

# **Let's talk about Pre-Exposure Prophylaxis: A participatory HIV prevention intervention with and for female sex workers in Durban, South Africa**

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## Declaration

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I, **Nosipho Faith Makhakhe**, declare that:

- i) The research reported in this thesis, except where otherwise indicated, is my original work.
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- iii) This thesis does not contain other person's data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
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## Abstract

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**Introduction:** Since the discovery of HIV/AIDS in the early 1980s, scientists have been in search of a cure. Significant scientific efforts have so far led to the discovery of antiretroviral treatment that suppresses the replication of HIV that leads to AIDS. Recently, Tenofovir or Tenofovir-emtricitabine as antiretroviral treatment for HIV-positive persons can now be used as prevention in the form of oral pre-exposure prophylaxis (PrEP). This HIV prevention therapy is currently being administered to people considered at high risk of HIV, such as men who have sex with men, intravenous drug users and serodiscordant couples. In 2015, the WHO expanded its oral PrEP guidelines to include female sex workers (FSWs) who are a high-risk group for HIV worldwide. In response to these WHO guidelines, the South African government approved oral PrEP distribution among FSWs in 2016, as part of combination prevention with the expectation that FSWs would take up PrEP and this will reduce the rate of new HIV infections. However, the response to PrEP was underwhelming. Identifying the reasons for the low uptake of PrEP among FSWs is the primary objective of this study. This was followed with engaging FSW peer educators in a participatory intervention mapping process to design an intervention plan to address these challenges to uptake and potentially inform PrEP programming in Durban in the KwaZulu-Natal province which is a high HIV prevalence area in South Africa.

**Methods:** This study was a participatory action intervention research that was conducted in two phases. The first phase was a qualitative needs analysis conducted from May to November 2018 to identify the challenges associated with PrEP uptake and retention, as well as to ascertain the motivating factors for PrEP use among FSWs. Interviews were conducted with 39 participants, 30 individual participants, and nine focus group participants. Eleven participants were FSW peer educators including one health worker and one researcher from sex work and PrEP distributing organisations (13 in total); the rest of the participants were FSWs (n=26). Consent was obtained from all participants. Data were analysed thematically. The second phase of this study was an intervention mapping phase during which a PrEP intervention plan was developed with eight FSW peer educators who were at the forefront of PrEP promotion among FSWs. This intervention plan was informed by data obtained from the needs analysis. A total of six meetings took place in which the individual, interpersonal and environmental determinants that have an impact on PrEP uptake, adherence, and retention were discussed. This resulted in the performance and change objectives, including a theory of change logic framework that systematically depicted the process of change. Furthermore, theory-based

methods and activities were established which culminated into a PrEP intervention workshop programme. Additionally, the implementation and evaluation plans were also formulated.

**Results:** The needs analysis showed that the majority of the participants could not distinguish between PrEP and antiretrovirals. This inability contributed to the stigma against PrEP. Another challenge was that distribution was fragmented with the research organisations distributing PrEP to FSWs through peer education and yet, PrEP was not well understood or promoted by health care providers from public health facilities. This resulted in the mistrust of PrEP efficacy among FSWs and delayed uptake and lessened retention. The FSWs taking PrEP were met with hostility from their friends who failed to understand that PrEP as an antiretroviral can be taken to prevent HIV. This resulted in HIV positive FSWs on antiretrovirals accusing PrEP users of deception, and HIV denialism. They also experienced similar reactions from intimate partners. These accusations were believed to arise because of lack of knowledge and competition for clients, given the preferred market for HIV-negative FSWs. PrEP users reported feeling stigmatised and thrust into interpersonal conflicts with their peers, which caused broken relationships, this led some FSWs to discontinue PrEP, while others took it secretly. The FSWs who remained on PrEP mentioned various motivating factors for adherence, such as PrEP being an empowering tool that gives them agency to prevent HIV and bodily autonomy as well as a sense of hope for the future, because HIV was no longer a consequence of sex work. The PrEP intervention mapping process which resulted in a workshop programme showed how FSWs can engage in reflexive dialogues that help promote agency, power, self-efficacy, hope and responsibility to the self and others, to encourage effective engagement in HIV prevention.

**Conclusion:** This study recommends for a wider promotion and dissemination of PrEP through public health care facilities. This will encourage the normalisation of PrEP and curb the stigma associated with PrEP being for high-risk groups. Biomedical interventions should be coupled with behavioural strategies that engage users on the personal, interpersonal, and environmental challenges that have an impact on behavioural change. FSWs should be involved in the design and implementation of their own interventions to ensure effective approaches and to create a sense of responsibility, power and ownership. It is important for future interventions to realise that simply promoting a prevention method because it is medically effective will not warrant uptake and adherence on the part of end users; therefore, interventions need to engage with the complexity of human behaviour. This makes it imperative for practitioners to invest in understanding the patient's deeper motivations that encourage or discourage behavioural change.

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## Dedication

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*To*

*Matlagolo, Moloto,*

*and*

*To black women, who follow their dreams, in a world that tells them that they are not good enough, with their voices shaking and their hands trembling, but get it done anyway.*

## Table of Contents

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<b>Declaration.....</b>	<b>i</b>
<b>Abstract.....</b>	<b>ii</b>
<b>Acknowledgements .....</b>	<b>iv</b>
<b>Dedication .....</b>	<b>vi</b>
<b>Table of Contents .....</b>	<b>vii</b>
<b>List of Figures.....</b>	<b>xiv</b>
<b>List of Tables .....</b>	<b>xiv</b>
<b>Acronyms and Abbreviations .....</b>	<b>xvi</b>
<b>Chapter 1</b>	
<b>Introduction.....</b>	<b>1</b>
1.1 Introduction .....	1
1.2 Problem statement .....	5
1.3 Study rationale.....	5
1.4 Study objectives.....	6
1.5 Research questions .....	7
1.6 Structure of the thesis .....	8
<b>Chapter 2</b>	
<b>The Global Emergence of HIV/AIDS Research Prevention and Treatment.....</b>	<b>12</b>
2.1 Introduction .....	12
2.2 Background of HIV/AIDS major breakthroughs .....	12
2.3 HIV in the 1980s and 1990s .....	13
2.4 HIV/AIDS in South Africa.....	17
2.5 HIV prevention campaign strategies .....	19
2.6 Factors contributing to HIV vulnerability of female sex workers.....	21
2.6.1 Importance of a combination of prevention strategies for female sex workers .....	22
2.7 Significant pre-exposure prophylaxis trials.....	24
2.8 Distribution of pre-exposure prophylaxis in South Africa among female sex workers .....	26
2.9 Feasibility and acceptability of pre-exposure prophylaxis among female sex workers in South Africa.....	28
2.10 Female sex worker interventions .....	29

2.11	Summary.....	34
<b>Chapter 3</b>		
<b>Scoping Review: Mapping the Evidence to Inform Oral Pre-exposure Prophylaxis Interventions for Female Sex Workers .....</b>		
<b>36</b>		
3.1	Introduction .....	36
3.2	Methodology.....	37
3.2.1	Identifying relevant studies.....	37
3.2.2	Study selection.....	38
3.2.3	Screening process .....	38
3.2.4	Data extraction and analysis .....	39
3.3	Results .....	45
3.3.1	Integration of pre-exposure prophylaxis with sexual and reproductive health care services for female sex workers .....	46
3.3.2	Community empowerment as a component of pre-exposure prophylaxis programming.....	46
3.3.3	Perceptions of female sex workers with regard to pre-exposure prophylaxis .....	47
3.3.4	Strategies to encourage the uptake and retention of pre-exposure prophylaxis .....	47
3.4	Discussion.....	48
3.5	Implications of the scoping review for this doctoral study .....	50
3.6	Summary.....	50
<b>Chapter 4</b>		
<b>Theoretical Framework.....</b>		
<b>51</b>		
4.1	Introduction .....	51
4.2	Critical reflexivity framework.....	51
4.2.1	Dialogical space.....	55
4.2.1.1	Power.....	56
4.2.1.2	Agency and responsibility .....	61
4.2.1.3	Values and identity .....	62
4.2.1.4	Performativity.....	64
4.3	Bronfenbrenner's bioecological theory.....	65
4.3.1	Processes.....	66
4.3.2	Person .....	66
4.3.3	Context.....	67
4.4	Summary.....	70

## **Chapter 5**

<b>Research Methodology .....</b>	<b>71</b>
5.1 Introduction .....	71
5.2 Study setting and background .....	72
5.3 Intervention Research paradigm.....	74
5.4 Intervention Research design .....	76
5.5 Intervention Mapping Planning Framework .....	76
5.5.1 Phase 1: Step 1 – Needs analysis.....	78
5.5.1.1 Research paradigm and design .....	79
5.5.1.2 Sampling strategy .....	81
5.5.1.3 Sample description .....	82
5.5.1.4 Data collection tool, processes and procedures .....	82
5.5.1.5 Data analysis.....	84
5.5.2 Phase 2: Steps 2, 3, & 4: Methodological processes of mapping the intervention .....	85
5.5.2.1 Feedback of the needs analysis data to stakeholders.....	85
5.5.2.2 Identifying a working group of FSWs and negotiate the creation of the dialogical spaces.....	86
5.5.3 Step 2: Creating matrices of change objectives.....	88
5.5.4 Step 3: Theoretical based methods and practical strategies to enable change .....	88
5.5.5 Step 4: Intervention workshop programme design.....	89
5.5.6 Step 5: Adoption and implementation and Step 6: Evaluation plan.....	90
5.6 Ethical considerations.....	90
5.7 Data verification .....	91
5.8 Summary.....	93

## **Chapter 6**

<b>Research Reflexivity .....</b>	<b>94</b>
6.1 Introduction .....	94
6.2 Caught between two worlds .....	96
6.3 New opportunities .....	97
6.4 Challenges .....	100
6.5 Relationships deepening.....	100
6.6 Mothers for the future.....	101
6.7 Becoming “friends” .....	102

6.8	#Say her name .....	103
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## **Chapter 7**

### **Challenges Associated with Oral Pre-exposure Prophylaxis among Female Sex Workers in Durban, South Africa.....104**

7.1	Introduction .....	104
7.2	Sociodemographic background of participants .....	105
7.3	Results .....	107
7.3.1	Pre-exposure prophylaxis stigma.....	107
7.3.1.1	Pre-exposure prophylaxis being marketed for high-risk groups .....	107
7.3.1.2	Inability to differentiate pre-exposure prophylaxis from antiretroviral treatment for people living with HIV .....	109
7.3.1.3	Contradictory messages from organisations distributing pre-exposure prophylaxis and public health facilities .....	110
7.3.2	Female sex workers' perception of risk.....	112
7.3.2.1	Belief among female sex workers that all sex workers are HIV positive .....	112
7.3.2.2	Underage girls and new entry female sex workers less likely to take pre-exposure prophylaxis.....	114
7.3.3	Pre-exposure prophylaxis and interpersonal relationships .....	116
7.3.3.1	Conflict between those taking pre-exposure prophylaxis and their intimate partners .....	116
7.3.3.2	Conflict between female sex workers on pre-exposure prophylaxis and female sex workers on antiretrovirals.....	117
7.3.3.3	Concern that pre-exposure prophylaxis will jeopardise their hidden sex work identity .....	118
7.4	Discussion.....	118
7.5	Conclusion.....	123

## **Chapter 8**

### **Personalised Care by Peer Educators to Encourage the Uptake and Retention of Oral Pre-exposure Prophylaxis Among Female Sex Workers in Durban, South Africa.....125**

8.1	Introduction .....	125
8.2	Results.....	127
8.2.1	Peer outreach .....	127
8.2.1.1	Pre-exposure prophylaxis awareness and distribution .....	128
8.2.2	Pre-exposure prophylaxis education.....	129
8.2.2.1	Perceptions of peer educators with regard to knowledge of pre-exposure prophylaxis among female sex workers.....	130

8.2.3	Adherence and retention strategies .....	131
8.2.3.1	Management of side effects .....	131
8.2.3.2	Ensuring continuous pre-exposure prophylaxis supply .....	132
8.2.4	Preference of pre-exposure prophylaxis as an injectable .....	132
8.2.4.1	Patient follow-ups .....	132
8.3	Discussion .....	133
8.4	Conclusion .....	136

## **Chapter 9**

### **Motivating Factors Associated with Oral Pre-exposure Prophylaxis Use Among Female Sex Workers in Durban, South Africa .....137**

9.1	Introduction .....	137
9.2	Results .....	139
9.2.1	Agency and identity .....	139
9.2.1.1	Pre-exposure prophylaxis as an empowering tool for HIV prevention .....	139
9.2.1.2	Taking pre-exposure prophylaxis as an expression of self-love .....	140
9.2.1.3	My body, my livelihood .....	141
9.2.1.4	Motherhood as an identity that inspires prevention .....	142
9.2.2	Hope .....	143
9.2.2.1	Pre-exposure prophylaxis as a source of hope .....	143
9.2.2.2	Freedom from HIV scars .....	144
9.2.2.3	Infection is an inevitable outcome .....	144
9.2.3	Life beyond sex work .....	145
9.2.3.1	Studies as preparation for a better life .....	145
9.2.3.2	Entrepreneurship .....	146
9.3	Discussion .....	146
9.4	Conclusion .....	148

## **Chapter 10**

### **Developing a Sex Worker-led Community Intervention Plan to Improve Pre-exposure Prophylaxis Uptake and Retention in South Africa: An Intervention Mapping Approach.....150**

10.1	Intervention mapping – Step 1: Summary of the needs analysis conducted in Phase 1 .....	150
10.2	Intervention mapping – Step 2: Matrices of change objectives .....	151
10.2.1	Behavioural outcomes .....	153
10.2.2	The broad social and environmental outcomes .....	153
10.2.3	Performance objectives .....	154

10.2.4 Theory of change logic framework.....	156
10.3 Intervention mapping – Step 3: Theory-based methods and practical strategies .....	159
10.4 Intervention mapping – Step 4: Programme design .....	161
<b>Chapter 11</b>	
<b>Synthesis, Limitations and Recommendations.....</b>	<b>183</b>
11.1 Objective 1: To outline the strategies that have been recommended in the literature to inform pre-exposure prophylaxis interventions for female sex workers .....	183
11.2 Objective 2: To understand the barriers and facilitators of pre-exposure prophylaxis use among female sex workers .....	184
11.2.1 Barriers 184	
11.2.1.1 Sex workers as vectors of disease .....	184
11.2.1.2 Getting lost in translation .....	185
11.2.1.3 Contradictory messages about pre-exposure prophylaxis .....	185
11.2.1.4 HIV positive by association.....	186
11.2.1.5 Pre-exposure prophylaxis as a source of conflict .....	187
11.2.2 Facilitators of pre-exposure prophylaxis use .....	187
11.2.2.1 Awareness raising and pre-exposure prophylaxis distribution.....	187
11.2.2.2 Peer educators take charge of pre-exposure prophylaxis messaging .....	188
11.2.2.3 Keeping a client on pre-exposure prophylaxis .....	189
11.3 Objective 3: To explore the intrinsic personal motivations for pre-exposure prophylaxis use among female sex workers .....	190
11.4 Objective 4: To outline the methodological processes and outcomes of a pre-exposure prophylaxis intervention plan designed by female sex worker peer educators .....	191
11.5 Contribution to knowledge .....	193
11.6 Limitations of the study .....	194
11.7 Recommendations .....	195
11.8 Conclusion.....	196
<b>Appendix A</b>	
<b>Intervention Mapping – Step 5: Planning Programme Adoption, Implementation and Sustainability .....</b>	<b>199</b>
<b>Appendix B</b>	
<b>Intervention Mapping – Step 6: Evaluation Plan .....</b>	<b>202</b>
<b>Appendix C</b>	
<b>Impact evaluation .....</b>	<b>206</b>

<b>Appendix D</b>	
<b>Ethics Approval Letter.....</b>	<b>212</b>
<b>Appendix E</b>	
<b>Gatekeepers Letter .....</b>	<b>213</b>
<b>Appendix F</b>	
<b>Informed Consent .....</b>	<b>214</b>
<b>Appendix G</b>	
<b>Interview Guides .....</b>	<b>218</b>
<b>References.....</b>	<b>220</b>

## List of Figures

---

Figure 1. Systematic reviews and meta-analysis flow diagram showing phases of literature search (Hopman-Rock & Westhoff, 2000).....	39
Figure 2. Narrative paradigm in the reflexivity framework (Gilbert & Sliep, 2009) .....	53
Figure 3. Laverack’s empowerment continuum (adapted from Laverack, 2004).....	60
Figure 4. Critical reflexivity within the context of the bioecological system (adapted from Bronfenbrenner, 1994) .....	69
Figure 5. Intervention Mapping Planning Framework (adapted from Bartholomew et al., 1998) .....	72
Figure 6. Study setting maps (ShowMe, 2020).....	73
Figure 7. Themes and subthemes for Chapter 7 .....	107
Figure 8. Themes and subthemes for Chapter 8 .....	127
Figure 9. Process of pre-exposure prophylaxis awareness and distribution by female sex worker peer educators .....	133
Figure 10. Themes and subthemes of Chapter 9.....	139
Figure 11. Synopsis of personal and environmental factors affecting pre-exposure prophylaxis uptake, adherence and retention among female sex workers (Chapters 7 and 8) .....	151
Figure 12. Logic model.....	158
Figure 13. Summary of recommendations from the literature for effective PrEP programming.....	184
Figure 14. T-shirt messages formulated by peer educators .....	189
Figure 15. Critical reflexivity framework and its role in the Walk in Hope intervention .....	193
Figure 16. Pilot study – Implementation and Evaluation Plan .....	199

## List of Tables

---

Table 1 <i>Evidence table of studies included in the scoping review</i> .....	40
Table 2 <i>Sociodemographic background of participants</i> .....	106
Table 3 <i>Demographic information of intervention working group</i> .....	152
Table 4 <i>Matrices of individual change objectives</i> .....	154
Table 5 <i>Matrices of interpersonal change objectives</i> .....	155
Table 6 <i>Matrices of environmental change objectives</i> .....	155
Table 7 <i>Theory-based methods</i> .....	159

## Acronyms and Abbreviations

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CDC	Centers for Disease Control and Prevention
FSWs	Female sex workers
HIV	Human immunodeficiency virus
KZN	KwaZulu-Natal
MaTCH	Maternal Adolescent and Child Health
MSM	Men who have sex with men
NGO	Non-governmental organisation
PAR	Participatory action research
PEP	Post-exposure prophylaxis
PEPFAR	President's Emergency Plan for AIDS Relief
PrEP	Pre-exposure prophylaxis
SANAC	South African AIDS Council
STI	Sexually transmitted infections
SWEAT	Sex Worker Education and Advocacy Taskforce
TB	Tuberculosis
TDF	Tenofovir
TDF-FTC	Tenofovir-emtricitabine
TFV	Tenofovir vaginal gel
UKZN	University of KwaZulu-Natal
UNAIDS	Joint United Nations Programme on HIV/AIDS
USA	United States of America
Wits RHI	Wits Reproductive Health and HIV Institute
WHO	World Health Organization

# Chapter 1

## Introduction

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### 1.1 Introduction

The act of exchanging sex for money or goods has been in existence among mankind for centuries. Women who were associated with this practice were referred to as harlots or prostitutes.

The term 'prostitution' comes from a Latin word *prostituta* which is derived from the words *pro + statuere* which means to 'cause to stand', which refers to the practice of standing in public to solicit clients ... for sexual activity in return for payment, but it can also mean to sacrifice of a person's self-respect for the sake of personal or financial gain (South African Law Reform Commission, 2009, p. 9).

Prostitution is said to have its origins in the pagan temples of ancient Babylon where women used their bodies as offerings to the goddess of love (Ringdal, 2007). Brothels have existed in ancient Greece and prostitution was legal and taxed in Rome. Prostitution was also common and rampant during the Middle Ages where prostitutes occupied demarcated areas, similar to today's red light districts (McClure & Faraone, 2006). Around the 16<sup>th</sup> century, the onslaught of syphilis, which was believed to have spread through prostitution, brought disdain towards this practice and attitudes towards prostitution began to change (Sarbu, Matei, Benea, & Georgescu, 2014). The association of prostitution with diseases started early, and with the rise of Christianity that values marriage and monogamy, prostitution was denounced. A practice once associated with ancient religion, degenerated into a stigmatised abhorrent activity associated with illness, condemnation, and a general breakdown of a person's life (Brundage, 2009).

Currently, there are two polarised feminist schools of thought, namely the anti-prostitution group and the pro-sex work movement. The former, which is influenced by patriarchy and religious morality, is of the view that prostitution is exploitative, and is a form of slavery that serves a misogynistic patriarchal system (Mgbako & Smith, 2009). This group strongly believes that women in prostitution need to be rescued and they do not believe that women have any agency but are downtrodden by the oppressive patriarchal capitalist system. In contrast, the pro-sex work movement is adamant that the exchange of sex for money between two consenting adults of legal age, which in most countries is above 18, should be viewed as

work, and be attributed similar human and labour rights like any type of work and should be legitimised and non-criminalised (Mgbako & Smith, 2009). This doctoral research takes a pro-sex work approach with the recognition of female sex workers (FSWs) agency and their ability to articulate their needs and inform interventions targeted at them. Over the years, the pro-sex work group has become highly vocal in an effort to drown out the voices of the sex work abolitionists. This is being done through sex work organisations that have been formed in different parts of the world (Kempadoo & Doezema, 2018). In some Western countries, sex work is legalised, which means that sex workers have to follow certain government restrictions such as compulsory health check-ups as well as operating in demarcated areas known as red light districts. They are also obligated to pay tax like any other employed individual. However, sex workers prefer the decriminalisation framework which places no restrictions on the trade (Open Society Foundations, 2015).

In South Africa, sex work is criminalised, which means that sex workers are jailed on the basis of the Sexual Offences Act, Act 23 of 1957, which states that any person who has unlawful carnal intercourse (sexual intercourse taking place between unmarried persons who are underage (under the age of 16 years) or sex for a reward) or commits acts of indecency with any other person for reward, commits an offense (South African Law Reform Commission, 2009). The law has also been amended to include those who buy sex to also face criminal charges. It has become increasingly difficult for law enforcement to prove that people are engaging in these kinds of 'sexual offenses', thus sex workers have been detained by contravening municipal by-laws and are jailed on the basis of loitering. In some instances, police officers have used the carrying of condoms by sex workers as proof of engaging in sex work (Open Society Foundations, 2015). The criminalisation of sex work has created an environment where sex workers are marginalised. This has had a ripple effect because it has contributed to their violation from the hands of clients and the police. Thus, because of societal stigma and discrimination, female sex workers (FSWs) face challenges in accessing health care and keeping themselves free from the risk of human immunodeficiency virus (HIV) (Howard, 2019). The legal and structural constraints have contributed to their vulnerability since they do not receive protection from any societal structure. This ostracism has rendered them hidden and hard to reach with health care services. Another reason for governments to criminalise sex work is because of the notion that sex work will fuel human trafficking, which is a belief not backed by any empirical evidence (Armstrong, 2017). However, recommendations from researchers have been that a non-criminalised environment for sex workers could provide an

opportunity for collaborative efforts where sex workers help the police in tracking down minors who have been trafficked (Albright & D'Adamo, 2017).

Due to the reasons mentioned above, FSWs in different parts of the world, particularly in countries with a high HIV prevalence, are considered a risk population in relation to HIV, and generally have a high prevalence compared to other women. In sub-Saharan Africa, which is known as the epicentre of the epidemic, women constitute 56% of all people living with HIV, and FSWs are a subset of this population that has a high HIV incidence and prevalence (Eakle et al., 2019). FSWs in this region are 13.5 times more likely to be HIV positive than women in the general population (Baral et al., 2012; Chersich et al., 2013; Shannon et al., 2015). In South Africa, HIV prevalence among FSWs is estimated to be 57.7%, which is higher than the prevalence of 20.4% among the general population (Avert, 2020). A survey conducted among FSWs in three South African cities reported an HIV prevalence of 71.8% in Johannesburg, 39.7% in Cape Town and 53.5% in Durban (Eakle, Bourne, Mbogua, Mutanha, & Rees, 2018; Grasso et al., 2018). Research shows that FSWs in South Africa are knowledgeable about HIV, the vast majority of FSWs have tested for HIV, and more than three quarters who are HIV positive are aware of their status (South African AIDS Council, 2016). However, despite knowledge, HIV prevalence among FSWs in South Africa remains high.

A significant number of research has been conducted worldwide towards the management and prevention of HIV. Research from various studies and clinical trials have proven the effectiveness and efficacy of programmes such as prevention from mother-to-child transmission, voluntary male medical circumcision, universal test and treat and the recent provision of pre-exposure prophylaxis (PrEP) (Dehne et al., 2016; Eakle, Mutanha, et al., 2018). The combination of these prevention programmes have somewhat contributed to the relative decline of HIV infections. Statistics show that new adult HIV infections in Southern Africa have declined by 50% in Malawi, Namibia and Tanzania and by 48% in South Africa. Despite this progress, new infections amounting to 1.9 to 2 million were occurring worldwide between 2010 and 2015 (Dehne et al., 2016). Furthermore, according to Dehne et al. (2016), countries with effective antiretroviral treatment programmes have seen a decline in HIV infections; however, this was not sufficient to end the HIV epidemic. A combination prevention approach comprising of both treatment and prevention is needed to reduce new adult HIV infections to 500 000 by 2020 and 200 000 (90%) by 2030, and ultimately ending AIDS by 2030 (World Health Organization [WHO], 2016).

A lack of access to good and effective health care services by key populations is a persistent challenge. These groups, which consist of injecting drug users, sex workers, gay men and other men who have sex with men (MSM), transgender people, young women and adolescent girls, face a disproportionately high HIV incidence and prevalence because of frequent exposure to HIV risk (WHO, 2017). It is thus important to have targeted tailored HIV prevention interventions and services for these groups, which include condoms, lubricants, antiretroviral treatment and PrEP (Dehne et al., 2016; WHO, 2016).

PrEP is an antiretrovirals given to HIV-negative people to prevent them from acquiring HIV. The introduction of oral PrEP (tenofovir and emtricitabine) among high-risk groups where HIV incidence exceeds 2–3 in 100 persons, as per the WHO guidelines (2015), was aimed at ensuring that those who are at high risk of contracting HIV have an additional prevention method to use concurrently with condoms (Eakle et al., 2019). The target is to ensure that three million people are on PrEP by 2020 (Dehne et al., 2016). Various randomised control trials have been conducted to test the efficacy of oral PrEP. These trials have been conducted among MSM, transgender women and serodiscordant couples where it was found that PrEP is highly effective in preventing HIV infection, provided that the user takes it consistently at the same time every day (Mack, Odhiambo, Wong, & Agot, 2014). Some countries in Southern Africa are currently implementing or piloting PrEP.

At the end of 2015, in a quest to reduce HIV among FSWs, the South African government committed to the distribution of oral PrEP as part of HIV combination prevention among FSWs as per WHO guidelines (2015). However, the distribution of PrEP did not automatically result in overwhelming numbers of FSWs taking up PrEP or adhering to it as the medical community had hoped. The PrEP distribution campaigns accompanied with a generic message for all groups targeted (*We are the generation that will end HIV*) tacitly assumed that FSWs will take PrEP to prevent HIV because that is rational behaviour, but so far, one of the early PrEP studies conducted at two clinics in Johannesburg and Pretoria that offer PrEP and antiretroviral treatment to sex workers showed that among the 642 women tested for HIV, 49% tested positive, 93% were eligible for antiretroviral treatment and 94% for PrEP; of those eligible, 98% took up PrEP and 94% took up antiretroviral treatment. However, at the end of the 12-month period, only 22% remained on PrEP, while 60% remained on antiretroviral treatment. The women cited reasons such as forgetting to take PrEP daily due to alcohol and drug use, the side effects of PrEP, as well as moving to another location, as deterrents to retention. The study concluded that long-term commitment to PrEP was a challenge (Eakle et al., 2017).

## **1.2 Problem statement**

Research on FSWs, and a broader body of research on vulnerable populations such as adolescents and MSM, has shown that individuals' behavioural decisions are influenced by a wide range of factors; in essence, individuals make decisions and act according to their priorities for living and perceived constraints upon their options (Coates, Richter, & Caceres, 2008). Research to date on PrEP programmes targeted at FSWs showed that promoting the use of PrEP was a more complex task than it might seem. It was therefore important to understand the complexities that may arise with promoting uptake of PrEP among FSWs.

Campaigns on HIV prevention in South Africa generally assume that once people are educated about HIV, they will engage in safer sexual practices to prevent getting infected with HIV. However, an indicator that this assumption is not valid in the case of interventions with FSWs, is that while most FSWs are knowledgeable and aware of the threat of HIV to their health, HIV prevalence among FSWs continues to increase (Gomez et al., 2017; Lancaster et al., 2016; Schwartz et al., 2017). Likewise, while widespread and consistent use of PrEP by FSWs would reduce new HIV infections among this group, there were already indications from some studies that FSWs do not immediately subscribe to using PrEP as a way to prevent HIV infection (Eakle et al., 2017). The problem that this study sought to address was to identify the reasons for low PrEP uptake and retention among FSWs, as well as to engage FSWs on what they think would be effective ways to improve PrEP uptake and retention amongst the sex work population.

## **1.3 Study rationale**

Through research PrEP efficacy has been established, however, limited insights have been gained concerning lack of support for and use of PrEP by FSWs, despite evidence that PrEP can significantly reduce risk of HIV infection among those who engage in 'high-risk' sex. To reduce HIV prevalence in South Africa FSWs are an important population to target, particularly with the aim of understanding their preferences pertaining to effective HIV prevention interventions. Therefore, current PrEP outreach initiatives for FSWs in South Africa are yet to address FSWs reasons for not using PrEP, by including appropriate sub-interventions in programme protocols developed in partnership with FSWs on what would encourage and enable FSWs to take PrEP regularly (adherence and retention). This study therefore focuses on addressing this need by developing a participatory intervention for and with FSWs to increase

their uptake and adherence to PrEP. To this end, the intervention mapping planning framework was used to ensure a deliberative, systematic but also participatory process involving FSW peer educators in developing a PrEP intervention programme for FSWs in a phased approach. The first phase, that is, the needs analysis, required the examination of the personal and environmental challenges that FSWs experience that hinder their involvement in the use of PrEP. Thus, an in-depth examination of the constraints and opportunities for the uptake, adherence, and retention of PrEP was conducted among a range of stakeholders. Using the critical reflexivity framework and the Bronfenbrenner's bioecological model as a theoretical lens, this phase of the study sought to understand the environmental constraints, and how individual and collective agency, values and power relations play a role in facilitating behavioural change. In the second phase, data from the needs analysis was used as a basis for identifying change and performance objectives and engaging the working group consisting of FSW peer educators in a participatory action research process to develop key components of the intervention. This process was guided by an intervention theory of change logic framework, and theory based activities of the intervention programme using a workshop approach. This process took the form of subsequent dialogues through a reflexive process of knowledge sharing and deliberations to provide practical suggestions for a human-centred and effective PrEP programming as well as reflecting and improving on ways the FSW peer educators conducted PrEP outreach. Furthermore, the study aimed to provide a deeper understanding of the factors that need to be considered in the design and implementation of PrEP interventions for FSWs. The future vision will be to subject the developed workshop programme to a pilot study before wider implementation among FSWs. This, however, is beyond the scope of this thesis.

#### **1.4 Study objectives**

The objectives of this study were as follows:

1. To map and outline the strategies that have been recommended in the literature to inform pre-exposure prophylaxis interventions for female sex workers.
2. To conduct a needs analysis in order to:
  - a. To identify the barriers and facilitators of pre-exposure prophylaxis use among female sex workers.
  - b. To explore the personal motivations for pre-exposure prophylaxis use among female sex workers.

3. To outline the methodological processes of a pre-exposure prophylaxis programme for female sex workers, designed by female sex worker peer educators.
  - This involved formulating intervention performance and change objectives informed by the needs analysis (Objectives 2 and 3).
  - A theory of change logic framework was constructed, informed by the change objectives to systematically map the intervention resources and activities, inputs, outputs and outcomes to achieve pre-exposure prophylaxis uptake, adherence and retention.
4. To assemble and prioritise the intervention components and theory-based activities into a coherent pre-exposure prophylaxis preliminary intervention workshop programme for female sex workers to encourage pre-exposure prophylaxis uptake, adherence and retention.

## **1.5 Research questions**

This study answered the following research questions:

1. What are the strategies that have been recommended in the literature to inform pre-exposure prophylaxis interventions for female sex workers?

Questions answered by the needs analysis:

2. What are the barriers and facilitators of pre-exposure prophylaxis use among female sex workers?
3. What are the personal motivations for pre-exposure prophylaxis use among female sex workers?

Questions answered through the intervention mapping:

4. What are the methodological processes of a pre-exposure prophylaxis intervention plan designed in collaboration with female sex worker peer educators?
5. How to best prioritise and assemble the outputs of the planning and participatory processes into a coherent preliminary workshop intervention programme for female sex workers to encourage PrEP uptake, adherence, and retention?

The operationalisation of the above objectives was as follows:

Objective 1: A scoping study was conducted to systematically review and report findings from the literature on the strategies proposed to inform PrEP intervention programmes for FSWs. This evidence was used to inform the approach of the PrEP intervention plan designed in this thesis.

Objectives 2a and b: A needs analysis was conducted and through key informant interviews and focus group discussions, data on the barriers and facilitators of PrEP use was generated, as well as understanding the motivational factors for PrEP use among those FSWs taking PrEP consistently.

Objective 3: An intervention mapping of key learning and performance objectives was conducted based on the results from Objective 2. The outcome of this process was shared with a group of FSW peer educators who formed part of a small working group and they collaborated in the design approach and activities for the creation of a community-based intervention plan that demonstrates how PrEP uptake and retention can be improved among FSWs.

Objective 4: A participatory process with the FSW working group was followed in the prioritisation of key programme objectives. Thereafter the different components were assembled into a coherent preliminary intervention workshop programme that shows how PrEP uptake, adherence and retention can be achieved.

## **1.6 Structure of the thesis**

The thesis is divided into the following eleven chapters:

Chapter 1:

This chapter covers the background of the study and outlines the origins of sex work and the rights-based stance that this thesis took in choosing to use the label of *sex worker* as opposed to *prostitute*. It describes the structural and behavioural factors that have contributed to the high HIV prevalence among FSWs, leading to the introduction of PrEP in South Africa. The problem statement and study rationale are outlined in this chapter, including the study objectives and questions.

Chapter 2:

This chapter consists of a comprehensive review of the literature to establish the knowledge gap with regard to PrEP uptake and retention among FSWs. The literature review shows the

historical developments and transformation of the HIV/AIDS prevention landscape internationally and in sub-Saharan Africa, including the current strategies in implementing a combination of prevention efforts among high-risk groups.

#### Chapter 3:

A systematic scoping review of the literature is presented in this chapter to map out existing evidence that informs PrEP interventions. The evidence presented in this chapter further crystallises the knowledge gap and promotes the need for participatory community-based PrEP interventions among FSWs, including other recommendations for PrEP programming.

#### Chapter 4:

The critical reflexivity framework and the Bronfenbrenner's bioecological model are the two theoretical frameworks that inform the study. These theoretical frameworks are discussed in relation to their application in this study both conceptually and theoretically, providing a lens with which to understand challenges associated with HIV prevention among FSWs as well as how PrEP programming can be approached among FSWs.

#### Chapter 5:

This chapter outlines the study setting, the intervention research paradigm, and the Intervention Mapping Planning Framework that was used for the development of the intervention as well as the methodological process of the needs analysis which is the first phase of this study as well as the intervention mapping process, which is the second phase. Furthermore the study sample and sampling method, data collection tools, process of data analysis and verification are discussed. This chapter also attends to the ethical considerations for the overall study.

#### Chapter 6:

This chapter explores my research reflexivity. I describe how my work with sex workers began and the intersection between my moral judgements, and the expectations of being objective as a researcher. In this chapter, I describe how, as a researcher, I attempted to resolve the disconnect and immerse myself in a world that I found both scary and fascinating, and emerging with a deep understanding and connection to my study participants and how these insights have influenced my decision to engage in participatory action research with FSWs.

#### Chapter 7:

This is the first chapter of results entitled "Challenges Associated with Oral Pre-exposure Prophylaxis among Female Sex Workers in Durban, South Africa." The results in this chapter

are divided into three main themes and subthemes: Theme 1: PrEP stigma, with subthemes: PrEP being marketed for high-risk groups; inability to differentiate PrEP from antiretrovirals for people living with HIV; and contradictory messages from PrEP distributing organisations and public health facilities. Theme 2: FSWs' perception of risk, with subthemes: Belief among FSWs that all FSWs are HIV positive; and underage girls and new entry FSWs being less likely to take PrEP. Theme 3: PrEP and interpersonal relationships, with subthemes: Conflict between those taking PrEP and their intimate partners; conflict between FSWs on PrEP and FSWs on antiretroviral treatment; and concern that PrEP will jeopardise their hidden sex work identity. The results of this chapter are discussed in relation to findings from the literature with a conclusion and recommendations.

#### Chapter 8:

The second chapter of results is entitled: Personalised care provided by peer educators encouraging oral pre-exposure prophylaxis uptake and retention among female sex workers in Durban, South Africa. The results of this chapter are divided into three main themes and subthemes. Theme 1: Peer educator outreach, with subtheme: PrEP awareness and distribution. Theme 2: PrEP education, with subtheme: Perceptions of peer educators with regard to knowledge of PrEP among FSWs. Theme 3: Adherence and retention strategies, with subthemes: Management of side effects; Ensuring continuous supply of PrEP; PrEP as an injectable and patient follow-ups. The results of this chapter are discussed in relation to findings from the literature with a conclusion and recommendations.

#### Chapter 9:

The third chapter of results is entitled: Motivating factors associated with oral pre-exposure prophylaxis use among female sex workers in Durban, South Africa. The results of this chapter are divided into four main themes and subthemes. Theme 1: Agency and identity, with subthemes: PrEP as an empowering tool for HIV prevention; Taking PrEP as an expression of self-love; My body, my livelihood; and Motherhood as an identity inspiring prevention. Theme 2: Hope, with subthemes: PrEP as a source of hope; Freedom from HIV scars; Infection as an inevitable outcome. Theme 3: Life beyond sex work, with subthemes: Studies as preparation for a better future; Entrepreneurship. The results of this chapter are discussed in relation to findings from the literature with a conclusion and recommendations.

#### Chapter 10:

This chapter is titled: Developing a sex worker-led community intervention plan to improve pre-exposure prophylaxis uptake and retention in South Africa: An intervention mapping approach. In this chapter, the process of intervention mapping is documented, the first four steps of intervention mapping are described, and the results are presented under each step. Step 1 is a needs analysis; Step 2 consists of matrices of change; Step 3 demonstrates the theory-based methods that inform the process of change; and in Step 4, the compiled intervention workshop programme for FSWs is presented.

#### Chapter 11:

This chapter is a synthesised conclusion of the thesis and includes the contribution that this thesis makes to the body of knowledge, study limitations and recommendations for future research.

## **Chapter 2**

### **The Global Emergence of HIV/AIDS Research Prevention and Treatment**

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#### **2.1 Introduction**

In this chapter the literature on the development of HIV prevention strategies is reviewed, starting with a brief history pertaining to the discovery of HIV and AIDS in the 1980s among gay men to how the epidemic advanced as one of the greatest health threats to humanity from the 20<sup>th</sup> century right into the 21<sup>st</sup> century worldwide. This review further shows how sub-Saharan Africa became the epicentre of the epidemic. Furthermore, various prevention methods are described and how they were implemented leading to the introduction of PrEP as an HIV prevention method for high risk groups. The knowledge gap has been identified in the literature and how this study addresses this gap and where the argument for this thesis lies in relation to the larger PrEP discourse.

