Original Article

A Qualitative Exploration of Sexual Assault Patients' Barriers to Accessing and Completing HIV Prophylaxis

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ABSTRACT

Sexual assault patients may encounter barriers when accessing, accepting, and completing nonoccupational postexposure prophylaxis (nPEP), such as lacking insurance or an understanding of nPEP. However, less is known about how sexual assault forensic examiner (SAFE) programs' protocols, approaches to discussing nPEP, and community resources may influence nPEP completion. Utilizing a qualitative case study framework, we conducted semistructured interviews with 10 SAFEs from an urban SAFE program in which emergency department physicians write prescriptions for nPEP before sending patients to the SAFE program. The participants identified barriers encountered by their patients, ranging from emergency department providers inconsistently offering prescriptions for the correct medication, to difficulty locating a local pharmacy stocking nPEP. The SAFEs also expressed concern that uninsured patients had to complete additional steps to access nPEP, while feeling overwhelmed by the immediacy of their assaults. Several participants raised concern that patients' emotional distress and fear of acquiring HIV may impede their ability to comprehend information and access nPEP. Participants also noted that the 28-day nPEP regimen might be a daily reminder for patients of the sexual assault. The SAFEs identified multiple strategies for discussing HIV and nPEP with these patients. Implications of the SAFE's role in reducing barriers are discussed.

KEY WORDS:

HIV; nPEP; sexual assault forensic examiners

Although research is limited on the risk of HIV transmission during sexual assaults, existing data suggest that risk increases from a penetrative sexual assault by an HIV-infected person or someone whose HIV status is unknown (Campbell, Lucea, Stockman, & Draughon, 2013; Centers for Disease Control and Prevention [CDC], 2016; Workowski, Bolan, & CDC, 2015; World Health Organization [WHO], 2007). Therefore, guidelines for nonoccupational postexposure prophylaxis (nPEP) treatment have been created (CDC, 2016; WHO, 2014). nPEP is a series of antiretroviral medications that must commence within 72 hours of a potential exposure to reduce the likelihood of HIV transmission (CDC, 2016; WHO, 2014). Thus, nPEP is widely recommended for individuals who have been sexually assaulted (CDC, 2016; WHO, 2014). Furthermore, the International Association of Forensic Nurses (IAFN) issued a joint position paper entitled "Position on Universal Access to Anti-HIV Medication," with the Association of Nurses in AIDS Care, the National Alliance to End Sexual Violence, and the National Sexual Violence Resource Center supporting universal access to nPEP, along with HIV risk assessment, education, and comprehensive follow-up (e.g., medication management, advocacy; Association of Nurses in AIDS Care, IAFN, National Alliance to End Sexual Violence, & National Sexual Violence Resource Center, 2013).

However, many emergency departments (EDs) do not offer nPEP consistently for victims. In a meta-review of 36 studies with sample sizes ranging from 6 to 179,149,

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Draughon and Sheridan (2012) found multiple factors of why ED providers do not offer nPEP, with "low-risk" exposure (where condom was used) as the most common. In addition, patients with health concerns or who were homeless were less likely to be offered nPEP. Alternatively, patients who were young adults, had insurance, or whose assailant was unknown were more likely to be offered nPEP.

Sexual assault forensic examiner (SAFE) programs provide specialized care for sexual assault patients, and research has shown that such programs improve both patient well-being and prosecution success (Campbell, Patterson, & Lichty, 2005). Although SAFEs provide a wide range of care, national studies surveying U.S. SAFE programs found that nPEP is not routinely offered (Campbell et al., 2006; Draughon, Anderson, Hansen, & Sheridan, 2014). The high cost of nPEP has been noted as a major barrier against SAFEs providing nPEP (Campbell et al., 2006; Draughon et al., 2014; Du Mont, Macdonald, Myhr, & Loutfy, 2011). Draughon et al. (2015) also noted that program protocols influence whether SAFEs offer nPEP.

