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**ANTI-RETROVIRAL THERAPY:** The perceptions of Female sex workers using Pre-Exposure Prophylaxis (PrEP) on their use of PrEP at Chris Hani Baragwanath Academic Hospital, Soweto.

A research proposal presented to

The Department of Social Work

School of Human and Community Development

Faculty of Humanities

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In partial fulfilment of the requirements

For the Degree Bachelor of Social Work

By

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Date: 30 January 2018

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# ABSTRACT

Background: In South Africa PrEP was primarily intended for sex workers, who have the highest HIV prevalence in South Africa and experience high levels of stigma and discrimination in societies. The services that have been put into place in partnership with the targeted group which is the sex workers are user-friendly. Yet the conclusion to use PrEP remains an individual choice and no one is coerced into using it.Purpose: The aim of this study is to explore the perceptions of women sex workers using Pre-Exposure Prophylaxis regarding their experiences on using PrEP as one of the antiretroviral drugs recently brought in South Africa as prevention from HIV, (the study will be conducted specifically at the Perinatal HIV Research Unit; situated in Chris Hani Baragwanath Academic Hospital, Soweto). The Secondary objectives of this study are; to explore the experiences of women sex workers on the use of PrEP, to explore the experiences and perceptions of women sex workers who use PrEP on unprotected sex and to explore what influences women sex workers to take PrEP regardless of the number of side effects versus its health benefits. Method: The study is qualitative as it will be exploring people’s lived experiences, their opinions and their subjective truths, and it will make use of case study individual interviews (semi-structured interviews) to collect data. The sample to be used includes 2 women sex workers who are PrEP users in the Baragwanath Hospital and have used PrEP for more than four months. A Narrative analysis will be used when analysing the data that will be gathered from the research study. Findings: The findings are presented in a form of themes that emerged as a result of the data collected through the interview schedules. The findings are also related to other studies with a similar interest to the study topic. Overall the findings suggested just PrEP is a harmful and an effective drug for preventing HIV.

**KEY WORDS:**

Pre-Exposure Prophylaxis

HIV prevention

Unsafe sex

Women at risk of HIV

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# CHAPTER ONE

## INTRODUCTION

Even though a cure has not yet been found; a preventative measure other than abstinence or the use of condoms has been put into place; Pre-Exposure Prophylaxis (PrEP) has been introduced as one of the antiretroviral therapies to prevent people from acquiring HIV. PrEP is an antiretroviral therapy drug that is induced by people who are not infected but considered to be at risk of acquiring HIV, this includes serodiscodent couples, sex workers, Men who have Sex with Men and people who are exposed to rape (Makwe & Giwa-Osagie1, 2013).

This study focused on exploring the perception of female sex workers who are PrEP users on PrEP intake. Informed consent from the participants, confidentiality, incentives, voluntary participation and doing no harm, all this was critically looked at when conducting the research. The potential limitation was the researcher bias, however the researcher was aware of that limitation and made sure that the questions that were asked were rational, fair and reasonable and also the final report based on the findings. The study made use of semi-structured individual interviews and narrative analysis to analyse the data.

## 1.1 PROBLEM STATEMENT AND RATIONALE

### Problem Statement

HIV and AIDS is associated with increased mortality rates, harm to physical and mental (stress that comes with having to take care of one’s self) health, social conflicts, unemployment, legal and economic problems (Hersen & Thomas, 2004). New prevention interventions have been put into place to try and prevent HIV acquisition. Pre-Exposure Prophylaxis is one of the most current prevention intervention strategies, which is given to people who are considered to be at risk of acquiring HIV. Since the inception of this drug, it has therefore become imperative to extend its use, to as many people as is possible to prevent new infections of HIV. There is urgent need to redesign the information used to educate and raise awareness on HIV treatment, to beam a new light of hope, particularly from the Social Work profession. Being the custodians of people’s hope, PrEP offers an extended significant chance to remain HIV-free. There is however limited lived experiences about using PrEP or any other ART in written text coming from Southern Africa, hence the need for this study.

### Rationale

1. Scientific relevance

HIV and AIDS have been observed for a long time in history and continue to be acknowledged as an urgent public health concern in many countries (Caldwell et al, 2000). PrEP was found to be harmless and suitable for both men and women (Bekker et al, 2016). According to van der Straten et al (2014) the Wits Reproductive health Institution (WHRI) conducted a trial study in 2013 and a concurrent qualitative study which was aimed at exploring the socio-cultural and contextual factors that influenced the participant’s (specifically women) experiences of PrEP daily vaginal gel and oral tablets taken by women. This study was conducted particularly in the Hilbrow Clinic. The participants of the study were women from Johannesburg and their mean age was 27 years. The participants were randomly selected from VOICE (Vaginal and Oral Interventions to Control the Epidemic) and were assigned to in-depth interviews, serial ethnographic interviews and or focused groups. The results showed that of the 102 participants, 92 % of the sample had a primary sex partner and 43% cohabitated. Women reported occasionally skipping and mistiming doses because they forgot, were busy or felt lazy and bored, fear or experienced side effects (van der Straten et al, 2014).

A challenge was the personal acknowledgment of non-use by the participants. This uncovered the perceptions women had on their participation and the experiences they had with investigational products. Whether this impaired women’s behaviours or may have contributed to ineffective trial results; further investigation is required (van der Straten et al, 2014). So the gap that this study is going to fill will be looking on the perceptions of female sex workers on PrEP usage as similar research has explored Women’s experiences with oral and vaginal Pre-Exposure Prophylaxis and the perception of the participant’s on the trial. This means that this study will be supplementing the research that has been done by the WHRI but in terms of focusing on the perceptions of female sex workers on PrEP intake.

1. Social relevance

PrEP is an important necessity as it will help people who are at risk to prevent acquiring HIV and bring the acquisition of HIV to an end. This includes; people with HIV positive sexual partners, partners of unknown HIV statuses, have a recent record of Sexually Transmitted Diseases, have multiple sexual partners, have a history of varying or no condom use, serodiscordant couples trying to conceive and people who have a recurrent history of sex whilst under the influence of alcohol or recreational drugs (Singhal & Rogers, 2003).

It is the value to be brought by this study to provide knowledgeand inform women who use PrEP to have alternative ways in which they can protect themselves from other sexually transmitted diseases without relying on Prep only.

1. Clinical relevance

This research is very important for Social Workers as it will help them inform people about PrEP as part of comprehensive ART in the public health sector. It will thus help Social Workers educate people about PrEP as it is mandatory for Social Workers to assume the role of an educator in groups and communities. This will also help Social Workers to enlighten communities about their resources and to offer recommendations for education and counselling targeting prospective PrEP users.

## 1.2 AIMS AND OBJECTIVES OF THE STUDY

Primary aim

The aim of this study was to explore the Perceptions of women sex workers using Pre-Exposure Prophylaxis on their experiences on using PrEP at Chris Hani Baragwanath Academic Hospital.

Secondary objectives

1.  To explore the experiences of female sex workers on the use of PrEP.

2. To explore the risks and benefits of using PrEP.

3.  To explore behavioural influences on the decision to use PrEP among female sex workers.

## 1.3 SUMMERY OF THE CHAPTER AND A SYNOPSIS OF THE OVERALL REPORT DESIGN.

This chapter has focused on the introductory part of the report where the overview of the study, the aims and objectives of the study, the problem statement and the rationale of the study has been presented. The proceeding chapters will be presented as follows; Chapter two constitute of the literature significant to the focus of the study. Chapter three will be composed by the research Design/ approach and other research processes that were followed when conducting this study. Chapter four is a presentation and discussion of the research outcomes. The last Chapter is Chapter five, which presents the conclusions and recommendations reached from the outcome of the study.

# CHAPTER TWO

## 2.1 LITERATURE REVIEW

### Introduction

This literature review is aimed at providing a detailed overview of the existing body of knowledge on the reality of the implementation of PrEP in South Africa, with specific reference to the perceptions of people on PrEP intake. The literature review will be investigating the new ways that have been put in to place as measures of treating, preventing, and eradicating HIV and AIDS. This study will however focus on exploring the perception of women sex workers who are PrEP users on PrEP intake at Chris Hani Baragwanath Hospital. The concluding part of this literature review will outline the theoretical framework relevant to this research study.