#### **2.2 Background of HIV/AIDS major breakthroughs**

Since the discovery of HIV/AIDS among gay men in the early 1980s in the United States of America (USA), there has been a continuous search for a cure which resulted in the discovery of prevention technologies that have since reduced the number of AIDS-related deaths worldwide (Greene, 2007; Smith & Whiteside, 2010; Joint United Nations Programme on HIV/AIDS [UNAIDS], 2008). The year 2000 was ushered in with the American government pledging to donate six million dollars towards HIV/AIDS and Tuberculosis (TB) prevention programmes in Africa. At the time it was reported that 5 000 Africans were dying daily from AIDS (Centers for Disease Control and Prevention [CDC], 2017). In 2002, financial efforts were focused on funding research to reduce mother-to-child transmission of HIV. More funds towards the reduction of HIV/AIDS, particularly in developing countries, were allocated through the US President's Emergency Plan for AIDS Relief (PEPFAR). In 2004, the CDC further released guidance for testing pregnant women during labour, particularly women with unknown HIV status so as to protect the unborn baby (Branson, Handsfield, Lampe, Janssen, Taylor, Lyss, & Clark, 2006). In the same year, PEPFAR launched their antiretroviral programme in 13 countries. From 2005 to 2009 more research was dedicated to HIV and AIDS with the discovery of post-exposure prophylaxis (PEP) which are antiretrovirals to be taken

within 72 hours of exposure to HIV. The initial target group for PEP became rape survivors (Greene, 2007).

In 2006, the focus shifted to the testing of adolescents and the recommendation was that people from the age of 13 to 64 should be screened for HIV at least once. That was the beginning of routine screening for HIV as part of medical care in the USA (Branson et al., 2006). In 2007, the CDC emphasised the importance of adherence on antiretroviral treatment to prolong the lives of people living with HIV and prevent the virus from advancing into AIDS, as well as the importance of male circumcision in reducing the chances of HIV infection among circumcised men (AIDS.gov, 2020; Watkins-Hayes, 2014). The Global Health initiative was announced in 2009 to focus on global health through PEPFAR. The Shuga initiative was also developed which promoted HIV/AIDS prevention among young people in Kenya, Nigeria, and Botswana through educational entertainment. The law against people living with HIV not being permitted to enter the USA was lifted in 2010. This was also coupled with emerging research that PrEP could prevent HIV transmission in HIV-negative people, and an HIV-positive person taking antiretroviral treatment consistently can reduce their viral load, eventually rendering the virus undetectable and therefore untransmittable. Through this discovery, transmission was reduced by 96%, which was the start of treatment as prevention (CDC, 2017; Greene, 2007). This was also the start of PrEP efficacy trials among MSM and serodiscordant partners in the USA.

In 2014, after considerable research through randomised control trials, PrEP was tested and found effective in preventing HIV transmission. The CDC released new clinical guidelines recommending that PrEP be given to patients who are at substantial risk for HIV. During this period, the CDC focused specifically on key populations, particularly MSM in the USA, when it observed increases in HIV infections among young gay men. Research also showed gaps in the accessing of health care services by gay and bisexual men and that only half were receiving HIV treatment. In 2016, the CDC focused on PrEP and reducing new infections among high-risk groups (CDC, 2017). However, it is important to understand that before the onset of this consolidated response to HIV/AIDS, the early 1980s and 1990s harboured a harrowing history of AIDS marred by silence, apathy, and death.

### **2.3 HIV in the 1980s and 1990s**

The approach of various governments globally and in the African context to the HIV epidemic during the early 1980s, was one marred with silence, and an unresponsiveness even in the face

of strong research evidence indicating the rising numbers of infections and deaths. Instead, as the attitude of avoidance prevailed, it was easy for governments to be dismissive of HIV because of the time it took for HIV infections to manifest as symptoms to full-blown AIDS (Greene, 2007; Iliffe, 2005). Thus, funding directed to HIV was limited and there was little to no support for those living with HIV. In low- and middle-income countries, HIV was seen as another added burden to the already struggling economies and underfunded health care systems, compounded by the prevalence of other diseases such as malaria and diarrhoea that were responsible for many deaths among children and adults (UNAIDS, 2008). By 1987, it was already too late to curb the spread of HIV, which was now estimated to have infected several million Africans (Black History Editorial Team, 2015).

World leaders refused to engage in dialogue about HIV. It was only in 1985 that American President Ronald Reagan made pronouncements on AIDS (Greene, 2007). In Africa, President Mobutu of the Congo banned the mention of HIV in the press for four years between 1983 and 1987 (Iliffe, 2005). Doctors in Zimbabwe were instructed not to mention AIDS as the cause of death when issuing death certificates. The white government in South Africa did not respond actively to AIDS and refused to have it taught in schools. In Zambia, President Kaunda refused to speak to the international press about AIDS; however, three years later he announced that he had lost his son to AIDS, becoming one of the first African presidents to speak up on the need to combat the epidemic (UNAIDS, 2008). Another outstanding example was that of the Ugandan government under President Museveni, who in 1987, through the Ugandan AIDS control programme, formulated a five-year plan in collaboration with the WHO to respond to HIV/AIDS in a way that was frank and decisive. HIV/AIDS was addressed openly for all to know of its existence and transmission. Other African governments did not display the same openness and preferred not to confront the epidemic (Thomas, 2015). The slow response by governments resulted in nearly 25 million AIDS deaths globally since 1981 (Greene, 2007; UNAIDS, 2008).

The spread of HIV in the 1980s in Africa is said to have started in West Africa and moved to East Africa (Iliffe, 2005). This spread was facilitated by the migrant labour system with men moving into urban areas in search of employment. The transmission rate in East Africa was said to have accelerated because Nairobi consisted of a growing sex work industry and it was alleged that by 1986, 85% of sex workers were infected with HIV (Black History Editorial Team, 2015). In the same year, 27% of sex workers in Kinshasa were said to be infected (Iliffe, 2005). Ugandan doctors referred to the virus as 'wasting disease' or 'slim disease'. Similar

opportunistic infections such as Kaposi's sarcoma seen in African patients, were observed by doctors in the USA among white homosexual males (Greene, 2007). It was difficult to make the connection because these two continents were far apart. However, through research, links were made between the 'slim disease' and AIDS (Quinn, Mann, Curran, & Piot, 1986; UNAIDS, 2008). By the end of the 1980s, HIV prevalence in countries such as Uganda was recorded to be 30% among pregnant women. The epidemic had also infiltrated West Africa but not in high proportions as East Africa, one of the possible reasons being a high prevalence of male circumcision in West Africa, which has been shown to reduce HIV acquisition by approximately 60% (Gazimbi, Magadi, & Kruger, 2019). The first few cases were reported in Côte d'Ivoire due to migration and urbanisation, and by the end of the decade, HIV was identified in all major West African states. The main contributing factor was attributed to sex work and prevalence among this group was allegedly 38%. Evidently, the narrative about sex workers being the vectors of disease was being formed as early as the 1980s, which has resulted in the current ongoing stigma and discrimination being experienced by sex workers to date (Ilfiffe, 2005). Sex workers were linked to long distance truck drivers, soldiers and miners because of their rapid mobility that facilitated the spread of HIV between countries and regions. Thirty-five percent of truck drivers and 30% of military personnel were said to have tested positive in Uganda and 36.7% of sex workers were tested positive in Guinea-Bissau (Black History Editorial Team, 2015; Ilfiffe, 2005). The second highest prevalence was found in Tanzania and spread through to Zambia, and further progressed through to Malawi, Mozambique, Zimbabwe and Botswana. By the end of the 1980s, Southern Africa was starting to display a higher prevalence than East Africa (Greene, 2007).

During this time, there was a lot of mystery and confusion about how the virus was transmitted. It became clear through research by scientists Luc Montagnier from the Pasteur Institute in Paris France and Robert Gallo from the National Institute of Health in the USA, that HIV was the virus that caused AIDS and was transmitted through blood and semen (Greene, 2007; Ilfiffe, 2005; UNAIDS, 2008). The misunderstandings with regard to how the virus was spread contributed to misconceptions, fear and stigma as HIV became associated primarily with promiscuity, prostitution, and high-risk lifestyles. The religious sector further fuelled these beliefs by propagating the notion that AIDS was a punishment from God for anyone who behaved sexually inappropriately or engaged in 'unnatural' sexual acts. This referred mainly to gay men, sex workers, injecting drug users and some minority groups such as Haitians living in the USA (Greene, 2007; UNAIDS, 2008).

The poor leadership in African countries, which was further incapacitated by corruption and plagued by poverty and hunger, were now dealing with an increasing epidemic with limited resources for response. Prevention campaigns were having a minimal effect and there were no prospects of implementing antiretroviral treatment. However, the situation in East Africa was slowly beginning to change in the mid-1990s, with HIV prevalence in Uganda dropping from 30% to 12% between 1992 and 1998 due to the government's rapid response in conscientising the nation to HIV/AIDS through open dialogue. However, the same could not be said of the rest of sub-Saharan Africa which had now become the epicentre of the epidemic, which reported estimated cases of nine million infections out of the global 14 million infected with HIV. In 1998, it was estimated that 70% of all people would become infected yearly and one in seven people being infected in South Africa. These high levels of infections were fuelled by limited knowledge, resistance to behavioural change and stigma (Thomas, 2015).

While most governments remained silent during this unprecedented epidemic, there was a raging unrest in civil society. Civil society consists of non-governmental structures such as non-governmental organisations (NGOs), faith-based organisations and other rights-based groups (Blas et al., 2008). HIV/AIDS activism started to take hold as early as the 1980s. The AIDS activist movements started by gay and lesbian activists in North America, such as the AIDS Coalition to Unleash Power, was launched as early as 1987 (Parker, 2011). Civil society movements spread to Europe and Latin America and to the rest of the world. The AIDS Support Organisation, founded in Uganda, is another early example of a civil society organisation that advocated for 'living positively with AIDS'. This organisation's efforts of community-based care became a blue-print for other HIV organisations worldwide. These organisations were pressuring governments to give attention to AIDS. They advocated for AIDS funding, challenged pharmaceutical companies on the exorbitant pricing of antiretrovirals and pressed governments to provide care and HIV treatment (Parker, 2011). Most importantly, activists used their voices to sound alarm of the silent killer by creating community awareness through community outreach and these organisations also played a pivotal role in providing home-based care to AIDS patients when hospitals no longer had capacity. These civil society movements presented HIV care as a basic human right and stood up for those who were now stigmatised for being HIV positive (Blas et al., 2008; UNAIDS, 2008).

## 2.4 HIV/AIDS in South Africa

Evidence of HIV in South Africa was said to have been discovered in a gay white male from the USA who died of an opportunistic infection (pneumonia), and there was a 16% infection rate among gay men who had been tested in Johannesburg. The discovery of HIV among gay men has also contributed to stigma toward MSM. In fact, upon its discovery among gay men in the 1980s, the disease was first identified as the gay disease (gay-related immune deficiency syndrome or GRID) (UNAIDS, 2008). The ushering in of a democratic South Africa in 1994 with the African National Congress coming into power, resulted in the restructuring and expansion of the primary health care system to include black Africans who were marginalised during apartheid (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). The government's inheritance of a broken fragmented system that was divided through racial lines posed a challenge, which made it even more difficult to respond rapidly to the growing epidemic (Coovadia et al., 2009). Statistics show that HIV prevalence in 1990 was 0.8%, which rose to 4.3% by 1994. The African National Congress government had its own pressing socio-economic concerns and distanced themselves from AIDS organisations, who were fighting for HIV/AIDS to be recognised as a state of emergency, a necessity for government to provide widespread awareness and treatment (Simelela & Venter, 2014). Due to this inaction from the government, the purpose of the Treatment Action Campaign, founded and led by activist Zackie Achmat, was to put pressure on the government to provide HIV treatment in South Africa (UNAIDS, 2008).

The approach of the South African democratic government to HIV/AIDS was one of ignorance and silence. The Thabo Mbeki era was marred with HIV denialism and misinformation (Nono Simelela, Venter, Pillay, & Barron, 2015). Highly Active Antiretroviral Treatment (HAART) for HIV-positive people was not being provided, coupled with the apprehensiveness of the then-President Thabo Mbeki had about whether HIV causes AIDS and whether antiretroviral treatment was the solution in treating HIV. Hence, the recommendations by the then Minister of Health, Dr Manto Shabalala Msimang, who encouraged people living with HIV to eat vegetables such as beetroot and garlic. This state of denialism further delayed progress in curbing the spread of the disease. HIV prevalence increased in the majority of the population who were black (Simelela & Venter, 2014). The provinces hardest hit by the epidemic were KwaZulu-Natal (KZN) (32.5%) and the Free State (27.9%), and they also had high unemployment rates (Avert, 2019a).

The majority of black people had a low socio-economic status, which coincides with research showing that HIV was most prevalent among poor people. South Africa is also a young population with 45% of the population being under the age of 20. There was also a high prevalence being reported among adolescent girls and young women, with over 60% of infections occurring among individuals aged 15–25 years of age, with women (35%) getting more infected than men (29%) in the same age groups (Coovadia et al., 2009). The epidemic, having been highly prevalent among the working group of the population, meant that the commercial sector suffered greatly with absenteeism and ill health in the workplace; this also meant that there was a growing number of AIDS orphans. The health care system was not able to cope with the number of people seeking treatment for opportunistic infections. The refusal of government to provide treatment meant that millions of infected South Africans were dying each year (Simelela & Venter, 2014). Research had projected that by 2010, four million South Africans would have died of AIDS.

It is upon this backdrop that South Africa's history with HIV/AIDS was established. It was also evident that South Africa's focus when it came to HIV/AIDS interventions would be on heterosexual transmission of HIV, to the neglect of preventive interventions among homosexuals, as well as minimal attention given to hidden and marginalised groups such as sex workers. This was also in part due to limited resource allocation and competing interests. Resulting in an uncontrolled and poorly documented rise in HIV prevalence among these marginalised groups (Gilbert & Walker, 2002).

South Africa's HIV history is one that started with a sense of hopelessness to that of triumph. Through civil society organisations, the democratic government was compelled by the law, and the Constitution of the Republic of South Africa (1996) to provide HIV treatment. This started with the provision of treatment for mother-to-child transmissions in 2002, as well as the provision of PEP, specifically to survivors of sexual assault (Barron et al., 2013; Venter, 2014). In 2002, protocols were drawn, and plans were made to expand HIV treatment to all adults who needed it. This was further made possible through various donor funders such as the Bill and Melinda Gates Foundation, Global Fund and PEPFAR. On 1 April 2004, South Africa implemented what would be one of the biggest antiretroviral treatment programmes in the world (Simelela & Venter, 2014). Like with any programme, there were initial implementation challenges, but by 2005, 85 000 people were receiving antiretroviral treatment from the public health sector. The 2006 National Strategic Plan, compiled by the South African National AIDS Council, reflected government's target to provide antiretroviral treatment to at least 80% of

those who were eligible and reduce HIV incidence by 50% (Venter, 2014). The Jacob Zuma administration, which came into power in 2009, bought about an accelerated approach to HIV prevention with a mass HIV testing campaign, with Aron Motswaledi as the new Minister of Health. They ensured that every facility in the country would be equipped to provide antiretroviral treatment, the target being to test 20 million people (Simelela & Venter, 2014). Evidence detailing the impact of male circumcision in reducing the chances of HIV infection by 60% in circumcised males, was found compelling (Padian, Buvé, Balkus, Serwadda, & Cates Jr, 2008; Prodger & Kaul, 2017). The Minister of Health and President Jacob Zuma launched the nationwide male circumcision drive, starting in KZN where HIV prevalence was the highest, which also had the highest number of uncircumcised males due to cultural reasons. By the end of 2010, a total of 131 117 males were circumcised. By 2013, statistics showed that there were 2,3 million people on antiretroviral treatment in South Africa (Simelela & Venter, 2014).

Significantly, on World AIDS Day in 2011, the third National Strategic Plan was launched and for the first time it included a strong focus on marginalised and high-risk groups (sex workers, MSM, truck drivers and adolescents) (Simelela & Venter, 2014). The inclusion of these key populations in the National Strategic Plan did not mean a change in the socio-economic circumstances that make them susceptible to HIV infection. This thesis focuses on FSWs, and the proceeding paragraphs will outline the vulnerabilities faced by FSWs that render them at risk for HIV infection, despite the remarkable developments in curbing HIV in South Africa.

## **2.5 HIV prevention campaign strategies**

Initial HIV prevention campaigns were simplistic in their approach and focused mainly on individual behavioural change. The *Abstinence, be Faithful, use a Condom* model was promoted in response to a growing epidemic in sub-Saharan Africa. However, this model was not as effective because new infections continued to rise. In 1996, the epidemic in the sub-Saharan Africa region had peaked to 3.4 million new infections. Following the early 2000s it was evident that HIV prevention needed to be comprehensive and respond to the underlying socio-economic, cultural, political, and legal factors that drive the epidemic. Thus, the approach to HIV prevention needed to be inclusive of all the various contextual factors affecting populations in the region, hence the shift towards a combination prevention started (Hankins & De Zaluondo, 2010). Combination prevention can be defined as a holistic, rights-based, evidence-informed and community-owned approach to HIV prevention that includes

behavioural, biomedical, and structural interventions (UNAIDS, 2017). To ensure that these interventions are implemented and evaluated, they consist of specific approaches to HIV prevention; for instance, behavioural interventions that include sex education, stigma reduction programmes, counselling and cash transfer programmes (Merson et al., 2008). Furthermore, behavioural intervention may aim to reduce the number of sexual partners of individuals, to improve treatment adherence among people living with HIV, to increase the use of clean needles among people who inject drugs, as well as encourage consistent condom use. These interventions are complemented by community mobilisation, condom distribution, HIV testing and voluntary male circumcision (Kurth, Celum, Baeten, Vermund, & Wasserheit, 2011). Research also showed that an intervention aimed at HIV-negative gay men encouraged them to set personal goals and to adjust their thinking of self, which resulted in a reduction of risky behaviour (HIV/AIDS, 2016). This is one of the components of the PrEP programme in this thesis which encourages HIV-negative FSWs to set personal goals and articulate how those goals can motivate them to stay HIV negative through adhering to PrEP.

Biomedical interventions use a combination of clinical and medical approaches to reduce HIV transmission such as prevention of mother-to-child transmission, HIV testing and counselling, PrEP, PEP, treatment as prevention, male and female condoms and needle exchange programmes for drug users, as well as opioid substitution therapy. Structural interventions aim to address all the systemic and environmental factors that make it difficult for individuals or groups to engage effectively in HIV prevention (Kurth et al., 2011). These interventions address the social inequality whereby some groups have access to health care services, and some do not, decriminalisation of sex work and homosexuality. Evidently, the South African government has resisted decriminalising sex work even in the face of compelling evidence that decriminalisation will assist FSWs to engage better in HIV prevention because they will have access to wider health care services free of stigma and discrimination. Decriminalisation will also make it possible for FSWs to report abuse from clients as well as help fight against syndicates that coerce minors to sell sex (Avert, 2019a). The government continues to give into moralistic views that decriminalising sex work would lead to more people engaging in sex work. Structural interventions also look at laws protecting the rights of people living with HIV as well as increasing access to school education for young girls.

Combination interventions are tailored to suite the context with consideration of the infrastructure, local culture as well as focused attention on populations most affected by HIV. Interventions are implemented at the individual, community, and population levels. For

combination prevention to succeed it is important to prioritise community empowerment elements as well as to address legal and policy barriers and an intentional action to fight against stigma and discrimination. This coincides with the purpose of this research which aimed at shifting power to FSWs to design their own community-based intervention that addresses the barriers attached to the use of PrEP to prevent HIV. Focusing on FSWs as the main constituents of the intervention creates a sense of ownership and puts them in a better position to promote the use of PrEP as an additional prevention method, which is one of the core principles of combination prevention (Avert, 2019a; Venter, Cowan, Black, Rebe, & Bekker, 2015).

Another crucial aspect of combination prevention is the *Know your epidemic, know your response* approach that helps programme planners to contextualise the epidemic. Through research, they are able to ascertain whether the epidemic is generalised or whether it is concentrated within certain groups in the population, often referred to as key populations. This information can be obtained by looking at the modes of HIV transmission and who the key affected populations are, as well as the number of new HIV infections (Hankins, 2013). For the purpose of this research it was established through evidence that in South Africa, FSWs fall under the category of key populations and have an HIV prevalence of more than 50%, which is higher than the general population and thus need to be prioritised in HIV prevention, particularly through the distribution of PrEP (Avert, 2019a). Structurally, the criminalisation of sex work in South Africa is said to be an added barrier to effective HIV prevention among this group and contributes to their 'hidden' nature, making it difficult to reach them with prevention materials as well as to design effective interventions (Vanwesenbeeck, 2017). Hence, the approach of this doctoral study was to ensure that FSWs are made visible by including them in the planning phase with regard to the type of PrEP services they prefer, to inform the awareness PrEP messages that they feel would resonate with them; and design a community-based programme that would make PrEP appealing for them to use.

## **2.6 Factors contributing to HIV vulnerability of female sex workers**

There are various biomedical, behavioural, social and structural challenges that FSWs face, which exacerbate their exposure to HIV infections (South African AIDS Council, 2016). From a biomedical perspective, the cumulative exposure to HIV among FSWs is due to frequent engagement in sexual intercourse with multiple partners and irregular condom use. Social factors known to influence irregular condom use stem from unequal power relations with clients and non-paying partners (Campbell & Mzaidume, 2001; Carney, Petersen Williams,

Pluddemann, & Parry, 2015; Hampanda, 2013). FSWs' clients frequently include men who refuse to use condoms or who use force and intimidate FSWs to consent to sex without a condom, or who pay more money for such sex, or who threaten to take their business elsewhere if the sex worker requires the use of a condom (Konstant, Rangasami, Stacey, Stewart, & Nogoduka, 2015; Parry et al., 2009; Voeten, Egesah, Ondiege, Varkevisser, & Habbema, 2002). Alcohol and drug use while working, also influence FSWs' capacity to negotiate and practice 'safer' sex (Needle et al., 2008; Parry et al., 2009). The structural conditions that make it difficult for FSWs to practice safer sex are limited availability of male condoms and scarcity of female condoms which have been reported in some studies (Lafort et al., 2016; Mathenjwa & Maharaj, 2012). Furthermore, FSWs who work in different locations are exposed to varying vulnerabilities, which may require context-specific responses to HIV prevention. FSWs who work in formal indoor establishments such as brothels, escort agencies, private houses and massage parlours do not necessarily experience the same challenges as street-based sex workers (Stadler & Delany, 2006). The conditions under which street-based FSWs sell sex are laden with danger due to selling sex on the streets at night. Sex takes place in isolated and unsafe environments such as abandoned buildings, the veld, in a client's car or at an apartment. These locations contribute to the vulnerability of FSWs to rape and assault by clients (Goldenberg, Duff, & Krusi, 2015; Pauw & Brener, 2003; Scorgie et al., 2013). The criminalised state of sex work in most countries in sub-Saharan Africa, including South Africa, has compounded the challenges of FSWs in practicing safer sex. Studies have shown that the police harass FSWs and arrest them. They are also said to confiscate condoms, and at times demand unpaid sex (Beyrer et al., 2015; Chersich et al., 2013; Gould & Fick, 2008; Richter, 2008; Scheibe, Drame, & Shannon, 2012). FSWs also have limited access to health care services due to issues of stigma and discrimination from health care providers, especially when they disclose that they are sex workers, or when they keep presenting for recurring sexually transmitted infections (STI) at health facilities, unable to bring their partners, facing judgement and ridicule from medical staff (Scheibe, Howell, et al., 2016; Scorgie et al., 2012; Scorgie et al., 2013).

### **2.6.1 Importance of a combination of prevention strategies for female sex workers**

As mentioned above, FSWs are considered a key population in need of combination prevention methods to curb the risk of new HIV infections. Research by Bekker et al. (2015) showed that 15% of female HIV infections were among FSWs, with the highest attributable fraction of

17.8% among FSWs in sub-Saharan Africa. New infections were estimated to be from 10% to 32% among FSWs in West African countries, and 7% to 11% among FSWs and their clients in Uganda, Swaziland and Zambia (Bekker et al., 2015). For combination prevention to succeed, it is important to take into consideration the diverse context in which sex work occurs. These different workspaces present with their own unique challenges pertaining to HIV risk and general safety of the women. Thus far there has been a considerable number of NGO research driven health programmes targeted at sex workers, for instance in South Africa, FSWs receive mobile health care services from organisations such as TB HIV Care, who provide HIV testing and counselling, TB screening, initiation of antiretroviral treatment and PrEP. Life-Line provides HIV testing and counselling, and psychosocial services. The Wits Reproductive Health and HIV Institute (Wits RHI) also provides services to FSWs in the Gauteng province where they have mobile services as well as a sex worker-friendly clinic. The services provided are comprehensive, consisting of HIV testing and counselling and sexual reproductive health services as well as antiretroviral treatment and PrEP. These services are dedicated solely to high-risk groups and are operational in different provinces in the country, particularly the major cities of Durban, Johannesburg and Cape Town (Makhakhe, Meyer-Weitz, Struthers, & McIntyre, 2019).

Other interventions for FSWs in low- and middle-income countries, such as Thailand and Cambodia, which have implemented a 100% condom use campaign, focused on condom distribution, coupled with community mobilisation, education on STI tracing in clients and follow-ups at brothels. The intervention resulted in some increases in condom use among sex workers and their clients, having some effect on the Thailand and Cambodian HIV epidemics (Kerrigan, Moreno, Rosario, & Sweat, 2001). The 100% Condom Use Programme has been criticised for its top-down approach but has been adapted in other settings such as the Dominican Republic, South East Asia, Africa, and South America. Thus far, existing strategies to curb HIV infection among FSWs consist of reproductive health care services, condoms, HIV testing and counselling, and supportive linkage to care. The basic prevention strategies have focused on free condom distribution which have played a significant role in reducing STI and HIV acquisition. One such programme in Santa Domingo in the Dominican Republic showed that condom use and rejection of condomless sex increased because of workshops and meetings with sex workers and brothel owners and managers, to create a collective commitment to ensure that sex workers use condoms with partners, as well as equipping FSWs with the ability to negotiate condom use with partners (Kerrigan et al., 2001). Other interventions that have

used motivational interviewing have improved condom use and have reduced harm among FSWs who inject drugs. Greater success in condom use has been reported by sex work programmes than any other high-risk population (Bekker, Johnson, Cowan, Overs, Besada, Hillier, & Cates, 2015). This research study also sought to utilise aspects of motivational interviewing incorporated in the intervention workshop programme designed by FSW peer educators to encourage PrEP adherence among FSWs.

In order to curb the issue of FSWs offering risky sex for more money, some interventions have utilised cash transfers and microfinance as a way to reduce economic vulnerability. Some of these studies have been successful in reducing FSWs' engagement in risky sex, with other studies showing minimal success (Cooper et al., 2017; Odek et al., 2009; Pettifor, MacPhail, Nguyen, & Rosenberg, 2012). The provision of HIV testing for FSWs has proven effective; studies have shown that in a review of 52 low-income countries in 2010, the median percentage of FSWs who had tested for HIV and who knew their status in the last 12 months were close to 50%; however, only 30% were accessing antiretroviral treatment (Avert, 2019a). Some barriers to HIV prevention among FSWs are access of services, time constraints and opportunity cost, as well as fear of stigma and discrimination in public health facilities (Yves Lafort et al., 2016). Thus, dedicated outreach services for FSWs have proven effective in addressing some of these challenges and encouraging HIV testing. Combining existing prevention methods with newer strategies is essential for effective prevention. In the last few years there have been biomedical interventions looking at the use of antiretrovirals by HIV-negative individuals in the form of PrEP or PEP. These drugs can be taken orally; some are in the form of vaginal or rectal gels and rings known as microbicides. There have been trials testing the effectiveness of microbicides (vaginal and rectal gels) and each study showed different results because of varied adherence (Avert, 2019b). Currently, the focus is on oral PrEP for HIV prevention because it has been proven to be effective in preventing HIV and it is being distributed among FSWs (Bekker, Johnson, Cowan, Overs, Besada, Hillier, & Cates, 2015).

## **2.7 Significant pre-exposure prophylaxis trials**

Oral PrEP consists of tenofovir (TDF) or tenofovir-emtricitabine (TDF-FTC). It is an antiretroviral administered to people who are at high risk of HIV transmission. The WHO (2015) categorised high-risk groups as having an HIV incidence of about three per 100 person-years or higher. Although PrEP is an effective HIV prevention method it does not require life-

long adherence but should be taken during periods of high risk. This requires effective risk perception on the part of the potential user; this is known as prevention-effective adherence (Mboup et al., 2018).

According to the WHO (2015), if users adhere to the daily dose, there is a 90% probability of preventing HIV infection. The WHO originally recommended the inclusion of PrEP in HIV prevention packages for MSM and serodiscordant couples in 2012; and in 2014, it recommended the distribution of PrEP more broadly among other key populations (sex workers, intravenous drug users, adolescent girls and young women) (WHO, 2015). Prior to the WHO's recommendation to expand the distribution of PrEP to include sex workers, there have been various clinical trials testing the efficacy of PrEP in different forms.

The first clinical trial was the iPrEX study which was the first to offer oral PrEP to 2 500 MSM in six countries namely Brazil, Ecuador, Peru, South Africa, Thailand, and the USA. The results of this trial were that HIV prevalence among HIV-negative MSM was reduced by 44%, compared to MSM who received a placebo. Additionally, among the MSM who took PrEP consistently for seven days as prescribed, the risk of infection was reduced by 99% (Anderson et al., 2012). The successful results of this trial were similar to another study, known as the Ipergay study, which offered oral PrEP at six hospitals in France and Canada. The results showed an 86% reduction in HIV incidence, compared to those taking a placebo (Molina, Capitant, Spire, Pialoux, Chidiac, et al., 2015).

The second oral PrEP trial involved women at high risk of HIV in countries such as Kenya, South Africa, and Tanzania. The results of this trial were inconclusive because an equal number of infections was seen in both the PrEP (33 women) and placebo (35 women). This may have been caused by poor adherence with low drug concentrations in participants (Van Damme et al., 2012). The third trial was conducted in Botswana among heterosexual men and women. The results from this trial showed a 63% reduction in HIV (Thigpen et al., 2012). The fourth trial investigated PrEP efficacy among serodiscordant couples in Kenya and Uganda. In this trial there was a total of 4 747 participants; 1 584 participants were given TDF once daily and 1 579 were given the combination of TDF-FTC, and the rest of the participants (n=1 584) were on a placebo. The results showed a 67% reduction in HIV incidence among the TDF group and a 75% HIV incidence reduction in the TDF-FTC group. The study thus concluded that the protective effects of both TDF and TDF-FTC were not significantly different and both medications reduced HIV-1 incidences in both men and women (Baeten et al., 2012).

The VOICE clinical trial conducted among women in Uganda, South Africa, and Zimbabwe, assessing daily oral TDF, daily oral TDF-FTC and daily topical TDF gel; all of these interventions were compared with placebos. The trial was stopped when interim results showed that a conclusion could not be reached as to the effectiveness of daily oral TDF and TDF gel. The trial continued to test the effectiveness of oral TDF-FTC, through which further research has proved to be effective (WHO, 2012).

Research showed that there are other successful topical PrEP gel studies such as the CAPRISA 004 study, which was the first successful PrEP study showing the efficacy of tenofovir topical vaginal (TFV) gel 1%. The TFV gel was given to 889 HIV-negative women at an urban and rural sites in South Africa. For effectiveness, the gel required that it be applied in the vagina up to 12 hours before and after sex for a maximum of two applications in a 24-hour period. After 30 months of follow-up, the study concluded that the TFV 1% gel was 39% effective at preventing HIV infection.

The outcome of all these clinical trials resulted in the approval of oral Truvada (PrEP) for daily intake in 2012 by the United States Food and Drug Administration. The conclusion was that PrEP was effective in reducing HIV acquisition among those who adhere to it (Holmes, 2012, Molina, Capitant, Spire, Pialoux, Cotte, et al., 2015, Baeten et al., 2012; Yi et al., 2017).

## **2.8 Distribution of pre-exposure prophylaxis in South Africa among female sex workers**

As mentioned in the preceding paragraphs, there is a combination of biomedical, social, behavioural, and structural factors which underpin the decision by the South African government in December 2015, to distribute PrEP to sex workers. This initiative was part of a global UNAIDS commitment to reduce the rate of new HIV infections by 75% in the year 2020 (UNAIDS, 2017). The decision to distribute PrEP also coincided with the UNAIDS 90-90-90 global strategy which stipulates that 90% of all people living with HIV should know their status, 90% of all people with HIV should be on antiretroviral therapy, and 90% of those receiving antiretroviral therapy to achieve viral suppression by 2020 (UNAIDS, 2016a). The distribution of PrEP commenced on 1 June 2016, making South Africa the first country in sub-Saharan Africa to fully approve the distribution of PrEP among sex workers (Cáceres, Borquez, Klausner, Baggaley, & Beyrer, 2016; South African AIDS Council, 2016).

In South Africa, PrEP is distributed to sex workers as part of a combination prevention strategy (South African AIDS Council, 2016). The package for sex workers includes the provision of condoms, lubricants, STI management, screening, sexual reproductive health services and HIV services, which include HIV counselling and testing, HIV management, antiretroviral treatment, PEP and PrEP (National Department of Health, 2016). There has, however, been some controversy over the decision to distribute PrEP. Some implementers and policymakers in different countries, including South Africa, have raised concerns that the likely consequences of low adherence rates, that is, low effectiveness and drug resistance, as well as the potential for PrEP to encourage risky sexual behaviour because of perceived protection, may lead to lower success rates of PrEP as a HIV prevention strategy (Cáceres et al., 2016; Felsher et al., 2018). One study conducted in South Africa among FSWs, concluded that 73% of its study participants regarded PrEP as an incentive for FSWs to engaged in condomless sex, because they can make more money (Quaife et al., 2018). However, some PrEP studies among MSM have shown that risk compensation was less common, and participants have continued to use condoms while on PrEP (McCormack et al., 2016; Parker et al., 2015; Rojas Castro, Delabre, & Molina, 2019). More research is needed to understand the effects of PrEP on condom use for more conclusive results. Other concerns have been about the associated negative side effects of PrEP which vary in each individual such as nausea, vomiting, dizziness, abdominal pain, weight gain and others; however, research has shown that PrEP has demonstrated a high tolerability and low toxicity profile (Mugo, Ngunjiri, Kiragu, Irungu, & Kilonzo, 2016). According to Mugo et al. (2016), it is important for health care providers to be educated about PrEP and potential users, in this case FSWs, to be provided with current and correct information regarding PrEP benefits and risks. It is important for implementers to work with target populations to understand the perceptions that may oppose PrEP and potential inhibitors to the use of PrEP. This underpinned the purpose of this doctoral thesis which was concerned with engaging FSW peer educators in dialogues through a reflexive process to understand how the barriers of PrEP use could be overcome, as well as giving the peer educators the space to design an intervention plan that includes a PrEP workshop programme that they felt would work to promote PrEP effectively.

## **2.9 Feasibility and acceptability of pre-exposure prophylaxis among female sex workers in South Africa**

In 2016, the Global Network of Sex Work Projects, in consultation with various sex work organisations in 72 countries, published a brief concerning the acceptability of PrEP among sex workers (International Treatment Preparedness Coalition [ITPC], 2017). This brief encompassed information coming from 300 individuals who participated in focus group discussions. The consensus was that PrEP as an additional preventive tool would be acceptable to sex workers and would provide added protection from HIV. With that said, the network outlined that there might be various challenges concerning barriers to uptake and retention such as issues of access due to stigma and discrimination, as well as potential side effects, and other unprecedented challenges that may arise which need thorough investigation if PrEP is to be successfully implemented among sex workers. The brief further outlined that more awareness and education about PrEP is needed for sex workers. Sex workers expressed the need for involvement in PrEP projects, not merely as end users but to be consulted at all levels of PrEP programming to ensure that programme approaches are tailored to their needs (ITPC, 2017). Sex workers expressed concern over the fact that the drive to promote PrEP is coming from external bodies such as researchers and MSM groups and not from within the sex work community. Thus, organisations led by sex workers need to be involved in the distribution of PrEP. One of the main recommendations from the brief was that community-led participatory research is needed to better understand the barriers faced by sex workers in the uptake of PrEP (ITPC, 2017). This was a further confirmation of the relevance of this doctoral study that has utilised a participatory approach through community dialogues led by sex worker peer educators to understand the issues associated with PrEP uptake and adherence, as well as outlining what is needed to promote PrEP effectively among FSWs.

A cohort study was conducted by Wits RHI in Hillbrow, Johannesburg, focusing on treatment and prevention of HIV for FSWs in South Africa. They published a protocol, which clearly outlined their intention to distribute PrEP to 400 HIV-negative FSWs and immediate treatment to 300 FSWs whose CD4 count was greater than the national guidelines (Eakle et al., 2017). Preliminary results from the qualitative research conducted during the PrEP efficacy trials have indicated low adherence on the part of the participants. A recommendation from this cohort study was that it is imperative to understand how PrEP may be best implemented from the point of view of potential consumers (Eakle et al., 2017). This recommendation was a validation for the need to engage FSWs in dialogues that help them uncover complex issues around

individual/collective agency, power, and their values which underpin the decisions they make regarding use or non-use of PrEP, which was the aim of this study.

A study conducted in Johannesburg and Pretoria looking at the acceptability of PrEP among FSWs prior to implementation and roll-out, found that prior to focus group discussions, participants did not know much about PrEP, and upon being educated about it, they then likened it to birth control pills, which participants felt were easy to forget or not always convenient to take (Eakle, Mutanha, et al., 2018). Furthermore, the participants felt that the taking of PrEP as prevention will require unwavering commitment on the part of the potential user. The participants expressed concern around issues of adherence, especially when one is expected to take a pill consistently when not sick. The participants also felt that the use of PrEP would help protect FSWs whose clients or partners do not want to use condoms but understand that PrEP had to be used concurrently with condoms to protect against unwanted pregnancies and other STIs. The participants also expressed concern of alcohol or drug use which are common among sex workers and would increase the likelihood of individuals forgetting to take PrEP. Potential side effects such as headaches, nausea, and vomiting were also listed as barriers to uptake and adherence (Eakle, Mutanha, et al., 2018). From the above, it was imperative that further research on PrEP is needed, especially research that goes beyond investigating issues of knowledge and acceptability of PrEP for users, but to couple that research with the complex social, behavioural and interpersonal challenges associated with power relations, and values pertaining to HIV prevention that influence FSWs' sense of agency that may hinder or enable the uptake of PrEP.

## **2.10 Female sex worker interventions**

Combination prevention strategies advocate for the meaningful involvement of sex workers in the design and implementation of prevention programmes. Furthermore, community empowerment reduces the vulnerability of FSWs and contributes to their sense of agency which is demonstrated by peer-led collective action, and self-help activities including education, health services and advocacy (Awungafac, Delvaux, & Vuylsteke, 2017; Cáceres et al., 2016; Zablotska, 2016). The WHO (2012) defined community empowerment in relation to sex workers as “a collective process through which the structural constraints to health, human rights and well-being are addressed by sex workers to create social and behavioural changes, and access to health services to reduce their risk of acquiring HIV”. Empowerment, on the other hand, is conceptualised as a process rather than an outcome, or the interaction of

both process and outcome. Laverack and Wallerstein's (2001) conceptualisation of community empowerment, which was the lens for this study to understand empowerment, was that of a continuum that begins with individual action growing to larger networks that facilitate collective social and political change.

There are a substantial number of studies in HIV research that advocate for the need to centre participants, who are at the core of the health care challenge, to articulate their needs and be given a platform to participate in initiatives aimed at improving their health (Masyuko et al., 2018; Ransome, Zarwell, & Robinson, 2019). Health communication refers to it as a culture-centred approach. At the core of this cultural approach is the meaning-making process. Meaning is constructed through the process of dialogue between participants and researchers. This approach recognises that participants are experts of their own lived experiences and that they have the agency to determine what is best for them (Basu & Dutta, 2009). FSWs are a marginalised community and mainstream health care initiatives tend to take a top-down approach in the provision of health care services or when introducing HIV prevention technologies. The cultural approach recognises that a step towards meaningful change is dependent on participation, which is facilitated by allowing marginalised voices to determine the terms of engagement and the kinds of approaches that are context-specific and relevant to them (Basu & Dutta, 2009).