Research has also examined rates of patients' acceptance and completion of nPEP. Draughon and Sheridan's (2012) meta-review found that recent studies reported a range of 43%–75% acceptance but a lower completion rate (0%–63%). The meta-review also indicated positive correlates of nPEP acceptance and completion, including patients of high-risk exposures and unknown assailants. In contrast, decreased acceptance and completion rates were linked to patients' lack of insurance and distressed emotional states. Younger victims were more likely to agree to be treated but less likely to complete the regimen. Additional barriers to completion included side effects, interference with daily routine, and misunderstandings about accurate use.

Emerging research suggests that healthcare interactions between providers and patients may also affect acceptance and completion (Du Mont et al., 2008; Loutfy, Macdonald, Myhr, & Husson, 2008; Vetten & Haffejee, 2005). Patients are more likely to accept nPEP with provider encouragement (Du Mont et al., 2008). Vetten and Haffejee (2005) interviewed health workers and survivors from South Africa and found that some workers hurried their explanations or failed to assess patients' understanding of instructions. An added complication may be patients' emotional distress during the examination, which may reduce comprehension of instructions. In contrast, patients with moderate-to-high anxiety levels are more likely to accept nPEP (Du Mont et al., 2008; Loutfy et al., 2008). Research is needed to understand how patients' emotional states play a role in acceptance and completion as well as providers' strategies to mitigate patients' emotional distress and promote patient comprehension.

Overall, studies show that nPEP access, acceptance, and completion are a complex multiple-step process, with patients possibly encountering barriers at each step (e.g., lacking transportation to obtain nPEP from a pharmacy). Furthermore, site-specific protocols and community resources may increase this complexity and potentially create additional barriers (Draughon et al., 2015). For example, community-based SAFE programs may need to partner with healthcare systems to help patients obtain prescriptions. Communities with medication assistance programs may improve access to nPEP but may add more patient and provider steps to accessing nPEP. Given this complexity, more in-depth research is needed to understand the barriers that patients may encounter. Therefore, we used a qualitative case study framework, focusing on an urban SAFE program, to identify steps leading to nPEP completion, the barriers within each step, and the program's strategies. Emerging research suggests that patients' emotional states may play a role. Additional research is needed to understand how SAFEs approach the nPEP discussion, especially with distressed patients. Thus, we examined SAFEs' perspectives on the role of emotionality in nPEP completion and approaches to discussing nPEP with distressed patients.

Methods

Research Setting

This community-based SAFE program employs healthcare providers and advocates who provide comprehensive medical, forensic, and crisis intervention services at multiple sites within clinical offices and hospital systems. The patient population is predominately female (70%), with a racial/ethnic composition of Black (65%), White (29%), Latina (2%), and other (4%), consistent with the county demographics. The focal program serves a sizable Midwest county housing a large city (population of 719,096) and surrounding suburbs (1,045,708). The HIV prevalence rate is 672 of 100,000 for urban residents and 190 of 100,000 for suburban residents.

Following IAFN's recommendations, the SAFE program's protocol dictates that all patients receive information on HIV risk and nPEP and be allowed to make an informed choice. The focal program, like many others, is unable to provide free nPEP. Thus, about 3 years ago, the program established agreements with their EDs to discuss HIV risk, provide an HIV baseline test, and offer patients an initial dose of medication, a starter pack (5- to 7-day supply of appropriate antiretroviral medications), and a prescription for the remaining dosage. ED providers assumed this role because most patients present to the ED after an assault, where they are triaged and medically screened before being directed to the SAFE program for medical forensic services. The SAFEs also routinely discuss HIV risks, address patients' concerns and questions, and confirm that the ED prescribed nPEP. At discharge, SAFEs reiterate information on nPEP and provide a detailed list of community resources, including pharmacies that carry nPEP. Patients also receive a schedule

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outlining when they should have an HIV test, along with a list of locations offering free HIV testing. When possible, advocates follow up with patients to assess their well-being, address concerns, and provide additional referrals as needed.

