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Perceptions of Pre-Exposure Prophylaxis Among American Indians

William Joshua Johnson
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Walden University

College of Nursing

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William Joshua Johnson

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Walden University
2024

Abstract

Perceptions of Pre-Exposure Prophylaxis Among American Indians

by

William Joshua Johnson

PMC, Anderson University, 2020

MSN, Duke University, 2015

BS, Duke University, 2011

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Nursing

Walden University

December 2024

Abstract

American Indians have seen a rise in the transmission of HIV infections compared to other racial and ethnic groups. Pre-exposure prophylaxis (PrEP), which is the use of antiviral medications to prevent HIV, there is insufficient literature to describe the acceptability, attitudes, or willingness to utilize PrEP by American Indians. The purpose of this descriptive qualitative study, guided by the health belief model, was to explore perceptions of PrEP among American Indians. Open-ended semi structured questions were used to interview eight participants to ascertain perceptions of PrEP to prevent HIV infections. Using coding and thematic analysis, four themes were identified: (a) advantages of PrEP, (b) barriers to implementation of PrEP, (c) facilitators to implementation of PrEP, and (d) female-specific concerns regarding PrEP. The findings and recommendations of the study have the potential to support positive social change by decreasing the incidence, prevalence, and mortality associated with HIV among American Indians given their positive perception of PrEP. Addressing barriers to the implementation of PrEP among American Indians can be remedied by educating American Indians about their risk factors for HIV, available options to decrease risk, provide referrals to providers who are offering PrEP. Future research is needed to validate these findings in a larger sample and to characterize further the facilitators and barriers to aid in implementing PrEP among American Indian tribes.

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Dedication

May this work change the HIV prevention experience among American Indians. As this work will demonstrate, the perceptions of American Indians at risk for HIV have continued to evolve as have the methods for HIV prevention. Now more than ever, American Indians desire a multimodal comprehensive approach to the prevention of HIV that takes into account the culture, values, and history of indigenous people. This work is dedicated to those who have died from a disease that may have once been prevented. May the prevention of HIV continue to be my life's work as an American Indian scholar-practitioner until a cure for HIV is found.

Acknowledgments

First, I acknowledge that this work would not have been possible without the God who reigns within me. His clarion call has been to serve Him and to make this world a better place until His triumphant return.

Second, I thank my father, mother, sister, brother-in-law, and my nieces and nephew, who believed I could achieve this lofty goal. To my friends, extended family, and church family, who urged me to put pen to paper until it was completed: I thank you for your encouragement.

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Chapter 1: Introduction to the Study

Introduction

Human immunodeficiency virus (HIV) is a virus acquired by the exchange of bodily fluids that attacks the host's immune system resulting in significant morbidity and mortality (Centers for Disease Control and Prevention [CDC], 2021). Advances in medicine have resulted in the development of antiretroviral medications that suppress the virus's effect on the immune system. Nevertheless, HIV remains a chronic, incurable infection that requires lifelong monitoring, laboratory studies, and medications (CDC, 2021). Consequently, researchers have sought to identify, evaluate, and implement strategies that effectively prevent HIV infections.

To date, HIV prevention has traditionally focused on sexual education, abstinence, and condom use. However, these interventions are not universally accepted or effective in diverse groups (King et al., 2022; Mayer et al., 2020). Furthermore, in resource-poor countries, access to condoms and the inability to negotiate condom use has fettered the preventive impact of condom use on HIV transmission (Grant et al., 2010; King et al., 2022). Consequently, researchers sought novel interventions with high efficacy to decrease HIV transmission across diverse populations and countries.

Pre-exposure prophylaxis (PrEP), the use of antiviral medications to prevent HIV, is a powerful tool in the armamentarium against HIV infection. Since PrEP's inception, Truvada (or emtricitabine/tenofovir fumarate) as a biomedical HIV prevention intervention had a 95% to 99% efficacy rate in clinical trials across resource-poor and rich settings (Grant et al., 2010). However, because Truvada required routine monitoring

of bone mineral density, liver function, and kidney function, its implementation in resource-poor and rural settings was limited (Grant et al., 2010; Mayer et al., 2020).

PrEP has continued to evolve in both safety and delivery modalities. Mayer and colleagues (2020) demonstrated the efficacy of Descovy (or emtricitabine/tenofovir alafenamide). Descovy provides the same efficacy as previous formulations of PrEP but is less likely to result in impaired renal function or to induce bone density changes (Mayer et al., 2020). As a result, resource-poor and rural settings were able to achieve similar reductions in HIV transmission. In 2022, a long-acting injectable formulation of PrEP became available, consequently reducing pill burden without sacrificing efficacy (King et al., 2022).

American Indians have seen a rise in the transmission of HIV infections compared to other racial and ethnic groups (CDC, 2021). Research has demonstrated PrEP's efficacy in other ethnic minorities (Alt et al., 2022; Grant et al., 2018; Iniesta et al., 2018; Johnson et al., 2020; Mayer et al., 2020; Shangani et al., 2021) but despite the prevailing disparities of HIV transmission in American Indians, there is insufficient literature to describe the acceptability, attitudes, or willingness to utilize PrEP by American Indians. Thus, this study is needed to better understand what American Indians know about this biomedical intervention and if they are willing to use it for HIV prevention. The study has implications for positive social change in that PrEP has the potential to alter the trajectory of HIV trends in this vulnerable population.

Chapter 1 will provide an overview of the topic, including the background of the problem and problem statement, the purpose of the study and the research questions, the

theoretical framework, the nature of the study, definitions of the key concepts, underlying assumptions, and the scope, delimitations, limitations, and significance of the study.

Background

American Indians continue to experience increased incidence and prevalence of HIV (CDC, 2021). The CDC (2021) reported that American Indians experienced 230 new HIV infections in 2019. Moreover, the prevalence of HIV among American Indians was approximately 200.8 HIV infections per 100,000 people in 2019 (CDC, 2021). American Indians have experienced an HIV pandemic, in which they are the only ethnicity with an increasing number of HIV infections; American Indians are more likely to be unaware of their HIV status and are more likely to die because of advanced HIV disease at the time diagnosis (Armenta et al., 2021; Ehrenpreis & Ehrenpreis, 2022; Town et al., 2021).

In the limited and dated research directed at HIV prevention in American Indians, researchers have concentrated on educational interventions and behavioral risk factor modification (Negin et al., 2015). To date, condom education, comprehensive sexual education, and harm reduction strategies have yet to demonstrate consistent, long-term efficacy in HIV prevention among American Indians (Shangani et al., 2021). However, the use of antiviral medications to prevent HIV infections, or PrEP, is 95% to 99% effective in preventing HIV among other ethnicities (Mayer et al., 2020; Shangani et al., 2021). Although the safety, efficacy, acceptability, attitudes, and willingness to use PrEP are well documented for most minorities (Alt et al., 2022; Fallon et al., 2017; Grant et al., 2018; Iniesta et al., 2018; Johnson et al., 2020; Volk, 2015), insufficient literature exists to describe the perceptions of PrEP among American Indians.

This qualitative study is needed because there is little understanding of what American Indians know about PrEP and whether they are willing to use it for HIV prevention. The information generated from this study can serve as the basis for further research to develop best practices when it comes to HIV prevention strategies tailored to address the needs of American Indians, a vulnerable and frequently overlooked population.

Problem Statement

HIV infections continue to grow among American Indians while other ethnic minorities in the United States have realized declines in new HIV infections (CDC, 2021). To date, studies that have sought to reduce HIV infections among American Indians have concentrated on educational interventions and behavioral risk factor modification despite their limited effectiveness (Lee et al., 2018). PrEP has been demonstrated to be 95% to 99% effective in preventing HIV among other ethnicities in the United States (Mayer et al., 2020; Shangani et al., 2021), yet no studies have explored American Indians' attitudes regarding or willingness to utilize PrEP. Consequently, the problem is that while PrEP is effective in preventing HIV infections (Mayer et al., 2020; Shangani et al., 2021); no studies have sought to determine the perceptions of PrEP among American Indians who remain disproportionately affected by HIV (CDC, 2021).

Purpose of the Study

Given the disparities among American Indians related to the incidence, prevalence, and rates of spread of HIV infections (CDC, 2020; CDC, 2021), the purpose

of this qualitative study is to explore perceptions of PrEP among American Indians utilizing a descriptive qualitative design.

Research Question

This qualitative dissertation will seek to address: What are the perceptions of American Indians regarding the use of PrEP to prevent HIV infection?

Theoretical Framework for the Study

Overview

The health belief model is a theory developed by Hochbaum et al. (1952) to explain why individuals are hesitant to practice health-promoting behaviors. The theory is composed of three central constructs: (a) modifying factors, (b) individual beliefs, and (c) action. Modifying factors are demographic variables (e.g., age), sociopsychological barriers (e.g., societal norms), and structural variables (e.g., awareness or knowledge) that influence the perception of risk (Hochbaum et al., 1952). Individual beliefs as a construct in the health belief model are a composite of five subconstructs regarding an individual's perception of susceptibility, perception of severity, perception of benefits, perception of barriers, and cues to action (Hochbaum et al., 1952). The final construct of the health belief model is action. Action is an individual's performance or nonperformance of health-promoting behaviors (Hochbaum et al., 1952). Exploring the attitudes of American Indians regarding the use of PrEP to prevent HIV infection aligns with the health belief model's constructs of modifying factors, individual beliefs, and action.

Theoretical Propositions

The health belief model has three underlying assumptions: (a) that individuals have a desire to avoid or prevent disease or illness, (b) that health-promoting behaviors or programs can reduce the likelihood of disease or illness, and (c) that an individual's perceptions, based upon their knowledge and attitudes, influence or preclude involvement in health-promoting behaviors or programs (Hochbaum et al., 1952). Additional information regarding the health belief model, its theoretical constructions, and assumptions are described in further detail in Chapter 2.

Theoretical Relevancy to the Research Problem

The logical connection between the health belief model and the nature of my study is that the health belief model is used in research to explain an individual's action or inaction to practice health-promoting behaviors (Hochbaum et al., 1952). The health belief model will serve as a theoretical framework to explore the perceptions that contribute to taking action or inaction in using PrEP. Given the health belief model's assumptions, the uptake of PrEP is more likely if American Indians are aware of and have a favorable perception of PrEP (Hochbaum et al., 1952). Consequently, the health belief model can be utilized to address this research problem. The health belief model lends itself to qualitative research to explore American Indians' perceptions of PrEP through semistructured interviews. I developed a semistructured interview guide utilizing the constructs from the health belief model to obtain qualitative data for constant comparative analysis.

Nature of the Study

I utilized a qualitative descriptive design to explore the perceptions of PrEP by American Indians. The qualitative descriptive design is utilized when: (a) the phenomenon has not been widely explored, (b) when the researcher seeks to describe the concept of interest rather than develop a theory, and (c) when the phenomenon is subjective and needs to preserve the differences among subjects (Doyle et al., 2020). Perceptions of PrEP to prevent HIV among American Indians have not been sufficiently explored in the literature. Consequently, I selected the qualitative descriptive design because this design facilitated my exploration of the perceptions of PrEP among American Indians using the participants' language from interviews. Furthermore, the perceptions of PrEP can vary from individual to individual, so the descriptive approach provided opportunities to highlight these commonalities and differences.

The inclusion criteria for this study were: individuals age 18 or older, those living in southeastern North Carolina, and those who speak the English language from a Facebook group who identify as members of an American Indian tribe located in the southeastern United States. The exclusion criteria for the study included: those individuals younger than 18; individuals who are not American Indian; and individuals who are patients, acquaintances, or colleagues of the researcher. Purposive sampling was used to recruit subjects because I was seeking the perspectives of adult American Indians who are at risk for contracting HIV (see Campbell et al., 2020). Additional participants would have been identified utilizing snowball sampling if required. Participants could

choose to complete the 60-minute interviews in person or via Zoom web-based conferencing platform.

The interviews were facilitated utilizing semistructured, open-ended questions. Follow-up probing questions were utilized based on participants' responses, stories, and comments to gain additional insight. The audio portion of the interviews was recorded using a Sony digital voice recorder. The interviews were transcribed by me to gain familiarity with the interview content. Data analysis began at the end of each interview utilizing the constant comparative analysis process. The interview data were utilized to develop codes, and codes were employed to derive themes. Interview data were compared to the audio recordings to ensure the validity and reliability of the content. Successive interviews were transcribed, and the codes developed were compared to existing codes to either validate current themes or develop new themes. Interviews ended when the data were saturated. Data saturation occurs when data from subsequent interviews no longer leads to the development of new codes or themes (Hennink & Kaiser, 2022).

Definitions

The following definitions are concepts and constructs utilized in this study:

American Indians: Individuals who identify as American Indian and have a “shared tribal culture, history, language, religion, or familial kinships” (Bureau of Indian Affairs, n.d.).

Attitudes toward PrEP: An individual's feelings or ways of regarding something (Voglino et al., 2021). In this study, attitudes towards PrEP American Indians' disposition or feelings towards using PrEP as prevention against HIV infections.

Awareness of PrEP: Knowing or being familiar with antiviral medications that can be taken to prevent HIV infection (Yi et al., 2017).

Perceptions of PrEP: Beliefs or opinions formed based on knowledge or experience (Protiere et al., 2023; Voglino et al., 2021).

Pre-exposure prophylaxis (PrEP): The use of antiviral medications to prevent HIV infection (Grant et al., 2020).

Assumptions

The following assumptions underly this study to explore the perceptions of PrEP among the American Indian population. I assumed participants would be honest in their responses to interview questions. It was necessary to assume the participants would be honest so the results have validity. An interviewer should establish a rapport with participants and address any privacy concerns so that participants feel they can speak freely (Marshall & Rossman, 2011).

Scope and Delimitations

The extant research on HIV prevention in American Indians has focused primarily on American Indian children and American Indian youth because condom use and sexual education can be introduced early to prevent the development of risky sexual behaviors. Research on the use of PrEP among American Indian adults remains lacking. Before the implementation of PrEP in the American Indian population it is important to understand

how American Indians perceive PrEP (Smith et al., 2022). Therefore, I explored the perceptions of PrEP among the adult American Indian population.