It is important to define what constitutes community participation for the importance of project monitoring and evaluation. For the purposes of this study, community participation will be defined according to health promotion practice. Community participation is at the heart of health promotion and stems from the ideology of shifting power and professional dominance away from biomedical practitioners towards a social model that creates an environment where people have greater control over their health and well-being (South, 2014). This is a bottom-up process that advocates for the marginalised to be the planners and implementers. The role of the researcher in this regard transforms from that of an expert to that of a listener who engages in dialogue with community members, as this was the case in the design of this doctoral study.

There are a number of programmes that claim to have incorporated an element of community empowerment in HIV prevention among sex workers, such as the Sonagachi project based in Calcutta, India. Initially, this programme focused mainly on condom distribution among sex workers, but over time it evolved into a multi-component, community-led structural

intervention that targets risk behaviour and broader structural factors that marginalise sex workers and increase their vulnerability to HIV (Jana, Basu, Rotheram-Borus, & Newman, 2004). According to Jana et al. (2004), the focus in HIV prevention models was largely on the individualistic aspect of prevention; however, the Sonagachi project sought to promote prevention at a community level. HIV prevention was largely framed as improving occupational safety of sex workers; thus, the focus was not only on sex workers preventing HIV, but the framing of prevention was focused on sex work being work that was in need of occupational safety measures. The message around HIV prevention was inclusive of other stakeholders that benefit from the existence of sex work such as brothel owners, regular clients, and political parties. It was in the best interest of the community to ensure that it is everyone's responsibility to prevent HIV and not only the individual sex worker. Thus, under this project, the rights of sex workers were articulated and the notion of sex work being an occupation and sex workers deserving of good health and safety, was promoted.

Sonagachi also utilised the peer outreach approach which is a model adopted by other sex work projects (Jana et al., 2004). These peer educators visited other sex workers and provided them with treatment for sexually transmitted diseases and antibiotics for other medical problems. The peer educators also encouraged adherence as well as tracing the sex workers visiting the clinics. The peer educators were trained to be accepting and non-judgemental; thus, when other sex workers struggled to adhere to certain medications, they were not labelled as non-adherent, but the peer educators created an environment where others could identify with them because they also recounted their own personal struggles with treatment and adherence. The peer's role modelled to other sex workers and presented themselves as relatable in their engagement with treatment, which created an environment of cohesion and trust. FSWs were also given an opportunity to provide feedback about the programme which was a form of participant evaluation. Collective power was established through the peer approach (Jana et al., 2004).

Individually, sex workers were assisted to gain skills and competencies such as the ability to use condoms. Through observing their peer educators, sex workers gained self-confidence and treated their work with respect. As a result of this project, sex workers cultivated a sense of hope. According to Jana et al. (2004), the healing value of hope is a key ingredient to shifting community and individual perceptions. Through the rights-based approach, sex workers started to value themselves, and this translated into self-care and a desire to protect themselves from disease, as well as striving to improve their situation such as supplementing their sex work

income with another means of making money, for example, a side business. Sex workers saw a future for themselves as well as their children.

The success of the Sonagachi project meant that similar community-led strategies were employed by other projects such as that of Ashodaya Samithi in India, which focused on reducing violence as a structural barrier to HIV prevention among sex workers. This project empowered FSWs to enter into dialogue with police officers and challenged their stigmatising notions about sex work. Through legal literacy, sex workers were able to express their rights and confronted the improper and violent behaviour of the police. There was a reduction in violence through the establishment of a 24-hour crisis outreach team and strong collaboration between the police, clients, local thugs, and shopkeepers. Thus, the empowerment of sex workers bought about a systemic change that shifted structural vulnerabilities over the long term. Similar to Sonagachi, Ashodaya Samithi applied a four-stage framework to achieve community empowerment, starting first with engagement with the sex worker community; second, involvement of the community in targeted activities; third, ownership of the project by the community; and fourth, sustainability of action beyond the community (Moore et al., 2014a).

The Avahan India AIDS initiative is another project that adopted the Sonagachi model. According to Moore et al. (2014a), such projects that have used a community approach to HIV prevention have achieved greater clinical and social outcomes, coverage, impact and sustainability than those focusing on individual responsibility to effect behavioural change. Similarly, the PrEP intervention in this study was designed to promote self-development and the cultivation of agency, hope and self-efficacy as the basis onto which FSWs engage with HIV prevention.

Moore et al. (2014b) conducted a systematic review that assessed sex worker projects in Africa using the four-stage framework. They included all projects that provided sexual and reproductive health services, which included HIV, family planning, safe abortion, sexual behaviour and gender-based violence. They included 129 articles from 5 413 screened, and 42 different projects were analysed from 26 African countries. This review found that peer education was the primary empowerment approach adopted by the majority of the projects reviewed. Peer educators who were also sex workers conducted outreach to recruit FSWs to access health care, HIV testing, STI screening, HIV education, condom demonstrations, condom negotiation skills, counselling and distribution of information education and

communication materials, and safer sex kits. Only one project provided peer-based family planning services to sex workers, and the Sex Worker Advocacy Taskforce based in Cape Town, South Africa, provided legal assistance and basic human rights education through sex work paralegals. Peer educators were usually trained by field coordinators who supervised and monitored peer educator's activities. Generally, the hierarchy in the projects was such that FSW peer educators reported to non-FSW personnel who occupied supervisory or managerial positions. The review only found three projects who went beyond the peer education model and engaged with community consultations. The depth of the consultations varied with one project in Kenya simply informing the community about their research project during the planning stage; whereas another project in Madagascar involved FSWs in their study design during a three-day workshop, and another Madagascan site involved FSWs in drafting project guidelines. A more formal and continuous consultation was in a Kenyan project whereby FSWs were elected by their peer educators as committee members to oversee research and make decisions on research priorities. One project in South Africa had FSW peer educators meeting weekly with the clinic nurse to plan activities and discuss community challenges. This review showed that the involvement of FSWs in projects in the African context has been largely marginal and limited due to various challenges pertaining to funding, and the capacity to foster empowerment which happens after continuous engagement with a community (Moore et al., 2014b). Thus, there is a need for projects that will make room for robust involvement of FSWs. This shows that there is a necessity for interventions that involve FSWs in design and implementation within the African context. Evidence shows that involving FSWs in project design and implementation improves acceptability and participation.

The research conducted by Reza-Paul et al. (2019) profiled various PrEP demonstration projects in various African countries that focused on community involvement. According to Reza-Paul et al. (2019), *community* is defined solely on the basis of the populations targeted by the demonstration projects (serodiscordant couples and sex workers) and key stakeholders working with these populations. The first PrEP project which focused on sex workers, was one in Benin, West Africa. This project was aimed at assessing feasibility and usefulness of integrating treatment as prevention and PrEP as part of combination prevention. Community involvement in this study was in the form of community workers who were non-sex workers engaging with small groups of sex workers to determine the feasibility of the intervention. Another feasibility project which explored the provision of daily PrEP to FSWs was conducted in Senegal, Dakar. In this study, peer educators worked closely with social workers to recruit

participants into the study and conduct health provider sensitisation. Peer educators played a key role in designing PrEP-based communication strategies and following up of participants and were role models in encouraging PrEP adherence. A project in Kenya that aimed at introducing PrEP as part of combination prevention, also worked with FSW organisations and peer educators on community mobilisation and PrEP education materials. Peer educators were also PrEP advocates or ambassadors in their communities and assisted with follow-ups. The last sex work demonstration project profiled in this paper was conducted in 2017 in the Gauteng province in South Africa. FSWs formed part of the community advisory board to advise on the study research questions and recruitment of participants. Peer educators were also engaged in PrEP outreach and PrEP education, as well as supporting participants on PrEP and making follow-ups on appointments (Reza-Paul et al., 2019). It is important to note that peer educators have been utilised as a resource in PrEP implementation. Their role in these studies have focused mainly on participant recruitment and follow-ups. These studies were also conducted to ascertain the feasibility of PrEP among FSWs; however, none of these demonstration projects profiled, engaged in intervention development aimed at addressing the challenges to PrEP uptake, which this doctoral study addressed. Thus far, the establishment of PrEP interventions have been biomedical in their focus and have not engaged in the human element of prevention. A study by Cowan and Delany-Moretlwe (2016) recommended biomedical interventions to be coupled with community-based interventions that focus on engaging FSWs with issues of human agency, self-efficacy, power relations and values that influence the actions of FSWs pertaining to HIV prevention. These insights and recommendations influenced the approach of this doctoral study.

## **2.11 Summary**

This review of the literature showed the complex nature of HIV upon its discovery in the 1980s. Since then, scientists have been relentless in trying to find a cure, and through this journey, multiple prevention methods were discovered as well as antiretrovirals for treatment as prevention. Initial approaches to HIV prevention through HIV education awareness campaigns, and condom promotion and distribution interventions were individualistic in nature and did not consider the social and structural challenges that impact on behavioural change. Thus, combination prevention came as a way to deal with HIV prevention holistically. The discovery of PrEP and the testing of its efficacy through various randomised control trials have rendered PrEP an effective prevention tool which has in some settings been targeted for high-risk groups.

FSWs in South Africa are being given PrEP through private donor-funded research organisations that have utilised the peer education approach in the promotion and distribution of PrEP among FSWs. To date, research on the acceptability of PrEP has shown that PrEP uptake and retention has been low among FSWs and studies have advocated for the integration of PrEP services as part of a holistic health care package for FSWs, as well as an infusion of existing biomedical approaches to PrEP with community-based strategies to encourage PrEP uptake.

## Chapter 3

### Scoping Review: Mapping the Evidence to Inform Oral Pre-exposure Prophylaxis Interventions for Female Sex Workers

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#### 3.1 Introduction

Scoping reviews emanate from the field of health research for the purpose of mapping out or summarising evidence to provide a comprehensive representation of the length and breadth of research that has been conducted in a particular field (Levac, Colquhoun, & O'Brien, 2010). Various definitions have been used to encapsulate what scoping studies are. Arksey and O'Malley (2005), who are the pioneers of scoping studies, defined scoping studies as a rapid process of mapping key concepts underpinning a research area in the quest to provide a better understanding of that area, as well as the main sources and types of evidence available in an area of research. Anderson, Allen, Peckham, and Goodwin (2008) also elaborated on Arksey and O'Malley's (2005) definition of scoping studies on contextualising knowledge by identifying what is currently known about a particular topic, and then establishing what is yet to be understood, as well as what is not yet known, positioning this within policy and practice. Anderson et al. (2008) further elaborated that the purpose of a scoping review is to map out relevant literature and synthesising findings from different kinds of studies. This mapping can be conceptual in nature and is concerned with providing an understanding on how a particular concept is used in the literature and by whom. Policy mapping is used to identify policy briefs and government documents, agencies and professional bodies that provide a directive on a particular practice in that field. Other researchers have adapted their definitions from similar constructs (Davis, Drey, & Gould, 2009; Grant & Booth, 2009).

Scoping reviews have in some instances been referred to as systematic reviews, but they are inherently different. Systematic reviews focus on a narrow subject matter, whereby scoping studies map the broader literature, particularly in an emerging area that is not well understood. Systematic reviews emphasise quality rather than volume of sources and the focus is on peer reviewed published material. However, scoping studies do not solely focus on the quality of the studies, but the purpose is to engage with a wide variety of sources, from peer reviewed journal articles to grey literature which include unpublished organisational reports and conference proceedings. Scoping reviews differ from narrative literature reviews because they

do not simply provide a descriptive narrative of the literature but an analytical reinterpretation of the literature (Levac et al., 2010).

A scoping study is guided by a six-step methodology framework as outlined by Arksey and O'Malley (2005). Step 1 involves identifying the research question; Step 2 searches for relevant articles; Step 3 selects studies; Step 4 is charting the data; Step 5 is collating, summarising, and reporting results; and an optional Step 6 that entails consulting with stakeholders to inform or validate the study findings. For the purpose of this thesis, only Steps 1 to 5 were conducted.

The objective of this review was to map out existing evidence pertaining to strategies for PrEP implementation and how this evidence informs effective PrEP interventions for FSWs. The mapping of this evidence was relevant as it would help articulate the suggestions made by literature as to the kinds of interventions needed to promote effective PrEP uptake and retention among FSWs, as well as to demonstrate the importance and relevance of this PrEP intervention that has been designed for the purpose of this doctoral study.

This chapter answers the following research question: What are the strategies that have been recommended in the literature to inform PrEP interventions for FSWs?

## **3.2 Methodology**

### **3.2.1 Identifying relevant studies**

The process of identifying relevant studies for this review involved a comprehensive literature search through articles published between 2015 and 2020. The year 2015 is significant because it was the year that the WHO released expanded guidelines for PrEP distribution among persons considered at high risk for HIV, which included FSWs. Thus, PrEP studies published from that period onwards were deemed relevant for this review because they included FSWs who were now targeted for PrEP. PrEP studies published prior to 2015 focused on PrEP among MSM and serodiscordant couples. Other studies investigated PrEP use in the form of microbicides such as vaginal rings or gels among adolescent girls and young women, as well as FSWs.

The literature search was conducted using various databases such as *PubMed*, *Science Direct*, *EBSCOhost* which includes selected databases such as *Health Source*, *Health Source – Nursing Academic Edition*, *Medline*, *Newspaper Source*, *APA Psych Info*, *Academic Search Complete*, *Scopus* and *Web of Science*. The key terms for the search were *sex workers* or *female sex*

*workers or commercial sex workers and oral PrEP or pre-exposure prophylaxis.* The search was kept open and not specific to a particular location or intervention so as to capture as many studies as possible.

### **3.2.2 Study selection**

In most studies, the search is commonly conducted by two reviewers; however, for the purpose of this thesis to ensure credibility of individual work, I as the author conducted a solo review of the literature. This may be a limitation, as some research on scoping studies advises that having a team of two reviewers for the screening process is advantageous to see the similarities and differences in the studies that have been selected. The literature was analysed based on the PICO criteria which can be broken down into Population = FSWs, Intervention = PrEP, Comparison and Outcome = recommendations for interventions. This search included journal articles, commentaries, editorials, and systematic reviews written in English and focusing on FSWs and oral PrEP for the purpose of informing PrEP interventions.

### **3.2.3 Screening process**

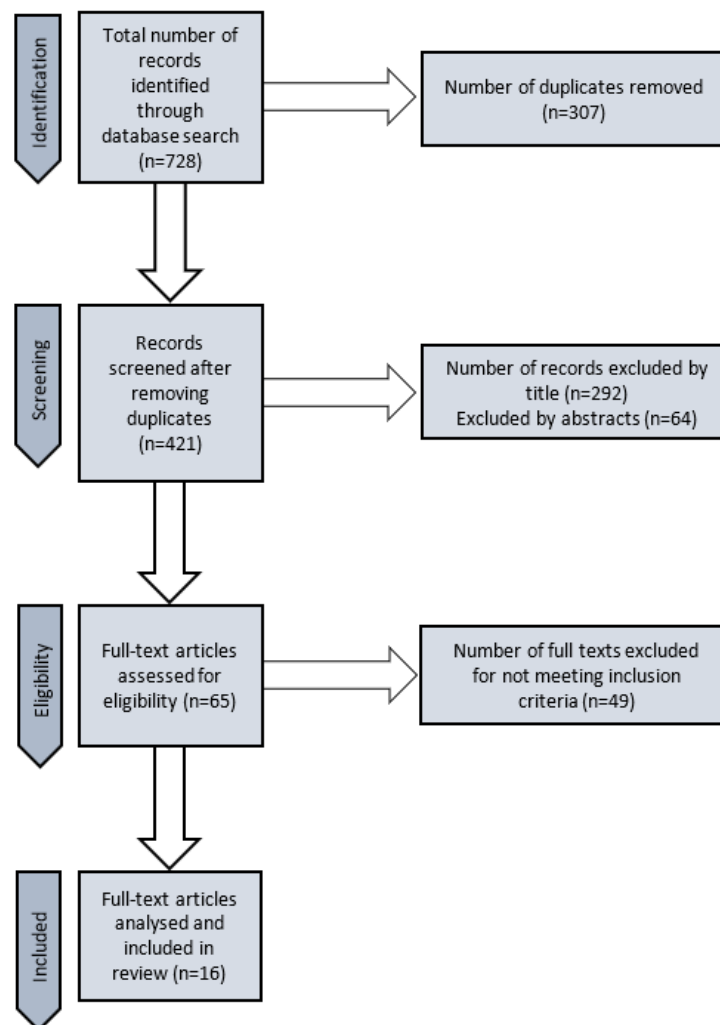
The search results from each database were exported to Endnote (version 8) where they were sorted into folders. The screening process started with the screening of titles, after which irrelevant titles were removed. This led to the screening of abstracts, and from the relevant abstracts, full papers were screened and of the full papers screened, 16 were selected to be analysed for the review. The screening process was guided by the following inclusion and exclusion criteria:

- **Inclusion criteria:** Accessible full text studies published in English that focused on FSWs and oral PrEP, as well as commentaries that cover the scope of oral PrEP engagement among key populations provided that sex workers were included as part of the analysis (these were included and analysed specifically for their contribution/data that focuses on FSWs). The location was not specified because this review wanted to capture recommendations for interventions from studies conducted in different contexts. PrEP distribution for FSWs started in 2015 and there was a need to capture studies from various contexts so as to have robust data.
- **Exclusion criteria:** Studies that focused exclusively on PrEP among other key populations such as MSM, adolescent girls and young women who are not sex workers,

serodiscordant couples and intravenous drug users, were excluded. Studies that did not investigate oral PrEP but looked at vaginal or rectal microbicides among FSWs were also excluded. Studies that were not written in English, inaccessible full texts as well as conference abstracts, were excluded.

### 3.2.4 Data extraction and analysis

The data was extracted from full papers. Figure 1 shows the phases of the literature search, this diagram is the standard reporting format for systematic reviews (Hopman-Rock & Westhoff, 2000).



**Figure 1. Systematic reviews and meta-analysis flow diagram showing phases of literature search (Hopman-Rock & Westhoff, 2000)**

Table 1 lists the articles that data was extracted from and are shown under the following headings: study title, author and year, study type and methods, study population, key findings, and recommendations for PrEP interventions. The data were analysed based on the

recommendations for interventions put forward in the selected articles. These recommendations formed the basis of the themes. Studies that had similar recommendations were grouped together under a dominant theme that emerged in those studies.

**Table 1**

*Evidence table of studies included in the scoping review*

Title	Author and year	Study type and methods	Study population and setting	Key findings	Recommendations for pre-exposure prophylaxis interventions
<b>Integration of pre-exposure prophylaxis into sexual and reproductive health services for female sex workers</b>					
Sexual health needs of female sex workers in Côte d'Ivoire: A mixed methods study to prepare the future implementation of pre-exposure prophylaxis (PrEP) for HIV prevention	Becquet et al. (2020)	Cross-sectional mixed methods study	FSWs Côte d'Ivoire	The majority of participants reported not using condoms with their regular partners as a proof of trust and devotion to their partners. Others did it to gain protection and some practiced condomless sex for more money with clients. Thus, PrEP proved necessary for suchlike situations. Thus, 98.6% of the participants showed an interest in PrEP and a willingness to periodically test for HIV and other necessary check-ups.	<ul style="list-style-type: none"> <li>• patient-centred approach to PrEP programming.</li> <li>• PrEP services need to encompass all sexual reproductive health services for FSWs in which PrEP is an option but not mandatory.</li> </ul>
HIV pre-exposure prophylaxis for female sex workers: Ensuring women's family planning needs are not left behind	Bowring et al. (2020)	Commentary	FSWs	Poor integration of sexual reproductive health services with HIV prevention services for FSWs. This paper raises concern that the promotion of PrEP could increase the rate of unintended pregnancies among FSWs due to the pressures of engaging in condomless sex and PrEP being used to compensate for risk. FSWs in low to middle-income countries are said to experience high rates of unintended pregnancy. Cohort studies have shown an incidence rate of 27.1 per 100 person-years (95% CI= 24.4 to 29.8)	<ul style="list-style-type: none"> <li>• interventions to consider integrating family planning services as one of the core components of PrEP programming.</li> </ul>
Preferences for pre-exposure prophylaxis service delivery among female sex workers in Malawi: A discrete choice experiment	Lancaster et al. (2019)	Mixed methods study	FSWs, Malawi	All the participants in this study did not know about PrEP, but upon understanding its use they felt it would be best to protect an FSW when a client insists on risky sex. FSWs felt that it would be beneficial to receive PrEP from family planning or HIV counselling and testing clinics. Some expressed the desire to have PrEP delivered to them and wanted to minimise the time they spend at the clinic for PrEP. PrEP needs to be integrated with other sexual and reproductive health services.	<ul style="list-style-type: none"> <li>• PrEP dispensing location being a family planning clinic and an NGO-run drop-in centre.</li> <li>• FSWs preferred PrEP being offered with cervical cancer screening followed by contraceptives.</li> <li>• Preferred service providers to be male and to pick up PrEP every 2-3 months. Clinic waiting time between 1 and 2 hours maximum.</li> </ul>

Title	Author and year	Study type and methods	Study population and setting	Key findings	Recommendations for pre-exposure prophylaxis interventions
<b>Community empowerment as an integral component of pre-exposure prophylaxis programming for female sex workers</b>					
Combination HIV prevention for female sex workers: What is the evidence?	Bekker et al. (2015)	Lancet series review	Sex workers	Research has outlined effective HIV prevention approaches for FSWs which can be categorised as biological, behavioural, and structural. However, these interventions have not been scaled up or adequately resourced in most parts of the world.	<ul style="list-style-type: none"> <li>• Include sex workers in programme design and implementation.</li> <li>• PrEP needs to be introduced in addition to already existing prevention methods and not as a replacement.</li> <li>• Biomedical interventions should be combined with behavioural and structural interventions</li> </ul>
Promise and pitfalls of pre-exposure prophylaxis for female sex workers	Cowan and Delany-Moretlwe (2016)	Review	FSWs	This review was written before PrEP was introduced to FSWs. It anticipated that PrEP will likely not be suitable or of interest to all FSWs because, sadly, the majority of FSWs are already HIV positive. With that said, the distribution of PrEP among FSWs will be of benefit to some FSWs and reduce HIV incidences. FSWs will most likely use PrEP, motivated by various reasons such as protecting HIV with a regular partner where they are unlikely to insist on condom use. As well as FSWs exposed to sexual violence as well as in situations where they fail to negotiate condom use.	<ul style="list-style-type: none"> <li>• Successful scaling up of PrEP among FSWs will depend on the involvement of FSWs in the development of PrEP programmes. These programmes will need to be contextually specific and relevant to meet the needs of FSWs.</li> </ul>
Bringing sex workers to the centre of the HIV response	Das and Horton (2015)	Lancet commentary	Sex workers	This commentary posits that sex workers are at the heart of the HIV epidemic and that more than 50% of sex workers living with HIV are in sub-Saharan Africa. As much as 92% of all HIV/AIDS deaths attributed to sex work, occur among African women.	<ul style="list-style-type: none"> <li>• Important to centre the role of sex work and the protection of sex workers.</li> <li>• In the establishment of HIV prevention technologies and approaches it is important to have sex workers evaluate these technologies to gain an understanding on what works for sex workers.</li> <li>• Interventions should acknowledge the cultural and trading diversity of sex workers which expose them to varying vulnerabilities; thus, each group will require specific priorities and responses.</li> <li>• Laws and policies pertaining to sex work can either contribute to the harm and protection of sex work. Thus, in countries where sex work is criminalised, sex workers are exposed to violence and abuse, which exacerbate their exposure to HIV.</li> </ul>
<b>Perspectives of female sex workers with regard to pre-exposure prophylaxis use</b>					
"I am still negative": Female sex workers' perspectives on uptake and use of	Eakle et al. (2019)	Qualitative study	FSWs, South Africa	In this study, participants understood PrEP as the second line of defence and mitigates the daily burden of HIV risk and fear of HIV acquisition,	<ul style="list-style-type: none"> <li>• The role of social networks, which in the case of FSWs comprise their peer educators, clients, and partners, are</li> </ul>

Title	Author and year	Study type and methods	Study population and setting	Key findings	Recommendations for pre-exposure prophylaxis interventions
daily pre-exposure prophylaxis for HIV prevention in South Africa				which was a strong motivating factor for the study. Some participants were disbelieving in the notion that there is a pill to prevent HIV, thus questioned PrEP efficacy. This was further fuelled by the limited availability of PrEP. PrEP was also viewed as providing FSWs with a sense of control and well-being.	<p>important to encourage confidence and acceptability of PrEP uptake.</p> <ul style="list-style-type: none"> <li>• Disbelief in PrEP efficacy contributes to low retention fuelled by the fact that PrEP had not been introduced nationally.</li> <li>• Generalised community PrEP would have reduced the mistrust surrounding PrEP efficacy. This means that communal-based messaging that goes beyond target populations is important. Without community endorsement, PrEP uptake and retention remains difficult.</li> </ul>
Community perspectives on barriers and challenges to HIV pre-exposure prophylaxis access by men who have sex with men and female sex workers access in Nigeria	Emmanuel et al. (2020)	Mixed methods	FSWs, MSM	<p>The majority of participants in this study were aware of PrEP as an HIV prevention method for HIV-negative people. Both FSWs and MSM groups supported its use. Only half of the participants were aware of the clinical requirements to start PrEP. With less than 30% knowing the requirements for blood draws and the effects PrEP has on kidneys, only 20% knew that women have to take regular pregnancy tests when taking PrEP. And some confuse PrEP with PEP. Main barriers to access of PrEP by both FSWs and MSM is stigma and discrimination from health care staff. And suspicion of taking antiretroviral treatment translating to being HIV positive. Cost of drugs associated with transportation, costs with regular supply of PrEP by government, as well as drug stock outs. Poor perception of HIV risk.</p> <p>Facilitators of PrEP use: Education of community members through community dialogues. Outreach, a training curriculum and education materials used for MSM and FSW peer education sessions.</p>	<ul style="list-style-type: none"> <li>• PrEP should be rolled out by state governments.</li> <li>• PrEP should be listed as one of the minimum prevention packages for key populations.</li> <li>• PrEP should be delivered through public health facilities, private health care and one stop shop HIV care centres for both MSM and FSWs and should be provided for free.</li> <li>• PrEP delivery should be integrated with other prevention services and provided through a one stop shop model. Training of health care providers with regard to PrEP initiation and strong referral systems are needed.</li> </ul>
<b>Strategies to encourage pre-exposure prophylaxis uptake and retention among female sex workers</b>					
Exploring acceptability of oral PrEP prior to implementation among female sex workers in South Africa	Eakle, Bourne et al. (2018)	Qualitative study	FSWs, South Africa	<p>Low initial awareness of PrEP among FSWs. After considerable explanation of PrEP FSWs likened it to the contraceptive pill, FSWs saw the value of PrEP to mitigate risk against condom breakage and other vulnerable situations with clients, for example, sexual violence. PrEP is also viewed as beneficial to protect FSWs from HIV transmission from their personal partner. The participants agreed that PrEP should not replace condoms but should be</p>	<ul style="list-style-type: none"> <li>• To encourage PrEP uptake, the development of clear education and accurate messaging will be crucial.</li> <li>• Positioning PrEP within the current knowledge of antiretroviral treatment and PEP, while equating it to contraception as a prevention tool, was an effective educational strategy.</li> <li>• HIV-negative and HIV-positive FSWs could provide support to</li> </ul>

Title	Author and year	Study type and methods	Study population and setting	Key findings	Recommendations for pre-exposure prophylaxis interventions
Designing PrEP and early HIV treatment interventions for implementation among female sex workers in South Africa: Developing and learning from a formative research process	Eakle, Matunha et al. (2018)	Qualitative enquiry for best practices for PrEP interventions	Stakeholders, FSWs, South Africa	used together to prevent pregnancy and other STIs, particularly because most participants are not using other contraceptives apart from condoms.	<ul style="list-style-type: none"> <li>one another in taking medication daily.</li> <li>Normalisation may be an important factor when considering PrEP rollout. PrEP should be rolled out to all men and women in the general population and that PrEP should be combined with early antiretroviral treatment in the same facility.</li> <li>Perspectives and advice from FSWs taking antiretrovirals may help alleviate the stress of daily pill taking among PrEP patients, thus it is important to bring HIV-positive FSWs into the conversation.</li> </ul>
How can programmes better support female sex workers to avoid HIV infection in Zimbabwe? A prevention cascade analysis	Fearon et al. (2019)	Quantitative study	FSWs, Zimbabwe	This study found that FSWs most likely to take PrEP were older, but began sex work at a younger age, and had a longer duration of sex work than those non-adherent to PrEP. FSWs who drank alcohol three times per week were less likely to adhere to PrEP than those who did not drink,	<ul style="list-style-type: none"> <li>For effective PrEP uptake there needs to be a combination of both PrEP and antiretroviral services. This will help normalise the use of antiretrovirals as both a prevention and treatment option for HIV-negative and HIV-positive FSWs.</li> <li>There was a general fear of drug resistance with PrEP among FSWs. Thus, it is important to provide education with regard to drug resistance.</li> <li>It is important to understand the different locations where sex workers operate as this will directly influence the modes of PrEP delivery.</li> <li>To encourage adherence and retention use of Medication Event Monitoring System caps (electronic bottle caps that count as bottle opening to track pill withdrawals).</li> <li>Mobile health through short messaging to encourage health choices and wellness messages.</li> <li>Sensitivity training around sex work needs to be conducted with health care staff to ensure non-stigmatising services for FSWs.</li> <li>Programmes need to support younger and newer entrants to sex work to take up and adhere to PrEP.</li> <li>Data shows that FSWs have a strong interest in PrEP and express the need for long-term support to encourage adherence.</li> </ul>

Title	Author and year	Study type and methods	Study population and setting	Key findings	Recommendations for pre-exposure prophylaxis interventions
PrEP 1.0 and Beyond: Optimizing a biobehavioural intervention	Mayer and Allan-Blitz (2019)	Narrative review	Key populations (FSWs, MSM)	but no correlation was established among those who engaged in binge drinking and PrEP adherence. Those using condoms with steady partners were more likely to adhere to PrEP.  This study reported that even though PrEP was found to be highly effective in preventing HIV, only 200 000 Americans have been initiated, and about 80–90% of those who are classified to be at risk of HIV in other countries have not yet been initiated on PrEP. There have been barriers to PrEP uptake such as the cost of PrEP, anticipated side-effects, stigma and an unsupportive health care system, particularly towards key populations such as MSM and FSWs who experience societal exclusion, stigma and discrimination.	<ul style="list-style-type: none"> <li>• Strategies to encourage PrEP uptake and adherence include engaging non-medical staff such as pharmacists, social workers, peer navigators in the delivery of PrEP services.</li> <li>• Engaging technology in the form of text messaging, dedicated apps to monitor adherence, as well as other sophisticated methods such as ingested electronic pill sensors.</li> <li>• PrEP can also be administered as an injectable, implant or vaginal ring. Some of these approaches may allow for infrequent dosing which means less interaction with health care facilities.</li> </ul>
Antiretroviral men who have sex with men: A new opportunity to slow HIV spread in India	Mayer, Chandhiok and Thomas (2016)	Editorial	Key populations (FSWs, MSM) India	This editorial supports the notion that PrEP can be implemented successfully among high-risk populations. However, implementation may need to be tailored to suite local context. The editorial further goes on to support the idea of PrEP being offered to high-risk groups as a cost-effective strategy. The concerns being PrEP and drug resistance which has not yet been reported in PrEP studies,	<ul style="list-style-type: none"> <li>• There are benefits in offering PrEP to high-risk groups because PrEP requires an extensive interaction with the health care system, thus, individuals who may otherwise avoid clinics now have reason to be integrated within the health system.</li> <li>• Through PrEP, other health care needs of key populations can be taken care of, such as family planning, STI treatment, psychosocial needs being undressed under a comprehensive HIV prevention package.</li> </ul>
Acceptability of HIV self-testing to support pre-exposure prophylaxis among female sex workers in Uganda and Zambia: Results from two randomised controlled trials	Ortblad et al. (2018)	Quantitative randomised control trial	FSWs, Uganda and Zambia	In this study, acceptability of oral PrEP was high among both FSW participants from Zambia and Uganda. A majority of participants in both sites were interested in quarterly injectable PrEP. Interest in vaginally applied PrEP was less common. Almost all participants in both sites showed willingness in testing for HIV every three months while taking PrEP. In this study, a greater number of participants expressed an interest in engaging in self-testing while on PrEP.	<ul style="list-style-type: none"> <li>• HIV self-testing could accompany PrEP distribution to lessen the burden of FSWs having to present regularly at health care facilities for testing, particularly if they have to contend with stigma and discrimination from health care providers.</li> </ul>
Prioritizing risk in preparation for a demonstration project:	Reza-Paul et al. (2016)	Mixed methods	FSWs, South India	Before the commencement of this feasibility study, FSWs were made aware of PrEP through campaigns.	<ul style="list-style-type: none"> <li>• Feasibility studies need to be conducted to ascertain</li> </ul>

Title	Author and year	Study type and methods	Study population and setting	Key findings	Recommendations for pre-exposure prophylaxis interventions
A mixed methods feasibility study of oral pre-exposure prophylaxis (PrEP) among female sex workers in South India				The participants demonstrated a good understanding of PrEP. The participants further expressed high levels of interest in being initiated on PrEP due to the risks they experienced. PrEP is seen as a prevention tool that would place control of HIV prevention in the hands of FSWs. PrEP is seen as a tool to ease the fear of infection. Some expressed a concern that PrEP might undermine condom use. The need for a daily intake was cited as a barrier due to volatile work schedules. Fear of partners who may not approve of PrEP. Peer educators, FSW community leaders, Drop-in centres were preferred channels for distribution of PrEP.	acceptability of PrEP interventions. <ul style="list-style-type: none"> <li>Community consent is important. PrEP scale-up needs to be situated within the trusted spaces of community-based organisations as a vehicle to support PrEP uptake and adherence.</li> <li>Counselling is an important feature in supporting adherence. Tailor-made approaches to PrEP delivery based on each individual's needs and preferences.</li> <li>Tap into wider sex worker networks, boyfriends and pimps to educate them about PrEP to curb stigma and fear.</li> </ul>
"The drug will help protect my tomorrow": Perceptions of integrating PrEP into HIV prevention behaviours among FSWs in Lilongwe Malawi	Shea et al. (2019)	Qualitative study	FSWs, Malawi	The participants in this study felt that condoms were a first line of defence is preventing HIV, and condomless sex was reserved for steady partners. The participants were highly motivated to prevent HIV transmission. This motivation was rooted in the love for one's life. The participants reflected on how acquiring HIV would impact on their livelihood. Taking precautions were seen as an essential and part of the job. PrEP was seen as an insurance to health and longevity. PrEP provided an opportunity to take ownership of health and life. Potential barriers were adherence, stigma (assumptions that PrEP is an antiretroviral), and side-effects.	<ul style="list-style-type: none"> <li>Motivations for FSWs to protect themselves from HIV were rooted in the love for one's life, thus the willingness for PrEP uptake was nestled in a desire to take control and protect oneself.</li> <li>FSWs may respond positively to PrEP outreach efforts that describe prevention as an act of self-love.</li> <li>Distribute PrEP through organisations with a successful HIV prevention community outreach. PrEP delivery can use empowerment messaging that resonates with FSWs.</li> </ul>

### 3.3 Results

The themes that have emerged from the 16 reviewed papers are the following: integration of PrEP with sexual and reproductive health services for FSWs (n=3 studies) (Becquet et al., 2020; Bowring et al., 2020; Lancaster et al., 2019); community empowerment as a component of PrEP programming (n=3 studies) (Bekker, Johnson, Cowan, Overs, Besada, Hillier, & Cates, 2015; Das & Horton, 2015; Cowan & Delany-Moretlwe, 2016) perspectives of FSWs with regard to PrEP use (n=2 studies) (Eakle et al., 2019; Emmanuel et al., 2020), as well as the various strategies to encourage PrEP uptake (n=8 studies) (Eakle, Bourne, Mbogua, Mutanha, & Rees, 2018; Eakle, Mutanha, et al., 2018; Fearon et al., 2019; Mayer & Allan-Blitz, 2019;

Mayer, Chandhiok, & Thomas, 2016; Ortblad et al., 2018; Reza-Paul et al., 2016; Shea et al., 2019).

### **3.3.1 Integration of pre-exposure prophylaxis with sexual and reproductive health care services for female sex workers**

Access to health care services by FSWs is a persistent challenge in many countries, particularly those who have criminalised sex work (Scorgie et al., 2013). Stigma and discrimination from health care providers is rife and discourages FSWs from accessing health care. In some contexts, FSWs do receive limited health care services from donor-funded mobile facilities. Some of these facilities, however, limit their services to HIV testing, STI screening, and condom distribution. In recent years, some of these facilities expanded to provide antiretroviral treatment and PrEP. Prior to that, FSWs were being referred to mainstream health facilities for other sexual and reproductive health services. According to Becquet et al. (2020) and Bowring et al. (2020), the recommendation to integrate HIV-related services with sexual and reproductive health services is a good way of engaging FSWs in regular health care prior to introducing PrEP. The FSW's regular contact with health care services opens up opportunities for persuasion and possible PrEP uptake, particularly among those FSWs who do not feel ready to start with PrEP. Furthermore, FSWs have expressed a desire for comprehensive services that include family planning, HIV and STI screening, and Pap smear screening. The need for family planning services was raised in light of the fact that FSWs are most likely to practice unsafe sex with their steady partners and this has led to unplanned pregnancies.

### **3.3.2 Community empowerment as a component of pre-exposure prophylaxis programming**

Community empowerment means the involvement of FSWs in the design and implementation of PrEP programmes being at the heart of PrEP programming, as recommended by various researchers who felt that more programmes need to provide FSWs with the opportunity to evaluate the current PrEP programmes and their suitability in serving the needs of FSWs. Furthermore, according to Bekker, Johnson, Cowan, Overs, Besada, Hillier, & Cates (2015), interventions that holistically combine the structural, behavioural and biological factors to promote HIV prevention are much more likely to have a positive effect on FSWs and HIV prevention. Cowan and Delany-Moretlwe (2016) asserted that FSWs that feel a sense of

knowledge and power, as well as the confidence to protect themselves from HIV, are more likely to perceive their exposure to risk and may initiate and adhere to PrEP.

### **3.3.3 Perceptions of female sex workers with regard to pre-exposure prophylaxis**

The studies that investigated the perspective of FSWs with regard to the use of PrEP found that FSWs in various settings expressed a willingness to use PrEP; however, there are various personal and interpersonal challenges that would impact on uptake and adherence, such as support from friends and intimate partners, side effects, concerns regarding drug resistance, the association of PrEP with antiretrovirals, questioning the efficacy of PrEP as a pill to prevent HIV, stigma and discrimination from health care providers, particularly if they are not sensitive or friendly towards sex workers (Eakle, Bourne, et al., 2018).

### **3.3.4 Strategies to encourage the uptake and retention of pre-exposure prophylaxis**

The selected studies mentioned various strategies for PrEP programmes to consider when planning PrEP interventions for FSWs. The main outcome for PrEP interventions is to encourage uptake and retention. The first crucial step in any prevention programme is education and accurate messaging. Eakle, Bourne, et al. (2018) suggested that PrEP should be positioned within the current knowledge of antiretroviral treatment and PEP, as well as using the analogy of the contraception pill to drive the point of daily pill intake, which has been said to be an effective education strategy. Another suggestion was that HIV-negative FSWs should be combined with HIV-positive FSWs so as to offer support to one another; HIV-positive FSWs can provide perspectives pertaining to the challenges of daily pill intake and how those challenges can be overcome. The combination of both PrEP and antiretroviral treatment services will promote antiretroviral treatment as both a prevention and treatment option for HIV-negative and HIV positive FSWs.

The research further advocates for the normalisation of PrEP through broader community roll-out to minimise stigma. If PrEP is rolled out to the general population, this will dispel suspicion and questions around the efficacy of PrEP (Eakle, Bourne, et al., 2018). The concern pertaining to drug resistance was cited as another potential deterrent to uptake; thus, it is vital to provide education with regard to drug resistance (Eakle, Mutanha, et al., 2018). It is also important for interventions to map out areas of sex work, both indoor and outdoor establishments, to inform modes of PrEP delivery to cater to all FSWs.

