THE LIVED EXPERIENCES OF YOUNG WOMEN ON THE USE OF HIV PRE-EXPOSURE PROPHYLAXIS IN NAMIBIA

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Thesis presented in partial fulfilment of the requirements for the degree of Master of Nursing Science in the Faculty of Medicine and Health Sciences Stellenbosch University



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December 2021

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously, in its entirety or in part, submitted it for obtaining any qualification.

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ABSTRACT

Background:

Young women have a higher risk of acquiring HIV than other population groups. In sub-Saharan African, at least five in six new HIV infections happen in girls between the ages of 15-19 years. This age group is particularly at a high risk of acquiring HIV due to issues affecting young women such as gender based violence, sexual abuse, limited access to education and health services, and inequalities and injustice. Pre-exposure prophylaxis (PrEP) is the use of antiretroviral medicines by HIV negative individuals before HIV exposure to avert HIV infection. However, since its introduction in Namibia, in 2016, PrEP uptake amongst young women remains low. Various conditions may influence women's decisions to initiate and continue PrEP. Little is known about the lived experiences of young women on the use of PrEP.

Aim and objectives:

The aim of the study was to explore the lived experiences of young women on the use of PrEP in Namibia. The objectives were to:

- explore the knowledge and understanding of young women about PrEP,
- describe the socio-cultural, educational and informational conditions that influenced their decision to use PrEP,
- describe the physical, emotional and social support needs of young women using PrEP.

Methods:

A qualitative descriptive phenomenological design was used. The study inclusion criteria were: young women aged between 21 and 24 years; current or previous use of PrEP; and attendance of at least one follow-up visit after commencing PrEP. The sample included nine participants from five clinics in and around the town of Rundu, in the Rundu district of the Kavango East region of Namibia. A purposive sampling method was used to obtain maximum variability. Data collection involved face-to-face in-depth interviews using a semi-structured interview guide.

Colaizzi's seven-step process was used to analyse data. Ethics approval was obtained from the Stellenbosch University Health Research Ethics Committee reference number, S19/02/031. Furthermore permission was obtained from the Ministry of Health and Social Services and the regional health director of Kavango East region.

Findings:

Three themes were identified: risk awareness, empowered for self-care, and persisting despite the challenges. Young women in this study were aware of their risk of acquiring HIV and this prompted them to use PrEP. These risks included lack of awareness of their partner's HIV status coupled with a lack of trust in their partners; or being in a sexual relationship with a partner living with HIV. Awareness also emanated from information provided by healthcare workers, peers and the media. Using PrEP empowered young women for self-care through enabling them to make choices about managing their risk. Some of the women persisted using PrEP despite several challenges which included the lack of privacy, stigma and inadequate support.

Conclusion and recommendations:

PrEP is an empowering HIV prevention strategy for young women, however, much still needs to be done to promote young women's willingness to initiate and continue PrEP. PrEP awareness campaigns should be expanded to address myths and misconceptions and positively influence social norms. Differentiated PrEP delivery models should be implemented, including integration with other services such as sexual reproductive health services, effective counselling and peer support.

Key words: HIV, PrEP, young women, HIV prevention, lived experiences.

OPSOMMING

Agtergrond:

Jong vroue het 'n hoër risiko om MIV op te doen as ander bevolkingsgroepe. In Afrika suid van die Sahara kom minstens vyf uit ses nuwe MIV-infeksies voor by meisies tussen die ouderdom van 15 en 19 jaar. Hierdie ouderdomsgroep loop veral 'n hoë risiko om MIV te kry as gevolg van kwessies wat jong vroue raak, soos geslagsgeweld, seksuele misbruik, beperkte toegang tot onderwys- en gesondheidsdienste, en ongelykhede en onreg. Preblootstelling profylakse (PrEP) is die gebruik van antiretrovirale medisyne deur MIVnegatiewe individue voordat MIV blootgestel word aan MIV-infeksie. Sedert sy bekendstelling in Namibië in 2016, is die opname van PrEP onder jong vroue egter steeds laag. Verskeie toestande kan vroue se besluite beïnvloed om PrEP te inisieer en voort te sit. Weinig is bekend oor die ervarings wat jong vroue met PrEP gebruik het.

Doel en doelstellings:

Die doel van die studie was om die ervarings van jong vroue oor die gebruik van PrEP in Namibië te ondersoek. Die doelstellings was om:

- die kennis en begrip van jong vroue oor PrEP,
- die sosio-kulturele, opvoedkundige en inligtingstoestande wat hul besluit om PrEP te gebruik, beïnvloed,
- die fisiese, emosionele en sosiale ondersteuningsbehoeftes van jong vroue met behulp van PrEP te beskryf.

Metodes:

'N Kwalitatiewe beskrywende fenomenologiese ontwerp is gebruik. Die kriteria vir die insluiting van die studie was: jong vroue tussen 21 en 24 jaar; huidige of vorige gebruik van PrEP; en bywoning van ten minste een opvolgbesoek na aanvang van PrEP. Die steekproef het nege deelnemers van vyf klinieke in en rondom die stad Rundu, in die Rundu-distrik van die Kavango-Oos-streek van Namibië, ingesluit. 'N Doelgerigte steekproefmetode is gebruik om maksimum wisselvalligheid te verkry. Die insameling van data het van diepgaande onderhoude van aangesig tot aangesig gebruik gemaak van 'n semi-gestruktureerde onderhoudsgids.

Colaizzi se sewe-stap-proses is gebruik om data te ontleed. Etiese goedkeuring is verkry vanaf die Universiteit Stellenbosch Gesondheidsnavorsingsetiekkomitee, S19 / 02/031. Verder is toestemming verkry van die Ministerie van Gesondheid en Maatskaplike Dienste en die streeksgesondheidsdirekteur van die Kavango-Oos-streek.

Bevindinge:

Drie temas is geïdentifiseer: risikobewustheid, bemagtig vir selfversorging en volgehoue ondanks die uitdagings. Jong vroue in hierdie studie was bewus van hul risiko om MIV op te doen, en dit het hulle aangespoor om PrEP te gebruik. Hierdie risiko's sluit in 'n gebrek aan bewustheid van hul maat se MIV-status, tesame met 'n gebrek aan vertroue in hul vennote; of in 'n seksuele verhouding met 'n maat wat met MIV leef. Bewusmaking spruit ook uit inligting wat deur gesondheidswerkers, eweknieë en die media verskaf word. Die gebruik van PrEP het jong vroue bemagtig vir selfversorging deur hulle in staat te stel om keuses te maak om hul risiko te bestuur. Sommige van die vroue het aangehou om PrEP te gebruik, ondanks verskeie uitdagings wat die gebrek aan privaatheid, stigma en onvoldoende ondersteuning insluit.

Gevolgtrekking en aanbevelings:

PrEP is 'n bemagtigende strategie vir die voorkoming van MIV vir jong vroue, maar daar moet nog baie gedoen word om die bereidwilligheid van jong vroue om PrEP te inisieer en voort te sit, te bevorder. PrEP-bewusmakingsveldtogte moet uitgebrei word om mites en wanopvattings aan te spreek en sosiale norme positief te beïnvloed. Gedifferensieerde PrEP-afleweringsmodelle moet geïmplementeer word, insluitend integrasie met ander dienste soos seksuele reproduktiewe gesondheidsdienste, effektiewe berading en portuurondersteuning.

Sleutelwoorde: MIV, PrEP, jong vroue, MIV-voorkoming, lewende ervarings.

DEDICATION

I dedicate this work to my father and my late mother. You have raised me in the best way you could, for that I shall forever be grateful. I can never thank you enough.

Aron Vasco

&

Mawano Secilia Nduva.

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LIST OF ACRONYMS

FDA Food and drug administra	tion
------------------------------	------

- HIV Human immunodeficiency virus
- HREC Health research ethical committee
- MoHSS Ministry of Health and Social Services
- PHC Primary Health Care
- PrEP Pre-exposure prophylaxis
- UNAIDS Joint United Nations Programme on HIV and AIDS

CHAPTER 1: FOUNDATION OF THE STUDY

1.1 INTRODUCTION

The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2020a:1) reports that in 2019, up to 38 million people worldwide were living with the human immunodeficiency virus (HIV) and 18.8 million were girls and women, constituting more than half of the total population. Despite several available methods and strategies for preventing HIV, about 5500 adolescent girls and young women aged 15–24 years are newly infected with the virus every week around the world. Sub-Saharan African contributes to 59% of these infections making it the region with the highest HIV infection rate (UNAIDS, 2020a:3). In Sub-Sahara Africa, at least five in six new HIV infections happen in girls between the ages of 15-19 years (UNAIDS, 2020a:2). This age group is particularly at a high risk of acquiring HIV due to issues affecting young women such as gender based violence, sexual abuse, limited access to education and health services, and inequalities and injustice (UNAIDS, 2014:3; UNAIDS, 2020a:3). UNAIDS (2018:3) indicates that more than one third (35%) of women around the world have already experienced rape and some form of sexual abuse in their life.

The high rate of HIV infection has led to the call for more HIV preventative strategies. One such strategy is the use of pre-exposure prophylaxis. Pre-exposure prophylaxis (PrEP) refers to the use of antiretroviral medicines by HIV negative individuals before HIV exposure to avert HIV infection (Ministry of Health and Social Services [MoHSS], 2016a:98). PrEP is a new strategy that has been implemented/tested in persons with a high risk of acquiring HIV, for example, men who have sex with men and in female sex workers (Siquier & Molina, 2018:1). However, the World Health Organization (WHO) has extended it to all people at risk of acquiring HIV, which includes young people with multiple sexual partners (WHO, 2015:42). The antiretroviral drugs tenofovir disoproxil fumarate (TDF) and emtricitabine (FTC) were approved by the United States Food and Drug Administration in 2012, to be used as PrEP (Centers for Disease Control and Prevention, 2014:1).

The success of the implementation of new prevention strategies hinges on ensuring that user needs are met (Silapaswan, Krakower & Mayer, 2016:192). Since most PrEP implementation studies have focused on the experiences of sex workers and men who have sex with men, little is known about the lived experiences of young women (Owens, Williams & Dodge, 2020:1; Siquier & Molina, 2018:1). As a high-risk group, the lived experiences of young women determine the continuous use of PrEP in this group and consequently, the

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future success of prevention strategies focused on young women. This study explored the lived experiences of young women residing in Namibia on the use of PrEP for the prevention of HIV.

1.2 BACKGROUND AND RATIONALE

Namibia reported its first case of HIV in 1986. Since then there has been a continued rise in the prevalence of HIV amongst pregnant women reaching a peak of 22% in 2002. In 2016, it was estimated that about 220 000 Namibians were living with HIV (MoHSS, 2016a:2). A Namibian national survey on the trends of HIV prevalence amongst Namibian pregnant women who received antenatal care in 2016 reported a higher HIV prevalence among women aged 35-39 years which was 32.3%, compared to women aged 20-24 years with a prevalence of 10.2% (MoHSS, 2016b:16). The national sentinel survey (MoHSS, 2014:16) reported an 8.5% HIV prevalence amongst the 3562 pregnant young women in the age group 15-24, while the age group 25-49 years had a 24% HIV prevalence out of the 4555 pregnant women who were tested in 2014.

Twelve percent of the world's population is composed of adolescents and young women totalling up to 1.1 billion (UNAIDS, 2018:2). In Namibia, an increase in new HIV infections was reported in the age groups 0-14 and 15-19 while all other groups reported a decline. In the former age group infections decreased from 3.15% in 2009 to 3.7% as reported in the 2010 National Testing Day (NTD) report, whereas in the latter infections increased from 2.16% to 2.63% as indicated in the same report in 2010 (MoHSS, 2010:1).

Young women are at high risk of acquiring HIV due to conditions such as gender-based violence, limited access to healthcare and education. These conditions prevent them from accessing health care and limit their agency to protect themselves against HIV. The violence against children surveys in 11 countries, most supported by the President's Emergency Plan for AIDS Relief (PEPFAR), found that one in three young women reported their first sexual experience as being forced or coerced (PEPFAR, 2017:1). Gender-based violence is a violation of human rights and facilitates the spread of HIV/AIDS (PEPFAR, 2017:1). About 870 000 new HIV infections occur among women and girls every year (UNAIDS, 2018:2). In 2019, 48% of all new HIV infection cases were among women and girls (UNAIDS, 2020a:2). Of note is that, globally, 80% of the 15% of young women and adolescent girls aged 15-24 years living with HIV are from Sub-Sahara Africa (Global Fund, 2017:3). Thus based on these findings, it can be concluded that preventative efforts need to be escalated amongst young women.

There are several methods of HIV prevention such as condom use or abstinence, however, these have not been successful in preventing the transmission of HIV amongst young women. Santelli, Kantor, Grilo, Speizer, Lindberg, Heitel, et al. (2017:4) investigated the efficacy of abstinence in preventing pregnancy and sexually transmitted infections, (STIs) and concluded that abstinence from sexual intercourse is a misleading and potentially harmful message. Furthermore, abstinence is not effective in the prevention of HIV in many young people as they fail to practise it. Other interventions that are important for the prevention of HIV among this population group include increasing knowledge about HIV and promoting awareness about HIV and risk perceptions. Social behaviour change communication programmes, which promote safer behaviours, increased service use, HIV disclosure, risk perception, reduced gender-based violence and positive changes in social and gender norms, through sexuality education, may assist in combating HIV infections (Global Fund, 2017:11).

The United Nations Political Declaration on Ending AIDS had set the target to lower new HIV infections in young women to less than 100 000 by the year 2020 (Global Fund, 2017:3). It is further stated that HIV prevention as well as testing for HIV, treatment and care services should be provided comprehensively. This should involve health services integrated with sexual reproductive health services to ensure cost-effectiveness, uptake, and access to PrEP, in order to ensure quality of care (Global Fund, 2017:3).

PrEP is a key strategy that may help to reduce new HIV infections amongst adolescent girls and young women. Policy makers in many countries are still considering making PrEP available as a prevention option for young women and research has been conducted about its acceptability in countries such as Tanzania, Kenya and South Africa (Population Council, 2017:1).

For successful HIV prevention, a combination of HIV prevention methods or strategies are ideal (UNAIDS, 2015:17). According to the Namibian antiretroviral therapy (ART) guidelines it is recommended that PrEP should be used as part of the combination prevention package which comprises HIV testing services, use of male and female condoms, lubricants, use of ART for HIV-positive partners in sero-discordant relationships, voluntary medical male circumcision and prevention and management of STIs (MoHSS, 2016a:99). As a result, young women are empowered to make informed, active, free and meaningful decisions.

PrEP has been introduced for key at risk population groups, which include people who inject drugs, sex workers, people in prison and other closed groups (WHO, 2015:42). There is no specific evidence related to the lived experiences of young women towards the use of PrEP

in Namibia. Although there have been studies looking at behaviours, attitudes and perceptions related to HIV/AIDS and PrEP, further studies in local contexts are needed since people's lived experiences may vary depending on their context (WHO, 2015:49). WHO has indicated a need for more studies that will generate knowledge and strategies related to the implementation of PrEP in diverse communities such as young women who are at substantial risk of contracting HIV (WHO, 2015:49).

Furthermore, societal, educational and cultural conditions may influence young women's decisions to use PrEP, and such conditions include societal attitudes as well as the educational level of young women (Wanjiru, 2014:22; Kabir, Rahman, Smith, Lusha, Azim & Milton, 2016:9). MoHSS (2019:47) emphasises the need for demand creation in order to influence the social behaviours of individuals in a way that can support PrEP uptake and use (MoHSS, 2019:47). Support from community based organisations plays a key role in increasing the uptake of PrEP services through demand creation (MoHSS, 2019:48).

PrEP for young women has been rolled out in Namibia since 2016, however, reports indicate that the uptake has been slow (MoHSS, 2016a:98). PrEPWatch Namibia (2018:1) indicates that there are less than 200 current users out of a target number of 2500. In the district where the researcher conducted the study, there were approximately 20 young women who were using PrEP at the time of the study. Through this study, the researcher attempted to explore the lived experiences of young women who were using or had previously used PrEP in the context of Namibia. The evidence from this study may inform policy makers and all stakeholders on the best approaches to improve the uptake and continuation of PrEP.

1.3 PROBLEM STATEMENT

There is an increase in new HIV infections amongst young women and they are at risk for HIV due to various social imperatives. In Namibia, an increase in new HIV infections was reported in the age groups 0-14 and 15-19 while all other groups reported a decline (MoHSS, 2016b:17). The Namibian sentinel survey report of 2016 indicates that the HIV rate increases with age (MoHSS, 2016b:17). Although PrEP has been available as a prevention option for young women since 2016, reports indicate that few young women are actually accessing it. This prompted the researcher to explore the lived experiences of young women on the use of PrEP. There is currently no evidence to inform HIV prevention campaigns that include PrEP in the context of Namibia. PrEP is a key strategy that may help to reduce new HIV infections amongst adolescent girls and young women and improving the uptake thereof is therefore important.

1.4 RESEARCH QUESTION

What are the lived experiences of Namibian young women on the use of PrEP?

1.5 RESEARCH AIM

The aim of the study was to explore the lived experiences of young women on the use of PrEP in Namibia.

1.6 RESEARCH OBJECTIVES

The objectives of the study were to:

- explore the knowledge and understanding of young women about PrEP;
- describe the societal, educational and cultural conditions that influenced their choices to use PrEP; and
- describe the physical, emotional and social support needs of young women while using PrEP.

1.7 RESEARCH METHODOLOGY

1.7.1 Research methodology

A qualitative descriptive phenomenological design was used for this research study.

Figure 1.1 depicts a brief overview of the research methodology. A detailed description will follow in Chapter Three.

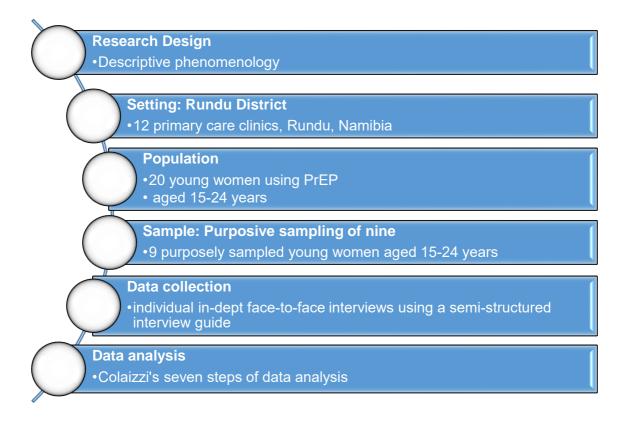


Figure 1.1: Summary of the methodology

1.7.2 Researcher's position

The researcher was previously employed as a Primary Health Care (PHC) registered nurse working at one of the PHC clinics that offers preventative services such as PrEP amongst other services in Rundu district, Kavango east region of Namibia. Currently the researcher is a lecturer and assistant dean of students at Welwitchia HealthTraining Centre, Nkurenkuru Campus, in the Kavango west region of Namibia.

The researcher had previous preconceived ideas towards the topic which she noted in her diary. One such an idea was that PrEP is effective and therefore t young women should have access to it and use it. Furthermore risky behaviours of young women such as, inconsistent use of condoms and multiple sexual partners may put some young women at risk for HIV infection and therefore the need for PrEP. Young women may as well fear using PrEP as they may be afraid of being stigmatized.

1.7.3 Trustworthiness

Qualitative researchers use four categories of trustworthiness to enable readers to evaluate the scientific rigour of their studies (Mabuza, Govender, Ogunbanjo & Mash, 2014:3). In order to ensure trustworthiness in this study, the researcher applied the four categories of

trustworthiness in qualitative studies namely: credibility, dependability, transferability and confirmability, which will be explained in detail in Chapter Three.

1.8 ETHICAL CONSIDERATIONS

The researcher sought ethical clearance and approval from the Health Research Ethics Committee (HREC) of the Stellenbosch University, reference number S19/02/031, as well as that of the Namibian Ministry of Health and Social Services, reference number 17/3/3 EV. The study was approved on the 22nd of May 2019 by the HREC of Stellenbosch University. On the 11th of October 2019 permission to conduct the study was granted by the MoHSS of Namibia. Table 1.1 outlines how the researcher applied the ethical principles before, during and after the study. A detailed description of how the researcher applied the ethical principles is also presented below.

Before the interview	During the interview	After the interview
 Ethical approval and permission to conduct the study from MoHSS of Namibia. Participants informed why selected for the study. Voluntary signing of informed written consent. No recording of names. 	 Right to withdraw at any point without penalty. No more than minimal risk. Risk of becoming emotional due to past experience assessed. Counsellor for the emotional participants was availed. No cost for partaking in the study, refreshments provided. Participants only answer questions they are comfortable with. Unpressured talking pace and time to think. Interviews were done in a private room 	 No recording of names. Right to privacy and anonymity, no labelling of audio recordings with information that could easily be linked to the participants. Storing of other documents likely to be linked to participants separately in a safe lockable cabinet. Audio recordings destroyed after transcription of data. Unlabelled transcripts kept in a lockable cabinet for five years. Anonymous publishing of study findings. Participant asked to inform their parent or nearest healthcare worker if they feel sad at a later stage.

Table 1.1: Application of ethical principles

1.8.1 Right to self-determination

Autonomy refers to the freedom of making decisions for oneself (Mulaudzi, Mokoena & Troskie, 2019:36). Autonomy was respected through the signing of an informed consent document (Appendix 3). Participation was entirely voluntary. Participants had the right to withdraw from the study even after having signed the informed consent without any penalty or being prejudiced and this was stated in the consent form. In Namibia only individuals

aged 18 years and above can legally give consent independently for taking part in studies or interventions. None of the participants who agreed to take part in the study were under the age of 18. However, had there been need, the researcher would have followed a standard procedure for obtaining assent for participants under the age of 18 that was approved by the HREC (Appendix 3).

1.8.2 Right to protection from discomfort and harm

Non-maleficence refers to not causing harm to the participants whereas beneficence is doing good (Mulaudzi et al., 36:2019). The study was non-experimental, therefore, the participants were not exposed to more than minimal risk. The talking pace was not pressured and the participants were given enough time to think. Participants were informed to notify their parent or nearest healthcare worker if they felt sad at any time after the interview. However, none of the participants became emotional as a result of past personal experience during the interviews. Seven (7) out of the nine (9) participants incurred travelling costs to the amount of N\$24.00 each and the researcher reimburse them. Additionally the researcher provided refreshments to the value of N\$30.00 for each participant which included 500 ml mineral water and 1 liter fruit juice.

On the 17th of March 2020, the president of the Republic of Namibia declared a state of emergency due to the COVID-19 pandemic after Namibia reported its first case of COVID-19 (Republic of Namibia, 2020a:1). The state of emergency allowed for the study to continue. Participants number eight and nine were interviewed during the state of emergency period under stage 2 and stage 4 respectively. Although at the time of the interviews, the Kavango East region did not have any confirmed COVID-19 positive cases (MoHSS, 2020: 3), the cumulative number of positive COVID-19 cases in the country was 1917. To reduce the risk of COVID-19 infection, the researcher observed all regulations relating to COVID-19 protocols as stated in the Government Gazette by the President of the Republic of Namibia (Republic of Namibia, 2020b:3; Republic of Namibia, 2020c:1). Furthermore, the researcher and participants both wore masks, maintained one-metre apart social distancing and washed their hands before and after the interview process as per the regulation. The researcher screened participants for COVID-19 related symptoms before scheduling the interviews. Neither of the participants showed COVID-19 symptoms. Additionally the researcher as well as the clinic at which the participants were interviewed kept a record of participants' names to assist in tracing the participants in the event that any one of them later tested positive for COVID-19. None of the participants were reported to have had developed COVID-19 symptoms after the interviews.