While PrEP has historically been a part of a comprehensive HIV prevention program to include condom use and comprehensive sexual education, PrEP is currently only FDA-approved for use in sexually active teenagers and adults to prevent HIV infections (Antoni et al., 2020; Grant et al., 2010; Mayer et al., 2020). As such, I recruited American Indians living in southeastern North Carolina who were 18 or older and who spoke English. Exclusion criteria included individuals who were my patients, acquaintances, or colleagues, given the sensitive nature of the patient-provider relationship and the sensitive content discussed during the interviews. Interviews ended when data saturation was reached. Data saturation is achieved when interview data no longer provides additional insights, when the codes are consistent with existing codes, and when no new themes emerge from the data.

Several theoretical models could have served as a lens through which the perceptions of American Indians regarding PrEP could have been explored. Icek Ajzen's (1991) theory of planned behavior utilizes three constructs to examine how intention influences behavioral changes. However, the theory of planned behavior's theoretical assumptions seek to describe how outside influences (e.g., an individual's partner's beliefs or societal norms) impact an individual's perception of health behavior. Similarly, Bronfenbrenner's socio-ecological model (1977) allows a researcher to examine the influence of many layers of personal attributes (e.g., various social determinants of health) on behavioral change. The socio-ecological model's theoretical assumptions

assert that interpersonal relationships, community, and societal influences have a significant impact on behavioral change (Ajzen, 1991; Bronfenbrenner, 1977). While these and other theoretical models have been utilized to understand a population's willingness to adopt behavioral interventions, their utility is in aiding researchers to explore how outside influences shape a population's perception of the intervention. Because the health belief model is a proven theoretical lens for researchers to understand how an individual's perceptions influence the adoption of a health behavior, it was selected to explore the perceptions of American Indians regarding PrEP (Felsher et al., 2018; Felsher et al., 2022; Ndebia, & Obioha, 2020; Van Gerwen et al., 2022).

Transferability, in qualitative research, is the extent to which the results of a study can be applied to other situations or settings; however, this is not the purpose of this study because each response is unique (see Creswell & Creswell, 2018). This study was conducted to explore the perceptions of PrEP among American Indians at risk for HIV. American Indians are not a homogenous population. American Indians' knowledge, values, and beliefs may vary not only from tribe to tribe but may vary from person to person within a particular tribe. Thus, the transferability of the findings of this study is unique to this tribe and may be limited to the tribe explored. Consequently, future studies will be needed to understand the commonalities and differences in perceptions regarding PrEP among American Indians from varying tribes.

Limitations

A significant limitation of this study is inherent in the population of interest. American Indians are not a homogenous population. Their opinions, practices, and beliefs

may vary from tribe to tribe, which limits the transferability of the study's findings.

While the findings of this study may not be generalizable to the entire American Indian population, it will contribute to describing the perceptions of PrEP in American Indians living in southeastern North Carolina.

Another limitation of the study is the recruitment of participants utilizing social media. While social media may help reach a broad segment of the intended population, it may unintentionally delay the self-selection (or election) of participants. Additionally, using social media for recruitment may result in a sample that underrepresents individuals who are not computer literate, who do not have a social media presence, or older American Indians who may not use computers. To address these challenges, purposive and snowball sampling was utilized to reach the largest sample for qualitative interviews. However, if saturation is reached by utilizing participants from social media alone, the sample may not be representative of those without social media, those who lack computer skills, and older adults. Finally, to address the challenge of reciprocity in the participant-researcher relationship, I provided a nominal \$15 gift card in remuneration for their time participating in the interviews.

Bias in qualitative studies is generally referred to in terms of the researcher and the participant (Creswell & Creswell, 2018). Researcher bias is generally overcome through recognition of bias. In this study, I acknowledged that I believe PrEP to be a powerful tool in the armamentarium of HIV prevention. However, the purpose of this study is to understand the perceptions of PrEP among other American Indians. To obtain objective results, I acknowledge that other American Indians may be unaware of PrEP,

uninterested in PrEP, or perceive they are not at risk for HIV. In addition, I utilized reflexive journaling during the data collection and analysis to mitigate any preconceptions I may have about the topic or the population (see Ravitch & Carl, 2021). To this end, I utilized open-ended questions to obtain the participants' narratives in their own words. When clarification was needed, follow-up questions were framed as objectively as possible to preserve the participant's autonomy. Similarly, as the data were analyzed and presented, I used the transparency of the participants' own words to describe findings regarding perceptions of PrEP utilizing direct quotations to code and derive themes.

Participant bias is introduced when participants know the researcher or when participants answer questions in a way to please the researcher (Creswell & Creswell, 2018). To avoid participant bias, I excluded any participants I knew personally, professionally, or academically. Furthermore, the interview guide contained open-ended questions. Similarly, follow-up questions and probing questions were also utilized in an open-ended fashion. For example, I might have said, "Could you say more about that?" or "How did you arrive at that conclusion?" Open-ended questions and non-leading terms assist in obtaining information, clarifying participants' answers or exploring participants' decision-making while avoiding undue influence in participants' responses.

Significance

HIV infections are a serious threat to the American Indian population. Infections continue to grow in the American Indian population while other ethnic minorities' infections remained stable or have experienced declines in infections (CDC, 2020).

Coupled with the increased incidence and prevalence of HIV, American Indians are often less aware of their HIV status, are more likely to be lost to follow-up care, and are less likely to be virologically suppressed than other ethnicities (CDC, 2020). Unless novel interventions are introduced, the American Indian population will continue to be disproportionately affected by HIV and experience disparate outcomes.

Nursing practice and the current HIV prevention strategy have inadequately addressed the disproportionate incidence and prevalence of HIV among American Indians. This descriptive qualitative study may inform practice and policy by providing a foundational understanding of American Indians' perceptions of PrEP. If American Indians are interested in PrEP as a form of HIV prevention, additional research will be needed to determine its transferability to other tribal nations.

While the perceptions of PrEP are well documented in the literature for most minorities (Fallon et al., 2017; Iniesta et al., 2018; Johnson et al., 2020), there is little to no literature describing the perceptions of PrEP by American Indians. Consequently, research is needed to understand the perceptions of PrEP in this unique population. If American Indians have positive perceptions of PrEP, this study has the potential to serve as a catalyst for implementing PrEP in the American Indian population. Thus, this study has the potential to create positive social change by adding to the armamentarium of HIV prevention tools among American Indians, which should decrease the incidence and morbidity of HIV infections that disproportionately impact American Indians.

Summary

American Indians continue to experience increased incidence and prevalence of HIV (CDC, 2021). Furthermore, American Indians are more likely to be unaware of their HIV status and are more likely to die because of advanced HIV disease at the time of diagnosis (Armenta et al., 2021; Ehrenpreis & Ehrenpreis, 2022; Town et al., 2021). The use of antiviral medications to prevent HIV infections, or PrEP, is 95% to 99% effective in preventing HIV among other ethnicities (Mayer et al., 2020; Shangani et al., 2021). However, insufficient literature exists to describe the perceptions of PrEP by American Indians. Thus, the purpose of this study was to explore the perceptions of PrEP to prevent HIV infections among American Indians. A descriptive qualitative design was used to answer the research question: What are the perceptions of American Indians regarding the use of PrEP to prevent HIV infection? The health belief model was utilized to frame this study. A sample of American Indian adults were recruited via social media utilizing purposive and snowball sampling. This study is significant because it will contribute to the dearth of literature that describes the acceptability, attitudes, and willingness to use PrEP among the American Indian population.

In Chapter 2, I present the extant literature on the topic of PrEP and its use among American Indians, including how HIV has affected American Indians, the research about the HIV prevention strategies previously utilized among American Indians, the efficacy and utilization of PrEP, and the rationale for exploring PrEP in American Indians.

Chapter 2: Literature Review

Introduction

Prevention of HIV has significantly evolved since the virus's debut in the 1980s. Prevention science has led scientists to focus on the prevention of HIV in two significant ways: behavioral modification or pharmacologic treatments (Antoni et al., 2020; Mayer et al., 2020). While medications aimed at preventing HIV will always be part of a comprehensive approach to HIV prevention, behavioral approaches such as sex education, condom use, and harm reduction have not yielded the same efficacy (Antoni et al., 2020; Iniesta et al., 2018; Mayer et al., 2020). Comprehensive sexual education programs and harm reduction strategies have yet to demonstrate consistent, long-term efficacy in HIV prevention (Shangani et al., 2021). PrEP, the focus of this research, is 95% to 99% effective in preventing HIV compared to condoms (90%; Antoni et al., 2020; Mayer et al., 2020; Shangani et al., 2021). Given the consistent, long-term efficacy of PrEP, HIV prevention researchers have sought to explore attitudes, perceptions, and willingness to use PrEP for HIV prevention across ethnicities, countries, and sexual orientations (Fallon et al., 2017; Iniesta et al., 2018; National Academies of Sciences & Medicine, 2021; Pinto et al., 2019).

Although there have been global attempts to explore attitudes, perceptions, and willingness to use PrEP for HIV prevention across ethnicities, countries, and sexual orientations, research has not examined these concepts in Native Americans, a population disproportionately affected by HIV (Fallon et al., 2017; Felsher et al., 2018; Iniesta et al., 2018; King et al., 2022). While every other ethnicity experienced a 9%-40% decline in

new HIV infections in 2019, American Indians experienced a 25% increase in HIV infections (CDC, 2020, 2021). The CDC reports American Indians experienced 230 new HIV infections in 2019 (CDC, 2021). Moreover, the prevalence of HIV among American Indians was approximately 200.8 HIV infections per 100,000 people in 2019 (CDC, 2021). Finally, American Indians are often less aware of their HIV status, are more likely to be lost to follow-up care, and are less likely to be virologically suppressed than other ethnicities (CDC, 2020). Thus, I aim to explore the perceptions of PrEP as a biomedical intervention to prevent HIV infection in American Indians utilizing a descriptive qualitative design.

In this chapter, I describe the literature search strategy utilized to perform a literature review, the theoretical framework used in this study, describe the health belief model, which is the conceptual model for this study, and present the extant literature on the topic of PrEP and its use among American Indians including how HIV has affected American Indians, the research pertaining the various HIV prevention strategies utilized with American Indians, the efficacy and utilization of PrEP, and the rationale for exploring PrEP in American Indians.

Literature Search Strategy

I searched for relevant literature from the PubMed, PsychInfo, PLOS, CINHAL, and Google Scholar databases. The search results were limited to peer-reviewed literature in professional journals, governmental reports and data, and books published in the last 5 years. I utilized the following search terms in various combinations: *human immunodeficiency virus, HIV, acquired immunodeficiency syndrome, American Indian,*

Native American, Indigenous American, pre-exposure prophylaxis, PREP, health belief model, and HIV Prevention.

Initially, I obtained 54 results using these search terms. However, when identical results (5) and irrelevant results (21) were removed, I was left with 28 results. Articles were considered irrelevant if they did not reference the American Indian population or if American Indians were not in the referenced sample.

The final search terms were utilized to identify peer-reviewed literature published in the last 5 years. The final search term combinations included: *American Indian or Native American and HIV or human immunodeficiency virus* (15 results), *American Indian or Native American and pre-exposure prophylaxis or PrEP* (2 results), and *health belief model and human immunodeficiency virus or HIV and prevention and American Indian or Native American* (11 results). Additionally, I identified seven articles utilizing the reference lists of articles above and five journal articles cited by the articles identified above. Ultimately, I was left with 40 articles for the literature review.

Conceptual Framework

Introduction

The health belief model is a conceptual model designed to explain why individuals decide to participate in health promotion programs (Hochbaum et al., 1952). During the health belief model's development, epidemiologists at the CDC were primarily involved in prevention research (Hochbaum et al., 1952). The health belief model helped researchers to explain human behavior from six points of view.

Hochbaum et al. (1952) conceptualized the model into six main concepts: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy. Perceived susceptibility is an individual's perception of acquiring the disease (Hochbaum et al., 1952). In contrast, perceived severity is the individual's perception of morbidity or mortality if the disease is acquired (Hochbaum et al., 1952). Consequently, perceived benefits are the individual's belief that the program will reduce the threat associated with the disease (Hochbaum et al., 1952). In comparison, perceived barriers are the subjective view of the impediments that prevent program adherence or behavioral change (Hochbaum et al., 1952). Cues to action are internal or external triggers that influence an individual's perceptions that change is necessary (Hochbaum et al., 1952). Finally, self-efficacy is the individual's belief they can perform the behavioral change or complete the program (Hochbaum et al., 1952).

Assumptions

Assumptions are guiding principles that one must adopt for the theoretical model to be of value in a research design (Creswell & Creswell, 2018). The health belief model has three main concepts: (a) that individuals have a desire to avoid or prevent disease or illness, (b) that health-promoting behaviors or programs can reduce the likelihood of disease or illness, and (c) the individual's perceptions, based upon their knowledge and attitudes, will influence or preclude involvement in health-promoting behaviors or programs (Hochbaum et al., 1952).

Previous Applications of the Health Belief Model

The health belief model has been utilized extensively in HIV prevention and treatment literature to clarify the knowledge, attitudes, and practices of individuals and healthcare providers (Felsher et al., 2018; Felsher et al., 2022; Ndebia, & Obioha, 2020; Van Gerwen et al., 2022). The Health Belief Model affords qualitative and quantitative researchers the ability to explore individual and group knowledge, attitudes, and practices from the purview of disease perception of risk, risk tolerance, and the likelihood of taking action to prevent or treat disease (Felsher et al., 2018; Felsher et al., 2022; Ndebia, & Obioha, 2020; & Van Gerwen et al., 2022). Additionally, the health belief model can also be used to identify how an individual's identity may modify their willingness to utilize prevention methods (e.g., PrEeP) (Van Gerwen et al., 2022). Moreover, the health belief model can also be used to explore the effectiveness of cues to action (e.g., advertisements) on the willingness to utilize prevention methods. Finally, the health belief model has been used deductively to explain prevention phenomena (Felsher et al., 2022; Ndebia, & Obioha, 2020; & Van Gerwen et al., 2022) and inductively to explain prevention phenomena (Felsher et al., 2020).

The health belief model has been utilized extensively to understand populations' willingness to implement HIV prevention interventions. The health belief model has been used to examine interventions (Calaguas, 2020; Funmilayo & Juliana, 2020; Lalo et al., 2020; Parent et al., 2020), diverse populations (Calaguas, 2020; Funmilayo & Juliana, 2020; Lalo et al., 2020), the concepts of health belief model in HIV prevention

(Funmilayo & Juliana, 2020; Lalo et al., 2020; Parent et al., 2020), and in previous PrEP studies (Parent et al., 2020).