Effective and accurate monitoring should not only rely on patient reports or pill counts but incorporate the use of technologies such as electronic bottle caps that count bottle opening to track pill withdrawals. The use of mobile health services in the form of short messaging services can be used to provide support to PrEP patients as well as a medium with which to send reminders for pill top-ups (Eakle, Mutanha, et al., 2018).

Training of health care staff with regard to PrEP administration and initiation was highly recommended, as well as sex worker sensitivity training to ensure that FSWs are not discriminated against. Peer educators play an integral role in PrEP programming since they can be used to conduct outreach, promote PrEP as well as deliver PrEP to FSWs. They can also encourage adherence through keeping in touch with PrEP patients (Mayer & Allan-Blitz, 2019). Some studies recommended that PrEP be offered as an injectable to reduce the need for daily intake as well as minimising interferences associated with pill intake. Injectables for one to two months were recommended (Mayer et al., 2016). One study also recommended HIV self-testing to accompany PrEP programmes (Ortblad et al., 2018). Self-testing would ensure that FSWs monitor their status, which can be a motivation to continue with PrEP use, or if seroconversion occurs, they can begin antiretroviral treatment as soon as possible.

### **3.4 Discussion**

Evidently, the majority of studies in this review were feasibility studies that focused on establishing the acceptability of PrEP among FSWs (Eakle et al., 2019; Eakle, Mutanha, et al., 2018; Mudzviti et al., 2019; Venter, Cowan, Black, Rebe, & Bekker, 2015). Some were formative studies conducted prior to PrEP demonstration projects (Eakle, Bourne, et al., 2018). In establishing the feasibility of PrEP, researchers received enthusiastic responses from FSWs pertaining to PrEP acceptability, with many participants saying that they would be happy to take PrEP for HIV prevention. However, further research across various contexts showed high numbers in the initial uptake of PrEP and low adherence rates among FSWs (Eakle, Gomez, Naicker, Bothma, Mbogua, Escobar, et al., 2017; Felsher et al., 2018).

The necessity of community involvement in PrEP implementation was also strongly recommended. In most of these studies the involvement of FSWs was in the form of key informants to ascertain the feasibility of PrEP projects or as peer educators used as ambassadors to spread the message about PrEP and provide ongoing support to PrEP patients through mobile health communication strategies (Reza-Paul et al., 2016). Recommendations call for

community empowerment, which means the involvement of FSWs in programme design and implementation for better PrEP uptake and retention (Bekker, Johnson, Cowan, Overs, Besada, Hillier, & Cates, 2015). PrEP education should be conducted in the form of community dialogues and this process should be led and facilitated by peer educators, health care workers and community-based organisations working with key populations (Emmanuel et al. 2020).

The integration of PrEP with other sexual reproductive health services, as well as the distribution of PrEP along with antiretroviral treatment, was described as a packaged comprehensive service acceptable to FSWs. Positioning PrEP as a parallel HIV prevention technology was discouraged, and it was recommended that it should be positioned among other long-standing and effective prevention methods, such as condoms, to prevent pregnancy and other STIs (Eakle, Venter, & Rees, 2018). FSWs also have limited access to contraception, and studies have shown that FSWs have expressed a desire for health care services that provide for all their sexual reproductive health needs. Distributing PrEP alongside antiretroviral treatment services will most likely dispel the myths and doubts pertaining to the efficacy of PrEP, as well as frame antiretroviral treatment not only as a regimen for HIV treatment but also for HIV prevention in the form of PrEP (Becquet et al., 2020; Bowring et al., 2020; Lancaster et al., 2019). Furthermore, other studies suggested an injectable form of PrEP as the solution to daily pill intake. Injectable contraception is popular in South Africa and therefore a PrEP injectable is likely to be acceptable (Pebody, 2016, Tolley et al., 2019). An ongoing HPTN 083 clinical trial found that the long-acting PrEP injectable (to be injected once in eight weeks) has shown effectiveness more than the oral PrEP (Landovitz et al., 2020).

Stigma as an unintended consequence was cited by some studies, coupled with doubts as to whether PrEP was effective, caused by the targeted distribution of PrEP to high-risk groups. It was recommended that PrEP needs to be normalised, which calls for the offering of PrEP to the general population as a way to build confidence in PrEP and curb stigma (Eakle, Bourne, et al., 2018). The initial targeted distribution of PrEP to persons considered to be at a high risk of HIV, came as a guideline from the WHO (2015), as a strategy to reduce new HIV infections, as well as to reduce the costs of PrEP by providing it to selected population groups.

Most of the reviewed papers focused on the biomedical aspects of PrEP uptake, with the exception of one study that explored the human element of PrEP uptake through exploring personal motivations of participants for engaging in HIV prevention (Shea et al., 2019). The participants mentioned PrEP as giving them hope to a longer life as well as a sense of

empowerment. Engagement in HIV prevention was associated with a sense of self-worth, and recommendations from this paper were for programmes to focus on outreach efforts that frame their prevention messages in the paradigm of valuing life as motivation for engaging in prevention (Hartmann, McConnell, Bekker, Celum, Bennie, Zuma, & Van der Straten, 2018).

### **3.5 Implications of the scoping review for this doctoral study**

The purpose of this review was to systematically engage with evidence from various studies about how PrEP interventions should be designed and implemented. Furthermore, this evidence informed the intervention mapping process of this study which focused on creating an empowering or enabling environment for FSW peer educators to design a PrEP intervention programme to address challenges to PrEP uptake and retention. This was an attempt to foster PrEP programming among FSWs to be community-based. Research considered in this review supports community-based programming for PrEP because of the likelihood of improving PrEP uptake. Community empowering approaches foster a sense of ownership of the programme. This encourages responsibility towards the programme which is good for sustainability as a result of prolonged meaningful engagement. Two studies in this review emphasised that PrEP messaging should be framed around the value of life and PrEP as a tool for sexual wellness. The community intervention programme designed for this study takes a human-centred approach to PrEP programming foregrounding the need to have dialogues around FSWs power relations, agency, values and responsibility relating it to PrEP as a mode of prevention.

### **3.6 Summary**

This scoping review was a systematic investigation of literature to map out evidence that informs PrEP intervention for FSWs. There were various recommendations from the literature. These recommendations were thematically analysed and synthesised. Through this process, the rationale for this thesis was expounded. The creation of a conducive environment for community empowerment and involvement of FSWs in PrEP programming was one of the recommendations for effective interventions. This recommendation coincided with the purpose of this research, namely, to involve FSWs in the design of a PrEP intervention. This analysis of evidence is crucial as it assisted the reader to identify what has been proposed for PrEP programming so as to understand the contribution of this thesis to the body of knowledge regarding PrEP programming for FSWs.

## Chapter 4

### Theoretical Framework

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#### 4.1 Introduction

This study was guided by the Critical reflexivity framework and the Bronfenbrenner's bioecological model. These theoretical perspectives informed the philosophical, methodological, and analytical approaches to the study. The purpose of the theoretical framework is to provide a blueprint that guides the researcher in selecting the appropriate research approaches (Osanloo & Grant, 2016). These theoretical frameworks have provided the researcher with a lens and a specific approach to meet the research objectives.

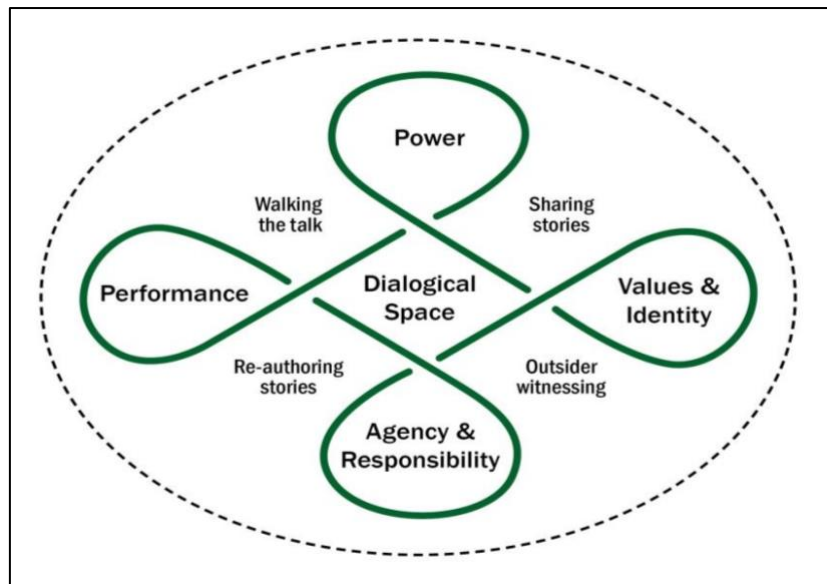
#### 4.2 Critical reflexivity framework

Critical reflexivity was the lens that guided the process of this study from the needs analysis to the intervention mapping and design of the programme in close collaboration with FSW peer educators. According to various authors, the terms *reflexive* and *reflective* are often used in multiple disciplines and, at times, used interchangeably (Fook, White, & Gardner, 2006; Gilbert & Sliep, 2009). However, it is crucial to shed light on the slight differences of these terms for this thesis, since one of the aims of this study was to engage FSW peer educators in a reflexive process to produce a PrEP intervention programme. This programme was designed to assist FSWs in developing a deeper personal and interpersonal engagement with health care, particularly HIV prevention through PrEP. Reflection is a process in which individuals become aware of how society influences the way they see themselves, taking into account their social context and the effects of that context on their socialisation. Reflexivity goes further than personally orientated reflection to a broader engagement with the social world. It is a process of becoming aware of one's positioning in relation to others. It is about moving away from a focus on personal beliefs and ideas to embracing and engaging with the opinions and views of others. It is moving beyond one's philosophical positioning to becoming open to multiple standpoints (Norton & Sliep, 2018). Door (2014) argued that "reflexivity is extended reflection, ... it includes the embodied self and its response to the other selves with whom that self-interacts, and that it incorporates thoughtful action" (p. 91). According to Gergen (1999), "reflexivity is an attempt to place one's premises into question, to suspend the obvious, to listen

to alternative framings of reality and to grapple with the comparative outcomes of multiple standpoints” (p. 50).

Reflexivity is a term used in social science literature and in the context of research, professional practice, or therapy to understand how one’s actions are influenced by how one perceives and assess the actions of others. This kind of reflexivity is self-reflexivity, which is a “critical examination of the self in action” (Gilbert & Sliep, 2009). Sliep and Gilbert (2006) referred to interrelational reflexivity, which occurs in the context of social action within a particular community and refers to the creation of a social space in which individuals who have common interests come together to engage on agency and to negotiate accountability and responsibility for action. This research relates to FSW peer educators’ engagement in the co-creation and design of an intervention plan to improve the uptake adherence and retention of PrEP among FSWs. This PrEP programme, designed by FSW peer educators, takes a reflexive approach to HIV prevention, creating a space for self-reflexivity through the engagement of individual exercises as well as interrelational reflexivity through group dialogue and deliberation.

Gilbert and Sliep (2009) have represented reflexivity in the form of a critical reflexivity model. The model encompasses social constructionist principles with the construction of reality through social interactions and social action. In a relational sense, this means that we create our understanding with others around us through relationships, facilitated by dialogue and interactions. Reflexivity is a process that is both dynamic and iterative; it is an ongoing practice of testing our assumptions and intentions and takes into account how context influences our actions and, in turn, how our actions influence our context. Meaning and self is created through ongoing interactions, not in isolation but with others in our context. Reflexivity demands that we question ourselves, and we strive to relate with those around us ethically. We have to question our assumptions and actions and engage more meaningfully with how and why we act in specific ways and position ourselves within society. In terms of the reflexivity model, our way of meaning-making involves us moving back and forth through four loops as part of a process of generating critical reflexivity, and social and relational interactions and understandings. Gilbert and Sliep (2009) represented their formulation of critical reflexivity, as shown in Figure 2, which encompasses the dialogical space, power, agency and responsibility, values and identity, and performance.



**Figure 2. Narrative paradigm in the reflexivity framework (Gilbert & Sliep, 2009)**

This critical reflexivity model has been useful in various contexts such as higher education (Norton & Sliep, 2020), qualitative research (Naidu, Sliep, & Dageid, 2012), school projects with youth (Norton & Sliep, 2019), as well as in a variety of community projects (Sliep & Gilbert, 2006). This model is flexible and can be applied in various circumstances concerned with promoting self-awareness, improving social understanding by bringing into focus power dynamics in social relationships, and bringing attention to one’s values and how they are related to identity, as well as linking one’s human rights which can be expressed through moral responsibility. The model promotes social action using personal, collective and proxy agency through collective performance, referring to performativity as a check if one is ‘*walking the talk*’ for collective transformation. It can be used as a tool for research and practice, as well as for analysing social issues, improving social cohesion and developing reflexive professionals.

The narrative approach is one way in which critical reflexivity is facilitated. This approach helps the user to create links between their individual experiences and those of others, as well as deconstruct dominant discourses shaped by socialising factors of power, values and identity, agency and responsibility, and performativity (action) (Sliep & Kotze, 2011). The dialogical space is at the centre of the framework. Reflexivity takes place through dialogue, which enables one to understand that there are many truths and what one person perceives as reality may not be so for another. For an honest and in-depth discussion to take place, people need to feel safe enough to narrate their stories; therefore, trust is an essential component that needs to be fostered and nurtured in the dialogical space. The dialogue that is encouraged is one that aligns

with a socially transformative agenda. A representation of all voices in the space is required to create an enabling environment of shared knowledge, experiences and views which may ultimately lead to personal and collective transformation (Sliep & Kotze, 2011).

The narrative approach is vital for developing critical reflexivity because stories help us to find meaning in our lives. Narratives are relational between self, others, and context; the process of sharing helps us move towards a comprehensive story of the self as well as a collective coherent story. The narrative approach helps us to understand how culture and context within a timeline shape the person, and it is in the process of understanding the self that we can understand others. The recognition that knowledge is not constructed in a vacuum by a singular self is important as it reinforces the notion that knowledge develops collectively (Sliep & Kotze, 2011). It opens a space for understanding our lives and those of others by examining our lived experiences and connecting these to the complexity of our society. The narrative approach recognises individuals as experts of their own lives and encourages externalisation of the problems they face to better deal with these and prevent internalisation of the problem as part of one's identity. It is an approach that believes that people possess the skills, competencies, values and beliefs that can help them to solve their own problems. It does not reduce people to their problems but believes that people can rise above their challenges and have the ability to find their own solutions. Narratives can be emancipatory, mainly when the experiences are narrated and interpreted in multiple ways (Andrews, Squire, & Tamboukou, 2013). Events that were once only associated with pain and defeat can be retold through a lens of strength and resilience.

Applying the narrative approach to reflexivity involves using stories as tools to help people view and act on their social situations. This approach stimulates people's need to think and find solutions to their problems. By telling of one's life story, the reflexivity process facilitates the ability to analyse and question the content and experience of events in their lives and to look at them in different ways. Telling stories and the process of deconstructing the meaning of events and experiences, help us to understand the world and to view it differently in relation to other people's stories in the dialogical space; then people learn to value others based on their own experiences. Deconstruction means the breaking down of old patterns and beliefs. It gives way to a re-authoring of a different narrative that encompasses a different reality from the micro-individual aspect to the macro-social, political, and economic context. In listening to each other's stories, we reinforce the notion that we live through multiple realities in the social world but can still collectively shape new stories (Sliep & Kotze, 2011).

Creating a shared meaning can lead to joining forces that can contribute to positive outcomes. This shared meaning is not an automatic process but requires activation of self and relational reflexivity in the dialogical space through the story-telling process. Telling and deconstructing our stories in the presence of others through the reflexive process, enables us to recognise and break down the influence of dominant discourses that reinforce our personal beliefs about ourselves and the world. Examining our values and identity through our stories allows us to be conscious of how we have positioned ourselves in the social world. Through agency, we can reposition ourselves, taking into consideration our responsibilities in the process. This process moves us to a place of living our preferred story. When this process takes place in the presence of others, the transformation is shared and witnessed. The goal is to move together towards a preferred collective story in which everyone is valued, and is a catalyst for change (Schauer, Schauer, Neuner, & Elbert, 2011)

For the purpose of this study, critical reflexivity, which consist of self and interrelational reflexivity was enabled and developed among FSWs through the telling of their own life stories in the dialogical space. Through these processes they grappled with their own and each other's realities, anchored on the need to prevent HIV at a personal level and as an FSW community. The engagement with their values and identity power, agency and responsibility are critical in facilitating positive performativity, referring to ways in which they can see themselves to 'walk the talk'. It is essential to have a clear understanding of each loop in the framework to guide the process.

#### **4.2.1 Dialogical space**

Dialogic spaces, using a life story approach, have been used in various settings such as educational and therapy. These spaces create platforms where every member of a group can freely express their opinions about specific issues. Dialogic spaces create an opportunity to engage with different perspectives that address complex social problems (Rober, 2005). The need for such spaces, especially among vulnerable and marginalised populations such as FSWs, are important to enable reflexivity.

*Dialogos* is a Greek word that means 'conversation' or 'discourse'. Thus, the term signifies a particular kind of speech that happens between two or more people and is associated with the pursuit of knowledge (reason, argument, discourse). In the words of Rule (2004):

It also has a connotation of difference (dia as ‘apart’): the two or more who partake in dialogue are separate and distinct as individual beings, as speakers and as thinkers, but the conversation brings them together and fashions a unity of process through their joint engagement (Rule, 2004).

Dialogue is an unfolding process, a search or quest for knowledge and understanding, usually through the medium of spoken language, but not excluding written and visual codes, involving partners committed to this quest. Thus, the dialogue assumes a relationship and is impossible without it (Rule, 2004).

A social space is a physical or virtual location or place where people meet to interact. It is associated with freedom and mobility, and it is produced by social relations which reproduce, mediate, and transform (Bourdieu, 1989). A dialogical space is, therefore, a social site that enables dialogue through the use of different means of communication, spoken words, body language, and written and visual means (Rule, 2004). Dialogue occurs at several related levels in this social space, between the members of a group or community that forms the dialogical space, and between outside agents (researchers, health promoters). Dialogical spaces are created to discuss issues of concern and to develop possible solutions. It is sometimes also created as a form of therapeutic intervention to allow a group of people, for example, a marginalised group, to express themselves and share their experiences (Errington, 2015). Occurring within the dialogical space, the four loops – power, agency and responsibility, values and identity, and performativity – will be explored in detail.

#### **4.2.1.1 Power**

The notion of power was informed and guided by Laverack and Foucault’s definition of power. Laverack (2004) started by providing a common understanding of power, which is zero-sum in nature. This is power over people, and it exists in the form of authority, force, manipulation, and persuasion. An individual or group can influence the actions or decisions of another through control. There is also the power of choice, which is the simplest form of power in which an individual makes choices that range from small, everyday decisions to more critical decisions that impact their health. However, in a situation where our personal preferences constrain those of others, it becomes an exercise of power *over*. Those who can control decisions at a sociopolitical macro level affect people’s choices at an individual micro level. As a way of example, Chapter 2 of this study outlined the negative impact of criminalisation

of sex work at a macro level and how this law impacts the individual sex worker at a micro level, affecting access to health care and HIV prevention.

The role of health promotion in society is to break down the zero-sum power (powerful versus powerless) and ensure that power is shared, and that previously disempowered and subjugated groups can gain some power and have some control over resources or decision-making that may affect their health. However, in doing this, the health promoter/researcher usually faces challenges when trying to delineate power to certain groups over others, creating competition and conflict, mainly if those groups are unpopular or seen to be involved in criminalised activities. Social justice dictates that priority be given to those groups facing inequality in health outcomes and socio-economic opportunities; sex workers fall into this category. The health promoter/researcher should aim for a non-zero-sum form of power. This is a view of power as non-static and is not of a belief that power is a finite commodity such as wealth or authority; rather, a non-zero-sum form of power is premised on the values of respect, generosity, and service to others. The health promoter/researcher facilitates the transfer of power between individuals and groups by making information and resources easily accessible. In this case, power is not a given, but communities are enabled by health promoters/researchers to gain power or tap into their internal power, which is power from within (Laverack, 2004). It was envisioned that through participatory processes, particularly in co-creating health-related interventions, FSWs may be able to tap into their internal power.

According to Laverack (2004), there are three distinctions of power: *power over*, which is zero-sum power and is usually exercised negatively; non-zero-sum power, which is *power with*; and *power from within*. Power with is a use of power over in a transformative way. It is a combination of power over and power with, to activate a person's power from within, which is a personal inner energy that includes a connection with self that encourages self-discipline, self-knowledge, and self-esteem. Power from within is a step towards psychological empowerment and self-determination and actualisation.

Laverack (2007) used an amalgamation of definitions from multiple scholars to define a community. Some of the characteristics of a community are shared identity, mutual influence, shared needs, and emotional connection. This study will use these characteristics to qualify FSWs as a community. Howe (1994) stated that the way a health promoter/researcher defines a community, dictates their approach when engaging with that community. Some describe a community using geographical location, and others use demographics (men, women, youth).

Another way for a health promoter/researcher to view a community is through believing in the ability of a community to work towards developing solutions to their own identified problems. The first two definitions of a community (geographical location and demographics) are synonymous with top–down health promotion programmes; however, the third interpretation of a community is associated with bottom–up community empowerment approaches.

Laverack and Labonte (2000) acknowledged the tension that exists between bottom–up and top–down approaches to community programmes. The top–down approach is usually applied or associated with disease prevention efforts. Donor/health agencies define the level of involvement of community groups. Changes in health behaviours measure indicators for success; community empowerment in such instances is viewed as occurring at a point of positive behavioural change. A top–down programme approach has a predetermined approach to programming, such as having an overall design, objectives, strategy selection, strategy implementation and programme evaluation. On the contrary, in the case of bottom–up programming, health promoters/researchers work with the community in identifying issues of importance and advise them by helping community members to solve their problems. The programme design and management are negotiated in tandem with the community, and these programmes usually take much longer to implement.

The tension exists when health promoters/researchers seek to implement a programme that addresses a particular health issue in a certain community. This particular health issue may not be a priority for the community members who may have other pressing matters that they would like to be addressed. The challenge for health promoters/researchers is balancing their research interests and the perceived health needs of the community, as well as the community's issues that may not be of interest or within the donor fund or agency's scope to address. Furthermore, Laverack and Labonte (2000) acknowledged that a purely bottom–up approach to programming is ideal and may not always be possible. They proposed a parallel track, an approach that allows for the integration of community empowerment goals within top–down programmes. These empowerment goals are positioned intentionally as a parallel track running alongside the conventional programme track. The complexity that the health promoter has to deal with is to ensure that the programme and empowerment tracks become linked during the progressive stage of programme development. Parallel tracking is intended to assist health promoters/researchers to systematically accommodate community empowerment goals within their programme objectives. The way a programme is designed is important, and regardless of programme content, a programme can have an empowering component by using participatory

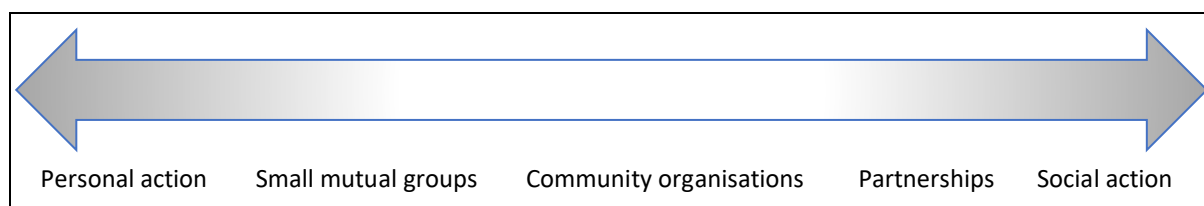
planning approaches. Rather than a programme being a once-off educational programme or marketing activity, the programme can be designed as a vehicle through which long-term relationships are formed between the health promoter/researcher and community members (Laverack & Labonte, 2000).

Furthermore, Laverack and Labonte (2000) cautioned that the process of community empowerment takes time (2–7 years), and empowerment may only be evident long after the programme has ended. Consequently, because of the limited time to complete doctoral studies, the focus of this study was not to implement and evaluate the intervention programme, but rather to focus on the processes of intervention design in close collaboration with FSW peer educators. Their central involvement in this intervention design is an outcome of creating an enabling and/or empowering process. To achieve parallel tracking, Laverack and Labonte (2000) advised that a programme starts with practical community issues that are achievable in the short term. This helps to maintain interest in the programme among community members and to promote positive progression to more complex initiatives. The programme can start with engaging small groups, and later these groups can form partnerships.

Laverack (2007) called for interventions to give attention to marginalised populations and stated that these groups are less likely to participate in programmes unless they form part of programme design and implementation, which is an integral component of this research, in which FSWs are the main programme designers and potential implementers. The process of empowerment in programmes can be assessed through the following domains: improving stakeholder participation, increasing problem assessment capacities, developing local leadership, building empowering organisational structures, improving resource mobilisation, strengthening the ability of stakeholders to ask why stakeholder control over programme management is increased and creating an equitable relationship with outside agents. Moreover, empowerment outcomes should include an evaluation of the subjective experiences of programme beneficiaries who can speak from their own experiences and knowledge.

The purpose of power negotiations and redistribution is meant to lead to empowerment. Empowerment is an overused term and has proven hard to determine and measure because of its subjective nature. However, there are broad definitions, such as the one by Werner (1998), who defined empowerment as the process by which disadvantaged people work together to increase control over events that determine their lives. Empowerment has also been conceptualised as an outcome that has to emerge from within a group rather than a given.

Theorists such as Rissel (1994), have broken up empowerment into small visible, and possibly measurable components. Rissel (1994) asserted that empowerment can mean a heightened or increased level of psychological empowerment in a community that may lead to political action, which involves a redistribution of resources or decision-making that is favourable to the previously disadvantaged group. Empowerment takes place in phases on a continuum, starting with psychological empowerment, which can lead to personal action, which in turn, can lead to the development of small mutual groups that grow into community organisations that form partnerships, that can eventually lead to social and political action. These five phases on a continuum are depicted as a linear process. However, each point on the continuum can be viewed as an outcome or progression to the next point. Figure 3 gives an adapted depiction of Laverack’s empowerment continuum. Significantly, dialogical spaces consist of individuals who form a small mutual group; this can be deemed an outcome of empowerment as depicted on the empowerment continuum.



**Figure 3. *Laverack’s empowerment continuum (adapted from Laverack, 2004)***

The Foucauldian understanding of power, as described in the critical reflexive framework, is also one of the approaches that informed the dialogical space. According to Foucault (1982), power is everywhere, not because it embraces everything but because it comes from everywhere. Power is not an institution or a structure or a possession that occurs at every given moment during social relations; thus, power is constantly present and fluid in its nature. “Power is diffused rather than concentrated, embodied and enacted rather than possessed, discursive rather than purely coercive” (Gaventa, 2003). Furthermore, power is not necessarily repressive, prohibitive, and negative, but may rather be positive. Discourse is essential to the operation of power because it is a vehicle through which knowledge is shared. Discourses are also essential to resistance. Through discourse, power can be produced, transmitted and reinforced, as well as undermined (Gaventa, 2003).

This understanding of power will help FSWs to realise that power is dispersed, and people are in a constant negotiation of power, and it is not concentrated to a particular group. It is

important for FSWs at an individual level to realise their power from within and power as a collective. While clients and intimate partners may seem to possess the power to dictate their sexual preferences, FSWs as a collective have power to negotiate what is acceptable and what is not. In most instances, FSWs have the power to dictate the price for sex, but feel powerless when it comes to ensure safe sex or saying no to a client because of fear that they will lose out on money. However, if FSWs acted as a collective and unwavering against risky sexual practices, they will be acting from a position of power. In this instance, PrEP will be positioned as an empowering tool for HIV prevention.

#### **4.2.1.2 Agency and responsibility**

The agentic perspective of Albert Bandura is one of the theories that informs this dialogical space. According to Bandura (2006), “to be an agent is to influence intentionally one’s functioning and life circumstances” (p. 164). As people, we are not merely onlookers upon our behaviours, but we are self-organising, proactive, self-regulating, and self-reflecting. In breaking down agency, Bandura explored four core properties of agency such as intentionality, forethought, self-reactiveness, and self-reflectiveness. Intentionality is when people make plans and include action strategies on how they are going to achieve those plans. Forethought is concerned with envisioning the future of those plans, where visualised future outcomes are used as motivation to engage in behaviour that aligns with the goals that people have set. Self-reactiveness means that people construct appropriate courses of action that will help them achieve their goals, and self-reflectiveness means that people examine their own actions in relation to their plans. They reflect on their self-efficacy, and the soundness of their thoughts and actions and what these mean in relation to their pursuits, and make adjustments in their lives as they see fit. Bandura (2006) asserted that agency does not necessarily translate to absolute autonomy whereby one’s functioning is determined solely by the self; on the contrary, there is reciprocal interplay between one’s interpersonal, behavioural, and environmental determinants. Thus, these components can have a direct or indirect effect on one’s sense of agency and the outcome of one’s decisions or plans.

When it comes to agency, Bandura (2006), made a distinction between three modes of agency: individual, proxy, and collective. To function in the social world, people utilise a blend of these three forms of agency. Individual agency is when we rely on our influence and functioning to realise what we need from the social world. However, we also function in a bureaucratic society, and at times we need the help of others to get what we need. We may not have control

over conditions that affect our lives, so we rely on socially mediated or proxy agency, meaning that we take it upon ourselves to influence others with the resources, knowledge, and means to act on our own behalf to secure the outcomes that we desire (Bandura, 2006). Realistically, we do not live in our autonomy and many of the things we seek, require an interdependent effort through working together. This is known as collective agency, grounded in the belief that a joint functioning is needed to achieve specific goals. Collective agency requires collective efficacy, meaning that all group members believe that as a collective, they can produce the desired results (Bandura, 2006).

The component of responsibility is central to this study. Responsibility implies being accountable for one's decisions and actions as well as being reliable to the self and others. Responsibility in this thesis is expanded from individual responsibility to social responsibility. Social responsibility is defined as a sense of duty or obligation to contribute to the greater good. It is related to agency that assumes the ability for individuals to be active in their development, which means that the individual is self-organising, proactive, self-regulating, and self-reflecting. This process incites individuals to feel a sense of duty to act in ways that are moral and prosocial. Furthermore, social responsibility is a value that manifests itself in our beliefs and the way we live and relate to others (Berman, 1997; Syvertsen, 2006; Wray-Lake, & Syvertsen, 2011). People feel connected to others when they see themselves as part of a larger community with shared needs (Flanagan, Cumsille, Gill, & Gallay, 2007). It stands on the pillars of care and justice, the care that extends beyond the personal and a sense of justice concerned with fairness and equality (Wray-Lake & Syvertsen, 2011). The values of social responsibility are assumed to motivate a person's behaviours that involve helping others and contributing to society. This implies that interventions designed to encourage social responsibility in different contexts may need to focus on various techniques such as modelling, values, and messages that are focused on promoting collective responsibility.

#### **4.2.1.3 Values and identity**

Values are an intrinsic part of an individual's identity and have been defined and conceptualised in various disciplines in the social sciences. According to Schwartz (1994), values are "desirable trans-situational goals that vary in importance, and serve as guiding principles in the life of a person or other social entity" (p. 21). In simpler terms, values are our beliefs pertaining to what we understand as right or wrong behaviours; they transcend specific situations and guide our engagement in events and ways of being and relating with others.

Furthermore, values incite a certain emotional intensity that inspires action and direction. Values are acquired through socialisation, and the values of the dominant group in society can dominate and become core values. Values are adopted by specific groups in society for the collective survival of that group by inhibiting actions that can be harmful to the group (Schwartz, 1994). Schwartz (1992) listed broad value types that are adopted by individuals and groups in society, namely power expressed through social status and dominance; achievement demonstrated through personal success; pleasure; the need for instant gratification; universalism through tolerance; benevolence concerned with the welfare of others; spirituality, and a search for meaning; traditional, through the expression of cultural or traditional customs; conformity, through the adherence of social norms; and security, evident through societal harmony and stability of self and others.

According to Gecas and Burke (1995), identity refers to the meaning that one attaches to the self and is attributed by others. Identity locates a person in a specific social space through the relational connections they form because of identifying with a certain group. The move from individual to group identity refers to a focus on the commonalities that people share within a group and the differences that set groups of people apart. The emphasis on self-identity arose in the early modern period of the 16<sup>th</sup> century when religion started having less influence at societal level. Institutional influences that moulded identities, therefore receded, and individuals were left to define themselves; thus, the personal identity is a fairly modern construct. According to Hewitt and Shulman (1979), personal identity is a “sense of continuity, integration, identification and differentiation constructed by the person not in relation to a community and its culture but in relation to the self and its project” (p. 179).

An individual’s identity is tied to their social roles. Recent theories of identity have included sociodemographic categories of race, class, and gender. An identity is patterned after values; understanding an articulation of one’s values which are central to the self, can also facilitate an understanding of one’s identity (Hewitt & Shulman, 1979). Gecas (2000) has theorised the connection between values and identity as value identities, where individuals perceive themselves in terms of the values they hold. Gecas (2000) used an example of someone helping an old lady to cross the street. This act relates to the value of benevolence; however, it is not the value per se that motivates the behaviour, but one could be identified as a good person and therefore does good deeds. However, through the process of reflexivity people can scrutinise their deeds and be helped to relate them to certain values this brings to attention their distal or unarticulated values. This was further clarified by Hitlin (2003), who said that values lead to

experiences of personal identity, which in turn lead to reflexive constructions of various roles, groups and value identities. These identities, without any reflexive engagement, are simply conceptualised as behaviours rather than values. Hitlin (2003) emphasised that a value identity focuses on an individual's relationship to the wider social world. These values are enacted and articulated situationally through various roles. The behaviours we engage in can help us change and to find other compelling values which shape our personal identities.

#### **4.2.1.4 Performativity**

The purpose of engaging research participants into the process of self and interrelational reflexivity is for them to eventually engage in external practices guided by their new-found critical consciousness. This course of action was described by Gilbert and Sliep (2009) as reflexive performativity. Performativity as a term has been theorised by various scholars (Butler & Butler, 1997; Jackson, 2004; Langellier, 1999). The meaning of performativity in a linguistic sense denotes an utterance that affects an action by being spoken or written. Furthermore, performativity as described by Butler and Trouble (1990), is a verb and action is central to it; in simpler terms it means doing what you say you do as you are saying it (Nealon, 1994). Communication informs conduct that is then enacted and incorporated in daily living. Performativity requires agency and at times one may be acting contrary to the dominant discourse; thus, it can be a source of disruption as a sociopolitical act (Conquergood, 1998; Denzin, 2001). In as much as the purpose is to achieve positive performativity, this is not always possible and performativity can be negative, for instance, the practice of racism through speech and action. Thus, for performativity to be positive, it needs to be guided by moral agency where actions are coupled with responsibility and accountability. It is therefore important to establish a common understanding among group members or a community seeking to achieve a specific change as to what constitutes positive performativity. In the process, it is important to realise how this consensus is reached, whose agenda is being advanced and who gets silenced in the process. It is natural that the involvement of different stakeholders will result in competing interests. It is important to establish a common vision and understanding which can be facilitated by discourse in the dialogical space (Gilbert & Sliep, 2009).

### 4.3 Bronfenbrenner's bioecological theory

The bioecological theory of Bronfenbrenner (1994) provided a guiding framework to the study. Bronfenbrenner is famously known for his ecological approach or ecological model introduced in the 1970s as a response to broaden the research and theoretical perspective of developmental psychologists. His conceptualisation of the term *ecological* was his way of recognising the implications of the changes in the environment on humans who live and grow in these environments. He further explained that the ecology of human development is the “scientific study of the progressive, mutual accommodation between an active growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger contexts within which settings are embedded” (Bronfenbrenner, 1979, p. 21). Bronfenbrenner believed so strongly in the ecological model that he criticised other studies that did not consider this approach. After the 1970s, the ecological theory developed further and advanced from simply considering context factors, to include proximal processes of the bioecological model (Rosa & Tudge, 2013). Due to this major theoretical advancement, Rosa and Tudge (2013) strongly recommend that researchers should state clearly which aspect of Bronfenbrenner’s theory are they applying. Furthermore, the authors have critiqued researchers for claiming to have used the bioecological model only to realise that they used the older version of the theory, which is the ecological model. Therefore, it is important for researchers to make a clear distinction between the two approaches and be clear which one they have applied to avoid theoretical confusion. Furthermore, if researchers fail to represent the theory appropriately, two kinds of mistakes can occur; the first being the misrepresentation of the theory which can mislead the readers and misconstrue the constructs of the theory. Second, this could result in an inaccurate application and testing of the theory (Tudge, 2009).

This study incorporates the developed version of the theory which is the bioecological model. This theory proposes that human development takes place through complex processes of reciprocal interaction between humans, objects, and symbols in the immediate environment. To be impactful, this interaction must take place regularly over an extended period. These interactions within the immediate environment are referred to as proximal processes. An example of this proximal process can be seen in the interaction between a child and a parent or child-to-child activities, group, or solitary play, and the performance of complex tasks. The second proposition, according to Bronfenbrenner (1994), is that the form, power, content, and direction of the proximal processes affecting one’s development vary systematically, based on

the biopsychological characteristics of the developing person and environmental factors, both immediate and remote, which influence the developmental outcomes of the individual. A practical application of this bioecological theory in research calls for an understanding of the process–person–context–time approach to human development (Bronfenbrenner & Morris, 2007).

#### **4.3.1 Processes**

Proximal or near processes involve various interactions between the child and the immediate surroundings responsible for the development of the child’s competencies and general well-being. These proximal processes involve a reciprocal interaction between the child and the environment. In the case of this study, the narrative methodology that will be used in the dialogical space will allow FSWs to engage with the processes that contributed to shaping their lives. These processes drive human development, particularly in the early stages of childhood. These processes are often seen as either protective or preventative. Common examples of proximal processes include parental warmth, affection, and discipline strategies. Distal processes are those factors that occur away from the centre of the child but still have a significant effect on the child; for instance, a parent’s ability to provide depends on whether they have a source of income (Hapunda, Abubakar, & Van de Vijver, 2017). The telling of life stories provides an opportunity for the understanding of the proximal and distal processes, and interactions with the environment provide an understanding of the childhood realities that shape the development of an individual FSW.

#### **4.3.2 Person**

The person component of the model centres on the biological and genetic aspects of an individual. These are the physical characteristics that one carries into the social world and can be divided into demand, resource, and force. Demand characteristics relate to a personal stimulus that influences how others react to you, such as age, gender, skin, colour, coping skills, reasoning, and physical appearance. These characteristics influence interactions because they are visible and elicit immediate reactions and expectations (Bronfenbrenner, 1994). Relating this phenomenon to the reflexivity framework, some dominant discourses are usually constructed around demand characteristics, for example, being a victim of racism or discrimination because of the colour of your skin or being privileged over other people because of your physical attributes that are celebrated in society and reinforced by stereotypes that

inform some of these dominant discourses. Demand characteristics are one of the factors that shape the nature of interactions involving family members, caregivers, or peers. Resource characteristics relate to mental and emotional resources such as past experiences, skills, intelligence, and social and material access. These force characteristics include differences in temperament, motivation, and persistence. Two children can grow up with identical resource characteristics but have different developmental trajectories, mainly if one is determined to succeed more than the other. This also speaks to the social construction of reality that no two people construct reality in the same manner, and growing up under similar circumstances may not constitute a similar experience (Bronfenbrenner & Morris, 2007).

Currently, FSWs in South Africa are discriminated against and marginalised. A lack of rights diminishes their well-being since sex work is criminalised. This distal process means that they suffer abuse at the hands of clients and even law enforcement officers. They cannot access health care freely because of stigma. The results are that the majority of FSWs are HIV positive because of engaging in risky sexual practices. Some are coerced or enticed by money to provide condomless sex. They also cannot report any sexual abuse because their trade is criminalised. The proximal and distal processes contribute to the vulnerability experienced by FSWs.

