely one of the most memorable things” (White female)

This information overload that the participant described led to her receiving the HIV PEP prescription in the hospital but never taking the medications as they sat in the bag with the rest of the hospital paperwork after she returned home.

Another participant described her experience with the health care provider as unhelpful to the point of feeling pressured or coerced into her decision:

“I definitely was pressured into taking the prophylactic medications. The doctor came in guns blazing like, ““You do”t know anything about this person. You could get sick and die”“ I was 21, and I was just like, okay.” (White female)

Later in the interview this same participant noted how the interaction with the health care provider about HIV PEP left her feeling further disempowered after an already traumatic set of circumstances,

“...I think I ran into a lot more condescension than empowerment. That’s what I wish I could have known is all of the information in an accessible way with no pressure, like if you could present the information without presenting it with your opinion.” (White female)

Participants also identified the importance of support persons in their HIV PEP decision making and adherence. Support was received from partners, relatives, friends, coworkers whom they were able to disclose to and took the form of encouragement to take the medication, supporting their decisions to not take the medications, and reminders to complete the full 28 days. One participant described her grandmother reminding her to take her PEP:

“My grandmother was. She would call me and she would be like, ‘Oh, I’m gonna take my medicines. You take your medicines.’ She would be like my pill popping buddy. [Chuckles] That’s what I called her, my pill popping buddy.” (Black, trans woman)

Providers noted the challenges of communicating information to patients during an acute traumatic event and presented a variety of strategies for navigating these conversations (see Table 2 for an exemplar). Examples included introducing the decision early in the post-sexual assault care encounter to allow patients time to process and ask questions and using therapeutic communication techniques (for example sitting on a chair below the level of the patient). The fact that there was no one “right way” for approaching the conversation of HIV PEP also came through as providers spoke of tailoring their conversion to the age, education level, and verbal and nonverbal feedback they were receiving from the patient. These provider strategies were contrasted by the message from patients that even when they described providers as kind and well-meaning, they also noted opportunities for providers and health care systems to be better at sharing information in ways patients wanted it and ensuring that their concerns (both in the moment and for the entire 28 days of medication) were addressed.

Theme 3: Daily Medication Management—Daily medication management included barriers and facilitators for patients and that impacted their HIV PEP decision making process. To facilitate success with medication completion, patients shared strategies such as use of daily alarms, apps, or integration with other daily routines or medications.

“I put those HIV pills next to my other daily medications. Definitely, seeing that new bottle there reminded me like, ‘Oh, this is an important new one. I should take

all my medication right now before stepping out of my room.' I did." (Multiracial female)

The trauma and stigma associated with sexual violence and/or HIV led some patients to hide the HIV PEP medications from the people around them. Patients described specific and detailed ways they could incorporate taking medications into their daily lives while not disclosing their assault or the fact that they were taking HIV PEP to their friends, partners, or roommates.

One thing I ensured was if I took those medications, I would never leave them out in the open, 'cause then if people see them, then they might make up some perceptions about me. What I did was I took a bottle of the normal painkillers, and then I filled the medicine, the [emtricitabine/tenofovir], in that bottle, so that people would think that it was just some normal painkiller. (Asian male)

Patients who were unable to integrate the medications into their daily lives due to stress, trauma, or side effects were noted within our data to be those who stopped taking HIV PEP before completing all 28 days. This included patients who stopped taking medications due to entirely controllable side effects such as nausea and vomiting, that patients simply did not know where or how to address; and more complex concerns such as a patient who never took a dose of medications after leaving the hospital because of a depressive episode that eventually required hospitalization.

Theme 4: Ensuring HIV PEP Access—Providers spoke at length about the challenges in ensuring seamless and timely access to HIV PEP for patients. These challenges appeared to be roughly divided between individual/institutional barriers—issues that might be corrected with educational-type interventions—and larger more structural barriers—things that will likely necessitate local, state, or federal policy changes. We present findings from each rough category in turn, noting that individual and institutional practices are deeply embedded in and influenced by the policy and regulatory landscape.

Individual/Institutional Level Challenges.: Providers noted that communication and workflows in their setting could impact the ease of the HIV PEP decision making process. On one hand, policies with multiple forms, payers, steps, and moving parts, made the process more challenging and decreased the likelihood that a provider would be able to complete the required steps to prescribe HIV PEP for the patient (especially in the 72-hour window they were acutely cognizant of). While policies that streamlined ordering, allowed for ease of medication delivery (e.g., on site pharmacies or medication samples for dispensing), and increased knowledge and communication between SANEs, ED physicians, pharmacists and advocates were seen as helpful.

Notably, despite CDC guidance on HIV PEP (Centers for Disease Control and Prevention, 2016) and recommendations from the U.S. Department of Justice, Association of Nurses in AIDS Care, and the International Association of Forensic Nurses (Association of Nurses in AIDS Care et al., 2014; Littel, 2013) which stipulate HIV PEP should be discussed with *all* post-sexual assault patients regardless of exposure, providers reported that they or their co-workers were not consistent in discussing HIV PEP as recommended. Reasons for this

inconsistency varied: whether due to provider lack of knowledge, or providers' personal belief that patients should not be making this decision if they were not deemed at "high risk" of HIV from their unique sexual assault exposure. One provider recalled a supervisor's recommendation for discussing HIV with patients:

"Her whole belief was, not every patient should be told about this because there's too much trauma, and there's too much going on in their brain, and they don't have the capacity to get all that information. I'm like, I get that, but that's not our job to decide who gets this information and who doesn't. It's not fair." (Asian female SANE)

The same provider noted her co-workers regularly displayed insufficient HIV PEP knowledge:

"There's just a lot of misinformation even among medical staff, nursing staff, a lot that's unknown. People don't even know what HIV PEP is. I'll get charge nurses that are like, "I don't know what that is. Tell me what it is." I've had doctors who called me and are really great, were just like, "Tell me what to do. I want to do the right thing." Then some who are just like, "This isn't my job." Yeah. Like I said, there's just all these gray areas, and it makes it hard to do the work sometimes." (Asian female SANE)

Structural Barriers to HIV PEP: Providers detailed structural barriers in getting HIV PEP medications to patients. Specific challenges described included insurance preauthorization requirements, drug company requirements, and medication dispensing requirements (e.g. who can dispense samples, dispensing "take home" medications from Emergency Departments), and hospitals or pharmacies not routinely stocking HIV PEP medications. To overcome these challenges, providers described complex and sometimes multilevel interventions they participated in. For eligible patients, providers took time to assist patients in completing drug company payment assistance paperwork during their already stressful acute post-sexual assault ED visit. Providers also described spending significant time partnering with local or in house pharmacies to ensure a sufficient stock of HIV PEP medications or creating alternate billing and delivery procedures with partner pharmacies to ensure HIV PEP could be obtained same day. Similarly, some providers maintained official and "unofficial" supplies of HIV PEP medications to supply patients who may be in need and reaching the end of their 72-hour window or unable to fill a prescription after discharge. Finally, providers worked to ensure that bills were not sent to patients but instead to drug company assistance plans, or hospital charity plans when declined by insurance providers. Box 1 provides an exemplar describing the challenges that providers and patients may navigate. Another provider described their experience working with a drug company patient assistance program and how the time needed to complete this extra work for one patient impacted their other patients and the provider's life:

"If you have to go through the drug companies, and you don't have the patients fill out the correct information, if they don't sign the bottom of the form, they have to come back in, re-sign the form, or fill out the form again. Then, just going through the drug companies' process to get the medication is a struggle....It's very

frustrating when you have either other patients in the Department, or you have other things going on during the day or the evening, and you're on the phone for two to four hours with drug companies trying to figure out how to get this patient medication." (White female SANE)

Another provider shared their frustration and time expended in attempting to work with the state's crime victim compensation fund:

"Once, it took up to eight hours to get that approved, because every time I turned in a piece of paper, "Oh, well, you forgot to cross this 'T.' You didn't dot this 'I' in the right location." It's never the same, so we deliver the medicine, we charge the state of [state], and it's done." (White female SANE)

It cannot be overstated that a post-sexual assault exam is already an incredible expenditure of provider time and energy. Time spent navigating byzantine paperwork is time that could be spent providing expert care to other patients.

Physical access to the medications was also a concern for providers who recognized that not all pharmacies carry HIV PEP.

"It does become complicated if they say, for instance, they live two hours away or whatever and they want a medication billed to a pharmacy near them...The complication we have with that is that not all pharmacies carry the medications. Sometimes we end up calling 10 or 15 places before we find a pharmacy in the area that will have the medicine." (White female SANE)

In addition to initial decision making, providers noted that policies and procedures preventing dispensing a full 28-day prescription were additional barriers to access and hindered adherence.

"...the most difficult ones were when we were givin' the five-day starter pack. The prescriptions or—and you can't put the onus of the work on these patients. This population, I realize that you said follow-up is hard, but these gals follow-up—they cope by avoiding. Telling them you have to do this, you have to do that, you have to do this, and making a lot of hoops for them to jump through, they just didn't do it. We had lots of fails where people didn't call, and then they'd call a week out, sayin', "Oh, I ran out of meds two days ago, and I don't have the money. I mean, just that. That was just miserable. It didn't happen just once." (White female SANE)

In contrast, patients in this sample spoke nearly universally about HIV PEP access and cost not being issues in their personal circumstances.

"The hospital provided them. I just had to sign the consent form saying that I was taking them home. I didn't have to pay for anything. They didn't even ask me for any of my insurance or anything like that." (White female)

While patients noted that costs in their personal circumstances were covered, they did note that there were systems and people in place to facilitate this - without which their outcomes may have been different.

“I didn’t even think about it [cost]...Well I guess the advocate did—she told me about the crime victim’s fund and that whatever my insurance didn’t cover, they would cover, so I think that’s why I didn’t think about it. I didn’t worry about it too much because I figured I was covered some way.” (White female)

Discussion

This qualitative study explored the HIV PEP decision making process among patients and providers following sexual violence. Our findings highlight differences between patient and provider priorities in HIV PEP. With respect to medical concerns, prior experience with both HIV and non-HIV related care factored into patient and provider decision making. Patients highlighted the importance of social support, stigma, and therapeutic communication in deference to the impact of their emotional state on HIV PEP decision making. Patients and providers both noted “real life” concerns that impacted decision making such as having to take daily medications or facilitating decision making in a busy ED. Finally, providers discussed—at length—factors such as lack of physical access and costs of care, while patients made little to no mention of these factors. Providers recounted multiple structural barriers within the medical system that pose challenges for post-sexual assault patients in accessing HIV PEP.

Our major contribution to the literature is the providers’ perspective detailing the logistical and access barriers that must be navigated to ensure timely access to HIV PEP for post-sexual assault patients. While some work has been done in Canada (Du Mont et al., 2011), and at a single community-based program in the Midwestern U.S. (Djelaj et al., 2017) our study represents a diverse sampling of providers from various U.S. locations demonstrating the widespread challenges in HIV PEP provision.