Rationale

As such, the health belief model is a model that has the key concepts and theoretical assumptions that guide this dissertation. American Indians desire to have safe and effective interventions to prevent HIV (Lee et al., 2018). PrEP has been demonstrated to be effective in other populations in the prevention of HIV (Grant et al., 2010; Iniesta et al., 2018). Similarly, studies have shown that attitudes and knowledge largely influence an individual's willingness to initiate PrEP (Fallon et al., 2017; Iniesta et al., 2018; Lee et al., 2018; Volk et al., 2015; Yao et al., 2018). Consequently, this dissertation meets the three main assumptions of the health belief model.

Relationship to this Study

Furthermore, the concepts of perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and self-efficacy can be operationalized to understand the attitudes, knowledge, and willingness to utilize PrEP among American Indians. Like others (Felsher et al., 2022; & Van Gerwen et al., 2022), I intend to develop my structured interview guide based on these operationalized concepts to understand American Indians' perceptions of PrEP's role in HIV prevention. This deductive approach facilitated the collection of rich qualitative data from semistructured interviews for analysis.

Literature Review Related to Key Variables and/or Concepts

Recent Epidemiologic Trends in HIV Infections Among American Indians

American Indians experience many health inequalities, but few are as distinct as those found in HIV. Unlike other minorities with stable or declining HIV infection rates, American Indians experienced a 20% increase in HIV infections in 2019 (CDC, 2021). This increase demonstrates that current HIV prevention efforts do not have the same effect on the American Indian population. Moreover, the prevalence of HIV among American Indians was approximately 200.8 HIV infections per 100,000 people in 2019 (CDC, 2021); thus, the prevalence of HIV in American Indians is roughly twice that of those observed in Caucasians. Moreover, the CDC and the Indian Health Service have not partitioned the data on HIV incidence and prevalence according to age and gender, rendering it impossible to identify and design prevention programs for subgroups of American Indians that may be especially at risk. Meanwhile, increasing infections and higher than average prevalence of HIV is a palpable threat to the American Indian population.

Strategies to Prevent HIV Infections Among American Indians

Despite these disparities, the number of studies involving HIV prevention in American Indian communities is limited. Researchers have instead focused on the reasons for the lack of American Indian study participants in research. American Indians are believed to be at high risk for HIV infection because of culturally insensitive care, discrimination, intergenerational trauma, early sexual debut, poverty, and substance abuse (Armenta et al., 2021; Ehrenpreis & Ehrenpreis, 2022; Hafner & Craig Rushing,

2019; Jongbloed et al., 2019; Reilley et al., 2018). However, the challenges to the inclusion of American Indians in HIV prevention research varied. Researchers have found that values and beliefs often differ from tribe to tribe, American Indians live in remote locations, and their hesitancy to trust researchers has significantly impeded inclusion in research (Armenta et al., 2021; Black et al., 2018; Lee et al., 2018). Despite these confounding variables, researchers should include American Indians and utilize culturally acceptable interventions if HIV disparities are to be addressed in American Indian communities.

Condom Use

Education regarding condom use has been a pillar of HIV prevention worldwide, including among American Indians. Recent studies involving condom use in American Indians are limited to the adolescent population. Thus, generalizations cannot be extrapolated to the larger American population (Chambers et al., 2018; Chambers et al., 2020; Rosenstock et al., 2020). Consequently, the ability to describe patterns of condom use and condom self-efficacy in American Indian adults who remain at risk for HIV infection is limited.

Condom use in American Indian youth is largely shaped by three factors: (a) perceived HIV severity, (b) perceived vulnerability to HIV, and (c) condom self-efficacy. American Indian youth, in studies by Chambers et al. (2018), Chambers et al. (2020), and Rosenstock et al. (2020), reported an awareness of the prevalence and severity of HIV; however, the youth did not perceive themselves to be vulnerable to HIV and additionally reported a lack of condom self-efficacy. Thus, condom use remains

sporadic in this population. Consequently, efforts to increase American Indian youths' intent to use condoms should center on risk perception and condom use skill building.

Despite the inability to describe condom use in American Indian adults, the existing research on American Indian youth utilized the health belief model. The concepts of perceived HIV severity, perceived vulnerability to HIV, and intervention self-efficacy are theorized in the health belief model to influence protective behaviors (Hochbaum et al., 1952). In other words, individuals must perceive sufficient morbidity or mortality and perceived risk for illness to induce health-promoting behaviors. Consequently, because the health belief model has been utilized in previous condom use studies in American Indian youth, one may hypothesize that it has some utility in future studies regarding the prevention of HIV in American Indians.

In a quantitative study by Hafner et al. (2019), the researchers utilized tenets of the health belief model to examine the forms of interventions that might best change risk perception in young adults ages 15–24. The researchers utilized a fact sheet about risk factors for HIV acquisition in the control group; the fact sheet and an educational video in experimental group one; and the fact sheets, educational video, and a facilitated discussion in the experimental group. Unfortunately, the low number of participants ($n = 199$), unequal age distribution, and the use of longitudinal percent change among groups (positive, negative, and no change) in risk perception resulted in statistically insignificant results.

Rosenstock et al. (2020) attempted to assess the intention to use condoms in adolescents and young adults by utilizing educational sessions to improve condom self-

efficacy. In this quantitative study, the researchers used the protection motivation theory, which had not previously been utilized in the American Indian population. The protection motivation theory's underlying assumption is that response efficacy and condom self-efficacy mediate condom use intention in American Indians. Again, these assumptions had not been demonstrated in previous studies of American Indians. While condom self-efficacy positively mediated condom use intention in American Indian women, it was not reproducible in American Indian men (Rosenstock et al., 2020). Finally, given American Indian men not women, 64% versus 34%, overwhelmingly have greater autonomy regarding condom use, this study does little to increase condom use in American Indians.

Comprehensive Sexual Education

Comprehensive sexual education programs also influence American Indians' HIV prevention efforts. However, like condom use interventions, these studies have also focused largely on adolescents (Lee et al., 2018; Skye et al., 2021; Thomas et al., 2021; Tingey et al., 2020; Yao et al., 2018). Previous attempts at comprehensive sexual education programs also had theoretical limitations. Both, Lee et al. (2018) and Skye et al. (2021) attempted to adapt the educational programs to involve native traditions such as storytelling. In doing so, they used the community-based participation model as a conceptual framework for their programs. To balance the cultural appropriateness of the study and to obtain approval from tribal leadership, the programs were subjected to content constraints that may have limited their effectiveness (Lee et al., 2018; Skye et al., 2021). Consequently, the results of comprehensive sexual education interventions were mixed, but those demonstrating protective effects found them to be temporary.

Pre-Exposure Prophylaxis

PrEP is a novel biomedical form of protection against HIV. PrEP is the daily use of antiviral medication to prevent HIV in individuals who are at increased risk for HIV. Furthermore, when taken as prescribed, Truvada and Descovy are 99.7% effective against HIV acquisition and transmission (Mayer et al., 2020).

Previous versions of PrEP, Truvada, were associated with bone mineral loss and renal dysfunction (Grant et al., 2010). However, the newer PrEP formulation, Descovy, is not associated with bone or renal issues (Mayer et al., 2020). However, despite the risk of bone mineral loss and renal dysfunction individuals across ethnicities, sexual orientations, and socioeconomic statuses have found PrEP to be an acceptable form of prevention against HIV (Iniesta et al., 2018; Parent et al., 2020; Roth et al., 2019; Shangani et al., 2021).

Furthermore, PrEP is widely accepted when individuals are knowledgeable regarding PrEP's indication, availability, and efficacy. Despite the number of and quality of studies that assert PrEP's safety and effectiveness (Grant et al., 2010; Mayer et al., 2020), American Indians are underrepresented in clinical trials. While this does not imply that American Indians do not currently utilize PrEP, it does represent a gap in the HIV prevention literature that has the potential to change the HIV epidemic in the American Indian population.

Strengths and Weaknesses of the Extant Research

To date, there have been considerable HIV prevention intervention studies involving condom use and culturally appropriate comprehensive sexual education

targeted at American Indian adolescents (Lee et al., 2018; Parent et al., 2020; Pinto et al., 2019; Rosenstock et al., 2020; Skye et al., 2021; Thomas et al., 2021; Tingey et al., 2020; Town et al., 2021; Yao et al., 2018). Culturally appropriate comprehensive sexual education programs have not yielded a lasting effect on American Indians. Furthermore, Pearson et al. (2019) is the only study to date to target American Indian adults. Targeting certain age demographics does little to address HIV prevention in totality because there is virtually no data available on the incidence and prevalence of HIV among subgroups of American Indians. However, Pearson and colleagues only sought to address HIV prevention in American Indian women with comorbid behavioral health and substance use disorders. None of the research examined the use or effectiveness of PrEP in American Indians.

Strengths

Studies to date aimed at preventing HIV in American Indians have focused on condom use and comprehensive sexual education; however, they have also been foundational in determining the behavioral and education programming that the American Indian youth and adult women need (Armenta et al., 2021; Black et al., 2018; Chambers & Stockton, 2022; Ehrenpreis & Ehrenpreis, 2022; Hafner & Craig Rushing, 2019; Lee et al., 2018; Rosenstock et al., 2020; Skye et al., 2021; Tigey et al., 2020; Yao; 2018). The authors have demonstrated that American Indians are willing to participate and share sensitive information with researchers, but are underrepresented in research (Armenta et al., 2021; Black et al., 2018; Chambers & Stockton, 2022; Hafner & Craig Rushing, 2019; Lee et al., 2018; Rosenstock et al., 2020; Skye et al., 2021; Tigey et al.,

2020; Yao; 2018). The findings of these studies will continue to improve future programming involving abstinence, condom use, and comprehensive sexual health education. Finally, the findings in these studies will inform my ability to ascertain if newer biomedical HIV interventions, like PrEP, will complement condom use and comprehensive sexual education (Armenta et al., 2021; Black et al., 2018; Chambers & Stockton, 2022; Hafner & Craig Rushing, 2019; Lee et al., 2018; Rosenstock et al., 2020; Skye et al., 2021; Tigey et al., 2020; Yao; 2018).

Existing research has also demonstrated that the health belief model can be used as a conceptual framework for understanding how American Indians adopt or forgo HIV prevention strategies (Lee et al., 2018; Pearson et al., 2019; Thomas et al., 2021; Tingey et al., 2020; Town et al., 2021). Each study demonstrates American Indians act decisively when they perceive themselves to be at risk for HIV (Lee et al., 2018; Pearson et al., 2019; Thomas et al., 2021; Tingey et al., 2020; and Town et al., 2021). While the benefits of condom use and comprehensive sexual education in American Indian youth and adult women were temporal, these works demonstrate that interventions need to be repeated at an undetermined interval. As Mayer et al., (2020) emphasize PrEP requires ongoing patient-provider contact in 3-month intervals for sexually transmitted infection (STI) screening, but also every 6 months for laboratory testing. This ongoing patient-provider contact enables the healthcare provider to not only continue to engage with the patient regarding PrEP, but also strengthens the patient-provider relationship, provides for condom distribution and ongoing education, and offers interval sexual education. Consequently, this dissertation will use recent literature to explore American Indians'

perceptions of PrEP as an HIV intervention to complement rather than replace condom use and comprehensive sexual education using the health belief model as a conceptual model.

Challenges

Even though the extant research supported the effectiveness of educational programs based on the concepts of the health belief model, there were several apparent weaknesses present including: the diminished effects of the interventions over time, their overwhelming focus on a single subgroup namely adolescents, and their relatively small sample sizes (Black et al., 2018; Chambers & Stockton, 2022; Hafner & Craig Rushing, 2019; Lee et al., 2018; Rosenstock et al., 2020; Skye et al., 2021; Tigey et al., 2020; Yao; 2018).

To date, there have been considerable HIV prevention intervention studies involving condom use and culturally appropriate comprehensive sexual education targeted at American Indian adolescents (Lee et al., 2018; Rosenstock et al., 2020; Skye et al., 2021; Thomas et al., 2021; Tingey et al., 2020; Town et al., 2021; Yao et al., 2018). However, those programs have not yielded a lasting effect in the population. While each of the studies demonstrated an initial improvement by decreasing the risk for HIV based on measurement with a variety of instruments (Lee et al., 2018; Pearson et al., 2019; Skye et al., 2021; Thomas et al., 2021; Tingey et al., 2020; Town et al., 2021), the modest decrease in risk began to taper at 6 months post-intervention suggesting that comprehensive sexual education may need to be repeated.

Another challenge was the targeting of certain age demographics, which does little to address HIV prevention in totality since there is virtually no data available on the incidence and prevalence of HIV among subgroups of American Indians. Nonetheless, Pearson et al. (2019) is the only study to date to target American Indian adults. Pearson and colleagues sought to determine if treatment of underlying behavioral health disorders and comprehensive sexual education would reduce HIV acquisition in American Indian women.

In their study of 73 adult American Indian women, Pearson and colleagues (2019) found sexual education and the treatment of underlying mood disorders reduced the frequency of sexual intercourse while intoxicated and improved posttraumatic stress disorder symptoms. However, comprehensive sexual education did not change the rates of unprotected sex in this subgroup. Given unprotected sex is a significant risk factor for HIV acquisition, Pearson and colleagues' (2019) work reinforces that sexual education does little to reduce HIV risk among adult American Indian women. Accordingly, Pearson et al. (2019), suggest that additional interventions are needed to reduce HIV risk in American Indians.

Research Approach

Finally, the extant research was overwhelmingly quantitative in design (Chambers & Stockton, 2022; Hafner & Craig Rushing, 2019; Rosenstock et al., 2020; Skye et al., 2021; Tigey et al., 2020). Lee and colleagues (2018) were the only qualitative study that explored HIV prevention efforts. The overwhelmingly quantitative design limits the findings of the studies performed to date. For example, many researchers cited that the

intervention's effects were short-lived in the American Indian population (Chambers & Stockton, 2022; Hafner & Craig Rushing, 2019; Rosenstock et al., 2020; Skye et al., 2021; Tigey et al., 2020). Given that quantitative studies lack the rich narrative data that well-designed qualitative studies contain (Creswell & Creswell, 2018), researchers are unable to explain why the interventions did not demonstrate lasting change. Finally, this design limits these and other researchers who may attempt to modify and advance prior interventions in future studies. To ascertain the reasoning for these failures, future researchers must recreate these studies and then, in a mixed-methods design, interview the participants to determine their perceptions of why the interventions did not achieve longevity.