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1.8.3 Right to confidentiality and anonymity

Confidentiality refers to keeping the participant's privileged information secret (Mulaudzi et al. 2019:40). While anonymity requires that participant's identity cannot be linked to participants responses. The researcher used purposive sampling, therefore, the selection was based solely on the inclusion criteria and the principle of maximum variability sampling. The researcher ensured anonymity of all recorded information by omitting the names of the participants and only used puesodonames so that their response cannot be linked to identities. Participants were not requested to provide their names to protect their right to confidentiality and anonymity. The researcher was able to communicate well with the participants as they either were fluent in Rukwangali and / or English. Thus a translator was not needed. To further ensure confidentiality the audio recordings were stored in a password protected computer. The researcher appointed someone to do the translation and transcription of data. This individual was requested to sign a confidentiality agreement before receiving the audio recordings. The researcher destroyed all the audio recordings after the supervisor had checked the transcripts (Brink, van der Walt & van Rensberg, 2012:36). The informed consent forms, which are likely to be linked to the participants, are being kept in a lockable cabinet and will be destroyed five years after data collection using a shredder. Due to implications of storing transcribed data, the researcher ensured that the transcripts did not contain identifying information and were labelled with information that could not easily be linked to the participants. The participants were also informed during consent signing, before the data collection, that the researcher was going to keep the data for at least five years (Ritchie & Lewis, 2009:68). The findings of the study will be published anonymously without linking the data to the participants.

1.9 DURATION OF THE STUDY

Ethical approval to conduct the study was obtained on the 22nd of May 2019 from the HREC of Stellenbosch and on the 11th October 2019 permission to conduct the study was granted by the MoHSS of Namibia. Data collection then commenced on the 9th of December 2019 and was completed on the to 18th of July 2020. The researcher analysed data throughout the data collection process. Report writing followed and was completed on the 28th of February 2021 when the researcher submitted the completed thesis for examination.

1.10 DEFINITIONS

Exploring: is when a researcher intends to describe concepts relating to a phenomenon that has little available information (Jooste, 2017:330). In this study, the researcher explored the lived experiences of Namibian young women on the use of PrEP.

Lived experience: refers to the familiar and functional source of knowledge gained through one's lived experience in a certain phenomenon (Brink, et al., 2015:6). In this study, the researcher explored young women's lived experiences on the use of PrEP.

Young woman: An individual between 15-24 years of age (UNAIDS, 2014:3).

Pre-exposure prophylaxis for HIV: The use of antiretroviral medicines by HIV negative individuals before body fluid exposure, for example, sexual exposure to avert HIV infection (MoHSS, 2016a:98).

1.11 CHAPTER OUTLINE

Chapter One: Foundation of the study

This chapter constitutes the background and motivation of the study as well as a brief overview of how the researcher planned to conduct the study.

Chapter Two: Literature review

In this chapter, a review of available and significant literature about PrEP is presented.

Chapter Three:Research methodology

This chapter includes a step-by-step description of the method that was used to collect the data as well as how the data were analysed.

Chapter Four: Findings

This chapter presents the findings of the study.

Chapter Five: Discussion, conclusions and recommendations

In this chapter, the researcher discusses the findings of the study in relation to the study objectives as well as the conclusions and recommendations.

1.12 SIGNIFICANCE OF THE STUDY

Evidence about the lived experiences of young women on the use of PrEP is not available in the context of Namibia. The study findings might help the MoHSS to be aware and to understand the lived experiences of young women on the use of PrEP. This might assist the MoHSS in implementing better strategies to improve the uptake and continuation of PrEP amongst young women.

1.13 CONCLUSION

Young women are vulnerable and at risk for acquiring HIV. Therefore, understanding their lived experiences on the use of PrEP might help to inform strategies that can improve the

uptake of PrEP amongst these young women in Namibia. This study explored the understanding of young women on the use of PrEP in Namibia, the conditions that influenced their decisions to use PrEP as well as the support systems that were available for them. In the next chapter, a review of the literature is provided.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

Brink, et al. (2012:71) defines a literature review as a process that is systematic in nature. It is a well-defined approach designed to identify and retrieve studies. The purpose of a literature review is to find information about a topic in order to make conclusions, identify gaps for future studies and thereby develop guidelines for clinical practice (Brink et al., 2012:71). The researcher conducted a preliminary literature review before the study in order to identify and describe the research problem and aim. An in-depth review, which is presented in this chapter, was performed after data collection and analysis in order to prevent bias. This was done to ensure that the literature review results do not influence the data collection and data analysis processes. Further, the researcher bracketed information from the preliminary literature review by keepting a refletive diary.

The literature review aided the researcher in understanding the lived experiences of young women on the use of PrEP in Namibia. The review included a summary of information related to PrEP guidelines and young women's lived experiences of PrEP in the context of Namibia and globally. This was done with the purpose of synthesising evidence related to young women's risk of acquiring HIV as well as that related to HIV prevention strategies for young women.

2.2 SELECTING AND REVIEWING THE LITERATURE

The researcher reviewed studies related to the use of PrEP in the prevention of HIV/AIDS. Databases such as Google Scholar, CINAHL, PubMed, SAGE and the Cochrane Library were used to search for studies related to the topic of study. The key words used were pre-exposure prophylaxis, WHO and pre-exposure prophylaxis, HIV prevention and young adults/adolescents/teenagers/college students. The search was limited to the English language only and to full text articles published not later than 2012, as this is when the FDA approved PrEP drugs for use. Some grey literature was used such as the Namibian National Guidelines for Antiretroviral therapy (MoHSS, 2019), the Ministry of Health and social service Sentinel Survey (MoHSS, 2014: MoHSS, 2016b) reports as well as WHO reports and fact sheets.

The researcher begins the literature review by looking at young women and HIV and moves on to HIV prevention strategies for young women before presenting literature related to the efficacy and safety of HIV PrEP. Thereafter, the researcher discusses the global and Namibian guidelines on the use of PrEP in terms of eligibility for PrEP. This is followed by a summary on the users' lived experiences of PrEP in broad themes, for example, negative and positive experiences. The researcher goes on to discuss conditions influencing PrEP uptake and continuation such as awareness and service availability, sociocultural, educational and informational conditions. Additionally, physical, emotional, social and informational support needs of young women while using PrEP are summarised. The researcher seals off the chapter by discussing the application of the Situated Information, Motivation, Behaviour Model (sIMB) to this study.

2.3 LITERATURE REVIEW

2.3.1 Young women and HIV

Globally, adolescents and young adults account for a disproportionate number of new HIV infections and there is a continuous projected increase (UNAIDS, 2020a:2; Avert, 2019:np). Young women are more likely to be involved in risky behaviours such as unprotected sex, multiple sexual partnership, non-use or inconsistent use of condoms and drug abuse (Allen et al., 2017:400). A study on youth risk behaviour amongst public, private and Catholic schools in the United States identified several risk behaviours such as tobacco, alcohol and drug use, and sexual risk behaviours. These risk behaviours can influence health outcomes, for example, resulting in sexually transmitted diseases, HIV infection and unintended pregnancies (R-Almendarez & Wilson, 2013:108). Another study by Sheferaw, Alemu, Girma, Getahun and Alemu (2011:1) in Gondar, northwest of Ethiopia, assessed the knowledge, attitudes and practices of male and female students regarding HIV/AIDS. The study found that 25% of the students already had had sexual intercourse before and or had been exposed to at least one risk behaviour in their lifetime. The study then made conclusion hat students lacked awareness about sexually transmitted diseases and methods to prevent them (Sheferaw et al. 2011:1). Early sexual debut is one of the health determinants of young women as it may put them at a higher risk of sexually transmitted diseases, including HIV (Shiferaw, Alemu, Girma, Getahun, Kassa, Gashaw et al., 2011:2). In South Africa, 7.6% of young women between the ages of 15 and 24 reported sexual debut before the age of 15 and 9% had multiple sexual partners in the past 12 months while only 49.8% reported that they had used a condom in the last sexual encounter (Simbayi, Zuma, Zungu Moyo, Miranda, Jooste, et al., 2017:82).

Furthermore, societal gender inequality and violence faced by women and girls increase their risk of HIV acquisition. Young women are twice as likely to acquire HIV than young men of the same age (Avert, 2019:np: UNAIDS, 2017:6). A study by Karletsos Greenbaum,

Kobayashi and McConnell (2020:6) on female students' willingness to use PrEP in Lesotho reports that amongst female students who participated in the study, 39% reported having more than one sexual partner while 37% reported that they found it hard to negotiate condom use with their sexual partners. This may be due to women and girls' vulnerability as a result of their social, cultural and economic status. Women and young girls' autonomy has been restricted by society and this has resulted in reduced capacity to access sexual reproductive health services (Avert, 2019:np: UNAIDS, 2017:2). Therefore, much more still needs to be done to reduce the HIV prevalence in this group. A range of HIV prevention strategies therefore need to be availed to this group.

2.3.2 HIV prevention strategies for young women

There are several methods of HIV prevention that are available for young women. In Chapter One the researcher discussed the various methods that are available. Preventative strategies, as identified by the Global Fund (2017:11) may include, but are not limited to increasing knowledge about HIV, promoting awareness about HIV, and risk perceptions. Social behaviour change programmes, which promote safer behaviours and increase service use, may assist in combating HIV infections (Global Fund, 2017:11). Furthermore, young women may protect themselves from HIV infection through the use of barrier methods such as male or female condoms or may decide to abstain from sexual intercourse (Santelli, Kantor, Grilo, Speizer, Lindberg, Heitel, et al., 2017:4). However, these methods may not be successful in preventing HIV transmission and may even be regarded as potentially harmful. For example, messages that advocate abstinence may withhold information about human sexuality and limit access to comprehensive sexual and reproductive health services, as illustrated by a review on the abstinence-only-until-marriage policies and programmes. The review found that most young women who planned to practice abstinence as a preventative measure for pregnancy, HIV and other STIs have failed to successfully do so (Santelli, et al., 2017:4). Confirming the notion that abstinence may not be an effective HIV prevention strategy. Fletcher et al. (2018:176-177) found that although African-American mothers believed that reducing their daughters' HIV risk was a priority and preferred abstinence, they realised that using abstinence as a long term method was not the best. The study further identified that mothers and daughters were likely to accept adolescent PrEP use (Fletcher et al., 2018:176-177).

PrEP, as was discussed in Chapter One, is an antiretroviral medicine that is used by HIV negative individuals before sexual exposure to avert HIV infection (MoHSS), 2016a:98). Therefore, PrEP is an alternative strategy in the prevention of HIV. PrEP has been implemented/tested in persons at high risk for HIV infection, for example, men who have sex

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with men and in female sex workers (Siquier & Molina, 2018:1). After men who have sex with men and female sex workers, young women were identified as a vulnerable group that may benefit from PrEP in the fight against HIV (WHO, 2015:42).

PrEP may be particularly beneficial when used effectively by young women. In the study conducted by Fletcher et al. (2018:176-177), African-American mothers of adolescent girls reported that they believed that the use of PrEP in addition to other preventative methods offered a worthwhile HIV prevention method. A study in Lesotho found that 32.1% of surveyed female university students were strongly willing to use PrEP if it were available. Perceived HIV risk and the presence of intimate partner violence (IPV) in peer networks were strongly associated with the willingness to use PrEP (Karletsos et al., 2020:1). Therefore, availing PrEP to young women has the potential to reduce the prevalence of HIV. PrEP is an adjunct to previously existing preventative HIV strategies and it has a high efficacy rate amongst adherent users (Calabrese & Underhill, 2015:1960). Daily PrEP intake is user-controlled since users take the pill in their own space and time (Calabrese & Underhill, 2015:1960). Thus PrEP allows for concealable administration by the user. The user can also rotate on and off PrEP as need arises, although consultations with their health care provider is still necessary (Calabrese & Underhill, 2015:1960). Success stories from Mississippi in the United States among men who have sex with men indicate that some participants who were in sero-discordant relationships who once discontinued PrEP, reengaged in PrEP care again (Arnold, Brinkley-Rubinstein, Chan, Perez-Brumer, Bologna, Beauchamps, et al., 2017:6). Furthermore, PrEP has the potential to support conception among sero-discordant heterosexual couples (Calabrese & Underhill, 2015:1960).

2.3.3 The efficacy, safety and side effects of HIV PrEP

Martin (2008:152) describes efficacy as the capability of a drug to bring about a desirable effect. Several randomised control trials of TDF/FTC also known as Truvada have demonstrated the efficacy of PrEP as a preventative strategy amongst men who have sex with men and female sex workers (Baeten, Donnell, Ndase, Mugo, Campbell, Wangisi, et al., 2012:1; Thigpen, Kebaabetswe, Paxton, Smith, Rose, Segolodi, et al., 2012:1). The first prospective, double blind, randomised study was called the Pre-exposure Prophylaxis Initiative (iPrEx) trial. The study tested the safety and effectiveness of the ARV medicine Truvada in reducing HIV infection amongst men who have sex with men. This study reported a 44% risk reduction of HIV infection in the treatment group compared to the placebo group of HIV-seronegative men and women (Marcus, Hurley, Hare, Nguyen, Phengrasamy & Silverberg, 2017:6). In the study by Marcus, et al. (2017:6), no new HIV infections were

detected amongst participants who had very good adherence to PrEP (above 92%). This brought about a conclusion that consistent use of PrEP reduces the risk of acquiring HIV.

PrEP is safe to use during pregnancy (Lambert, Marrazzo, Amico, Mugavero & lopre, 2018:840). And it does not reduce the effectiveness of hormonal contraception (Lambert et al., 2018:840). However, there seems to be inadequate data on the efficacy, safety and implementation of PrEP in young women (Allen et al., 2017:400). PrEP is safe to use as statistical data have not reported significant differences regarding serious side effects in the experimental groups when compared to control groups (Baeten et al., 2016 as cited in Lambert et al., 2018:840). Furthermore, a study from Kenya found that 83% of men who have sex with men and female sex workers who volunteered for a clinical trial showed willingness to use the pill regimen provided there was proven safety and effectiveness, and that it came at a low-cost (Mutua, Sanders, Mugo, Anzala, Haberer, Bangsberg, Barins, Rooney, Mark, Chetty, Fast & Priddy, 2012:4-6).

According to the MoHSS guidelines (2019:3), side effects that are associated with PrEP include minor side effects that usually arise within the first two weeks of starting PrEP. The minor side effects may range from nausea, vomiting, dizziness, abdominal cramps, headache and fatigue. These side effects are usually self-limiting. Clients may sometimes experience TDF-induced renal impairment, which is a severe side effect, especially if they have been on PrEP for more than four months. This may present as reduced urination, swelling of the face, hands and lower limbs. Others experience general body weakness, fatigue and dizziness, general body itchiness, confusion, trouble thinking clearly and shortness of breath (MoHSS, 2019:3). Arnold et al. (2017:5) reports of two participants who had to discontinue PrEP due to perceived side effects. Mutua et al. (2012:4) conducted a study on the safety and adherence to PrEP in African men who have sex with men and female sex workers in Kenya. The study reports that 97% of the adverse events reported were non-serious as they ranged from mild to moderate. Although a number of studies do talk about side effects of PrEP, these side effects are mostly headaches, nausea and diarrhoea, which are known as start-up syndrome (Silapaswan et al., 2016:192; Siquier & Molina, 2018:4; Mutua et al., 2012:4-6; Lambert, et al., 2018:840). These symptoms resolve on their own (Silapaswan et al., 2016:192; Siguier & Molina, 2018:4; Mutua et al., 2012:4-6; Lambert, et al., 2018:840).

Although PrEP is generally safe and effective, there are some concerns. These include that using PrEP may lead to more risky behaviours or not using other forms of protection such as condoms. Maljaars, Gill, Smith, Gray, Dietrich, Gomes and Bekker (2017:1-4) enrolled adolescents on a demonstration PrEP study, called Pluspills, which was conducted in Cape

Town and Soweto. The study aimed to address concerns that were raised about PrEP having a potential to lead to an increase in sexual risk behaviours, sexually transmitted infections and reduced condom use among adolescents. The study employed a questionnaire that was used to assess the use of condoms through assessing sexual behaviours at start then at four (4), eight (8), and twelve (12) months. The results indicated that there was an increase in the use of condoms amongst this group. However, the researchers recommended that future studies should include other biomarkers of unprotected sex as well as a longer follow-up time as this may be helpful in understanding the relationship between PrEP use, sexual risk perception and outcome behaviours in adolescents. Therefore, there has not been substantive evidence to support the notion that PrEP use increases HIV risk behaviour amongst users (Calabrese & Underhill, 2015:1960).

The other challenge regarding PrEP use is adherence, which may be particularly difficult for adolescents. Adherence to PrEP is fundamental for the effectiveness of PrEP in preventing HIV (Shiferaw et al., 2011:2). The efficacy of PrEP depends on the medicine concentration in the blood (Marcus et al., 2017:6). Studies found that, in general, adherence to PrEP is good amongst other population groups. For example, Mutua et al. (2018:4) report an adherence rate of 83% amongst men who have sex with men and female sex workers. However, little is known about PrEP adherence amongst young women.

2.3.4 Global and Namibian guidelines on the use of PrEP

2.3.4.1 Eligibility for PrEP

There are specific criteria required for PrEP use. The WHO implementation tool for PrEP of HIV (WHO, 2017:5) states that to be eligible to use PrEP, an individual should be HIV negative and without suspicious signs of acute HIV infection. The MoHSS, (2016a:98) indicates that PrEP can be used by any sexually active individual who is HIV negative. However, the person should be at high risk for HIV acquisition. A person at high risk for HIV is defined as someone who resides in an area or population of high HIV prevalence and exposed to risk factors in the past six months (WHO, 2017:6).

Risk factors for HIV include vaginal/anal sexual intercourse without a condom with more than one partner and a history of sexually transmitted infections within the last six months. Indications for PrEP vary according to local HIV epidemiology and population groups. For instance, people who inconsistently use condoms, those with a recent STI diagnosis, a person requesting PrEP and people who inject or use drugs are also eligible for PrEP service (WHO, 2017:6). PrEP is further indicated for HIV negative people in sero-discordant relationships whose partners have not been confirmed as virologically suppressed to a viral load of less than 40 copies/ml. HIV negative people in sero-discordant relationships who want to conceive, irrespective of the viral load of their partners, may also qualify for PrEP (MoHSS, 2016a:98). Hence there is a need for healthcare workers to assess patients individually to determine their risk and PrEP eligibility (WHO, 2017:5). Persons can cycle on and off PrEP depending on their current risk status, as it is not a lifelong medication. However, they have to be willing to attend three monthly follow-up visits to monitor their renal function, adherence and HIV/STI status (WHO, 2017:5).

The presence of evidence or suspicion of HIV primary infection and abnormal creatinine clearance of less than 60ml/min may serve as contraindications for PrEP (MoHSS, 2016a:98). In addition adolescents who weigh less than 35kg, are less than 15 years of age or who are not on the Tanner stage 3 of development may not be eligible for PrEP (MoHSS, 2016a:98). Furthermore, PrEP should not be given to those not willing or not able to be tested, individuals who cannot return after three months for follow-up, those with known allergies or patients taking other nephrotoxic drugs, like aminoglycosides (MoHSS, 2016a:98).

2.3.5 Lived experiences of using PrEP

PrEP users may have positive and negative experiences of using it. These lived experiences may influence their decision to continue using PrEP. Below is a summary of the positive and negative experiences identified from literature. The researcher has included both qualitative and quantitative studies in this summary. Since few studies have been conducted amongst young women, the lived experiences of other population groups are included.

2.3.5.1 Positive experiences

PrEP users have reported some positive experiences of using PrEP. Arnold et al. (2017:3) conducted a study that explored the structural, social, behavioural, and clinical conditions that affect PrEP use and retention in care among young men who have sex with men in Jackson, Mississippi. The authors reported that by using PrEP young men who have sex with men felt empowered as they were in charge of controlling their sexual decision-making and were more conscious of their risk of HIV acquisition than they were before they started using PrEP (Arnold et al., 2017:3). Studies amongst adolescent girls and young women using PrEP report that by using PrEP, these girls and women, felt at peace and protected as they could avoid uncomfortable reprimand about infidelity from their partners (Rogers, 2020:11; Baron, 2020:10). The Oregan Health Authority in the US (2020:4) conducted a

study that was aimed at gathering descriptive epidemiological information on people who reported taking PrEP and who had recently been diagnosed with HIV in order to improve PrEP services. The study reported that among the people who were newly diagnosed with HIV but had been using PrEP, none reported adherence problems. Furthermore, reported benefits included decreased anxiety and increased peace of mind in relation to sexual experiences (Oregan Health Authority, 2020:4). Whereas some of the participants continued to use condoms to protect themselves from other sexually transmitted diseases some reported sexual pleasure due to condom-less coitus which, however, may be a dangerous practice for people using PrEP (Calabrese & Underhill, 2015:1960).

2.3.5.2 Negative experiences

Negative experiences of PrEP use were mostly centred on stigma and discrimination. Caliari, Teles, Reis and Gir (2017:2) term stigma as a label that is used to define others which diminishes them through negative stereotypes, discriminatory and prejudiced labels. Caliari et al. (2017:2) and Pilgrim et al. (2016:5) added that using PrEP for HIV prevention could bring about stigmatisation to the users. Furthermore, the Population Council (2017:1) and Pilgrim et al. (2016:5) state that because PrEP consists of ARVs, young women may fear that people may see them as being HIV positive. Similarly, Wal and Loutfi (2017:2) and Amico et al. (2017:1365) state that young women who seek PrEP services may be judged as admitting to promiscuity. Because PrEP may be viewed as for those with promiscuous behaviour, implementation of PrEP to a diverse population is likely to improve the understanding of people about PrEP, thereby reducing stigmatisation and discrimination faced by PrEP users (WHO, 2015:49; Pilgrim et al., 2016:5). Calabrese and Underhill (2015:1961) in their commentary, reviewed literature on sexual behaviour change related to PrEP use and PrEP stereotypes. The commentary identified that most people associated PrEP with sexual risk taking, which may reduce young women's motivation to use PrEP. Velloza (2020:3) reports that young women and adolescent girls who used PrEP are called prostitutes by family members and friends. Lambert (2018:840) identifies stigma as a significant barrier to PrEP uptake. Some women who participated in a study that explored the experiences with open-label PrEP among young women in Cape Town, South Africa reported that the community had misconceptions such as that by participating in PrEP research studies, they will get infected with HIV or that they were participating because they wanted money (Amico et al. 2017:1365; Nydegger, 2020:589).