Our findings regarding the inordinate provider time and commitment to provide HIV PEP to patients within the time frames required are similar to concerns and barriers noted in a mixed methods study of HIV PEP provision sustainability conducted in multiple programs in a single province in Canada (Du Mont et al., 2011). Similar to our findings, Du Mont and colleagues’ (2011) sample of providers described overworked providers, inadequate support for protocols and workflows, variations in HIV PEP knowledge and training, and lack of institutional support as barriers to sustainable provision of HIV PEP to patients post-sexual assault. In their qualitative study at a single community-based program in the Midwestern U.S. Djelaj and colleagues (2017) describe providers’ challenges with attaining a prescription (in the event that the clinic providing post-sexual assault care was not themselves a prescriber) from prescribers without adequate knowledge of HIV risk following sexual assault. They similarly described some of the same challenges patients faced in obtaining the physical medications, for example, concerns over whether local pharmacies stocked HIV PEP medications. While the patients interviewed in our sample appeared largely unaware of the behind-the-scenes efforts of providers to get HIV PEP in a timely manner. Prior research has found that cost of the medications impacts whether patients initiate and adhere to HIV PEP following sexual assault (Babl et al., 2000; Diniz et al., 2007; Draughon Moret et al., 2021), and those who have insurance are more likely to complete HIV PEP (Malinverni et al., 2018).

We also found that patients' stated medical concerns were dependent on prior knowledge and health care experiences. Prior research supports that patients may not be aware of the risk of HIV following a sexual assault exposure (Djelaj et al., 2017; Draughon Moret et al., 2021; Resnick et al., 2002) or aware that HIV PEP is an available prevention modality (Kilonzo et al., 2008). Patients in our sample also considered medication side effects in their HIV PEP decision-making. Concerns about medication side effects have been found in most studies of HIV PEP following sexual assault, both those that interviewed patients directly (Abrahams & Jewkes, 2010; Draughon Moret et al., 2021; Vetten & Haffejee, 2005, 2008), and those that included provider or medical record level data (Inciarte et al., 2020; Krause et al., 2014; Loutfy et al., 2008).

Providers in this study appeared to largely base their decision to offer PEP on medical concerns such as HIV risk transmission. They described framing the HIV risk and PEP discussion based on aggregate risk statistics vs its perceived benefits, in the context of concerns for the patient's emotionally activated state. This is similar to a study where providers discussed offering PEP based on HIV transmission risk, but couched their recommendations to patients in terms of "peace of mind" and mitigating emotional distress (Djelaj et al., 2017). Patients in our study described the impact that making a decision during a time of acute trauma had on their ability to adhere to a prescribed medication regimen. Similar results have been found in other qualitative research studies in the U.S. (Draughon Moret et al., 2021) and sub-Saharan Africa (Abrahams & Jewkes, 2010). Several also described how support from friends, family, professional sexual violence advocates, and health care providers made the decision and subsequent recovery less traumatic. Higher perceived social support has been associated with quicker recovery after an assault (Borja et al., 2006; Frazier et al., 2004).

Some patients shared the difficulty of taking HIV PEP for 28 days and the daily reminder of the trauma they experienced while taking the medications. Similar emotional reactions to taking HIV PEP have been reported in other studies where the authors suggested appropriate emotional preparation and support to the patients (Abrahams & Jewkes, 2010; Draughon Moret et al., 2021; Vetten & Haffejee, 2005, 2008). This concern has also been acknowledged by providers in a previous study (Djelaj et al., 2017), but was not raised by providers in our sample. This incongruency between patients and providers regarding how patients manage 28 days of HIV PEP (e.g., when do they take the pills in a safe and private way, who do they tell about the medications, and what do they do if they have side effects) represents an opportunity for providers and systems to improve their communication and follow up with patients.

Providers in the sample noted ways in which their own institutions allowed or did not allow for trauma-informed practices related to HIV PEP decision making and prescribing. However, providers who share information on follow up options noted they were not officially able to provide follow up of more than a single phone call—usually in the first days or week following an acute sexual assault visit. Recent guidelines from New York State (McGowan et al., 2022) outline the difficulties patients may have making a time-bound decision to initiate PEP and recommend providers give patients the first dose of HIV PEP

as soon as possible and then allow patients to take the next 12–24 hours (depending on HIV PEP regimen) to make their decision for the remaining 27 days of the PEP regimen.

Implications for Practice

Two overarching priority areas for practice implications were highlighted through our findings: 1) The need for systemic changes to make access to medications an easier process for providers to navigate on behalf of their patients; and 2) the discordance between patients and providers in defining and weighing priorities during a period of acute trauma.

Systemic changes to allow access—Despite multiple recommendations in favor of HIV risk discussion (Association of Nurses in AIDS Care et al., 2014; Littel, 2013) and HIV PEP provision (Association of Nurses in AIDS Care et al., 2014; Centers for Disease Control and Prevention, 2016; World Health Organization & International Labour Organization, 2007), there remain substantial gaps in healthcare facilities and providers being able to provide access to HIV PEP medications to patients in a way that the providers we interviewed felt was necessary for patients to actually obtain and take the medications. Barriers discussed were systemic and multilevel. Ranging from federal, state, and local policies around prescribing and dispensing medications to challenges with finding a pharmacy that stocked the medication, and accepted the payment types available to the patient, and was within a distance the patient could travel to obtain the prescription, to the myriad challenges with payment and reimbursement discussed that providers in this sample noted fell back to them to manage if they wanted patients to be able to access the medications.

The lengths that providers went to while attempting to ensure their patients had access to HIV PEP demonstrate incredible dedication to trauma-informed and evidence-based care given the information available to us on processing trauma and completion of the medications when patients are given the entire 28 day supply vs a prescription or starter pack (Ford et al., 2015). It also aligns with some of the data we heard in our own sample from patients who noted that the acute care encounter itself was largely forgotten and that written information provided was never read. Ensuring that patients who are appropriate for and would like HIV PEP have the 28-day supply in hand prior to leaving the acute care visit or that arrangements for delivery have been made by the care team so that a patient does not need to take on these complex tasks is one important intervention that the healthcare system can undertake to improve HIV PEP completion rates.

