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The Effect of an Educational Handout on Knowledge, Awareness and Attitudes of Pre-Exposure Prophylaxis (PrEP) Among Participants at a Needle and Syringe Exchange Site

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The Effect of an Educational Handout on Knowledge, Awareness and Attitudes of Pre-Exposure
Prophylaxis (PrEP) Among Participants at a Needle and Syringe Exchange Site

Submitted in Partial Fulfillment of the Requirements for the Degree of Doctor of Nursing
Practice at the University of Kentucky

By

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Abstract

Background: In 2018, the total number of HIV cases in the United States was 1.2 million. Almost 186,500 of these cases were attributed to intravenous drug use. With the adherence to pre-exposure prophylaxis (PrEP) there is approximately a 49% decrease in the rates of HIV among people who inject drugs and the most significant barrier to PrEP among this population is a lack of awareness and knowledge.

Objective: The purpose of this study was to determine participants' of a needle and syringe exchange site knowledge, awareness and attitudes of PrEP after reviewing an educational handout about PrEP.

Methods: A quasi experimental one-group posttest-only design was used. Participants verbally consented after reading a cover letter and were provided an educational handout about PrEP. After reviewing, participants completed a post-survey. The sample included 33 participants who presented to the clinic on the two days of data collection.

Results: Almost half of participants (45%) had never heard of PREP and 73% learned something new about PrEP from the educational handout. Although only 21% were interested in taking PrEP and only 18% were willing to be referred to a provider to start PrEP. Twenty four percent were not sure about their interest in taking PrEP and 30% were not sure about willing to be referred to a provider to start PrEP.

Conclusions: This study showed an educational handout can be an effective way of disseminating information about PrEP among this population. Knowledge and awareness about PrEP in this population remains low, although this study showed an increase. Future research is needed to understand and address reasons for uncertainty about PrEP.

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Background and Significance

Substance abuse is a global epidemic that can lead to many serious health consequences. One specific consequence related to those who abuse substances in the intravenous (IV) form is human immunodeficiency virus (HIV). HIV is a virus that attacks the body's immune system and has no cure (CDC, 2021). HIV can be spread from infected person to uninfected person via contaminated needles and syringes that are shared during drug use (CDC, 2021). A person with HIV can have vague symptoms such as fever, chills and muscle aches or they may exhibit no symptoms at all (CDC, 2021). If a person is asymptomatic or unaware of a positive status, transmission to others could occur without one being aware. This likely increases HIV's overall transmission rates. In 2018 alone, there were 37,881 new cases of HIV in the United States, increasing the total number of cases to almost 1.2 million (CDC, 2021). Of these almost 1.2 million cases, 186,500 of them were attributed to intravenous drug use (IVDU) (CDC, 2021). Outbreaks of HIV can also occur and lead to the spread to many individuals in a short period of time.

In 2014, a small, rural area of Scott County, Indiana saw an HIV outbreak of vast proportion. In the 10 years prior to the outbreak, Scott County, Indiana had only seen five cases of HIV but from December 2014 to April 2016 there were 188 new cases (Janowicz, 2016). A single case of HIV was introduced into the IV drug use population via contaminated drug paraphernalia of this small county and spread rapidly (Janowicz, 2016). An outbreak of this magnitude, and even a single diagnosis, is detrimental as there is no cure for HIV and its long-term consequences are numerous.