Sample

Sample eligibility included SAFEs who were employed by the focal program and provided medical forensic services when recruited. To recruit participants, the first author attended a staff meeting to introduce the study and asked interested staff members to complete contact forms. Eleven of the twelve SAFEs completed forms and were contacted to schedule interviews. Ten nurses agreed to participate (83% response rate). This is a reasonable sample size for a qualitative case study examining processes in depth (Creswell, 2012). The average number of years of experience among participants was 4 years, with a range of 1–15 years.

Procedures

After obtaining consent, we conducted semistructured, in-person interviews, which were recorded and transcribed. To augment the interviews and analysis, we collected written organizational policies and patient paperwork. Research team meetings (first and second authors) were conducted to identify emerging themes and topics that needed more exploration in subsequent interviews (Creswell, 2012). The interviews ranged from 32 to 62 minutes, with an average of 49 minutes. The procedures used in this study were approved by the Wayne State University Institutional Review Board.

Measures

The interview protocol was informed by the literature on barriers to nPEP access and completion and pilot-tested with a key informant to assess the content and probes and revised accordingly. The interviews focused on multiple topics: (a) the HIV preventive care protocol and barriers; (b) the health-care interactions between the patient and SAFE, specific to discussing HIV and nPEP; (c) SAFE's comfort level discussing HIV prevention and treatment; and (d) post-SAFE-care barriers. The SAFEs rated themselves as feeling very comfortable with discussing HIV, as most of them have experience working in EDs where treating patients living with HIV is common. Consequently, the third topic was not indicated as a barrier and thus not a focus for us.

Data Analyses

We used Creswell's (2012) method of case analysis, which began with writing a detailed description of the HIV preventive care protocol discussed during the interviews. Two analysts independently read the transcripts and developed initial codes and coding definitions before coding all of the transcripts. Subsequently, we reviewed the codes to identify patterns and relationships among the codes, which led to thematic formation. The analysts compared and discussed the meaning of the thematic codes and revised the coding framework until consensus was reached. Next, the researchers utilized analytic induction to finalize the results by returning to the data to assemble confirming evidence of the themes (Patton, 2015). Consistent with Patton's (2015) "ultimate test" of credibility, the SAFE program directors and staff were shown the findings and agreed with the results.

Results

The participants identified multiple steps leading to nPEP completion and the barriers within each step. The results begin with barriers that may be encountered by patients during their visit at the ED or SAFE program including attaining an nPEP prescription and comprehending information about nPEP. The findings also identify the potential barriers that may occur after their SAFE visit such as accessing nPEP from a pharmacy and seeking postexposure care.

Step 1: Attaining an nPEP Prescription

In the focal community, ED staff members are responsible for discussing HIV risk with sexual assault patients and writing prescriptions for nPEP before sending patients to the SAFE program. The participants noted, however, that several of their patients have encountered difficulty with accessing nPEP at an ED. Some were never offered the option of nPEP, some were informed by the ED provider that nPEP was unnecessary, and some received a prescription for an incorrect medication or dosage. As illustrated in the participants' quotes, the SAFEs believed that there were several reasons for this gap in care, with the most common being the ED providers' lack of knowledge of state nPEP guidelines. Furthermore, some SAFEs have encountered providers who did not view sexual assault as an HIV risk factor or perceived nPEP side effects as too severe. Finally, some noted that providers might not offer a prescription for patients without insurance because additional effort is required.