Disclosure is directly related to the issues of stigma and discrimination. It is also a known determinant of adherence amongst people using ART and is therefore important in the context of PrEP. Disclosure varies amongst PrEP users depending on the type of

relationship shared. PrEP users have varying preferences as to whom to disclose to. A study by, Khoza, Baron, Lees, Harvey, Ramskin et al. (2020:160) among young women in Johannesburg, South Africa and Mwanza, Tanzania, states that PrEP users were found to disclose to their family members, friends and other at risk peers for support. PrEP users reported that they preferred disclosing about their use of PrEP to those who would support, advocate and encourage them on the uptake and continuation of PrEP (Scorgie et al., 2020:257). Velozza (2020:4) reports that some PrEP users only disclose to their close friends and family members whereas others delay disclosing about their use of PrEP due to anticipated stigma. Whereas disclosure to partners who were known to be judgemental and violent was found to be low it was found to be high where the partners were seen as nonjudgemental and non-violent (Velozza 2020:4). Non-disclosure has negative repercussions, for instance, women in Cape Town reported that dosing time was difficult because of nondisclosure to their important others (Amico et al. 2017:1365). Therefore Scorgie et al. (2020:257) recommend that counselling for PrEP should be based on helping young women to develop strategies for safe disclosure and that communication skills should be strengthened amongst this group.

There are other challenges directly related to taking the medication. According to Amico et al. (2017:1365), women find taking PrEP challenging due to the size and unpleasant smell of the tablet.

2.3.6 Conditions influencing PrEP uptake and continuation

Certain conditions may influence the motivation towards PrEP uptake and continuation. The condition may include awareness and service availability, societal/cultural condition (social norms) and educational/information condition.

2.3.6.1 PrEP awareness and service availability

In order to improve access to PrEP, awareness about PrEP is needed as well as service availability and healthcare worker training. Training healthcare workers enables them to safely provide PrEP to young women. For services to be utilised effectively the intended user and the provider should be aware and be able to provide the service respectively. Although there are reports about people being aware of PrEP (Oregan Health Authority, 2020:1), some studies report that there is a lack of PrEP awareness and knowledge amongst both healthcare workers and women (O'malley, 2020a:427; Camlin, 2020:2157). One of the studies done in the US amongst healthcare workers providing family planning, revealed that there was limited knowledge about PrEP amongst the healthcare workers (O'malley, 2020a:427; Camlin, 2020:2157). Provision of HIV education was part of the

services provided together with the family planning services, however, the healthcare workers reported lack of knowledge about PrEP (O'malley, 2020a:427). Interestingly, there was some degree of awareness of PrEP within lesbian, gay, bisexual, or transgender communities where information was communicated informally, for example, between friends or on social media platforms (Oregan Health Authority, 2020:2).

PrEP service availability also depends on healthcare worker willingness to provide PrEP services to young women. There seems to be a variation in healthcare workers' willingness to prescribe PrEP. Adams, Balderson, Brown, Bush and Packettll (2018:2) report that some health care workers have low intentions to prescribe PrEP to people who inject drugs, whereas Allen et al. (2017) report 100% willingness to prescribe PrEP to sexually active adolescents amongst healthcare workers. These variations in healthcare worker attitudes may hinder young women from accessing PrEP services and may further lead them to discontinuing PrEP (Amico & Bekker, 2019:3).

Poor counselling services may also lead to PrEP discontinuation. Young women have reported that they do not feel motivated to use PrEP after consultations with healthcare workers who initiated PrEP topics as the healthcare workers seemed to lack sufficient knowledge about PrEP (Nydegger, 2020:589). Other PrEP users discontinue PrEP due to perceived side effects and/or fear of it harming their unborn babies (Rogers, 2020:11). Arnold et al. (2017:7) reports that more than half of users who discontinued PrEP had intentions to restart using it. It is therefore necessary to re-invigorate and sustain demand creation activities to reach to populations that are in need of PrEP. Demand creation activities may include improved PrEP awareness and sensitisation amongst communities, addressing PrEP misconceptions and reducing behaviour related stigma (Rogers, 2020:4).

2.3.6.2 Socio-cultural conditions

Socio-cultural conditions also influence young women's motivation towards using PrEP. Young women's willingness to use and adhere to PrEP is based on their own understanding of social and cultural issues which may influence beliefs about the perceived effectiveness of PrEP, the available health options and how socially acceptable a strategy for HIV prevention is (Pilgrim et al., 2016:5). Pilgrim et al. (2016:5) further states that conditions such as community context, family and partner dynamics, social norms and characteristics of the young women themselves may influence the young women in deciding to use PrEP. Furthermore, community knowledge about PrEP, parental consent for PrEP use, the presence of violence within sexual relationships, social support as well as young women's own HIV risk perception are likely to influence their decision to use PrEP (Pilgrim et al.,

2016:5; Baron, 2020:10). Some women report lack of trust towards their partners as the reason why they started using PrEP (Baron, 2020:10; Karletsos et al., 2020:1).

Pilgrim et al. (2016:5) and Wanjiru (2014: 22) are of the opinion that societal attitudes might deter people from accessing PrEP as they give rise to some common misconceptions about PrEP. The limitations or risks associated with the use of PrEP may be overemphasised and this may hinder how the youth perceive PrEP. At times young women who take PrEP are stereotyped as being immoral (Pilgrim et al. 2016:5; Wanjiru 2014: 22). Societal myths such as PrEP reducing one's libido or causing HIV infection as identified by Digolo, Ochieng, Ngunjiri, Kiragu, Kyongo, Otiso and Mukoma (2018:16), may influence the willingness of young women to initiate PrEP. Digolo et al. (2018:13) further state that conflicting priorities like work or school may affect PrEP continuation by making it challenging to attend PrEP follow-up appointments.

Women may be influenced by underlying beliefs such as the safety of PrEP and the real benefit of PrEP. Pilgrim et al. (2016:5) state that cultural and gender norms may contribute greatly to lack of decision-making powers amongst young women who may want to use PrEP for HIV prevention (Wal and Loutfi, 2017:1; Rogers, 2020:12). This is because gender inequity norms are strongly linked to risky sexual behaviours, sexual and gender-based violence (Rogers, 2020:11).

2.3.6.3 Educational and informational conditions.

Education and knowledge can provide a basis for decision-making (Filho, Úbelis, & Bērziņa, 2015). The level of education of an individual is important as it may influence the individual's understanding of a certain concept and its impact on health (Kabir et al, 2016:9). Wal and Loutfi, (2017:1) state that lack of education in Sub-Saharan Africa may be a contributor to the increased number of HIV infections. Because the women lack knowledge about PrEP and other prevention strategies, they are at a greater risk of HIV acquisition. The knowledge that young women have about PrEP may influence their uptake of it. The accessibility of education and information influences young women's HIV risk perception and equally influences their decision to use PrEP (Pilgrim et al., 2016:5; Baron, 2020:6; Nydegger, 2020:589). Fletcher et al. (2018:176-177) assessed adolescents' perceptions on the use of PrEP. The study used focus group discussions with African-American mothers and their daughters and discovered a lack of health information concerning PrEP amongst the participants as both the mothers and daughters indicated that they were surprised and disappointed that they had never heard of PrEP (Fletcher et al. 2018:176-177). In another study that was aimed at determining participants' interest in PrEP and facilitators and barriers to PrEP adoption amongst black women, it was uncovered that there was a lack of awareness about PrEP amongst black women (Nydegger, 2020:589). Confusion about ARVs as prevention, individuals' low perception of their own HIV risk and forgetfulness may be an influencing factor to PrEP uptake and continuation (Lambert, 2018:840).

2.3.7 Support needs

Young women face challenges while using PrEP, therefore, they may need support to improve their adherence to and continuation of PrEP. Support needs of young women may be physical, emotional, social or informational.

2.3.7.1 Physical support needs

In a study by Celum, Delany-Moretlwe, Beaten, Van der Straten, Hosek, et al. (2019:2) that assessed HIV PrEP for adolescent girls and young women in Africa, young women were willing to use PrEP however; they faced challenges in balancing this with their normal lives. Adherence support clubs were found to be acceptable and feasible to improve adherence amongst adolescent girls and young women in Africa (Celum et al., 2019:26).

Due to poverty, young women experience challenges to pay for transport to and from clinics (Celum et al., 2019:26; Nydegger, 2020:589. Therefore Celum et al. (2019:26) suggests integrating PrEP with other reproductive health services like family planning to improve efficiency and continuity. The provision of small incentives such as transport money may improve adherence (Celum, et al., 2019:26). Pike, Celum, and Bekker (2020:1) suggest a need to decentralise PrEP services through provision these services through mobile outreach services and in school health programmes as this may promote young women's access to PrEP.

2.3.7.2 Emotional support needs

Provider-patient interaction is key to high quality PrEP service provision to young women. Emotional support can include counselling on the correct and consistent use of PrEP and the management of side effects (Pilgrim et al., 2016:5). The way in which health care providers interact with young women is important in improving the quality of care provided. This may promote willingness to continue taking PrEP. Therefore, to improve and ensure equitable access to PrEP, health care providers through their routine PrEP consultations with young women should try to converse with the patient about PrEP just as they would usually do about HIV testing and care (Adams et al., 2018:2). Calabrese, Krakower and Mayer (2015:1960) state that when health care providers integrate asking about PrEP in their consultations, they are likely to reach out to potential PrEP candidates, destigmatise PrEP, facilitate patient centred care as well as transmit knowledge about PrEP to the wider community. Integration of care would also promote privacy and confidentiality to avoid the risk of undesired disclosure about PrEP use (Amico et al. 2017:1365; Digolo et al. 2018:14).

2.3.7.3 Social support needs

Families and friends can be a source of support for young women using PrEP. According to Lambert (2018:840), limited social support is a barrier to PrEP uptake. For example, in one American study, mothers were found to be a source of support for their adolescent daughters using PrEP (Fletcher et al., 2018:176-177). Therefore, introduction and engagement of young women in peer support clubs especially women who lack partner and family support may be worthwhile. HIV prevention peer support clubs amongst South African adolescent girls and young women offered worthwhile support, especially to young women who lacked partner and family support (Fletcher et al., 2018:176).

Digolo et al. (2018:13), Rogers, (2020:11) and Pike et al. (2020:1) state that encouragement and linkage to support from the young women's sexual partners, peer groups and guardians may promote PrEP normalisation and thereby reduce stigma and promote continuation of PrEP. Celum et al. (2019:26) and Pike et al. (2020:1) further suggest possible strategies of promoting peer support through virtual groups such as WhatsApp groups as this has proven to assist in overcoming logistical barriers such as transport to centralised support group venues.

2.3.7.4 Informational support needs

Information about specific health-related facts is a health behaviour determinant for young women which may influence their use and continuation of PrEP (Lambert, 2018:842; Amico & Bekker, 2019:3). Therefore, young women may need information about PrEP, so that they are well aware of their HIV risk and are continuously motivated to use and continue using PrEP (Smith, Fisher, Cunningham & Amico, 2012:345). Additionally, this may help them overcome misconceptions about PrEP effectiveness, safety and side effects.

Due to disclosure related challenges faced by young women, Velloza (2020:6) suggests that PrEP counselling sessions should include discussions about PrEP disclosure strategies for young women. Velloza (2020:6) further suggests that young women should be provided with information materials such as PrEP brochures and T-shirts with PrEP messages that may help in explaining and disseminating PrEP messages amongst young women.

2.4 THE SITUATED INFORMATION, MOTIVATION, BEHAVIOUR MODEL

The researcher applied the Situated Information, Motivation, Behavior (sIMB) Model to this study. The model was used to assess whether the lived experiences of young women could

be explained in full or partly by this model. The sIMB is a model of health behaviour change that has a strong base in evidence-based evaluation of health outcomes in HIV prevention such as PrEP (Lambert, 2018:842; Smith, et al., 2012:345). Young women may need individualised approaches that can be used to identify key conditions that influence their lived experiences of PrEP. Furthermore, the sIMB model is a great tool that can be used to explain the lived experiences of young women on the use of PrEP in terms of uptake, adherence, stigma and disclosure that may influence their use of HIV PrEP. It examines the level of information, motivation and behaviour of an individual.

Below is a diagram (Figure 2.1) showing how the researcher applied the sIMB model to the lived experiences of young women in the use of PrEP. It illustrates that young women's behaviour of accessing and continuing to use PrEP is influenced by 1) Information about PrEP, 2) Social norms such as societal beliefs/practices and stigma and 3) Motivation to use PrEP that includes internal motivation such as the young women's own risk perception as well as external motivation such as support.

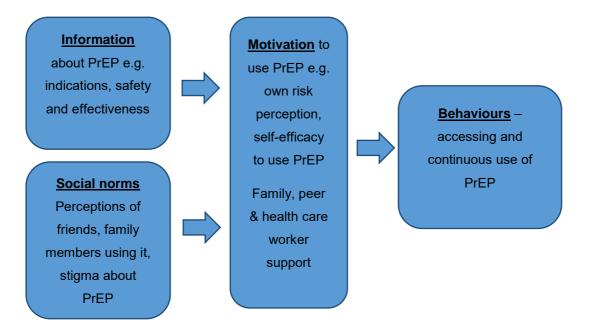


Figure 2.1: sIMB model (as applied to PrEP uptake and continuation).

2.5 CONCLUSION

In this chapter the researcher presented the literature review. The review highlighted that young women are at risk of acquiring HIV and that alternative strategies such as PrEP may be useful in decreasing HIV prevalence amongst this group. The researcher noted that information from previous research on the lived experiences of young women on the use of PrEP is limited. However, data from other population groups indicate that there are positive and negative experiences and that several conditions influence the use of PrEP. Young

women using PrEP need physical, emotional, social and informational support. The sIMB model may be helpful in understanding the lived experiences of young women on using PrEP as well as the conditions influencing its uptake and continuation. In the next chapter the researcher presents the methodology that was used in this study.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter, the researcher discusses the research methodology that was used in the study. The aim and objectives of the study, the setting as well as the research design are presented. Furthermore, the population, sampling, instrumentation and how trustworthiness was ensured during the study are discussed. Thereafter an overview of how data collection and analysis was done is laid out.

3.2 AIM AND OBJECTIVES

The aim of the study was to explore the lived experiences of young women on the use of PrEP in Namibia.

The objectives of the study were to:

- explore the knowledge and understanding of young women about PrEP;
- describe the societal, educational and cultural conditions that influence their decisions to use PrEP; and
- describe the physical, emotional and social support needs of young women using PrEP.

3.3 STUDY SETTING

The Rundu district, in Namibia, has twelve clinics/healthcare facilities. All the facilities render PrEP services to the youth and other age groups seeking such services (MoHSS, 2018:1). All facilities provide integrated services, meaning a client can receive all services from one healthcare provider. At the time of the study most of the healthcare facilities, in this district had registered between 6 and 100 clients on PrEP since its introduction in 2016 (Tsuma, 2018:np).

In this study, five clinics in and around the town of Rundu were included.. Figure 3.1 below shows a map of Namibia.



Figure 3.1: Map of Namibia

Source: Google maps, 2020

Most of the clients accessing healthcare services at these clinics are namibians, and 79.4% speak the Rukavango languages. The Rukavango languages include Rukwangali, Rumanyo and Thimbukushu (Thiem & Jones, 2013:3). These are local languages in the Kavango East region, within which the Rundu district is situated. The majority of the people in Rundu are able to speak Rukwangali. Rundu also hosts people from other parts of the country who speak languages such as Oshiwambo, Damara-Nama, Afrikaans and Oshiherero. There is also an influx of people from Angola who mostly speak Runyemba, Rusiwokwe and Umbundu, as Rundu boarders Angola.

3.3.1 PrEP services

MoHSS (2016a:98) recommends specific procedures to be followed when providing PrEP services to clients. During screening the nurse/healthcare worker assesses the patient's risk and eligibility. This is done through thorough history taking on sexual behaviours as well as a physical examination. After establishing the need for PrEP and before its initiation, the

healthcare worker educates the client about its risks and benefits. Contraceptive counselling and testing for HIV, renal function (creatinine clearance) and Hepatitis B are carried out with the consent of the client. An HIV negative test and an acceptable creatinine clearance confirms eligibility for PrEP (MoHSS, 2016a:98).

The PrEP client is also provided with STI treatment should there be a need. Furthermore, the clients are provided with information about PrEP side-effects and how to manage them. Such side effects include signs and symptoms of acute HIV infection. The healthcare provider will also discuss the adoption of healthy life-styles such as avoiding alcohol, tobacco and recreational drugs. Condoms and lubricants are provided followed by a one-month TDF/FTC (fixed dose combination, FDC) prescription and arrangements for a follow up visit (MoHSS, 2016a:98).

After a month, the client comes for the first follow up and at this time the assessments and tests performed during the initial visit are repeated. In addition, the healthcare worker assesses the tolerability, risk, side-effects, as well as the effective use of and adherence to the medication. The healthcare worker will manage any side-effects. In the absence of serious side-effects, the healthcare worker provides a three month prescription/supply and a follow up date in three months (MoHSS, 2016a:98). At this subsequent follow up and during the three-monthly maintenance visits, the healthcare worker repeats the same procedures performed at the the first follow-up visit (MoHSS, 2016a:99). The client may cycle on and off PrEP depending on their current risk for HIV infection. The client should therefore inform the healthcare provider if they would like to stop the treatment.

3.4 RESEARCH PARADIGM

Rehman and Alharthi (2016:51) describe a paradigm as a basic belief system and theoretical framework. Paradigms have assumptions based on ontology and epistemology and are ways of understanding the reality of the world and studying the world.

The researcher adopted a constructivist paradigm. The constructivist philosophical paradigm is associated with qualitative research and concerned with the understanding of a phenomenon through lived experience (Adom, Yeboah & Ankrah, 2016:5). According to Rodriguez and Smith (2018:96), the philosophy of phenomenology usually falls in the naturalistic paradigm which is also known as the constructivist paradigm. This is because the phenomenological researcher usually asks questions such as 'what is the lived experience like?', or 'what is the meaning of the lived experience to the participant or to the researcher?'

In the constructivist paradigm, the researcher constructs meaning of the phenomenon under study through the lived experience of the participants (Adom et al., 2016:5). Constructivists believe that reality is subjective as it is shaped by the individual's perspective. This, however, is contrary to the positivist paradigm that assumes that reality is not facilitated by one's senses, but rather exists independently of human experience (Rehman & Alharthi, 2016:53).

Rehman and Alharthi (2016:51) are of the view that for one to understand phenomenology, it should be based on ontology and epistemology. Husserl, a German philosopher who established the school of phenomenology, asserts that in descriptive phenomenology, the researcher sets aside or brackets his or her perceptions in order to allow him/herself to describe the lived experiences of the participants so as to enter into the life world of the research participant without any presumptions (Rodriguez & Smith, 2018:96).

3.5 RESEARCH DESIGN

This study used a qualitative descriptive phenomenological design, which, according to Jooste (2011:300), enables one to gain insight about people's lifestyles. Jooste (2011:300) further states that qualitative research describes participants' lived experiences and the meaning that they assign to their lived experiences. The process and approach of qualitative designs is systematic, interactive and subjective as it describes the participant's lived experiences. With this approach the researcher studies the participant's experience as it is lived (Jooste, 2011:300), thus leaving no room for manipulation of participants.

Phenomenology can be applied in several forms such as the Goethean and Brentanian prephilosophical phenomenological approaches, grass-roots phenomenology, interpretive phenomenology, the descriptive phenomenological method and phenomenological analysis (Giorgi, Giorgi & Morley, 2017:179). However, Rodriquez and Smith (2018:96) group phenomenology in two main groups, interpretive and descriptive phenomenology. Husserl's approach is the descriptive, whereby the researcher sets aside his/her perceptions (called bracketing) and describes the participant's lived experiences as they are. It is done in order to avoid any presumptions. In contrast, although Heidegger's approach of interpretive phenomenology is also interested in interpreting and describing human lived experience it rejects the concept of bracketing, because Heidegger believed that prior knowledge and understanding influences our interpretation of the world (Rodriquez & Smith, 2018:96). In this study the researcher practiced reflexivity and bracketing in which she questioned her own believes toward PrEP use. One example of a preconceived idea was the idea that young women may fear using PrEP as they may be stigmatized. The researcher discussed preconceived ideas with the supervisor and peers and also wrote them down in a reflective diary while reflecting on how they may influence the data collection and analysis processes.

In this study, the researcher has adopted descriptive phenomenology that attempts to carefully describe the lived experiences through a psychological analysis of raw data (Giorgi et al., 2017:179). Furthermore the practice of bracketing will upkeep the validity of interpretation, thereby allowing for a level of objectivity (Rodriguez & Smith, 2018:96).

Descriptive phenomenology was deemed more appropriate as it allowed the young women to describe their lived experience of using PrEP (Giorgi et al., 2017:180). Descriptive phenomenology also allows for better understanding of the lived experience due to its ability to indicate some unspoken meaning linked to one's being and experience of a phenomenon (Christensen, Welch & Barr, 2017:115). In this study, the experiences described are those of young women on the use of PrEP in the Namibian context. Hence, the study focused on exploring and describing the young women's lived experiences on the use of PrEP. There are only a few young women using PrEP in Namibia hence eliciting their lived experiences may bring valuable insights on this matter.

3.6 POPULATION AND SAMPLING

3.6.1 Population

Population, according to Brink et al., (2012:131), is the entire group of people that possess the characteristics that the researcher is interested in. In this study, according to the clinic records, the population comprised, approximately, 20 young women aged 15-24 years who were using PrEP from five clinics in and around the town of Rundu (Tsuma, 2018:np).

3.6.2 Sampling

Sampling refers to the process that the researcher adopts to select participants who will represent the whole population (Brink et al., 2012:131). Purposive sampling method ensures that the researcher obtains specific characteristics of people suitable to answer the study question (Brink et al., 2012:141). In this study the researcher purposively selected participants from five local health facilities around the town of Rundu. These clinics provide services to clients from different socioeconomic, ethnic and cultural groups. Although one of these facilities is called a health centre, it operates from 08h00 to 17h00 just like the clinics. Due to financial constraints, as the study was self-funded, the researcher only selected the said clinics. It is important to point out that the researcher did not work in any of the clinics at the time of the study. Purposive sampling entails that the researcher chooses participants who are knowledgeable about a phenomenon (Reid & Mash, 2014:2). Thus the researcher

chose participants who have been or had once used PrEP in order to ascertain their lived experiences on its use.

3.6.2.1 Inclusion criteria

The inclusion criteria were as follows:

- Young women aged 15-24 who were using PrEP were selected. PrEP can only be provided to women above the age of 15 years with a weight of > 35kg due to it containing tenofovir (MoHSS, 2016a:98).
- Those who had previously used PrEP and attended at least one follow-up visit for PrEP were included in the study.

3.6.3 Recruitment and participant selection

For the purpose of respect for confidentiality of personal data the researcher contacted and arranged with the nurse in charge within each clinic to ask healthcare workers to inform eligible clients about the study. Thereafter, arrangements were made with the clients who agreed to be contacted by the researcher. The researcher made arrangements to meet the clients so as to provide information about the study and obtain consent. The researcher selected nine participants and eventually reached data saturation. Data saturation occurs when participants can no longer provide any new information (Brink et al., 2012:144).