While all patients in our sample were recruited specifically because they were offered HIV PEP, the narratives given by providers about the lengths they went to ensure patients could access the medications were at times extraordinary. This work should not fall on the shoulders of individual providers leading sexual assault examiner programs. Payers (e.g. insurance companies, criminal justice funds, pharmaceutical companies) should consider establishing more streamlined mechanisms for approval of and ensuring dispensing of these medications to patients who have experienced sexual assault. While outside the purview of this particular study, prior work has noted cost and access to be barriers to patients

obtaining HIV PEP following sexual assault in the United States (Draughon & Sheridan, 2012; Draughon, 2013; Draughon et al., 2014, 2015; J. E. Draughon Moret et al., 2021).

On an individual level, the medical concerns and priorities patients described were not the same as those described by providers. Patient concerns were wide ranging, while providers were primarily concerned with providing medically accurate information. While providing accurate information is important, perhaps providers could better tailor their HIV PEP discussion to address patients' fears about side effects and strategies for managing the medications on a day-to-day basis.

Limitations

In our sample, all patients sought and received care following sexual assault. We know that the majority of people who experience sexual assault do not seek care for the assault (Thompson & Tapp, 2022). Our sample also actively chose to reach out and participate in a study about sexual assault and HIV PEP based on online advertising. There may be selection bias among those who chose to participate and those who did not, with patients who faced barriers to care, were less satisfied with care, or were unable to access all aspects of not participating in a study advertised as about “care after sexual assault” or “being offered HIV medications after sexual assault”. This likely influenced the fact that our sample, like other samples from clinical and non-clinical settings of people who sought care after sexual assault, was well educated, employed, and insured (Draughon Moret et al., 2023; Draughon Moret et al., 2021; Du Mont et al., 2008; Lechner et al., 2021).

Similarly, while interviewing primarily SANEs in our provider group, we are likely failing to capture the “typical” experience for people seeking sexual assault care in the United States given the small number of SANEs (approximately 2,320; [(International Association of Forensic Nurses, n.d.-b, n.d.-a)]) to Emergency Departments (3,000. [(“Stats. AHA Services Survey: Gainers, Losers.,” 1999)]) and estimated sexual assaults annually (300,000, [(Department of Justice, 2017)]). Lastly, among the patients in our sample, there is a chance that recall bias influenced the responses as some of them had experienced the sexual assault years before their participation in the study as a defined time limit on when the assault happened was not enforced in our inclusion criteria for this study.

Conclusion

Taking HIV PEP following a sexual assault today is a complex process that requires the coalescence of patient and provider knowledge, beliefs, and abilities. We found that while several themes overlap between patient and provider decision making, the nuance in both how patients and providers talk about these themes and the *importance* they place on each varied between the two groups. Providers largely focused on providing medically accurate recommendations in a way that felt non-judgmental while simultaneously addressing the many technical and logistical challenges to acquiring the medications for their patients. Patients on the other hand focused on how taking medications would impact their daily lives—side effects, the daily reminder of taking HIV medication every day for 28 days, or the challenges of integrating new medications into their lives while also not disclosing the assault to those closest to them. It is imperative that clinicians recognize and address

the perspectives and needs of patients regarding HIV PEP decision making to best serve patients.

Acknowledgements:

The authors would like to thank the study participants who shared their experiences with HIV PEP and to the following research team members who helped with aspects of data collection and analysis: Morgan Decker, Brookelin Hoard, Brianna Lockwood, & Gabrielle Peruggia. Preliminary results from this study were previously presented at the Eastern Nursing Research Society Conference and internally at the Pennsylvania State University Colleges of Nursing and Medicine. Final results were presented at the International Conference on Forensic Nursing Research and Practice.

Funding:

Research reported in this publication was funded by International Association of Forensic Nurses Research Grants (PI: Anderson) and the National Institutes of Alcohol Abuse and Alcoholism (K23AA027288; PI: Anderson). The content is solely the responsibility of the authors and does not necessarily represent the official views of their employers or the funders.

References

- Abrahams N, & Jewkes R (2010). Barriers to post exposure prophylaxis (PEP) completion after rape: a South African qualitative study. *Culture, Health & Sexuality*, 12(5), 471–484. 10.1080/13691050903556316
- Association of Nurses in AIDS Care, International Association of Forensic Nurses, National Alliance to End Sexual Violence, & National Sexual Violence Resource Center. (2014). Position on Universal Access to Anti-HIV Medication. *The Journal of the Association of Nurses in AIDS Care*, 25(1 Suppl), S104–S106. 10.1016/j.jana.2013.10.004 [PubMed: 24536100]
- Babl FE, Cooper ER, Damon B, Louie T, Kharasch S, & Harris JA (2000). HIV postexposure prophylaxis for children and adolescents. *The American Journal of Emergency Medicine*, 18(3), 282–287. 10.1016/s0735-6757(00)90123-2 [PubMed: 10830685]
- Borja SE, Callahan JL, & Long PJ (2006). Positive and negative adjustment and social support of sexual assault survivors. *Journal of Traumatic Stress*, 19(6), 905–914. 10.1002/jts.20169 [PubMed: 17195986]
- Cardo DM, Culver DH, Ciesielski CA, Srivastava PU, Marcus R, Abiteboul D, Heptonstall J, Ippolito G, Lot F, McKibben PS, & Bell DM (1997). A case-control study of HIV seroconversion in health care workers after percutaneous exposure. *Centers for Disease Control and Prevention Needlestick Surveillance Group. The New England Journal of Medicine*, 337(21), 1485–1490. 10.1056/NEJM199711203372101 [PubMed: 9366579]
- Centers for Disease Control and Prevention. (2016). Updated guidelines for antiretroviral postexposure prophylaxis after sexual, injection drug use, or other nonoccupational exposure to HIV—United States, 2016. <https://www.cdc.gov/hiv/pdf/programresources/cdc-hiv-npep-guidelines.pdf>
- Cohen MZ, Kahn DL, & Steeves RH (2000). *Hermeneutic Phenomenological Research*. Sage Publications, Inc.
- Dedoose. (2021). Dedoose, web application for managing, analyzing, and presenting qualitative and mixed method research data (9.0.17) [Computer software]. SocioCultural Research Consultants, LLC.
- Department of Justice. (2018). National Crime Victimization Survey, 2016. Office of Justice Programs, Bureau of Justice Statistics. <https://bjs.ojp.gov/content/pub/pdf/cv16re.pdf>
- Diniz NMF, de Almeida LCG, dos S Ribeiro BC, & de Macêdo VG (2007). Women victims of sexual violence: adherence to chemoprevention of HIV. *Revista Latino-Americana de Enfermagem*, 15(1), 7–12. 10.1590/s0104-11692007000100002 [PubMed: 17375226]
- Djelaj V, Patterson D, & Romero CM (2017). A qualitative exploration of sexual assault patients' barriers to accessing and completing HIV prophylaxis. *Journal of Forensic Nursing*, 13(2), 45–51. 10.1097/JFN.000000000000153 [PubMed: 28525428]