> And I'm like she needs to be on HIV prophylaxis, she needs her first dose there and then she needs a prescription for thirty days. And they're like oh okay…I didn't know. And they truly just they don't know. (P006)

> A physician will be telling a patient it's [nPEP] not necessary and I'm like okay she got pulled up off of the street and into an abandoned house. That's an uncomfortable position to be because then you have a patient or a parent saying, well the doctor said I didn't really need it so. (P008)

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> …the doctor had never ordered the medication and said that they don't even have them [nPEP] at their facility, but I helped her [physician] find a referral for the patient to get the HIV meds. So I mean there's always a way to get them, it's just that if the doctor doesn't want to do it…. (P009)

The SAFEs noted that they are typically successful with advocating for prescriptions, after they spoke with the ED provider. However, the SAFEs worried that patients might be apprehensive about taking nPEP if they hear conflicting information from the ED provider. For instance, patients may not begin nPEP if their ED provider initially discouraged use.

Step 2: Patient Comprehension and Acceptance of nPEP

These patients may encounter further emotional distress when learning that they may also be at risk of acquiring HIV, especially if they view HIV as a terminal rather than a chronic disease. Several participants expressed concern that this distress may impede their patients' ability to comprehend information about HIV and nPEP.

> …there's already so much going on and we know all this about neurobiology, trauma and the ability to process all this information that we're giving…. [Patients] may not potentially at that point in time comprehend what we just tried to go over with them…. I feel like our/my biggest concerns or challenge is the fact that because we're seeing patients in such an acute state of trauma in many cases, one of my biggest concerns is that they're not getting the importance of it [taking nPEP]. (P001)

Participants expressed concern that these patients might not accept a prescription for nPEP if they do not comprehend its importance. However, several participants were concerned that overemphasizing the HIV risk or the importance of nPEP might cause additional emotional distress. On the other hand, they worried that downplaying concerns about HIV risk might lead them to perceive that nPEP is unnecessary. As noted in the next quote, these participants noted that conversations about HIV had to have a delicate balance between helping the patient understand the importance of following medication instructions to decrease their risks while not exacerbating their fear of a potential HIV exposure.

> We want to make sure that patients understand the importance of it without scaring them too much either. We want them to understand the importance and maybe for some they need to be scared enough to remember to take it, but at the same time, that's not really conducive to what they just went through. I think there are some fine lines sometimes when you're sitting with a patient, one-on-one and the words that you say at this time, in this person's life, can really have a huge impact. (P001)

> And I say that, the chance of you contracting this are extremely low but here's the deal, people do contract it. So my recommendation is 28-days on these medications give you a peace of mind to know that you proactively made sure that you protected yourself in the chance that you were exposed to it. (P008)

As noted in the second quote, framing medication adherence as a means to achieve "peace of mind" and to "protect yourself" is one approach that might achieve the needed balance.

Participants also indicated concern that a lack of complete comprehension might lead to nonacceptance. For instance, some participants' patients have declined nPEP but then requested a prescription later, unaware that treatment must commence within 72 hours of the assault. The participants also feared that patients may not complete nPEP if they do not understand the importance of completing the entire regimen. Because emotional distress may affect understanding, several participants wait to discuss nPEP after the history-taking portion of the examination, when patients seem calmer. Furthermore, participants believed that rapport is strongest at this time, which helps patients openly discuss concerns about HIV and nPEP and trust the information being provided.

> You can get the most thorough teaching in [after history-taking] because you've already gained that really good rapport with them. And they're at ease with you…they feel safe with you at that point, so they trust you to give them good information. (P010)

During these discussions, some participants asked their patients to repeat the instructions, to assess their understanding, and to reinforce the information.

Step 3: Accessing nPEP From a Pharmacy

If patients decide to take nPEP, they must obtain the medication at a pharmacy. However, not all local pharmacies carry nPEP or have it consistently available. Thus, the SAFE program makes a concerted effort to maintain an accurate list of pharmacies that do. Despite these efforts, many SAFEs expressed concerns that there were not enough pharmacies that kept nPEP in stock, causing additional stress.