Amongst those who agreed to partake in the study, the researcher assessed whether participants were able to consent for themselves based on their age or whether parental consent needed to be obtained. However, all the participants who agreed to partake were above the consent age 18 years. The researcher requested for participants within the study age range 15-24, however, she was informed by the healthcare workers that there were few young women under 20 years of age that the researcher would be able to access. This was attributed to some of the younger women not owning a cell phone. Some of the cell phone numbers for the younger women were unreachable and some did not meet the inclusion criteria of previously having used or attended at least one follow-up visit for PrEP.

The researcher approached 15 women referred to her by the nurses from the various clinics. Out of the 15 young women, only nine (9) were interviewed. The remaining six (6) participants could not be interviewed for several reasons. The researcher also requested clients from Kaisosi clinic, only one agreed to be contacted by the researcher. However, when the researcher contacted the young woman, she preferred to be interviewed telephonically and therefore was not included as this was not according to the initial proposed protocol methodology. Two of the young women who refused to be referred to the researcher informed their healthcare workers that they were either not interested because they were not using PrEP anymore, while one indicated that she was not available because she was out of town. Furthermore, making appointments with the other five potential participants was challenging, as sometimes, although the client agreed to be contacted by the researcher, their numbers were unreachable, they cancelled appointments or indicated that they were either out of town or not interested anymore. Two other potential participants, who were aged 17 and 18 and were school-going, later refused to participate. One indicated that she had gone for holiday as schools were closed due to the COVID-19 state of emergency. One stated that she would not be able to answer the questions because she never drank the PrEP medication after collecting it. Of the nine (9) women who participated three (3) were from Sauyema Clinic while Nkarapamwe, Rundu and Ndama clinics were represented by two (2) participants each.

3.7 INTERVIEW GUIDE

A semi-structured interview guide, designed by the researcher in English, was used in the data collection. The interview guide was translated into Rukwangali, a local language, using forward and backward translation. This translation to Rukwangali only was done because the majority of the Kavango East people are able to speak and understand Rukwangali (Thiem & Jones, 2013:3). The translation was done in order to obtain information about the lived experiences of young women aged 15-24 years old on the use of PrEP in a language that they understood well. The researcher asked questions like "Tell me a bit more about what you understand about PrEP?" Probing questions were asked such as "What is it used for?; What were your reasons for starting to use it?; How do you think it will benefit you?; Who provided you with information about PrEP?". The complete interview guide can be found in Appendix 4. The interview guide was structured according to the study objectives.

3.8 PILOT INTERVIEW

A pilot interview, which lasted 30 minutes, was conducted with one participant to assess whether the interview process would be feasible. The interview was done in Rukwangali as the participant could not speak English. The participant responded well to the questions. Feedback was sought from the supervisor after the data collected was transcribed and translated into English. According to the input from the supervisor there was need to ask more probing questions so that the participants could provide in-depth information about their lived experiences on the use of PrEP. The data from the pilot interview were included in the final data analysis as the researcher did not experience any challenges during the piloting of the study. Information gathered from the pilot interview was considered to allow the participant's voice to be heard.

3.9 DATA COLLECTION

Data collection is a systematic process of collecting pieces of information or facts during or in a scientific investigation (Nieswiadomy, 2012:39). In the data collection process, the researcher conducted face-to-face interviews to obtain the participants' lived experiences. The interview sessions lasted approximately 30 to 60 minutes. The researcher adopted a face-to-face interview approach because of the sensitivity of the topic that was studied. The first interview, which was also the pilot interview, was done on the 9th of December 2019 whereas the last interview was done on the 18th of July 2020. The first seven interviews were done before the president declared the state of emergency due to COVID-19. The last two interviews, interview number eight and nine, were done during Stage 1 and Stage 4 of the state of emergency period. Although the cumulative number of positive COVID-19 cases in the country were 1917 Kavango East region did not have any confirmed cases at the period of data collection (MoHSS, 2020:3). The researcher observed all the COVID-19 protocols of washing hands, use of face masks in public places and social distancing as explained in Chapter One.

The interviews were conducted in a private area and at a time chosen by each individual participant. This happened after the researcher had obtained informed consent from each participant which also included permission to record the interviews. An audio recorder was used to record the interviews which was also password protected. Seven interviews were done in Rukwangali and a mix of English here and there only two were conducted in English. Although an interpreter was available for those who could not speak English or Rukwangali, which were the languages that the researcher was fluent in, none of the participants were unable to speak either English or Rukwangali.

The researcher, upon meeting with the participant, started off with greetings and introductions of herself, the rights and responsibilities of the paticipants and the research topic. Thereafter a short general discussion with the participant followed. This was seen as useful as it helped get the profile of each participant which was then used to describe the characteristics and background of the participant during the the study write up. Furthermore, such a discussion aids in creating a good rapport between the researcher and the participant (Reid & Mash, 2014:4). Silverman (2017:476) concurs with this stating that the aim should be to encourage the participant to speak personally and for a lengthy time about the study phenomenon. Through this, issues of interest to the researcher and participants are both covered. A constant balance between the researcher's and participant's interest should be maintained, thus the interviewee-interviewer relationship depends on creating a rapport (Silverman, 2017:476). In situations where the participants grossly divert from the focus of

the research, the researcher needs to guide them back to the focus of the study (Reid & Mash, 2014:4) and this, the researcher exercised during data collection. Furthermore reflection and summarizing were used to obtain additional data and verify the information given by the participants.

During the interview process, the researcher listened very attentively to what was said by the participants. The participants were also encouraged to speak freely and reflect on what they had said previously, as it might be important to other PrEP users. Reflection and summarizing questions were used to obtain additional data and verify the information given by the participant. The researcher also used closed-ended questions to confirm information. The researcher followed the suggestion by Ritchie and Lewis (2009:208) that the responses of the participants should be probed and respected without being judgemental. At the end of the interview, the researcher thanked the participants. A reflective journal was also kept to document reflections after the interviews. Contact details of contact persons and the researcher were provided to the participants so that they could contact for further information about PrEP and any other enquiry pertaining to the study and support system.

The researcher provided refreshments to all the participants during the interview process. Transport money to the amount of N\$24.00 was reimbursed to seven participants who travelled to and from the health centre for the interview. This included the participants who chose to have the interview away from the health facilities or on a different day.

Colaizzi's data analysis method was utilised in this study. This method requires memberchecking of the final themes with participants (Mabuza et al., 2014:3). Thus the researcher tried to contact all the nine women for member checking, however, only four participants were successfully telephonically contacted in order to ask if they would be comfortable with telephonic feedback. All four participants agreed to have telephonic feedback regarding the final themes. No new information arose from the process of member checking and therefore no new themes were formulated. The duration of each member checking session was between seven (7) and nine (9) minutes.

3.10 TRUSTWORTHINESS

Trustworthiness in qualitative research enables the reader to evaluate the scientific rigour of the study (Mabuza et al., 2014:3). The four categories of trustworthiness in qualitative studies were applied, namely: credibility, dependability, transferability and confirmability.

3.10.1 Credibility

Credibility relates to the validity of the conclusions made from the data collected and how this data relates to the reality reported (Mabuza, et al., 2014:3). The researcher ensured that only the targeted group participated and the same semi-structured interview guide was used. This helped the researcher to get findings congruent with the reality. During the interviews the researcher also enhanced credibility by rephrasing and asking clarifying questions where necessary. Peer debriefing was done during online meetings with the supervisor. Member checking was with four of the nine participants after data analysis by the researcher but no new information was provided. Furthermore, the supervisor went through the transcripts and the emerging themes and this, according to Mabuza et al. (2014:3), is done to see whether the researcher has really reported what was said by the participants and not the researcher's own ideas.

3.10.2 Transferability

This element refers to how the conclusions made from this study findings are going to be applied to other settings with the same characteristics. It is less likely to demonstrate that the findings and conclusions will be applicable to other situations and populations. Shenton (2004: 69) notes that "many naturalistic inquirers believe that, in practice, even conventional generalisability is not possible as all observations are defined by the specific contexts in which they occur". However, in an effort to ensure transferability, the researcher used a purposive sampling method to select the participants. In addition a thick description of the research processes applied in the study was given and this, as is stated by Mabuza et al. (2014:3) helps ensure transferability.

3.10.3 Dependability

This refers to the degree to which one will get the same findings even if the study was to be repeated, in the same context, with the same methods and with the same participants (Mabuza et al. 2014:3; Shenton, 2004:72). To ensure that the study is reliable the researcher described, step-by-step, the techniques and methods employed during the study thus keeping an audit trial. The same interview guide was used and peer debriefing was also done. Furthermore, the researcher stated the study's limitations.

3.10.4 Confirmability

Readers are concerned whether the results are genuinely from the data and not from the characteristics of or preferences of the researcher. Confirmability assesses the degree of objectivity of the researcher in the collection of data and reporting of findings (Mabuza et al. 2014:3). To ensure confirmability in the study, the researcher took steps to help ensure, as

far as possible, that the study findings were the result of the lived experiences and ideas of the participants, rather than the characteristics and preferences of the researcher. In addition the researcher practised bracketing through reflexivity by writing down her assumptions in a diary, thus reducing the influence of researcher bias. Furthermore the researcher, during the proposal and in Chapter One, stated her credentials, training, occupation, prior relationship to the participants of the research study as well as her preconceived ideas towards the study participants. The aforementioned actions should be done in respect of reflexivity (Mabuza et al., 2014:3).

3.11 DATA ANALYSIS

Data analysis refers to a process in which the researcher organizes and interpret raw data to give it meaning (Brink et al., 2018:165). Colaizzi (1978), (in Morrow, Rodriguez and King, 2015:2), refer to the seven-step process of data analysis of Colaizzi and this is the process that the current researcher employed in data analysis.

3.11.1 Step one: Familiarisation

The researcher sent the audio recordings to a transcriber for verbatim transcription as soon as the interviews were completed. The transcriber was first required to sign a confidentiality form. Upon receipt of the transcripts, the researcher took time to familiarise with the data. This was done through reading the transcripts while also listening to the audio recordings repeatedly until the researcher understood what all the accounts of the participants meant. Only one participant spoke English throughout the whole interview while the others either spoke Rukwangali or mixed Rukwangali with English. Therefore, translation into English was also done on most of the transcripts by the transcriber. The researcher and the transcriber were fluent in English and Rukwangali, thus the researcher was able to ensure that the translations were valid. The transcriptions were also sent to the supervisor for checking, who provided feedback.

3.11.2 Step two: Identifying significant statements

Through reading the transcripts the researcher identified accounts that were significant and directly linked with the phenomenon that was under study and highlighted them. Table 3.1. below shows a significant statement that was identified by the researcher and highlighted in yellow. The significant statement indicates the source of information about PrEP.

Table 3.1: Example of significant statement

Significant statement

I: Who informed you about these prevention pills or where were you informed about these pills? P: I came at the hospital and got tested. I then asked them; "if your partner is on medication for HIV, while you are negative, what can you do"? Then the nurse told me that, you need to start using these pills by taking them so that you can prevent yourself from getting the disease.

Key: I: Interviewer; P: participant

3.11.3 Step three: Formulating meanings

In Step three, the researcher started forming a picture of the true meaning that was relevant to the phenomenon. Table 3.2. below, on the left column under the formulated meaning shows the meaning that was formulated from the highlighted significant statement under the coding column.

Significant statement	Formulated meaning
I: Who informed you about these prevention pills or where were you informed about these pills? P: I came at the hospital and got tested. I then asked them; "if your partner is on medication for HIV, while you are negative, what can you do"? Then the nurse told me that, you need to start using these pills by taking them so that you can prevent yourself from getting the disease.	Informed by the nurse.

Table 3.2: Formulated meanings

Key:I: Interviewer; P: participant

3.11.4 Step four: Clustering themes

With the fourth step, the researcher clustered the different themes and identified the meaning of those themes that were common. The clustered formulated meanings are presented in Chapter Four, for example, the formulated meaning "PrEP is used when partner is HIV positive/on medication (ARVs)", was clustered into the sub-theme "Knowledge and understanding".

3.11.5 Step five: Developing an exhaustive description

In the fifth step, the researcher then developed an exhaustive description of the phenomenon while also including all the themes that had been developed during the fourth step. Table 4.2 in Chapter Four of this thesis depicts the exhaustive description. For example, the main theme "Risk awareness" was induced from sub-themes: "Knowledge and

understanding"; "Sources of information"; "Family and community members' awareness of PrEP"; and "Reasons for using PrEP".

3.11.6 Step six: Producing the fundamental structure

Thereafter in Step six, the researcher condensed the exhaustive description to include only the information relevant to the structure of the phenomenon. Furthermore, the researcher provided a narrative description with participant quotes. Three themes contained the essential information and description relevant to the phenomenon under study and were developed through a condensed exhaustive description. The main themes that emerged are, "Risk awareness", "Empowered for self-care" and "Persisting despite the challenges".

3.11.7 Step seven: Seeking verification of the fundamental structure

Finally, the verification of the fundamental structure was conducted. This was done in order to find out if the description captured the real lived experiences of the participants. However this exercise is not always obvious since the participant and the researcher usually have varying perspectives about the phenomenon (Morrow et al., 2015). The researcher telephonically discussed the main themes with four of the nine participants who agreed to be contacted telephonically. The researcher attempted to contact the other five participants telephonically but failed. No new information arose from the process of member checking and therefore no new themes were formulated. The duration of each member checking session was between seven (7) and nine (9) minutes.

3.12 SUMMARY

In this chapter, the researcher discussed the methodology applied in this study. A detailed discussion about the aim and objectives, study setting, research design, population and sampling, inclusion criteria, interview guide, trustworthiness, data collection as well as data analysis was presented. In the next chapter, the study findings are presented.

CHAPTER 4: RESULTS

4.1 INTRODUCTION

In the previous chapter, the researcher discussed the methodology that was used in the study. In this chapter, a presentation of the analysed data is done. The discussion is based on the themes, sub-themes as well as formulated meanings, which were induced during the data analysis process.

4.2 SECTION A: BIOGRAPHICAL DATA

The researcher interviewed nine (9) young women who met the inclusion criteria. Their ages ranged from twenty-one (21) to twenty-four (24). None of them were married, however, five (5) were cohabiting with their boyfriends, and four (4) were single (see Table 4.1). With regards to occupation, two (2) participants were still school going, one was a university student, one was working as a shopkeeper, while five were unemployed. All the participants had been on PrEP for more than three months with the longest duration of use being more than a year.

Pseudonym	Age	Marital status	Occupation	Duration PrEP	on
Participant 1	23	Cohabiting	Unemployed	4 months	
Participant 2	24	Single	Unemployed	2 years	
Participant 3	21	Single	Scholar	12+ months	
Participant 4	21	Single	Student	3 months	
Participant 5	24	Cohabiting	Unemployed	9 months	
Participant 6	24	Cohabiting	Unemployed	3 months	
Participant 7	22	Single	Scholar	6 months	
Participant 8	24	Cohabiting	Unemployed	5 months	
Participant 9	24	Cohabiting	Casual worker (shopkeeper)	5 months	

Below is a brief description of each individual participant:

Participant one was 23 years old, in a cohabiting relationship and unemployed. At the time of the interview, the participant had been on PrEP for four months and was pregnant. She was the pilot participant. On the day of the interview the participant had come to escort her sister in-law for her ART follow-up. The participant indicated that she started using PrEP because her partner was on ART.

Participant two was 24 years old, single and unemployed. During the time of the interview, she had been on PrEP for two years. The participant brought her one year old baby to the interview. According to the participant, she started using PrEP after she discovered that her partner was HIV positive.

Participant three was 21 years old, single and school going. At the time of the interview, she was repeating grade 10 through Namibia College of Open Learning (NAMCOL). She had been on PrEP for more than a year. The participant had once used PrEP in the past, stopped after falling pregnant and then resumed after she delivered. The participant stated that she was on PrEP to protect herself. She further indicated that she did not trust her boyfriend since their relationship was a long distance one.

Participant four was 21 years old, single and a university student in her first year of study. During the time of the interview, she was not using PrEP. However, she had previously been on PrEP for three months, six months prior to the interview. The participant had a boyfriend who lived in another town, about 800 km away. She indicated that she did not trust her boyfriend and did not know his HIV status which made her decide to use PrEP.

Participant five was 24 years old, in a cohabiting relationship and unemployed. During the time of the interview, the participant had been on PrEP for nine months. The participant stated that her partner was HIV positive and that she started using PrEP to protect herself from being infected. The participant further stated that she was motivated by one of her friends who was using PrEP.

Participant six was 24 years old, in a cohabiting relationship and unemployed. During the time of the interview, she had been on PrEP for three months and was pregnant. She said she started using PrEP after she discovered a container of ART medication in the bedroom that she shared with her partner.

Participant seven was 22 years old, single and a scholar in grade 9. During the time of the interview, she had been on PrEP for six months. She stated that she started using PrEP after she found suspicious messages that pointed to infidelity on her boyfriend's phone.

Participant eight was 24 years old, in a cohabiting relationship and unemployed. During the time of the interview, she had been on PrEP for five months and had recently delivered a baby. She started PrEP while she was pregnant after discovering that her partner was on ART medication.

Participant nine was 24 years old and in a cohabiting relationship. She was employed as a shopkeeper at a local shop. At the time of the interview the participant had been on PrEP for five months and was pregnant. She indicated that she started using PrEP after she discovered that her partner was HIV positive. By the time she started PrEP she was already pregnant.

4.3 SECTION B: THEMES AND SUB-THEMES

During the data analysis process, the researcher identified three major themes. Table 4.2 depicts the major themes and sub-themes while Table 4.2 depicts formulated meanings per sub-theme.

Themes	Sub-themes
4.3.1. Risk awareness	4.3.1.1. Knowledge and understanding
	4.3.1.2. Sources of information
	4.3.1.3. Awareness of PrEP by family and community members
	4.3.1.4. Reasons for using PrEP
4.3.2. Empowered for self-care	4.3.2.1. Positive feelings and experiences
	4.3.2.2. Role models
	4.3.2.3. Partner and family member support
	4.3.2.4. Healthcare worker support during follow-up appointments
	4.3.2.5. Use of PrEP in future
	4.3.2.6. Enablers of using PrEP
4.3.3. Persisting despite challenges	4.3.3.1. Disclosure
	4.3.3.2. Stigma
	4.3.3.3. Treatment-taking behaviours
	4.3.3.4. Experiencing possible side-effects
	4.3.3.5. Financial implications
	4.3.3.6. PrEP services restrictions
	4.3.3.7. Negative feelings
	4.3.3.8. Stopping PrEP

Table 4.2: Themes and sub-themes

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Sub-themes	Formulated meanings
4.3.1.1. Knowledge and understanding	 PrEP used when partner is HIV positive/ on medication (ARVs) PrEP prevents against HIV/AIDS Perception that PrEP is life-long Knowledge about other prevention methods e.g. using condoms, fewer partners Promiscuous behaviour increases HIV risk
4.3.1.2. Sources of information	 Informed by nurse Informed by friends Informed through other sources e.g. books/internet/radio
4.3.1.3. Awareness of PrEP by family and community members	Family members aware of PrEPCommunity members aware of PrEP
4.3.1.4. Reasons for using PrEP	 Partner HIV positive, on medication (ART) Lack of trust in the partner I take PrEP to protect/care for myself Worried about becoming infected with HIV
4.3.2.1. Positive feelings and experience	 Expresses positive feelings about using PrEP Happy when testing negative Feeling normal, protected, happy about using PrEP
4.3.2.2. Role models	Family members or partner taking ART/PrEPFamily members wanting to use PrEP
4.3.2.3. Partner and family member support	 Supported/encouraged to start PrEP Encouraged to continue with PrEP Reminded to take PrEP Encouraged to eat healthy/well
4.3.2.4. Healthcare worker support during follow-up appointments	Support from healthcare workersReassurance from nurses
4.3.2.5. Use of PrEP in future	Wants to continue using PrEP
4.3.2.6. Enablers for using PrEP	Continuity of PrEP supplyEncourage others to come for testing and be faithful
4.3.3.1. Disclosure	 Disclosure to close relatives Not disclosing beyond close family Lack of disclosure to partner

Table 4.3: Sub-themes and formulated meaning

4.3.3.2 Stigma	 May be seen as HIV positive Judgmental attitudes of community No experiences of stigma Feels stigma against PrEP users should be condemned
4.3.3.3. Treatment taking behaviours	 Taking medication every day Easy to use, only one pill per day Time of taking PrEP Forgetting to take PrEP sometimes Pills are strong, big
4.3.3.4. Experiencing possible side- effects	 Experienced no problem, no challenges. Experienced some side-effects, but not sure if the symptoms were related to PrEP Onset of symptoms Self-managing side-effects Given treatment for side-effects/symptoms
4.3.3.5. Financial implications	Needs financial supportPoverty, in need of food assistance
4.3.3.6. PrEP services restrictions	 PrEP services not available for unmarried women
4.3.3.7. Negative feelings	 Worried about possible stigma Thinks family members are hard to deal with Thinks other people do not care Regrets coming for PrEP Doubts/unsure about effectiveness of PrEP
4.3.3.8. Stopping PrEP	Stopped PrEP due to pregnancyStopped PrEP due to side effects

4.3.1 Theme one: Risk awareness

Risk awareness concerns young women's awareness of their risk for acquiring HIV. Therefore, risk awareness enables younger women to make decisions about using PrEP, in order for them to prevent themselves from acquiring HIV. The theme risk awareness had four sub-themes that emanated from it namely: knowledge and understanding; sources of information; family and community members' awareness of PrEP and; reasons for using PrEP.

4.3.1.1 Knowledge and understanding

Several young women had knowledge that PrEP is used when one is at risk of being infected with HIV. They knew that if their partner is HIV positive or on medication (ARVs)

they were at risk of contracting HIV. Therefore, in order to be protected, they needed to use PrEP.

"They are used in order for you not to get the disease. Yes, because if your partner is on medication [antiretroviral treatment] you [the HIV negative partner] can be on a safe side not to contract the disease [HIV]." (Participant 1)

"It's used for prevent mmmm you can take because if you have a partner who is positive and you are negative, you can use to prevent yourself." (Participant 5)

The young women knew or were aware that taking PrEP was beneficial to prevent HIV transmission and infection. They were aware of the benefits of using PrEP.

"I have heard that it's [PrEP] a good thing, it prevents and it helps and so forth. Because the pills are good when it comes to prevention and can help you not to contact the disease." (Participant 1)

"It's [PrEP] used for, It's used to like it can prevent, like this one that I take it prevents from getting HIV and AIDS." (Participant 4)

Some young women had a misunderstanding that PrEP needs to be taken life-long. Their understanding was that they should never stop it. This may mean that there is confusion between the taking antiretroviral drugs (ARVs) for the prevention of HIV (PrEP) and taking it for the treatment of HIV (ART).

"He [nurse] said that medicine you can't stop it. When you start to take it just take it don't decide to stop it. Yes they [nurse] told me that this medicines you cannot stop it." (Participant 5)

The participants also understood the importance of combined precautionary measures, including individual behaviour change, rather than just relying on PrEP. This included using a condom every time they have sexual contact, in addition to using PrEP medication. Furthermore, they also understood the importance of having one sexual partner at a time as it further reduces one's risk of acquiring HIV.