### HIV IN THE SA CONTEXT

HIV and AIDS have been observed historically since 1981 and continue to be acknowledged as an urgent public health concern in many countries (Caldwell et al, 2000). Moreover HIV is a global epidemic and the mode of spread is predominantly through sexual intercourse, mother to child transmission and transmission from unsafe medical practices (Caldwell et al, 2000).

Stigma and people’s beliefs in South Africa historically were very influential in people’s health decisions; this is because AIDS related stigma is socially and culturally pervasive. Byrn (1997) suggests that an awareness of stigma creates a sense of shame and difference within individuals and a sense that they may “stick out”. Stigmatisation may also adversely affect the health of those who use illicit drugs though exposure of chronic stress such as discrimination as a barrier to accessing care.

According to Kalicham and Simbayi (2003), before people were more informed about HIV, they would refuse to share food, sleep in the same room and would not talk to a person who is identified as infected with HIH/AIDS. This was because people had prejudice in the belief that suggested that people with HIV/AIDS were cursed (possessed with demons, dirty and untrustworthy) (Kalichman & Simbayi, 2003). As a result, people who had HIV feared disclosing their status because they knew they would have been alienated from their societies and treated like less of human beings and undeserving of respect, acceptance love and support. Further this made people to have negative attitudes on testing for HIV as they were scared of the results and the reactions people would have on their outcomes (Kalichman & Simbayi, 2003).

However because of more education about HIV/AIDS, in terms of the cause(s), prevention and treatment and life after the exposure, people have become more aware and informed of HIV, therefore stigma beliefs have decreased from there. People are now able to have children even if they are serodiscordant couples, people are being supported and motivated to live healthier lives. Most importantly those who are uninfected also are able to participate in health promoting activities such as the use of condoms and more (Kalichman & Simbayi, 2003).

### PREVALENCE OF HIV/AIDS IN SOUTH AFRICA

According to Levitt, Steyn, Dave, and Bradshaw (2011), compared to the non-communicable diseases; there are promising signs that the HIV/AIDS epidemic is decreasing, both in the African region and in South Africa. For example, the number of people newly infected with HIV in sub-Saharan Africa declined from 2.2 million in 2001 to 1.8 million in 2009. In South Africa, the annual HIV incidence among people who are 18 years old declined from 1.8% in 2005 to 0.8% in 2008, and halved among women aged 15 to 24 years old from 5.5% in 2003 to 2005 to 2.2% in 2005–2008 (Levitt, Steyn, Dave, & Bradshaw 2011).

Evidence from the South African statistics shows that between 2002 and 2008 HIV prevalence was restlessly stable; ranging from 10, 6% and 11.4% (Rehle et al, 2016). There has been a decline in the rate of HIV transmission of mother to child at six weeks, signifying the efficiency of policy change and improved implementation of the prevention of the mother to child transmission (PMTCT) programme (Pillay, Dinh, Goga & Jackson, 2012). According to Makwe and Giwa-Osagiel (2013) Serodiscordant couples (where one partner is infected with HIV and the other is not) show a high prevalence of HIV amongst heterosexual couples in Africa.

According to (Stats SA, 2011, p. 1), “the estimated overall HIV prevalence rate is approximately 12, 7% of the total South African population. The total number of people living with HIV is estimated at approximately 7, 03 million in 2016. For adults aged 15–49 years, an estimated 18, 9% of the population is HIV positive.”

### MORTALITY & MORBIDITY

Because access to ART has increased substantially over the past 4 to 5 years, mortality rates have decreased and life expectancy has risen. In South Africa, average life expectancy is now 61 for men and 69 for women, with an average of 65. It would thus be important to revisit the earlier analyses, but one would now need to factor in the possible effects that ART per se would have on the incidence of diabetes (Levitt et al, 2011).

Patients who are infected with the Multidrug resistant TB have lower cure rates and high mortality than do patience with drug susceptible TB. TB is the leading cause of death amongst HIV infected persons and may accelerate the cause of HIV infection, increasing HIV load in some patience. On the other hand HIV infection may also contribute to the increase of MDR-TB, especially in industrialised sites (Wells, 2007).

Sexually Transmitted diseases like Syphilis is also one of the conditions that are known to increase HIV as it increases the viral load of HIV and further decreases the cd4 cell count in people who are infected by HIV And further other sexually transmitted diseases also have the same effect on HIV, however’ some of the treatments of these sexually transmitted diseases may also decrease the viral load of HIV for those who are infected with HIV (Buchacz, 2004).

According to Bor, Herbst, Newell and Bärnighausen (2013); due to the expanded access to Antiretroviral Therapy and a declining incidence of HIV infection, there has been a decrease in the number of adults and children dying from HIV related causes. The estimated 1.1 million [940 000–1.3 million] people dying from HIV globally in 2015 were 45% fewer than in 2005 and 26% fewer than in 2010 in spite of a period of substantial population growth in many high burden countries (Bor, Herbst, Newell, M, & Bärnighausen, 2013).

According to Statistics South Africa  from 2012 (as sighted in Bor, Herbst, Newell, M, & Bärnighausen, 2013) there was a major difference in the mortality rate compared to the time from 2008 to 2011, the number of deaths in South Africa began and continued to subside. This was not only a decline in mortality but deaths were now normalised, the highest death proportion was amongst the older age group, and also many deaths were related to non-communicable diseases for example diabetes and heart disease (Bor, Herbst, Newell, M, & Bärnighausen, 2013).

### TREATMENT

Even though a cure has not yet been found; a preventative major other than abstinence or the use of condoms has been put into place. Pre-exposure prophylaxis is one of the anti-retroviral therapy drugs that are given to people to prevent infection. This is done as one of the methods designed to prevent people that are not infected but are considered to be at risk of being infected by HIV for example sex workers (Makwe & Giwa-Osagie1, 2013). This drug is legal and it contains two medicines that are also used as an HIV treatment (Anti-retroviral). This drug is similar to contraceptives as people who take it are required to take the pill everyday of their lives and at the same time, for the drug to work effectively (Makwe & Giwa-Osagie1, 2013).

According to Bekker et al (2016), because South Africa is one of the countries that are adversely affected by the HIV epidemic; after the Southern African HIV Clinicians Society distributed its first set of oral PrEP safety majors and guidelines in June 2012, which was for men who have sex with men and who are considered to be at risk of  being infected with HIV; it was clear that revised and expanded guidelines for oral PrEP were a need in a number of populations; comprising of heterosexual men and women, serodiscordant couples, transgender people, sex workers and men who have sex with men (MSM) (Bekker et al, 2016). This speaks to the World Health Organisation Consolidated Treatment Guidelines that were issued in September 2015. These guidelines highlight that PrEP is a harmless, biomedical decision for HIV prevention that can be combined with other prevention strategies that are already implemented in South Africa (Bekker et al, 2016).

### Aims of these new treatments

According to Bekker et al (2016) the South African PrEP model is aimed at incorporating the rights and needs of people especially those who are vulnerable to the acquisition of HIV and AIDS. In South Africa PrEP was primarily intended for sex workers, who have the highest HIV prevalence in South Africa and experience high levels of stigma and discrimination in societies (Syvertsen et al, 2014). The services that have been put into place in partnership with the targeted group, sex workers, are user-friendly. Yet the conclusion to use PrEP remains an individual choice and no one is coerced into using it (Bekker et al, 2016).

Syvertsen et al (2014) highlighted that the Centre for Disease Control and prevention (United States) is partnering with other organisations working towards safe and effective PrEP usage. Further it is working towards addressing important issues around, access, adherence, behavioural risks, and patient outcomes in community settings. This stems from the findings of the research released that discovered approximately 72 percent of sex workers that were interviewed were living with HIV. “The good news is that sex workers are showing a lot of responsibility and about three-fourths of sex workers are using condoms with their clients,” said South African National AIDS Council (SANAC) CEO Dr Fareed (Syvertsen et al, 2014, p. 74).