Although there is treatment for HIV to help those with the disease live longer with better outcomes, there is no cure and those with HIV carry the burden of the potential to transition from

HIV to acquired immunodeficiency virus (AIDS). Once a person develops AIDS from HIV, their life expectancy, if left untreated, is approximately 3 years (CDC, 2021). This is mostly due to opportunistic infections that those with AIDS may acquire (CDC, 2021). Opportunistic infections are infections that may be deadly to those with a weakened immune system from AIDS and can include *Pneumocystis Carinii* pneumonia (PCP), tuberculosis (TB) and cytomegalovirus (CMV) (Solomon et al., 2018). In the AIDS population, 90% of morbidity and mortality is linked to opportunistic infections (Solomon et al., 2018). According to the World Health Organization, in 2018 alone, approximately 770,000 deaths were attributed to HIV-related illnesses worldwide (n.d.). Not only does HIV and AIDS have significantly increased morbidity and mortality compared to those who do not, the diagnosis also places a substantial burden on the healthcare costs associated with it. According to Ritchwood et al. (2017), “based on the adjusted mean, the aggregate cost of HIV/AIDS was approximately \$10.7 billion higher than the costs for those without HIV/AIDS” (p. 1). HIV is accompanied with long-term consequences, increased morbidity and mortality and high healthcare expenditures. However, there are steps that can be taken to decrease transmission of HIV among people who inject drugs (PWID).

One potential solution to the HIV crisis among PWID is pre-exposure prophylaxis (PrEP). PrEP is a daily medication regime that can decrease chances of contracting HIV if an HIV-negative person is exposed. According to Sherman et al. (2019), adherence to PrEP can decrease the rates of HIV among the entire population of PWID by approximately 49%. Additionally, the CDC (2021) states PrEP is 74%-84% effective at preventing HIV among each individual person who injects drugs. Unfortunately, there are many barriers to PWID taking PrEP. These include lack of knowledge, worries about costs, fears about behavioral and health consequences, social stigma and adherence to the medication regime (Pleuhs et al., 2020). After a

literature review, there were no studies found evaluating interventions or strategies to increase the utilization of PrEP among PWID. Mayer et al. (2020) found one of the most significant barriers to PWID taking PrEP is a lack of awareness and knowledge. This project sought to improve understanding and education about PrEP among PWID.

Purpose and Objectives

The purpose of this study was to determine if participant teaching through an educational handout would increase knowledge and awareness of PrEP and increase the intent to take PrEP at a needle and syringe exchange clinic in an urban area of a large city in Kentucky. After implementing participant education, the specific aims were to:

1. Evaluate participants' knowledge and awareness about PrEP
2. Assess attitudes and intentions of participants about PrEP
3. Increase number of participants who agree to be referred to a provider to start regime

Review of the Literature

The use of PrEP among PWID has been shown to drastically decrease the transmission of HIV (CDC, 2021). The most effective way to increase the usage of PrEP among this population remains uncertain. Therefore, using the PICO format, the question guiding the review was: Among the population of PWID, what is the most successful approach to increase the utilization of PrEP to decrease transmission of HIV? To conduct this review of the literature the search engine used was PubMed and the search terms used were pre-exposure prophylaxis, HIV and people who inject drugs by searching the title and abstract and using MeSH headings. This yielded 96 articles and was further narrowed down by articles from the last five years that focused on the utilization of PrEP. Articles that were excluded were those that discussed

providers awareness and usage of PrEP and those that examined PrEP among people who had high risk sexual behaviors.

After filtering through the literature based on the criterion stated, 17 articles were reviewed. The locations of the studies were in various geographical areas including rural and urban parts of the United States (Allen et al., 2019; Biello et al., 2018; Carter et al., 2021; Earlywine et al., 2021; Jo et al., 2020; Ranjit et al., 2020; Roth et al., 2018; Schneider et al., 2020; Sherman et al., 2019; Walters et al., 2020), India (Belludi et al., 2021), Scotland (Smith et al., 2021) and Portugal (Simões et al., 2021). The settings of the studies took place in community based organizations such as syringe service programs and drop-in HIV and hepatitis C testing sites. Three studies were systematic reviews while 14 were qualitative studies that retrieved information from participants through survey or interview.