"Mmmm the way that you can protect yourself is using condoms. Yes, using condoms each day if you will be close with your partner." (Participant 2)

"If they are not taking good care of themselves because they are drinking the PrEP medicine and that means they can go sleep around. That won't help." (Participant 4) The young women knew when to use PrEP and the benefits thereof in preventing HIV infection. Additionally, they also understood that in order for PrEP to work effectively, there is need for one to use a combination of HIV prevention measures. Young women in this study were aware of the danger of relying solely on PrEP for prevention against HIV.

4.3.1.2 Sources of information

Information about PrEP was mostly received from nurses during consultations. Nurses provide all women, including young women, with sexual reproductive health services such as information about PrEP as well as family planning at points of contact with them. Some young women stated that they were informed about PrEP during antenatal care visits.

"I never heard it anywhere, when I came they tested [HIV test] me then after then they asked me whether they can give me PrEP tablets or injection for family planning because I explained everything before." (Participant 7)

"... the nurses, when I started ANC they told us [women attending antenatal care] about it [PrEP]. So when I got my result [for HIV] it was negative". (Participant 9)

Young women showed concern for other women. Some young women, after hearing about PrEP from healthcare workers, informed their peers about it.

"I got it [PrEP information] from my friend, my friend introduced me about this medicine, her boyfriend took her to the hospital at NAPPA [Namibian Planned Parenthood Association] when they went there, they got tested and the boyfriend was positive and the girlfriend was negative, then the nurse introduce them. If you love each other you can just use PrEP and your boyfriend will be on treatment, when she got home, then she introduce us, me and my friends about PrEP." (Participant 3)

PrEP information appeared to be readily available in the community. The participants stated that they were informed about PrEP through various sources such as through reading books (pamphlets), the internet or listening to the radio. The information they obtained appeared to motivate them to use PrEP.

"I heard it from the radio and when I used to come at this clinic. I used to hear [from the radio] some people are saying about PrEP is a better medication to prevent HIV. I heard it kama [apparently] it was like a drama. Some people they say that PrEP is better medication, to encourage people to take medicine." (Participant 5)

Young women in this study had access to reproductive health information, including PrEP, from healthcare workers as well as from their peers and other community members who informed them about PrEP and its benefits.

4.3.1.3 Awareness of PrEP by family members and the community

Although PrEP services have been available since 2016, and information appeared to have been available as indicated in the previous section, some participants were still surprised to learn that their family members were also aware of PrEP or even using it. This may mean that although information is readily available, it is not always shared amongst family members.

"No because my sister is the one who told me that the same pills that I have been given, are the same pills which were given to my, our Aunt. So I was puzzled, and she confirmed that they were the ones." (Participant 1)

From the above quote it can also be induced that although there may be reluctance to share information related to being on PrEP, older and younger women appeared to educate and encourage each other to use PrEP.

PrEP was being discussed amongst community members and it appeared that some community members were aware of the availability of PrEP as well as the indications for its use.

"I really do not know, because some of them [community members] use to say that there are some pills at the hospitals which people are using in order to prevent themselves not to contact the disease, and I tell them that, it's true they are available there. You can just go to the clinic, in case you are aware that your partner is on medication." (Participant 1)

It appears family and community members were aware of PrEP. In some cases, family and community members informed others about PrEP and encouraged those at risk of HIV infection to use it.

4.3.1.4 Reasons for using PrEP

Young women who partook in the study indicated their reasons of using PrEP. A discordant HIV status amongst couples influenced young women's decisions to use PrEP, as many of the participants identified that as the main reason for using PrEP.

"What motivated me is because my partner is on medication for HIV." (Participant 1)

Multiple sexual partners, long distance relationships and lack of trust amongst partners also influenced the participants' decisions to use PrEP.

"Ok, what made me to start taking it is our male counterparts who are not well, and the other is that one time I went to the clinic to start with my antenatal sessions, so I told the nurses that my husband travels a lot and I think he has many women...I explained that I got medication in my husband's house." (Participant 6)

Most young women appeared to have agency in making independent decisions about their health. Young women indicated that they took PrEP with the understanding that they were caring about their own health by protecting themselves from acquiring HIV. The decision to use PrEP was motivated by being aware of and worrying about the risk of acquiring HIV, including the possible consequences of not using prevention.

"My reason was I will use PrEP because I want to prevent myself from getting the disease." (Participant 3)

"My reason is I do not want to get HIV positive because I was worried about my life, I don't want to lose my life." (Participant 2)

Many young women in this study were aware of their risk of acquiring HIV, which mostly appeared to be heightened by being in a discordant relationship and risky sexual behaviours. The awareness of the risk prompted many young women in this study to use PrEP.

4.3.2 Theme two: Empowered for self-care

The second theme that was identified during the analysis was empowered for self-care. For young women to be empowered for self-care, they need to have knowledge about PrEP and the benefits thereof. By using PrEP, most young women appeared to be empowerment for self-care – it provided a means for them to protect themselves against the risk of acquiring HIV. The participants in this study were empowered by their own positive experiences of using PrEP, role models and support from their partners and family. Some of the participants shared future goals or plans of using PrEP as well as what would enable them to continue the use of PrEP. The sub-themes under this theme were: positive feelings and experience; role models; partner and family member support; attending follow-up appointment, PrEP services, use of PrEP in future; and enablers of using PrEP.

4.3.2.1 Positive feelings and experience

Some of the young women who participated in this study experienced positive outcomes from using PrEP. They relayed feelings of happiness about testing negative for HIV when attending follow-up appointments and general feelings of well-being. Because they experienced these benefits of PrEP, young women appreciated the PrEP intervention and were willing to continue using it.

"There is a lot of goods because I am free my body is health so I encourage myself to take it continuously like they told me. I feel good, I just say that thank God for bringing me this opportunity to prevent myself." (Participant 5)

"Like since I started using it, my body is still fine I can see that the pills are working well." (Participant 9)

Although some of the participants narrated feelings and experiences of anxiety related to the efficacy of PrEP and apprehension about the results of HIV tests, they were relieved when they tested HIV-negative. Realising that PrEP is effective led to reduced stress levels and motivated the young women to continue taking their PrEP medication.

"I was scared I thought maybe they will get HIV in my body but it was come negative, I was happy I stay stress free." (Participant 7)

The young women in this study appeared to have integrated taking PrEP into their daily lives. They viewed using PrEP as a normal and good thing. Using PrEP made them feel in charge of their own health.

"I don't feel bad at all. I just feel normal and happy that I am taking care of myself." (Participant 1)

The young women who participated in this study had positive experiences of using PrEP. By using PrEP, they took charge of their own health and self-managed their HIV risk. Testing negative after using PrEP encouraged and motivated them to continue using PrEP. Using PrEP allowed them to have self-control over their health.

4.3.2.2 Role models

Participating young women appeared to view their peers and family members who were using PrEP as role models. In this study many of the participants reported that their family members or peers were either on ART or also using PrEP. These family members and peers acted as role-models for young women and motivated them to either start or continue using PrEP. Some of the family members became interested in using PrEP after hearing that the young women were using PrEP. They appeared to have noticed that the use of PrEP is beneficial. Having role models in the community assists to normalise the use of PrEP and facilitates its acceptance amongst communities.

"Then she said that she will also go get [PrEP] but from there I did not ask her of it. But she said that she also wants to start or to come tell that she wants to start but when I told her, she said that she will come [go to clinic for PrEP]." (Participant 7)

"Because I have seen one of my friends is using that medicine. Is her body is good and she is in good condition that is why I decided yes to use the medicine also." (Participant 5)

Young women were motivated by other women using PrEP and they felt a sense of belonging or connection to other young women, family members and friends who were also using PrEP. Therefore, the participants were more willing to use PrEP because they saw how it benefitted others.

4.3.2.3 Partner and family member support

Most of the participants in this study narrated that they received emotional support and encouragement to use and continue with PrEP from their partners or family members. Family members and partners of participants provided advice to the participants about the benefits of PrEP, the need for HIV testing and abstinence.

"She [sister in-law] just supported me that, in-law take it so that the child is prevented. At first she told me not to take already but to rather be tested and that my husband and I should not have sexual intercourse so that I go for 3 months tests repeatedly until I give birth." (Participant 6)

"He [boyfriend] just said no it's not a problem, I just need to go to the hospital early so that nurses can help me..." (Participant 9)

Family members and partners encouraged some of the young women to continue to use PrEP by emphasising on the benefits of the PrEP in preventing HIV.

"He [partner/boyfriend] only say that these pills are good when it comes to prevention...She [sister in law] says the same thing (Laughs)." (Participant 1)

The young women also received instrumental support, through reminders to take the medicine. This illustrates that family members were concerned about the wellbeing of young women.

"Like my mother, she used to ask if I use to take it." (Participant 3)

"Sometimes she calls me like around 8 o'clock did you take your medicine did you drink medicine and I used to tell her that yes I drank." (Participant 2)

Some of the participants experienced interest and concern from their partners about their well-being. Their partners were responsive to their nutritional needs. This also shows that some men are involved in health issues that affect young women.

"He used to give me food and we use to stay together the same roof." (Participant 2).

"Yes, my partner he is always provide the food when I experience with the hunger." (Participant 8)

Young women received various forms of support from family members, friends and partners while using PrEP. They were reminded to take their medication at the prescribed time/s and supported to eat well.

4.3.2.4 Healthcare worker support during follow-up appointments

Using PrEP required young women to continuously attend follow-up appointments. The young women who participated in the study stated that they attended follow-ups as was arranged by the healthcare workers. Most young women were given a follow-up date one month after the first visit and the consecutive follow-up appointments were scheduled at 3 month intervals. The follow-up dates were well spaced out and this the follow-ups much more acceptable.

"I started in September, they asked me to come back in October, and I came back. And now, they asked me to comeback in January the 14th that is when I will come back again." (Participant 1)

"They told me to come after one month because they gave me follow up." (Participant 5)

At follow-up most women were asked how they were taking their PrEP medicines and on some of these visits blood was collected to check their HIV status, which thereafter

determined their eligibility to continue using PrEP. It seemed as if the young women viewed the follow-up visits positively.

"Mhuu. The second follow up she took me blood to see the blood again." (Participant 5)

"We just enter in the room, they give the pills then they ask you questions on how you take the tablets." (Participant 7)

The participants reported that they interacted well with healthcare workers during follow-up visits. Those who worried about PrEP side effects were reassured. Furthermore, the healthcare workers also provided the young women with more information on PrEP.

"Then the nurse told me no problem I can just continue when it will get finished then you come back and get the other ones." (Participant 7)

"She told me to use the medicine if I am HIV negative and my partner is positive, because I told her that my partner is positive then she told me that you must take this medicine to prevent yourself from HIV, for me not to get HIV." (Participant 5)

Follow up arrangements were well received by participants, none of the participants raised complaints regarding the same. Young women received assurance from the healthcare workers through provision of information on PrEP.

4.3.2.5 Use of PrEP in future

Many young women indicated their plans and willingness to continue using PrEP in the future. It appeared that some participants knew that they were still at risk for HIV infection and therefore still needed to use PrEP. However, other participants were afraid of being judged by healthcare workers for their decisions of rotating on and off PrEP.

"I want to continue taking them." (Participant 1)

"Yah, I, I eh, I still feel like I need to go and continue taking PrEP but then I fear like I will be questioned "why did you stopped taking it, and why are you back again?"" (Participant 4)

Young women in the study were willing to continue using PrEP, probably because they were aware of the risk for HIV infection. Some of the women who had stopped taking PrEP, were afraid of being scolded and questioned by healthcare workers in the event that they decided to take PrEP again.

4.3.2.6 Enablers of using PrEP

Young women believed that for them to be able to keep themselves protected throughout, they needed continuity in PrEP supply. They knew that interruption in supply would hinder continuity of PrEP use.

"The only support that we need is to see that the pills are forever available and they must continue supplying them." (Participant 1)

Some young women believed that parental involvement in motivating and supporting young women to test for HIV and use PrEP was needed. Community and peer support was also emphasised. The young women thought that standing up for one another was crucial in the fight against HIV. Furthermore, the participants stressed the danger of using a single HIV prevention measure and the need to get tested and to be faithful to one HIV-tested, trusted partner.

"I just want parents to motivate and encourage young people like us to take PrEP....we must just stand for one another. Like to encourage one another. To take in PrEP and not to sleep around with men just because you are having PrEP medicine." (Participant 4)

Many participants indicated that they were positively influenced by other family members who were using PrEP. They also admitted to receiving support from their partners and family members. This enabled them to look forward to continuing or restarting PrEP.

4.3.3 Theme three: Persisting despite the challenges

Often times an intervention comes with challenges, however, individual persistence determines the success of it. Most young women revealed that they faced some challenges while using PrEP. The challenges faced may affect adherence to PrEP and determine its continuation. Although the participants of this study narrated several challenges such as disclosure, stigma and side effects of the medication, most persisted to use PrEP. The following sub-themes therefore emanated from this theme: disclosure; stigma; treatment-taking behaviours; experiencing possible side effects; financial implications; negative feelings; and stopping PrEP.

4.3.3.1 Disclosure

Most young women had preferences as to whom they would disclose their use of PrEP. They mostly preferred disclosing to immediate family members such as a mother or a sister than disclosing to extended family members. It also appeared that most young women who partook in the study preferred disclosing to and confiding in their fellow females such as a mother, aunties and female siblings than the opposite gender.

"I only told my mother and don't know whether she told my father." (Participant 5)

"Yah, like my young aunties, they knows, even my mom knows, and she once saw it." (Participant 4)

Some young women feared disclosing beyond close family members, as they feared what other people would say about them using PrEP. Young women had the knowledge that PrEP is for for discordant couples, therefore, they felt that by disclosing their use of PrEP to extended family members meant they would have disclosed that their partners were HIV positive.

"Because even me I cannot say it to the other person. What if that other person will ask that where did you hear about it? Me I'm afraid to tell the person that person can think that oho! This one is using those medicines maybe the partner is positive, no I cannot do it in that way." (Participant 8)

For fear of being judged and stigmatised by their partners, some young women hid their use of PrEP from their partners. They feared being seen as promiscuous as well as being seen as having a lack of trust in their partners.

"I didn't tell him, I was just scared he would question me a lot. He might think that I am only using it because I want to sleep around with men or I don't trust him or something." (Participant 4)

Most young women preferred disclosing their use of PrEP to close family members to disclosing to those with whom they were not closely related. They feared that other people might associate taking PrEP with having an HIV-positive partner or being promiscuous.

4.3.3.2 Stigma

Although most facilities offered integrated health services, ART services were still being provided separately in these facilities at the time of the study. PrEP services were provided together with ART services, thus PrEP clients were seen together with ART clients. This led to PrEP clients feeling that people could mistakenly think that they were taking ART and not PrEP. PrEP medication, including the packaging, is similar to ART medication. Those on PrEP, young women included, had to endure being seen as HIV-positive. They also had to endure going through explaining themselves to others. The young women reported that they

had to explain to the family members who knew they were taking PrEP that what they were taking was PrEP medication and not ART.

"Actually my mum was thinking that maybe the medicine is for HIV but when I explained to her then she understand that it's PrEP." (Participant 8)

"Yah, when I started, not my friend because my friend they knows, they use PrEP also. My parents thought maybe I am lying. Maybe I am HIV positive, just pretending that PrEP is preventing HIV. Even if you come for follow up, when you enter in that room, maybe people thought, they will think that, no this person is HIV." (Participant 3)

Community members may not have accurate knowledge about PrEP, therefore, there may be misconceptions about it. Some young women faced judgmental attitudes from their families as family members had the misconception that PrEP causes infertility in women. This misinformation may cause confusion about PrEP.

"One of my male cousins found it on the table and he goes to school in Windhoek... a male and when he found me he asked what the pills were for. I explained to him in detail, everything. Then I don't know if he was joking or it was true what he told me then he said, "Oohh now I know why you are not giving birth." Then I felt bad thinking that maybe it's the one making me not to give birth." (Participant 4)

Although some women reported being stigmatised for using PrEP, others reported that they had not experienced any form of stigmatisation from community members. However, those who stated that they did not experience stigma also indicated that it could be because the community members were not aware that they were using PrEP.

"Not at all. (Laughs) Maybe it's because they have never heard about me using them (*PrEP*)." (Participant 1)

"I have never seen that yet." (Participant 2)

Some young women condemned stigma directed to young women who were using PrEP. They felt that the use of PrEP should be seen as a normal thing and therefore communities should refrain from negative attitudes and behaviour directed towards PrEP users such as laughing and teasing, as this could cause emotional harm.

"They must just be normal with people who are taking these pills. They must avoid teasing, laughing at or saying negative things they must not hurt them in any way, like by saying something which might hurt them emotionally." (Participant 1)

Some of the young women in this study experienced stigma from family and community members towards their use of PrEP. They were seen as being HIV-positive due to the similarity between the PrEP and ART medication. This was further compounded by the fact that PrEP and ART services are offered in one department, separate from the rest of the health services which are integrated. The young women in this study condemned stigma towards the use of PrEP.

4.3.3.3 Treatment-taking behaviours

The young women on PrEP each developed a routine for taking their medication. Whereas some of the young women complained of challenges with swallowing the PrEP tablet others said another challenge was remembering to take the tablet every day. However, the young women appreciated the fact that the tablet was just one and had to be taken only once a day.

"Oh really! But when I started using the PrEP neh [right], like the time you take in [swallowing the pill] it's a headache also you have to remember like every time it's 6 o'clock if it's just 6 o'clock or 5 o'clock then you have to take it one time a day." (Participant 1)

"(Laughs) They are easy to use, because they are taken in the evening and it's just one pill in the evening." (Participant 1)

Some of the young women indicated that their acceptance of PrEP had made them not face any challenges in taking PrEP. They felt free to use PrEP because they had disclosed to someone within their families members and did not have to hide it.

"Ahh the med I used, is not, it is easy but they I don't use to see difficult thing that people are afraid of drinking me I am free to drink my medicines. Cannot give me difficulties." (Participant 2)

Most of the young women chose a convenient time of taking PrEP. This time varied from one woman to another depending on personal preference. Whilst some of the women preferred morning hours some opted for evening hours. This indicates how they selfmanaged taking their treatment. "I used to drink them around 09:00 in the morning only once in a day." (Participant 7)

"Ahh, I take it 9 o'clock evening once a day." (Participant 3)

Other life commitments, which kept the young women busy during the day, caused some difficulties for some of the young women. They would, for example, end up forgetting the exact time of taking PrEP.

"(Laughs) Sometimes you might end up forgetting about your specific time which you use to take them and only remember it after the time has passed. Or you are maybe kept busy with some work which will make you forget to take your pills, they are truly difficult to use." (Participant 1)

Some of the young women stated that the tablets were strong causing them to feel dizzy while others stated that the tablets were too big in size to swallow with ease. The size of the tablets made some of the young women dislike taking them.

"(Laughs) They are very strong, they make you to feel dizzy." (Participant 1)

"I don't like it, drinking, and taking because it's too big." (Participant 3)

Although some young women indicated that taking PrEP was easy as the medication was taken only once a day, others experienced some difficulty in swallowing the tablets due to the big size. Others experienced some minor side effects, which they related to the strength of the medication. Some women integrated taking PrEP into their daily routines but others struggled with this.

4.3.3.4 Experiencing possible side effects

Young women who participated in the study were asked whether they experienced any side effects as a result of using PrEP. Most young women experienced some side effects such as having facial pimples, diarrhoea, vomiting, dizziness and itchy vaginal discharge. Only a few did not experience side effects. On the other hand, some women were not sure if some of the signs and symptoms that they had experienced were really related to PrEP or if it were due to other unknown conditions.

"This medication I did not have any sign of allergic or get sick since I started using it." (Participant 8)

"When I started PrEP, i was having some symptoms, sores, and having diarrhoea, Ahh! and vomiting." (Participant 3) "I experienced itchiness inside my vagina and there were some white discharge coming out of it." (Participant 1)

Most of the young women reported that the onset of the symptoms were mostly during the first days of using PrEP and the symptoms were mainly just minor. After a few days the side effects disappeared.

"I am fine when I started to use it the first day I feel it is like some dizziness but now I am okay, I am fine." (Participant 5)

Some of the young women were able to manage the side effects of PrEP by ensuring that they ate in order to prevent the side effects related to drinking the tablet on an empty stomach. Such side effects include dizziness, nausea and hunger.

"Especially like if I did not eat is how, is where I used to feel dizzy or feel hungry. If I eat then there is no problem." (Participant 9)

The young women who presented with some possible side-effects were given medicines to manage the side effects. However, some of what was thought to be side effects were symptoms of other diseases. Whereas some of the young women recovered from whatever they were presenting with others did not, even with treatment. It appeared that some of the symptoms reported suggested sexually transmitted infections and were not related to PrEP.

"But I didn't experience any changes, the only changes that I experienced is that I started losing appetite, but we were given ah vitamins just to drink, to drink it with but it didn't help." (Participant 4)

"I experienced itchiness inside my vagina and there were some white discharge coming out of it. I then went to the hospital, and I was given pills to take. They then told me to come after 7 days if there was no improvement, and it stopped completely." (Participant 1)

Some of the young women did not experience any side effects from using PrEP, while others had side effects such as dizziness and diarrhoea. Most of the possible side effects that were reported by the young women appeared at the onset of using PrEP. Some young women were able to self-manage their symptoms while others accessed treatment from healthcare workers.

4.3.3.5 Financial implications

Some of the young women who participated in the study indicated that there were financial implications to using PrEP. They spoke about the need for financial support. Money was said to be needed by some for travelling to and from the health facilities for PrEP services.

"Mmmh, I think is like to support if they know that you are drinking PrEP they must support this people they are on medicine for PrEP they must support them, Ahhh to give them food, and give them money to go to hospital, to the clinic." (Participant 2)

Among the young women who participated some lived in poverty, unemployment and lack of food. This could have led them to struggling with adherence to PrEP. Hunger could have enhanced the side effects of PrEP medication. The young women. therefore, requested support with securing food

"...Some of us we are not working and you cannot get food to eat. which means they must provide us with food... those health workers wherever they go they need to teach people because those medicine some people they don't know about it. I just heard of it here at the hospital, but for people and community they do not know." (Participant 8)

"According to our way of living, as you, because those pills you can't just drink them, some live in poverty. They need to be looked in in terms of their living standard or maybe assist them with food." (Participant 9)

The young women indicated challenges with travel costs to access PrEP. Others said there were challenges related to food security due to unemployment and poverty.

4.3.3.6 PrEP services restrictions

Challenges related to PrEP services included that there appeared to be differences in opinions and practices amongst healthcare workers regarding eligibility criteria for PrEP. One young woman reported that she was initially denied to use PrEP since she was not married. This could indicate that there are judgemental attitudes amongst healthcare workers.

"The first day neh, when I came here we were told like this is not, it is not for everybody, PrEP medicine is not welcome for everybody. It was supposed to be for partners only like those ones that are married. Is what I was told." (Participant 4) Some healthcare workers may be of the opinion that PrEP is only for married couples or people in serious relationships. This can prevent PrEP uptake amongst single young women at risk of acquiring HIV.

4.3.3.7 Negative feelings

In this study, negative feelings were mostly associated with stigma. The participants worried about possible stigma such as being seen as HIV-positive, leading to feelings of shame. Furthermore, they also feared the unknown, for example, what people would say if they were to found out about them using PrEP.