- Draughon Jessica E, Anderson JC, Hansen BR, & Sheridan DJ (2014). Nonoccupational postexposure HIV prophylaxis in sexual assault programs: a survey of SANE and FNE program coordinators. *The Journal of the Association of Nurses in AIDS Care*, 25(1 Suppl), S90–S100. 10.1016/j.jana.2013.07.001 [PubMed: 24103741]
- Draughon Jessica E, Hauda WE, Price B, Rotolo S, Austin KW, & Sheridan DJ (2015). Factors Associated With Forensic Nurses Offering HIV nPEP Status Post Sexual Assault. *Western Journal of Nursing Research*, 37(9), 1194–1213. 10.1177/0193945914530192 [PubMed: 24733232]
- Draughon Jessica E, & Sheridan DJ (2012). Nonoccupational postexposure prophylaxis following sexual assault in industrialized low-HIV-prevalence countries: a review. *Psychology, Health & Medicine*, 17(2), 235–254. 10.1080/13548506.2011.579984
- Draughon Jessica Eileen. (2013). HIV non-occupational post-exposure prophylaxis following sexual assault: Program and patient characteristics and protocol adherence. [Doctoral dissertation]. Johns Hopkins University.
- Draughon Jessica E. (2012). Sexual assault injuries and increased risk of HIV transmission. *Advanced Emergency Nursing Journal*, 34(1), 82–87. 10.1097/TME.0b013e3182439e1a [PubMed: 22313905]
- Draughon Moret J, Choe L, & Anderson JC (2023). Psychosocial health factors among men reporting recent sexual assault. *Journal of Forensic Nursing*. 10.1097/JFN.0000000000000428
- Draughon Moret JE, Sheridan DJ, & Wenzel JA (2021). “Reclaiming Control” Patient Acceptance and Adherence to HIV Post-Exposure Prophylaxis Following Sexual Assault. *Global Qualitative Nursing Research*, 8, 23333936211046580. 10.1177/23333936211046581
- Du Mont J, Macdonald S, Myhr T, & Loutfy MR (2011). Sustainability of an HIV PEP Program for Sexual Assault Survivors: “Lessons Learned” from Health Care Providers. *The Open AIDS Journal*, 5, 102–112. 10.2174/1874613601105010102 [PubMed: 22216082]
- Du Mont J, Myhr TL, Husson H, Macdonald S, Rachlis A, & Loutfy MR (2008). HIV postexposure prophylaxis use among Ontario female adolescent sexual assault victims: a prospective analysis. *Sexually Transmitted Diseases*, 35(12), 973–978. 10.1097/OLQ.0b013e3181824f3c [PubMed: 18836390]
- Edinburgh L, Pape-Blabolil J, Harpin SB, & Saewyc E (2014). Multiple perpetrator rape among girls evaluated at a hospital-based child advocacy center: seven years of reviewed cases. *Child Abuse & Neglect*, 38(9), 1540–1551. 10.1016/j.chiabu.2014.05.008 [PubMed: 24933707]
- Ford N, Venter F, Irvine C, Beanland RL, & Shubber Z (2015). Starter packs versus full prescription of antiretroviral drugs for postexposure prophylaxis: a systematic review. *Clinical Infectious Diseases*, 60 Suppl 3, S182–6. 10.1093/cid/civ093 [PubMed: 25972501]
- Frazier P, Tashiro T, Berman M, Steger M, & Long J (2004). Correlates of levels and patterns of positive life changes following sexual assault. *Journal of Consulting and Clinical Psychology*, 72(1), 19–30. 10.1037/0022-006X.72.1.19 [PubMed: 14756611]
- Guest GS, MacQueen KM, & Namey EE (2011). *Applied Thematic Analysis* (1st ed., p. 320). SAGE Publications, Inc.
- Inciarte A, Leal L, Masfarre L, Gonzalez E, Diaz-Brito V, Lucero C, Garcia-Pindado J, León A, García F, & Sexual Assault Victims Study Group. (2020). Post-exposure prophylaxis for HIV infection in sexual assault victims. *HIV Medicine*, 21(1), 43–52. 10.1111/hiv.12797 [PubMed: 31603619]
- International Association of Forensic Nurses. (n.d.-a). IAFN-Certified Nurses (SANE-A). Retrieved March 23, 2022, from <https://www.forensicnurses.org/page/SANE-A/>
- International Association of Forensic Nurses. (n.d.-b). IAFN-Certified Nurses (SANE-P). Retrieved March 23, 2022, from <https://www.forensicnurses.org/page/SANE-P/>
- Kilonzo N, Taegtmeier M, Molyneux C, Kibaru J, Kimonji V, & Theobald S (2008). Engendering health sector responses to sexual violence and HIV in Kenya: results of a qualitative study. *AIDS Care*, 20(2), 188–190. 10.1080/09540120701473849 [PubMed: 18293127]
- Krause KH, Lewis-O’Connor A, Berger A, Votto T, Yawetz S, Pallin DJ, & Baden LR (2014). Current practice of HIV postexposure prophylaxis treatment for sexual assault patients in an emergency department. *Women’s Health Issues*, 24(4), e407–12. 10.1016/j.whi.2014.04.003 [PubMed: 24981399]