In as much as PrEP may present as a much needed prevention method against HIV and AIDS; it won’t be suitable for everyone and it is not aimed at being utilised solely but in conjunction with other methods to reduce the potential risks that may contribute to one’s acquisition of HIV. This speaks to the methods that are already put into place as preventative majors against HIV (Eakle, Venter, & Rees, 2013), for example; condom use. According to Eakle, Venter, & Rees (2013) PrEP may contribute heavily in helping to reduce the possibilities of continued new HIV infections.

Worldwide; Women are unable to negotiate successfully with their male partners to use condoms or to be faithful towards them, so this is one of the main reasons that make PrEP much of a need as situations as these contribute to the rise of the HIV pandemic (Farmer, 2001).

### Safety and side effects

ART’s’ causes a change in the distribution of fat deposition. Data are beginning to emerge from various African countries that show a high prevalence of dysglycemia and increased visceral adiposity and dysglycemia in HIV-infected patients on combination, this then leads to an increase in obesity to people who use ART treatment for HIV because of the lack of control of fat in their bodies (Van der Walt, Lancaster & Shean, 2016).

Although providers worry about the long term risks of reducing kidney function or completing bone mineral when PrEP is used for over two years, however we should also realise that PrEP also has short term side effects such as fatigue, diarrhoea dizziness, vomiting, feeling nauseas, headache abdominal cramps and more (Mutua, Sanders, Mugo, Anzala, Haberer, et al. 2012). This shows that there is more to PrEP than the side effects that people are experiencing as their main focus is on making sure that they are protected from acquiring HIV.

### Efficacy

Ten randomised controlled trials of PrEP stating HIV outcomes were considered by the Food and Drug Administration (FDA) in 2015, these trials were considered to accept PrEP in the Sub-Saharan Africa. The results indicated that PrEP was effective for both men and women. 17000 people were involved in the study and have demonstrated an overall reduction in HIV acquisition risk of 5% in women. However in the study the lowest adherence of PrEP intake, involving heterosexual women in the eastern and Southern Africa had no influence on the findings of the study (Bekker et al, 2016).

Recently, proof-of-concept clinical trials of vaginally applied and daily oral Tenofovir-based PrEP have proved to be efficacious in preventing HIV-1 infection in different populations at risk, with no major safety concerns or increase in sexual risk-taking behaviours. However, other PrEP trials failed to show efficacy, presumably because of poor adherence or other biological factors presently unknown (Peinado et al, 2013).

According to Mutua, Sanders, Mugo, Anzala, Haberer, et al. (2012), up to 15% of all new infections are probable to be directly attributable to men who have sex with men (MSM). Recently, the use of oral antiretroviral Pre-Exposure Prophylaxis (PrEP) was shown to be effective in preventing HIV in MSM: the iPrEX study of approximately 2500 MSM and transgender women demonstrated a 44% reduction in the incidence of HIV following daily use of the fixed dose combination pill, this shows how effective PrEP is regardless of the side effects that comes with it.

### Cost/accessibility

Davis and Squire (2010) highlighted that there is strong demand for Pre-Exposure Prophylaxis (PrEP) from many people at high risk of HIV infection, but in many areas it is not yet available. Where PrEP is not available through well-structured programmes, people may seek to obtain it through back door (unofficial) channels. Self-prescribing PrEP in this way would result in inadequate follow-up with no linkage to health service support and an increased risk of using substandard products, drug resistance and reduced impact. So it is important that people start getting educated and exposed to the new PrEP, and how it works to avoid such consequences (Davis & Squire, 2010).

## 2.2 THEORETICAL FRAMEWORK

The theoretical framework that was used for this study is the Biopsychosocial model of health.

The Biopsychosocial model is a broad view that attributes diseases outcome to the intricate. It includes variable interactions of biological factors (genetic, biochemical etc.), psychological factors (mood, personality, behaviour etc.) and social factors (cultural, familial, socio-economical, and medical) (Borrell-Carrió, Suchman, & Epstein, 2004).

This model counters the biomedical model, which attributed diseases roughly only based on biological factors such as viruses, genes or somatic abnormalities. The biopsychosocial model applies to disciplines ranging from medicine to psychology to sociology. Its novelty, acceptance and prevalence vary across disciplines and across cultures. This model was establishes in 1977 as Engle called for a need to a new medical model (Engel, 1989).

Thus others see the Biopsychosocial model as causational; this is because its biological component seeks to understand how the cause of the illness stems from the functioning of the individual’s body. Its psychological component looks for potential psychological causes for a health problem such as lack of self-control, emotional turmoil and negative thinking. Its social part investigates how different social factors such as socio economic status, culture, religion, and technology can influence health (Borrell-Carrió, Suchman, & Epstein, 2004).

According to Borrell-Carrió, Suchman, & Epstein (2004), this model is based on the argument that the treatment of a disease requires a healthcare team to address biological, psychological and social influences upon an individual’s functioning. This means that the working of the body can affect the mind as equally as the functioning of the mind can affect the body (the body and the mind cannot be looked at as separate entities). This model presumes that it is important to use the three factors as the drawing body of the empirical literature, it also suggests that the perceptions of health and diseases as well as barriers in an individual’s social or cultural environment appear to influence the likelihood that an individual will engage in health promoting or treatment behaviours, such as medication taking, proper diet or nutrition and engaging in physical activity (Borrell-Carrió, Suchman, & Epstein, 2004).

This model is thereof appropriate as it helped the researcher to understand individual issues, families, societies and other systems that are inherently involved as social influences that must be considered when trying to assist and understand an individual. For example HIV and AIDS is associated with increased mortality rates, harm to physical and mental (stress that comes with having to take care of one’s self) health, social conflicts, unemployment, legal and economic problems (Hersen & Thomas, 2004).

This approach helped the researcher to be able to explore the participant’s environments so as to understand their decisions to take PrEP better. For example a participant might be taking PrEP because their partner is infected with HIV, meaning that the partner is socially influencing the participant to find ways to protect themselves from acquiring HIV (also it is upon the psychological influences such as self-care and self-control to make such decisions). This theory also helps us understand where people are coming from in light of their real world experiences, and to have insights on how different experiences can help people achieve solutions in different ways for one challenge experienced by different people.

## 2.3 SUMARY OF THE CHAPTER

This chapter has looked at detailed overview of the existing body of knowledge on the reality of the implementation of PrEP in South Africa, with specific reference to the perceptions of people on PrEP intake and the theoretical framework for the study. Chapter three which follows focuses on giving a detailed account of the research design and methodology that was used in the study.

# CHAPTER THREE

## INTRODUCTION

This chapter is aimed at highlighting the research design and methodology that was used for this research study, further; the research instrument that was used, population sample, data collection, ethical considerations, scientific rigour and the limitations to the study will be presented.

## 3.1 RESEARCH APPROACH AND DESIGN

The research study was a case study and it was qualitative as it was exploring the perceptions of women sex workers in relation to their context and personal and subjective truths; in terms of their perceptions on their use of PrEP. A qualitative study is used to gain an understanding of underlying reasons, opinions, and motivations (Creswell, 2003). This research study specifically focused on the experiences and perceptions of female sex workers who are taking PrEP in Soweto, particularly going to Chris Hani Baragwanath Hospital. Gupta and Awasthy (2015) explains qualitative research as providing details about the lived occurrences of individuals that are regularly conflicting behaviours, beliefs, opinions and emotions and  in different kinds of relationships. The strong point of qualitative research is its capacity to offer multifaceted theoretical descriptions of how people experience an event in different contexts. Qualitative research design was therefore found to be valuable and appropriate for this research study due to the fact that it supports the aim of the research study which is to explore the perceptions and experiences of women sex workers who are using PrERP on PrEP given their context (Gupta & Awasthy, 2015). This also contributed to the achievement of substantial data from the participants and it is hoped that it has further contributed to the already existing researches with similar focus.

## 3.2 POPULATION SAMPLE

The population that was used in this study is women sex workers who go for PrEP therapy at the Chris Hani Baragwanath Academic Hospital. The inclusion criteria was women sex workers from the age of 18 years and above; there were two participants that were included in the study. The participants are both black and their age is 24 and 30 years.

The type of sampling that this study used is purposeful sampling, according to Creswell (2007); purposeful sampling refers to a sample of participants that were thoughtfully and purposefully recruited in order to fully answer the research question. The researcher used this type of sampling because it is the best suited method of selecting participants that meet the inclusion criteria.