"But sometimes ashamed, as if I am positive." (Participant 3)

"Yes. I use to again wonder about what people might say upon knowing that I am taking pills." (Participant 1)

For some of the young women it was hard to interact with family members because, they felt that their reactions and opinions about PrEP were likely to differ from theirs own. They also felt like some family members were insensitive about the needs of young women using PrEP.

"Family members? (Pause for a while).Those are not easy to deal with (Laughs)." (Participant 1)

"No they [siblings] don't mind." (Participant 3)

The way in which one participant reported to have been treated by a certain healthcare worker made her regret accessing PrEP services. The young woman felt humiliated as she was told PrEP was only for married couples and people in serious relationships. She wondered why it was so. The following are the sentiments from the woman:

"I felt bad. I felt like why did I even came here? Like why did I come here? Yes. If it's only, and why should it only be for married or only people with serious relationship? If you are not in a serious relationship or are youth regarded as not in serious relationships or they are just playing or something like that?" (Participant 4)

Although the young women were interested in using PrEP they were sometimes doubtful and unsure of its effectiveness. They wondered how ARVs worked and if PrEP really prevented HIV infection. "Aahh sometimes I used to doubt, doubting. Like it's true this pills can prevent me from getting a disease." (Participant 3)

Negative feelings were experienced due to fear of stigma, feeling humiliated or being disappointed by the behaviour of healthcare workers and family members as well as due to being unsure about the effectiveness of PrEP.

4.3.3.8 Stopping PrEP

One participant had to stop using PrEP. She indicated that she experienced poor appetite whilst using PrEP. The lack of appetite further resulted in loss of weight, which the young women did not like. Three participants were pregnant at the time of the interview and were still on PrEP. Although PrEP is safe to be used during pregnancy, one participant in the study seemed to fear the effects of PrEP on her unborn baby and therefore decided to stop using PrEP. She, however, later restarted using it.

"The reason why I stopped it is because it made me to lose my appetite of eating, then I thought I just have to stop it... The only thing I didn't like about using PrEP is when I lost weight, if it was really PrEP that was taking my appetite..." (Participant 4)

"When I got pregnant then I stopped [using PrEP]." (Participant 3)

Falling pregnant as well as PrEP side effects made some women decide to stop using PrEP.

4.4 SUMMARY

In this chapter the researcher discussed the findings of the study based on the three themes that were identified during the analysis of the study data. In the next chapter, the researcher presents a detailed discussion about the findings of the study according to the study objectives, the conclusions as well as the recommendations that were made thereafter.

CHAPTER 5:

DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION

In Chapter One, the researcher stated the aim, purpose as well as the objectives of the study. The researcher gave a comprehensive review of literature in Chapter Two whereas in Chapter Three, the research methodology was presented. In the previous chapter, Chapter Four, the findings of the study were presented. In this final chapter, the researcher presents a discussion of the study findings as well as recommendations and conclusions.

5.2 DISCUSSION

The aim of the study was to explore the lived experiences of young women on the use of PrEP in Namibia. Three major themes that exemplified the essence of the phenomenon were identified and these were: risk awareness, empowered for self-care, and persisting despite the challenges.

The lived experiences of young women are discussed based on the objectives of the study.

5.2.1 Objective 1: Explore the knowledge and understanding of young women about PrEP

An individual's understanding and knowledge about a certain phenomenon influences their decision-making capacity (Lambert, 2018:842). Therefore, young women need to have knowledge and understanding about PrEP in order for them to make decisions on whether to use it or not. Knowledge areas could include its indications, contra-indications, side-effects and the follow-up visits. In this present study young women were aware that women at risk of acquiring HIV should take PrEP. The study participants, especially those in discordant relationships and those who did not trust their partners acknowledged their risk. They understood that PrEP could protect them from acquiring HIV, although not all were aware that they could cycle on and off the medication without negative consequences. Young women in this study correctly understood that PrEP should be used in conjunction with other preventative measures, and that the use of PrEP does not increase women's risk behaviours (although risk behaviours were not explored as they were not the focus of this study). The young women also understood that PrEP is to be taken daily and at the same time to ensure effectiveness.

Information about PrEP is communicated through various sources such as through healthcare workers, the community and media. The sIMB model indicates that information

may influence motivation and behaviour (Lambert, 2018:842). In general, the information that the participants had about PrEP appeared to be accurate, although there were gaps identified. For example, some women did not know that they could cycle on and off PrEP and that they could restart if they stopped. The lack of information about cycling on and off PrEP may negatively affect women's behaviours towards deciding whether to take PrEP or not. Another gap in knowledge was the apparent lack of information about other risk factors that could be indications for PrEP. Only two women reported that they were using PrEP because they did not trust their boyfriends, otherwise all the other women in the study indicated that PrEP is for those in discordant relationships. Baron (2020:10) and Karletsos et al. (2020:1) report that women used PrEP due to a lack of trust towards their partners, indicating that in other African settings it is understood that PrEP is not only for discordant couples.

In general, women in this study had a good knowledge and understanding about PrEP, which is similar to studies conducted by Camlin (2020:2157) and O'malley (2020a:247) in Kenya and Uganda, and in Pittsburgh, Pennsylvania respectively. These studies reported about lack of PrEP awareness as well as lack of knowledge about the effectiveness and side effects of PrEP amongst women which is similar with the findings of the current study in which some of the young women who reported that they were somehow unsure about the effectiveness of PrEP. The MoHSS (2016a:98) and WHO (2017:6) indicate that PrEP can be used by HIV negative individuals who are at risk of acquiring HIV. According to MoHSS (2016a:98) and WHO (2017:6) eligibility criteria are not limited to those in discordant relationships but include those with multiple sexual partners, those who do not use condoms consistently, those with a recent STI diagnosis, a person requesting PrEP and people who inject or use drugs. If one considers the components of the sIMB, the lack of information and awareness of the broader indications for PrEP may lead to its low uptake amongst young women. Further, the young women may not reengage in care if they are not aware that one could restart PrEP after stopping it.

5.2.2. Objective 2: Describe the socio-cultural, educational and informational conditions that influenced young women's choices to use PrEP

5.2.2.1 Socio-cultural conditions

Socio-cultural conditions such as attitudes, beliefs and social norms may influence young women's decisions about using PrEP (Lambert, 2018:843). The young women in the present study reported some conditions that influenced their decisions to use PrEP. The socio-cultural conditions ranged from the social influence of role models in the community like

friends and family members who were using PrEP to behaviours of partners such as relationships and uncertainty about the HIV status of their sexual partner. Baron (2020:10) reports that women decide to use PrEP because of their HIV risk perceptions while Pilgrim et al. (2016:5) confirms that women use PrEP because they do not trust their partners and are unaware of their partner's HIV status.

One young woman reported that she decided to start PrEP after she had heard about it from one of her friends who was using it. Some of the family members and friends of the young women who participated in the study wanted to start using PrEP after hearing about PrEP from them, illustrating that their use of PrEP influenced others to want to use it too. No other studies could be found that reported on the subtle influences of social interactions on women's decisions to use PrEP as was found in the present study.

None of the participants in this current study mentioned the need to get permission from their partners and or parents to use PrEP, which is different to what was reported in other studies (Pilgrim et al., 2016:5; Baron, 2020:10). Permission and laws around the use of PrEP varies from country to country. In Ukraine, PrEP can be provided to people from the age of 14 years if they are at risk whereas in Australia there is no specific age limit for use of PrEP (Taggart, Bond, Ritchwood & Smith, 2019:7). In South Africa and the UK, the national guidelines recommend that PrEP should be provided to adolescents who fall in the key population category such as young women (Taggart et al., 2019:7). The Namibian ART guidelines on the other hand do not indicate a need for parental permission when providing PrEP to young women and adolescents (MoHSS, 2016a:98).

Myths and misconceptions towards PrEP use made some of the young women feel uncomfortable about continuing with PrEP as they felt stigmatised. One woman reported that she was told by a family member that PrEP is the reason she has not been able to conceive. Other women reported that they feared being judged as being immoral and this led some women to not disclose their PrEP use. Furthermore some women reported that they had to convince family members that they were really using PrEP and not ARVs. Societal attitudes such as PrEP users being seen as immoral and myths about PrEP reducing one's libido are reported by Digolo et al. (2018:16). Similarly, Amico et al. (2017:1365) and Nydegger (2020:589) report that women stated that they were told by family members that they would get HIV from using PrEP or that they were using PrEP for so as to benefit from research participation incentives.

Busy lifestyles pose adherence-related challenges for young women as they may fail to integrate attending appointments for PrEP services and taking the treatment into their

lifestyles. Some young women reported that on days that they were overwhelmed with other daily activities, they ended up forgetting to take their PrEP medication. Digolo et al. (2018:13) report that conflicting priorities such as work and school are likely to affect the commitment of young women to continue PrEP as they may struggle to attend PrEP follow-up appointments.

The sIMB model indicates that social norms may influence behaviour (Lambert, 2018: 843). An individual's behaviour is usually influenced by information, attitudes of people they know and the general acceptability of a health behaviour. Public attitudes influence the individual's desire to take up interventions that are related to promoting their own health (Lambert, 2018:843). In the present study, normalising taking PrEP for example by seeing others taking it, was a motivating factor towards taking PrEP for some of the young women. Contrary to this, stigma was identified as a barrier to continuing with PrEP. One aspect that is not addressed in the sIMB model is the possible influence of social responsibilities/lifestyle conditions and how to assist women to integrate taking PrEP into their daily schedules.

5.2.2.2 Educational and informational conditions

The level of knowledge and awareness about PrEP may influence young women's motivation and willingness to use PrEP. In this study, the researcher could not identify differences in the knowledge and understanding of PrEP between women with a high educational level and those with a lower educational level. Furthermore, the researcher could not find literature on the influence of education on PrEP uptake.

The young women who were interviewed in this study had experience of using PrEP since they were either taking PrEP at the time of the study or had used it before. It could therefore be expected that these women had been informed about the indications, efficacy and sideeffects of PrEP. Although there was a gap in knowledge as explained in 5.2.1, most young women who participated in the study were well informed about PrEP, as they reported that HIV negative individuals whose partners were HIV positive should use PrEP. This is supported by MoHSS (2016a:98) who states that the indications for PrEP include partners with HIV discordant results. The young women also had knowledge that PrEP is used when one is at risk of being infected with HIV. Furthermore, they had the knowledge that taking PrEP was beneficial to prevent HIV transmission and infection as some women reported that they took PrEP with the understanding that they were caring for their own health. Awareness about their risk enabled the young women to make decisions about using PrEP.

A lack of information about the efficacy and effectiveness of PrEP was identified in this current study. Some of the young women who participated in the study reported that they

doubted or were unsure about the effectiveness or safety of PrEP. One young woman in the study reported that she stopped using PrEP after falling pregnant as she was unsure about the safety of PrEP in pregnancy. This is in contrast to assertions by Lambert et al. (2018:840), that PrEP is safe to use in pregnancy and does not reduce the effectiveness of hormonal contraception. Another participant reported that she stopped using PrEP due to perceived side effects. O'malley et al. (2020b:9) reports that there was limited awareness of PrEP and misconceptions around the effectiveness, side effects and eligibility criteria amongst women receiving family planning in Pittsburgh, Pennsylvania. Suggestions by O'malley et al. (2020b:9) include the need to intensify PrEP awareness amongst women. Fletcher et al. (2018:176-177) also report that most mothers and daughters in their study reported that they were not aware of PrEP prior to participation in the study. Furthermore, Lambert (2018,:840) reports that some women confused PrEP for a treatment than a preventative measure. Whereas the lack of knowledge about HIV prevention measures may put young women at greater risk for HIV acquisition, knowledge about PrEP, as indicated by Baron (2020:6) and Nydegger (2020:589), may influence young women's willingness to adopt certain health behaviours [such as HIV prevention] and thereby influence their decisions towards PrEP use.

The participants' sources of information, as mentioned in 5.2.1., included healthcare workers, friends, and other sources such as books, the internet and media. Information about PrEP was shared amongst family members and communities as some young women in the study reported that family and community members were already aware or informed about the availability of PrEP and its indications. Similarly, the Oregan Health Authority (2020:2) reports that informal communication about PrEP was observed amongst the lesbian, gay, bisexual, or transgender communities and was done through the social media. Furthermore, Pillay et al. (2020:6) report that amongst sex workers and men who have sex with men in South Africa, printed information, and education communication materials about PrEP influenced their decision to initiate or continue PrEP.

From the findings, it appeared that information about PrEP led to young women being aware of their risk and empowered them to make choices to manage this risk. Some of the young women in this study indicated that their reason for using PrEP was because their partners were either HIV positive and or on medication (ART), while others reported that they lacked trust towards their partners. Karletsos et al. (2020:7) report that young women in Lesotho perceived themselves to be at risk of acquiring HIV if they had a history of an STI, experienced being sexually coerced, had sexual partners who were in polygamous relationships or had multiple concurrent sexual partners. Furthermore, they also reported

that their perceived risk was associated with intimate partner violence and difficulty negotiating condom use. Similar to what was found in the present study, HIV risk awareness was associated with a willingness to use PrEP (Karletsos et al., 2020:7). Information about PrEP may influence young women's HIV risk perception and equally influence their motivation to start and continue using PrEP (Pilgrim et al., 2016:5; Baron, 2020:6; Nydegger, 2020:589). Furthermore, feelings of empowerment to manage their risk and take care of themselves are also reported in other studies for example Collins, McMahan and Stekler (2017:1) report that men who have sex with men view PrEP as empowering.

Although the knowledge of healthcare workers was not measured in this study, some of the participants' lived experiences alluded to that healthcare workers may not be aware of all the indications for PrEP. A lack of knowledge about PrEP amongst healthcare workers may negatively affect access to and the quality of services provided. Equally this may affect the uptake and continuation of PrEP amongst young women. Some healthcare workers were not so keen to prescribe PrEP to young unmarried women as indicated by the study participants. One woman reported that she was nearly denied of PrEP by a healthcare worker who indicated that it was only for married individuals. Nydegger (2020:589) reports that due to a lack of sufficient knowledge about PrEP observed amongst healthcare workers during consultation, young women lack motivation to use PrEP. Information provision to young women about the indications for PrEP, efficacy and side effects, according to the sIMB model, influences young women's decisions to use PrEP (Lambert et al., 2018:844).

5.2.3 Objective 3: Describe the physical, emotional and social support needs of young women while using PrEP

5.2.3.1 Physical support needs

In this study, several physical support needs were identified. These included facilities with privacy, continuity of services and financial support for travel and food.

With regards to privacy and confidentiality concerns, the young women reported that they were attended to in the same room with clients who had visited the health centre for ART services. This compromised privacy and confidentiality in the healthcare setting. Along the same line, young women had a need for privacy in their homes. For example, one young woman reported that a family member discovered her PrEP medicine and questioned her. This is similar to a study by Celum et al. (2019:2) which reports that young women who took part in the study had limited private space for storing their PrEP pills to avoid unintended disclosure of PrEP use. Digolo et al. (2018:15) further reports that women experienced stigma in healthcare facilities due to the preferred area of dispensing PrEP in the facility.

Young women reported that they believed that for them to be able to keep themselves protected they needed continuity in PrEP supply. They knew that interruption in the availability of the PrEP medication will hinder continuity of PrEP use. This can be related to Pike et al. (2020:2) who emphasise the importance of securing stock to meet the demands of product consumers. In addition the young women experienced challenges regarding access to services as they reported that they had to travel long distances in order to access PrEP services. In the same way, in a study by Celum et al. (2019:2) adolescent girls and young women in Africa were reported to live in poverty and therefore experienced challenges with accessing PrEP services as they had to travel long distances to access such services.

To avoid side effects associated with taking PrEP on an empty stomach, as was reported by the young women in the study, it may be necessary to provide financial and or food support so as to assist those living in poverty to minimise such side effects. Although some of the women in this study reported that they experienced some side effects, they were not sure if the symptoms were related to PrEP or not. Whilst some of the women self-managed the side effects of PreP others reported that they were given treatment for the side effects. PEPFAR (2019:100), states that initial counselling for PrEP should include provision of information describing the common PrEP side effects and the management thereof.

5.2.3.2 Emotional support needs

Emotional support includes the provision of care, empathy, love, appreciation and trust (Atoum & Al-Shoboul, 2018:7). When women are supported, they may experience positive feelings, whereas a lack of support may result in negative emotions. Young women who participated in this study expressed both positive and negative emotions as a result of using PrEP. Getting a negative HIV result was reported to be comforting for the young women whilst negative feelings and emotions emanated from being worried about possible stigma and a lack of emotional support for using PrEP.

The women who had an HIV negative result felt protected and happy to use PrEP. These women reported that using PrEP made them feel secure and empowered. Similarly, the Oregan Health Authority (2020:4) and Arnold et al. (2017:3) state that users of PrEP, in their studies, reported benefits such as decreased anxiety and peace of mind relating to their sexual experience. It can therefore be said that taking PrEP can be emotionally supportive in itself, which is augmented receiving satisfactory follow-up care and receiving negative results.

It was evident that some women lacked emotional support from healthcare workers and family members resulting in the negative feelings. With regards to healthcare worker support, one participant reported that she was denied PrEP service as the healthcare worker indicated that PrEP was for married couples only. Thus, the young woman reported that she experienced negative emotions for being denied a service that she felt she deserved.

Some of the young women also reported that they felt uncared for, stigmatised and that family members were hard to deal with. This may therefore hinder their uptake and continuation of PrEP. Population Council (2017:1) and Pilgrim et al. (2016:5) state that because PrEP consists of ARV drugs, young women are likely to fear being seen as being HIV positive. Likewise, in the study by Velloza (2020:3), young women and adolescent girls who were using PrEP reported that they were called prostitutes by family members and friends. Similarly, Wal and Loutfi (2017:2) and Amico et al. (2017:1365) also state that young women who participated in their studies reported that by seeking PrEP services they were judged as acknowledging promiscuity.

Pilgrim et al. (2016:5) indicate that provider-patient interaction is key to high quality PrEP service provision to young women. Such an interaction may help to strengthen positive experiences and equally empower young women. Strengthening the provider-patient interaction, promoting family involvement and mitigating stigma may further help to avert negative emotions among young women using PrEP (Pilgrim et al., 2016).

5.2.3.3 Social support needs of young women while using PrEP

Social support refers to the care, support and a sense of belonging that social members can get from others (Yang & Jiang, 2020:1). In this study young women reported social support ranging from being encouraged to start or continue taking PrEP, being reminded to take PrEP and to eat well and be healthy. Young women appreciated the support that was received from family members, friends, partners and healthcare workers. According to Yang and Jiang (2020:1), social support can improve a person's social adaptability, which can therefore influence their decisions to take and continue PrEP.

In this study, young women who reported parental involvement and support were more motivated to use PrEP. For example, one woman reported that she received support from her mother who reminded her of the time to take her medication. Correspondingly, Fletcher et al. (2018:176-177) report that families and friends are sources of support for young women using PrEP as they may motivate them to continue using PrEP. Some young women in the present study reported that they received support from healthcare workers who advised and encouraged them to use PrEP, as well as how to cope and manage PrEP side

effects. Young women may require support from healthcare workers in terms of preparing them for possible side effects and the management thereof. This may further promote adherence and continuation which is a crucial factor in the effectiveness of PrEP (Shiferaw et al., 2011:2).

Digolo et al. (2018:13), Rogers (2020:11) and Pike et al. (2020:1) specify that encouragement and linkage to and promotion of partner, peer group and guardians support may encourage PrEP normalisation and thereby reduce stigma and promote continuation of PrEP. The sIMB model confirms that societal influences such as social support may influence the behaviour of an individual in the uptake and continuation of PrEP (Lambert et al., 2018:844).

5.3 STRENGTHS AND LIMITATIONS OF THE STUDY

The study employed a phenomenological design that provided an in-depth understanding about the lived experiences of young women on the use of PrEP. It is the first study known to the researcher to explore young women's lived experiences on PrEP in Namibia.

Some limitations were noted. Although the researcher had intended to interview young women aged between 15 and 24 only those aged from 21 to 24 took part in the study. None of the young women interviewed were between 15 and 20 years of age. The researcher was unable to conduct member checking of all the participants. Therefore, the findings may not represent the lived experiences of young women under the age of 21 years. Moreover the study setting comprised only clinics around the town of Rundu, and as such the findings may not represent the lived experiences of other young women from outside the Rundu district.

5.4 **RECOMMENDATIONS**

Recommendations are based on the objectives and findings of the study as identified by the researcher. The recommendations, when considered, could assist young women to initiate or continue PrEP. A summary of the recommendations is provided in Table 5.1, with a more detailed discussion thereafter.

Objectives	Recommendations	
 Explore the knowledge and understanding of young women about PrEP. 	• Expand PrEP awareness campaigns which should focus on indications, effectiveness, side effects and the management thereof as well as clearing PrEP myths and misconceptions.	

Table 5.1: Recommendations based on the study objectives

2.	Describe the socio-cultural and educational informational conditions that influence decisions to use PrEP.	 Strengthen the training of healthcare workers on PrEP guidelines. Expand PrEP delivery models to include the integration of PrEP into family planning, antenatal care and other healthcare services. Provide and promote PrEP counselling and include safe PrEP disclosure.
3.	Describe the physical, emotional and social support needs of young women while using PrEP	Promote support in various forms.Provide small incentives.

5.4.1 Expand PrEP awareness campaigns

PrEP awareness campaigns should focus on the indications, effectiveness, side effects and the management thereof as well as clearing PrEP myths and misconceptions. Lack of awareness about PrEP may cause a low uptake of PrEP due to lack of knowledge and information about PrEP. UNAIDS (2020b:1) states that awareness campaigns through platforms such as the media and school curriculums may improve the uptake of PrEP. Furthermore, because many people associate PrEP with promiscuous behaviour and many other myths and misconceptions exist, it may be necessary to embark on awareness campaigns that focus on clearing up myths and misconceptions surrounding PrEP.

PrEP counselling sessions according to WHO (2017:4), should strive to create awareness about dosing requirements to ensure best protection as well as what to do following a missed dose. Common adherence strategies, importance of ongoing monitoring while on PrEP, side-effects and their management, how to safely discontinue and restart PrEP, sexual health protection strategies beyond PrEP, and comprehensive HIV prevention planning should be included in the counselling sessions. It can be said that these steps may further assist young women to integrate PrEP into their daily routines.

Awareness campaigns need to reemphasis PrEP for all populations. This may improve the understanding of people about PrEP, thereby reducing stigmatisation and discrimination faced by PrEP users (WHO, 2015:49; Pilgrim et al., 2016:5).

5.4.2 Training of healthcare workers on PrEP guidelines

Lack of knowledge amongst healthcare workers on PrEP compromises the quality of healthcare services rendered. Furthermore, it may cause decreased willingness to use PrEP amongst young women and reduce the willingness of healthcare workers to prescribe PrEP (Nydengger, 2020:589). Young women in Africa may have limited access to sexual and reproduction health services due to negative healthcare worker attitudes directed towards

unmarried sexually active young women. Therefore healthcare worker in-service training and workshops may improve their knowledge about PrEP particularly on issues such as autonomy, privacy and consent to testing and HIV services that may vary in young women. WHO (2017:6) emphasises the need to train healthcare workers on the use of PrEP. WHO (2017:6). further states that refresher training on a regular basis is needed to ensure that healthcare workers provide accurate and up to date information and service to clients.