Overwhelmingly, the studies displayed low knowledge and awareness of PrEP among PWID (Allen et al., 2019; Bazzi et al., 2018; Belludi et al., 2021; Biello et al., 2018; Carter et al., 2021; Earlywine et al., 2021; Jo et al., 2020; Koechlin et al., 2016; Roth et al., 2018; Schneider et al., 2020; Sherman et al., 2019; Simões et al., 2021; Walters et al., 2020) but high interest in taking, more than 50% of participants from all studies reviewed, after being given a description of PrEP (Allen et al., 2019; Bazzi et al., 2018; Belludi et al., 2021; Biello et al., 2018; Jo et al., 2020; Koechlin et al.; Mistler et al., 2020; Schneider et al., 2020; Sherman et al., 2019; Simões et al., 2021; Smith et al., 2021; Walters et al., 2020). Unfortunately, none of the literature or articles evaluated an actual intervention in an attempt to increase utilization of PrEP. The current literature only seeks to understand the knowledge, awareness, perceptions and attitudes of PrEP among PWID. The proposed project attempted to increase PWID's knowledge and awareness about PrEP through an educational handout. This project aimed to address the gap of knowledge

by providing education and increase those who agree to be referred to a provider and prescribed PrEP.

Theoretical/Conceptual Framework or Model

An appropriate theoretical framework that guided the project was the Humanistic Learning Theory. The humanistic learning theory that was developed by Abraham Maslow, Carl Rogers, and James F. T. Bugental in the early 1900's accentuates emotions and feelings and revolves around viewing the person as a whole (Rich & Butts, 2017). The literature also states humanistic learning theory's approach is to encourage individuals to make wise choices by giving them freedom of choice in a non-judgmental environment. Humanistic theory provides a safe and comforting environment so that one may be able to self-motivate and remain autonomous (Rich & Butts, 2017). This theory helped guide the project because ultimately patients made the decision to take PrEP or not and by providing awareness and education, they can be empowered to make their own informed decisions about their health. The decision to take PrEP is a difficult, personal choice and the humanistic learning theory will promote making a choice in a safe, comforting and non-judgmental environment.

Methods

Design

The design of the study was a quasi-experimental one group posttest-only. This study sought to determine if an educational handout will increase awareness, education about PrEP, and increase agreeance to be referred to a provider for prescription of PrEP among PWID at a needle and syringe exchange site.

Setting

Agency description

The setting was at a needle and syringe exchange site in Kentucky. They have a centralized location but also offer a mobile unit that travels to nine different locations throughout the city. The services are free and anonymous and offer proper disposal of used needles, distribution of new injection equipment, treatment and recovery for addiction resources, testing for blood-borne pathogens that are common among PWID, and medical and mental health resources. From 2014 to 2015 this program assisted approximately 20,000 people and had 115,000 encounters with these participants (Ristevski, 2019).

Congruence of project to selected agency's mission/goals/strategic plan

The mission of this program is to reduce the spread of HIV and bloodborne diseases. This project is in congruence with this mission because PrEP has shown to reduce the transmission of HIV among PWID by at least 74% (CDC, 2021).

Description of stakeholders

This project involved a multitude of stakeholders. More specifically, stakeholders for the project included clinic staff, participants of the clinic and people at risk for HIV.

Potential site-specific facilitators and barriers to implementation

Facilitators to implementation were support of the clinical mentor and the staff of the facility. The staff voiced need that they need to increase participants' awareness of PrEP and therefore were confidently supportive of this study. An anticipated barrier was participant willingness to engage in the educational handout and survey and stigma associated with this population.

Sample

The sample consisted of a convenience sample of voluntary participants. The study population consisted of all participants that were there for services on the days of data collection. The inclusion criteria were any PWID that visited the facility during the two days of data collection. The exclusion criteria were those with an already positive HIV status. There was no way to know a participant's status unless the participant voiced this during contact with them. If they verbalized, they had a positive status, they were excluded from the study. The dates of enrollment were two days in November and December of 2022. The participant characteristics of the services vary greatly.