## 3.3 RESEARCH INSTRUMENTATION

Interviews were used for this research. The interviews that were conducted were semi-structured interviews as there were planned specific questions and questions that immerged as follow up questions through the interview process refer to appendix A for the interview questions. This was done so as to encourage prolonged engagements to enhance reliability and validity (Creswell, 2007).

## 3.4 DATA COLLECTION

These interviews were conducted on individual bases. The rationale for using individual and semi-structured interviews is because they are useful to obtain detailed information about personal feelings, perceptions and opinions. They allow more detailed questions to be asked. They usually achieve a high response rate (Creswell, 2007). Each individual interview time span was approximately 17 to 34 minutes.  According to Higson –Smith and Kagee (2006) a pilot study is a small study conducted before  the big part of a research study to establish whether the methodology, sampling, instruments and  methods of analysis are appropriate for the type of proposed study (De Vos, 2011).  In addition, Barker (1998) highlights the significance of the pilot study after the interview questions have been formulated; this helps the researcher to know how long the interview will take, examine whether the questions are clear and understandable to the participants, and lastly to allow for the researcher to recognise any areas of interests that might emerge and have not been incorporated. The pilot study was conducted at the Perinatal HIV Research Unit at Chris Hani Baraganath Hospital and made use of one participant from one of the peer educators who works with the female sex workers on the field. The participant was only to be used for piloting the research and the data was used to inform the interview guide that was used in the study.

## 3.5 SCIENTIFIC RIGOR

According to Guba and Lincolin (1985) (as cited in Padgett, 2005) a reliable study is one that is conveyed out legitimately and ethically and whose results signifies as thoroughly as possible the experiences of the participants. The researcher has made use of a research diary where all the things that have transpired from data collection in terms of measuring the characteristic from the pilot study and the rest of the population has been noted. A research diary is a written record of the researcher's activities, thoughts and feelings throughout the research process from design, through data collection and analysis to writing and presenting the study (Bloor & Wood, 2006).

## 3.6 DATA ANALYSIS

The form of data analysis that was used for this study is narrative analysis as the researcher analysed the emerging themes out of the data that was collected, in narrative analysis the researcher should make sure that the final report describes the context of the story, its setting and the people involved, most importantly the researcher should closely collaborate with the participants providing the stories (Ollershaw& Creswell, 2002). De Vos (2011) describes qualitative data analysis as a process of inductive reasoning, assessing and theorising which drifts from structured, procedures to make conclusions from experiential data of societal existence. According to Patton (2002) a qualitative analysis process requires converting data into results. Cutting down the capacity of unused data information, shifting implications from facts, identifying meaningful patterns and constructing a framework for communicating the core of what the data shows or reflect, all these are required when analysing qualitative data (O’ Leary, 2004).

## 3.7 ETHICAL CONSIDERATIONS

It is important for the researcher to make sure that the conducted research is based on mutual trust, acceptance, cooperation and support and well-accepted agreements and expectations between all parties concerned in a research study (De Vos, 2011). The following ethical considerations were taken into account when conducting the research study;

Doing no harm

According to Creswell (2003) it is the researcher’s ethical responsibility to make sure that all participants are protected from any possible realistic limits and from any form of physical discomfort or harm that may be as a result of the research study. The researcher is was well aware of this ethical consideration and ensured that every concerned participant is not harmed emotionally, physically, cognitively and the research was conducted in a safe space. This is because the interviews took place at the research centre in the Chris Hani Baragwanath Hospital in a room where no harm was going to be inflicted and made sure that the participants are fully comfortable, no disturbance was encountered.

Voluntary participation

No one should be forced to become a participant in a research study, and therefore Participation should at all times be voluntary (Rubin & Babbie, 2005). The researcher made sure that Participation remained voluntary throughout the study. The participants were not coerced to become part of the study and were respectfully asked to participate in the study and they were made aware that they have the right to refuse; most importantly they were allowed to pull out from the study if they feel like they no longer want to be part of the study as it is their right, however no participant withdrew from the study meaning that they were willing to part of the study throughout the process. The participant information sheet helped the participants know what they were involving themselves in and clarifications were made where necessary, this allowed the participants to be able to decide whether they want to be part of the study or not. Refer to appendix B for the participant information sheet.

Informed consent

According to Royse (2004) it is important that participants are well informed about all the possible aspects of the research that are encompassed in the study, this includes; the goal of the research study, the expected duration of the participants’ commitment in the study, the procedures that will have to be followed by both the researcher and the participant, possible benefits and shortcomings to which the participants might be exposed to and the trustworthiness of the researcher. The participants were informed on all the information concerning their participation in the study before the research study was conducted and an informed consent form was provided to be signed by both the research participant and the researcher, every detail of the information was explained to the participants to make sure that they are consenting to what they fully understand and know. The participants were given a participant information sheet prior to the collection of data, and it contained a brief description of the research, what is required from the participants, why were they chosen, and most importantly clarity about who the researcher is, refer to appendix C and D for inform consent forms.

Confidentiality/ Anonymity

Participants have the right to privacy and it is important that researchers respect their right to choose how, when, where, why, to whom, and to what degree their privacy (attitudes, beliefs and behaviour) will be disclosed (De Vos, 2011).  The researcher ensured and kept the confidentiality of the participants and made use of pseudonyms for anonymity’ sake and did not ignore the required degree of the participant’s anonymity, most importantly the researcher also alerted the participants that the information gathered will also be shared with the research supervisor for guidance and supervision’ sake.

Incentives

According to Grant and Sugarman (2004) incentives are benefits intended to motivate action, and therefore researchers should be cautious when offering participants incentives. Most importantly incentives should not be monetary. For this research study there was lolly pops that were given to the participants just as an appreciation for their participation. The research centre helped the researcher with giving the participants transport money as they always do when the participants go for their visits as scheduled.

## 3.9 LIMITATIONS

Studying a biomedical treatment through a social science perspective

The researcher is not knowledgeable about what PrEP constitutes chemically that will work, how it’s supposed to work and what would be the desired outcomes, in a year, 2 to 5 years post use. Therefore the researcher’s curiosity of PrEP as a new preventative method against HIV and its efficacy is what influenced the research questions.

Time to conduct the study versus my required registration period as a student

Another limitation that affected this study was the clashes between the time it took the researcher to conduct and compile data, and the required registration period as an honours student. This is because it took the researcher longer to find participants, get sight approval to conduct data; because of this the researcher was not able to present the collected data to the department of Social Work due to the limited time. Also because of time I wasn’t able to work with the participants throughout the study, but I only interviewed them once and relied on the interviews we have had.

## 3.10 SUMMARY OF THE CHAPTER

This study made use of an explorative-descriptive design and a qualitative approach was followed. Semi-structured interviews were administered and participant’s identifying information was kept confidential and pseudonyms were used for anonymity’s sake, this means that ethical considerations were considered throughout the study. The only incentives that were used in this study were lolly pops and the research centre offered to give the participants transport money which helps them to be able to come to the research centre. Possible limitations to the study were also highlighted. The following chapter which is chapter four presents the findings that emerged on the process of data collection throughout the study.

# CHAPTER FOUR

## INTRODUCTION

This chapter gives a detailed overview of the findings that were obtained from the study. The findings will be discussed and analysed in terms of the themes that emerged from the responses the participants gave in answering the objectives of the study. Direct quotations form the interviews will be used so that a clear idea of the findings will be presented.