5.4.3 Expand PrEP delivery models

PrEP delivery models need to integrate PrEP into family planning, antenatal care and other healthcare services. Some of the young women who took part in the study experienced challenges as they had to travel long distance for follow-up appointments. The integration of PrEP services into other healthcare services would ensure that clinic visits are utilised effectively (Celum, 2019:26). Furthermore, as Pike et al (2020:1) assert, the delivery of PrEP services through school health and outreach services may promote young women's access to PrEP.

5.4.4 Provide and promote of PrEP counselling services which include safe PrEP disclosure

The young women in this current study experienced challenges with safe disclosure because their family members did not believe that they were on PrEP and not ARVs. This problem can be emotionally draining for young women who may already be facing other challenges related to using PrEP. Therefore, PrEP counselling sessions, according to WHO (2017:4), should include discussions about problem-solving and address challenges of disclosure to partners, family members and friends. This may assist young women to handle or solve problems related to PrEP disclosure well.

5.4.5 **Promote support in various forms**

Some of the young women lacked support from family members. Therefore peer group support may act as a substitute source of support where young women can motivate and support each other to circumvent challenges faced when using PrEP and thereby promote their willingness to continue using PrEP (Fletcher et al., 2018:176). Atoum and Al-Shoboul (2018:7) state that it is in the character of human beings to require attention, communication, trust and moral guidance from their peers. The need for attention, communication, trust and moral guidance from other peers provides a chance for human beings to open up their emotions, which may therefore help influence young women's confidence and self-efficacy to access and continue to use PrEP (Atoum, & Al-Shoboul, 2018:7).

Young women using PrEP also need family members and healthcare workers who can listen to them, be empathetic and provide reassurance. This can further assist the women to integrate PrEP into their daily activities without the fear of being stigmatised.

5.4.6 Provision of small incentives for young women living in extreme poverty

Whereas some of the young women had to travel longer distances to access PrEP others stated that they lacked enough food to eat which therefore aggravated the side effects of PrEP. Therefore, the provision of incentives like travel reimbursements and food for those in dire poverty may promote the continuity of PrEP. Celum (2020:26) reports that the provision of small incentives such a transport money may improve adherence amongst young women using PrEP.

5.5. FUTURE RESEARCH

Exploration of knowledge, attitude and willingness of healthcare workers towards the provision of PrEP is recommended. Furthermore, future studies may also look at the lived experience of healthcare workers in the provision of PrEP. This may assist in identifying provider associated barriers to the uptake of PrEP amongst adolescents and young women. Other studies may explore the different PrEP delivery models.

5.6 **DISSEMINATION**

The researcher intends to present this report at relevant conferences. Furthermore, the researcher aims to publish an article in a peer reviewed journal. The study will be available on the website of the Stellenbosch University. Additionally, the reported will be shared with the MoHSS through the permanent secretary.

5.7 CONCLUSION

PrEP is one of the HIV prevention methods in which young women can be empowered to make decisions about their own health. This study was aimed at exploring the lived experiences of young women on the use of PrEP in Namibia. The study achieved its objectives through the identification of three themes which were: 1) risk awareness, 2) empowered for self-care, and 3) persisting despite the challenges. PrEP is especially important for young women who may be at risk of HIV acquisition such as those with HIV positive partners and those with multiple partners or partners with multiple sexual partners. Further, PrEP awareness amongst health workers and women should be promoted as a lack of awareness about PrEP may result in the under utilisation of this beneficial HIV prevention measure for women at risk of acquiring HIV. Many studies have revealed the efficacy of PrEP in preventing HIV acquisition amongst users. Although there were gaps in the

knowledge about PrEP amongst young women, it was noted that most of the young women in this study comprehended the indications and benefits of using PrEP and therefore were aware of their risk. The use of PrEP made young women in this present study feel empowered for self-care. The young women's experiences and choices to use and continue PrEP were influenced by socio-cultural, educational and informational conditions. Most women in the study indicated that they were using PrEP because their partners were HIV positive. Furthermore, it appeared that young women endured some challenges such as being stigmatised, experiencing side effects, disclosure challenges, lack of support and travelling longer distances. Addressing these challenges is crucial in promoting PrEP uptake and continuation amongst young women.

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APPENDICES

Appendix 1: Ethical approval from Stellenbosch University



New Application

22/05/2019

Project ID: 8997

HREC Reference #: \$1902/031

Title: EXPLORING THE EXPERIENCES OF YOUNG WOMEN OF THE USE OF HIV PRE-EXPOSURE PROPHYLAXIS IN NAMIBIA

Dear Miss Ester Vasco,

The New Application received on 08-Feb-2019 was reviewed at the convened meeting for Health Research Ethics Committee (HREC) 1 on 06-Mar-2019, and modifications to this project were requested. This additional information was provided 29 – April-2019 and reviewed. The study is now approved with a stipulation as of the above date.

Please note the following information about your approved research protocol:

Protocol Approval Period: 22-May-2019 - 21-May 2020.

The stipulation of your ethics approval are as follows:

1.Data will be collected in Namibia and stored at Stellenbosch University therefore participants must be told and approve of such movement of their personal data. In addition, the South African researchers must treat the data according to international agreements

Please remember to use your project ID 8997 and ethics reference number (\$19/02/031) on any documents or correspondence with the HRECAUREC concerning your research protocol.

Translation of the consent document(s) to the language(s) applicable to your study participants should now be submitted to the HREC.

Please note that this decision will be ratified at the next HREC full committee meeting. HREC reserves the right to suspend approval and to request changes or clarifications from applicants. The coordinator will notify the applicant (and if applicable, the supervisor) of the changes or suspension within 1 day of receiving the notice of suspension from HREC. HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

After Ethical Review:

Please note you can submit your progress report through the online ethics application process, available at: <u>https://apply.ethics.sun.ac.za</u> and the application should be submitted to the Committee before the year has expired. Please see <u>Forms and Instructions</u> on our HREC website for guidance on how to submit a progress report.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Provincial and City of Cape Town Approval

Please note that for research at a primary or secondary healthcare facility, permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Please consult the Western Cape Government website for access to the online Health Research Approval Process, see: <u>https://www.westerncape.gov.za/peneral-publication/health-research-approval-process</u>. Research that will be conducted at any tertiany academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and instructions on our HREC website (www.sun.ac.za/healthresearchethics)

If you have any questions or need further assistance, please contact the HREC office at 021 938 9677.

Page 1 of 2

Yours sincerely,

Mrs. Melody Share

Coordinator, HREC1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130406-012 (HREC-1-REC-230306-010 (HREC2)

Federal Hide Assurance Number: 50051372 Office of Human Research Protections (CHRP) Institutional Review Roard (RB) Number: IR68005240 (HREC1)-R85005230 (HREC2)

The Health Research Effect Controlline (HREC) complies with the SA National Health Act No. 61 of 2003 as it persists to health measures. The HREC oblines by the othical names and principles for measures, astablished by the joint Health Research (2013). Controlline of Health (2015), Edited and the Context on the Context on Deleter Theorem Devicement in South Affect (Internal Principles), and the Context on t

The Health Research Ethics Constitute reviews measurch involving human subjects conducted or supported by the Department of Health and Human Services, or other Indenti departments or agencies that apply the Federal Falley for the Projection of Human Subjects to such research (Unlind States Cade of Federal Regulations Title 45 Part 46); and/or clinical investigations regulated by the Food and Drug Administration (FDA) of the Department of Health and Human Services.

Page 2 of 2

Appendix 2: Permission obtained from institutions / department of health

		5. 1/2			
		REPUBLIC OF NAMIE	BIA		
	Min	istry of Health and Social	Services		
Private Bag 13198 Windhoek Namibia		Ministerial Building Harvey Street Windboek	Tel: 061 – 203 2562 Fax: 061 – 222558 E-mail: hnangombe@gmail.com		
	OFFI	CE OF THE EXECUTIVE D	the second state of the second		
	17/3/3 EV iries: Dr. H. Nangombe				
2006					
Date:	11 October 2019				
	Ester K. Vasco				
PO B Rund	ox 1162 lu				
Nami	bia				
Dear	Ms. Vasco				
Re- F	volation the evolution .	from women of the use of	HIV Pre-Exposure Prophylaxis in		
Nam		I FOUND RUMEN OF INC BAL OF	HIT THE REPORT FROM PARTY IN		
I.	Reference is made to yo	ur application to conduct the a	bove-mentioned study.		
2.	The proposal has been e	evaluated and found to have me	erit.		
3.	Kindly be informed that permission to conduct the study has been granted under the following conditions:				
3.1	The data to be collected must only be used for academic purpose;				
3,2	No other data should be collected other than the data stated in the proposal;				
3.3 Stipulated ethical considerations in the protocol related to the protection of Human Subjects					
			of will lead to termination of the study		
	at any stage;		and the state of the		
	ar any mapes				

- 3.4 A quarterly report to be submitted to the Ministry's Research Unit:
- 3.5 Preliminary findings to be submitted upon completion of the study;
- 3.6 Final report to be submitted upon completion of the study;

.....

- 3.7 Separate permission should be sought from the Ministry for the publication of the findings.
- All the cost implications that will result from this study will be the responsibility of the applicant and not of the Mol1SS.

Yours sincerely, CU XE NGOMBE B ECUTIVE DIRECT E)

Appendix 3: Participant information leaflet and declaration of consent by participant and investigator and standard procedure for obtaining consent for participants younger than 18

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM FOR YOUNG WOMEN OLDER THAN 18 YEARS.

TITLE OF THE RESEARCH PROJECT: Exploring the lived experiences of young women of the use of HIV pre-exposure prophylaxis in Namibia.

REFERENCE NUMBER: S19/02/031

 PRINCIPAL INVESTIGATOR:
 Vasco Ester K.

 ADDRESS:
 Faculty of medicine and health sciences

 Department of nursing and midwifery, Stellenbosch University

 P. O. Box 241

 Cape Town, South Africa

Francie van zijl drive

Tygerberg

Tel +27219389036

Fax +27219389854

CONTACT NUMBER: +264813321349

Dear participants

You have been invited to participate in a research project. Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to accepted and applicable National and International ethical guidelines and principles, including those of the international Declaration of Helsinki October 2008.

What is this research study all about?

- This study is about the lived experiences of young women on the use of PrEP in the Kavango East region of Namibia. It aims at finding out what they have/are facing and/or experiencing while using PrEP.
- PrEP refers to the use of antiretroviral medicines by HIV negative individuals before sexual exposure to prevent HIV infection.
- About six to ten young women who are accessing PrEP services from the primary healthcare facilities around Rundu town will be recruited in this study.
- They will be interviewed about their lived experiences and this interview process will be recorded with an audio recorder. This will be done to get an understanding of their lived experiences.
- Privacy will be insured by insuring anonymity of all recorded information. As participants will not be requested to provide their names.
- > The recordings will be destroyed once the data has been transcribed.
- However, the researcher is going to publish the findings of the study anonymously without linking the data to the participant's name.

Why have you been invited to participate?

> You have been invited to participate in the study because you are a young woman aged between 18-24 years who is using or have been using PrEP.

Who is doing the research?

My name is Vasco Ester K, a second year student at the University of Stellenbosch in South Africa, doing my master's degree in nursing science. I am a lecturer at Welwitchia health training centre, Nkurenkuru campus. I am doing this study as it might help the Ministry of Health and social services to be aware and to understand the lived experiences of young women on the use of PrEP. Thus, assist the Ministry in setting up better ways in implementing PrEP amongst young women.

What will happen to me in this study?

You will be involved in a face-to-face interview whereby I will be asking you some questions. An audio recording of the interview will be made with a tape recorder. The estimated duration of the interview is 45-60 minutes. The interview will be done at a private area and at a time of your choice, but not outside the suburb. The interview will be conducted in English, however, if you cannot speak English you will be given the choice to participate in the interview using the language of your choice. An interpreter will then be sought in the case whereby the researcher also cannot speak your preferred language.

Can anything bad happen to me?

The study does not include doing any experiments on you, therefore you will only be exposed to minimal discomfort. However, a counsellor will be availed for those participants who might become emotional during the interview due to personal past lived experience. Furthermore, you do not need to pay for you to participate. Should you incur any cost to travel to attend the interview, the researcher will reimburse you for the cost incurred. Additionally if you later on after partaking in the interview feel sad, you may inform your parent or a healthcare worker nearer to you.

Can anything good happen to me?

There is no direct benefit to you, but the study findings may inform policy makers and implementers about better ways to use when dealing with PrEP.

Will anyone know I am in the study?

Your participation in this study will be kept confidential. You do not need to give your name for you to participate in the study.

What will my responsibilities be?

Your responsibilities will be to participate in an interview that is estimated to take up to 45-60 minutes and to make sure that you answer honestly and truthfully.

What will I benefit from taking part in this research?

There are no direct benefit to you but the study outcome may inform policy makers and implementers about better approaches to PrEP implementation.

Are there any risks involved for me in taking part in this research?

The study is not an experimental one, therefore you will only be exposed to minimal discomfort. If you decide to agree to participate the interview might take up 45-60 minutes of your time. You do not need to answer questions that you feel uncomfortable to answer. However, a counsellor will be availed for you in the case when you become emotional during the interview due to personal past lived

experience. Furthermore, you do not need to pay for you to participate. Should you incur any cost to attend the interview, the researcher will reimburse you for the cost incurred. Additionally if you later on after partaking in the interview feel sad, you may inform your legal guardian and/or healthcare worker nearer to you.

If I do not agree that I take part, what alternatives do I have?

Your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you have agreed for you to take part.

Who will have access to your information?

The information that the researcher has collected is treated as confidential and protected. The researcher plans to publish the findings of this study, however your identity as a participant will remain anonymous. The only people who will have access to your information is the researcher and her study supervisor.

What will happen in the unlikely event of some form of injury occurring as a direct result of me taking part in this research study?

We do not anticipate that you will suffer any injury or harm as a result of taking part in the study. If you become distressed during the interview process, you will be referred to the counsellor who will be availed to you by the researcher.

Will I be paid to take part in this study and are there any costs involved?

- You will be reimbursed for travel cost to attend the interview for each study visit. You will not have to pay for anything, if she does take part.
- Refreshments will be provided during the interviews. There will be no costs involved for your child, if he/she does take part.

Is there anything else that I should know or do?

- You can phone Ms Vasco Ester at +264813321349 if you have any further queries or encounter any problems.
- You can phone the Health Research Ethics Committee of South Africa at 021 938 9677/9819 if there still is something that your study nurse has not explained to you, or if you have a complaint.

If you are willing to participate in this study, please sign the attached Declaration of Consent and hand it to the investigator.

DECLARATION BY PARTICIPANT

By signing below, I agree to take part in a research study entitled: Exploring the lived experiences of young women of the use of HIV preexposure prophylaxis in Namibia

I declare that:

- I have read or read to me this information and the consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way as a consequence.
- I consent to the audio recording of the interviews that I may be involved in.

Signed at (*place*) 2019.

Signature of participant

Full name and Signature of Witness

Date

STANDARD PROCEDURE FOR OBTAINING CONSENT FOR PARTICIPANTS UNDER THE AGE OF 18.

The standard procedure for obtaining consent for participants under the age of 18 will be as follow:

- Check if participant meets eligibility criteria for the study.
- Provide full information about the study as contained in the assent form, including that parental consent needs to be obtained if a participant is younger than 18 years.
- Obtain participant assent to participate in the study and to contact their parent or legal guardian for consent.
- The participant should document on the assent form whether they agreed or refused for their parents to be contacted and informed. For those who want their parent/guardian to be informed, parental/guardian contact details are documented.
- The participant signs the assent form.
- A witness signs the assent form to confirm that the participant understood the information and agreed/refused their parent/guardian to be contacted.
- The researcher signs the assent form.

Appendix 4: Interview guide

Semi-structured interview guide for lived experiences of young women of the use of HIV pre-exposure prophylaxis in Namibia.

Age:

Demographic information.

Marital status:

Occupation:

Duration on PrEP or previously on PrEP:

Qualitative interview introduction

My name is Vasco Ester nursing master student at the University of Stellenbosch. As you know from the consent form, of which I have explained to you and you have consented to participate in this study. I would like to ask you about your experiences towards using PrEP. The interview will take about 45-60 minutes. The aim of the study is to explore the lived experiences of young women of the use of PrEP in Namibia.

Research question:

- Tell me a bit more about what you understand about PrEP? {Probing questions: What is it used for? Your reasons for starting to use it? How you think it will benefit you? Who provided you with information about PrEP?}
- 2. Tell me more about your lived experiences of using it. {Probes: How do you take it, side effects, follow-up visits at the clinic, does anyone know you are using it, is it easy to use, do you remember to take treatment, stigma, cultural beliefs. What do you like or not like about PrEP? How do

you feel about using PrEP as a pre exposure prophylaxis for HIV do you feel bad, good, secure?}

3. Tell me what makes it easier or difficult to use PrEP? {Probing questions: Does your family/partner know that you are using it? Do they support you? What does the society/community think about the use of PrEP? What do you think can be done to young women in order to better support them to use PrEP? How do you feel about using PrEP as a pre exposure prophylaxis for HIV do you feel bad, good, secure?}

Appendix 5: Confidentiality agreement with data from transcriber

By signing below, I______ on

this_____ day of_____ do hereby agree to the following conditions:

- ✤ I agree to keep all information confidential.
- I will not use any part of the audio or transcript for any purpose other than that of the requested purpose.
- The content of the audio recording will not be distributed/shared to a third party in any form.
- That I will store the audio and transcript in a password protected computer during the transcription period.
- After transcription of the audio i will delete the audio as well as the transcript as soon as the researcher confirms that she is satisfied with the content of the transcript.
- I fully understand the implications that may come due to breach of this agreement.

Transcriber's signature:	Date:
Transcriber's name:	

Appendix 6: Transcribed interview

Participant three (3)

Keys: I-interwier R-respondent

I: Good morning Ma'am.

R: Morning

I: How are you?

R: Fine. How are you?

I: I'm fine. So before we start with our interview let me just start by introducing myself although I have introduced myself to you already. Like I said earlier on, my name is Ester, I'm a nurse, I am also studying nursing on an advanced level. So you have agreed to partake in this study of which you have already signed a consent form, the paper that I gave you to sign.

R: Yes

I: And I have explained to you on regarding your permission to partake in the study and just to remind you that this questioning or this type of interview that we are going to have may take up to about an hour. So I will be glad if you can bear with me. In anyways you have already agreed to take part, however as said earlier that you may also cancel the interview if at some point you feel comfortable so I will also like to inform you that the aim of this study just to explore on the lived experiences of young woman on the use of PrEP, ok! So before we start with our first question, can you just brief me, tell me more about yourself although there is no need for you to mention your name.

R: Mmmmhhh... more about myself?

I: Yah! Something about yourself that you want to tell before we can start perhaps do you go to school or what grade are you? Are you working, do you have any kids and all that?

R: Yah! I'm doing Namcol, Grade 10, no I did last year Namcol Grade 10, but I did well so I plan I want to go to school, I'm having a kid a three months' kid, I don't work, that's all.

I: That's all, thank you for that you said you passed your Grade 10

R: Mmmmmhhh

I: With how many points?

R: With 23

I: 23 okay well done. So our first question is can you just tell me a bit about what you understand about this medication that we are calling PrEP, pre-exposure prophylaxis? Can you just tell me anything on how you understand this medication? R: Aaahhh...just anything about it, PrEP is like, when you are using prep it prevent from getting HIV, not when you are sleeping with a aaahhh...it can prevent you when you maybe when you are having a boyfriend, then your boyfriend is on treatment and

you are using a PrEP, so you will not get, HIV.

I: Hmmmm okay. So you are saying when your boyfriend is HIV positive and is on treatment then you as the partner, you use PrEP, to prevent you from aaahhh... from getting HIV-infection.

R: Mmmmmmm

I: Is that all or there is something you want to add on,

R: That's all

I: Okay so can you just tell me more again this PrEP, medication what is it used for?

R: It's for prevention

I: For

R: For HIV

I: Oh so it's to prevent you from HIV?

R: Mmmmhhh

I: Okay so what is your reason, when you decided to start using PrEP, what was your reason of using PrEP?

R: My reason was I will use prep because I want to prevent myself from getting a disease, If I bring HIV

I: So can you tell me, what made you to use this medication

R: Actually because I don't trust my boyfriend

I: Hmmm

R: Because he is working too far

I: Mmmmmm

R: Yah...

I: So

R: That's why I decide

I: So he is working very far and you are in a distance relationship

R: Mmmmm

I: Okay, okay so now, you personally, how do you think this medication, how does it benefit you? What benefit do you get from using this prep medication?

R: The benefit

I: Mmmmmm

R: The benefit that I get from this medicine, when I was not using the medicine I was not using the medicine, I was not having the appetite to eat, but when I start using it, I have appetite to eat

I: so you are saying after starting using after starting using this medication it has boosted up your appetite or desire to want to eat

R: Mmmm

I: Okay... so ...how did you come to learn about the prep medication? Where did you get the information about prep?

R: I got it from my friend

I: Can you tell me more about how?

R: My friend introduced me about this medicine

I: Hmmm

R: Or the boyfriend took her to the hospital at NAPPA when they went there, they got tested and the boyfriend was positive and the girlfriend was negative, then the nurse introduce them. If you love each other you can just use prep and your boyfriend will be on treatment, when he got home, then he introduce us, me and my friends about prep

I: So it's your friends that informed you about this prep medication?

R: Hmm

I: That it can be used to prevent one from getting HIV infection, should the other partner be HIV positive?

R: Hmm

I: Okay. Is that all or is there anything your friend informed you about or something you have read or whatever situation, where you have learned about this about the information prep, when can it also be used regarding that?

R: I

I: Anything regarding prep?

R: Eeeh, I got it from my friend and on the newspaper

I: Mhhhuuu

R: Mmmm

I: So on the news what information did you get about prep?

R: Just read that in Namibia we have preps its allowed to young woman to have preps

I: okay so you are saying that your understanding about prep is that prep is the medication that is used to prevent one from getting HIV, from their partner who are HIV positive and are on treatment?

R: Hmmm

I: Is it what you said?

R: Hmmm

I: Okay. And you said this prep medication is actually used for prevention of HIV infection or from getting or from being infected with HIV infection?

R: Hmmm

I: Okay. And one of the thing that made you to start using prep is because your partner is HIV+?

R: Hmmmm

I: Is it the reason that made you to start to want to use prep medication?

R: Yah

I: Okay. You also told me that one of the benefits that you get from using prep is that it's because it has given you an appetite. Ever since you started using prep, your appetite has improved

R: Yes

I: And this information you got it from your friends and you read about it in the newspaper?

R: Hmmm

I: Okay before we move on to the next question, is there any anything you want to add in that regard?

R: No

I: Okay. So our next question is: can you tell me more about your experience, for how long have you been using prep?

R: Since 2016

I: You started using prep?

R: 2016. When I get pregnant then I stopped.

I: is it The pregnancy with this baby you came with today?

R: Hmmmm.