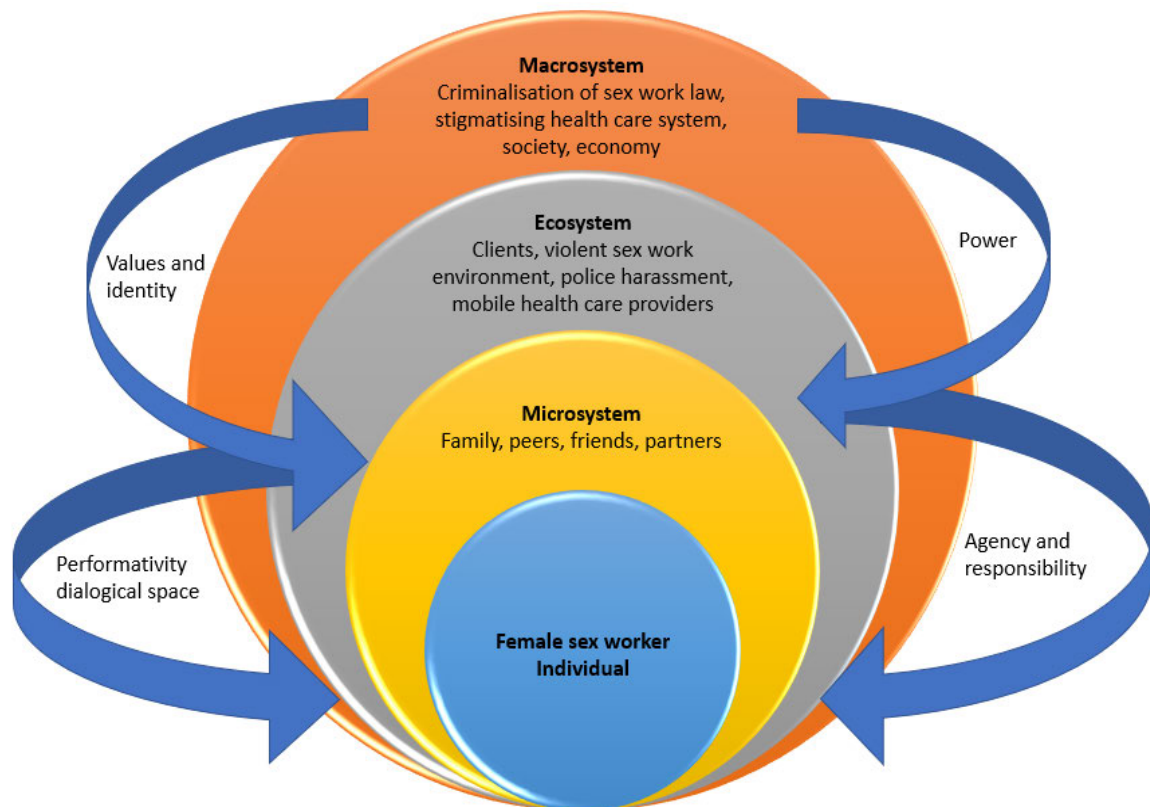
### **4.3.3 Context**

The context is the popular aspect of the bioecological model and perhaps the most crucial consideration when conceptualising and designing interventions. The context is divided into four distinct systems: micro-, meso-, exo-, and macrosystems. Each of these systems has either a direct or indirect effect on the individual (Rosa & Tudge, 2013). The microsystem is the primary environment in which an individual is embedded, such as home, school, or peer group. For FSWs, the people who form part of their microsystem include family members, friends, neighbours, fellow FSW peer educators, clients, and intimate partners. The second system is the mesosystem. This system focuses on connections between two or more systems in the microsystem. The theory posits that socialisation occurs through interaction between an individual with family, friends, and neighbours. The exosystem is a third layer that encompasses a distant context that has an impact on an individual. For example, health care facilities are part of the impact of the exosystem on the health-seeking behaviour of FSWs and their effectiveness in HIV prevention. FSWs experience stigma and discrimination from health care providers. The fourth context is the macrosystem, which is a context that encompasses a society's culture, laws, and belief systems, resources, and life choices. In South Africa, sex

work is viewed from a moralistic point of view and is criminalised. The criminalisation of sex work has affected FSWs in various ways; they are victims of human rights violations from their clients and the broader community.

As discussed in the literature review, the police arrests FSWs for contravening municipal by-laws and sometimes for carrying condoms. The broader societal beliefs regarding sex workers as vectors of disease and moral degradation have a negative effect on an individual sex worker's sense of self-worth, which could lead to internalised stigma and other mental health challenges such as depression and a sense of hopelessness. Time is the final element of the bioecological model. Time is also known as the chronosystem, which includes components of age, duration, and nature of periodicity. The chronosystem accounts for the change or consistency over time in both the person and the environment. The changes that affect an individual's circumstances include family structure, socio-economic status, and employment. In this study, the narrative methodology will enable FSWs to document the significant changes that took place during their lives and how they influenced their response to HIV prevention.

Figure 4 shows that critical reflexivity occurs within the context of the bioecological system in which an individual is embedded. The use of these two theoretical approaches in this study is to demonstrate that individual behaviour does not happen in a vacuum and it is not simply determined by agency, but includes the physical, social, and organisational environments in which individuals live. To ensure that an intervention is effective, it is important to consider whether it is relevant, acceptable, as well as culturally appropriate and implementable. In essence, to achieve optimal health there needs to be an interplay between the individual and the environment, which includes the family, social networks, organisations, and the broader society. Thus, interventions that seek to focus on individual behaviour without taking the environment into consideration, have had limited impact. The focus has, therefore, been on the planning and implementation of complex interventions that include the different environmental levels of influence upon the individual (Kok, Peters, & Ruiter, 2017).



**Figure 4. Critical reflexivity within the context of the bioecological system (adapted from Bronfenbrenner, 1994)**

This study advocated for a critical reflexivity approach to HIV prevention. In the bioecological framework and critical reflexivity framework, FSWs have to feel a sense of agency as well as a personal responsibility to prevent HIV effectively. Agency is better practiced when there is an enabling environment; even though access to health care is generally a challenge for FSWs because of stigma and discrimination. There are mobile facilities providing health care and HIV prevention to FSWs, particularly in the Durban eThekweni Municipality where this study was based. An enabling environment for PrEP access has been created; however, other factors in the social world make PrEP uptake and retention a challenge for FSWs. It is therefore not enough to provide a biomedical intervention without considering the behavioural and social difficulties that FSWs face prevalent in the micro-, exo-, and macrosystem in which the FSWs are embedded.

FSWs are engaged in various interpersonal relationships within the bioecological system, and there is a constant negotiation of power within these relationships. Research has shown that intimate partner relationships are a space where power relations are skewed, and where the male partner is dominant (Bhattacharjee et al., 2018). Furthermore, HIV prevention in these

types of relationships is complicated and is conflated with issues of trust and fidelity, which has made insistence on condom use difficult (Decker et al., 2020). PrEP as a prevention method has been introduced within this milieu and needs to be carefully negotiated. FSWs need to be armed with the tools to engage in these negotiations. Power also presents itself within the FSW community in the form of peer pressure. If PrEP is not properly introduced to this community and is not widely endorsed by FSWs, it will be difficult for FSWs to engage freely and openly about the use of PrEP. For a human-centred prevention approach to be successful, it is essential to understand the values of individuals and the broader community they are a part of. These values can provide the health promoter/researcher with an intervention approach that is relevant and resonates with the target community.

#### **4.4 Summary**

This chapter discussed the two theoretical frameworks that guided this study: the critical reflexivity framework and Bronfenbrenner's bioecological model. These theories informed the methodological approaches in different phases of the study. Phase 1 was a situational analysis which was important for understanding the personal, interpersonal, and environmental challenges that FSWs experience with regard to PrEP uptake. Phase 2 was participatory intervention mapping approach which utilised the critical reflexivity framework and dialogical space format to engage FSW peer educators in designing a PrEP intervention programme that takes a reflexive approach to HIV prevention through the narrative method.

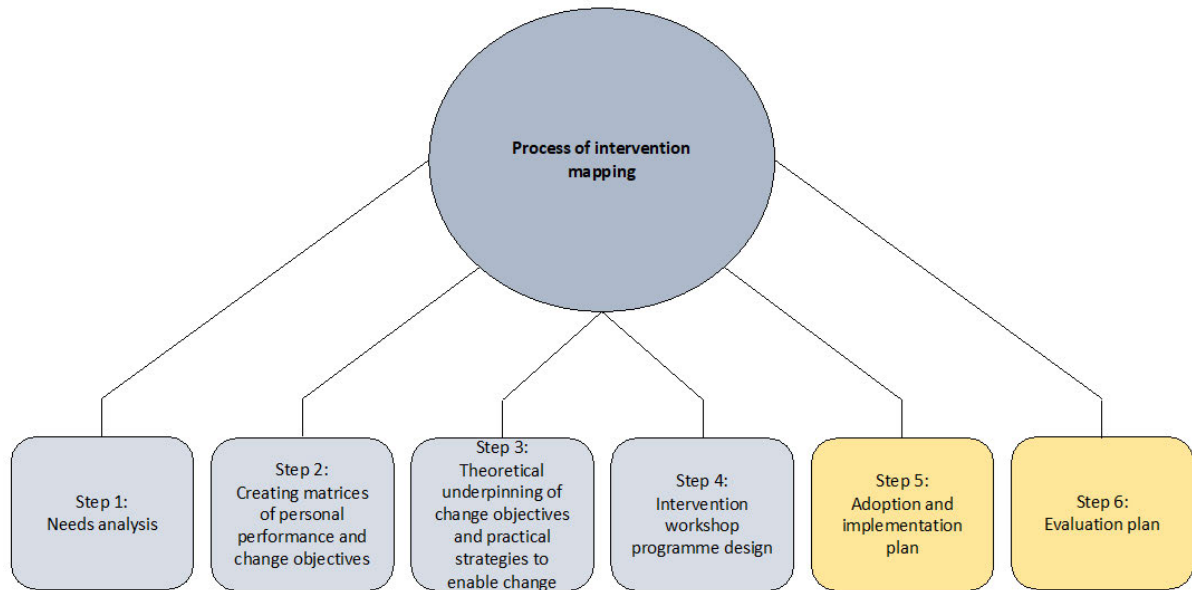
## Chapter 5

### Research Methodology

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#### 5.1 Introduction

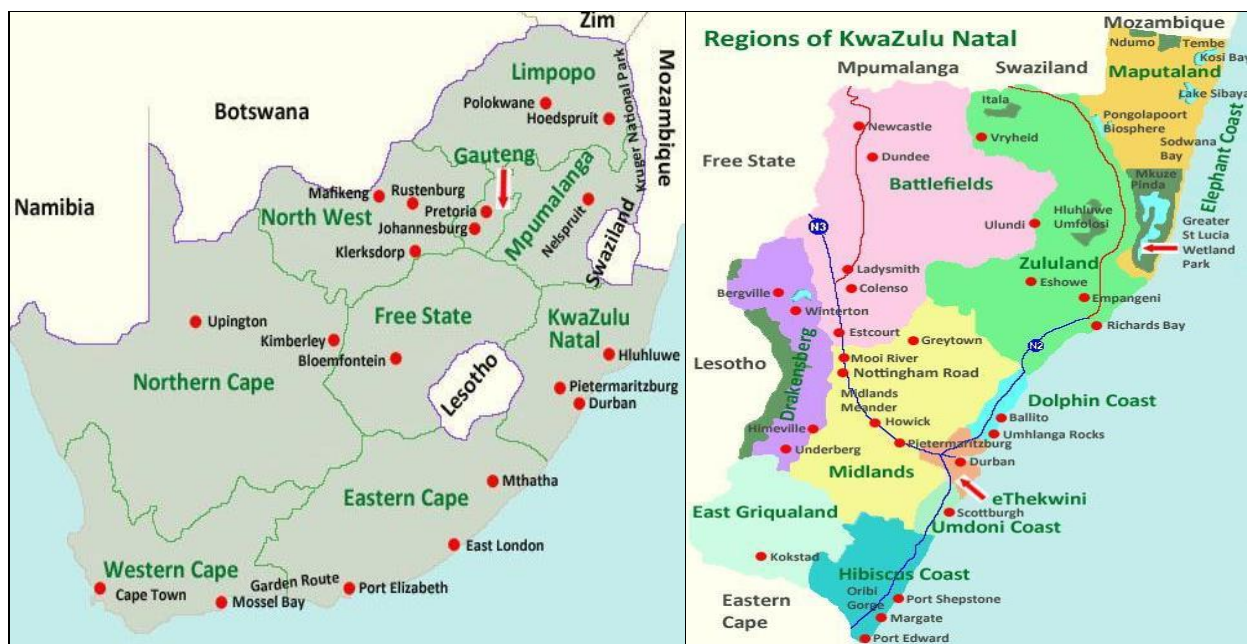
This intervention research is located within the participatory paradigm and followed the principles of participatory action research design in the process of intervention development in collaboration with FSW peer educators who were involved in all the relevant steps of developing the intervention. The study followed the Intervention Mapping Planning Framework (IMPF) of Bartholomew, Parcel and Kok, (1998) as a guide in developing the intervention. In this chapter the study setting will be described followed by a discussion of the participatory paradigm that underpins the development process of the intervention. This is followed by the overall study design as well as an overview of the IMPF and the different steps that were carried out in planning the intervention. The methodological processes of each step depicted in Figure 5 below are explained in the subsequent paragraphs. The needs analysis was the first phase of this study to identify the barriers and facilitators of PrEP use among FSWs, using an interpretivist social constructionist approach. The second phase of this study was the participatory intervention mapping process which involved the creating of matrices of personal performance objectives and change objectives, followed by the theoretical underpinning of change objectives and practical strategies to enable change which all culminated into a preliminary PrEP workshop programme. The adoption and implementation plans as well as the evaluation plan were formulated but their application was beyond the scope of this thesis. Later in the chapter the overall ethical considerations of the study are discussed as well as the data verification processes.



**Figure 5. *Intervention Mapping Planning Framework (adapted from Bartholomew et al., 1998)***

## **5.2 Study setting and background**

This study was conducted in the coastal city of Durban in KZN (Figure 6). KZN is one of the nine provinces in South Africa, and Durban is the third largest city in South Africa with over 3 442 398 people. It has one of Africa’s busiest harbours and is a major tourist destination with its warm, subtropical climate and extensive beaches (eThekweni Municipality, 2020). The mapping of epidemiological data in the UNAIDS data report (2018) has revealed that KZN has a high distribution of HIV infections, making it a hotspot where 40.8% of people aged 15 years and older are living with HIV. Furthermore, the mapping showed that people within this geographical area have a 46% higher risk of acquiring HIV than people living outside of this region (UNAIDS, 2018). A respondent-driven sampling revealed a 53.7% HIV prevalence among FSWs in Durban (University of California, San Francisco, 2015). This is an indication of the importance of this PrEP study conducted among FSWs in this region.



Map of South Africa

Map of KwaZulu-Natal

**Figure 6. Study setting maps (ShowMe, 2020)**

The first part of this study was a needs analysis conducted from May to November 2018, with the purpose of understanding FSWs' experiences with PrEP. It also sought to capture the experiences of PrEP service providers with regard to how service users were responding to PrEP as an additional HIV prevention method. This situational analysis was conducted among inner-city women who sell sex in the city of Durban in KZN. The FSWs who participated in this study worked mainly in indoor establishments such as hotels and private houses, with a few women working in both indoor establishments and on the streets. The researcher, as well as the counsellor and peer educators interviewed were from two organisations: Sisonke and TB HIV Care. Both these organisations serve the health care needs of FSWs.

Sisonke is an organisation led by sex workers, which falls under the Sex Worker Education and Advocacy Taskforce (SWEAT) which advocates for the decriminalisation of sex work. Sisonke operates in all nine provinces in South Africa. The Sisonke peer educators, who are also sex workers, conduct four outreaches a week, consisting of both day and night outreaches. Their purpose is to educate FSWs about their human rights and collect cases of human rights violations that FSWs experience, with the purpose of addressing the cases through SWEAT. Furthermore, the Sisonke peer educators distribute condoms and lubricants to FSWs and refer them to organisations such as TB HIV Care for other health care services. Additionally, Sisonke host monthly sessions aimed at improving the psychosocial wellness of sex workers, known as the creative space. The creative space provides sex workers with an opportunity to

voice their concerns and the challenges they experience in the sex trade. It is a safe space where sex workers are able to comfort one another and advise each other on how to deal with the stigma and discrimination and violence they experience at the hands of their clients and the police.

TB HIV Care provides tailored health care to sex workers through their mobile health facility. TB HIV Care provides sexual reproductive health care in the form of family planning, HIV screening and testing, STI screening, antiretroviral treatment initiation, PrEP initiation, and TB screening. The operating hours are from Monday to Friday, 08:00 to 17:00, and night shift which starts at 17:00 up to 01:00. They also provide health education and give talks on health problems and social issues such as gender-based violence and substance abuse. The TB HIV Care peer educators, who are also sex workers, are the ones who reach out to other sex workers with health information, encourage HIV testing as well as the initiation of antiretroviral treatment for those who are positive, and PrEP for those who are negative. Furthermore, TB HIV Care has a specialised peer-led PrEP initiation programme through their mobile clinics, which target sex workers at their work venues. Once an individual has been initiated on PrEP, the peer educators follow them up to ensure that they receive their monthly medication; they also do regular telephonic check-ups to assist them in the management of side effects. The patients are also encouraged to confide in the peer educators pertaining to the challenges they experience while taking PrEP. The PrEP programme has been running since June 2016.

### **5.3 Intervention research paradigm**

A paradigm is a belief system or world view; it is concerned with ways in which people define and engage with the reality what they know and how they go about attaining that knowledge (Rehman & Alharthi, 2016). A paradigm is made up of four components: ontology, epistemology, methodology and methods. Ontology is concerned with the nature of reality. (Neuman, 2006). Epistemology is concerned with how knowledge is created, acquired and communicated to human beings. Guba and Lincoln (1994) conceptualised epistemology as the relationship between the “knower and what can be known” (p. 108). The epistemological question guides the researcher to decide on issues of objectivity, subjectivity, causality, validity, trustworthiness and generalisability. The epistemological position of the researcher is informed by their ontological belief system (Rehman & Alharthi, 2016). Methodology refers to the critical analysis of data production techniques. It is an approach that informs the choice

of research methods; furthermore, it guides the researcher to determine the type of data required for the study as well as the appropriate tools for data collection (Ellen, 1984). Methods are the specific techniques and procedures of collecting and analysing data (Crotty, 1998). The data collected could be qualitative or quantitative; tools used in the process of data collection could be in the form of questionnaires or open-ended or semi-structured interviews (Scotland, 2012).

This study is situated within a participatory paradigm. According to Heron and Peter (1997), the participatory paradigm allows humans to join in collaborative forms of inquiry. It allows for research to be conducted in a relational manner, and enables experiential engagement between the participants and the researcher. According to Creswell (2007), research should have an action agenda for reform that has the potential to change the lives of participants. This paradigm is orientated towards culturally sensitive and community focused approaches such as critical action research and critical discourse analysis and ideology critique. The participatory paradigm works on the premise that participants are knowledgeable beings united by a shared language, values, norms and beliefs and through dialogue it presupposes a mutual experiential knowing and understanding through shared meaning. Hebron and Peter (1997) further explained that the knower articulates the world from four interdependent perspectives; these are experiential, presentational, propositional and practical. These four forms of knowing are subjective. Experiential knowing stems from the knower's direct encounters with a particular phenomenon; "experiential knowing thus articulates reality through inner resonance with what there is and through perceptually enacting its forms of appearing" (p. 281). Presentational knowing emerges in experiential knowing and is grounded in intuition and imagination, an imagination informed by experience. Propositional knowing is knowing something conceptually by description; this knowledge is also acquired through language and expressed in the spoken or written word. Practical knowing is informed by skill or competence; this form of knowing is rooted in practice, presentational elegance and experiential grounding of a particular situation or phenomenon. This form of knowing completes the other three forms of knowing, resulting in purpose and accomplishment. The participatory paradigm believes in shared meaning which is the basis of the communal exchange through dialogue, feedback and exchange with others (Hebron & Peter, 1997).

## **5.4 Intervention research design**

Within this participatory paradigm, the participatory action research (PAR) design was used in the development of the intervention. A research design is described as a roadmap that links the research questions to the actual implementation of the study (Durrheim, 2006). According to Bradbury and Reason (2003), PAR is premised on the principles of engaging with the lived experiences of members and the development of a collaborative partnership with members. Research is aimed at addressing a significant problem that is of interest to the participants, with the purpose of working with participants to address an issue of social concern as well as developing new ways of problem-solving and engaging with the world. According to Reason (1994), PAR aims at producing knowledge that results into action that is useful for the people involved. This can be done through research, adult education and sociopolitical action as well as to empower people through the process of constructing their own knowledge for the use and benefit of themselves and their community. This is also referred to as consciousness raising or conscientisation, which is a process of self-awareness through collective self-enquiry and reflection (Fals-Borda & Rahman, 1991; Freire, 1970).

The process of intervention research is both creative and evaluative. It requires the intervention agents and participants to evaluate and incorporate existing research and theory with contextual knowledge or settings (Fraser, Richman, Galinsky, & Day, 2009). The co-production of knowledge between the researcher and collaborators is for the purpose of taking action to impart social change (MacDonald, 2012). Change is facilitated by members with the assistance of the researcher through an intentional iterative process of inquiry, problem identification, diagnosis, planning, intervention, and the evaluation of the results of the action to learn and to plan subsequent interventions (Baum, MacDougall, & Smith, 2006).

## **5.5 Intervention mapping planning framework**

The purpose of the intervention is focussed on health promotion by motivating the uptake, use and adherence to PrEP to prevent HIV infection among FSWs. The intervention planning framework was used to guide the development stages of the intervention aligned with the participatory paradigm and the PAR study design. This took the form of a dialogical space or community meetings where FSW peer educators came together to share their concerns on topical issues in a way that promotes mutual understanding and consensus about how to solve

issues pertaining to PrEP programming. According to Bartholomew, Parcel and Kok (1998), intervention mapping is a step-by-step framework that guides programme planners in the intervention development process. The steps included in intervention mapping provide a systematic integration of theory, empirical findings from the literature as well as information collected from the target population. The six intervention mapping steps followed in this study, as proposed by Bartholomew and colleagues (1998), are outlined below. The involvement of participants as mentioned above were facilitated through dialogue, which is an exchange of knowledge and information between intervention agents (the researcher) and the participants. Each session provided a platform for participants to express their views and opinions on a matter of crucial concern in relation to PrEP uptake. Furthermore, strategies for discussion and feedback were incorporated; for example, discussion topics for the actual preliminary workshop programme were developed by FSW peer educators from Sisonke and TB HIV Care, based on the data generated during the needs analysis. Thus, the process of intervention mapping and development was a collaborative effort between the FSW peer educators and the researcher.

**Step 1:** A needs analysis involves accessing health, quality of life, environmental influences and capacity for the intervention, as well as establishing programme outcomes (Eldredge et al., 2016). This was achieved through a qualitative, participatory exploration with the FSWs. Chapters 7, 8 and 9 of this thesis report on the findings from the needs analysis.

**Step 2** involved drawing up matrices that outline the desired expected changes in behaviour and the environment. The working group and I (researcher) formulated the performance objectives and change objectives as per intervention mapping guidelines by using the information and insights gained from the needs analysis. These matrices helped shape and focus the intervention to achieve specific goals and change outcomes as related to the needs identified in the first step (Fernandez et al., 2019; Kok, Gottlieb, Commers, & Smerecnik, 2008). A theory of change logic framework was adopted for this phase to depict the process that should be followed by the intervention to achieve change as well as prioritise the focus of the intervention.

**Step 3** consists of theory-based methods and practical strategies. This involved formulating programme activities with the working group. In this step, it was important to identify theoretical orientations to inform the intervention activities (Kok, 2018). This refers to the

application of theory to practice and a selection of strategies to enable the desired changes as outlined in Step 2.

**Step 4** involved the formative processes of producing the preliminary intervention programme in collaboration with the working group (Bartholomew et al., 2006; Stetler et al, 2006). A programme framework was developed that outlines the themes and objectives of each activity, followed by a detailed workshop programme for facilitators to use during the implementation phase. This programme will be refined during the piloting phase to include the time spent on each activity, the materials required and evaluation.

**Step 5** consists of an implementation plan, showing that prior to implementation there will be a pre-testing or pilot phase which will be used to assess the feasibility and practicality of the proposed intervention as well as the refinement of programme materials, followed by the actual implementation of the intervention (Bartholomew et al., 2006; Fernandez et al., 2019).

**Step 6** entails the evaluation plan which consists of possible process evaluation questions as well as an impact evaluation assessment that have been developed by the working group (Bartholomew et al., 2006; Fernandez et al., 2019).

It should be noted that Steps 5 and 6 are beyond the scope of this doctoral study. Preliminary planning drafts are presented and attached in the thesis as Appendices A and B. These will be refined and thoroughly addressed during postdoctoral studies. The methods used in the different steps are explained in the sections below.

### **5.5.1 Phase 1: Step 1 – Needs analysis**

A needs analysis is the first step of intervention design. It is the exploration of the problem and to gain understanding whether there is a need for the intervention as well as to establish appropriate ways to intervene (Bartholomew et al., 2006). This process means involving the target population to articulate their problems and participate in the planning of their own health interventions. Furthermore, participation by community members and stakeholders increases the probability that health goals will be achieved, and this will further encourage trust in the process. It is important for the health promoter or researcher to gain a deeper understanding of the target group and to acknowledge that understanding takes time and prolonged engagement (Eldredge et al., 2016). During the needs analysis, health promoters and/or researchers must be committed to building relationships based on listening and sharing in order to achieve higher

levels of understanding. They must ensure that they access various members of the community to gain multiple perspectives about the problem (Bartholomew et al., 2006). The focus of this study was to explore FSWs engagement with PrEP, which necessitated that as a researcher I had to engage deeply with the personal experiences of FSWs and the meaning they placed in their use or non-use of PrEP for HIV prevention.

### **5.5.1.1 Research paradigm and design**

This needs analysis was based on the interpretivist paradigm which is rooted in the understanding of how humans interpret the world and how they act based on those unique interpretations. There is no single external reality, but reality is subjective, constructed and interpreted in different ways and the role of the researcher is to gain a deep and specific understanding of that reality, hence findings cannot be generalised to the whole population (Creswell, 2007). Interpretivist researchers aim to understand the diverse ways in which people experience the world located in their different contexts and cultures (Hammersley, 2013). The understanding is that knowledge is socially constructed. It should be noted that social constructionism and interpretivism is often combined (Creswell, 2007).

Social constructionism is a concept concerned with the nature of reality. The belief among social constructionists is that reality is subjectively constructed by people and does not exist independently or externally from people. Reality is constructed and shaped through human interaction; it is the manner in which people or groups socially construct the world of experience and how they make meaning from those experiences (Cunliffe, 2008; Gergen, 1999; Potter, 1996). The construction of reality and the meaning attached to it is facilitated by language; language helps people to transmit their thoughts and feelings as well as to name their experiences to construct concepts and articulate the meaning of their reality (Walker, 2015; Shotter, 1993). Thus, the focus of social constructionism is on how meaning is created, sustained, negotiated, and modified. This understanding of meaning is from the perspective of people and their lived experiences. Social constructionist concern themselves with what is known and understood about humans through their social experiences. Knowledge emerges from people and they make it significant through the meaning they attach to it (Au, 1998; Creswell, 2014; Walker, 2015; Creswell & Creswell, 2017; Denzin & Lincoln, 2005; Neuman, 2006; William, 2007). This approach was utilised because it was important to understand the meaning that FSWs attached to PrEP as an HIV prevention tool, as well as to engage with multiple realities and experiences among FSWs pertaining to their use or non-use of PrEP.

A qualitative research design was utilised for the needs analysis. Qualitative research necessitates that people be studied in their natural setting to understand the circumstances that shape their lives, such as the social, economic, cultural, and physical contexts in which they live (Creswell, 2014; Norum, 2008). This enables the researcher to understand the contextual factors that influence the participants as well as the phenomenon under investigation. To this end, the process of engagement with study participants is achieved through various methods of inquiry such as in-depth interviews, focus group discussions, observations, content analysis, dialogical spaces, life stories, as well as visual methods (Cuthill, 2002; Neuman, 2007, 2014; Sutton & Austin, 2015). For the purposes of this study, in-depth interviews and focus group discussions were utilised for data collection for this needs analysis phase.

In-depth interviews are one-on-one discussions that a researcher has with participants on the research topic, to tap into individual practices, beliefs and opinions (Harrell & Bradley, 2009). Additionally, in-depth interviews provide insight into each individual's unique experience, free from peer influence (Harrell & Bradley, 2009). In this study, the in-depth interviews provided participants with the opportunity to speak freely about their personal experiences regarding PrEP without any reservations; some opened up about taking PrEP and shared their personal experiences. To receive this subjective information, I had to listen, be open-minded, curious, and empathetic to the expressions of study participants as suggested by Henrick, Hutter and Bailey (2020).

Focus group discussions can be defined as a qualitative data collection technique where in-depth interviewing is used to elicit information from a purposefully selected group of participants who are somewhat characteristically homogenous (Kitzinger, 1995; Rabiee, 2004). Data collected from focus groups is rich, echoing various viewpoints and perspectives from study participants (Kitzinger, 1995). Participants are selected on the basis that they have something to say on the subject of discussion, are within a similar age range, have similar sociodemographic characteristics and are comfortable talking to the researcher, as well as to one another (Rabiee, 2004). Focus groups are able to give the researcher insight into the attitudes, perceptions and feelings of participants, as suggested by Krueger and Casey (2014). The focus group discussions also provide an opportunity to observe the participants in a group setting, which is viewed as a more natural environment of peer-to-peer discussion and influence, producing socially orientated authentic research, which captured real life expressions (Krueger & Casey, 2014; Morgan & Krueger, 1993 ). Through the focus group discussions, I was able to get a sense regarding what the general thoughts and feelings of FSWs

were towards PrEP as well as the prevailing beliefs that FSWs hold pertaining to HIV prevention as a community of FSWs.

### **5.5.1.2 Sampling strategy**

Snowball sampling was the primary sampling method used to find participants for the needs analysis. According to Heckathorn (2011), snowball sampling is a non-probability type of sampling that is used among hidden populations; in this case FSWs. It is a chain-referral method where one participant refers others into the study. This chain referral begins with a purposive sample of initial subjects who then refer other members of the population to the study (Heckathorn, 2011; Goodman, 2011). This sampling method is often used for groups that are stigmatised and involved in criminalised or deviant behaviours (Feild, Pruchno, Bewley, Lemay & Levinsky, 2006; Neuman, 2006). The limitation with this sampling method is that it makes it difficult to break into other networks because recruitment can take place in one network of friends or acquaintances (Biernacki, & Waldorf, 1981). I however relied on two groups of peer educators, as outlined above, who had access to various networks of FSWs because of their outreach work, and it was anticipated that drawing from various networks would bring in FSWs from indoor and outdoor establishments for the purpose of variety.

In order to gain entry into the target population and to start the snowball process, one peer educator from Sisonke was purposively sampled. (See Chapter 6 on how this connection was made.) Purposive sampling is defined as a deliberate process of selecting individuals or groups that are knowledgeable and well informed about the phenomenon under study (Suen, Huang, & Lee, 2014; Tongco, 2007). After interviewing this peer educator (see data collection details below), other peer educators from Sisonke snowballed into the study. The participants were interviewed based on their willingness to participate and their ability to communicate experiences and opinions in a detailed and articulate manner to provide rich and valuable data that enabled me to gain a deeper understanding about PrEP use among the sex work population, as outlined by Etikan, Musa and Alkassim (2016).

With regard to sampling participants from the TB HIV Care group, the peer educator from Sisonke that was purposively sampled, introduced me to the researcher and site coordinator of the PrEP programme at TB HIV/Care who agreed to participate in the study. Through them, I was introduced to one of the peer educators who put me in contact with the rest of the peer educators and a counsellor who were willing to participate in the study. The other FSWs who

participated into the study were linked via other networks of peer educators (Sisonke and TB HIV Care).

### **5.5.1.3 Sample description**

The sample for the needs analysis consisted of a total of 39 participants. This sample was determined by data saturation. Data saturation is reached when there is enough data to replicate the study as no new information emerges from the interviews that are conducted, and extended coding is no longer feasible because there are no new emerging themes that arise from the interview data (Faulkner & Trotter, 2017; Hancock, Amankwaa, Revell, & Mueller, 2016). In order to reach data saturation, it is important to pose the same key interview questions to multiple participants. It is also important to elicit information from other data collection methods, in this case focus group discussions, to get multiple perspectives about a phenomenon, and from key informant interviews, as well as collecting data from different stakeholders. This will assist the researcher in concluding whether there is a consistent message being communicated by the respective participants (Fusch & Ness, 2015).

There was a total of 30 in-depth key informant interviews with 11 peer educators, one programme coordinator/researcher and one counsellor (thus, a total of 13), while the rest were FSWs (17). Nine other FSWs formed part of the focus group discussions (Group 1, five members and Group 2, four members). In total, 26 FSWs were interviewed, of which 20 were on PrEP, with two having defaulted but had resumed with PrEP at the time of this study. Another two who were using PrEP were dependent on drugs and were sober at the time of participating in the interviews. Six FSW participants were not on PrEP.

### **5.5.1.4 Data collection tool, processes and procedures**

One-on-one in-depth interviews and focus group discussions were conducted in English and isiZulu. A semi-structured interview guide was used as a data collection tool for both in-depth interviews and focus group discussions (See appendix G). According to DiCicco-Bloom and Crabtree (2006), semi-structured interviews is a popular data collection method because it is versatile and flexible and can be utilised for individual and group discussions. The semi-structured interview format allows the researcher to probe so as to explore an issue with greater detail and this is done through asking follow-up questions and allows the participants to express themselves freely (Kallio, Pietallia, & Johnson, 2016; Rubin & Rubin 2011). Through the questions posed from the semi-structured interview guide, I was able to elicit the

sociodemographic information of participants and understand the process of PrEP outreach, education, initiation and efforts to encourage retention among FSWs. Furthermore, I learned how FSWs were responding to PrEP as an additional HIV prevention method, and the role of peer educators in supporting PrEP users to ensure long-term retention, as well as the challenges associated with PrEP programming. Through the interviews and focus group discussions, I was able to probe to gain a deeper understanding of the environmental, personal and interpersonal challenges in the uptake of PrEP among FSWs. I was also able to understand the personal motivations for some FSWs to take PrEP consistently. Individual interviews were approximately 40 minutes long and focus group discussion were about 60 minutes long.

The scheduling of interviews was through two specific peer educators from Sisonke and TB HIV Care. Telephonic contact was made with a peer who had the first personal contact with the participants. The peers explained the aims and objectives of the study to the participants and to ascertain their willingness to participate in the study. Arrangements were made for the physical location where the interviews and group discussions were to take place. I would then get introduced to participants prior to the interviews. Some interviews and focus group discussions took place at both TB HIV Care and Sisonke offices. The participants felt comfortable coming to both offices because they were a safe and familiar environment. Participants were used to coming to TB HIV Care for medical care and counselling and some accessed Sisonke offices to report human rights abuses. They also came to attend psychosocial creative space meetings. Both offices provided me with a private room where I could conduct interviews. The participants communicated with a peer educator and the peer educator would let me know through WhatsApp instant messaging how many participants were scheduled to arrive. Each participant was given a time of arrival depending on the number of participants who had confirmed. Those who arrived early waited until it was their turn to be interviewed.

Some participants who could not come to the TB HIV Care offices were interviewed at their homes and others were interviewed at the brothels where they worked. One of the peer educators was generous enough to offer her time and accompany me to see these participants. She was a valuable guide because some of the areas were unsafe. She was also a good sounding board and offered me advice on how to approach the FSWs that we met.

Prior to each interview and focus group discussion, I handed out consent forms to participants and explained the contents of the form (See Appendix F). This was also very important as some participants could not read. Consent forms were translated into isiZulu because it is the main

language spoken in Durban. Participants were made aware that their identities would be kept confidential and that their participation was voluntary; they were free to stop participating at any point during the interview. The participants were also made aware that they would be reimbursed for their time (R100/\$6,86). It was mandatory for a participant to sign both the consent form for participating and another form agreeing to the audio recording of the interview or discussion (See appendix F). Most participants accepted to be recorded, except for one participant who was not comfortable and so I opted to take down notes for that interview. The participants were also made aware that their recorded interviews would be stored electronically on an external hard drive which will be kept in a secure office along with the transcript for a period of five years, and that only myself and the supervisor will have access to the files.

#### **5.5.1.5 Data analysis**

All audiotaped data were transcribed and translated verbatim by a research assistant with an honours degree in psychology who was proficient in both English and isiZulu. The transcripts were generated after each interview and I went through the transcripts for quality checks as well as to identify patterns or inconsistencies in the data, which I addressed with the next group of participants.

The data were analysed thematically. This involved the steps outlined by Braun and Clarke (2006), namely sorting and coding the data into themes and categories by identifying and analysing repeating patterns that existed in the data. According to Braun and Clarke (2006), themes are important patterns emerging from the data that are related to the research objectives and help to answer the appropriate research questions. The analysis followed six steps as outlined by Braun and Clarke, namely to translate and transcribe the data verbatim, familiarising oneself with the data by reading and rereading the data so as to generate codes, generate themes from the codes, define and refine the identified themes, and employ the identified themes in the final presentation of the study findings.

The data were analysed using Microsoft Excel. Each Excel spreadsheet consisted of a particular theme and related subthemes. These were populated with various quotes related to the specific themes and subthemes as communicated by the participants in the key informant interviews and focus groups. Each quote was marked with an interview number and each participant was given a unique identifier. This enabled me and the research assistant to see what the various participants were saying concerning a particular theme.

## **5.5.2 Phase 2: Steps 2, 3, & 4: Methodological processes of mapping the intervention**

In this section the methodological process of Steps 2, 3 and 4 in the intervention mapping framework are discussed. The first aspect pertains to the data feedback meeting held with stakeholders, followed by the identification of the working group and logistics of setting up the dialogical spaces. The next section pertains to the aspects discussed in the dialogical spaces and outcomes. The suggestions, ideas and other information that was generated in these spaces were recorded for further analysis as outlined in the data analysis section. This was then reported to the working committee for verification and further refinement and then used in the compilation of the intervention programme as suggested in Step 4 of the intervention mapping process.

### **5.5.2.1 Feedback of the needs analysis data to stakeholders**

The process of intervention mapping commenced on 16 September 2019 with the needs analysis data feedback meeting held at the TB HIV Care offices. This meeting consisted of 12 stakeholders involved in PrEP programming, namely one doctor, two nurses, one counsellor from TB HIV Care and eight FSW peer educators of which three were from Sisonke and five from TB HIV Care. Four peer educators from TB HIV Care and the three from Sisonke and one counsellor had participated as key informants during the needs analysis.

The agenda for the meeting required that I shared the major themes that were identified in the data analysis. Direct quotations from the participants were also shared to demonstrate the authenticity of the findings. Afterwards, a discussion was held with the group to share their views of the data presented and whether the data analysis and interpretation was an accurate description and representation of what the participants meant and whether the challenges described, were still relevant. The participants confirmed that most of the challenges identified in the situational analysis regarding PrEP uptake were accurate and still present. The data presented in Chapter 7 to Chapter 9 of this thesis were checked and verified by the participants during the data feedback meeting. The stakeholders outlined a few changes that occurred regarding PrEP distribution after the needs analysis was conducted. They explained that an NGO known as MatCH (Maternal Adolescent and Child Health) had started a PrEP programme based in two health facilities in Durban focusing on initiating sexually active adolescents on PrEP. MatCH uses peer navigators, who play a similar role as peer educators, they recruit adolescents to test for HIV and those who test negative are initiated on PrEP.