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Even though we have numbers and places for them to follow-up, we still sometimes get patients that call me on the pager and are like, so I tried this place, this place, and this place and nobody is willing to help me out here. What do I do? And you know we're on a time window. We have up to 72 hours to get these patients the prophylaxis that they needed. (P005)

The SAFEs worried that difficulty in locating nPEP might cause patients to give up. Patients without insurance must complete additional paperwork at a local infectious disease clinic through a medical coverage assistance program, which creates additional steps that may feel overwhelming to assault victims.

…if they [patients] don't have insurance, they have to go through different programs for reimbursement. Sometimes they don't wanna ask for help from these services and they don't wanna have to go through the different organizations that help with that so then they're just like just forget it. (P007)

As noted, some SAFEs had concerns that these patients would forego nPEP if they felt overwhelmed in navigating the healthcare system.

Step 4: Postvisit Care and Concerns

Patients should follow up with a provider to monitor their nPEP adherence and tolerance. However, participants expressed concerns that there was a dearth of qualified follow-up resources for providing this care. Furthermore, some participants have had patients say that they are discontinuing nPEP because their primary care provider felt the benefits were negated by the side effects.

Emotionality also might influence nPEP completion as some participants worried that nPEP might evoke daily memories of the sexual assault during completion of the 28-day regimen.

HIV [nPEP] is more of a commitment…you're going to be on this for 28-days, you need to take the medications, you need to stay on the medications, you may require follow-up at certain points for certain labs…what I do kinda feel like is that a vast majority probably starts it and then stops…. (P008)

I: Why do you feel that?

Probably like PTSD. It's kinda this constant reminder so I don't wanna deal with it so I'm just gonna stop taking this. Plus it's a hassle right and they don't wanna talk about it for the three hours, four hours that they're with me much less not have to go have an appointment somewhere and talk about it. (P008)

Thus, counseling might help patients to manage these triggers while they complete nPEP.

Discussion

Utilizing a qualitative case study framework, this study examined the steps leading to nPEP completion, the barriers within each step, and the programmatic strategies within an urban SAFE program. Overall, this study found that patients may encounter barriers with every step needed to access and complete nPEP. In terms of accessing nPEP, the SAFEs reported multiple barriers, ranging from not receiving a prescription to encountering difficulty locating a local pharmacy offering nPEP. Interviewing ED providers about their nPEP practices was beyond the scope of this project, but prior studies have found that many providers have limited knowledge about nPEP, which may have contributed to incorrect prescriptions or the lack of any prescription (Cohen, Liu, Bernstein, & Philip, 2013).

The participants also noted several barriers to accessing, accepting, and completing nPEP for highly stressed patients. For instance, several participants expressed concern that patients' emotional distress affects their ability to comprehend information about their HIV risk, which in turn might result in patients not accepting an nPEP prescription or completing the regimen. Research has shown that the general population is reluctant to believe that they are at risk of HIV, even when indicated (Obermeyer & Osborn, 2007). However, these patients also may have difficulty understanding their HIV risk, because emotional trauma may impede their comprehension (Green et al., 2015).

Several participants also worried that patients may feel overwhelmed trying to access nPEP, while also coping with acute emotional distress. Sexual assault patients can become emotionally paralyzed if they become overwhelmed (Badour, Blonigen, Boden, Feldner, & Bonn-Miller, 2012) and may forego accessing nPEP. Given that patients without insurance must complete additional steps to access nPEP, these patients may be at a higher risk of becoming overwhelmed and subsequently cease their efforts.

Finally, participants noted concern that the 28-day nPEP regimen might serve as daily reminders of the assault, which in turn might serve as triggers whereby the patient experiences unwanted emotions associated with the assault. Triggers can create a state of immobility or inaction when patients attempt to distance themselves from negative emotional reminders of their assault (Badour et al., 2012). Therefore, it is possible that some patients may not complete nPEP. Given that emotional distress is common after a sexual

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assault, additional research is needed to understand the role of this stress in accessing and completing nPEP.