Summary and Conclusions

American Indians are experiencing an HIV pandemic in which they are the only ethnicity with an increasing number of HIV infections; American Indians are more likely to be unaware of their HIV status and are more likely to die because of advanced HIV disease at the time diagnosis (Armenta et al., 2021; Ehrenpreis & Ehrenpreis, 2022; Town et al., 2021).

HIV prevention interventions in American Indians have targeted mainly adolescents and adult women (Armenta et al., 2021; Black et al., 2018; Chambers & Stockton, 2022; Ehrenpreis & Ehrenpreis, 2022; Hafner & Craig Rushing, 2019; Lee et al., 2018; Rosenstock et al., 2020; Skye et al., 2021; Tigey et al., 2020; Yao, 2018).

While those studies have demonstrated that the health belief model is a robust theoretical framework to examine HIV prevention in American Indians, the results have also

determined that the benefits of interventions focusing on condom use and comprehensive sexual education in American Indian youth and adult women are temporal and that such interventions may need to be repeated for reinforcement at undetermined intervals.

Despite its known effectiveness in preventing HIV transmission and infection, no work to date has been identified that has explored the use of PrEP in this unique population (Grant et al., 2010; Mayer et al., 2020). If American Indians are to experience long-term decreases in the rates of HIV infection throughout their population, then researchers must consider the possibility of introducing and emphasizing the use of PrEP in this unique population. Furthermore, since the literature describing American Indian exposure to PrEP is in its infancy, one must begin with qualitative inquiry to evaluate American Indians' awareness, attitudes, and willingness to use PrEP.

In Chapter 3, I describe the research design of this qualitative dissertation utilizing evidence obtained from the literature review performed in this chapter. I describe the descriptive qualitative design and its appropriateness as a methodology in this study, the role of the researcher, participant recruitment, instrumentation, data analysis, issues of trustworthiness, and the ethical issues pertinent to the design.

Chapter 3: Research Method

Introduction

Given the disparities among American Indians related to the incidence, prevalence, and rates of spread of HIV infections (CDC, 2020; CDC, 2021), the purpose of this descriptive qualitative study was to explore the perceptions of PrEP among American Indians as a method to prevent HIV infections. In this chapter, I describe the descriptive qualitative design and its appropriateness as a methodology to explore the perceptions of PrEP among American Indians, the role of the researcher, participant recruitment, instrumentation, data analysis, issues of trustworthiness, and ethical issues pertinent to the design.

Research Design and Rationale

Research Question

I utilized a descriptive qualitative design to address the overarching research question: What are the perceptions of PrEP among American Indians to prevent HIV infection? Descriptive qualitative designs are utilized in research that aims to preserve participants' answers to a researcher's questions (Creswell & Creswell, 2018). In this descriptive qualitative design, I described the participants' perceptions of PrEP.

Concepts and Phenomenon

The concepts of interest in this study included: American Indians, PrEP, awareness of PrEP, attitudes of PrEP, and perceptions of PrEP and HIV infection. In this study, American Indians are defined as individuals who identify as American Indian and have a "shared tribal culture, history, language, religion, or familial kinships" (Bureau of

Indian Affairs, n.d.). PrEP is defined as the use of antiviral medications to prevent HIV infections (Grant et al., 2010). Awareness of PrEP is defined as knowing or being familiar with antiviral medications that can be taken to prevent HIV infection (Yi et al., 2017). Attitudes are an individual's feelings or ways of regarding something (Voglino et al., 2021). In this study, specifically, attitudes toward PrEP are defined as an individual's feelings or ways of regarding antiviral medications taken to prevent HIV infection. Perceptions of PrEP are defined as the beliefs or opinions of antiviral medications taken to prevent HIV infection based on their knowledge of or experience with PrEP (Protiere et al., 2023; Voglino et al., 2021). HIV infection is defined as a chronic viral infection in a human that attacks the host's immune system (Grant et al., 2010). Finally, the phenomenon of interest in this study was the perceptions of PrEP among American Indians as a form of HIV prevention.

Research Tradition

Descriptive qualitative design, as described by Sandelowski (2000), is a premier qualitative methodology used to describe how individuals feel about concepts of interest. The descriptive qualitative design describes participants' thoughts, opinions, and perspectives utilizing their own words. Consequently, the design lends itself to data collection through interviews, focus groups, and observations of participants.

Interviews and observation allow a researcher to spend time with the participant in a neutral setting. Qualitative interviews are vehicles that allow research participants to provide extended answers that would otherwise be limited by utilizing other approaches (Creswell & Creswell, 2018). Furthermore, the format uniquely provides the researcher

the ability to ask additional questions or probing statements to qualify and clarify participants' responses (Creswell & Creswell, 2018). Consequently, a researcher operates as a data collector but simultaneously as a data analyst throughout the research process.

The flexibility of a descriptive qualitative design provides opportunities for many forms of analysis. Conventional content analysis is often utilized in this design as it allows the themes to emerge from participants' responses rather than starting from themes found in the literature.

Rationale

A descriptive qualitative design was selected for this dissertation because it provides flexibility in sampling, data collection, and data analysis while preserving the objectivity, fidelity, and credibility of the subjects' responses. A qualitative design is often utilized when studying topics that are in their infancy and lack substantive literature and theoretical underpinnings (Doyle et al., 2019). As such, the descriptive qualitative design was utilized to describe participants' thoughts, opinions, and perspectives of PrEP utilizing direct participant quotes. Furthermore, the design lends itself to the use of interviews of participants. I interviewed participants utilizing an interview guide to obtain rich responses from American Indian participants who described their perceptions of the use of PrEP as a biomedical intervention to prevent HIV infection. Participants' responses were analyzed utilizing constant comparative analysis, which allowed me to highlight the perceptions of PrEP among American Indians utilizing their own words.

Conventional content analysis uses the participants' words to develop codes inductively through ascribed meanings or similarities rather than using a deductive

coding approach from a theory (Kleinheksel et al., 2020). I utilized NVivo qualitative software to organize the transcribed interviews and facilitate manual coding. The conventional content analysis method allows a researcher to ascribe meaning from the participants' words and phrases to form codes (Kleinheksel et al., 2020). The codes' commonalities and differences allow for the formation of groups of categories (Kleinheksel et al., 2020). Similarities and differences of the categories develop into themes. To maintain the fidelity of the participants' responses, data analysis tables are constructed demonstrating how participants' responses evolved into categories and later themes.

Role of the Researcher

In this study, my role as a researcher was defined as an observer-participant. Observer-participant researchers are defined as researchers who are involved in the collection of data from the participants but also are involved in the interpretation of the data collected using established qualitative designs (Collins & Stockton, 2022). The researcher is positioned to engage with the participants during data collection in a way that fosters participants' ability to express their answers freely, which may at times be perceived by the interviewer as supporting or opposing views.

As an observer, the researcher is also positioned to make observations of the participants. Consequently, I made observations regarding the participants' familiarity with the content, asked the participants to expound on their answers, and acknowledged the participants' hesitations or quickening in their responses (Collins & Stockton, 2022). Finally, I was also be involved in the analysis of the data collected. While a researcher

uses established qualitative data analysis by manually coding and deriving themes, the process of reflexivity provides opportunities for the researcher to engage with the participants and data collected in a manner that acknowledges the researcher's experiences, assumptions, and biases but prevents them from influencing the interview and data analysis.

Researcher's Biases

As a nurse practitioner, a prescriber of PrEP, and an American Indian, my biases toward acceptance and adoption of PrEP to prevent HIV infection across age groups, ethnicities, and genders are undeniable. However, the goal of this study was to ascertain the perceptions of American Indians regarding the use of PrEP as a biomedical intervention to prevent HIV infection. To reduce bias, I utilized reflexivity throughout the data collection and data analysis process. As I interviewed participants, I used reflexivity to examine unconscious bias in the interview process, asking myself what I was thinking during the interview, acknowledging my biases, and questioning if my bias was introduced during interviews with participants to reduce bias during the interview process. Furthermore, excluding patients, friends, and relatives from the study helped prevent bias in the study.

Addressing Potential Ethical Issues

I excluded individuals from the study who were my patients, acquaintances, or colleagues, given the sensitive nature of the patient-provider relationship and the sensitive content discussed during the interviews. While participants received a \$15 gift card, the gift card was a nominal amount to provide remuneration for participants' time

spent participating in the interviews and is not an amount considered coercive or exploitative. In addition, I utilized a reflexive journal to examine my feelings and reactions to the answers provided by the subjects to protect against the introduction of bias and safeguard against the massaging of data in a manner that coincides with my individual beliefs and opinions.

Methodology

Participant Selection Logic

Purposive sampling was employed to recruit subjects because I could ensure that participants were American Indians and that participants included could answer the research question by sharing information at a level of detail that only they could provide (see Campbell et al., 2020). The target population for this study was adults, 18 years or older, who identify as American Indian, and who spoke English. To support the feasibility of this study and the ability to reach saturation, recruitment will be limited to a single American Indian tribe located in the southeastern United States. I also employed snowball sampling to obtain additional participants. In the case of snowball sampling, volunteers who met the inclusion criteria were asked to share recruitment flyers with friends, family, and others whom they believe met the inclusion criteria.

I sought to enroll 15 participants, with interview data being transcribed and analyzed on an ongoing basis to ensure data saturation; however, saturation was reached at six participants (Hennink & Kaiser, 2022). While the sample size in qualitative research is heavily debated, consensus exists that data saturation is more important than a specific number of participants (Campbell et al., 2020; Creswell & Creswell, 2018). Data

saturation is reached when a researcher is no longer able to gain new information or insights from additional interviews (Creswell & Creswell, 2018). In this study, interview data were transcribed and analyzed on an ongoing basis to ensure data saturation. Because I am a novice researcher, I consulted my committee chair throughout the data analysis to ensure that data saturation had occurred.

To recruit participants, I posted a recruitment advertisement (Appendix A) in a Facebook group that was composed of American Indians living in the southeastern United States. In this study, potential participants were invited to contact me via telephone, email, or Facebook messenger if they were interested in participating in the research study. Individuals who volunteered to participate in the study were screened to determine if they met the inclusion criteria (Appendix B). If the volunteer met the inclusion criteria, I scheduled an interview at a date and time convenient for the participant.

Participants of the study received an informed consent form in one of two ways. Subjects opting to have a telephone or teleconference-based interview received an electronic version of the IRB-approved consent form. They provided verbal consent. Subjects who elected to have a face-to-face interview signed the IRB-approved consent form at the time of their interview.

Audio interviews were conducted by teleconference-based software and interviews performed face-to-face were recorded by a Sony digital recorder. I transcribed all recorded interviews. To ensure fidelity of the data, I replayed the interviews while reading the text to ensure that the interviewers were accurate and complete several times.

Again, interview data were transcribed and analyzed on an ongoing basis to ensure data saturation.

Instrumentation

Interviews were conducted utilizing two instruments: a demographic questionnaire and a researcher-developed interview guide. The demographic questionnaire requested basic demographic information and was administered prior to the interview. The demographic questions collect information such as age and gender (Appendix C). The demographic questionnaire was utilized to describe the sample and to determine if the sample was representative of the larger American Indian population. The interview guide was composed of the research question: What are your perceptions regarding the use of PrEP to prevent HIV infection? Based on the participants' responses, I asked probing questions to seek clarification of previous responses or to obtain additional information regarding a response previously provided. Every participant was asked the same main research question.

The content validity of the instrument utilized in this dissertation is determined based on questions extrapolated from the literature and the health belief model conceptual framework. To explore the perceptions of PrEP as an intervention to prevent HIV infections among American Indians; American Indians were asked to describe their perceptions regarding the use of PrEP to prevent HIV infection. Follow-up questions were asked based on their responses to clarify or to obtain a more in-depth response to this question. Because this study is unique, the research instrument is one of a kind and is not congruent with a survey. Therefore, each response to the research instrument was

unique. As such, the research instrument has not been validated in other studies, but its construction was informed by the literature review and the health belief model described in Chapter 2.

Procedures for Recruitment, Participation, and Data Collection

Participants for this study were recruited from a Facebook group that individuals who self-identify as American Indian members of the tribe selected for this study participate in online. At the time of this writing, there are currently 8,202 members who participate in this Facebook group. In addition to purposive sampling, I also employed snowball sampling to recruit participants for this study. Snowball sampling is commonly utilized when the desired participants are difficult to recruit or when desired participants have unique characteristics (Aurini et al., 2023). In this study, snowball sampling will: (a) augment the recruitment of a sufficient sample of American Indians if needed, (b) assist with the identification of American Indians who may not have a social media presence, and (c) assist with the identification of American Indians who are not computer or internet literate.

Potential participants were invited to contact me via telephone, email, or Facebook messenger if they were interested in participating in the research study. Individuals who volunteered to participate in the study were screened to determine if they met the inclusion criteria (Appendix B). Inclusion criteria for this study included adults who speak English who are recruited from a Facebook group who identify as members of an American Indian tribe located in the southeastern United States. The exclusion criteria were individuals younger than 18; individuals who are not American Indian; and

individuals who are patients, acquaintances, or colleagues of the researcher. If the volunteer meets the inclusion criteria, I scheduled an interview date and time with the volunteer at a time convenient for the participant. Participants had the opportunity to schedule the interviews for in-person sessions or remote interviews performed via Zoom, which is a confidential web-based conferencing platform.

Participants of the study receive a consent form in one of two ways. Subjects opting to have a teleconference-based interview received an electronic version of the IRB-approved consent form. They affirmed their consent by affirming such on the recording. Subjects who elected to have a face-to-face interview sign the IRB-approved consent form at the time of their interview.

Data collection began as the individuals were interviewed. Interviews conducted by teleconference-based software and interviews performed face-to-face were audio recorded by a Sony digital recorder. I transcribed all recorded interviews to ensure accuracy and to enhance my familiarity with the data. To ensure the fidelity of the data, I replayed the interviews using the constant comparative approach while reading the text to ensure that the interviews were accurate and complete. Again, interview data were transcribed and analyzed on an ongoing basis to ensure data saturation.