Procedure

Permission/IRB Approval

Institutional Review Board (IRB) approval was obtained from the University of Kentucky Medical IRB before the study began. Initial submission to IRB was on August 26th, 2022 and final approval was obtained on November 9th, 2022. As mentioned, the facility uses anonymous patient identifiers, so data and information obtained has no specific patient information connected to it.

Description of evidence-based intervention

It has been demonstrated in the literature that there is low awareness and education about PrEP among PWID (Allen et al., 2019; Bazzi et al., 2018; Belludi et al., 2021; Biello et al., 2018; Carter et al., 2021; Earlywine et al., 2021; Jo et al., 2020; Koechlin et al., 2016; Roth et al., 2018; Schneider et al., 2020; Sherman et al., 2019; Simões et al., 2021; Walters et al., 2020). More specifically, only 6.1% of participants were aware of PrEP in a study by Belludi et al. (2021), only 12.4% were aware in a study by Roth et al. (2018) and only 32.6% had heard of PrEP in a

study by Schneider et al. (2020). However, two of these studies demonstrated that more than half of participants were interested or willing to use PrEP, 52.4% were willing to use per Belludi et al. (2021) and 58.3% were interested in taking per Schneider et al. (2020). To address this lack of knowledge and awareness among this population, an educational handout was given to every participant during their visit in order to increase their knowledge and awareness so they could make the decision to be referred for PrEP.

When participants arrived at the needle exchange site they completed their reasons for attending the site, for example disposing of used needles and syringes, obtaining sterile needles and syringes or testing for blood borne disease. The PI then made contact with participants, and they were provided with the cover letter that detailed the study. After they read the cover letter willing participants provided verbal consent. The cover letter can be located at Appendix A. Consented participants were then handed an educational handout and given time to review the handout and ask any questions. The handout can be located at Appendix B. After reviewing, they were provided a paper survey to complete immediately following review of handout.

Measures and instruments

The main outcome measures for this study were evaluating the knowledge and awareness of PrEP post educational handout and number of participants who agreed to be referred for PrEP. The survey consisted of four statements that were followed by participants indicating yes, no or not sure for each statement. The survey can be located at Appendix C.

Data collection plan

The electronic charting system was not accessed during data collection. The anonymous surveys completed by the participants were kept in a locked box at the site and collected at the end of each data collection day.

Data analysis plan

The survey results (yes, no, not sure) are nominal so data was analyzed using frequencies and percentages.

Timeline of project phases

From start to finish, the project took place over a 9-month time frame. Data collection occurred November through December 2022 and data analysis occurred in January of 2023. DNP final project presentation occurred April 19th, 2023.

Feasibility and plan for sustainability

The feasibility of the study was improved by the support of the staff which appeared to be strong. The study seems to be the first of its kind to address if an educational handout increases utilization of PrEP among PWID. If successful, hopefully this will be incorporated into every patient encounter at this site and potentially others.

Resources

Resources needed were access to computers and data analysis software. As for budget, the only costs came from printing of the educational handout which were minimal.

Results

A total of 33 participants completed the survey after reading the educational handout. Almost half of participants (45%) had never heard of PrEP and nearly three-quarters (73%) learned something new about PrEP from the educational handout that they did not know prior to. When asked about their interest in taking PrEP, over half said no (55%), and one-quarter of the remaining said they weren't sure (24%). Over half of participants were not willing to be referred to a provider to start PrEP (52%), and nearly one-third said they were not sure (30%). All survey results can be found in Table 1.

Discussion

This project aimed to evaluate and increase participants' knowledge, awareness and attitudes about PrEP after being provided an educational handout and increase the number of participants who agree to be referred to a provider to start regime. It is evident that there continues to be a gap in the knowledge and awareness of PrEP among this population and this study was successful at increasing that. The study displayed that an educational handout can be effective at increasing knowledge and awareness about PrEP and would be an efficacious tool to use in the future. As far as attitudes about PrEP, it appears that many participants are not interested or uncertain about PrEP. Their willingness to be referred to a provider was also low or uncertain.