### **5.5.2.2 Identifying a working group of FSWs and negotiate the creation of the dialogical spaces**

After the feedback and discussion of the needs analysis findings I shared the need for a working group consisting of key stakeholders to play a central role in the planning and development of the PrEP intervention programme. I inquired whether any were willing to participate as collaborators in this process to provide guidance and offer solutions to existing challenges to improve the uptake and adherence of PrEP. The peer educators from both organisations met my request with great enthusiasm. Nine of the eleven people who participated in the data feedback meeting volunteered to form part of the intervention working group. This group comprised of eight peer educators and one counsellor. However, one FSW peer educator was not able to attend any of the working group meetings; thus, there was a total of eight working group members.

It was important for the intervention working group to comprise not only of informants but also involve FSW peer educators as collaborators. See the detail on their sociodemographic backgrounds in Chapter 10. My hope was that they would not only be able to inform the process but also gain ownership of the programme. Due my extensive interaction with the peer educators during the process of community entry, I was confident that they were more than capable to play a meaningful role in the planning and development of an acceptable, relevant and effective PrEP programme.

Through my engagement with the FSW peer educators during the needs analysis I was able to build a trust relationship with them and this seemed to have contributed to their willingness to participate in the intervention design. It is important to note that the initial power relations had shifted from viewing me as an external expert to someone who is willing to learn from them and someone they can trust. Power sharing created a sense of ownership of the process among the peer educators as suggested by Laverack (2004). This was evident in their remarks about this doctoral study as being their own doctorate, implying that they were claiming ownership of the intervention itself. This extensive process of trust building (Sliep & Kotze, 2011), meant that they were able to speak freely and authentically around me without worrying about confidentiality and ethical management of shared information. In addition, this increased their confidence to challenge some of my ideas and in turn offer their views, concerns and suggestions. However, the planning phase required that I could not be complacent about their

goodwill, but to continuously ensure their involvement at every stage of the process and engage with their experiences and concerns.

The working group decided that it was important to inform their respective organisations about their involvements in the intervention mapping exercise of the study and requested that I wrote an email to their organisations, which they all approved before sending it off. They also suggested that we utilise WhatsApp as a communication tool to facilitate easy communication and decision-making. While no feedback was received from their organisations, the peer educators were nevertheless determined that they would participate in the intervention mapping process in their personal capacities. They selected a venue in the Durban city centre that was convenient to everyone. We discussed a preferred time for the meetings, refreshments and suitable transport reimbursements. We all agreed that we should meet once a week on Saturdays from 10:30 to 13:00. A total of six meetings were held over a period of two months, October and November 2019.

I also consulted with the peer educators about having a research assistant who would play the role of a quiet observer and to take notes in our sessions. The idea of bringing another person not known to them, into the room and the likely impact this might have on them, was a concern. They however all assured me that they did not mind having another person in the room as long as I trusted the research assistant. We all came to the agreement that the research assistant will sit in one corner of the room and will not be part of the ‘dialogical space’ to minimise any interference with the process. To ensure confidentiality and sensitivity, I took time to orient the research assistant on sex workers and by the time we started the intervention mapping phase she was more familiar with sex work. In addition, her experience with the transcriptions of the needs analysis data gave her a deeper perspective and understanding of the study and the participants.

The dialogical space was set up in such a way that we all sat in a circle, and as a researcher I was cognisant of my body language and avoided standing during discussions to flatten the hierarchy. Peer educators engaged with one another in a way that demonstrated mutual respect and understanding. This dialogical space afforded the peer educators from these two separate organisations a first-time opportunity to work together and synchronise their understanding of PrEP, and to strategise effective approaches in promoting PrEP in their outreach activities. Prior to this, the peer educators worked as separate groups and did not have a common vision and approach for promoting PrEP. This intervention mapping process provided them an

opportunity to learn from one another and to share similar and different challenges they experienced in the field. This also allowed them to collaboratively resolve these challenges.

### **5.5.3 Step 2: Creating matrices of change objectives**

During each meeting, challenges pertaining to the uptake and retention of PrEP deduced from the needs analysis were discussed among the participants, inclusive of suggestions and solutions that were debated and then collectively agreed upon. These discussions contributed meaningfully to the formulation of the change matrices that were developed as part of the intervention plan and the development of the programme content in Step 4.

I prompted the discussions by presenting themes from the data pertaining to challenges of PrEP uptake. The challenges were divided into personal, interpersonal, and environmental aspects. In order to assist the working group to see the links between the performance and change objectives, matrices were drawn in the form of tables. (See Chapter 10, intervention mapping Step 2; Tables 4–6.) The first table reflected individually-based performance and change objectives; the second table had interpersonal change objectives, and the third table consisted of environmental performance and change objectives. Each theme sparked conversations that provided deeper perspectives on why these challenges exist and what the possible solutions might be, and were also aligned to the change objectives.

In order to show how change should be systematically achieved, an intervention theory of change logic framework was drawn. I designed the logic framework guided by the data that emerged in Step 2 to show a systematic way in which change can be achieved. I then presented this theory of change logic framework to the working group during a follow-up meeting. The peer educators were given an opportunity to comment on the theory of change logic framework and provided their own perspective and ideas which were incorporated into the final model.

### **5.5.4 Step 3: Theoretical based methods and practical strategies to enable change**

This step involved the linking of intervention determinants and change objectives to the theoretical methods. The theory provided guidance on how a particular activity should be carried out and the parameters of that activity as well as the anticipated outcomes (Kok, 2018). Discussions with the working group were focused mainly on the change objectives identified in Step 2 and associated activities and less about the theoretical underpinnings of activities. It was my responsibility to link activities to theory. I then created a table that I presented to the

working group, showing refined activities based on their ideas and how each activity should be carried out, as well as how theory informed the process. (See Chapter 10 intervention mapping Step 3, Table 7.) The working group was concerned with the practical aspects of the intervention. I however took time to engage with the theoretical aspects and found ways to explain these aspects to the group. After our meetings, some peer educators would test out some of the strategies in their outreach sessions and would come back and report to the group how these were received by the FSWs on the ground. This pertains particularly to the improvement of PrEP education and the provision of more information regarding the differences between PrEP as an antiretroviral for prevention versus the use of antiretrovirals as treatment for HIV.

#### **5.5.5 Step 4: Intervention workshop programme design**

This step involved the actual workshop programme design. A formative evaluation took place prior to the finalisation of the workshop programme.. Formative evaluation is the gathering of information for the purpose of planning, refining and improving on the intervention programme; it involves back and forth discussions prior to the finalisation of the programme. This is a necessary step in articulating programme goals and objectives as well as action strategies(Waa et al., 1998). (See Chapter 10 for further detail.) It is through these discussions that the working group concluded that the programme should consist of two parts. Part 1 was to focus on personal development for FSWs to engage in reflexive dialogues and activities to develop self-love, agency, self-efficacy, hope and resilience, by engaging with their life stories. This part of the programme was meant to assist FSWs to consciously seek for personal factors that may motivate them to prevent HIV and encourage long-term retention on PrEP. This decision was informed by results from the needs analysis on the enablers of PrEP use. This process was facilitated through the narrative methodology (Andrews, Squire, & Tamboukou, 2013; Sliep & Kotze, 2011) as explained in Chapter 4.

The second part of the programme was designed to focus specifically on PrEP education. All the activities identified in the intervention mapping Step 3 were listed on a flip chart with each change objective paired with a theoretical method. By way of example one of the change objectives was to assist FSWs to learn how to explain the use of PrEP to their partners and friends. The theory identified was guided practice; this theory advocates for role plays and the use of vignettes or realistic scenarios. Role plays and scenarios were selected in this regard. The working group brain-stormed ideas on how role plays and scenarios could best be

organised and carried out within the programme. This involved multiple discussions and deliberation on each change objective and activity and an exploration of possible ways in which these could be incorporated into the intervention workshop programme. This resulted in the formulation of the *Walk in Hope* workshop programme. (See Chapter 10 intervention mapping Step 4.) As the researcher, it was important to take time to engage with the data from the discussions in the dialogical spaces and to make sense of these, guided by the principles of intervention mapping. I also ensured that I presented the workshop programme to the participants so that they could see how their ideas have been rearranged and organised into a coherent workshop programme, which they all endorsed at the end of this process.

#### **5.5.6 Step 5: Adoption and implementation and Step 6: Evaluation plan**

Step 5 of Intervention mapping involved formulating the intervention adoption and implementation plan, and Step 6 is the evaluation plan. Based on the discussions with the working group, I was able to compile a draft implementation plan that indicated a train-the-trainer format. The FSW peer educators were to be the main implementers of the intervention programme as they would facilitate the workshops as well as train other FSWs who would be willing to be PrEP ambassadors and thus future facilitators of the workshop programme. For Step 6, I considered the intervention objectives and used them as indicators to design questions for both process and impact evaluation, which were also presented to the working group. Step 5 and 6 were added as appendices in this thesis as drafts to be further developed for future work, as they were beyond the scope of this thesis but presented merely for additional information.

### **5.6 Ethical considerations**

Ethical clearance for this study as a whole (both Phase 1 and Phase 2) was obtained from the Humanities and Social Sciences Research Ethics Committee at the University of KwaZulu-Natal (UKZN; IRB number HSS/0203/018D). Participation was voluntary. The participants signed an informed consent for participation and provided permission for recording of the data. The participants were encouraged to use pseudonyms, especially those who were participating in the focus group discussions. Group confidentiality in the focus groups was also encouraged. Principles of confidentiality and anonymity were explained, including the right to withdraw at any stage.

## 5.7 Data verification

To address issues of data validity and reliability within a participatory paradigm, qualitative researchers have formulated their own terminology and criteria. Trustworthiness is a term coined by Lincoln and Guba (1985) to determine the quality of qualitative research. Trustworthiness consists of four criteria, namely credibility, transferability, dependability, and conformability.

A number of research strategies that can be used to enhance credibility, such as prolonged engagement, persistent observation, peer debriefing, triangulation, negative case analysis and member checking (Seale, 1999). For the purpose of this research, credibility was first ensured through prolonged engagement and persistent observation as suggested by Cohen and Crabtree (2006). Prolonged engagement and persistent observations were done through the extensive process of community entry where I engaged with FSW peer educators from the two organisations. I attended various activities organised by the peer educators such as community advisory board meetings, and various functions and meetings involving sex workers. Furthermore, prolonged engagement was through providing assistance to peer educators with regard to capacity building and skills sharing. (The activities are detailed in Chapter 6.)

Secondly, I engaged in triangulation of sources where I compared and contrasted data from the focus group discussions as well as data from the in-depth interviews with FSWs, FSWs peer educators, the researcher and counsellor. This helped to compensate for various limitations encountered with each data collection technique (Brewer & Hunter, 1989; Shenton, 2004). I encouraged honesty among the participants by assuring them that there were no right or wrong answers. I made sure that each participant felt free to narrate their own unique experiences, and that they did not feel pressured to agree or disagree with the rest of the group.

Thirdly, I engaged in debriefing sessions with the research assistant on the identified themes from the data and the outcomes of the dialogical space discussions during the intervention development phase.

I also conducted member checks in the form of data feedback meetings with FSW peer educators who had also participated in the situational analysis. These member checks were important to ascertain whether the data analysis process captured the essence of the ideas that FSWs presented and to prevent any form of misrepresentation of what the participants said and meant. This process also made me accountable and helped me to rectify any possible

preconceived biases or emotions that may have clouded my judgement during the data analysis process, as cautioned against by various authors (Cohen & Crabtree, 2006; Shenton, 2004).

According to Lincoln and Guba (1985), thick descriptions are employed as a way to ensure 'external validity', that is, in the case of qualitative research, transferability. This is achieved through detailed description of events or phenomena so that conclusions drawn could be transferred to different contexts, situations, and people. In this study, I have provided a detailed narrative with regard to the organisations I consulted with for participating in the study and how I gained access, including how I managed to find the study participants and the methods employed for data collection and the duration of the data collection process. I further provided a detailed explanation pertaining to how I engaged with peer educators in the process of intervention mapping, including the logistical planning and data collection techniques. Providing these details was to ensure that any researcher can transfer or replicate a similar study in another context.

Dependability involves external audits conducted by a researcher who is not part of the research. My supervisors were the primary external auditors of this study and as outsiders they questioned the research process and challenged the themes derived from my findings. They provided comments on the adequacy of the data as well as the results. The methodological aspects of the study, such as the research design and implementation, as well as the operational aspects of data collection, have been outlined in detail to enable a future researcher to carry out a similar study to ensure dependability (Marshall & Rossman, 1999).

The concept of confirmability refers to the qualitative researcher's concern with whether the findings reflect the ideas and sentiments of the participants rather than the researcher's own preferences and ideas (Seale, 1999). Furthermore, the use of more than one data collection technique was to provide depth and to reduce investigator bias. According to Shenton (2004), researchers should be clear about their own preconceived notions, and provide a rationale for the research method and data collection techniques adopted. The researcher should acknowledge the limitations of the chosen techniques as well as why one technique is favoured over others. In Chapter 6 on research reflexivity, I outlined the events that have influenced my approach to this study and how the way I have been socialised could have contributed to the way I positioned myself in this study, as well as the methods I have decided to use. In Chapter 4, I have provided comprehensive reasoning for my research paradigm and research approaches as well as why I chose in-depth interviews and focus group discussions as data collection

techniques for the first part of this study; similarly, why it was suitable to utilise a participatory action research design, anchored in dialogue, as the approach for the intervention mapping process. Quotes have been included in the findings to demonstrate the authenticity of the participants' views and, as the researcher, I am indeed giving voice to their input. This transparent process allowed for scrutiny of my interpretations and ensured that as the researcher I stay true to the participants' own ideas and meanings.

## **5.8 Summary**

This chapter outlined the study setting, research paradigms, sample and sampling techniques, methods utilised in the process of data collection, techniques for data analysis, how the study was verified for quality purposes, the ethical procedures followed in the engagement of study participants and ensuring confidentiality. Data were collected in two phases: The first phase was a needs analysis which employed a qualitative approach through key informant interviews and focus groups discussions to understand the acceptability of PrEP among FSWs. The interviews were conducted with a programme coordinator/researcher, HIV counsellor, peer educators and FSWs. The second component of this study was an intervention mapping process guided by the IMPF to engage FSW peer educators in a participatory action research to design an intervention to address the challenges with PrEP uptake. Data were generated through facilitated dialogues with the FSW peer educators who engaged with the challenges to PrEP uptake identified in the needs analysis.

## Chapter 6

### Research Reflexivity

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#### 6.1 Introduction

Researcher reflexivity is seen as an important step in qualitative research because it provides an opportunity for researchers to acknowledge and grapple with how their personal experiences, characteristics, and beliefs have impacted on the research process (Berger, 2015). Researchers further expand on the concept of researcher reflexivity to mean a continuous internal dialogue and critical evaluation of the researcher's positionality. It is showing a conscious understanding of the knowledge produced and how it was produced (Guillemin & Gillam, 2004). This process is important because researchers acknowledge their subjectivity and do not try to claim objectivity (Gergen & Gergen, 1991). The way in which researchers acknowledge their positionality is through an intentional and explicit process of critically questioning their choices throughout the research process, a deliberate scrutiny of the aims and objectives, research design and paradigm and methods employed for data collection (Berger, 2015). This positionality can be tracked in various ways, such as being reflective about the commonalities and differences that the researcher has with study participants using a log to document this data, as well as through peer consultation with study participants and involving participants in the process evaluation (Berger, 2015). Another way is through keeping a reflective journal that helps one to track the process and make links between theory and practice (Watt, 2007).

In this chapter, I provide accounts of my personal journey with sex work research and how the personal changes I have undergone have influenced how I have positioned myself during the research process. I take a narrative approach into how my work with FSWs began and how this doctoral study came about, and the relationships I forged with study participants whom I am more comfortable referring to as collaborators or co-creators. I trace my personal transition and how the growth I have undergone at a personal level impacted how I approached my current research with FSWs who are a marginalised and stigmatised group. Working with FSWs requires sensitivity and understanding in the midst of societal influencers of morality and value judgements. I show how I have grappled with complex emotions and conflicting world views and how I resolved these internal battles which resulted in my birth and growth as a researcher.

My work with sex workers started in 2013 while I was working as a research assistant for a health institute in Johannesburg. I was a qualitative interviewer for a project that aimed to design a biobehavioural survey to determine the prevalence of HIV and syphilis, as well as the population size estimation of FSWs in three major South African cities: Durban, Johannesburg, and Cape Town. My role was to generate formative data through focus group discussions and key informant interviews about the feasibility of this biobehavioural survey, consulting with FSWs on what may or may not work. This process was also a way of informing FSWs about the survey to ascertain their willingness to participate. Before the interview process, we engaged with the Sex Worker Education and Advocacy Taskforce (SWEAT) , Sisonke and TB HIV Care who were gatekeepers and working with FSWs in the three cities.

We went on outreach activities conducted by Sisonke and TB HIV Care to observe and have a feeling of what working with FSWs would be like. During my first outreach trip I was filled with feelings of fear and dread. I saw how the dimly lit streets came to life at night with women in search of clients. Some were fully dressed, and others were half naked, their demeanour being one of desperation, hustle, and aggression, others stood quietly with an aura of shame. The peer educators conducting the outreach were confident, outspoken, organised, and enthusiastic. I could not imagine what interviewing these women would be like. Interestingly, when we conducted the interviews, some of the women we saw at night were a stark contrast to the ones that were sitting in a circle quietly waiting to sign their consent forms. Participation varied; some were dominating while others were timid. It was interesting for me to see that there were variations in age; some women were in their early 20s, while others were in their 50s. Sex work meant different things to the women depending on age; the older women told stories of sex work having rescued them from absolute poverty and abusive marriages. The younger ones spoke of entering sex work through friends who came to the township or village wearing fancy clothes, while they themselves suffered unemployment, compounded by orphanhood and having to look after younger siblings. Either way, all their stories were peppered with some kind of adversity. The majority, not having gone past secondary school, could not secure decent employment and resorted to selling sex. Apart from the financial aspects, sex work was a means out of the village or township to living in tall, abandoned buildings in the city. Sex work presented a seemingly alluring freedom and permission to live life on one's own terms.

## 6.2 Caught between two worlds

My work as an interviewer was routinely robotic and superficial. I did not allow myself to connect with participants because I thought that objectivity meant a total disconnect so as to render the research uncompromised. After a day of fieldwork, all I wanted was to forget the faces and the stories I heard. Taking off my clothes and entering into the shower was to not only wash my body, but to wash away a world which I associated with danger and debauchery. At the time I was also naively religious and devoted to a punitive God, which rendered me self-condemning. My work was interrupted by feelings of guilt and images of a disapproving God. Instead of focusing on the research and engaging deeply with participants, in the crevices of my mind I centred myself, and my beliefs took precedence and overshadowed the experience. My beliefs attempted to be the gatekeeper of my mind in an effort to protect me from the ‘contaminated’ stories of the sex workers. The lingering thoughts about what was said during interviews tormented me and it was as though the act of thinking about what the participants expressed, would mean that I was condoning this lifestyle and I wanted no room for empathy and justification of sex work, no matter how compelling the reasons of the women were. I was a researcher into an unknown world that I myself feared, I feared contamination because of the stigma associated with sex work. I did not tell my friends or family about the research and whenever I saw sex workers where I lived in Hillbrow, Johannesburg, I played ignorant, distancing myself from something that was outwardly far from those around me and yet so close to me. Nobody prepared me for the cognitive dissonance and the conundrum of being caught between two worlds. My employers wanted data and did not have the time nor the insight to try and understand how this work would affect someone like me, if at all, or how my own personal prejudices would affect the research process. Instead, the assumption was that I would do what is mandatorily explained in research textbooks, to suspend my feelings, remove myself from the research and be objective. However, this was highly impossible as I could not suspend myself and all the things that are part of my socialisation, particularly my cultural and religious beliefs. Thus, I do firmly believe, as mentioned by Sliep (2010), that the ‘personal is indeed the professional’ and a denial of this does a disservice to the researcher and the research process.

When I left the health institute in 2014, it felt like I had left the complicated world of sex work research. However, there were so many interviews that I had conducted and letting that data sit, felt like an injustice to the participants. With the encouragement of my partner, I decided to write up the formative data into journal articles and having been granted permission by the

institute, I analysed some of that data for my master's degree in health promotion (*Characterising inner city female sex workers in Durban, South Africa: A qualitative inquiry*) which I obtained in 2017. This meant that I had to revisit data I collected in 2013, but I was more mature now. Having undergone a personal transformation, I strive to be more spiritual than religious as well as less judgemental. Having resolved my complicated relationship with God, I had grown to understand Him as more gracious and less punitive. Furthermore, the distance I now had from the data, coupled with my personal transformation, gave me a clearer perspective. This made me realise the opportunities I missed in collecting good data because of my fears and prejudices. It saddened me that I did not connect with the participants and missed the depth in some of their responses that would have enriched my understanding through better probing. Having taken a step back, looking at the data with a clarity of mind, I was disappointed in myself for the gaps that existed in the data and for having missed an opportunity to ask more questions. Realising how badly my prejudices affected the quality of my work, was humbling and I vowed to do better should an opportunity to do research come my way.

### **6.3 New opportunities**

The writing of papers presented an opportunity to attend conferences. In November 2017, I received an opportunity to present some of this research at the International AIDS Impact Conference in Cape Town. After my presentation at this conference, one of the FSWs, who was a participant in the research that I conducted back in 2013, raised her hand during the question-and-answer session, and boldly validated my findings. She further declared to the audience that she was a sex worker; this gave her a sense of authority in recounting her experiences which were echoed by the research. I recognised her face and was pleasantly surprised when she approached me after the session calling me by name. I did not expect to see any sex worker at this conference, but I soon learned that Sisonke and SWEAT make arrangements for FSW peer educators to attend conferences. I was once again challenged by the thoughtful engagement and strong impression that she made at an academic conference.

We ended up having tea together, while she told me about the growth of Sisonke in the other provinces. We spent lots of time together at this conference, having caught the attention of other researchers who wanted to pick her brain, and she was adamant that she was not going to let others use her for their own research agenda. However, she was generous with me because, instead of asking questions to advance my own interests, I simply listened to her, not as a

researcher but more as an acquaintance. The stories she told me inspired me to pursue the research idea for a doctoral degree. Our interaction convinced me that I needed to continue with my work with sex workers. Seeing her transformation and her strong will to survive, made me realise how empowered she had become and how different she was from the person I met back in 2013. She was now a strong activist who was boldly advocating for the human rights of sex workers and I knew at that moment that I too had a responsibility towards the women whom I had met years ago. I was mature now with an open heart and a willingness to understand this underworld.

I then opened up to her about my thoughts of doing a doctorate with a focus on PrEP use among FSWs in Durban. She got excited and told me that it would be important to investigate PrEP since it was a new prevention method. She further confessed that she herself did not know much about it. Since she was not based in Durban, she offered to connect me with the coordinator of Sisonke Durban. True to her word, she connected us via email. Arrangements were made and I visited the Sisonke offices based in the Durban central business district. The lady I met was young and hospitable, she ensured that all five of her colleagues were there for my visit. I introduced myself and the intention of my doctoral study which was based initially on trying to understand the availability and acceptability of PrEP use among FSWs. The ladies agreed that the study was something they thought was important. Our interaction was polite, but I sensed that the women were quite suspicious of my intentions. I realised I still needed to earn their trust.

A week later, UKZN hosted a dialogue looking at the effects of the criminalisation of sex work on HIV prevention. I felt it was important to invite Sisonke to become part of the conversation. One of the woman came and provided a meaningful perspective to a discussion that was filled with academics and researchers, people who were far removed from the situation and not well versed in sex work research. She took the opportunity to clarify some of the misconceptions about FSWs and to articulate their need for decriminalisation. The women were grateful to have been given the opportunity to speak at UKZN. This invitation opened up another layer to our interaction and the ladies were much more receptive when I visited them again.

My second visit was to inform them of my fieldwork plan as well as to check with them whether this plan was feasible and if they would be willing to participate as key informants. During my visit they offered me lunch. Eating together resulted in another layer of comfortability. It also gave them an opportunity to get to know me and my connection to the other sex worker who

introduced us who is someone they look up to and respect. She was also scheduled to come to Durban for a site visit and they invited me so I could reunite with her and also meet the national coordinator of Sisonke who was kind enough to authorise my gatekeeper's letter (see Appendix E).

The day of the meeting arrived, and the ladies were happy that I joined them. The meeting was a reporting of the activities of the Sisonke Durban office and their plans to intensify their outreach services. I was introduced as the researcher that they have agreed to accommodate, and I was given time to explain the purpose of my research to the Sisonke national coordinator. It was also good to see my friend from the conference, she also introduced her new initiative, *Mothers for the future*, which would target sex workers and their children. I felt a sense of being welcomed by these women and this gave me optimism for my research. I also developed a newfound respect for Sisonke and the outreach work that they were doing. The dedication of their peer educators was something I found admirable. Being at this meeting exposed me to the creative thinking that the peer educators had and how they were able to come up with ideas to troubleshoot some of the problems they were experiencing.

Through Sisonke I was able to connect with TB HIV Care where I also conducted key informant interviews. There was one particular peer educator at TB HIV Care who was generous enough to act as a fieldwork assistant. She took me to different brothels and houses to speak to FSWs on PrEP. She figuratively held my hand through this process. That part of the fieldwork was hard because it meant going into sex workers' private rooms where they see clients. This also meant that I had to allow myself to be immersed in their world without judgement. I felt the fear from my previous experience creeping in from time to time. Some of those houses and brothels were very dark places that had swallowed these women, some of them were on drugs, addicted to alcohol and using sex work to feed a habit. In the midst of all the dysfunction, the women who were willing to be interviewed were warm. They ensured that I sat comfortably at the edge of their beds where they worked, even though it was also the only place to sit. I could not help but be touched by those simple acts of kindness which veiled any discomfort I could have felt. There were moments where my fieldwork assistant would leave me with a participant in one of the many shabby, dimly lit rooms to conduct an interview, while she went to find other participants. In those moments, my thoughts would sometimes betray me, and I would wonder whether I would make it out alive. But the warm voice of a participant would quickly bring me back into the room; their reassuring eyes would let me know that I am

safe, and nothing would happen to me. Nonetheless, I still felt a sigh of relief when my assistant again joined me because it was then that I felt a sense of real safety and familiarity.

#### **6.4 Challenges**

Interviewing a number of women in a particular brothel resulted in a challenge that neither myself nor my assistant anticipated. Word got around that there was a researcher here with a peer educator doing interviews and participants were receiving reimbursement for their time. We found ourselves being hounded by a group of women who wanted to get interviewed; however, they did not meet the criteria because we were focusing on women who were on PrEP or those who started and defaulted. It was interesting to see how the peer educator calmed everyone down and explained the purpose of the study. She reassured the women that there will be an intervention which will provide an opportunity for those who did not participate this time to get a chance to participate in future. She skilfully averted trouble without jeopardising the integrity of the research as well as that of her own. She treated the sex workers with dignity and respect and acknowledged and thanked them for their enthusiasm. This taught me something because I personally would not have known how to navigate that tricky situation. At the end of the situational analysis I treated the peer educators from both Sisonke and TB HIV Care with tea and cake to thank them for their assistance and participation. I now found myself acquainted with both groups and forging strong bonds with peer educators from both organisations. I had a few of them on WhatsApp and some of them would send me messages of encouragement even going as far as checking in on how the research was going.

#### **6.5 Relationships deepening**

Having conducted 39 interviews for my situational analysis I needed time to transcribe and analyse the data before I could plan the second phase of the study, which would be intervention development. During that time, Sisonke invited me to many of their meetings. There was one particular meeting where they had researchers coming in to do body mapping to collect data on issues around sexual violence experienced by sex workers. When I arrived at that meeting, one of the ladies from Sisonke who I communicated with on a regular basis, had listed me as a participant who would also be joining them on the body mapping activity. I was surprised because the criteria were strictly sex workers. So, when it came time to introduce myself, the researchers were shocked that I was listed as a participant when I was a doctoral student from UKZN, whom they clearly assumed was unlikely to be a sex worker. I thanked the peer

educator for having invited me and I offered to observe rather than participate. She smiled shyly and confessed that she simply just wanted me there for support. It touched me that the women were comfortable to tell their sensitive stories around sexual violation and abuse in my presence. In fact, they were happy that I could help them with their paintings by asking questions and being a source of support. The researchers later relaxed when they noticed that my presence did not cause any obstruction to their work.

From that day onwards my relationship with the peer educators from Sisonke solidified and deepened. I became someone they consulted with on a regular basis. Another incident that stood out was when I referred them to the UKZN Law Clinic because they wanted some basic paralegal training. They wanted to know how they could refer incidents of the human rights violation cases that their members experienced and reported. A researcher from the law clinic was having students from the USA coming to South Africa and she wanted to take them on a field trip to Sisonke to have an understanding of issues faced by sex workers. The peer educators invited me to that meeting because they were feeling unsure about the purpose of the meeting and they needed my opinion. This was also the woman that had agreed to organise paralegal training and case referral. However, after the field trip, the peer educators never heard from her again. This left them feeling used and discarded. They vented to me about it and in fact they felt put off by researchers who come and extract data and then just leave. They felt happy with the bond that we had, and they wanted to make me a permanent feature in their engagements, but at the same time were understanding of my limited time and study commitments. They checked in with me constantly about the data analysis process and were urging me to start with Phase 2, Intervention development.

## **6.6 Mothers for the future**

*Mothers for the future* was officially launched in Durban by the end of 2018 and I was invited to the launch. The founder who was now my friend that I met at the AIDS Impact Conference, approached me and asked if I was willing to be a ‘friend’ of *Mothers for the future* to provide them with research-related support. This was an honour and I agreed to render my services. I assisted the woman with putting together the standard operating procedure for *Mothers for the future*, as well as the scope of services that they wanted to provide. During that meeting I sat with the ladies for hours trying to brainstorm and ascertain what *Mothers for the future* Durban seeks to accomplish and what funding resources we could tap into. Being part of this process helped me realise the potential that sex workers had and their ability to be critical thinkers and

problem-solvers. I had the privilege of seeing the women apply their deep knowledge and experience and come up with innovative ways of helping their fellow sex workers become better parents. I was also asked to deliver a workshop on public speaking because the women would at times be interviewed by the media or invited to speak at certain meetings; thus, they felt that public speaking was an added skill they needed. After two days of the strategic meeting and planning I was officially welcomed, and I am now a part of the *Mothers for the future* initiative.

## **6.7 Becoming “friends”**

A colleague who is part of the organising committee of the South African AIDS Conference in June 2019, asked me if I knew anyone who would be willing to speak on the challenges of sex workers as part of their community voice segment. I instantly recommended one of the peer educators from Sisonke. She was thrilled at the opportunity, she prepared her presentation and asked me to proofread it for her. This was her first opportunity to speak at such a large conference. She represented herself and fellow sex workers well and I was extremely proud of her. Her colleagues came to the conference to support her, but unfortunately, they could not all get access to the conference, but we all spent lunchtime together and I sent videos of the speech to them via WhatsApp so that they could share in the moment.

At this stage, these women started to feel more like my friends than participants. I felt immensely supported by them. They went as far as inviting me to their year-end function. Sharing a meal and listening to them talk about their experiences in the sex trade gave me a clear perspective that no interview could have given me. Seeing how they laughed at themselves in the midst of the pain they have experienced, incited in me immense respect for them. I heard them tell stories about their children, about their forgotten lovers and current clients. In my eyes, I no longer saw sex workers, but I saw women who were dealt a tough hand in life. I realised that at the end of the day these women were more than just sex workers, they were activists, mothers, sisters and friends, and most importantly, we were all connected by a similar struggle that connects women all over the world, that of navigating the complexity of living under a capitalist patriarchal society, and no one has a right to judge another how they chose to negotiate life in a world that treats women as subhumans.

At this point, it started to feel like my role as a researcher was being foregrounded by the friendships that were forming. Thus, it was important for me to constantly reflect on this

process and to journal my thoughts and emotions so that I would not lose perspective. The way in which I resolved the metamorphosis of my fieldwork experience was to be honest with myself and not try put up a fake wall of objectivity. The purpose was to join forces with FSWs to create an enabling and empowering space for dialogue and possibility for change, and I knew that for this process to be meaningful trust, needed to be the main currency. As an outsider, working with a community that faces stigma and discrimination, trust is a scarce commodity and I understood that I needed to be open and less guarded. Hence, when I felt my walls come down, I welcomed the process because ultimately participatory action research thrives on strong partnerships, and change can only be realised when we hold hands and bond together. I also understood that this process might come under a lot of scrutiny and some researchers from a different school of thought might disagree with how I went about the process of community engagement. However, this was the risk I was willing to take if it meant that the FSWs in this study would feel that in me they have an ally, and that having just one more person on their side infused their courage to use their voices for change.

## **6.8 #Say her name**

On 6 December 2019, the Sisonke peer educators held the *#Say her name* event for 16 days of activism which is observed annually to increase efforts against gender-based violence. For Sisonke, they commemorated the FSWs who were killed because of gender-based violence. This event was attended by 100 FSWs coming from the eThekweni Municipality, including the Durban inner city and surrounding areas such as Richards Bay, Pietermaritzburg, and Port Shepstone. The peer educators felt that it was a good opportunity to announce the PrEP intervention so as to introduce it to the FSWs and to encourage support and participation when the time came for implementation.

It was at this event that the peer educators and the rest of the attendees sang a song for me as I walked up to address the crowd. The song they sang was an affectionate song that they sing for one another. This made me feel one with the group and was a sign that I had become integrated in their group. The song was sung in isiZulu with the following English translation:

*This is Nosipho,  
This is our Nosipho,  
that we know,  
They may not have seen her,  
but we know her,  
and we have seen her!*

## Chapter 7

### Challenges Associated with Oral Pre-exposure Prophylaxis among Female Sex Workers in Durban, South Africa

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*“Whatever is in the ARVs, is also in the PrEP”*

#### 7.1 Introduction

Globally, the goal is to end AIDS by 2030. Significant declines in AIDS-related deaths have been observed among people from all ages living with HIV, from a staggering 1.9 million in 2004 to 940 000 in 2017 (Sidibé, 2018). AIDS-related mortality has declined by 34%; however, a further decline of 150 000 deaths per year is needed to achieve the UNAIDS 90-90-90 targets which stipulate that 90% of people should know their HIV status, 90% should be on antiretrovirals, and 90% of those receiving antiretroviral therapy should achieve viral suppression by 2020. The current decline in AIDS-related deaths is mainly driven by the upscaling of antiretroviral therapy, which is currently being made available immediately to those who test positive (test and treat) to achieve viral suppression and curb transmission (Sidibé, 2018).

A significant decline of global deaths from AIDS-related illnesses has been observed, particularly in sub-Saharan Africa and more specifically in Eastern and Southern Africa, which is considered as the epicentre of the epidemic; it is said to have 53% of the world’s population living with HIV, with the epidemic being higher among women (56%). AIDS-related mortality declined by 42% from 2010 to 2017 due to the increase in treatment in this region (Sidibé, 2018).

Despite the progress made in the decline of AIDS-related deaths and ways to limit new infections, there are still populations among which the epidemic is still highly concentrated. These are key populations which require strategic focus (Awungafac, Delvaux & Vuylsteke, 2017). As discussed in the literature review (Chapter 2), the added complexity with these populations is that they are hidden because their lifestyles are either criminalised or deemed morally unacceptable, which makes it challenging to design prevention strategies for these groups (Awungafac et al., 2017). Data has shown that 47% of new HIV infections worldwide are associated with key populations and their sexual partners (Sidibé, 2018). Research,

specifically among FSWs in sub-Saharan Africa, has shown that approximately 37% of FSWs are HIV positive due to exposure to a number of multiple intersecting vulnerabilities such as multiple sexual partners, lack of access to health care because of stigma and discrimination, violence from partners and clients, as well as consumption of drugs and alcohol as a coping mechanism (Awungafac et al., 2017).

In South Africa, HIV prevalence among FSWs is said to be at 57.7%, which is higher than the estimated national prevalence of 19.07% (Avert, 2020; Sidibé, 2018). Thus, as explained in the previous chapters of this thesis, the South African government, with the aid of the WHO guidelines, instituted the distribution of PrEP among FSWs (PrEPwatch, 2017). There is substantial research that has investigated the barriers and facilitators for uptake, adherence to retention of PrEP among MSM (Bak, Van Dam & Janssens, 2018; Chakrapani et al., 2015; Han et al., 2019; Ogunbajo, Kang et al., 2019; Ogunbajo, Leblanc et al., 2019; Pelletier et al., 2019). There are also various studies from different contexts that have documented challenges to PrEP adherence and retention among minority groups, adolescents and serodiscordant couples (Gengiah, Moosa, Naidoo, & Mansoor, 2014; Hosek, Celum, Wilson, Kapogiannis, Delany-Moretlwe, & Bekker, 2016; Hunt, Lalley-Chareczko, Daughtridge, Swyryn, & Koenig, 2019). However, there are only a few studies from the South African context that have looked at barriers and facilitators of PrEP use among FSWs. These studies are mainly qualitative studies among FSWs in one part of the country (Gauteng province) (Eakle et al., 2019; Eakle, Bourne et al., 2018; Eakle, Mutanha et al., 2018). Thus, more studies are needed to understand the challenges to PrEP use among FSWs in other parts of South Africa. This study is a qualitative needs analysis that was conducted in Durban, KZN, which is a part of the country where PrEP knowledge among FSWs is sparse and distribution is limited. In the process of PrEP implementation and scaling up, it is important to consider the end user's perspective of PrEP in order to understand and deal with factors that hinder uptake, adherence, and retention. This will also inform the implementation of complex holistic interventions that intervene, not only at a biomedical level but also at a psychosocial and behavioural level.

## **7.2 Sociodemographic background of participants**

Table 2 shows the sociodemographic background of the participants.

Table 2

*Sociodemographic background of participants*

Participants	Female sex workers	Female sex worker peer educators	Health care providers/ researcher
<b>Gender</b>			
Female	26	11	1
Male	0	0	1
<b>Age groups</b>			
19–23	1	0	0
24–28	6	3	0
29–33	4	0	0
34–38	11	2	2
39+	4	6	0
<b>Educational level</b>			
Primary school	0	1	0
Secondary school	16	5	0
Matric (Grade 12)	10	4	0
Tertiary	0	1	2
<b>Home language</b>			
isiZulu	17	8	1
isiXhosa	2	2	0
Sesotho	1	1	0
English	1	0	0
Other*	5	0	1
<b>Racial group</b>			
Black	25	11	2
Coloured	1	0	0
Indian	0	0	0
White	0	0	0
<b>Country of origin</b>			
South Africa	21	11	1
Zimbabwe	5	0	0
Congo	0	0	1
<b>PrEP uptake</b>			
Taking PrEP	20	1	0
Not taking PrEP	6	10	2
<b>Total number of participants: 39</b>			

\*Foreign nationals.

## 7.3 Results

The results for this component of the study are discussed under the following themes as depicted in Figure 7.