## 4.1 THEMES THAT EMERGED FROM DATA COLLECTION

### 4.1.1 Perceptions and knowledge on PrEP

PrEP has been a lifestyle Anti-retroviral therapy since its inception. It has not been as widely advertised and for the most part it has been undergoing clinical trials for its safe use. For most people, anti-retroviral drugs are used by those infected by HIV only. Consequently the knowledge people have about PrEP influences how they perceive the drug. There seems to be limited knowledge, however, about what PrEP is, where it can be accessed and who it is meant for. Evidence from this research points out that for example, the participants only got to know about PrEP when they joined aa project that is meant to empower sex workers In the interview, one can clearly pick this up;

“*Uhm, I first heard about PrEP ko creative space at PHRU, so… I heard it from our peer educators, they introduced PrEP from us the SW’s, we call ourselves SW’s the sex workers, and then they came with it and then they introduced PrEP to us to say you what if you are HIV negative you can use PrEP, but if you are HIV positive you cannot use PrEP, and, you’ve been screened before they can give you that PrEP, they know ukuthi who is HIV and who is not HIV.’ (Sthe, interview, 2018). Similarly the other participant also heard about PrEP* from the research centre in the same way participant 2 found out about *PrEP. “I was at creative space, and then they introduced it that there is this pill; PrEP, you take it once then it prevents…” (Joan, Interview, 2018).*

It is quite common practise that the use of any new method of treatment is made public knowledge considering its effectiveness. At the moment there have been 5 clinical trial studies done on Truvada\*, the PrEP drug, and all these have significant side effects. It is therefore not surprising that, the participants did not know of PrEP until they joined the sew work project at PHRU. It is also quite possible to assume that, within the Sex Workers constituency, the knowledge of PrEP is as scarce as in the ordinary populace.

Having been exposed to PrEP, the participants couldn’t wait but start the therapy (treatment) considering the industry they work in. Sex work exposes both the sex workers and their clients to multiple sexual risks including HIV among other sexually transmitted infections. Having been in the industry for some time without any form of protecting themselves from HIV infection other than the consistent use of condoms, PrEP was therefore a lucrative option. Sthe expressed this in the following quote, *“Because there…like, this job that I am doing is not safe again; condoms burst, so I am negative, so what if uhm…I sleep with a guy that is positive and then the condoms busted? It’s not his fault it’s not my fault, but what I must do is to…prevent, yeah.” (Sthe, Interview, 2018).*

That there is fear of contracting infections is by no means the only reason why some sex workers use PrEP. Whilst it may be a logical reason to consider using PrEP, some people find the anti-retroviral therapies a point to explore their curiosity. PrEP is probably the only drug that is used for prevention against HIV infection and therefore it generates interest among people who then use it. In the interview with Joan, it is evident that, unlike Sthe who had a rational process for using PrEP, she was more curious about what the drug can do for her. In fact, she would have wanted to test it and see the results for herself. She said the following:

*“(Breathing in) Uhm…my decision for PrEP Is because of uhm… I am always this person who is curious and I am not scared to test. I like testing things like, so… uhm, yeah I like to explore, so what made me take PrEP is because of It was made for people who are HIV negative and I was so interested and I went through the pamphlet and I have read the advantages and disadvantages of taking PrEP, so I was cool with it, and then I have taken the decision.”* (Joan, interview, 2018).

It cannot be under-emphasized however, that there is an urgent need to protect oneself from infections, particularly HIV. Regardless of her curiosity, Joan, considered being safe a priority. At the end of the day, she needed to find a way of knowing that, even at times when she couldn’t use condoms, because of the client’s needs, she would still be protected. She continued to say that,; “*Yes, but don’t say because of I’m taking PrEP, PrEP is a way of saying we are reducing HIV, but they don’t say that you must not use a condom because there is a lot of STIs and you know that us women we are so sensitive, lilets and there is a lot of things we catch. Yeah.”(Joan, Interview, 2018).*

Communities are less informed about PrEP and because of this they have their own different ideas about what PrEP is and what it can do. Often they confuse it with ARVs and therefore perceive it with a negative mind-set thinking that all people who use PrEP are HIV positive. Thus they end up having negative attitudes/stigma towards people who use PrEP. For those who don’t use PrEP, they see it pointless for them to use PrEP and condoms at the same time, this goes back to them having a lack of knowledge about PrEP and the consequences using it solely as a preventative method.

This is what Sthe had to say about her community regarding their knowledge and perceptions about PrEP; “*No, not all of them but I’ve taken few pamphlets…I’ve given people pamphlets, but they were like, there were many negative people that were saying “Why are we taking PrEP if we cannot use condom? Why are we taking PrEP while we using condom” yeah, I explained to them that “you know what this is the disadvantages of not taking condom if you taking PrEP”, they were like “no, this is zero moss” mm…so…” “Because…they are so negative, because of they don’t know, they don’t know, because there is no one who is on board on the street about PrEP…Do you understand?” (Sthe, interview, 2018)*

In other instances, PrEP is perceived as an ARV and they do not see any need for them to take it, as they think that it is meant for people who are HIV positive, Joan added saying; *“they’ll be like, they were like “ha! Isn’t it an ARV?”, then I was okay, yes it’s an ARV to prevent HIV not to that, now you are positive and you must take it. I am taking it but I am preventing HIV, but I’m negative, yeah.”* in these instances people often perceive those taking PrEP as sick and in need for treatment. In one event Joan narrated, people often accused her of misinforming them, suggesting that she, (Joan) was sick. She had this to retell of an encounter she had in her community, “*Yeah, which means wena you are lying to us, you are positive, ay this thing, even ARVs they take them once a day like you see, so I…it’s a pity.” (Joan, Interview, 2018)*

In these interviews, it is evident that PrEP is largely unknown and misunderstood. People have limited knowledge about PrEP if any, however, they know about other ARVs. ARVs are perceived to be associated with illness and therefore anyone that indulges must be sick. This kind of thinking is prejudicial and detrimental to the benefits of using PrEP. This misinformation, is the biggest cause for spreading myths about the drug and consequently its non-use. It is important therefore to improve the knowledge about the drug, especially for the constituency it is intended for.

### 4.1.2 Adherence

Adherence and compliance have historically been used interchangeably to refer to a patient’s efforts to follow healthcare advice. The term compliance was initially defined as “the extent to which a person’s behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with the clinical advice” (Sackett & Haynes, 1976, p. 11). Compliance suggests that the patient obeys or conforms to the provider’s instructions without regard to the patients’ independence, autonomy, and ability to take an active role in their health care ([Lutfey & Wishner, 1999](http://onlinelibrary.wiley.com/doi/10.1111/j.1745-7599.2008.00360.x/full#b26)).

With this being said the two participants reported effectively adhering to their PrEP intake; there are still other PrEP users who have challenges with complying with their daily intake of it, this is due to a number of reasons which some of them includes; fear of embarrassment as people associate PrEP with being HIV positive, people forget due to other commitments like over drinking, and also some do not comply with taking PrEP because they see it as a pointless thing to do because the manner in which you take it is very similar to taking ARVs and more especially if it means using it and using a condom at the same time.

Sthe (Pseudonym) reported adhering and complying very well to PrEP since she started taking it (She has been using PrEP for one and a half year), however she also shared her knowledge about how other people that she know they use PrEP are failing to adhere to it because of their own reasons, here is what she had to say; “*Most of the people they drink a lot, they are always on the streets, like most of the people nje…when you know you are a party animal, and you not used to eh…a pill, you cannot take that pill in the bar because you having that mentality; people will be saying “I’m taking”…because that pill you are using it as a eh…HIV pill, you drink it time to time. So now you will be scared “ah, when I’m going out with this pill, what will people say? What will people think” yeah.”(Sthe, Interview, 2018.)*

Joan had not much to say about adherence as she only has two weeks taking PrEP and is still adjusting perfectly. This also shows that adherence to PrEP intake is also affected by the attitudes people have on those who use it. So this concludes the fact that with better PrEP education such barriers can be cut off and people can be liberated and they can liberate themselves without fearing stigmatization with their use of PrEP.

There are limited challenges that PrEP users experience with taking it and therefore their challenges become the side effects that they get after taking PrEP, these side effects are experienced differently because people are different also and they adjust differently to the pill as a way of overcoming the side effects. The side effects, short term side effects such as feeling nauseous, hunger, dizziness, tiredness etc. none of the participants mentioned long term side effects.