- Lechner M, Bell K, Short NA, Martin SL, Black J, Buchanan JA, Reese R, Ho JD, Reed GD, Platt M, Riviello R, Rossi C, Nouhan P, Phillips C, Bollen KA, & McLean SA (2021). Perceived Care Quality Among Women Receiving Sexual Assault Nurse Examiner Care: Results From a 1-Week Postexamination Survey in a Large Multisite Prospective Study. *Journal of Emergency Nursing*, 47(3), 449–458. 10.1016/j.jen.2020.11.011 [PubMed: 33516463]
- Littel K (2013). A National Protocol for Sexual Assault Medical Forensic Examinations: Adults/Adolescents Second Edition. <https://www.ojp.gov/pdffiles1/ovw/228119.pdf>
- Loutfy MR, Macdonald S, Myhr T, Husson H, Du Mont J, Balla S, Antoniou T, & Rachlis A (2008). Prospective cohort study of HIV post-exposure prophylaxis for sexual assault survivors. *Antiviral Therapy*, 13(1), 87–95. DOI: 10.1177/135965350801300109 [PubMed: 18389902]
- Malinverni S, Gennotte A-F, Schuster M, De Wit S, Mols P, & Libois A (2018). Adherence to HIV post-exposure prophylaxis: A multivariate regression analysis of a 5 years prospective cohort. *The Journal of Infection*, 76(1), 78–85. 10.1016/j.jinf.2017.10.008 [PubMed: 29074102]
- McCormack D, & Koons K (2019). Sexually Transmitted Infections. *Emergency Medicine Clinics of North America*, 37(4), 725–738. 10.1016/j.emc.2019.07.009 [PubMed: 31563204]
- McGowan JP, Fine SM, Vail R, Merrick ST, Radix A, Hoffman CJ, & Gonzalez CJ (2022). Post-Exposure Prophylaxis (PEP) to Prevent HIV Infection. New York State Department of Health AIDS Institute.
- Miller T, Fulton D, & Lee D (2018). The Cost and Consequences of Sexual Violence in California. California Coalition Against Sexual Assault. https://www.calcasa.org/wp-content/uploads/2018/02/CALCASA_CCoSV_FINALSpreads_2018.pdf
- Otten RA, Smith DK, Adams DR, Pullium JK, Jackson E, Kim CN, Jaffe H, Janssen R, Butera S, & Folks TM (2000). Efficacy of postexposure prophylaxis after intravaginal exposure of pig-tailed macaques to a human-derived retrovirus (human immunodeficiency virus type 2). *Journal of Virology*, 74(20), 9771–9775. 10.1128/jvi.74.20.9771-9775.2000 [PubMed: 11000253]
- Resnick H, Monnier J, Seals B, Holmes M, Nayak M, Walsh J, Weaver TL, Acierno R, & Kilpatrick DG (2002). Rape-Related HIV Risk Concerns Among Recent Rape Victims. *Journal of Interpersonal Violence*, 17(7), 746–759. 10.1177/0886260502017007003
- Saldana J (2021). *The Coding Manual for Qualitative Researchers* (Fourth, p. 440). SAGE Publications Ltd.
- Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, Burroughs H, & Jinks C (2018). Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality & Quantity*, 52(4), 1893–1907. 10.1007/s11135-017-0574-8 [PubMed: 29937585]
- Stats. AHA services survey: gainers, losers. (1999). *Materials Management in Health Care*, 8(10), 56.
- Thompson A, & Tapp S (2022). *Criminal Victimization, 2021* (No. 305101; Criminal Victimization). Bureau of Justice Statistics. <https://bjs.ojp.gov/library/publications/criminal-victimization-2021>
- Thorne S (2008). *Interpretive Description*. Left Coast Press, Inc.
- Tsai CC, Follis KE, Sabo A, Beck TW, Grant RF, Bischofberger N, Benveniste RE, & Black R (1995). Prevention of SIV infection in macaques by (R)-9-(2-phosphonylmethoxypropyl)adenine. *Science*, 270(5239), 1197–1199. 10.1126/science.270.5239.1197 [PubMed: 7502044]
- Vetten L, & Haffeejee S (2005). Factors affecting adherence to post-exposure prophylaxis in the aftermath of sexual assault: Key findings from seven sites in Gauteng Province (pp. 1–34). Gauteng Department of Health. <http://www.csvr.org.za/docs/gender/factorsaffectingadherence.pdf>
- Vetten L, & Haffeejee S (2008). Supporting rape survivors in adhering to post-exposure prophylaxis (PEP) to prevent HIV infection: The importance of psychosocial counselling and support. *Southern African Journal of HIV Medicine*, 31, 24–33.
- Wieczorek K (2010). A forensic nursing protocol for initiating human immunodeficiency virus post-exposure prophylaxis following sexual assault. *Journal of Forensic Nursing*, 6(1), 29–39. 10.1111/j.1939-3938.2010.01062.x [PubMed: 20201913]
- World Health Organization, & International Labour Organization. (2007). Post-exposure prophylaxis to prevent HIV infection : Joint WHO/ILO guidelines on post-exposure prophylaxis (PEP) to prevent HIV infection. World Health Organization. <https://apps.who.int/iris/handle/10665/43838>

Box 1.