Some similarities and differences were noted when comparing the findings of this study to those in the existing literature. There were many studies from the literature review that found the majority of participants were interested in being prescribed PrEP, although this project was not necessarily congruent with those findings. Even though PrEP has been shown to be effective at reducing transmission of HIV among this population, there continues to be a sense uncertainty about interest in PrEP.

Many participants expressed hesitation in taking and being referred to a provider to start PrEP. This study did not enquire about participants' reason(s) for their uncertainty but provides an opportunity for future research. One possible reason for their uncertainty could have been they felt their risk of contracting HIV was low due to their utilization of harm reduction services. It is also possible that participants desire was low because of the time and effort it would take to find transportation, attend an appointment and take a new medication daily. Participant

agreement to take PrEP could be increased by having a provider and medication to dispense on site. For future research, it would be helpful to assess why participants are not interested in PrEP.

Recommendations for Future Practice and Research

This study, along with the literature revealed many recommendations for practice. It is evident that PrEP can decrease rates of HIV among this population, but awareness and knowledge of PrEP remains low. The first recommendation for practice is understanding the importance of increasing the knowledge and understanding of PrEP among this population. A lack of thorough comprehension of PrEP may have been the reason many participants chose 'Not sure' as their response for the last two statements on the survey. It is possible that they were not provided enough education about PrEP to make an informed decision. An additional recommendation for practice is outreach to PWID who do not participate in harm reduction services such as needle and syringe exchange. PWID who do not use sterile injection equipment are at a much higher risk of contracting blood borne pathogens such as HIV. Although, it may be challenging to access this subpopulation of PWID who do not use sterile supplies.

Additionally, an implication was generated from a limitation. One of the initial goals of the project was to refer participants to a provider for PrEP regime if they were interested. However, on the first day of data collection, when a participant expressed interest in being referred to a provider for PrEP, the staff was unsure of how the referral process worked. After the first day, the program director was contacted and then the process was explained but unfortunately the second day of data collection was on a weekend and referrals can only happen during weekday business hours. A recommendation would be to educate staff about the referral process, ensure they are discussing PrEP with every participant, and assessing each participant's interest.

Limitations

There were numerous limitations in this study. The first being the sample size as there were only 33 participants in this study. Furthermore, the only participants were those that happen to be there on the days of data collection. Also, the program does not keep any participant information or identifiers so there was no way to keep track of patient demographics. As mentioned, an additional limitation was the staff's understanding of the referral process. Time was another limitation and constraint. IRB approval was lengthy due to the sensitive and vulnerable nature of the population which limited the time frame for data collection. Lastly, there being only one study personnel was a limitation to the study. If there had been more study personnel, the sample size could have been larger. Despite limitations, valuable research was conducted, and helpful data was obtained.

Conclusion

In summary, HIV is a deadly bloodborne pathogen that can be spread through IV drug use. PrEP has shown to drastically decrease its transmission, however utilization rates among PWID is low. Low awareness and limited knowledge of PrEP among PWID is a known barrier to start PrEP as demonstrated by existing evidence and the current study. Finding an effective way to disseminate information about PrEP among all PWID, not just those that partake in harm reduction services, is a critical step to decrease rates of HIV through the use of PrEP. Additionally, establishing a streamlined referral process for those interested in PrEP is crucial to success so that opportunities are not missed when an individual is ready to take action. Significant research is still desperately needed about this topic and population, but an important starting point has been established with this study.

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Table 1. PrEP Survey Results

PrEP Survey Results (N=33)

	Yes	No	Not sure
Prior to reading this handout, I had heard of pre-exposure prophylaxis (PrEP) for HIV.	16 (48%)	15(45%)	2(6%)
I learned something about PrEP that I didn't already know.	24(73%)	6(18%)	3(9%)
I am interested in taking PrEP.	7(21%)	18(55%)	8(24%)
I am willing to be referred to a provider to start PrEP.	6(18%)	17(52%)	10(30%)

Appendix A. Cover Letter

Dear Potential Participant:

Researchers at the University of Kentucky are inviting you to take part in reviewing an educational brochure and completing a short questionnaire about pre-exposure prophylaxis (PrEP) for HIV prevention.