Limitations

Some methodological limitations warrant consideration. The cross-sectional design of this study prohibits causal inferences being drawn and the extent to which the results can be generalized to the barriers patients encounter in dissimilar communities. For example, patients in rural communities may have additional concerns about confidentiality when accessing nPEP from a pharmacy. Furthermore, this study used a small sample of SAFEs in one urban program, which is appropriate for a qualitative case study. However, it is likely that we did not capture all of the barriers related to nPEP access and completion. Although the SAFEs who participated have had many discussions with ED providers about why they did not prescribe nPEP, there may be other barriers (e.g., high patient caseload). SAFEs are only able to offer insight into patients' concerns based on their observation during their care, but they have less contact with patients after the examination. Thus, there may be postcare factors that prevent patients from accessing nPEP from pharmacies. For example, research that has examined barriers to sexually transmitted infection testing in the general college student population found that sexually transmitted infection-related stigma and shame prevented care seeking (de Visser & O'Neill, 2013). These emotions have not been examined as barriers to sexual assault patients around nPEP. However, research has found that sexual-assault-related stigma and shame can prevent help seeking for other services (Patterson, Greeson, & Campbell, 2009). Thus, understanding how stigma and shame related to sexual assault and HIV influence nPEP completion and follow-up care merits additional research.

Implications for Clinical Practice

Despite these limitations, our findings suggest several implications for practice. First, although the steps required for patients to access nPEP vary by community, this study highlights the importance of SAFEs assessing and reducing the barriers that their patients encounter at each step, through patient advocacy and continuing education. However, advocacy and education may not yield sustainable change, as the focal program continued to encounter providers who did not follow the nPEP protocol. Written resources and information hotlines for providers have been found to improve nPEP access (Minas, Laing, Jordan, & Mak, 2012). Written resources might include guidelines for communicating about HIV risk and nPEP and information on medications and dosages.

This study suggests that emotional distress may serve as a barrier to accessing, accepting, and completing nPEP. For example, patients with high levels of distress may have difficulty comprehending or recalling instructions on completing nPEP. Trauma-informed, patient-centered communication has been shown to improve patients' recall of information and acceptance of recommendations (Green et al., 2015). The SAFEs in the focal program identified strategies related to trauma-informed, patient-centered communication that they have found helpful. For example, many SAFEs wait to discuss HIV and nPEP until rapport has been established and patients are less stressed. The SAFEs also approached these discussions with a delicate balance of presenting a realistic picture of HIV risk, without exacerbating their patients' fear of a potential HIV exposure. Many SAFEs also recommended a teach-back method during which they requested their patients to repeat the information to evaluate understanding. Together, the SAFEs believed that these strategies may improve their patients' comprehension and recall of information on HIV risk and nPEP.

Finally, the SAFEs expressed concern that patients may not complete the regimen if nPEP provokes assault memories and emotions. Crisis counseling can help patients manage their triggers (Badour et al., 2012). Similarly, crisis text messaging may be helpful, as it has been effective with management of other emotional crises such as suicidal ideation (Berrouiguet et al., 2014). Some of the SAFEs conceptualized nPEP adherence as a form of restoring patients' sense of control (e.g., giving oneself a "peace of mind" or "protecting oneself"). It is possible that framing nPEP as one mechanism to regain control may help patients view nPEP completion as a more empowering experience. Future research should examine whether this framework helps restore patients' sense of control and increases nPEP completion.

Conclusion

In conclusion, the current study identified multiple steps leading to nPEP completion and the potential barriers that patients may encounter within each step. Furthermore, the SAFEs raised concern that their uninsured patients often have to complete additional steps to access nPEP, while feeling overwhelmed by the immediacy of their assaults. The current study focused on a SAFE program in a large urban community, and thus, the steps and barriers reflect this program's nPEP protocol and community resources. Because nPEP protocols and community resources vary among SAFE programs, it is important for SAFE programs to assess how their protocol and community resources influence their patients' barriers with accessing, accepting, and completing nPEP.

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