Example of provider navigation of HIV PEP access challenges

Interviewee: It's crazy. We sent a patient—a nurse sent a patient there. The ED director—I was gonna say his name—the ED director ended up calling [County] Health Care Agency, [county] Department of—the Health Department of [county], complaining. It went full circle to [doctor], who was headed into an airplane, and he said—he was like, “Oh, call [name] She'll help you.” He called me. I was like, “Oh, yeah. Let me tell you why it went back to me.” He was like, “I don't think this is our issue. This isn't—” and I'm like, “So what do you expect me to do if it's 9:00 at night on a Friday? I'm gonna tell that patient, 'You're just gonna have to wait until Monday.'”

Interviewer: I'm sorry. You don't get these medications because 72 hours expires on Saturday, and there's nobody open. Sorry.

Interviewee: Yeah. There have been times when I've called [hospital] to take a patient, and they're even baffled where they're like, “But you're in [another hospital]. Why are you sending them to another hospital?” Sometimes, I'll just be really frank to the charge nurse. I'm all, “Because they're assholes over here, and I need this patient to be helped.” They're like, “Okay. Bring 'em over.” Then I have to explain to this poor patient, “I have to send you—”

Interviewer: Why you're getting them in a car and sending them someplace else.

Interviewee: Sometimes, most of the time—I'd say 50 percent of the time maybe, they're transported by law enforcement. Then I have to convince law enforcement to be willing like, “Can you just please?” Sometimes, they'll say no. Then I'll have to call watch commander and say, “This is the situation,” and then they'll have to—and then I'm not liked for that reason 'cause I'm a little tattletale.

White female SANE

Key Considerations

- Patient and provider HIV PEP decision making factors do not always align.
- Patients focus on the impact of the medications on their life including: their ability to prevent HIV, the side effects they would or did face, the challenges of integrating a medication into their life for 28 days.
- Providers' decision making was shared as a multistep process: ensuring the patient met CDC criteria, then sharing risk and benefit information related to HIV PEP.
- Providers also described several structural barriers impacting their ability to offer HIV PEP to patients.

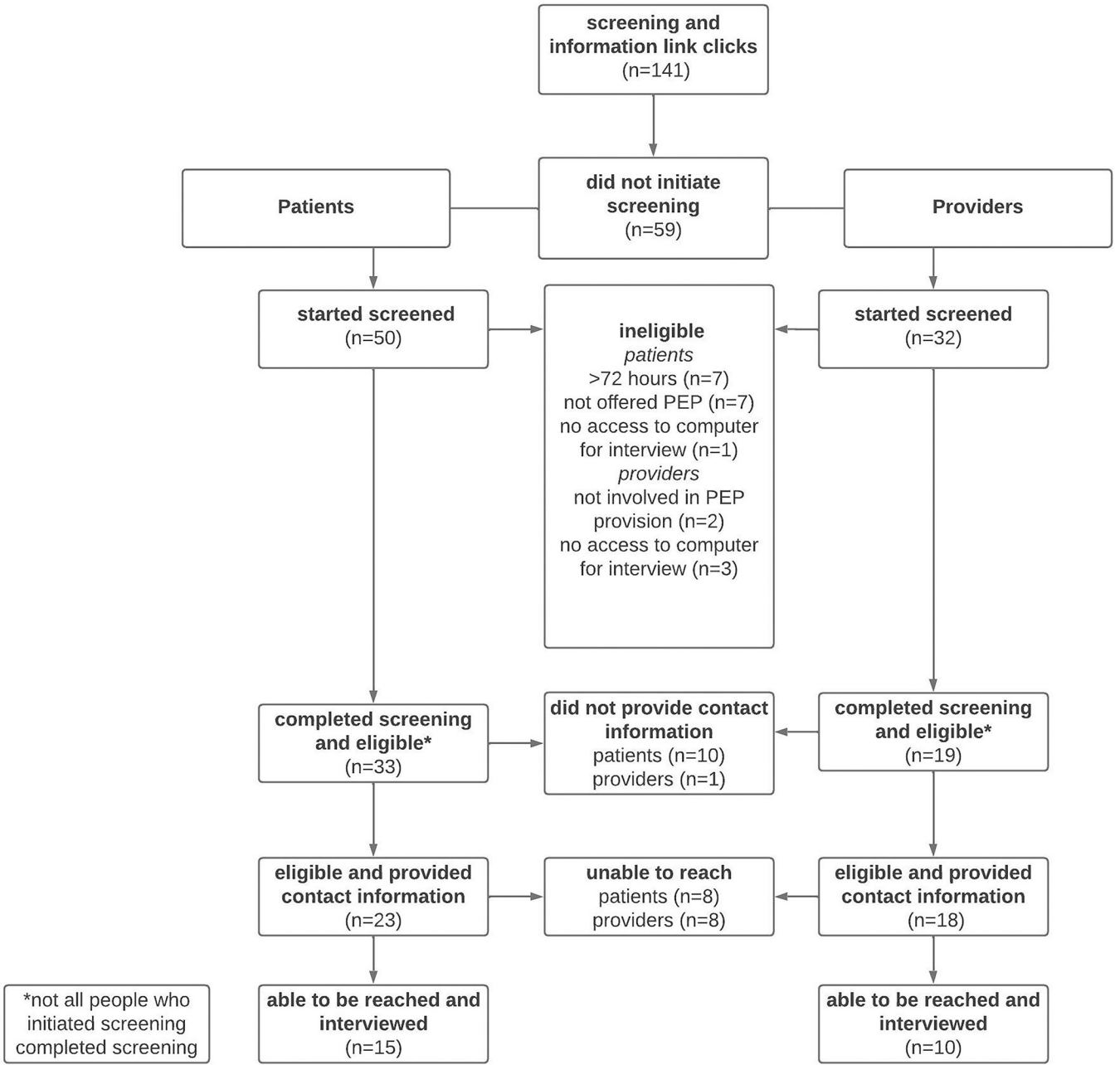


Figure 1. Enrollment and participation flow diagram

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 1:

Patient and Provider Demographics

	Patients (<i>n</i> = 15)		Providers (<i>n</i> = 10)	
	%	n	%	n
Gender				
Cisgender Male	27	4	20	2
Cisgender Female	67	10	80	8
Transgender Female	7	1	0	0
Age (years)				
20–29	60	9	20	2
30–39	20	3	40	4
40+	20	3	40	4
Race				
Black or African American	27	4	0	0
White/Caucasian	53	8	90	9
Asian	7	1	10	1
Race Not Listed/Multiple	13	2	0	0
Hispanic/Latinx/Spanish Origin				
Yes	7	1	0	0
No	93	14	100	10
Highest Level of Education*				
High School Diploma or GED	13	2		
Some College	7	1		
Associates Degree/Vocational Degree	7	1		
4 Year College Degree/Bachelor's Degree	67	10		
Post-Baccalaureate/Master's Degree/Ph.D.	7	1		
Sexual Orientation*				
Straight/Heterosexual	40	6		
Gay/Lesbian	27	4		
Bisexual	20	3		
Heteroflexible/Mostly Straight/Other	13	2		
Working Outside of the Household*				
Yes, Part-time	20	3		
Yes, Full-time	67	10		
No	13	2		
Type of health insurance*				
Public	67	10		
Private	33	5		
Enrolled in Trade School/College/or University*				
Yes	20	3		

	Patients (<i>n</i> = 15)		Providers (<i>n</i> = 10)	
	%	<i>n</i>	%	<i>n</i>
No	80	12		
Health care facility worked at *				
Hospital			80	8
Community-based setting (e.g., child advocacy center, family justice center)			20	2

* = Demographic recorded for one group of participants only*

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2: Highlighted quotes regarding patient and providers HIV PEP decision making across the four themes

Theme	Patients	Providers
Medical concerns	<p>I took the first dose and was so nauseous, I couldn't really sit upright. Then I had the diarrhea. Just everything felt like shit, but I still took the next dose and pumped with a manual pump so as to not totally keep my milk supply all the way up 'cause she was already so close to 18 months. By three days, I was so fatigued and just sick feeling. I didn't want to pump. I didn't want to have to do all of that, so I stopped taking the meds and then just muddled through. I gave it an extra 24 hours to make sure everything's out of my system. I still felt like shit, but at least I could nurse my child. <i>White female</i></p> <p>Interviewer: When they were talking to you about those medications that you were gonna be taking when you went home... did they give you any information about what that was gonna look like when you went home? Interviewee: No, they didn't tell me none of that. No. Interviewer: How did you find that information out? Interviewee: I just looked for the information on the internet. Interviewer: What did you learn? Interviewee: I learned I was a victim of sexual assault. I looked up different stuff and looked up who helped or what to do and how to calm myself down about it. I went to counseling about three days after that. <i>Black male</i></p>	<p>These are intense medications, and then frame that in the light of, "Here statistically, is your likelihood of seroconverting based off of what specific exposure you've had." I know we have graphs for TPA and, "Here's 100 people, and these are people that won't be helped by TPA. I discuss that with them, and I frame it in that - okay. "so if this were to happen to you 100 times, this is how many times you would get HIV. Based off of that risk, would you like to go ahead with these medications that are likely to make you feel miserable for a month?" <i>White male physician</i></p> <p>...it's not necessarily walking on eggshells, but you want to not say anything further injurious. You patient's already had a terrible thing happen to them, and you wanna make sure that you use language that is deliberate and caring, so I do - and I'm by not means the best person in the world at this. I try to level with people and say, "Listen. Your risk is small; however, it is 0.3 percent." for example, or 10 percent - or it's 0.1 percent, for example, and these are the medicines that are available. The question that usually comes back because these numbers are difficult to interpret, is, "What would you do?" and that is a difficult question to answer. <i>White male physician</i></p>
Daily Medication Management	<p>Well, nobody really knew what was goin' on. If somebody asked, I was like, "Oh, well, I had a little sinus infection. I just have to take antibiotics." That was pretty much it. Sometimes it [the alarm] would go off in public. Most of the time, I was secluded by myself, so there wasn't anybody necessarily in my business. <i>Black female</i></p>	<p>You're chasing the pharmacist, and you're chasing the resident trying to get the orders, and you're chasing this person and that person, and then somebody's gotta go walk the meds over. Sometimes it's just the logistics. <i>White female SANE</i></p>
Access to HIV PEP	<p>The insurance covered it. I mean, I would think, well, I had additional—or call it the proper insurance, too, but I didn't know it would be—I don't know where I would have gone. I would've probably been playing musical doors—musical health facility to try and get the answers. <i>White male</i></p>	<p>Depending on the state that you're in, getting those medications actually filled and paid for can be a huge hurdle. In some states, it's pretty straightforward, because the states got the system figured out. In other states, it's nearly impossible, 'cause the state payors don't pay for them. The private insurances don't pay for them. The drugstores don't have them. It can be really challenging. <i>White female SANE</i></p>