Sthe said that *“The first 2 days yes, I experienced morning sickness, something like; I was feeling nauseous more in the morning but these two days, first two days yeah, I was dizzy, only in the morning only.”(Sthe, Interview, 2018).*

Joan reported something similar where she said; *“Uhm…I feel nauseous, I …ehm…vele my eyes I can’t see proper sometimes, I…I eat a lot, that’s it.”*

Here is how Joan reported how differently people experienced the side effects; *“…yeah, they are similar, uhm…some of them they feel uhm…they vomit, some of them they have rash, yeah.” (Joan, Interview, 2018).*

Other people are facing challenges to adhere to PrEP because their situations don’t allow them to overcome their situations; for example other people are not well financially so if they experience one of the side effects of taking PrEP like feeling hungry most of the time, it affects them because now they are not able to buy enough food so they can sustain the side effects of taking PrEP, Participant two reported that *“PrEP makes you hungry most of the people I’ve, I’ve seen…those who give up on PrEP, is those people who are not sur whether this is right or wrong, some they say “I’ve taken this pill it makes me nauseous I’m tired, I…I…” some of them “hhai I eat too much! I don’t have groceries”, they use excuses and that’s not an excuse eh…yeah.” (Joan, Interview, 2018).*

Even though, there are challenges or side effects that have to do with taking PrEP; self-dedication and taking one’s life seriously is what drives people to adhere to PrEP. This is because knowing the benefits and shortcomings of taking PrEP makes one to what to expect from taking PrEP and findings ways in which they can adjust to it and deal with any side effect and challenge they might be experiencing with taking PrEP. Counselling also helps a lot as they get encouraged to adhere to their daily PrEP intake and to place much effort into making sure that they comply and consistent with their intake. For example Sthe reported setting an alarm as a way of making sure that she does not forget but take her PrEP at the right time every day. *“I set an alarm (chuckling).”* On the other hand Joan shared how she overcomes the side effects as she said that they don’t last longer and she sleeps not for long but just to cool down the side effects, she reported not having a problem with the side effects because she knew from the beginning that such was going to happen *“…I don’t have a problem with that because of…definitely it’s what I know that this I am going to go through…yeah.”(Joan, Interview, 2018).*

### 4.1.3 Support

Support is very essential to people who use PrEP or any kind of medication as it gives them a sense of encouragement and knowing that they are not alone in every process they get involved in, what Sthe said supports this as she said that; “*They always encourage me to continue to take it, and not to forget to take it.*”. Giving up on PrEP is very easy as it comes with a lot of challenges and side effects that are very difficult to endure; but with the right kind of support from either family, friends, partners, or even the providers through counselling they are able to overcome and continue with their PrEP intake. However sometimes PrEP users do not get the support they need form their loved ones because of the fear of disclosing the fact that they are using PrEP due to fear of stigma and negative attitudes towards their decisions to take it.

Both the participant reported not having told their clients about their use of PrEP but they told their families and friends of which they support them very well, this what Joan had to say about not telling her clients that she uses PrEP; “*You know when it comes to your client, it’s like…clients are very difficult people and either way I’m not there to pitch, eh to pitch myself to them like as, eh…to give them info but it’s about money, we don’t have time; you give me what I want, I give you what you want, that’s it. No time for chit chat.” (Joan, Interview, 2018).* This then goes to show the kind of relationship sex workers have with their clients as they do not have time to socialise but the relationship they have is just transactional making it even more important to protect themselves.

### 4.1.4 Sexual history

Sex workers engage sexually with a lot of clients and this exposes them to a lot of risks, such as rape, violence, STIs, unwanted pregnancies and the acquisition of HIV because a lot can happen like condom bursts. Joan shared; “*That’s one of the reasons I’m taking PrEP. I’ve been raped, but luckily I didn’t get HIV and I didn’t get pregnancy, so I…” (Joan, Interview, 2018).* Sometimes this arises out of fear of getting sick because it is inevitable that sex workers are a population that is mostly exposed to HIV, Sthe said one of her fears are getting sick due to the number of people she works with; *“…Mmm…like…getting sick, yes.”* She also said it herself that this industry is not safe as she said; *“Because there…like, this job that I am doing is not safe again; condoms burst, so I am negative, so what if uhm…I sleep with a guy that is positive and then the condoms busted? It’s not his fault it’s not my fault, but what I must do is to…prevent, yeah.”* (Sthe, Interview, 2018). These also answers to the behavioural influences that make sex workers to protect themselves from any sexual consequences that comes with their job.

### 4.1.5 Other

The two participant’s reported PrEP as a necessity in their lives because they reported that without PrEP their chances of acquiring HIV are high because they work with a lot of people whom they don’t know very well and matters such as their HIV statues are not talked about so PrEP is indeed a good intervention in their industry. The participants also so a need for an awareness campaign to be created so that people can be better informed about PrEP so as to understand it better, like Joan said that; “*Hence I’ve said people must put str…eh, clinics, I don’t know who is going to provide them with this thing, but I’m pref…I’m preferring clinics, ehm…they should provide eh…tent and pamphlets to come outside the streets and say…this is youth, even they can they might even represent it at UJ or any campus or university…* *Uhm…what do you think about what I’ve said…about uhm…clinics providing a camp…like maybe they can provide a campaign on universities and campuses to acknowledge people about PrEP.” (Joan, Interview, 2018).*

## 4.2 SUMMERY OF THE CHAPTER

This chapter has presented a detailed overview of the findings that were obtained from the study. The findings were discussed and analysed in terms of the themes that emerged from the responses the participants gave in answering the objectives of the study. Direct quotations from the interviews were used so that a clear idea of the findings can be presented. Overall the themes that emerged included; Perceptions and knowledge on PrEP (where we looked at the knowledge people have about PrEP and their perceptions around that), Adherence (The focus was on challenges, side effects and ways in which the side effects can be overcome), support (where we looked on the support the participants get and if it has any significance on their PrEP intake), sexual history (Which answered the sexual activities/ influences that led the participants to take PrEP) and other (where we looked on other matters that have to do PrEP and its intake).

# CHAPTER FIVE

## SUMMARY, CONCLUSION AND RECOMMEDATIONS

## INTRODUCTION

The first chapter has focused on the introductory part of the report where the overview of the study, the aims and objectives of the study, the problem statement and the rationale of the study has been presented. Proceeding; chapter two constituted of the literature significant to the focus of the study. Chapter three composed of the research Design/ approach and other research processes that were followed when conducting this study. Chapter four was a presentation and discussion of the research outcomes. This chapter will summarise the findings and discuss it with the reference to existing literature. The theme is discussed as an illustration of chapter four, further the limitations, and implications of the study will be looked as well as relating this study to other similar studies that have been carried out.

## 5.1 RECAPITULATION OF PURPOSE AND FINDINGS

### 5.1.1 Study aim

This study was aimed at exploring the Perceptions of women sex workers using Pre-Exposure Prophylaxis on their experiences on using PrEP at Chris Hani Baragwanath Academic Hospital.

### 5.1.2 Study objectives

* The objective of this study was to explore the experiences of female sex workers on the use of PrEP.
* Another objective of the study was to explore the risks and benefits of using PrEP.
* The last objective of this study was to explore behavioural influences on the decision to use PrEP among female sex workers.

### 5.1.3 Overall findings of the study

What the research found was that Overall PrEP use is voluntary and is influenced by various factors; one of the factors that influence PrEP usage includes the knowledge people have about it which in turn determines the way in which they perceive PrEP and people who use it. This is in such a way that when people are well knowledgeable about PrEP they make rational informed decisions when it comes to deciding whether to use it or not; they doing this knowing all the benefits and shortcomings of using it and basically knowing exactly what it is they are putting themselves into without relying on unsupported assumptions. All this sums up to inform the second objective which is to explore the risk and benefits of using PrEP, where a focus is placed on the participant’s knowledge and perceptions about PrEP.

The main findings also suggest that Adherence to PrEP is influenced by side effects and the tolerance people have on those side effects that are as a result of taking it, this also if influenced by the support that sex workers who use PrEP get from their loved ones and the clinic which is their provider though counselling. This informs the first objective which was to explore the experiences of female sex workers on their use of PrEP.

More over last but not least the findings also suggest that the sexual activities and sexual histories have a big influence on the decision of the female sex workers to use PrEP as a preventative method against HIV, this is because they are well aware of the fact that they are expose to risks that are associated with HIV like rape, condom bursts and basically them working with HIV clients without them knowing that. This informed the third objective of the study which was to explore behavioural influences on the decision to use PrEP among female sex workers.

## 5.2 RELATING TO PREVIOUS RESEARCH

These findings are broadly aligned with those of researchers such as the study of stigma by Bryn (1997), where he argues that an awareness of stigma creates a sense of shame and it affects those accessing care. This is because the findings suggests that people who use PrEP are afraid of disclosing their PrEP intake as they are afraid that people in their communities will assume that they are sick and therefore making them stick out from others, creating a sense of shame. This also makes it difficult for them to adhere to PrEP.