I: So you stopped, you started in 2016 and then you stopped when you fell pregnant. When did you fall pregnant?

R: No I...

I: Last year?

R: Mhhhh

I: 2019?

R: Mhhhhh

I: So you started using prep from 2016 up until January 2019, then you fell pregnant and then you, after you delivered then you started again or how?

R: Yes, I started mmm ... last of last month

I: So you started last of last month? So can you just tell me more about what are some of your experience of how has the journey been of you using prep since 2016? Can you just tell me about how it has been going?

R: When I started prep, was having some symptoms, sores, and having diarrhea

I: Is that all?

R: Mmmhhhh.

I: Okay

R: Ahh! and vomiting

I: And vomiting also?

R: Mmmh

I: So you are saying when you started using prep you have been having sores...?

R: Mmmmh

I: Sores?

R: On the face

I: On the face?

R: Mmmm

I: What kind of sores or can you describe the type of sores that you had on the face?

R: It was not the big sores, the small ones

I: Is it like pimples

R: Yah

I: On the face?

R: Mmmmhh

I: Were they a lot?

R: No

I: Were they only on the face or is there any other parts of the body?

R: Only on the face

I: Only on the face?

R: Mmmmh

I: So you are saying you had...

R: Pimples

I: Pimples

R: Diarrhea

I: Diarrhea and vomiting. That is all you had?

R: Mmmhhh

I: Okay. So that is now in terms of whatever the bad things that came out. Anything that you want to add on some of the things which you experienced perhaps your follow up, how often you used to come, the treatment you used to receive... just anything about that?

R: The treatment

I: From the health care workers

R: Sorry, I didn't understand

I: Okay I was asking and still asking your experience or how you experienced the journey form 2016 when you started using this medication, how has it been? How in terms of this medication taking, this medication in terms of the treatment you were receiving from the hospital when you come to the facilities, in terms of the follow ups, anything you want to tell me about using prep.

R: Whenever I used to come for follow up, I used to be tested

I: And?

R: Yah, negative

I: Okay. So every time you come for a follow up they used to test you

R: Mmmmh

I: Before they can give you...

R: The medicine

I: The medicine?

R: Mmmhhh

I: Okay. So how do you take this medication? This prep medication, how do you can you just explain to me how do you take your medication?

R: Ahh, I take it 9 o'clock evening once a day

I: You use to take your medication at 9 o'clock in the evening?

R: Mmhh

I: Just once daily?

R: Mmhh

I: Okay. So you have told me that some of the bad things that you have told me about using prep, or the side effect is you had some rashes when you started,

R: Mmh

I: And vomiting,

R: Mmh

I: And diarrhea also. Is there anything else, some of the bad things you were really experiencing when you were using med, this medication

R: Mhu-mhuu

I: Whether in the beginning or now or anytime?

R: No only in the beginning

I: Its only in the beginning where you experienced the rashes, the pimples, vomiting, diarrhea, but now you are okay?

R: Mhhhh now I am fine

I: Okay. You do not have any of those?

R: Mhhh

I: Okay. So can you tell me a bit about your follow ups? How are your follow ups scheduled, how often do you come, and so forth?

R: I use to come after 3 months

I: You come after every 3 months?

R: Mmhhhh

I: Is it all you want to tell me or there is something you want to add on?

R: That is all

I: That is all? So are you able to remember? Are you always able to remember to take your medication? You said you take your medication at 9 o'clock in the evening once a day, so are you always able to remember that it is now 9 o'clock I need to take my medication?

R: Yes, I put my alarm

I: So your alarm is the one that assist you to remember to take your medication?

R: Mmmhhhh

I: Everyday? Is there anything else that you use to remind you on the time?

R: No. Only the alarm

I: Okay. So I have asked you what is your experience. So you said you have been using prep since 2016?

R: Mmmhhhuuu

I: So, what are the people saying? The people in the community, people from anywhere, your friends, what do they say about you using prep? Do you receive, do you have any stigma like people looking at you in a different way?

R: Yah, when I started, not my friend because my friend they knows, they use prep also. They told, my parents though maybe I am lying. Maybe I am HIV+, just pretending that prep is preventing HIV. Even if you come to the follow up, when you enter in that room, maybe people thought, they will think that, no this person is HIV.

I: Mmhhu?

R: Because that those medication is like the same. Because people will think.

I: Who are drinking?

R: Those medication for HIV.

I: Okay. So you are saying some of the stigma that you receive is people will see you as if you are pretending but you are actually HIV+, and you are on HIV medication? R: Mmhuu

I: Oho! You also said that when you enter in that room, people will just say you are also HIV+ and taking the medication. Which room is that and how is the setting? Can you just tell me more?

R: The room that we used to enter is the same room they used to enter those people who are getting the medication for HIV/AIDS.

I: Mmhhhu?

R: Yes.

I: So it is only the one room which is used for people who are positive,

R: Mmmhhh

I: ... and the negative ones coming for prep?

R: Mmmhhh

I: So there is no this other room or where one can say that, so there is only a certain room that is set for the HIV+ clients? In that room where you are treated, is it only the HIV+ clients who are getting their medication and you who are coming for the prep medication who are using that room or are there other clients or patients that are using that room?

R: We all use the same room

I: You all, you the patients who are coming for prep and the ones who are coming for HIV treatment?

R: Mmhhh

I: Is it just you, the two of you or are there other clients who come for other services like maybe baby injection, also use the same room?

R: Only the two, those people who are getting prep and HIV medication use the same room

I: So does anyone know about your using this medication?

R: My parents and my boyfriend

I: So you only informed your parents and your boyfriend?

R: and my friends

I: And your friends. So what did they say?

R: My friends?

I: Yes

R: Nothing, because they use prep also

I: Oh your friends are also using prep?

R: Mmhhuu

I: Do you have friends who are not using prep?

R: Yes

I: What do they say?

R: Nothing

I: They say nothing about you using prep?

R: Mhuu

I: Okay. And you parents? What did they say about you using prep?

R: For now they understand me, but when I started they thought maybe I am HIV+, I

am just pretending

I: And your partner?

- R: My partner?
- I: What did he say?
- R: Nothing
- I: When you told him that you are using...

R: No complain

I: What did he say, what was his response

R: He said

- I: Mmmhu?
- R: He is also using prep

I: Oh he is also using

R: Where he is working yes

I: Ooh, so he didn't have a problem with you using prep?

- R: Mmmhhh
- I: Okay. So how do you ding prep? Do you think it is easy to use?

R: no

I: It's not easy to use?

R: Mmmmm

I: Why do you think so?

R: Its paining ..

I: It's paining? Where does it pain?

R: For me. Like me it's at my heart when I started using.

I: can you explain that to me?

R: When I, mmhhu like when I, when I was drinking I will feel like my heart is burning.

I: So you used to like heartburn?

R: Mmmhu

- I: After taking the medication
- R: When I started
- I: Is it immediately after you take your medication or a few

R: A few, minutes

I: A few minutes after taking the medication?

R: Mmhu

I: It used to give you heart burn?

R: Mmhhuu

I: Okay so what did you used to do when the pain comes?

R: Nothing

I: Okay. So later on it just stopped?

R: Mmhhuu

I: So now you do not experience the pain?

R: Mmhhuu

I: Oho so you said you take your medication when the alarm rings that it's time for you?

R: Mmhhu

I: Is there any other ways or means in which you use, you remind yourself of taking your medication?

R: I am used when its 9 oclock I will just check my phone when it's 9 oclock I will know because I am used

I: So now can you tell me just a bit on what do you like about using prep? Is there something you like about using this prep and what is it?

R: I like using prep because it prevent me from a disease

I: Mmhu

R: Its what I love

I: That's what you like about it? Anything that you do not like about this prep? Can you think on anything that you think you do not like about it?

R: Drinking, and taking because it's too big

I: Mmmhhuu

R: I don't like it

I: Oh so what you don't like about prep is because the pill is too big?

R: Mmhh

I: And you don't like it when you drink it?

R: mmhh

I: Okay. Okay is that all or is there something again that you don't like about it?

R: That's all

I: That's all? So, how do you feel about using prep?

R: I feel good

I: You feel good or is there any other feeling that when you look at yourself and say I

am using prep, what other feelings do you have? Feeling?

R: Feeling... Aahh sometimes I used to doubt, doubting.

I: Mmhu

R: Like its true this pills can prevent me from getting a disease

I: Mmhu

R: That is the thinking that I used to have sometimes

I: so sometimes you are doubtful, and you wonder if really this prep medication is able to prevent you from HIV?

R: Mmmhh

I: Infection? Okay what have you done about this, what have you done in this regard now this doubt that you have?

R: Nothing, I just used to drink it

I: Mmh. Okay, so you are saying that your experience with prep is that you have used prep since 2016, until somewhere around 2019 January you stopped because you were pregnant,

R: Mmhh

I: ... then you started again after you had delivered,

R: Mmhh

I: You started like two months ago?

R: Mmhh

I: Mmhhuu. And you said you take one pill per day, in the evening?

R: Mmhh

I: And then you take it at 9 oclock?

R: Mmhh

I: Okay, and some of the side effects that you have been experienced in using prep is that sometimes it makes you vomit, and diarrhea also, and sometimes you have pimples on the face

R: Mmmmm

I: and this only happened when you started in 2016?

R: Mmmhhh

I: Okay.So you are also saying your follow ups are usually after three months?

R: Mmhhh

I: So after 3 months is when you will come for follow up?

R: Mmhh

I: And when you come for follow up they will start by taking checking testing you for HIV?

R: Mmhh

- I: And only then are you given your medication?
- R: Mmhh

I: And your status has been negative throughout?

R: Yes

I: Okay. So you said you have only informed your partner, your parents, and your friends that you are using prep, and that your friend are also using prep?

R: Mmhh

I: Okay. You also said the pill is easy to take?

R: Mhu?

I: You said the pill is, the prep medication is easy to take?

R: (laughs)

I: Its not easy to take?

R: Mmmm

I: So it's difficult to take?

R: Yes.

I: Why is it difficult to take?

R: The pill is too big

I: Okay you are also saying that the pill is too big,

R: Mmhh

I: ... therefore it makes it too big, and difficult for you to take the pill?

R: Mmhh

I: You said, the alarm helps you to remind you remember the time that you are supposed to take your medications. Is that correct

R: Mmh

I: And you said with regards to stigma, you have not experienced that much especially from friends, because your friends are also using prep?

R: Mmh

I: So you do not have or usually face negative comments from your friends, but mostly perhaps when you started your mother could not believe that they were really pills to prevent you from getting HIV, she thought maybe you are HIV+.

R: Yes

I: And you also said that when you come to the clinic, to the clinic, because you use the same room with the clients who are coming for HIV treatment, people sometimes think that you are also HIV+, and that you are coming to get your medication. Is it correct?

R: Yes

I: Okay. So you said there are no cultural beliefs, in your culture there any no any believes that are against or for this prep medication? There are no cultural beliefs?

R: Mmhhh

I: With regards to prep whether to treat bad or to look down on you for using prep? R: Mmh

I: Okay. You said the one thing you like about using prep is because they are able to prevent you

R: Mmhh

I: To prevent you from getting HIV, but you have been somehow doubtful and have been wondering whether really this prep medication is able to protect you from HIV? Is that correct?

R: Yes

I: Okay so we is there something you want to say before we move on?

R: No

I: Is there anything perhaps you want to add on or to rectify about what I have just ah said?

R: No. Its fine

I: If it's okay we will continue. So remember something, if you remember something you can just say it, you can stop me and then you can say something that you remember.

R: Okay

I: Alright. Can I continue?

R: Mmhhhu

I: Okay. So again I will ask you, what makes it easier or what makes it difficult for you

to use prep?

R: What makes it difficult?

I: What makes it difficult or what makes it easy to use prep? Or maybe I should start asking you by do you think it is easy to use prep?

R: Yah, to me it's easy

I: what makes it is easy to use prep. Can you just tell me what makes it easy to use prep?

R: Because it's free, it's for free

I: Mmmhh

R: And it is allowed for young women like us to use it

I: Anything else?

R: That is all

I: So you are saying because prep is ah allowed to be used by young women, and also because it is offered for free of charge, you are saying it is easy to use?

R: Mmhhh

I: Is there something by the way that makes it difficult to use prep?

R: Yah

I: What is it?

R: Especially the first time. You don't know whether you are positive or you are negative. And when you think about it, Prep because when you go there they will test you first

I: So you are saying

R: It's difficult whether you are positive or negative.

I: Mmhu so you are saying that at the beginning it's difficult to use prep because for you to be allowed to use prep you have to be first tested to see whether you are negative or positive?

R: Mmmhhuu

I: Anything else again?

R: Nothing

I: Nothing? You don't want to add anything?

- R: Mhu-Mhu
- I: Okay. So you said you have informed your family, like your mother
- R: Mmmhu mmhuu
- I: Your father also?
- R: Mmh, my father doesn't stay here
- I: So you only informed your mother?
- R: My mother and my sisters
- I: Your mother, your sisters, your brothers, and your partner and friends?
- R: Mmmmh
- I: They know that you are using prep?
- R: Mmmmh
- I: So what is their response when they heard that you were using prep?
- R: Because I explained that it can prevent from getting HIV

I: Mmhh?

- R: Yes, then that's why they do not have a problem
- I: Oho! So do they support you?
- R: Yes
- I: How do they support you?
- R: Like my mother, she used to ask if I use to take it
- I: So she is always asking you if you have taken your medication.
- R: Mmhh
- I: That is trying to always remind you
- R: Mmhhuu
- I: Okay. How, which other ways do they support you also?
- R: That's all
- I: Okay.
- R: He just used to ask me
- I: Okay. And your partner?
- R: No, my partner...
- I: Does he support you?
- R: Yes. He doesn't have a problem because he used to take also
- I: so does he support you?
- R: Mmh

I: How does he support you?

R: He used to ask whether I went for my follow up

I: Mhu?

R: Mmhh

I: Okay. So and your siblings, your brothers and sisters do they also support you?

R: No they don't mind

I: They don't mind?

R: Mmmhu

I: So they do not support you?

R: Mhu

I: But do you think you need support from them?

R: Yah

I: What kind of support do you need from them? What kind of support would you think of? That you think your sisters and brothers should support you on?

R: To encourage me to take it. To take prep

I: Mmhu?

R: Mmhh

I: Okay. Anything else?

R: No

I: So you are saying it is easy to use because it is free, this medication is free to be taken, and it can also be offered to young women,

R: Mmhh

I: ... but the difficult part of it is eh is it's difficult to take because

R: The pill is too big to swallow

I: The pill is too big to swallow and also at the beginning you have to be tested before you can be given the medication?

R: Mmhu

I: Oho, And you have informed your family, your partner about this, and your mother and your partner are supportive, however your sisters are not supportive?

R: Mmh

I: They do not mind whether you take or don't take?

R: Mmh

I: And however you feel or you think you need support from them in terms of reminding you to take your medication?

R: Mmmh

I: To encourage you to take your medication? So now your community, in your community, do people know about prep?

R: Mmmmm

I: Like your neighbourss, your surrounding friends? Do people apart from the ones you stay with at home?

R: No really

- I: They do not know about prep?
- R: They do not know

I: So those who know perhaps your sisters, brothers, your mother and father ah and your partner?

R: Mmmh

I: those people I have mentioned, what the you, what do they think about prep?

R: Like one of my sister...

I: Mmmhh

R: She used to say that she wants also to start

I and R: To start using

- R: Prep
- I: So is that the only thing that your sister said?

R: Mmmhh

I: Other people what did they say?

R: Nothing

- I: They did not say anything?
- R: They don't know
- I: Okay. They do not know about prep?
- R: Mmmh

I: So in your own view perhaps, what do you think should be done to support young women like yourself in order to better support them when they are using prep? What do you think should be done? To support young wo... people those who are using prep?

R: To do what? Sorry.

I: the question is what do you think should be done to support young women like yourself who are using prep? How do you think they should be supported?

R: To be encourage them to use prep to prevent themselves from getting HIV

I: Mmh. Is it all?

R: Mmm

I: So you think young women like yourself should be supported to encourage them to use prep medication?

R: Mmmhh

I: So who do you think should do this? Which people should encourage the young women to take prep?

R: Especially the nurses and the person who knows about prep

I: So you think the nurses as well as people in the community who knows about prep should encourage their young women...

R: Mmmhh

I: ... to use prep in order to prevent themselves from HIV?

R: Mmmh

I: Okay. So yourself now being one of the young girls who are using prep, how does it make you feel?

R: I feel good

I: It makes you feel good...

R: But sometimes ashamed, as if I am positive

I: Sometimes you are ashamed?

R: Yah

I: Why are you ashamed?

R: Because every day taking that pill

I: Mmhu?

R: Mmmhh

I: So you are ashamed sometimes that people would think you are HIV+, because you are drinking the medication every day?

R: Mmhhh

I: Anything else on how it makes you feel?

R: Mmh nothing

I: Nothing

R: That is all

I: So it makes you feel good,

R&I: Sometimes it makes

R: It makes me feel good

I: Oohh. So why does it make you sometimes feel good?

R: Because I am preventing myself

I: Is that all?

R: Mmhh

I: Or anything you want to add on?

R: Ah ah, that is all

I: So you are saying, that prep medication is easy to use because it's just one pill per day, and sometimes it is also difficult to use especially at the beginning if you want to use this prep medication you first have to go through eh HIV testing...

R: Mmmmmhhh

I: ...before this medication can be supplied to you? And the people you have informed in the family is your mother, your partner, and your siblings, and these people have been supportive apart from siblings who have not been very well supportive, ...

R: Mmmhhu

I: ... however, you wish they could give you support and courage, in terms of encouragement to make, to take your medication. Okay, you said one of the things you would, or you think should be done in order to support young women is you think the nurses and the other people who are knowledgeable about prep should try to encourage people or young women actually to be specific, to encourage them to, to take prep?

R: Mmhh

I: And you said knowing or the feeling of you as a young woman using prep it gives you a good feeling sometimes, because you feel you are protecting yourself, however, sometimes it makes you feel ashamed about yourself because you are taking this medication everyday as if you are HIV+?

R: Mmmh

I: Is that correct?

R: Yes

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I: Okay. So I am just going through to see whether I have captured about what you said.

R: Mmhhh

I: So you said your understanding about prep is that prep is the medication that is used to prevent one from getting HIV infection if your partner is HIV+?

R: Mmmhhh

I: Is it so?

R: If he doesn't ... if your partner maybe is on treatment then it can prevent you from getting HIV, but when he is not ah ah,but he is positive and Even you will end up getting HIV.

I: So you are saying, that your understanding about prep is you use prep to prevent yourself from getting HIV if your partner is HIV...

R: Positive

I: ... positive, and he is on medication...

R: Mmmhh

I: ...but if your partner is not on medication, this medication will not be effective? It may not work well?

R: Mmhh

I: Okay. So, okay. So you said this medication is used to prevent one from getting HIV?

R: Mmh

I: Okay. So your reason for starting it is because? Can you just repeat that for me? What did you say your reason?

R: My reason?

I: Mmhu

R: I don't trust my boyfriend

I: Because we are

R& I: in a distance relationship

I: So you are saying your reason for starting this medication is because you do not trust your partner?

R: Mmhhh

I: And you are in a distance relationship with your partner?

R: Mmmhh

I: That is why you decided to start using prep. And ah you think this prep has been benefitted you so well because it has eh improved your appetite? Okay. And you came to know about prep through friends, a friend of yours who, went for testing with the boyfriend,

R: At school, I forgot

- I: And at school also?
- R: Yes, its because I did that course of nursing
- I: Mmhu
- R: That is where, I learned it
- I: The course of nursing?
- R: Mmh?
- I: Which course is that?
- R: Assistant
- I: Oh you did nursing assistant?

R: Mmmhhh

I: MMmhu. That is where you learned about prep?

- R: Mmmhh
- I: So you are an assistant nurse?
- R: Yah I did it last year
- I: Did you complete it?
- R: Yah, I did my practical at private, Rundu private hospital

I: Rundu Private

R: Mmh

I: Okay, alright. So that is where you got this information about prep and from your friends, from school, did you also say from reading?

R: Mmhh in the news...

I: In the newspaper okay. So you said your experience about using prep is has been good and the medication has not been giving you so many, it has given you so many side effect such as vomiting, diarrhea, and pimples that you experienced on the face, but after a while they disappeared?

R: Mmmh

- I: You you do not experience them now?
- R: Mmhu

I: Okay. And that you are always coming after every month for the follow up and during this follow ups when you come the nurse start by first testing you...

R: Mmhh

I: ...for HIV before you are resupplied with your medication?

R: Mmhh

I: And you said you have only informed your partner, your mother, your brothers and sisters that you using prep, and the alarm is the one that assists you in remembering what time to take the medication?

R: Mmmhh

I: Okay. So stigma, with regards to stigma and you said at first your mother could not believe

R: mmmhh

I: that this medication, is.., this medication is for prevention

R: Mmhhu

I: Is that what you said?

R: Yes

I: And you said... another stigma that you experience is that you are seen in the same room with the clients who are coming for their HIV treatment.

R: Yes

I: So in the end other people will look at you and think you are also coming for HIV treatment because you are maybe HIV+

R: Mmhhh

I: you said you do not experience regarding to cultural believes, where by perhaps your culture is against someone using prep?

R: YAh

I: So the, your culture does not prohibit?

R: Yes

I: Someone from using prep? They are fine with people using prep?

R: Mmmmhh

I: Okay so you said one thing you like about prep is because it prevents you from getting HIV...

R: Mmmhhh

I: And what you do not like about prep is because the pill is too big for you to swallow

R: mmhh

I: Okay. and you said using prep actually gives you a good feeling, you feel good about yourself and because you are protecting yourself?

R: Yes

I: Okay. So thank you for taking part in this study, and this marks the end of our interview.

Appendix 7: Declaration by language editor

Language editing

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23 February 2021 To whom it may concern

LANGUAGE EDITING: ESTER K VASCO

This letter serves to confirm that a postgraduate research thesis for the above-named student was language edited by me, Sithangezie Gwatkunda. The title of the thesis is THE EXPERIENCES OF YOUNG WOMEN ON THE USE OF PRE-EXPOSURE PROPHYLAXIS IN NAMIBIA.

Attention was given to spelling and consistency; punctuation; grammar use and style; and Harvard referencing. The track changes and the suggested comments, if correctly considered, will assist the student in the submission of a linguistically sound research report.

Yours faithfully

Care.

Mrs S. Gwalkunda

Sikhangezile Gwatikunda Copy editor and Proof reader (UCT) MPH (UNISA) MA. Nurs. (UNISA) Post grad. Public Health (UNISA) Post grad. Midwifery Science (UNAM) Bsc. Hons. Nurs. Sci. (UZ) Lecturer (WHTC)

Appendix 8: Declaration by technical formatter



To whom it may concern

This letter serves as confirmation that I, Lize Vorster, performed the technical formatting of Ester K Vasco's thesis entitled:

The experiences of young women on the use of HIV pre-exposure prophylaxis in Namibia

Technical formatting entails complying with the Stellenbosch University's technical requirements for theses and dissertations, as presented in the Calendar Part 1 -General or where relevant, the requirements of the department.

Yours sincerely



Lize Vorster Language Practitioner

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