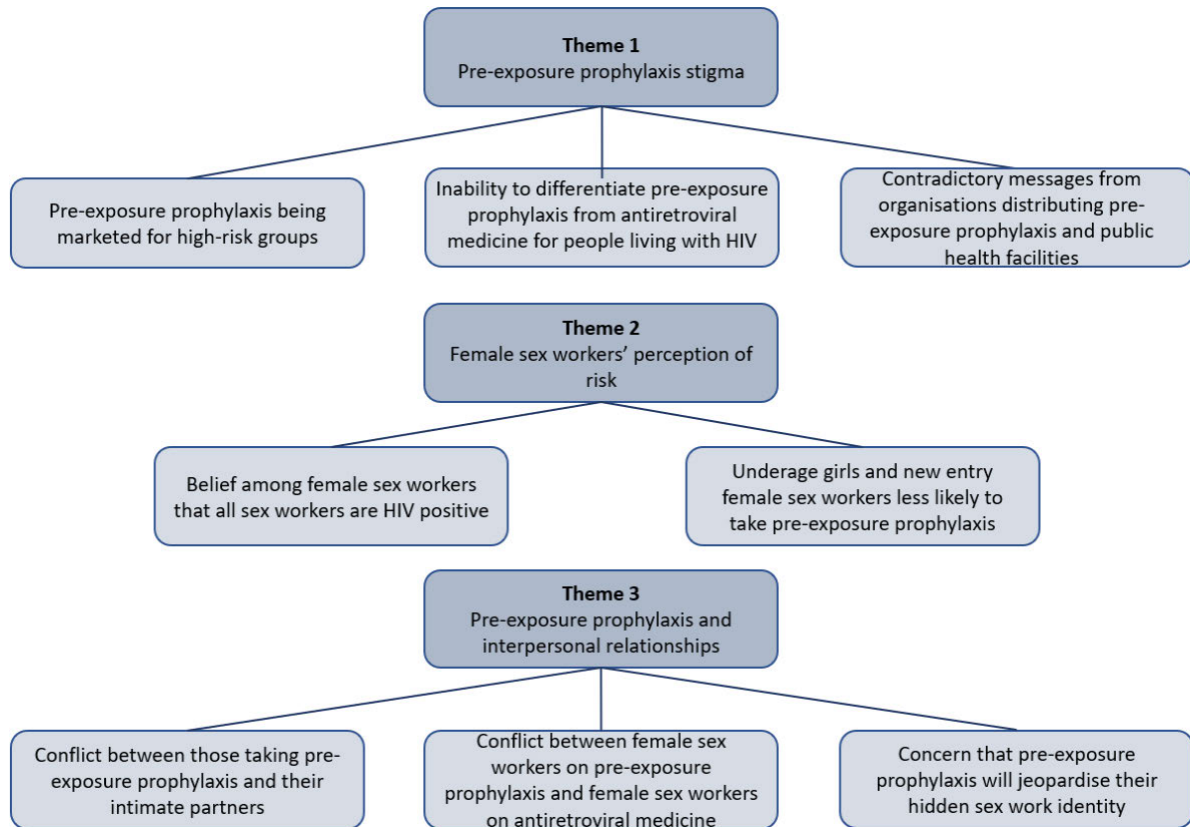


Figure 7. Themes and subthemes for Chapter 7

### 7.3.1 Pre-exposure prophylaxis stigma

The subthemes identified in the data pertaining to stigma were PrEP being marketed for high-risk groups, inability to differentiate PrEP from antiretrovirals for people living with HIV, as well as contradictory messages from organisations distributing PrEP and public health facilities.

#### 7.3.1.1 Pre-exposure prophylaxis being marketed for high-risk groups

With the exception of one person, all the participants agreed that PrEP being marketed and distributed specifically to high-risk groups is stigmatising. The participants felt that the emphasis on high-risk groups reinforced the belief that FSWs are the carriers of HIV.

*I can really say that stigma on HIV is still prevalent in our society. Now, for any person taking PrEP, when PrEP is not well known, this is difficult. The fact that PrEP is not well known to the general population creates a big stigma and saying that you are taking ARVs [antiretrovirals], this may be difficult to explain to any person (Researcher age 35)*

*I think once they take off that thing, that this thing [PrEP] is for people who are really at risk which categorises sex workers only, it will be fine with everybody because they will start giving education like even on the radio, like they are doing with ARVs ... (Counsellor age 37).*

*I think you can say this pill is for people who are sexually active, it does not matter how old you are, you are young, old, a sex worker, but as long as you partake in sexual activities you must know that you must find a way to protect yourself (FSW peer educator, age 50).*

Furthermore, the participants argued that the normalisation and wider distribution of PrEP would assist to curb stigma, and this would increase the likelihood of PrEP uptake among FSWs.

*The government should give it to everyone just like they do with the ARVs, and it must not be specifically given to sex workers ... (FSW peer educator, age 42).*

*they can advertise PrEP everywhere. Right now, there is nothing-nothing that's being done. We as mobile clinics, we as organisations, we need to push we need to go out and tell people about PrEP (Counsellor, age 37).*

Some participants strongly felt that there are other women in need of PrEP but are being overlooked due to the focus on FSWs. Those who engage in transactional sex with multiple partners, those at risk but do not identify themselves as sex workers, as well as married women who may not be able to negotiate condom use with husbands that engage in multiple sexual relationships:

*We have got various sex workers, some do it in the clubs, some do it in the neighbouring areas in a community and we have 'sex workers' who have never come out in public/admitted that they are sex workers. she does not know she is doing 'sex work', why, because she has never carried her handbag and went out to sell sex and that person is at high risk because she is the one who does not wear a condom totally because she is deceiving herself. She's scared to make money publicly the way I am making it (FSW peer educator, age 42).*

*Yes, I think it is because there are married women out there who need such protection [PrEP]. I was once married before and got divorced, both my kids are from wed-lock. So, if you are married you cannot say no to unprotected sex, so married women can*

*also get infected by HIV, because some men are not faithful. So, these pills must be given even in public health sectors, to avail it to those who are faithful and want to protect themselves, especially married people. I feel sorry for them because they have got no say when it comes to sex, their men want to have unprotected sex with them while they know that they sleep around with multiple partners. Do you know that men can hide that they are taking antiretrovirals, and they can take them at work without telling their wives? So, I think it should be provided to those who are married (FSW, age 38).*

The wider distribution of PrEP was viewed as a solution to increase confidence in PrEP efficacy and lessen the current suspicion that PrEP is a drug being tested on FSWs simply for scientific purposes:

*Now as a scientific organisation the suspicion is that we are simply testing PrEP on FSWs and this makes it difficult for them to accept it (Researcher, age 35).*

### **7.3.1.2 Inability to differentiate pre-exposure prophylaxis from antiretroviral treatment for people living with HIV**

Due to PrEP being essentially an antiretroviral pill (tenofovir), the participants felt that this contributed to further confusion among FSWs and led to the difficulty in PrEP uptake and adherence, because some sex workers could not tell the difference between the two regimens (PrEP for prevention and antiretrovirals for people living with HIV). This compounded the fear of stigma and cast a sense of doubt among those who were keen to take up PrEP because of its association with antiretrovirals, which are stigmatised:

*Some are understanding, and some are still not understanding, we tell them but still they have not understood it. They have not understood it because we give others PrEP and when they open it, others will come and tell them that it's ARVs. We tell them that these are not ARVs because the colour is not the same and PrEP has two components because it is for protection, and the ARVs has three components for treatment. That is how we tell them and some default because they think it's ARVs. A lady (FSW) will call and say why did you give me ARVs? because the ladies that I live with say it's ARVs. You will then call the lady to explain to her because you may find that someone has explained to her differently and we have come across such things that she may come for further explanations and may continue taking PrEP. We encounter a lot of challenges (FSW peer educator, age 46).*

*They [FSWs] are also saying that whatever is in the ARVs is also in the PrEP, so they are the same (FSWs, age 26).*

PrEP as tenofovir, which is an antiretroviral, has created a situation where some FSWs felt that there is no difference between someone who is on antiretrovirals and someone who is on PrEP

because the adherence requirements for both mean a pill a day at a specific time. Thus, an FSW on PrEP also engages in a similar daily routine as an FSW on antiretrovirals. This reinforced the idea that the two regimens are the same, as expressed by the following participants:

*The stigma is around the fact that tenofovir [PrEP] is an ARV, when a person actually googles it, it is going to give all the options of an ARV, now the question out there we can say it's 2018, everyone knows about HIV but trust me, still few people are accepting the fact (Researcher, age 35).*

*Me, one day I didn't want to take the tablet because the person who takes an HIV tablet and the person who takes PrEP are not different. Why I say so is because when I compare those tablets, I have one of my friends who is taking the HIV [ARV] tablets. When I compare there is no difference. They look the same, the size, the way they are, everything. So, one of my friends asked me "why are you taking those pills because you are not HIV positive?" I said I just want to protect myself. She told me "which means we are the same. Why are you still taking meds"? I said it's for preventing HIV. Then they went on Google. They googled that tablet and there was so many information. You know people can discourage you saying these pills are no different from the ones for HIV [ARVs] there is only one difference, but all these things are the same. They keep on talking. I said I can't do anything because they are not the ones that take that tablet. If I have a problem or if I want to quit, I must go to the people who introduced me to those tablets not these ones because these ones and me we are the same we know very little (FSW, age 33).*

*At times you end up explaining but some will not understand and ask why I am taking pills that they have never seen in public clinics before, and I keep on saying I am not sick. Can you imagine that thing. A friend of mine is also teasing me that I should just start eating ARVs because this thing is the same as ARVs. I think if it can be provided in public clinics then it will be okay. It would be good (FSW, age 35).*

The views expressed above call for the normalisation of PrEP. This means that PrEP needs to be marketed as an HIV prevention method and should be made available to anyone who is at risk for HIV and not only to specific groups. This will prevent the association of PrEP with sex work or with being HIV positive. It is also important for PrEP education to be explicit about PrEP being a tenofovir, which is an antiretroviral regimen that can be utilised for HIV prevention.

### **7.3.1.3 Contradictory messages from organisations distributing pre-exposure prophylaxis and public health facilities**

Another challenge that contributed to the stigmatisation of PrEP among FSWs was that most health care professionals that participants came across in the public clinics and hospitals, did

not know about PrEP, and simply labelled it as an antiretroviral, which discouraged FSWs from taking it. In addition, the fact that PrEP was being distributed through one local non-governmental health research organisation that is known to target FSWs with health care services, created a situation where FSWs were curious as to why a vital pill that is said to prevent HIV was not being widely distributed to the general public through government health facilities. This created another layer of confusion among FSWs who went to their local clinics to enquire about PrEP for more information to gain a sense of clarity. These factors contributed to scepticism among FSWs regarding PrEP.

*Even the public clinics, sometimes the nurses don't know what is PrEP is, because the other lady said the nurses said this is an ARV, yes there are two combinations of the ARVs in PrEP but it is not an ARV for positive clients that's the problem, now the nurses also discourage them in the public clinics and tell them that this thing is an ARV. The FSW will phone me back and say "I'm not taking this thing because even the sister [nurse] told me that this thing is an ARV, they don't explain nicely that in PrEP there are two combinations of the ARVs because we want to protect, we are not suppressing the virus, this person is not infected so she doesn't need the whole three combinations, only two combinations from the ARVs but the sisters needs knowledge too. I think even in the hospitals they need something like a workshop, they need to be taught about PrEP because like some other ladies will make sure that they understand in front of you what you are telling them about this PrEP, and they are worried that it's only this organisation distributing it. They will go straight to the clinic and ask "do you know PrEP, what is PrEP?" and the sister who don't know nothing about PrEP she will tell them that "oh is that ARV we put on those who are on second regiment, so that thing is an ARV" and all the clients will come back telling you that "PrEP is an ARV so I don't need PrEP because I am not positive" (PrEP counsellor, age 37).*

*Nurses in the public clinics do not know about PrEP and even people from townships they do not know, because I have also experienced some challenges with my neighbours. The fact that you know that they are not HIV treatment you will just place them anywhere in the house, not that you are proud of being negative, but when your neighbour comes in and see it, she will just ask if you are also taking ARVs, some will say you have finally found this sickness, and you do not know how to explain to them because they are clueless (FSW, age 34).*

Furthermore, the contradicting messages from public health care providers and the PrEP distributing organisation, contributed to lower retention rates because the FSWs who were initially enthusiastic to take up PrEP, experienced discouragement from the public health care professionals who simply dismissed PrEP as an antiretroviral without explaining that PrEP is for HIV prevention because of their inadequate PrEP knowledge. The lack of coherence that

existed between the two health care structures resulted in unintended consequences that slowed down PrEP uptake and retention among FSWs:

*We had issues with people accepting PrEP because somebody will say it is only for sex workers and until now there's another organisation that is also in eThekweni that has started to implement PrEP among students, for example. However, all this time it was not done, meaning it was only sex workers who were actually getting PrEP. So, now because there was no sensitisation done to our local clinics, and the lack of information from our health professionals, the health professional is not just a nurse. I'm referring to the level of doctors, clinicians basically, if they do not understand what is it, they will just go to tell to stop that treatment, these NGOs [non-government organisations] are giving you, just stop it. This ended up being one of the reasons that our retention of PrEP dropped drastically because people they were willing to start, but because any oral medication has side effects. So, when they ask somebody else who is not sensitised, who is not being actually trained on PrEP, because they do not know, they just go to advise the person to stop. That was also one of the reasons, it means also that if a person is on PrEP and decides to go to the clinic, the question the sister will ask, meaning a nurse will ask is why are you taking this? That is why I hope that it will be implemented in a larger scale and I am hoping that the fact that people will be knowing much more about that we may see some improvement in uptake (Researcher, age 35).*

### **7.3.2 Female sex workers' perception of risk**

The themes that will be discussed under risk perception are the belief among female sex workers that all sex workers are HIV positive, as well as limited risk perception among underage girls who enter sex work and new entry sex workers being unlikely to take PrEP.

#### **7.3.2.1 Belief among female sex workers that all sex workers are HIV positive**

The majority of the participants mentioned that there is a general misconception among FSWs that everyone who is a sex worker is HIV positive; therefore, as mentioned above, being in possession of PrEP is associated with being HIV positive. First, this belief resulted from the fact that these women shared clients, and condom use was inconsistent:

*Most girls like deceiving themselves and say we are all sick and if you tell them that you are taking PrEP, they will make you a laughing stock and say you are fooling yourself by taking PrEP, thinking that you are not HIV negative. Some understand, and some do not, and they also laughed at me that I am fooling myself, why am I not taking ARVs. So, the belief is that we are all sick (FSW, age 27).*

*They talk because my other friend found out that she is positive, but she hasn't started taking ARVs. So, when I was experiencing rash with PrEP, she said these pills are not good, I was hoping I would take them too, and I asked which pills you are going to take because these ones are meant to protect against HIV. She said no these pills are for HIV, I have seen them from other people, and I said no they are not for HIV, and she said "no, it's because you guys are keeping it a secret and you can't accept that you are sick", so she was quick to judge me and it is common that people will judge you and even some clients when they see you they will just say you are taking ARVs (FSW, age 32).*

Second, the idea of a daily pill that is essentially an antiretroviral that prevents HIV seemed highly improbable. The FSWs on PrEP were accused of HIV denialism or having blood type O, which among this population is understood as a blood group that cannot be infected with HIV. The group mentality and the assumption that all FSWs are HIV positive could lead to a misguided perception of risk or apathy and FSWs may therefore not take adequate precautions to prevent HIV:

*There is a girl I shared a boyfriend with. I found them together, the girl was taking ARV pills. Therefore, when I told her I was on PrEP, she asked how come? And I explained, she then said maybe I am blood type 'O' and whatnot. I told her there is no such thing about blood types or whatever, and nobody believed me when I told them I don't have the virus (FSW, age 27).*

Some of the participants who were on PrEP mentioned that they were surprised that they tested negative because of the risks incurred in sex work. Others believed that the HIV was hiding in their blood and it was only a matter of time until it showed itself. Thus, those taking PrEP were told by their friends to stop wasting their time and start taking antiretrovirals since it was highly possible that they were HIV positive:

*Maybe it could be somehow hidden in my system, but when the sisters [nurse] who usually come here paid us a visit I asked if it is possible for the virus to not be detected in my system? they said it is rare, especially if your blood type is susceptible to it. So, before I started taking PrEP, they also run me some blood tests and they said there is no such, if you are positive or negative nothing will change that ... (FSW, age 27).*

*They will say that you think you are better that is what my friend told me, she said it's not like you are HIV negative, but it's because it is still invisible in your system (FSW, age 35).*

In the midst of the misconceptions and doubts, there were some participants who refuted the myths and felt strongly about taking PrEP. They trusted that they were HIV negative and focused on protecting themselves by taking PrEP consistently:

*So, there is a lot of peer pressure to say all of us are positive even though it's not true, but the belief that "we are all doing the same job then why are you negative and why am I positive"? It's like there is that thing that we are all the same. But they use to tell me "you are taking these tablets and still working in this business but one day you will get it". I just tell myself that I will not get it because I know what I am doing, and for sure I can't get it. I am not saying I am clever, and I am not saying that those that get it are stupid. No, I didn't say so but, on my side, when I am still negative, I have to thank God. I have to keep taking those PrEP tablets. I can't stop them (FSW, age 33).*

*I just have that attitude that I know myself and I don't need someone to tell me what to do, yes it is true that if you take bottles for both PrEP and ARVs, they are almost in the same bottles, so they say why are they giving you this pill if you do not have the virus? So, it's either you got it too, or it is invisible, or they are giving you pills to hide HIV and it will come out later. So, it is better to take ARVs because you know that you are taking ARVs than to think you are clean when you know that you are sick. It seems like there is a feeling that because we are doing the same job, we must all be infected (FSW, age 34).*

### **7.3.2.2 Underage girls and new entry female sex workers less likely to take pre-exposure prophylaxis**

Some participants were adamant that young girls who sell sex and new entry FSWs were less likely to take PrEP because of their low perception of HIV risk and thus they do not engage in preventative and protective behaviours as they might be oblivious to the dangers involved:

*They only see later after experiencing some challenges, but when they are new, especially the young girls who are entering the industry they are not aware of the risks in this job. What happens is that you may find that these girls are young ... (FSW, age 26).*

The young, underage girls who sell sex were viewed to be financially desperate and eager to make money even at the expense of their own health. Their risk is compounded by high levels of client demand because of being new to the trade they are considered 'fresh' and therefore more desirable to clients. The inexperience with negotiating condom use with clients also puts new recruits at a disadvantage and a likelihood of contracting HIV:

*Clients are after those who are new since they are fresh, and they do not have an experience with this job [selling sex]. Clients do not want people like us who are old and have a lot of experience, so these young girls only realise the risk of doing this job when they are being infected by STIs and other diseases, that is when they discover that*

*this job is risky, but as long as they are getting money to buy whatever they need, they will not even listen to us even if we are advising them (FSW, age 26).*

Women who are new to the sex trade, were also categorised by participants as high risk for HIV and less likely to take precaution because of being in denial about doing sex work, they do not immediately acknowledge their sexual transactions as sex work:

*Firstly, when you are new in this industry you do not even tell yourself that you are doing that thing [sex work], you just take it lightly, think that you were just being naughty because you are desperate. Yes, you do not think about what you must do or not do to protect yourself. Also, it is not easy for a person to just go and stand on the streets or go in a certain brothel to work (FSW peer educator, age 51).*

The refusal to accept that one is a sex worker means that their focus is purely on making money and not necessarily on taking the needed precautions to ensure that they remain HIV negative:

*Your spirit is always pleased by the money you are receiving/making that you have never had before. Or maybe you have been doing this job but you did not know you were doing it because it happens that you have five boyfriends, and this is part of this job because amongst those five boyfriends, it is not like you love them all, amongst those five boyfriends, one of them might not want to use a condom, maybe three or two of them can ask to use a condom. So, you may not realise that you might be in trouble because you are used to having sex with multiple people maybe a day, without knowing that you are being a sex worker (FSW peer educator, age 42).*

In some instances, new entrants into the trade may not know of the mobile HIV prevention services available to them and may miss out on the educational prevention programmes pertaining to PrEP. At times, the older FSWs would have already discouraged the new recruit from initiating PrEP because of the stigma surrounding PrEP:

*The problem is that each and every year, or I can say each and every month, there is a new sex worker joining all those old sex workers, for sure there is not enough education on PrEP, so that is our challenge because every time when we go there you will find out that sometimes they have already polluted her mind, telling her to not even try this PrEP thing. She's new in the business, she's new on the streets, now you have to take your time trying to convince her to see PrEP as the real thing not as something that is a threat to her life because those who don't like PrEP or those who are already on ARVs are the cause of the confusion (PrEP counsellor, age 37).*

Some participants take the time to explain to new comers the challenges that they can expect in the trade and how they can go about navigating those challenges to protect themselves;

however, situations differ because the industry is unpredictable and therefore everyone has to make their own decision based on the circumstances they find themselves in:

*We usually say to those who have been there doing it that if they bring someone here, they must tell her the challenges, tell her ways of behaviour and what she must do now that she is here and what she must not do. It is easier to talk than doing it, because no matter how much I can tell you, you will follow your mind with your client because it is only you and him in the room ... Yes, this is not a degree that you will plan that I am going there to do such and such. No, it something that happens automatically without planning for it, you grow or get to learn along the way (FSW peer educator, age 51).*

### **7.3.3 Pre-exposure prophylaxis and interpersonal relationships**

The themes that are discussed under PrEP and interpersonal relationships include conflict between those taking PrEP and their intimate partners, conflict between FSWs on PrEP and FSWs on antiretrovirals as well as concerns that PrEP will jeopardise the women's hidden sex work identity.

#### **7.3.3.1 Conflict between those taking pre-exposure prophylaxis and their intimate partners**

Some participants mentioned that the lack of understanding regarding the function of PrEP has led to conflict with their intimate partners with whom they have steady relationships with. They asserted that when partners happened to come across the PrEP pills, their first instinct was to suspect that the female partner was taking antiretrovirals, and they found it hard to believe that the partner was in fact engaging in HIV prevention. This misunderstanding occurred because the majority of PrEP users in this study found it difficult to speak to their partners about PrEP because they did not have the proficiency to explain its use as an antiretroviral that prevents HIV infection:

*We once separated with my partner, because he thought I was lying that this medication is to prevent HIV. I was just keeping them in a bag, and I was seeing no issue with that, and he said, "you are also taking ARVs and you do not bother telling me, because last time I checked we were both negative?" then I told him that we must both go to the clinic and test for HIV and now he understands (FSW, age 34).*

*It creates a lot of stigma because as times goes on your partner will know that these pills are given to certain people and he will start doing research about them and ask doctors who really gets these pills, or he will just go to the clinic to consult more about it maybe they will clearly tell him at the clinic that it is not given to anyone, we are currently giving them to certain people. So due to the fact that it is given to specific*

*people you see he will then come back to me and start accusing me that I am such and such “how many secrets have you been hiding from me?” So, maybe they must not say it is specific for those people [sex workers] because it is creating a lot of stigma (FSW peer educator, age 28).*

*So, some of the challenges is that some ladies have boyfriends, and they will not understand if you are telling them that you are taking these pills. My boyfriend that I had said I was taking the pills because I am HIV positive, and he said he has never seen such a big pill with these colours, so I had to tell him to search and google it. Unfortunately, he was slowly coming to terms with that and we had one sister explaining to him, because I think he took the pill and went to someone else to explain to him ... But since this incident we broke up and are no longer together (FSW, age 34).*

### **7.3.3.2 Conflict between female sex workers on pre-exposure prophylaxis and female sex workers on antiretrovirals**

The conflict regarding PrEP was not only experienced between FSWs and their intimate partners but it also included FSWs and their friends. This conflict was as a result of the belief that all FSWs are HIV positive as explained above. Thus, some FSWs in this study mentioned that when they opened up to their friends about taking PrEP to remain HIV negative, they received backlash and negative feedback with undertones of envy:

*We are not talking to each other with my friend even now because we fought over that thing [PrEP]. She is the one who told me about PrEP, and we went for HIV testing, and when she found out that she was positive, and there was no way I could hide my status from her, so we showed each other. Then when they have started delivering our pills since they deliver where we are staying, she said it's not like you are not HIV positive it's just that ... they can't find the virus in your system. She ended up hating me and saying bad things about me to other people, saying that I am taking PrEP, but I have HIV it's just that it is not yet visible in my system and things like that. However, I do not benefit anything from someone who is saying bad things behind my back (FSW, age 34).*

The negative reaction that FSWs taking PrEP received from their friends led some to make the decision to take PrEP secretly to avoid facing the ridicule that comes with taking an antiretroviral for the purpose of prevention:

*You end up hiding that you are taking your pills if you are still staying with people who are sex workers, because you know that you will be criticised (FSW, age 35).*

### 7.3.3.3 Concern that pre-exposure prophylaxis will jeopardise their hidden sex work identity

Some participants were genuinely concerned that taking PrEP could result in jeopardising one's confidentiality. One of the concerns was that because PrEP is for high-risk groups, it might raise suspicion among close family members if they should discover that their family member is using PrEP. Thus, some PrEP users in this study were burdened by whether to tell their family or not. This was coupled with the self-doubt of not having the ability to adequately explain the use of PrEP:

*Some know about it, but a person might say "I might take this PrEP and what am I going to say what are these drugs for because these pills are well known to be taken by only sex workers. My boyfriend or my husband does not know that I am a sex worker, so if they see me with these pills it will be clear that I am a sex worker" (FSW peer educator, age 42).*

*So when they are asking you where you are getting these pills [PrEP] and that you should take them to where you are getting them it's a big challenge, because you will meet people you are doing sex work with there and some do not mind to just talk to you about sex work and you might get exposed at home just like that, and your family will know what kind of a person you are (FSW, age 34).*

To deal with this challenge of potential exposure, some FSWs advocated for the hiding of the pills from their families and significant others in order to avoid being questioned and run the risk of having their occupation discovered:

*I have been selling sex for more than 12 years on the streets and no one has ever known that I was doing sex work. But if you are a woman, women think faster than men, so by the time I would be cooking in the kitchen, I know where I am keeping them and I know that by eight o'clock I should have eaten and have taken the pill [PrEP]. So I will go fetch the pill where I keep it, fold it with a tissue or hide it in my apron so while I would be cooking it would be with me, and by the time I finish eating, I will go as someone who is going to brush my teeth in the bathroom and then drink it there and I have bailed myself in that way. Even if one of them is in my bag, I will go as someone who is going to take something in my bag, then I will take the pill and drink it. I would also change the containers, empty the PrEP from its original container and put them in a headache pill container and so on (FSW peer educator, age 37).*

## 7.4 Discussion

The participants in this study raised a number of pertinent issues that contributed to the challenges regarding PrEP uptake, adherence, and retention among FSWs. The marketing and

distribution of PrEP at the time of this study was premised on targeting groups that were at high risk to HIV acquisition such as FSWs. However, the majority of participants in this study felt that this approach undermined their privacy and could potentially expose them to scrutiny from their families and partners should they decide to take PrEP. This perceived lack of privacy resulted in some FSWs feeling apprehensive about taking PrEP. Due to PrEP essentially being an antiretroviral, this resulted into PrEP stigma, and the labelling by friends of those taking PrEP as being HIV positive. This labelling came as a result of the prevailing belief among FSWs that the majority of women selling sex are HIV positive because they share and rotate clients. This belief has resulted in FSWs questioning the efficacy of PrEP, with some going as far as not being sure whether they were truly HIV negative, given their sexual engagement with multiple partners. This doubt manifested itself through the belief and expectation that the HIV will eventually 'show itself in their blood'. This finding was similarly reported by Eakle et al. (2019). These false beliefs could lead to some FSWs accepting HIV acquisition as their fate and not acting in a decisive manner to prevent HIV infection. Furthermore, unique to this study, the participants mentioned that they were confused by the inverse notion peddled by their peers that they were probably 'blood type O' and not susceptible to HIV infection. This idea is similar to findings that were released by a study published in 2015 that was conducted in Kenya among FSWs, which found that the HIV incidence was higher among blood group A as opposed to blood group AB, B and O counterparts (Chanzu, Mwanda, Oyugi, & Anzala, 2015). However, other studies have concluded that blood groups have no effect on HIV susceptibility or resistance (Okorie, Ifeanyi, Vincent, & Prayer, 2020; Siransy, Nanga, Zaba, Tufa, & Dasse, 2015).

The environment in which PrEP was being rolled out was characterised by contrasting messages between the private donor-funded research organisations and the public health care providers who simply dismissed PrEP as being an antiretroviral, without providing accurate information regarding antiretrovirals being used in the form of PrEP to prevent HIV. This created a sense of uncertainty with regard to the legitimacy and efficacy of PrEP among some FSWs.

PrEP as an antiretroviral is being rolled out in an environment where HIV stigma is rife. According to Golub (2018), HIV stigma originates from the association of HIV acquisition with socially unacceptable behaviour or promiscuity; therefore, those contemplating or taking PrEP do not want to be associated with HIV medication, which in turn confers HIV-related

stigma. PrEP is described as socially discrediting because PrEP is an antiretroviral and by its association with HIV medication it is stigmatised. The stigma incurred by PrEP is attached to the persistent stigma towards people living with HIV, despite thirty years of HIV awareness campaigns and advocacy. Studies have shown that the stigma associated with HIV has not been sufficiently abated (Boyes, Pantelic, Casale, Toska, Newnham, & Cluver, 2020; Cuca, Onono, Bukusi, & Turan, 2012; Mhode & Nyamhanga, 2016; Visser & Sipsma, 2013; Visser, Kershaw, Makin, & Forsyth, 2008). Various research studies among other high-risk groups such as MSM, echo similar concerns regarding the fear of being labelled HIV positive because of the choice to take PrEP (Biello et al., 2017; Golub, 2018; Van der Elst et al., 2013). As a result of societal disapproval, individuals who experience stigma tend to internalise the negative attitudes that they experience. This results in internalised stigma, characterised by feelings of shame, guilt, and worthlessness. Studies that have investigated internalised stigma among HIV-positive individuals, have reported that internalised stigma has prevented HIV-positive individuals from initiating antiretroviral treatment because of internalised expectations of rejection, which may lead to withdrawal, isolation, secrecy and non-disclosure of HIV status to partners (Pantelic, Shenderovich, Cluver, & Boyes, 2015; Scambler & Paoli, 2008). Similarly, stigma-related challenges need to be anticipated and addressed for FSWs contemplating to take PrEP. This is particularly important for FSWs because they are most likely to experience intersecting stigma for engaging in sex work (Baugher et al., 2017).

Another source of stigma was as a result of the targeted approach to PrEP. The argument made by FSWs in this study was that this targeted approach reinforced the notion that FSWs are the carriers of HIV. Furthermore, some participants in this study argued that this approach sidelined other women who may be at risk for HIV but do not identify as sex workers, such as women engaging in transactional sex. Most participants felt strongly about the need for the distribution of PrEP to be available to all people who are sexually active. They felt that this would facilitate more awareness and education around PrEP and, in turn, lessen the stigma. Similarly, there are studies that advocate for the normalisation of PrEP through wider societal distribution (Eakle, Bourne et al., 2018; O'Malley, Barnabee, & Mugwanya, 2019).

For effective PrEP uptake, it is important for FSWs to have an accurate perception of risk. The findings from this study showed that young girls selling sex, as well as new entry FSWs, have difficulty in navigating the high-risk exposure in sex work. The reasons provided were that young girls are unable to negotiate condom use with clients because of the power imbalances

in relationships due to issues associated with hegemonic masculinity where men dictate the terms of engagement in sexual transactions (Connell & Messerschmidt, 2005; Mkhize & Njawala, 2016). Young women were also said to focus more on making money fuelled by their desirability, seen as ‘fresh’ by men, as opposed to older sex workers. Another reason provided for ineffective risk assessment on the part of new entry older FSWs is that some FSWs are oblivious to the risky lifestyles they lead because they enter sex work gradually through transactional relationships that lack the boundaries of sex work, whereby condoms are expected and at times successfully negotiated. Various studies have shown that accurate risk perception plays an important role in effective HIV prevention (Evangeli, Baker, Pady, Jones, & Wroe, 2016; Evangeli, Pady, & Wroe, 2016; Ndugwa Kabwama, & Berg-Beckhoff, 2015). Research published from other PrEP trials such as the Pre-exposure Prophylaxis Trial for HIV Infection among African Women, found that FSWs who did not accurately assess their own exposure to risk, were less likely to prevent HIV (Van Damme et al., 2012).

The majority of FSWs in this study reported that they experienced interpersonal conflict because their HIV-positive friends see them as being in denial of their HIV status. This conflict is fuelled by jealousy due to HIV acquisition being an expected by-product of engaging in sex work. Some participants recounted incidents of conflict which led to the breakdown of relationships with their intimate partners because they did not disclose that they were taking PrEP out of fear that the partner will think that they are HIV positive or sexually promiscuous. Some decided not to disclose because they felt ill-equipped to explain the mechanisms of PrEP being an antiretroviral for HIV prevention. Moreover, the participants felt that the use of PrEP by one partner in the relationship has the potential to raise questions about trust and fidelity which may result in conflict (Golub, 2018). Results from a study by Yi et al. (2017) among MSM showed that the reaction or support from partners, peer educators and family could either be a facilitator or barrier to PrEP use. In a multi-country study by Eisingerich, Wheelock, Gomez, Garnett, and Dybul (2012), 68% of the participants who formed part of a sample of young women and MSM, replied that they would definitely like for their partner to know that they are taking PrEP. In a study among female partners of migrant miners (Falcao et al., 2017), the women felt that the reaction of their husbands towards them taking PrEP could either be a motivating or demotivating factor to uptake. Some women in that study felt that it was important to talk to their partners about PrEP and expressed a moral obligation to inform their partners that they were taking PrEP. Others felt that in some instances it might be necessary to broach the subject with their husbands, and judging by their reaction, they may decide to take

PrEP without their partners' knowledge. Some male partners in the study by Falcao et al. (2017) were adamant that if they found out that their wife was taking PrEP secretly, there would be consequences which could lead to divorce. All these examples demonstrate the impact that male partner influence has on the decision a woman makes regarding PrEP uptake.

According to the participants in this study, the messaging on PrEP is not clear because health care providers at public clinics and hospitals simply dismiss PrEP as antiretrovirals for people living with HIV, without providing a clear differentiation of the two regimens either as a source of prevention or treatment. This miscommunication has contributed to some FSWs either stopping to take PrEP or needing further convincing by peer educators from the research organisations that provide PrEP (Van der Elst et al., 2013). Studies have shown that it is important to have effective follow-up systems to help PrEP users adhere and clarify any misconceptions that may arise. The peer education approach has been proven to be an effective way for disseminating knowledge and encouraging HIV prevention inclusive of PrEP among FSWs (Andrew Scheibe, Richter, & Vearey, 2016; Mack, Odhiambo, Wong, & Agot, 2014). However, there is a need to couple peer education with other community-based structural and behavioural interventions as encouraged by the combination prevention framework (Pettifor, Nguyen, Celum, Cowan, Go, & Hightow-Weidman, 2015).

A study by Eakle, Bourne et al. (2018), which explored the acceptability of oral PrEP prior to implementation, provided insights from FSWs to ensure effective PrEP uptake, and the suggestion was that clear and accurate education and messaging are important. However, the results from this study have shown that this is not yet the case because of the confusion that exists among HIV-negative and HIV-positive FSWs in relation to what PrEP is and how PrEP works. Another issue that casts doubt regarding PrEP efficacy reported in this study, was the fact that it was available through research organisations implying that it is still in the development phase and it was being tested on FSWs. There have been various randomised control trials that have involved FSWs in microbicides PrEP and those products did not become mainstream HIV prevention methods (Klatt et al., 2017; Manssor et al., 2014; Sokal et al., 2012). This was also reported by Eakle et al. (2019) where the participants suggested that PrEP needed to be promoted to the broader community, and be made available to others to reduce the stigma which resulted because of a lack of knowledge about PrEP. Evidence showed that the lack of awareness about PrEP is generally still high. A systematic review of studies from low- and middle-income countries by Yi et al. (2017) found that of the 13 quantitative studies

conducted in various parts of the world that reported on awareness of PrEP among MSM, only a total of 29.7% of MSM were aware of PrEP; however, the awareness did not necessarily translate into an understanding of PrEP and its clinical components. In a study conducted in India, a few of the participants confused PrEP with PEP. Evidently, there is a dearth of studies that reported on the statistical representation of PrEP awareness among FSWs, particularly in sub-Saharan Africa; therefore, more PrEP awareness and education coupled with behavioural interventions are needed to facilitate better uptake and possible retention (Pillay et al., 2020).

## **7.5 Conclusion**

In conclusion, this chapter has established the barriers to effective PrEP uptake and retention among FSWs. The barriers identified, were PrEP stigma which was one of the main hindrances to PrEP uptake. PrEP stigma occurred as a result of PrEP being associated with being HIV positive and thus with antiretroviral treatment which is still highly stigmatised. The concern among PrEP users was that they did not want to be identified as HIV positive because of taking PrEP. The labelling of PrEP users as high risk was a compounding factor to PrEP stigma because it reinforced the notion of FSWs as drivers of HIV. These factors made it difficult for FSWs to open up to their intimate partners and friends about PrEP because of its association with HIV. This also led to conflict among FSWs with their HIV-positive friends who failed to understand that antiretroviral treatment can be used for prevention purposes in the form of PrEP. The root of this conflict was intensified by the prevalent belief among FSWs that all FSWs are HIV positive because they share clients and, therefore, some felt that it was not possible to be on an antiretroviral and be HIV negative. Another barrier to early prevention was inaccurate assessment of risk, particularly among adolescents entering the sex trade, as well as older FSWs who are oblivious to the risks incurred in the trade. These groups were unlikely to take up PrEP for early HIV prevention. The participants felt that it was important for the South African government to avoid the targeted approach and provide PrEP at a larger scale to people of all ages who are sexually active and HIV negative, as this will promote widespread PrEP education to curb the PrEP-related stigma. There was also a call for a synchronised approach to PrEP provision among research organisations and public health facilities who provide PrEP. As a recommendation, public health care providers need to be trained on the uses of antiretrovirals, both as a treatment for HIV as well as a prevention option in the form of PrEP. FSWs need to be assisted on how they can explain their use of PrEP to their intimate partners, and more PrEP education is needed among FSWs to promote risk awareness and early

prevention, as well as to correct the misconceptions about HIV prevalence in this group. Programmes need to encourage both HIV-negative and HIV-positive FSWs to support one another in daily pill intake to avoid conflict and misunderstanding, as well as to create a cohesive HIV prevention environment for both groups.

## **Chapter 8**

# **Personalised Care by Peer Educators to Encourage the Uptake and Retention of Oral Pre-exposure Prophylaxis Among Female Sex Workers in Durban, South Africa**

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### **8.1 Introduction**

Peer education has become a popular strategy for health education and prevention. This strategy has been utilised by health and prevention programmes in various countries among diverse populations and ages such as youth, sex workers and injecting drug users (Agha & Van Rossem, 2004; Basu et al., 2004; Broadhead et al., 2006; He, Wang, Du, Liao, He, & Hao, 2020). Peer education can be defined as the teaching or sharing of health information, values, and behaviours by members of similar age or status (Tolli, 2012). The use of peer educators in health care programmes is common as it is assumed that peers have a powerful influence over one another's perceptions and behaviours. The credibility of peer influence is attributed to factors such as shared background and interests, which renders peer educators relatable and fosters a sense of trust and understanding (Simoni, Nelson, Franks, Yard, & Lehavot, 2011). Peer educators are non-threatening because they do not assume a position of authority in telling others how to behave, but they speak as members of the group (Medley, Kennedy, O'Reilly, & Sweat, 2009). Through educating others, peer educators gain a sense of empowerment and become role models for positive behavioural change (Webel, 2010).

Peer education has been widely used in HIV prevention programmes among sex workers in various contexts (Cornish & Campbell, 2009; Ford, Wirawan, Suastina, Reed, & Muliawan, 2000; Leonard, Ndiaye, Kapadia, & Eisen, 2000; Rekart, 2005; Sarafian, 2012). The underlying assumption in utilising peer educators in programmes targeting sex workers is that the participation of sex workers in project implementation serves to empower sex workers by entrusting them with health-related knowledge and an opportunity for them to educate others. This contributes to an enhanced perceived self-efficacy and a willingness to engage in HIV prevention behaviours. Peer education creates an environment of prevention that goes beyond individual responsibility as it is linked to the norms and characteristics of the social group or collective. Peer educators provide assistance and support to members of their community

which fosters an enabling environment for healthy behaviours (Campbell & Mzaidume, 2001; Webel, Okonsky, Trompeta, & Holzemer, 2010).

There are currently a number of donor-funded health programmes in South Africa that target sex workers. These programmes utilise the peer education approach as their core component of service delivery. Statistically, between 2012 and 2015, there were 2 240 peer educators employed as part of the National Department of Health's high transmission areas programme, 560 sex worker peer educators through the Global Fund-supported Red Umbrella programme, and 122 through PEPFAR-supported programmes (Scheibe, Richter, & Veary, 2016). The purpose of this peer education approach implemented in 14 districts of the eight provinces was to engage peer educators in supporting male and female sex workers with their health care needs and human rights education. Peer educators mobilise, inform, and provide services to sex workers through outreach activities, risk reduction workshops, support groups and condom distribution. They also ensure that sex workers have access to health care services such as HIV testing, sexual and reproductive health services, antiretroviral treatment, PEP and PrEP, as well as screening and referrals. Peer educators are also involved in advocacy of community sensitisation of sex work through dialogues as well as advocating for the decriminalisation of sex work (Rangasami & Konstant, 2019).