Participants exited the study when their interviews were completed. Throughout the interview process, I asked probing and clarifying questions. After each interview was complete, I asked if the participants had any additional statements to make or questions to ask. If the answer was no, I thanked them for their participation. Finally, I let the participants know that they could receive the results of the study by obtaining a final

copy of the dissertation once it is published by ProQuest Dissertations and Theses. The participants were then provided their honorarium for their participation in the study.

Data Analysis Plan

In this study, data collected followed a linear systemic approach. Once approved by the IRB, I began to recruit participants for the study. I assigned each participant a pseudo-ID. As participant interviews are completed, I personally transcribed the interviews to become acquainted with the data. The analysis of the data was completed as described below.

Demographic Data

Demographic data will be collected using the form (see Appendix C) only to the extent necessary to sufficiently describe the basic demographics of the study's participants. In lieu of collecting the participants' names, I assigned each participant a pseudo-ID to ensure they were deidentified. The pseudo-ID, such as P1, P2, and so on, was placed on the corresponding interview guide and used later to identify discrete pieces of data during the data analysis. The demographic information was collected after the consent form was signed.

Interview Data

The interviews were be recorded as described above. After the interviews are completed, I transcribed all recorded interviews to ensure accuracy and enhance my familiarity with the data. Interview data was imported into NVivo qualitative analysis software to facilitate its organization purposes only. I manually coded all interview data. The manual coding process followed the method outlined by Saldana (2021). I read and

reread the interviews several times to enhance familiarity with the data. First-level coding or opening coding was performed manually (Saldana, 2021). Second-level coding or axial coding was performed using the process outlined in the constant comparison method, comparing all codes back to the audio recording to ensure the validity and reliability of the data (Aurini et al., 2023; Creswell & Creswell, 2018; Saldana, 2021).

During open coding, the constant comparative method was utilized inductively to develop codes, code definitions, and themes (Aurini et al., 2023; Creswell & Creswell, 2018; Lassig, 2022). The data from interviews with new participants were compared and contrasted with established codes and themes to determine if new codes or themes have emerged. During the axial coding process, interviews with new participants may lead to the development of new codes and themes or result in revising established codes and themes (Aurini et al., 2023; Creswell & Creswell, 2018). Once the codes and themes were finalized, I highlighted commonalities, differences, and relationships among the data (Aurini et al., 2023; Creswell & Creswell, 2018; Lassig, 2022). The degree to which additional data supplements the codes and themes identified from re-reviewing the taped interviews promotes triangulation of the data. Thus, the interview data, codes, and themes were utilized to answer the research question for this study. Interviews with incomplete or missing data were disregarded.

Issues of Trustworthiness

Tools used to undergird the trustworthiness of qualitative research demonstrate that the design utilized, and conclusions reached are reliable, valid, and objective. In this

study, trustworthiness is enhanced by attention to credibility, transferability, dependability, and confirmability (Aurini et al., 2023).

Credibility

Credibility enhances the trustworthiness of this study by accurately representing the answers or responses of the participants (Aurini et al., 2023; Creswell & Creswell, 2018). I attended to the credibility of this project by having read, re-read, performed a literature review, personally interviewed the participants, using the constant comparative approach, and asking clarifying questions during the interviews to clarify unclear responses (Aurini et al., 2023). Credibility is also enhanced by collecting data from multiple participants rather than basing conclusions on data from a single participant (Aurini et al., 2023; Creswell & Creswell, 2018).

Transferability

Transferability enhances the trustworthiness of this study by providing sufficient detail that other researchers or consumers of research to make conclusions about the data to other settings (Aurini et al., 2023; Creswell & Creswell, 2018). Transferability, in qualitative research, is not the degree to which statements from this study can be generalized to broader populations or other settings (Aurini et al., 2023; Ravitch & Carl, 2021). I addressed transferability by (a) utilizing purposive sampling, (b) providing thick descriptions, and (c) describing the contexts and settings of the study. Purposive sampling ensures that the participants are individuals who have the requisite background to provide answers to the research question (Aurini et al., 2023). Thick descriptions provide as much of the participants' responses and the context of these answers so they can be evaluated

against findings from other studies, contexts, and settings (Aurini et al., 2023; Ravitch & Carl, 2021). Finally, I attempted to describe the settings outlined in this study with sufficient detail such that consumers of the study can consider its transferability to other qualitative methods, to design future studies; and to underscore unique findings. Consequently, transferability was not the purpose of this study.

Dependability

Dependability enhances the trustworthiness of this study, demonstrating that research method, approach, sampling, and analysis are appropriate methods for analyzing the data to answer the research question (Aurini et al., 2023; Ravitch & Carl, 2021). Dependability was also attended to by ensuring I compared the transcribed interviews against the original audio recording using a constant comparison approach. The design of this study was developed in consultation with my dissertation adviser, Walden University methodologists, and through a comprehensive review of the literature. Furthermore, I have addressed the dependability of the study by sufficiently describing the purpose, sampling method, and data analysis method including using the original audio tapes and constant comparative approach such that the consumer of this study can conclude the dependability of this design to answer the research question (Aurini et al., 2023; Creswell & Creswell, 2018; Ravitch & Carl, 2021).

Confirmability

Confirmability enhances the trustworthiness of this study demonstrating by ensuring the findings are free of bias and are based on the sources of data (Aurini et al., 2023; Ravitch & Carl, 2021). To enhance the confirmability of this study, I presented

direct quotes from the interview data to substantiate the research findings. Furthermore, my use of the constant comparative method facilitates confirmability when direct quotes of the data are compared to other direct quotes of the data during the coding and data analysis stage of this study (Lassig, 2022; Ravitch & Carl, 2021).

Ethical Procedures

Ethics in research are paramount to the development of a study that has social value, scientific validity, withstands independent review, maintains informed consent, and treats participants with respect (Emanuel et al., 2000). To maintain the social value, the scientific validity, and to ensure this study withstands independent review, I continuously attended to the principles outlined in the research methods texts and journals. When questions arose, I sought the advice of my dissertation chair, committee, and Walden University's methodologists.

To ensure that participants are treated with the utmost respect, to preserve their autonomy, to maintain their confidentiality, and to decrease the likelihood of undue influence, I adhered to the procedures outlined by Walden University's Institutional Review Board process and policies outlined in Walden University's Ethics and Compliance Policies. When there were questions, I sought the advice of my dissertation chair, committee, and Walden University's Institutional Review Board (# 04-01-24-0723942). No data was collected without Institutional Review Board approval.

Subjects were recruited utilizing principles outlined in the research methods texts. Participation in this study is voluntary. Participants were able to withdraw at any time without consequence. Any participant who is or was a patient, friend, or acquaintance of

the researcher was excluded from this study to prevent undue influence or power deference. Each participant of the study was be provided with informed consent. All research forms, tools, and interview guides were designed with the intent to do no harm. Participants were able to refuse to answer any question on the demographic instrument and interview guide without consequence. Each of the participants' information was kept confidential. All participants in this study were treated fairly and equally throughout the recruitment, scheduling, consent, and interviewing process. If any conflict arose during their participation, all deference was given to the participant. Finally, the honorarium provided for participation in this study is consistent in amount and method with other dissertations performed at Walden University. The full honorarium will be tendered immediately after the subject's participation irrespective of when the subject exits the study.

Given the qualitative nature of the research design, participants were confidential not anonymous. However, data collected during this study was immediately deidentified to protect the confidentiality of each of the participants. No personal information was transcribed on any of the tools or guides utilized in this study. All data was saved on a flash drive for safekeeping. The flash drive is in a locked safe accessible only by myself. All files are password-protected and are accessible only by myself. All data will be maintained for 5 years as required by Walden University then the data will be destroyed. The data will only be made available to Walden University following its guidelines.

Summary

In this chapter, I have outlined the methodology to be employed in this research study. The qualitative research design and rationale have been described in detail. The role of the researcher as an observer-participant has been described, how biases will be addressed, and any underlying special ethical considerations affecting the researcher's role have been addressed. The recruitment of subjects, instrumentation, data collection, data analysis, trustworthiness, and ethical considerations associated with the research methodology have also been described in detail.

In Chapter 4, I describe the findings of this study. I review the setting of the study, describe the demographics of the participants, review the data collection process, describe how the data were analyzed, and review how I ensured the trustworthiness of the findings.

Chapter 4: Results

Introduction

American Indians continue to experience increased incidence and prevalence of HIV (CDC, 2021). Furthermore, American Indians are more likely to be unaware of their HIV status and are more likely to die because of advanced HIV disease at the time of diagnosis (Armenta et al., 2021; Ehrenpreis & Ehrenpreis, 2022; Town et al., 2021). American Indians are believed to be at high risk for HIV infection because of culturally insensitive care, discrimination, intergenerational trauma, early sexual debut, poverty, and substance abuse (Armenta et al., 2021; Ehrenpreis & Ehrenpreis, 2022; Hafner & Craig Rushing, 2019; Jongbloed et al., 2019; Reilley et al., 2018). Researchers have found that values and beliefs often differ from tribe to tribe, American Indians live in remote locations, and their hesitancy to trust researchers has significantly impeded inclusion in research (Armenta et al., 2021; Black et al., 2018; Lee et al., 2018). At present, the literature has only described the use of condoms and comprehensive sexual education as HIV prevention interventions in American Indians.

Chambers et al. (2018), Chambers et al. (2020), and Rosenstock et al. (2020), reported an awareness of the prevalence and severity of HIV; however, the youth did not perceive themselves to be vulnerable to HIV and additionally reported a lack of condom self-efficacy. Consequently, efforts to increase American Indian youths' intent to use condoms fail when centered on risk perception, condom education alone, and condom self-efficacy.

Comprehensive sexual education programs have focused largely on American Indian youth in the school setting. Lee et al. (2018) and Skye et al. (2021) attempted to adapt sexual educational programs to involve native traditions such as storytelling. In doing so, they used the community-based participation model as a conceptual framework for their interventions. To balance the cultural appropriateness of the study and to obtain approval from tribal leadership, the programs were subjected to content constraints that may have limited their effectiveness (Lee et al., 2018; Skye et al., 2021; Thomas et al., 2021). As a result, comprehensive sexual education interventions were mixed in preventing HIV, but those demonstrating protective effects found them to be temporary.

The use of antiviral medications to prevent HIV infections or PrEP is 95% to 99% effective in preventing HIV among other ethnicities (Mayer et al., 2020; Shangani et al., 2021). However, insufficient literature exists to describe American Indians' perceptions of PrEP. Thus, the purpose of this qualitative study was to explore the perceptions of PrEP to prevent HIV infections among American Indians.

Setting

As stated in the inclusion criteria, participants included those who self-identified as American Indian adults (18 years or older) from a tribe located in southeastern United States. Subjects were recruited from a Facebook group of American Indian tribes, independently owned and managed, located in southeastern United States. The qualitative interviews were performed over Zoom (audiovisual internet-based software), via telephone, or in person with audio recording. No participants opted to participate in in-person interviews. Finally, after each interview, I reminded participants that there were

free resources outlined in the Institutional Review Board (IRB) consent form should they experience any personal distress to provide free counseling and free mobile psychiatric care.

Demographics

Demographic questions I developed were each completed by the participants after providing informed consent. I interviewed eight subjects, six of which were male, who met the study inclusion criteria. Three individuals expressed interest in participating in the study but were excluded because they were active patients of mine. The participants were all younger than 55. The participants were overwhelmingly single. Finally, seven of the participants had earned a bachelor's degree or higher. The demographics of the participants are further described in Table 1.

Table 1*Study Participant Demographics, N = 8*

Demographic	<i>n</i>
Gender	
Male	6
Female	2
Other	0
Prefer not to say	0
Age of participant	
19–24 years old	1
25–34 years old	1
35–44 years old	4
45–54 years old	2
55–64 years old	0
65 years old and older	0
Marital status	
Single	6
Married	2
Divorced	0
Widowed	0
Highest education level attained	
Some high school	0
High school	1
Bachelor's degree	4
Master's degree	2
Ph.D./professional doctorate or higher	1

Data Collection

The eight participants of this study met the inclusion criteria mentioned in the recruitment flyer. Six of the eight participants contacted me to express interest in participating in interviews after seeing the advertisement in the Facebook group of American Indians living in the southeastern United States. Two participants in the study were identified by snowball sampling. Every participant was emailed the IRB informed consent form and demographic form. After reading the IRB informed consent and

submitting the demographic form (see Appendix C), the participant returned the demographic form via electronic mail and indicated they had read the document by responding “I agree.” After receiving a participant’s assent to participate in the study, I scheduled them for a Zoom interview in which the audio content would be recorded using a Sony video recorder. Interviews began in July 2024 and continued through August 2024 until data saturation was reached. Unfortunately, after sending three participants the IRB document, they declined to participate in the study citing concerns that the interviews would be recorded despite my best attempts at reassuring them that the recordings were confidential. Data saturation was met after the sixth interview, but two more interviews were completed to ensure saturation.

The interviews with each participant were approximately 45–60 minutes except for one interview that lasted approximately 15 minutes. During the interviews, individuals were reminded they were free to take a break if needed and urged to avoid mentioning names, places, or other potentially identifiable information. Following each interview, the interviews were transcribed personally by me to provide another opportunity to become familiar with the content provided, to reflect on the role of the researcher as a facilitator and data collector (rather than providing additional information to the participants), and to ensure the fidelity of the interview content expressed by the participants.

During the interview, each interview participant was assigned a pseudonym (e.g., P1) that corresponded with the order of the participant’s interview. Each participant was asked if they knew what PrEP was; if not, they were read the statement describing PrEP

in the interview guide (see Appendix D). After verbalizing understanding, the participants were asked the interview question from the interview guide with probing questions used to gain additional information from the participants to further understand their responses. A notebook was utilized during each interview to place responses in quotes, to prompt myself to follow up on items mentioned in the interview, and to provide for reflexivity during the research process (Peddle, 2022).

There were no deviations from the data collection steps outlined in Chapter 3. The interviews were straightforward and were completed in one sitting. The participants seemed at ease during the interviews, but some participants were hesitant as they described those perceived to be a high risk for HIV. This generally presented itself as word searching or the use of the words “they” or “them.” However, the population they were speaking of was easily clarified by asking probing questions to identify who they were referring to. Other than this observation, the participants spoke quite candidly about their own sexual experiences (though they were never asked about this by me), their backgrounds, and their experiences with PrEP.