According to Eakle, Venter, & Rees (2013) PrEP may contribute heavily in helping to reduce the possibilities of continued new HIV infections. The findings of this study also suggest a similar thing especially in the sex work industry because a lot of people are involved in which they are exposed to almost every risk of acquiring HIV and also the participants reported PrEP as a necessity in their industry because it is not safe and they also highlighted the fact that without PrEP it becomes easier for them to be exposed to HIV. This study also supports the idea that PrEP works well with other prevention methods such as condoms as it is not meant to be used solely. This is because the participants reported that the fact that one uses PrEP does not mean that they should not use condoms because PrEP does not prevent STIs nor does it Prevent pregnancy.

This study also suggest that PrEP is not yet broadly distributed out there for people to access it hence that is why people lack knowledge about it and their assumptions are fed by the little information they get about PrEP from those who access it or have heard about it. Davis and Squire (2010) Highlighted that PrEP is not yet available at many places whilst its demand is very strong and people get it in doggy channels of which it interferes with their health because they do not get proper counselling or even follow the instructions of using it.

## 5.3 LIMITATIONS OF THIS RESEARCH / ANTICIPATION OF CRITICISMS

The number of interviews I had with the participants

According to Ollershaw & Creswell (2002) in a case study the researcher should engage in long conversations with the participants and when analysing data the researcher should collaborate closely with the participants. Because of time the researcher was only able to have on interviews with the participants and had to rely on the responses that were found on the first interview so as to meet requirements. However the researcher made sure that the interview questions consist of long open ended questions so as to allow the participants to give open ended and detailed responses to get saturated data.

Studying a biomedical treatment through a social science perspective

The researcher is not knowledgeable about what PrEP constitutes chemically that will work, how it’s supposed to work and what would be the desired outcomes, in a year, 2 to 5 years post use. Therefore the researcher’s curiosity of PrEP as a new preventative method against HIV and its efficacy is what influenced the research questions.

Time to conduct the study versus my required registration period as a student

Another limitation that affected this study was the clashes between the time it took the researcher to conduct and compile data, and the required registration period as an honours student. This is because it took the researcher longer to find participants, get sight approval to conduct data; because of this the researcher was not able to present the collected data to the department of Social Work due to the limited time. Also because of time I wasn’t able to work with the participants throughout the study, but I only interviewed them once and relied on the interviews we have had.

## 5. 4 IMPLICATIONS OF THE FINDINGS

These findings implies that stigma is still a big challenge and barrier to accessing care as people become limited from accessing or using resources that are meant for their wellbeing. The findings also imply that education and awareness is still a need in our society which will serve as a solution to the stigma people are affected by and also the negative mind-set around PrEP and people using it. This research also implies that in as much as there are short-term and long-term side effects (when taken for over 2 years) PrEP is a very positive initiative of trying to reduce the HIV pandemic meanwhile a cure for HIV has not yet been found.

## 5.5 RECOMMENDATIONS

The recommendations that emerged from the study are directed to future researchers and the social work practice.

5.5.1 Recommendations for the Social Work practice

Social workers should start educating people about PrEP and creating awareness about it as it is something that only a few knows about and it is not in all cases that what they know is the truth about PrEP.

5.5.2 Recommendations for Further Research

Future research should focus on why PrEP users continue taking PrEP despite all the long term effects/risks of PrEP.

## 5.6 CONCLUSION

This research has managed to present and discuss the perceptions of Female sex workers using PrEP on their use of PrEP. The participants were able to respond and share on their experiences their ideas and overall the knowledge they have about PrEP. The researcher has learnt gained insights and has grown throughout the study process.

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# Appendix: A

**INTERVIEW QUESTIONS AND PARTICIPANT’S DEMOGRAPHICS**

***Introductory paragraph:***

*Thank you for taking the time to talk with me today. My name is Vuma Gloria and I am currently in my final year of studying Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting research based on the perceptions of female sex workers who are using Pre-Exposure Prophylaxis. There are no right or wrong answers; I am here to learn from you. You may stop the interview at any time and you may choose to not answer any question you would prefer not to answer.*

*Do you have any questions before we start?*

Personal information

* Tell me more about yourself
* When did you start selling sex?
* How did you get into the industry?
* Tell me more about your biggest fears in this industry,
  + in terms of your sexual practices,
  + condom use/burst and exposure to violence such as rape

Perceptions and knowledge of PrEP

* Where did you first hear about PrEP?
* What did you first hear about PrEP?
* What made you decide to take PrEP?
* How does someone get PrEP?
* Where do you get this PrEP?
* What do you know about PrEP,
  + How it should be taken?
  + How long do you take PrEP for?
* What is the general people’s perception around PrEP,
  + Does the community know about it?
  + Does the community know about the use of prep and people using it?

Adherence

* How long have you been on PrEP for?
* Are the any challenges that you experience with taking PrEP?
* If not, are you aware of other people who are on PrEP having challenges with taking it?
* Have you ever heard of other PrEP side effects or do you know someone who has side effects from PrEP?
* Have you experienced any side effects of PrEP?
* If yes, what are the side effects?
* How long do they last?
* What are the effects of these side effects on people who take them?
* What do people do to overcome these side effects?
* Have you ever forgotten to take PrEP?
* What was your next action after you realised that?
* Is there anything that led you to forget to take PrEP?
* If not, what would you do if you were to forget to take PrEP?
* Do people adhere to PrEP?
  + If not why not?
  + If they do what makes it easy for people to adhere to PrEP

Support

* Does your partner/family/clients/friends know about PrEP and that you use it?
  + How did you tell each of them (partner, family, clients, and friends)?
  + If not, why did you not tell your partner/family/clients/friends that you are using PrEP?
* What type of support do you get with your PrEP intake from both your family and the clinic?
  + Does the type of support you get help you in any way?
  + Is there any additional help you need with your PrEP intake?
* How regular do you go for check-ups for sexually transmitted diseases and HIV? How does than help with maintain your health?
* Tell me more about the counselling you get when you go to get your PrEP,
  + Does the counselling help in taking care and protecting yourself sexually?

Sexual activities

* How many clients do you have, and how many do you work with per day?
* What sexual risks are you aware of in your industry?
  + And in your personal life?
* What contraceptive method do you use?
* How does it work with PrEP?

Other

* Tell me more about other challenges of taking PrEP?
* Are there any Risks of taking PrEP that you are familiar with??
* In your opinion what would make it easier for people to take PrEP?
* Would you like to ask any questions?

***Participant profile (Demographics): Sthe***

**Date of Interview: 23 / 01 / 2 0 1 8**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Age (years)** | **30** | | | | | | | | | |
| **Nationality** | South African: **x** | Other (please specify) | |  | | | | | | |
| **Race** | Black: **x** | White | | Asian | | Coloured | | | Other | |
| **Ethnic group** | Zulu | Sotho | | Tsonga | | Venda: **x** | | | Other | |
| **Relationship status** | Married | Single: **x** | | Widowed | | Divorced | Living Together | | Other | |
| **Type of residence** | Flat | Shack | | Hostel | | Brick House: **x** | | | Other | |
| **Is this residence** | Permanent | | | Rental: **x** | | Informal | | | Other | |
| **Who do you live with/ living arrangements** | Alone | | | Family | | Spouse/Partner | | | Other  **x** | |
| **Employment** | Self Employed | | Disability Grant | | Pensioner | Unemployed | | | Other  **x** | |
| **Province that you spend most your time in** | **Gauteng** | | | | | | | | | |
| **Level of education** | No Education | | Primary School | | High School | Matriculated | | Higher Education | | Other |

***Participant profile (Demographics): Joan***

**Date of Interview: 23/ 01 / 2 0 1 8**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Age (years)** | 25 | | | | | | | | | |
| **Nationality** | South African:  **x** | Other (please specify) | |  | | | | | | |
| **Race** | Black: **x** | White | | Asian | | Coloured | | | Other | |
| **Ethnic group** | Zulu | Sotho | | Tsonga: **x** | | Venda | | | Other | |
| **Relationship status** | Married | Single **x** | | Widowed | | Divorced | Living Together | | Other | |
| **Type of residence** | Flat | Shack | | Hostel | | Brick House: **x** | | | Other | |
| **Is this residence** | Permanent : **x** | | | Rental | | Informal | | | Other | |
| **Who do you live with/ living arrangements** | Alone: **x** | | | Family | | Spouse/Partner | | | Other | |
| **Employment** | Self Employed | | Disability Grant | | Pensioner | Unemployed: **x** | | | Other | |
| **Province that you spend most your time in** | **Gauteng** | | | | | | | | | |
| **Level of education** | No Education | | Primary School | | High School | Matriculated | | Higher Education:**x** | | Other |

# Appendix: B

***PATICIPANT INFORMATION SHEET***

**TITLE**

The perceptions of young women using Pre-Exposure Prophylaxis (PrEP) at the Perinatal HIV Research Unit; situated in Chris Hani Baragwanath Academic Hospital, Soweto.