The purpose of this study is to educate the public about PrEP and to understand the public's awareness and attitudes towards PrEP. It is important for you to know that researchers will not be reviewing or collecting any information that identifies you. If you do not want to be in the study, there are no other choices except not to take part in the study. Reviewing the brochure and completing the questionnaire should take less than 5 minutes.

Although we have tried to minimize this, some questions or the subject of the survey may make you upset or feel uncomfortable and you may choose not to answer them. If some questions do upset you, please notify a staff member and they will direct you to a mental health counselor you can speak with.

Your response to the questionnaire is anonymous which means no names, email addresses, or any other identifiable information will be collected with the survey responses. We will not know which responses are yours if you choose to participate.

We hope to receive completed questionnaires from up to 500 people, so your answers are important to us. Of course, you have a choice about whether or not to review the brochure and complete the questionnaire, but if you do participate, you are free to skip any questions or discontinue at any time. You will not be penalized in any way for skipping or discontinuing the survey. Once you are finished with the survey, tear it off and place it in the locked box. The brochure is yours to keep.

If you have questions about the study, please feel free to ask; contact information is given below.

Thank you in advance for your assistance with this important project.

Sincerely,

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If you have complaints, suggestions, or questions about your rights as a research volunteer, contact the staff in the University of Kentucky Office of Research Integrity at 859-257-9428 or toll-free at 1-866-400-9428

Appendix B. Educational Handout

WHAT IS PREP?

PrEP is a daily medication that can decrease your chances of getting HIV through intravenous drug (IV) use and sex (CDC, 2022)



REFERENCES

CDC. (2022, June 3). *PrEP (Pre-Exposure Prophylaxis)*. Centers for Disease Control and Prevention. Retrieved July 1, 2022, from <https://www.cdc.gov/hiv/basics/prep.html>

NPS. (2018). *Prep on the PBS: An opportunity in HIV prevention*. NPS MedicineWise. Retrieved July 1, 2022, from <https://www.nps.org.au/news/pr-eps-on-the-pbs-an-opportunity-in-hiv-prevention>

PrEP Daily. (2020, May 12). *How does prep prevent HIV transmission?* PrEP Daily. Retrieved July 1, 2022, from <https://prepdaily.org/how-does-prep-prevent-hiv-transmission/>


PRE-EXPOSURE PROPHYLAXIS (PREP) TO PREVENT HIV



HOW EFFECTIVE IS PREP?

When taken as prescribed, PrEP:

- Decreases risk of HIV from sex by **99%**
- Decreases risk of HIV from IV drug use by **74%**



➤ To achieve the *best protection* from HIV from **receptive anal sex**, it will take **7 days** of taking PrEP

➤ To achieve the *best protection* from HIV from **receptive vaginal sex and IV drug use**, it will take **21 days** of taking PrEP (CDC, 2022)


DOES PREP HAVE SIDE EFFECTS?

While PrEP is safe, some people may experience side effects such as headache, diarrhea, nausea, fatigue or abdominal pain (CDC, 2022)

HOW MUCH DOES PREP COST?

PrEP is free with most health insurance and with Medicaid (CDC, 2022)

ONLY YOU CAN DECIDE IF PREP IS RIGHT FOR YOU.



Appendix C. PrEP Survey

PREP SURVEY



Prior to reading this handout, I had heard of pre-exposure prophylaxis (PrEP) for HIV.

Yes No Not sure

I learned something about PrEP that I didn't already know.

Yes No Not sure

I am interested in taking PrEP.

Yes No Not sure

I am willing to be referred to a provider to start PrEP.

Yes No Not sure