Data Analysis

Data analysis was carried out as described in Chapter 3 using a descriptive qualitative design as described in Creswell and Creswell (2018) and Ravitch and Carl (2021). Each interview was transcribed into a Microsoft Word document and uploaded in NVivo qualitative data analysis software. The interview transcripts were reviewed several times to ensure that the transcript matched the recorded interviews. Analysis began by the

iterative review of each interview transcript in which I engaged with the text to identify repeating words, patterns, and eventually, themes began to emerge from the transcripts.

The next step of the process was to begin with initial coding. NVivo was utilized to highlight the text, organize the transcripts, and inductively build a codebook. During the initial coding stage, I separated the interviews from those who were aware of PrEP ($n = 6$ from those who were not ($n = 2$). These interviews were identified by the presence or absence of the description of PrEP read to the participants from the semi-structured interview guide (see Appendix D). During the first level of coding using NVivo for organizational purposes, I began to highlight words and phrases from each interview paying special attention to patterns that would later emerge as subthemes and themes in level two coding (Ravitch & Carl, 2021).

Next, I identified subthemes and themes using axial coding utilizing NVivo to organize the patterns (or codes) identified in the initial coding as described by Ravitch and Carl (2021). During axial coding, the codes were grouped into themes and subthemes which were conveyed in the responses from the interviews (Ravitch & Carl, 2021). It is important to note that this process was iterative (as was the initial coding) given the descriptive approach seeks to maintain the fidelity of the content conveyed in the interviews provided by the participants. When quotations and codes overlapped, they were judiciously assigned to multiple themes. Furthermore, as gaps were identified in the codebook, I added codes that also evolved into subthemes and themes.

The following themes were identified from the research question: Aware of PrEP and Unaware PrEP. Of note, each participant felt that PrEP was a good tool for HIV

prevention with each participant suggesting they would be willing to take PrEP as a HIV prevention method. Utilizing probing questions, the following sub-themes were identified as perspectives of PrEP: Advantages of PrEP, Disadvantages of PrEP, Barriers of Use, Facilitators of Use, and Female Concerns.

It is important to note that while some participants were more knowledgeable of PrEP there were no discrepant cases that required exclusion from the data analysis process. The authenticity, detail, and verbal and nonverbal communication demonstrated that each of the participants were actively engaged in the interview process.

Evidence of Trustworthiness

While trustworthiness in qualitative research is a debated topic in the qualitative and quantitative research methods world, qualitative researchers agree that the trustworthiness of the qualitative study is a hallmark sign of rigor. Trustworthiness in qualitative research is assessed by considering the credibility, transferability, dependability, and confirmability of the results (Ravitch & Carl, 2021).

Credibility

Credibility is akin to internal validity in quantitative studies in that the researcher attends to the setting, sampling methodology, and the researcher's role in interpreting the data collected from multiple sources to ensure a rigorous design (Ravitch & Carl, 2021). I attended to the concept of credibility by recruiting participants from a Facebook group that was a diverse group of American Indians of all ages, genders, and tribal affiliations. Next, I utilized both purposeful sampling and snowball sampling to obtain multiple sources to add to the richness of the study. Finally, I utilized a notebook to attend to the

reflexivity of this study; to consistently examine my role as a researcher in the study; being careful to use open-ended questions; and probing questions to ensure that the participants provided most of the research content. Finally, I attempted to develop a rapport with each of the subjects so that they felt they could speak freely throughout the interviews.

Transferability

Transferability is akin to external validity in quantitative studies in that the researcher assures that there is sufficient transparency to both protect the confidentiality of the source and to ensure that there is sufficient information to consider if the study can be applied to other contexts and individuals (Ravitch & Carl, 2021). In this study, I strove to identify a diverse group of participants; describe the participants' demographic information; share their answers to questions in sufficient detail so that future researchers can use or improve upon the design; and provide enough context and the participants' quotes to allow the readers to formulate independent conclusions from the responses.

Dependability

Dependability enhances the trustworthiness of this study demonstrating that research method, approach, sampling, and analysis are appropriate methods for analyzing the data to answer the research question (Aurini et al., 2023; Ravitch & Carl, 2021). To ensure dependability I utilized a descriptive qualitative research design to ensure that the answers provided were consistent with the participants' responses. Furthermore, I meticulously listened to the records multiple times to transcribe the interviews and ensure the transcripts were consistent with the participants' responses. Finally, employing a

descriptive qualitative design and using the constant comparative approach to compare against the original recordings ensures that the participants' answers are provided rather than the researcher's interpretation of the participant's responses.

Confirmability

Confirmability is akin to objectivity in that the researcher takes care to ensure that the researcher has considered any biases but presents the participants' answers in a manner that ensures they can be confirmed (Ravitch & Carl, 2021). To ensure confirmability, I employed the use of a reflexive journal to ensure that I acknowledged my biases; followed up on vague participant responses with probing questions rather than assuming what the participant meant from my theoretical orientation; and employed a constant comparative approach to ensure the answers of the participants were presented.

Results

The research question for this study was: What are your perceptions of the use of PrEP to prevent HIV infection? Using semistructured interviews, I first asked each participant if they were aware of what PrEP to prevent HIV infection was. If they did not know what PrEP was, I read an overview of PrEP prophylaxis. Throughout the interview, I used probing questions to elicit more information about PrEP, including what advantages it provides, what facilitates PrEP's use among American Indians, what barriers prevent PrEP use among American Indians, and what female participants were concerned about compared to male participants. The themes and subthemes that emerged from analysis of the interview data will be discussed in the remaining portion of this section.

Table 2*Participants' Awareness and Views of PrEP*

Participants' awareness of PrEP	Participants' views of PrEP
Aware of PrEP ($n = 6$)	Favorable view ($n = 5$) Ambivalent view ($n = 1$) Unfavorable view ($n = 0$)
Unaware of PrEP ($n = 2$)	Favorable view ($n = 2$) Unfavorable view ($n = 0$)

Awareness and Unawareness of PrEP*Awareness of PrEP: Favorable View*

Of those aware of PrEP, five participants had a favorable view of PrEP. Of those with favorable responses, all the participants described that PrEP was a safe and effective method of HIV prevention, especially when compared to abstinence, safe sex education, and condom use. Participant 1 stated that he would use PrEP if he were to become sexually active. He described knowing that several patients who were on his case management roster had used PrEP and did “good with it” in terms of adherence and prevention of HIV. He remarked that he knew individuals on his caseload at high risk who did not use condoms or experienced condom failures during sexual intercourse, but many individuals whom he case managed with HIV had not used condoms during their sexual encounters.

Participant 6 and Participant 8 remarked that they were not sexually active at the present, but when they were, they utilized PrEP. Both participants stated that PrEP provided an extra layer of protection for them when they use condoms. Both described incidences when their partners did not want to use condoms or the condom broke or

slipped off, and Participant 8 remarked that a friend reported that his sexual partner intentionally removed the condom during sex without his knowledge.

Similarly, Participant 3 remarked that she used PrEP as well because she and her sexual partners did not like using condoms because the condoms decreased sensitivity during sex and resulted in decreased pleasure. She felt better protected against HIV than not utilizing condoms at all with her sexual partners.

Participants 5 and 6 described that they had been on PrEP for many years and had both condom and condomless sex but felt much safer with PrEP than without it. Both stated that they often acquiesced to their partner when deciding to use condoms, so PrEP offered protection for them against HIV and AIDS. Participant 5 reported that he had performed his own research regarding PrEP and opted to seek care to start the medication. Participant 6 stated that his primary care provider knew his sexual orientation and broached the subject of PrEP with him.

Awareness of PrEP: Ambivalent View

One participant reported ambivalence toward PrEP. She acknowledged that PrEP does not protect against other STIs, which can be a significant concern for individuals engaging in sexual activity. This limitation raises questions about the effectiveness of PrEP as a standalone preventive measure. She believes that barrier methods, like condoms, are essential for preventing STIs. This perspective suggests that she views PrEP as a supplementary measure rather than a complete solution. She emphasized the importance of comprehensive sexual education in promoting the use of both PrEP and barrier methods. This viewpoint highlights the need for informed decision making and

responsible sexual behavior. Overall, the participant's ambivalence reflects a balanced understanding of PrEP's benefits and limitations. She recognizes the value of PrEP as a preventive tool but also emphasizes the importance of complementary measures like barrier methods and comprehensive sexual education.

Awareness of PrEP: Unfavorable View

Of those interviewed, no participant verbalized an unfavorable view of PrEP.

Unaware of PrEP: Favorable View

Participant 2 and Participant 7 both stated that they were not aware of what PrEP was. However, after listening to the overview of PrEP in the interview guide, they both recalled seeing commercials on TV about PrEP. One had seen the video about the pill-based formulation, and another indicated having seen a commercial on TV about the once-monthly injectable form of PrEP. Both participants indicated that PrEP would be something they would take to prevent HIV if needed in the future. Participant 2 stated that it was only one more pill that he would have to take daily. Furthermore, he stated he had no concerns about taking another medication as long as he was aware of the side effects before initiating it because he had a bad experience with a medication for his back pain. Participant 6 reported that she would take PrEP too. She related that she was very proactive about her health because she has two autoimmune disorders, which would place her at higher risk for poor outcomes with HIV/AIDS, including death, compared to the general population.

Unaware of PrEP: Unfavorable View

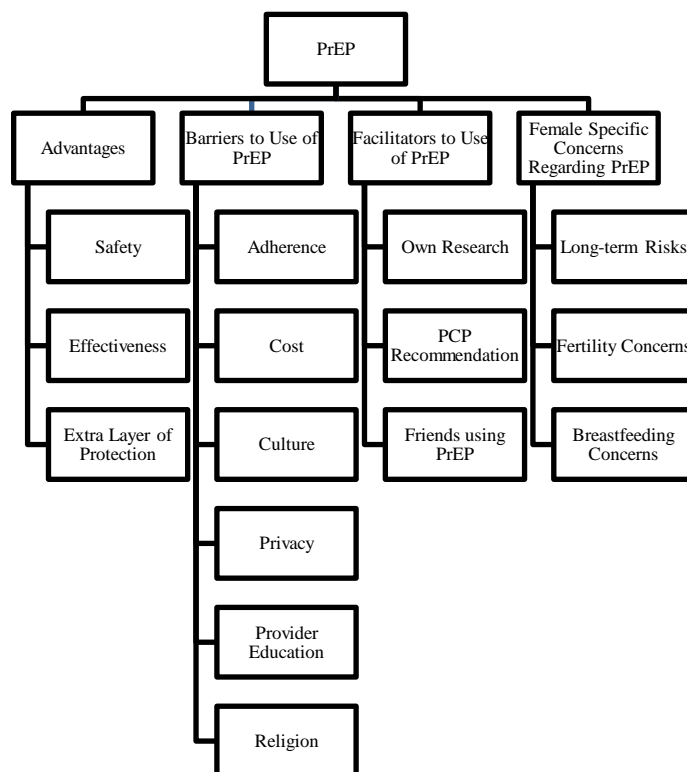
Of those unaware of PrEP, no participant reported an unfavorable view of PrEP.

Themes, Categories, and Participants' Responses

I began each interview by asking about whether the participant knew what PrEP was. If the participants knew what PrEP was, I asked them to share what they felt about it. If the participants did not know what PrEP was, I read them a brief overview of PrEP from the semistructured interview guide. I asked if the participant understood what I had read and if they wanted it reread. I read the brief overview of PrEP as many times as the participant indicated they wanted it reread. I then asked the research question: What are your perceptions of the use of PrEP to prevent HIV infection? Based on the probing questions, I collected data for analysis and identified themes and categories of PrEP. The participants spoke candidly regarding their perceptions of PrEP's advantages, barriers, facilitators, effectiveness, and sex-specific considerations. The themes and categories are depicted in Figure 1.

Figure 1

Perceptions of PrEP: Advantages, Barriers Facilitators, Effectiveness, Sex-Specific Considerations



Theme 1: Advantages of PrEP—Safety

Five participants aware of PrEP felt that it was safe for the prevention of HIV among American Indians (see Table 3). When asked to explain more, most of those on PrEP mentioned they had been on PrEP for many years. They described how their blood work was drawn before starting PrEP and every 3 months while taking PrEP. Two participants indicated they were concerned about side effects such as nausea or gastrointestinal side effects, but neither experienced those side effects. Three of the five mentioned that ongoing lab monitoring was necessary to have PrEP prescribed. A few

described using the appointments for ongoing lab work as a means to have routine screening for other STIs. Furthermore, they stated they would recommend PrEP as HIV prevention to friends or family who broached the subject of PrEP with them.

Table 3

Perceptions of PrEP: Participants' Responses About the Advantages of PrEP

Theme	Categories	Participant responses
Advantages of PrEP	Safety	<p>P1: "I think it is safe and effective for most people."</p> <p>P3: "There are some side effects, but not of them would keep me from taking it. But certainly, the benefits of the medication, I think, would outweigh the risk as far as the meds."</p> <p>P5: "I feel that PrEP is safe. I have been on it since June. I do have my labs monitored every three months to check my cholesterol, kidneys, and all that. So far my labs have been completely normal."</p> <p>P6: "At first, I was a little unsettled by some of the side effects that I read about, but my doctor reassured me that these were rare. I have been on PrEP for 8 years now and have always had normal labs. Several friends have also been on it and all their tests have been normal as well."</p> <p>P8: "My doctor explained that it is safe and effective. I do have to have my labs monitored, but everything has always been good since I started it in 2015 [10 years ago]."</p>

Theme 1: Advantages of PrEP—Effectiveness

Five participants described that while PrEP did not protect against other STIs, PrEP was effective in acquiring HIV. While each participant had a different perception of the effectiveness of PrEP in preventing HIV all of them viewed PrEP as 97% effective in preventing HIV when taken as prescribed. Many of them commented that sex was an important part of their identity and that while PrEP was not 100% effective it was

superior to sexual education and condom use. Each participant mentioned that abstinence was unlikely based on their personal experience and that others should seek out ways to prevent HIV if they were sexually active. The participants' responses are outlined below in Table 4.