Good day,

My name is Vuma Gloria and I am currently in my final year of studying social work at the University of the Witwatersrand. As part of the requirements for the degree, I am conducting a research based on the perceptions of young women who are using Pre-Exposure Prophylaxis at the Prenatal HIV Research Unit. It is hoped that the information gathered could assist social workers to enlighten communities about their resources.

You are being requested to participate in this study because you are using PrEP. If you accept my invitation, your participation would be entirely voluntary and you are welcome to withdraw at any time without any penalty. There are no consequences or personal benefits of participating in this study. If you agree to take part, I would arrange to interview you at the time and place that is suitable for you. The interview will last approximately 1 hour. If you choose to participate, you may withdraw from the study at any time and you may refuse to answer any of the questions that you feel uncomfortable with answering. The recording of the interview is part of the study and I would like to ask for your permission to record the interview. No one other than the researcher and the supervisor will have access to the tapes.

The recording will be kept in a password protected computer forever for future research if you agree, and if you don’t the recording will be destroyed. You will not be paid to participate in the study nor will it cost you to partake in the study. However I will be giving out lolly pops as a token of appreciation.

A copy of your interview transcript without any identifying information (personal information such as your real name and your actual address) will be stored permanently in a locked cupboard and may be used for future research if you agree and if not the copies of the interview transcripts will be destroyed. Please be assured that your name and personal details will be kept confidential and no identifying information will be included in the final research report. The results of the research may also be used for academic purposes (including books, journals and conference proceedings) and a summary of findings will be made available to participants on request.

Please do contact me on 072 272 3197 or on my email [845499@students.wits.ac.za](mailto:845499@students.wits.ac.za), or my supervisor; Elvis Munatswa on 087 566 5840 or email him on [416771@students.wits.ac.za](mailto:416771@students.wits.ac.za) if you have any questions regarding my study. We shall answer them to the best of our ability. If you have any concerns and complain about the study, please contact Human Research Ethics (Medical), HREC (Medical) contact details: Prof P Cleaton Jones, Tel 011 717 2301, email [peter.cleaton-jones1@wits.ac.za](mailto:peter.cleaton-jones1@wits.ac.za), Ms Z Ndlovu/ Mr Rhulani Mkansi/ Mr Lebo Moeng; Administrative Officers 011 717 2700/2656/1234/1252 [zanele.ndlovu@wits.ac.za](mailto:zanele.ndlovu@wits.ac.za); [Rhulani.mkansi@wits.ac.za](mailto:Rhulani.mkansi@wits.ac.za); and Lebo.moeng@wits.ac.za

Thank you for taking the time to consider participating in the study.

Yours sincerely,

Vuma Gloria

# Appendix: C

***CONSENT FORM FOR PATICIPATING IN THE STUDY***

**TITLE:** Anti-Retroviral Therapy: Perceptions of young women using Pre-exposure prophylaxis (Prep) in Hillbrow.

I hereby consent to participate in the research study. The purpose and the procedures of the study have been explained to me.

I understand that:

* My participation in this study is voluntary and I may withdraw from the study without being disadvantaged in any way.
* I may choose not to answer any specific questions asked if I do not wish to do so.
* There are no foreseeable benefits or particular risks associated with participating in this study. However lolly pops will be given for appreciation.
* My identity will be kept strictly confidential, and any information that may identify me, will be removed from the interview transcript.
* A copy of my interview transcript without any identifying information will stored permanently in a locked cupboard and may be used for future research.
* I understand that my responses will be used in the write up of an Honors project and may also be presented in conferences, book chapters, journal articles or books.

Name of Participant:

Date:

Signature:

# Appendix: D

***CONSENT FORM FOR DIGITAL-TAPING OF THE INTERVIEW AND KEEPING THE RECORDING AND THE INTERVIEW TRANSCRIPTS FOREVER.***

**TITLE:** The perceptions of young women using Pre-exposure prophylaxis (Prep) at the Perinatal HIV Research Unit; situated in Chris Hani Baragwanath Academic Hospital, Soweto.

I hereby consent digital-recording of the interview.

I understand that:

* The recording will be stored in a secure location (password-protected computer) with restricted access to the researcher and the research supervisor.
* The recording will be transcribed and any information that could identify me will be removed (Actual name, address etc).
* When the data analysis and write-up of the research study is complete, the audio recording of the interview will be kept forever following any publications.
* The transcript without any identifying information directly linked to me will be will be stored permanently and may be used for future research.
* Direct quotes from my interview, without any information that could identify me may be cited in the research report or other write ups of the research.

**Consent for audiotaping Consent for keeping audiotape and transcript forever**

Participant No: Participant No:

Date: Date:

Signature: Signature:

# Appendix: E

**LETTER FOR RESEARCH SANCTION**

 Private Bag 3, Wits, 2050 • Tel: 011 717 4524 • Fax: 011 717 4556 • E-mail: umthombo.SHCD@wits.ac.za

Dear Sir/Madam

Letter of request

To whom it may concern

My name is Vuma Gloria and I am currently in my final year of studying Social Work at the University of the Witwatersrand. As part of the requirements for the degree, I need to conduct a research based on the perceptions of female sex workers who are using Pre-Exposure Prophylaxis at the Baragwanath research centre. It is hoped that the information gathered could assist social workers to enlighten communities about their resources and link them to necessary services such as facilities where they can access PrEP, also it is the value to be brought by this study to provide knowledgeand inform women who use Prep to have alternative ways in which they can protect themselves from other sexually transmitted diseases without relying on Prep only.

I write this letter to request for your permission to conduct my research at your site, and to also use the patients who are PrEP users at the institution as my sample for data collection. I will ensure that participation is voluntary, seek consent of and from participants to interview and audio record the interviews, and any information that will discredit the participants will be kept confidential; identifying information such as names will be replaced with pseudonyms.

Please do contact me on 072 272 3197 or on my email [845499@students.wits.ac.za](mailto:845499@students.wits.ac.za), or my supervisor; Elvis Munatswa on 087 566 5840 or email him on [416771@students.wits.ac.za](mailto:416771@students.wits.ac.za) if you have any questions regarding my study. We shall answer them to the best of our ability. Thank you for taking your time to consider this request. I look forward to your response.

Kind Regards

Vuma Gloria

4th year Social Work Student

# APPENDIX: F

**SUPERVISOR’S CONSENT LETTER**

Private Bag 3, Wits, 2050 • Tel: 011 717 4524 • Fax: 011 717 4556 • E-mail: umthombo.SHCD@wits.ac.za



Research Reference Letter for Gloria Vuma

**To whom it may concern**

This serves as a letter of support for Miss Gloria Vuma from the Research Supervisor.

Gloria is a student in the School of Human & Community development, in Social Work Dept, doing her fourth year of studies. I am currently her research supervisor. She is required to conduct a mini study and this letter serves to confirm that she indeed is required to obtain permission to conduct the study at the site she has indicated.

Please assist her as is necessary

If you have any questions please feel free to contact me at 0785665840 or 011-7174489

Yours sincerely

Elvis Munatswa

(Ph.D. Candidate, Graduate Teaching Assistant- School of Human & Community Development)

# APPENDIX: G

**LETTER OF SUPPORT**

# APPENDIX: H

**CLEARANCE CERTIFICATE**