Table 4

Perceptions of PrEP: Participants Responses about the Effectiveness of PrEP

Theme	Categories	Participant responses
Advantages of PrEP	Effectiveness	<p>P1: "While it is not 100%, I know several clients who take it who are in relationships with HIV positive people. They have not contracted HIV during the time that they have been on PrEP. I think it is safe and effective for most people."</p> <p>P3: "It is like 97% effective in preventing HIV from what I have read and seen advertised so it is effective for those who engage in riskier behaviors."</p> <p>P5: "My ID doctor explained that it is very effective. It is not 100% but it is a lot safer than using condoms alone."</p> <p>P6: "It isn't 100% but is what we have to keep us safe for now."</p> <p>P8: "To my understanding it is about 99% effective in preventing HIV. It doesn't prevent other STIs but it is effective in preventing HIV."</p>

Theme 1: Advantages of PrEP—Extra Layer of Protection

Two of the participants spoke about PrEP being an extra layer of protection for them (see Table 5). They described their fear acquiring of HIV/AIDS despite effective treatment that allows individuals to get to an undetectable viral load. One of the individuals spoke about a sexual encounter when their sexual partner did not want to use condoms or when a condom broke during intercourse. He related that PrEP provided an

extra layer of protection irrespective of condom use. Another participant, older than most in the study, described having grown up during the HIV/AIDS pandemic and repeated losses he experienced when individuals died from HIV/AIDS. Furthermore, he described how the stigma prevented families and community members from explaining how the individuals died.

Table 5

Perceptions of PrEP: Participants' Responses About PrEP as an Extra Layer of Protection

Theme	Category	Participant responses
Advantages of PrEP	Extra layer of protection	<p>P5: "It's very scary the thought of becoming HIV positive. It's coming very rapid in that type of community [LGBTQ]. But I think PrEP provides an extra layer of protection for me whether I use condoms or not."</p> <p>P6: "Well, it just offers that extra little bit of comfort. Because, of course, we're human, we're going to be sexually active. We're going to be sexually active with those that we're attracted to. So, it's [PrEP] is more or less a comfort, not only just for me, but watching in the past, coming up as a small child with AIDS pandemic I just remember people disappearing."</p>

Theme 2: Barriers to Implementation of PrEP – Adherence

Two participants spoke of perceived barriers to the implementation of PrEP being adherence (see Table 6). The first participant described her experience working with college-age students who had little money and often had to prioritize tuition, fees, and other college-related expenses over other expenses such as condoms, PrEP, feminine hygiene items, and other necessary medications. She related that the college she worked for had adopted programs for students to order safe sex kits consisting of barrier methods

(e.g., condoms and dental dams). She explained that if they were not distributing these kits for free, she did believe that students could afford them. As a result, she also mentioned that adherence would be a barrier because students would have to purchase the medication, have appointments, and frequent labs. Consequently, she wondered if the students would remain adherent to the treatment.

Another participant described that while he received PrEP for free, he felt that adherence would also be a challenge. He described how friends admitted they started and stopped PrEP when they were not sexually active, but then resumed PrEP when they became were sexually active. In the interview, he describes how individuals rarely plan sex so he felt if PrEP was not in their bloodstream at certain levels when they engaged in unpredicted sexual activity then PrEP is less effective at preventing HIV. However, Vuylsteke et al., (2019), have compared daily use of PrEP versus casual use of PrEP and found no change in the effectiveness of PrEP in preventing HIV. Instead, Vuylsteke and colleagues (2019) found a high number of non-HIV STIs like gonorrhea and chlamydia.

Table 6

Perceived Barriers to Implementation of PrEP: Adherence

Themes	Category	Participant responses
Barriers to implementation of PrEP	Adherence	<p>P4: “Having working on a college campus in student health, I think adherence would be a barrier. College is expensive and student may not always be consistent with the medication, condom use or other barrier methods for many reasons including costs.”</p> <p>P8: “I think adherence is big issue because you know it’s you have to take it for a little over a week in order to build that resistance back up and get that level back into your blood.”</p>

Theme 2: Barriers to Implementation of PrEP—Costs

Three participants perceived that a barrier to the implementation of PrEP was cost (see Table 7). Of note, participants of the tribe interviewed were not members of a federally recognized tribe thus they are not eligible for services by Indian Health Services. As a result, one participant believed that cost might be a barrier because many of the American Indians in her community were below the poverty level and are typically of a lower socioeconomic status. Another participant shared that if American Indian students could not afford tuition, fees, feminine hygiene items, and condoms then they might not be able to afford PrEP even if it was covered by their health insurance. Finally, another participant responded that his insurance did cover the cost of PrEP, but that a prior authorization was required to obtain it. He described his healthcare provider's willingness to complete the prior authorization but stated that the medicine would have otherwise been \$1600 for one month's supply. Alternatively, he stated without the prior authorization he would not have been able to afford to take PrEP for prevention of HIV.

Table 7

Perceived Barriers to Implementation of PrEP: Costs

Themes	Category	Participant responses
Barriers to implementation of PrEP	Cost	<p>P3: "Cost might be a barrier because many American Indians, folks from our culture are on the low end of the income range."</p> <p>P4: "Having working on a college campus in student health, I think adherence would be a barrier. College is expensive and student may not always be consistent with the medication, condom use or other barrier methods for many reasons including costs. Some can't afford barrier methods or even feminine hygiene</p>

products so I think it would have to be affordable or covered by insurance.”

P5: “I could not have taken it if it wasn’t covered by my insurance. It costs \$2600 a month for Descovy, but I only have to pay \$4 after the prior authorization”

Theme 2: Barriers to Implementation of PrEP—Culture

Six of the participants described that culture was a perceived barrier to the implementation of PrEP (see Table 8). Each of the six described that the culture of American Indians was not very forthcoming in talking about sex and HIV prevention. Of those who had had some form of sexual education, they described that it consisted of abstinence-only education. Most acknowledged that culture perpetuated not only stigma against pre-marital sex, but also against homosexuality, HIV/AIDS, and sexual education. One female participant reported that she led to the placement of Narcan in areas of high fentanyl-related deaths throughout American Indian country. She replied that many American Indians described increased access to Narcan would promote opioid and fentanyl use. Consequently, she perceived that if PrEP was implemented more broadly American Indians would say it encouraged members to be more sexually promiscuous rather than focus on disease prevention and health promotion. Similarly, a male participant described that when he discussed PrEP with another gay male, the other male questioned how much sex he was having. Consequently, he perceived that American Indians would also believe that PrEP led to more sexual promiscuity than its effectiveness at HIV prevention.

Table 8*Perceived Barriers to Implementation of PrEP: Culture*

Themes	Category	Participant responses
Barriers to implementation of PrEP	Culture	<p>P1: “Education about PrEP is a barrier because with our people and the culture or the way we were raised, it hard enough to talk about sex much less sexuality.”</p> <p>P2: “Our culture sometimes has a stigma about sexual identity and while PrEP is a good thing. It is difficult for families to talk about sex and HIV prevention options other than abstinence.”</p> <p>P5: “Our culture and religion promotes abstinence because people are pretty conservative still and I don’t think they would want to have people talk to their children about sex outside a doctor’s office.”</p> <p>P6: “Our culture is secretive about sexuality so I guess it’s just that secretiveness not only about PrEP but HIV, but it’s just, both still have a stigma among our people.”</p> <p>P7: “In our culture, I could imagine that stigma would be an issue. You know. People are going to say that it [PrEP] would cause you to be more sexually promiscuous. They already say that placing Narcan in the community promotes drug use.”</p> <p>P8: “In our culture, even among men who have sex with men, do you have that much sex? And I say well, it’s not really about how much sex I have.... I guess attitudes depending location from other men who have sex with men kind of viewing people who choose to take it as promiscuous.”</p>

Theme 2: Barriers to Implementation of PrEP – Privacy

Six of the participants described that privacy was a perceived barrier to the implementation of PrEP (see Table 9). Each of the participants related information about how while we have HIPPA it is strictly followed leading those who may benefit from PrEP to avoid obtaining it locally. One participant described how individuals with HIV would travel to other counties (up to two hours away) and even non-contiguous states to

receive care from Infectious Disease specialists to protect their privacy. Furthermore, each participant unanimously agreed that the American Indians would prefer to receive the medication via mail order delivery rather than obtaining PrEP at a local pharmacy where they might know someone who works in the pharmacy.

Table 9

Perceived Barriers to Implementation of PrEP: Privacy

Themes	Category	Participant responses
Barriers to implementation of PrEP	Privacy	<p>P1: “I think picking it up at a local pharmacy would be an issue. Some of my clients seek care 2 hours away and even as far as Georgia to protect their privacy because HIPAA isn’t 100%. It should be but it isn’t.”</p> <p>P3: “People really don’t want their business out in the streets or out in the community. I’ve had many people say that they’re more likely to take PrEP if it is mailed to their home and they believe that their privacy is more protected in that way.”</p> <p>P4: “You know there’s HIPAA, but I mean, in a small town you might not feel comfortable going to the doctor’s office or pharmacy because people might think or know that’s what they are there to get.”</p> <p>P7: “I’ll be honest with you I used to drive all the way to Fayetteville which is 45 minutes away every other week. I mean, because there’s so much stigma attached to picking things up in a small-town pharmacy.”</p>

Theme 2: Barriers to Implementation of PrEP—Provider Education

Three participants described that the knowledge of local provider’s was also a perceived barrier to the implementation of PrEP (see Table 9). As described in the literature, PrEP continues to struggle to find a home (Pleuhs et al., 2020). Many infectious disease specialists believe that primary care providers should prescribe and manage PrEP while primary care providers believe that PrEP is best managed by

Infectious Disease Specialists (Pleuhs et al., 2020). Many of the participants described that their primary care providers did not have enough clinical knowledge to manage PrEP (see Table 9). Thus, they sought care as far as 45 minutes away. Transportation remains a challenge in rural areas. Consequently, three of the participants felt that primary care providers needed to seek out education in PrEP so they could better screen for those at high risk for HIV and intervene with PrEP as necessary.

Table 10

Perceived Barriers to Implementation of PrEP: Provider Education

Themes	Category	Participant responses
Barriers to implementation of PrEP	Provider's knowledge of PrEP	<p>P1: "Being in case management, some doctors just want to treat HIV. They think other doctors can prescribe PrEP."</p> <p>P5: "I went to my local PCP clinic and they didn't work with PrEP. They referred me to an ID clinic about 45 minutes away so I didn't have a choice to get it from my personal doctor."</p> <p>P7: "While my PCP doctor prescribes my PrEP, my friends were not that lucky. They had to find other clinics that were farther away so I feel more doctors need to get educated on it more."</p>

Theme 3: Facilitators to Implementation of PrEP—Own Research

Two of the participants described that they did their own research and discovered PrEP (see table 11). Both participants mentioned that they had access to a primary care provider but no one discussed their sexual history with them to make an informed decision about recommending PrEP. One participant stated that when he discussed PrEP with a close friend, they assumed he had been on it suggesting that PrEP is even

discussed freely amongst friends in the American Indian community. Another participant discussed that she did her research and decided to start it. She reported that she was a large proponent of disease prevention and health promotion, so she opted to start the medication herself based on her perception of her risk for HIV and the autoimmune disorders she already had. Based on these participants, responses it is evident that at least some American Indians are considering their risk factors for HIV and making decisions to protect themselves using PrEP.

Table 11

Facilitators to Implementation of PrEP: Own Research

Themes	Category	Participant responses
Facilitators to implementation of PrEP	Performing one's own research	<p>P5: "I basically just wanted to start on it on my own. I did my own research when trying to decide about how to best protect myself. When I talked to a friend about it, he was like, I thought you had been on it. He automatically assumed that I was on it. So, no one really told me it existed before I choose to start it".</p> <p>P6: "For me, personally, I'm a proactive when it comes to physical and mental health. Like, when the HPV stuff first came out, the preventative medications, I did that. I think that was like almost, let's see, I was maybe 22, so almost 20 years ago, about 18 years ago. Yeah, because I think it was like three that you had to do like three rounds at that time. I'm definitely did the COVID vaccine and the booster. So I did my own research and found out about ways to protect myself against HIV."</p>

Theme 3: Facilitators to Implementation of PrEP—PCP Recommendation

Only one participant mentioned that his primary care provider recommended PrEP based on his sexual orientation and other risk factors (See Table 12). He described being concerned about some of the side effects; however, he ultimately decided to start PrEP based on his conversation with his primary care provider’s discussion of the risks, benefits, and alternatives to PrEP. Most of the participants described asking their primary care provider about HIV and receiving a referral to an Infectious Disease Clinic.

Table 12

Facilitators to Implementation of PrEP: Own Research

Themes	Category	Participant responses
Facilitators to implementation of PrEP	PCP recommendation of PrEP	P6: “My primary care provider knew about my sexual orientation. He recommended that I start PrEP. There was a couple of side effects that was a little unsettling. Like I said, the consultation with my physician. He reinforced that the minor side effects of this medicine outweigh all the positives of it.”

Theme 3: Facilitators to Implementation of PrEP—Friends Using PrEP

Three participants described their friends’ use of PrEP as reasons they began using PrEP (see Table 13). In one case, a participant had a friend who was using the older formulation of PrEP, but had experienced no side effects. Another reported that his two friends had been on PrEP for two different reasons and had experienced no side effects which reinforced his decision to start PrEP. In the third participant’s case, he described how someone removed the condom during sex without his friend’s knowledge. He witnessed the efficacy of the PrEP first-hand so he began to

use PrEP soon thereafter. In each case, most of the participants were concerned about the side effects of PrEP, but one participant recognized the efficacy of the PrEP.

Table 13

Facilitators to Implementation of PrEP: Friends Using PrEP

Themes	Category	Participant responses
Facilitators to implementation of PrEP	Friends using PrEP	<p>P5: “Well, one of my best friends basically was on it a few years. He was taking it first, he’s still taking Truvada. I discussed it starting it with hi, and he was like, no I would just do it. I’m fine. He had just had a re-evaluation he hasn’t had any problems with Truvada. I think he’s been taking it for, I think, 2 or 2years.”</p> <p>P6: “I have two really good friends. One works for public service. He started taking PrEP very shortly after I started. Then I have another friend of mine who started when he went into the military and Don’t Ask, Don’t Tell was repealed. And they have had a positive experience. Neither one of them has had any side effects, nor have I had any side effects.”</p> <p>P7: “I will also say I had a friend really a friend of friend who have had partners who took the condom off during intercourse without them knowing. So thank God they were on PrEP and some of them were even on PrEP before PrEP became mainstream.”</p>

Theme 4: Female-Specific Concerns Regarding PrEP

Three of the participants were women, so I asked probing questions to ascertain if there were any female-specific concerns regarding PrEP (see Table 13). All the participants were concerned about PrEP’s implications regarding fertility, breastfeeding, and the long-term implications of taking PrEP. One participant mentioned that she would inform her ObGYN about using PrEP and seek their specific recommendations about

where she would need to stop the medication and when she could safely restart the medication following pregnancy.

Table 14

Female-Specific Concerns Regarding PrEP

Themes	Category	Participant responses
Female-specific concerns regarding PrEP	Long-term risks Fertility concerns Breastfeeding	<p>P3: “Well, certainly being a female, you think about, you know, a family or possibly having, you know, children. So what are the side effects there, as far as starting a family or, you know, trying to get pregnant or doing any kind of IVF. If breastfeeding, not passing the medication to the child, and that kind of stuff, as far as a female’s perspective are important?”</p> <p>P4: “As a nurse, I would I would want to know about the long-term implications of taking these medicines, fertility concerns, and if PrEP appeared in breast milk?”</p> <p>P7: “I would definitely let my ObGyn know that I take the medication and follow their directions about when to stop or resume the medication if I were to decide to become pregnant or became pregnant.”</p>

Summary

The purpose of this research was to determine American Indian’s perceptions of PrEP. Utilizing the principal research question, I was able to identify that American Indians are overwhelmingly interested in PrEP and believe it to be a reasonable option in the armamentarium in preventing HIV. While many participants believed that PrEP was both safe and effective, most had varying opinions about the use of condoms and comprehensive sexual education. More importantly, this study demonstrates that culture,

religion, and privacy concerns impact the use of PrEP and must be mitigated in some way to expand both access and awareness of PrEP.

Furthermore, themes that limit the use of PrEP not described in the literature related to PrEP in American Indians included adherence, cost, and primary care provider awareness of PrEP. Of note, none of the participants indicated that they would not be willing to take PrEP because it was a medication a finding that the current literature suggested was a barrier to its implementation. Finally, this study's participants demonstrated that female American Indians were concerned about fertility, breastfeeding, and the impact of long-term use of PrEP. All three participants reported they would see guidance from their primary care provider or OBGYN to determine when to stop, start, or restart the medication following pregnancy.

Chapter 5 of this dissertation will discuss the findings from the participants' analysis, including study limitations, recommendations, implications for social change, and conclusions.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

American Indians continue to experience increased incidence and prevalence of HIV (CDC, 2021). Furthermore, American Indians are more likely to be unaware of their HIV status and are more likely to die because of advanced HIV disease at the time of diagnosis (Armenta et al., 2021; Ehrenpreis & Ehrenpreis, 2022; Town et al., 2021). Researchers have discovered that tribes are not monoliths. Values and beliefs often differ from tribe to tribe (Armenta et al., 2021; Lee et al., 2018).

At present, the literature has only described the use of condoms and comprehensive sexual education as HIV prevention interventions in American Indians. Yet current efforts to increase American Indian youths' intent to use condoms fail when centered on risk perception, condom education alone, and condom self-efficacy (Chambers et al., 2018; Chambers et al., 2020; Rosenstock et al. 2020). Similarly, comprehensive sexual education programs must balance the cultural appropriateness of the study and to obtain approval from tribal leadership, the programs were subjected to content constraints that may have limited their effectiveness (Lee et al., 2018; Skye et al., 2021; Thomas et al., 2021).

However, the use of antiviral medications to prevent HIV infections or PrEP is 95% to 99% effective in preventing HIV among other ethnicities (Mayer et al., 2020; Shangani et al., 2021). However, insufficient literature exists to describe American Indians' perceptions of PrEP. Thus, the purpose of this qualitative study is to explore the perceptions of PrEP to prevent HIV infections among American Indians. Based on the

study findings, American Indians favorably view PrEP as a safe and effective method to prevent HIV.

Interpretation of the Findings

Existing Studies of PrEP in American Indians

An exhaustive literature review did not reveal any studies that had explored PrEP in American Indians despite their continued increased incidence and prevalence of HIV (CDC, 2021). Interventions, in American Indian populations, performed to date have only explored condom use and comprehensive sexual education, which demonstrate limited short-term and long-term effectiveness and suggest that the intervention should be repeated frequently (Chambers et al., 2018; Chambers et al.; 2020; Lee et al., 2018; Skye et al., 2021; Rosenstock et al., 2020; Thomas et al., 2021). Furthermore, American Indians are more likely to be unaware of their HIV status and are more likely to die because of advanced HIV disease at the time of diagnosis (Armenta et al., 2021; Ehrenpreis & Ehrenpreis, 2022; Town et al., 2021). This is the first study to explore perceptions of PrEP among an American Indian population despite their increased prevalence, incidence, and worsening HIV outcomes.

Interpreting Findings Using Health Belief Model

The health belief model has been utilized effectively to both explain and predict healthy behaviors, yet it has not been utilized to explain or predict how American Indians protect themselves from HIV outside comprehensive sexual health or condom use (Felsher et al., 2018; Felsher et al., 2022; Hochbaum et al., 1952; Ndebia, & Obioha, 2020; Van Gerwen et al., 2022). In this study, those participants with same-sex partners

volunteering their use of PrEP obviously perceive themselves as susceptible to HIV given their use of PrEP.

However, as described earlier in Chapter 2, the decrease in perception of HIV susceptibility among heterosexual American Indians was evident in participants' use of words such as *gay*, *high risk*, or *they/them*, meaning participants excluded themselves from this demographic. For example, Participant 2 stated that PrEP was a good idea. Participant 2 stated he might use it but did not perceive himself to be a risk despite later volunteering at least two STIs.

Many participants described American Indian clients, family, and friends who were disappearing from HIV and HIV-related complications. If PrEP is to be used as HIV prevention tool among American Indians, using the health belief conceptual framework, then education must attend to HIV's perceived susceptibility as clearly as it has attended to HIV's severity (Prescott et al., 2023).

Findings of This Study

Given the effectiveness of PrEP and the limitations associated with the use of condoms and comprehensive sexual education among American Indians, I used descriptive qualitative analysis to interview eight American Indians to ascertain their perceptions of PrEP to prevent HIV infections among American Indians. All the participants indicated they believe PrEP is a safe and effective means to prevent HIV in the American Indian population. Only one of the eight participants was considered ambivalent regarding PrEP. Of note, she favored barrier methods (e.g., condoms, dental

dams) due to the cost and the potential for long-term side effects of PrEP but believed this was most applicable to college health settings.

During the analysis of the data, four themes were identified: (a) advantages of PrEP, (b) barriers to implementation of PrEP, (c) facilitators to implementation of PrEP, and (d) female-specific concerns regarding PrEP. Among the advantages of PrEP, participants described the safety, efficacy, and the belief that PrEP offers an extra layer of protection when used in combination with condoms. Numerous barriers to the implementation of PrEP were identified and included adherence, cost, culture, privacy, need for provider education, and religion. Facilitators of the implementation of PrEP were identified and included American Indians performing their research, primary care provider recommendations for PrEP, and friends who also use PrEP without side effects. Finally, I used probing questions to identify female-specific concerns regarding PrEP, which included long-term use risks, fertility concerns, and breastfeeding concerns.

While I sought to identify the perceptions of study participants regarding PrEP, many of the barriers to the implementation of PrEP identified among American Indians can be remedied. For example, cost was mentioned as a potential barrier; however, all the manufacturers of PrEP have patient access programs that provide the medication for individuals with certain income levels. Privacy was also a concern raised by participants in this study; however, many of the participants reported they would prefer to have the medications shipped discretely to their homes as opposed to picking them up locally at the pharmacy. Because PrEP is considered a specialty drug it is commonly shipped from specialty pharmacies to local pharmacies or directly to the consumer.

Furthermore, Participant 8 described accessing PrEP through a telehealth platform that mailed a kit with the supplies to perform all necessary testing, provided the prescription for PrEP, and completed any needed prior authorization to obtain the medicine for his copay with his insurance including coupons. Moreover, telehealth platforms for the treatment of STIs and PrEP are expected to continue to grow and offer unmatched privacy for consumers (Bonett et al., 2024; Refugio et al., 2019; Touger & Wood, 2019).

Limitations of the Study

American Indians are hard to recruit for research studies (Wieland et al., 2021). A chief limitation to the trustworthiness of this study was the number of participants. While data saturation was met, future studies should seek to recruit larger samples of American Indians from across the country. Furthermore, because I only sought to recruit American Indians living in southeastern North Carolina, consumers of this research should recognize that American Indian tribes are not monoliths and that values and beliefs often differ from tribe to tribe (Armenta et al., 2021; Lee et al., 2018). As a consequence, it may be difficult to extrapolate these findings to all American Indians living in the Southeast much less the United States.

Recommendations

Based on this study's findings, American Indians in southeastern North Carolina are interested in viewing PrEP favorably and are already utilizing PrEP to prevent HIV infections. Other researchers should seek to recruit a larger American Indian population across the United States to ascertain if these findings extrapolate to the larger Native

American Indian community. Future researchers should devise cross-sectional survey designs to further understand the advantages, perceived barriers, and perceived facilitators to the use of PrEP to reduce the spread of HIV in American Indian populations.

Researchers should seek to identify what American Indians perceive to place them at risk for HIV. One participant indicated because he lives in a densely populated city, he was at higher risk for HIV/AIDS based on a conversation with his healthcare provider. While other American Indians used terms like PrEP is for those who engage in risky sexual behaviors while simultaneously having sexual intercourse without a condom or being prescribed PrEP. Having condomless anal sex is a risky behavior and seems to be a consistent paradox among those who did not use condoms or use PrEP. Finally, researchers may seek to identify how stigma, culture, and religion influence how American Indians classify their sexual identity. Many of the American Indians stuttered, hesitated, or seemed to be word searching when attempting to describe those at risk for HIV based on their sexual identity, the type of sex engaged in, or the frequency with which they had sexual intercourse.

Implications

This research study has the potential to generate positive social change by decreasing the incidence, prevalence, and reduce mortality associated with HIV among American Indians. Consumers of this research who are healthcare providers may seek out continuing education regarding PrEP and consider offering it as a service within their primary care clinic or at least minimally provide education to their American Indian

patients about PrEP. Consumers of this research who are involved in disease prevention and healthcare policy advocates should work to develop campaigns and marketing material that educate American Indians about their risk factors for HIV, available options to decrease their risk, and seek to provide referrals to providers who are offering PrEP for those interested. Further, consumers of this research who are involved in research should continue to build on this research to validate its findings in other tribal groups. Finally, consumers of this research who are involved in case management should help provide education about PrEP to American Indians, help American Indians obtain PrEP through their insurance, distribute copay cards, and when needed help access Patient Assistance Programs to obtain the medications for free.

Conclusion

This descriptive qualitative study was conducted to identify the perceptions of PrEP of American Indians living in southeastern North Carolina. While American Indians experience disparate HIV outcomes there is hope on the horizon with the implementation of PrEP. The findings of this study can inform culturally relevant PrEP education and outreach programs; help identify strategies to address barriers to PrEP access and adherence; and contribute to a better understanding of PrEP's impact on HIV prevention among American Indians.

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Interview study seeks adult American Indians for HIV prevention study

There is a new study that seeks to explore the perceptions of adult American Indians regarding the use of Pre-Exposure Prophylaxis (PrEP) to prevent HIV infection. You are invited to share your perceptions of Pre-Exposure Prophylaxis to prevent HIV infection.

About the study:

- One 30 to 60-minute audio-recorded interview that can be performed face-to-face, by telephone, or via teleconferencing software at your request
- You would receive a \$15 Visa gift card for your participation
- To protect your privacy, the published study would use fake names

Volunteers must meet these requirements:

- 18 years old or older
- American Indian
- Live in the southeastern United States

This interview is part of the doctoral study for William Johnson, a Ph.D. student at Walden University. Interviews will take place during May 2024.

To confidentially volunteer, contact the researcher: William Johnson

Appendix B: Inclusion and Exclusion Criteria

Inclusion Criteria

18 years old or older

American Indian ethnicity

Live in the southeastern United States

Exclusion Criteria

Individuals less than 18 years of age

Any ethnicity other than American Indian

Patients, friends, and acquaintances of the researcher

Appendix C: Demographic Questionnaire

Pseudo I.D.: _____

Participant Age:

_____ 19-24 years old
_____ 25-34 years old
_____ 35-44 years old
_____ 45-54 years old
_____ 55-64 years old
_____ 65+ years old
_____ Other

Gender:

_____ Female
_____ Male
_____ Other

Marital Status:

_____ Single
_____ Married
_____ Widowed
_____ Divorced
_____ Other

Education Level Obtained:

_____ High School
_____ Some College
_____ Bachelor's degree
_____ Master's degree
_____ PhD/Professional Doctorate or Higher

Appendix D: Interview Guide

Research Question: What are your perceptions of the use of pre-exposure prophylaxis to prevent HIV infection?

- Please tell me more about your experience with... [what the participant mentioned]?
- Please tell me more about that...
- Please tell me about how you reached that conclusion?
- Is there anything else you would like to share with me?
- Thank you for sharing...

If the participant is unaware of PrEP or request an explanation of PrEP, I will provide the information in *Figure 1*. The text will be provided on a handout (for interviews in person) or screen shared via Zoom (for virtual interviews).

Figure 1: *Overview of Pre-Exposure Prophylaxis*

Pre-exposure prophylaxis (or PrEP) is the use of a daily pill that an HIV-negative person can take to prevent HIV infection. PrEP is commercially available throughout the United States. PrEP is covered by most prescription drug insurance plans including Medicare and Medicaid. Additionally, individuals who meet the income criteria established by the manufacturer and who do not have prescription drug coverage may receive PrEP at no cost through a patient assistance program. Individuals who have HIV or Hepatitis B should not use PrEP. The most common side effects of PrEP may include: fatigue, headache, nausea, vomiting, diarrhea, decreased bone density, decreased kidney function, and lactic acidosis.

Adapted from *Descovy: Highlights of prescribing information* by Gilead, 2022
(https://www.gilead.com/~media/Files/pdfs/medicines/hiv/descovy/descovy_pi.pdf)