The launch of PrEP distribution in South African was through health research organisations targeting sex workers. These organisations are currently utilising the peer education approach to promote PrEP among the sex worker communities. Since the launch of PrEP, a number of studies were conducted in South Africa to ascertain the acceptability of PrEP among FSWs. The results have shown that FSWs are willing to take up PrEP; however, these studies reported various challenges affecting long-term retention by FSWs, such as knowledge and belief in the efficacy of PrEP, forgetting to take PrEP, stigma, side effects, mobility and missing of clinic appointments (Eakle, Bourne, et al., 2018; Eakle et al., 2019). In order to mitigate these challenges, Ortblad and Oldenburg (2018) recommended that a combination of prevention approaches need to factor in the long-term support needed for PrEP users through peer support and community-based empowerment activities to encourage long-term PrEP use. The purpose of this qualitative needs analysis study was to outline the benefits of peer education and support and the description of the personalised care provided to PrEP users by peer educators in this particular context to encourage uptake and retention.

## 8.2 Results

The results for this component of the study were divided into three themes and five subthemes (Figure 8) that have been identified from the data of the peer educators providing personalised care and support to encourage PrEP uptake and retention among FSWs.

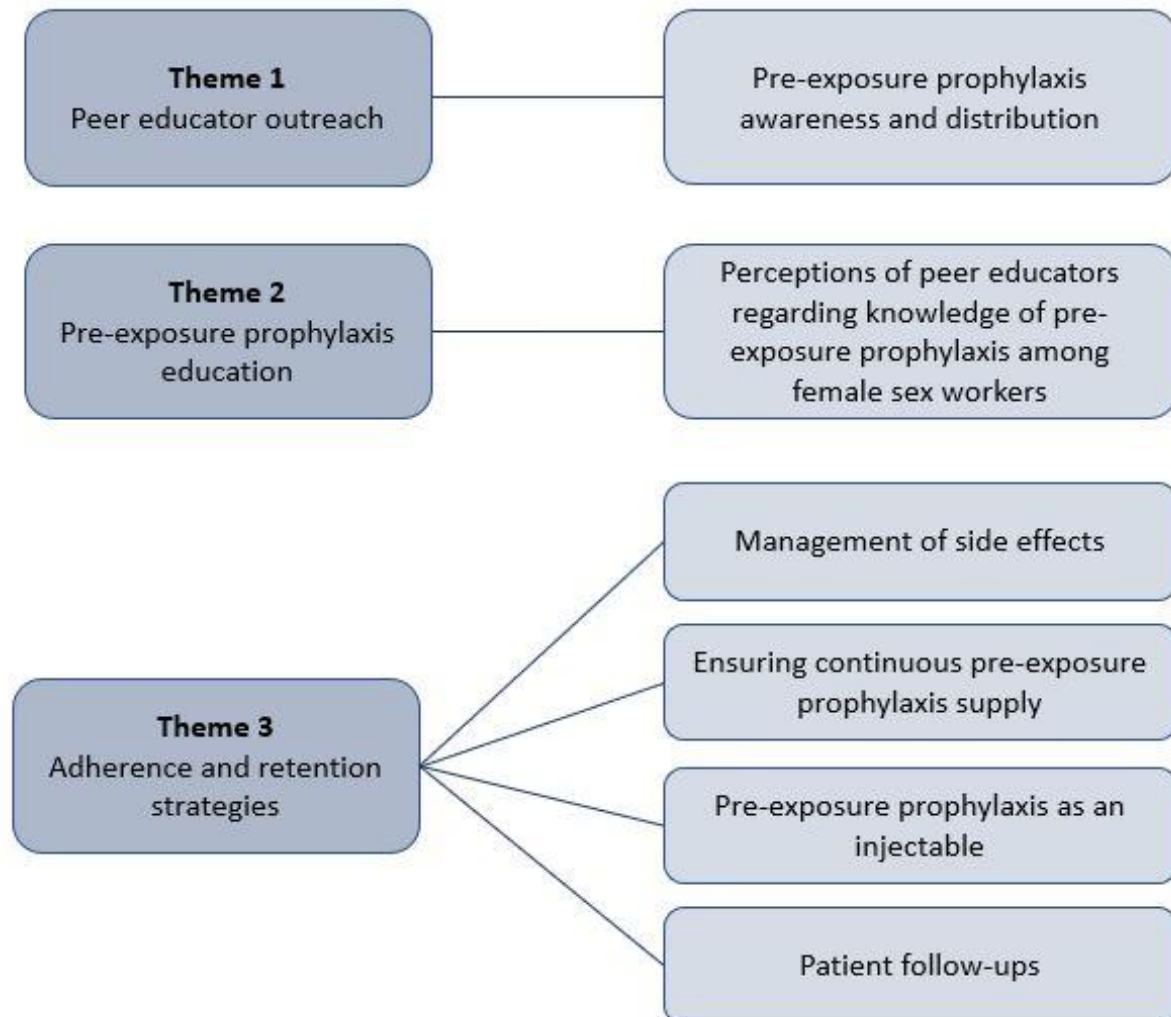


Figure 8. *Themes and subthemes for Chapter 8*

### 8.2.1 Peer outreach

The process of PrEP outreach explored under this theme focuses on PrEP awareness and education as well as areas in which PrEP is distributed among FSWs by peer educators.

### 8.2.1.1 Pre-exposure prophylaxis awareness and distribution

Awareness campaigns regarding PrEP use for FSWs are conducted mainly by the research organisation TB HIV Care, with the assistance of peer educators. Peer educators conduct outreach activities to educate FSWs about PrEP and mobilise FSWs to attend the community advisory board meetings where they are taught about PrEP as an additional HIV prevention strategy. The response to these meetings has somewhat yielded mixed results with some FSWs showing a willingness to attend the meetings and others preferring to approach the mobile facility to learn about PrEP from peer educators during outreach conducted in the streets, as well as at indoor sex work establishments such as brothels, hotels and private houses:

*For TB HIV Care it was so easy, there were no challenges, because that time PrEP was launched, each and every month there was something called community advisory board meeting, where the Durban sex workers were being educated about PrEP (TB HIV Care PrEP counsellor, age 37).*

*We go out for an outreach, and we get to the outreach that is where we tell them about PrEP. Then, we explain to them that here we are testing for HIV, if you have tested positive you can start taking the ARV treatment. However, if you have tested negative, we also explain to them that there is a pill that is called PrEP and we explain how it works, some get excited to take it, some say I am still going to think about it and then we give pamphlets and our contact details to those who have not decided so that when they have decided they can read about it and contact us (TB HIV Care peer educator, age 44).*

In raising awareness regarding PrEP, TB HIV Care covered the whole of eThekweni Municipality and surrounding areas such as Pinetown, Pietermaritzburg, Tongaat and Verulam:

*Interviewer: Which areas do you do outreach in Durban, which places do you go?*

*Interviewee: There are a lot of places, Tongaat, Verulam, Durban, Hilcrest, Pinetown, Clairwood. There are a lot, and the list is endless. There are about 170 and above sites that we visit, both indoors and outdoors in bars, there is no place that we do not get into, we get into ever place (TB HIV Care peer educator, age 47).*

On the contrary, some of the Sisonke peer educators felt that the community advisory board meeting approach used by TB HIV Care was somewhat limited since not all FSWs attended the meetings.

*TB HIV Care used to have community advisory board meetings where sex workers are invited so other people end up not getting the information discussed in those meetings, because they do not attend meetings (Sisonke peer educator, age 25).*

When asked whether they mentioned PrEP as one of the prevention methods during their outreach, the Sisonke peer educators expressed that they still needed a deeper understanding of PrEP and did not have the confidence to spread awareness about it, but instead referred those who enquired about PrEP to TB HIV Care.

*Okay, from my own knowledge PrEP is a ... I do not know whether I can say it is a pill or a drug that is being used by people who are HIV negative to prevent risk, because I cannot say that if you are using PrEP you cannot be infected by HIV, but yes, it is just to prevent risks. I do not have all the information, but rumour has it that it takes 28 days for it to start working in the body, but I don't know what happens thereafter, I still need to acquire more knowledge for me to provide others with adequate information. Therefore we just refer those who ask us about it to TB HIV Care (Sisonke peer educator, age 25).*

The Sisonke peer educators felt that there were conflicting messages about HIV prevention methods which created confusion and a hindrance to using and promoting these methods. Thus, they needed more knowledge and clarification between PrEP and PEP:

*Okay, firstly we are confused about PrEP because we can't differentiate them, it seems like there are two [PrEP and PEP] or many, so maybe we are supposed to be taught about PrEP so that we can know the difference at how does each work because you end up telling yourself that there are two, you end up confused which is which since they both work in different ways. In as much as you are also asking me about PrEP there is nothing much I know about PrEP so I think I need to know what PrEP is really, how does it work (Sisonke peer educator, age 27).*

*Guys because you come with different stories and different studies. I just know that okay fine, what I always hear of which we hear because we never have anybody that comes here and say this is what is happening with PrEP, but we know that this is for prevention for those who are HIV negative to stay negative, that is what I can say about it (Sisonke peer educator, age 40).*

### **8.2.2 Pre-exposure prophylaxis education**

This theme explores the perceptions of peer educators in relation to the levels of PrEP knowledge among FSWs and the implications of this knowledge with regard to the use or non-use of PrEP.

### 8.2.2.1 Perceptions of peer educators with regard to knowledge of pre-exposure prophylaxis among female sex workers

The majority of peer educators expressed that since the launch of PrEP in 2016, there existed a gap in knowledge with regard to the function of PrEP as an additional prevention method. They felt that more awareness about PrEP was needed among FSWs, as well as how it can be used alongside other prevention methods such as condoms:

*Some [sex workers] understand, and some still do not understand, we tell them but still they have not understood it [PrEP] (TB HIV Care peer educator, age 47).*

The FSWs also needed to be made aware of the importance of consistency in taking PrEP. Some questioned the notion of daily pill intake which they associated with being HIV positive and did not understand why PrEP was not taken prior to unprotected intercourse or once a week, which they felt would be easier:

*Some FSWs still do not want to agree to take a pill every day, they ask a lot of questions that they are negative so why they must take a pill every day at the same time, it is like they are positive, or will they test HIV positive one day? ... why is it not a once a week pill or why is it not a pill you take before you practice unsafe sex? (TB HIV Care peer educator, age 40).*

According to what this peer has mentioned above, some FSWs struggled with the idea of taking PrEP daily because of the unpredictability of their lives which involve spending the night with clients and in those instances, may not have the pills with them. Some also felt that the pills were an inconvenience to carry around because the pills may be identified as antiretrovirals, which is stigmatising:

*Some of them like partying, some like going out and they leave their PrEP and tell themselves that they will come back and then you get a client that will book you for the whole day, that is why they do not start taking PrEP. They also say they do not like carrying it when going out because it makes some noise, so it has to be pressed with a tissue or a sponge to avoid making noise because we do not urge them to take pills out of their container or expose them to air, so they say they cannot go and party with this as it will keep on making some noise (TB HIV Care peer educator, age 40).*

Another concern for peer educators was that it was difficult to reach all the sex workers with knowledge about PrEP because there were new sex workers every month; thus, a larger medium was needed to create awareness and educate FSWs regarding PrEP:

*The problem is that each and every year, or I can say each and every month, there is a new sex worker joining all those old sex workers, for sure there is not enough education on PrEP, so that is our challenge (TB HIV Care Peer educator, age 28).*

### **8.2.3 Adherence and retention strategies**

Under this theme various strategies utilised by peer educators to encourage PrEP retention are discussed. These strategies include the management of side effects, ensuring continuous supply of PrEP medication, the preference of PrEP as an injectable as well as patient follow-ups.

#### **8.2.3.1 Management of side effects**

It is expected that when people take oral PrEP as prevention, they will experience side effects. Peer educators take it upon themselves to maintain contact with the PrEP patients beyond the initial consultation period. They take the time to explain the possible side effects that may arise when a person takes PrEP, particularly during the first couple of weeks. They also give advice on how patients can manage those side effects:

*We then explain to her how PrEP works and ask her to give us her contact details so that we will call her and check if she has experienced any side effects. At times we call her aside and explain that people experience different side effects, it does not treat everyone the same, some can take it and experience nothing. Therefore, it is important that she takes it [PrEP] so she will stay negative at all times, so some do not take it because of those challenges (TB HIV Care peer educator, age 40).*

As part of the management of side effects, peer educators also provide advice to every patient based on their individual needs. They explain to the patient that side effects are short-lived; however, there have been instances where some FSWs stopped taking PrEP due to the side effects, and this has created a situation where those FSWs discouraged other FSWs who were willing to start PrEP:

*We usually explain to them as peer educators that if a person comes to tell us that she is vomiting or experiencing a rash, we encourage her to come back to us and the doctor gives them a treatment to apply on their skin, and we explain to her that this is just a phase and she may even come and tell us that it has gone. However, others end up wanting nothing to do with treatment at all, they say they do not want to take it, and end up influencing others not to take it, because of what it has done to them, some even say they experienced some bleeding, some have gained weight, lost appetite, it makes some of them eat a lot, the side effects vary (TB HIV Care peer educator, age 44).*

### **8.2.3.2 Ensuring continuous pre-exposure prophylaxis supply**

In order to encourage adherence and retention of PrEP, PrEP is delivered to FSWs who miss their pick-up appointments. Medication top-ups are most likely to occur towards the end of every month at a time when FSWs have an influx of clients. Thus, some get preoccupied with work and they miss their appointments:

*We try to deliver PrEP to them on sites because if a person misses her appointment, she will tell you that time is money because they become busy at the end of the month, so that is why at times they lack a little bit, but they are willing (TB HIV Care peer educator, age 28)*

### **8.2.4 Preference of pre-exposure prophylaxis as an injectable**

According to the peer educators, some FSWs have suggested for PrEP to be administered as an injection similar to the Depo-Provera contraceptive that is known to last in the body for a period of three months. They felt that injectables would be much easier, because it would relieve the stress of the daily intake of pills:

*They really do not understand, some they come up with ideas/questions asking why it is not an injection (TB HIV Care peer educator, age 40).*

*They say they wish PrEP could be given as an injection or as a contraceptive, maybe an injection of two to three months, then it could be better for them (TB HIV Care peer educator, age 40).*

#### **8.2.4.1 Patient follow-ups**

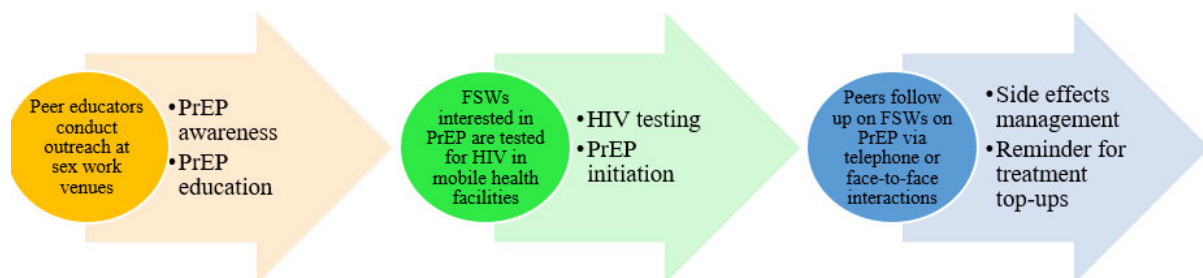
Another technique used to increase the adherence numbers of FSWs on PrEP is through a dedicated team of peer educators who follow up on PrEP users. Initially, TB HIV Care used to create awareness of PrEP, and once an FSW is initiated, they were expected to adhere and pick up treatment. However, this led to a decrease in adherence numbers. The follow-up system is personal. Peer educators call on PrEP users to check on their progress as well as the challenges they may be experiencing. They are also sent text message reminders for treatment top-ups:

*January and February 2018 we started changing the messaging and we saw the numbers going up, but because we did not maintain the same system and if you look at March and April 2018 it ended up giving us very low numbers, we ended up pulling up again in May, June and July which gave us very high numbers. What we did was we created a team on its own that actually follows up on PrEP patients because the thing is you need time, you need to put time to explain to a person about PrEP, 20 minutes or 30 minutes is not enough. You need to be patient, meaning you can talk to a person*

*about PrEP today but still need to really keep on communicating until you win that person. It is not really something where I sit with you for 30 minutes and I am like you can start using it, that is why we ended up with 74% initiation, but 20% retention. So, we did not want to do the same mistake again this year, thus even though we have fluctuating numbers, but at least our retention is remaining high (TB HIV Care health researcher, age 35).*

### 8.3 Discussion

Peer educators in this context are instrumental in providing awareness and PrEP education to FSWs. Peer education requires commitment and persistence. Outreach efforts that start with the process of creating general awareness, coupled with persuasion, has resulted in some FSWs taking up PrEP and accepting to use it as an additional HIV prevention method. It is important that the distribution of PrEP is coupled with clear guidelines on the management of side effects. As seen from the data, convincing a patient to take PrEP and adhere to the regimen takes time, repeated discussions, and persistent follow-ups. FSWs face challenges pertaining to the unpredictable nature of their work, which makes pill adherence difficult. In this study, peer educators initiated face-to-face and telephone follow-ups, as well as individualised advice for the management of side effects. They also sent text message reminders and deliveries for treatment top-ups. This has somewhat improved retention numbers for TB HIV Care as stated by the researcher on site (See Figure 9). There was a suggestion from some users for an injectable form of PrEP so as to curb the challenges that come with taking a pill daily. However, it was also evident from the data that some peer educators from another organisation were confused about PrEP and therefore felt that they could not provide accurate information during outreach. Thus, the synchronisation of peer education and messaging in the different organisations working with sex workers is important.



**Figure 9. Process of pre-exposure prophylaxis awareness and distribution by female sex worker peer educators**

The utilisation of peer-led HIV interventions for FSWs in South Africa was a result of the need to provide friendly, non-stigmatising health care services to FSWs (Stadler & Delany, 2006).

Numerous studies have reported on the human rights violations that FSWs experience at public health care facilities because they open up about being sex workers (Scheibe et al., 2012; Scorgie et al., 2013; Strathdee, Wechsberg, Kerrigan, & Patterson, 2013). As shown in the literature review in Chapter 2, some nurses requested that FSWs should bring their partner to the clinic, particularly when repeatedly presenting with STIs. Because FSWs have multiple partners, some public health care staff pass moral judgements on FSWs, instead of treating them as clients accessing a service (Wanyenze et al., 2017). This has resulted in FSWs facing challenges in accessing sexual reproductive health care. The presence of donor-funded health care services for FSWs became a necessity and their mandate was to fill the health care gap and provide tailored health care services that suite the needs of FSWs (Richter, 2008; Schwartz et al., 2017; Stadler & Delany, 2006).

According to Scheibe, Richter and Veary (2016), it is important to create a health care environment that is safe, effective and non-judgemental for sex workers. Interventions that are peer delivered have been deemed as best practices for sex work programming (He, Wang, Du, Liao, He, & Hao, 2020). As evidence for the effectiveness of peer delivered services, a behavioural and psychosocial survey conducted in Vietnam among 300 male sex workers looking at experiences with HIV prevention and interest in PrEP, found that the participants who had contact with a peer educator indicated an increased willingness to use PrEP, than those who had not. This study concluded that to upscale roll-out of PrEP, peer educators play a significant role in recruiting and educating potential PrEP users as well as assisting them to adhere and manage side effects, which will contribute greatly to the success of PrEP as prevention (Oldenburg et al., 2014).

Marcus et al. (2014) undertook a systematic review of studies that reported on adherence interventions. They found that a significant number of studies that reported on the use of long-term complex multimodal interventions, which included counselling, incentives, peer education, short messaging and telephone-based interventions, were effective. Even though the research reviewed by Pladevall et al. (2010) and Ruppap (2010), reported on studies that tested for adherence in patients with hypertension, the recommendations from these studies were that these interventions can be adapted and translated across other clinical settings and could be adopted for PrEP users. In an attempt to provide recommendations for PrEP-specific interventions, Marcus et al. (2014) asserted that PrEP researchers should consider testing multimodal intervention approaches with a tool to evaluate the effectiveness of each approach.

Components of this multimodal approach to encourage PrEP uptake and adherence could include PrEP education, counselling to improve adherence skills such as suggestions on how patients can incorporate pill taking into their daily routines, as well as having the ability to handle disruptions such as travelling, and still being able to adhere to their daily doses.

The peer educators in this study expressed concerns regarding the low levels of knowledge of PrEP among FSWs. The suggestion from Marcus et al. (2014) could be of value in this case, namely that education-based interventions for PrEP users should focus not only on providing printed materials on PrEP but should aim to improve users' understanding and self-perception of HIV risk infection, as well as to provide information about the actual drug and its components and potential side effects. Furthermore, PrEP demonstration sites require rigorous monitoring and evaluation of their intervention approaches to locate the gaps and engage with the ways in which the interventions can be modified and improved. These suggestions coincide with the results reported in this study, whereby the PrEP TB HIV Care programme has incorporated multiple ways of encouraging PrEP adherence among FSWs.

A study by Amico, Mansoor, Corneli, Torjesen and Van der Straten (2013), which investigated adherence support approaches in biomedical HIV prevention trials, recommended that studies need to shift from a biomedical to a biobehavioural or biopsychosocial framework that will help build the evidence base for effective PrEP adherence interventions. This suggestion is in line with the larger objective of this doctoral thesis which was to design a human-centred behavioural intervention plan that shows how PrEP uptake and retention can be improved among FSWs.

A suggestion from some participants in this study was for PrEP to be an injectable similar to the Depo-Provera contraceptive to limit the frequency of clinic visits. The injectable would also curb the stigma associated with taking an antiretroviral, and the pressure that comes with having to explain the use of PrEP to family members and intimate partners. There are some studies that have reported on the benefits of the injectable form of PrEP that will provide a more adherence friendly schedule (Biello et al., 2018; Landovitz, Kofron, & McCauley, 2016; Meyers et al., 2018; Parsons, Rendina, Whitfield, & Grov, 2016). Efficacy trials of the Cabotegravir were undertaken, which is an HIV transfer inhibitor that is favourable for both treatment and prevention. This transfer inhibitor has the potential to be administered once daily as an oral dose, or monthly to quarterly. The HPTN083 efficacy trials have been ongoing since 2018 through the HIV Prevention Trials Network to compare the safety and efficacy of a

bimonthly injectable Cabotegravir to oral PrEP. The conclusion is that this injectable is far more superior to the oral PrEP because it can persist in the body for up to a year. It was furthermore observed that there were less seroconversions that occurred, as opposed to the daily tenofovir pill (Hosek & Pettifor, 2019; Landovitz et al., 2020).

## **8.4 Conclusion**

This chapter explored the engagement of peer education in PrEP promotion and HIV prevention among FSWs. Various studies showed that the peer education approach has been utilised particularly among high-risk and vulnerable populations. The assumption of many projects is that peer education is effective because peer educators are relatable, and that they are not authoritative in their engagement with one another, and are most likely to be well received when conveying health awareness messages among members of their community. The role of peer educators in this study was further explored in the context of PrEP distribution among FSWs. The peer educators in this study expressed the need for more PrEP education among FSWs. Furthermore, peer educators explained the various ways in which they engage in PrEP awareness through outreach and health talks, as well as connecting with FSWs through telephone, by providing individually tailored advice for management of side effects, sending reminders for treatment top-ups, as well as delivering PrEP to FSWs. This study also found that there are various organisations providing health care through peer education among FSWs; however, some peer educators from these organisations did not feel equipped to speak about PrEP due to limited knowledge. As a recommendation, there is a need for a more synergised approach to PrEP messaging among peer educators from various organisations. This will ensure that there is less confusion regarding PrEP, and this may increase the chance of uptake and retention.

## Chapter 9

### Motivating Factors Associated with Oral Pre-exposure Prophylaxis Use Among Female Sex Workers in Durban, South Africa

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#### 9.1 Introduction

HIV risk reduction programmes have evolved over the years from simply being educational, to include psychological components focused on behavioural skills training. Numerous studies have reported on the effectiveness of this approach to HIV prevention among various population groups (Anderson et al., 2006; Kalichman, Sikkema, Kelly, & Bulto, 1995; Mongkuo, Lucas, & Taylor, 2012). These interventions recognised that behaviour is linked to one's environment, which Bandura (1994) referred to as reciprocal determinism. Thus, both factors need to be considered when facilitating behavioural change. The factoring in of psychological components in health interventions includes the concept of self-determination theory and motivation.

The self-determination theory states that all humans have an innate ability to develop a unified sense of self, that is, harmony with self and others (Deci & Ryan, 2002). The hallmark of this is autonomy, which is inner organisation and holistic self-regulation, as well as homonomy, which is an integration of self with others. Healthy development is evident by the complementarity and interplay between the two, which means that it is important not to assume that self-determination is always present or successful; there is a need for an enabling environment for it to thrive. Some environments are hostile, rather than a regulated balanced self, bringing forth a passive, reactive or alienated self. The environment can bring out the best in people or it can bring out the worst side of human nature (Deci & Ryan, 2002). This is evident in the lives of FSWs where the majority of FSWs have to be contend with an environment of violence, stigma and discrimination that emerges as feelings of apathy and hopelessness. Only a few FSWs are able to utilise their sense of autonomy and self-regulate so as to make choices that have a positive impact on their lives and the lives of others in the social environment.

Self-determination is achieved when the following factors are at play: competence, relatedness and autonomy. Competence is the feeling of being capable, humans seek for and are faced with challenges and competence is the belief that one has the skills to face those challenges and

engage in the necessary activities. Competence is less about attaining skills and has more to do with feeling confident in one's ability to make use of those skills and take appropriate action when the need arises. Relatedness refers to the feeling of intense connectedness and belonging with others, caring and being cared for, being part of a community and having a deep sense of belonging. Autonomy is when one operates from interest and integrated values. Autonomy means that people engage in behaviours that they feel strongly about, irrespective of whether these behaviours are endorsed by others or not (Deci & Ryan, 2002).

The self-determination theory comprises of sub-theories such as the cognitive evaluation theory, which looks at the effects of social contexts in relation to intrinsic motivation. The organismic integration theory is concerned with extrinsic motivation. According to Carey and Lewis (1999), the inclusion of motivational factors in risk reduction strategies has both an empirical and theoretical basis. Motivation according to psychology is defined as the forces that determine the direction and intensity of the behavioural change effort (Carey & Lewis, 1999). Motivation can be broken down into categories, such as intrinsic motivation, which is concerned with personal disposition and autonomy such as one's perspective and optimism; extrinsic motivation stems from social factors such as support; and the interaction between personality characteristics and situational influences. Personality characteristics include self-efficacy, the belief in one's ability to perform a certain task, as well as the optimism to engage in that protective behaviour (Carey & Lewis, 1999; Mongkuo et al., 2012).

PrEP as a prevention strategy among FSWs in South Africa has just gained traction through PrEP distribution programmes; however, studies have shown that the response to PrEP was not as overwhelming as had been initially anticipated by biomedical interventions (Mudzviti et al., 2020; Pillay et al., 2020; Spinelli et al., 2018). In the preceding chapters of this doctoral thesis, various factors were outlined as barriers to PrEP uptake. Like any new HIV prevention technology, it is realistic to expect that there are early and late adopters; likewise, with PrEP, this study found a group of FSWs who were taking PrEP consistently. As part of the needs analysis phase of this study, it was imperative to understand what the motivation for taking PrEP was among this group of FSWs, with the hope of incorporating some of these insights into the intervention plan presented in Chapter 10 of this thesis.

## 9.2 Results

In this study the participants taking PrEP were asked to express their deepest personal motivations for taking PrEP daily. The results for this component of the study are presented under the following main themes and subthemes as presented in Figure 10.

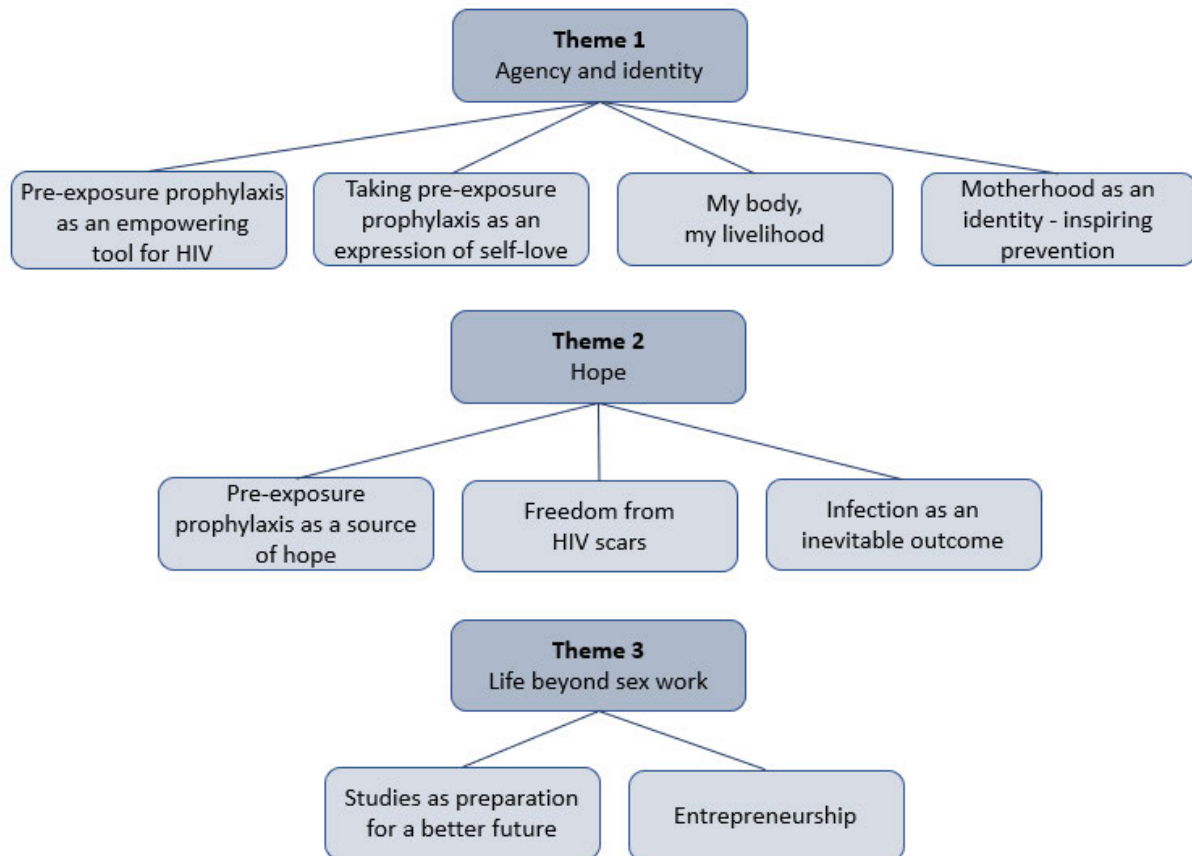


Figure 10. *Themes and subthemes for Chapter 9*

### 9.2.1 Agency and identity

The major theme of agency and identity encompasses the following subthemes: PrEP as an empowering tool for HIV prevention, the taking of PrEP as an expression of self-love; the body as a source of one's livelihood, and motherhood as an identity that inspires PrEP use.

#### 9.2.1.1 Pre-exposure prophylaxis as an empowering tool for HIV prevention

Some participants felt that the motivation to take PrEP came from having a sense of agency and the power to make decisions that are beneficial for themselves. They felt that the decision to take PrEP is personal and no one should interfere with that choice, including their intimate partners, and for as long as they are in sex work it was imperative to continue with PrEP:

*When I choose to take that thing, that tablet [PrEP]. That is my own decision. If I don't want, I don't want. No one can force me. But I couldn't do the job I am doing. It's a must. I think it's a good idea to take it. Unless if I stop working in this business, yes, I can say I can't carry on with this tablet. I must stop it because I would no longer be a sex worker. But if I am still doing this job, I must still take it (FSW, age 33).*

Some participants felt a sense of pride and reclaiming of power because PrEP offered them an opportunity to prevent HIV. They no longer felt dependent on their partners to be faithful or make responsible sexual choices such as practicing safe sex when engaging with other sexual partners. HIV prevention was something that they themselves could be proactive about; even if they struggled to negotiate condom use in their relationships, they still felt a sense of control and protection.

*Yes, it gives me that confidence that even if he is cheating wherever he is, I am safe. I have told myself and decided and I do not need someone to remind me, it is within me now. I just take PrEP without any problem. You cannot know where a person goes and you can't tell your partner that you have spent your whole life with to start using a condom now, he will ask you why. Therefore, it is better to protect myself with these pills, that is why I do not need anyone to remind me to take it, I just take them voluntarily, and also the nurses have told me that it is too risky if I stop taking them. You have to make sure that you never stop taking them once you have started, because if you stop them it is too risky, and you can easily be infected with HIV (FSW, age 35).*

It was also evident from these participants that they were willing to use PrEP regardless of how their partners felt about it. They strongly believed that the use of PrEP was a personal decision, and it was an important step in gaining control of their sexual safety, especially since most partners did not want to use condoms.

### **9.2.1.2 Taking pre-exposure prophylaxis as an expression of self-love**

Some participants equated taking PrEP to self-love. They felt that PrEP gave them added protection from HIV and self-love inspires them to have a strong conviction to protect themselves and refuse unprotected sex even at the insistence of their partners:

*Self-love plays a significant role in human beings because anything comes from loving yourself, starting PrEP too is also part of loving yourself. However, taking PrEP, especially if you have a partner, your partner might say now that you are on PrEP, we must not use a condom. If you are a person you must have self-love, have a goal and values. If you are a woman, tell your partner that I am on PrEP, but we still use a condom, because I am not feeling okay to practice unsafe sex. It is not about praising someone, do not beg a relationship when you are a woman, be true to yourself and if*

*that person is not willing to sacrifice it means you are not in a relationship, you are worshipping someone which is something that must not happen in a relationship (FSW peer educator, age 27).*

Furthermore, the participants felt that taking PrEP encouraged a strong sense of independence and a responsibility towards oneself, as opposed to relying on external love and protection from male partners who were deemed untrustworthy:

*I think that person loves herself because there are those boyfriends who would lie and tell us they love us, and of which these days ... In our line of work, we are encouraged to test together with our boyfriends, and the men around don't want to hear anything about testing they also don't want to use condoms. So, I think it is safe for me to continue loving myself other than listening to the men busy lying to us since even when you ask them to come with to the clinic they refuse. So, I feel like those sex workers who think we are all sick, they don't love themselves, that is why they are doing whatever and have the belief that everyone is sick because they are not taking care of themselves. My self-love comes from being able to take care of myself and my children through this job, so I am doing some things to help myself, so I feel like I can take pride in myself because I can afford doing things by myself (FSW, age 27).*

Participants under this theme echoed similar sentiments about no longer seeking to please their intimate partners at their own expense. Thus, self-preservation became central in how they engaged with intimate partners, and PrEP was a great resource which aligned with the need to gain sexual agency.

### **9.2.1.3 My body, my livelihood**

One FSW identified her body as her source of livelihood and felt strongly about loving and taking care of it because she viewed it as her source of income. Viewing her body in this way translated into her being intentional about engaging in healthy behaviours, preventing HIV and warding off internalised stigma and negative self-perception that comes with engaging in sex work:

*I am also a sex worker my love, so we do not undermine ourselves. We should take care of ourselves and also teach each other some things that it is a good thing to use a condom, to never undermine yourself and do not blame yourself of being a sex worker. Because at the end of the day, you must focus on what you are benefiting since you are making money from sex work, you are nursing your family's needs, there is nothing that you are in need of and you do not beg from others. So stop undermining yourself. What you must do is to take care of yourself and use a condom when you are meeting a person for the first time and exchange the benefits in a good manner. You give him your body while protecting yourself too, because it is your responsibility to protect your*

*body that makes you get money. If you do not take care of your business it will fall apart, because if you have unprotected sex with people you will get infected by diseases and besides HIV, there is Ebola and others. There are people who have diseases such as Amalumbe [genital worms]. You will be infected by these diseases because you do not take care of your business. You must take care of your business in a way that you must always look beautiful to attract clients and in that way, you will make money out of your body (FSW peer educator, age 35).*

Viewing the body as a business that needs love and care is a way of gaining control from the narratives pertaining to sex workers as being carriers of disease. It is a process towards personal restoration as well as realising inherent worth and repairing the damage caused by stigma.

#### **9.2.1.4 Motherhood as an identity that inspires prevention**

Another compelling personal reason given by some FSWs for taking PrEP was the motivation to live longer for themselves as well as for their dependents. The desire for a long life is so that they can raise their children and see their children gain access to opportunities that they themselves did not have:

*The reason that motivates me to take PrEP is the job that I do and my kids since they are my priority. I need to live longer but taking PrEP doesn't mean that I have to be irresponsible, I am cautious, and I want to die from something else not HIV. So, I just want to live longer and have a healthy life. At the moment PrEP is available but not everyone is taking it, not every sex worker is taking PrEP, PrEP is all about yourself, you have to protect yourself. You must think about your kids, especially if you are a mother, a single mother, because you have to protect your kids too, because if anything goes wrong the kids will suffer too. I do not want my daughter to do this job [sex work], it has to end with me. I will have to make sure that she studies from a good school where she will get good grades and study great courses, and it is better to say she is just a nurse or a teacher because she is getting something out of it (FSW, age 38)*

*Ok it's because I have kid in Zimbabwe. I have to look after my son, my mother, my family. That's why I care about myself. That's why I care about my health. And I love myself. And I am still young and I am still fresh so I must care about what I am doing because I have a family to look after. So, if I don't care about my life anytime I would die. So, I must care each and every time. That's why I must care (FSW, age 33).*

The need to stay alive came from the desire to protect and provide for one's children so that they are not caught in a life cycle of poverty and desperation and end up engaging in sex work to survive. Most participants in this study referred to poverty as a push factor into sex work. Thus, these FSWs felt that they needed to sell sex to provide a future for their children so that sex work stops with them and does not become generational:

*Most sex workers are young poor girls who are ranging from 17 to 23 years old, they need to be taught because they are getting money right now but are not educating themselves (FSW, age 38).*

*In my family I am the first born and our parents died long time ago and left us when we were young, so there are lot of kids at home and I also have children, so I am taking care of the whole big family. So, I decided to take PrEP so that I will always be protected, even if a condom burst, I will always be safe (FSW, age 39).*

What is evident from some participants is that being a sex worker was the means in which they used to take care of their families and they felt that being in sex work was a sacrifice that they made to ensure that the next generation has better prospects through education to make different choices.

## **9.2.2 Hope**

The discussion under this theme focuses on three subthemes, which are PrEP as a source of hope, PrEP as a source of freedom from HIV scars, as well as a contrasting theme of which some FSWs believe that HIV infection is an inevitable consequence of sex work which leaves these participants hopeless.

### **9.2.2.1 Pre-exposure prophylaxis as a source of hope**

Other participants took PrEP because it gave them a sense of hope for the future, and even though they engaged in risky work, PrEP provided them with a chance to remain HIV negative. Initially, the feeling among the majority of sex workers was that every sex worker who enters this business will eventually contract HIV due to exposure and vulnerability to HIV infection. With the onset of PrEP, some FSWs have come to the understanding that HIV infection does not have to be their fate and that they can make a choice to manage HIV risk:

*Sometimes it did happen before, whereby I lose hope and everything and that is where I thought this is the life I was meant to live, then I pick up myself again and I realised that I am still too young, I am 27 years, I can still move on and I can live a good life, and then I decided to change from there and there. There are some people who have given up on themselves, who don't have a dream that they could change life, who never dream of working and doing a decent job one day. When we are chilling as girls, we talk a lot and there are some that you never hear them mentioning about getting a decent job, they have told themselves that their lives end here in this job [sex work]. Some of them know their HIV status but they are not even serious about taking medication. So, I think it depends on what the person thinks and dreams about her life (FSW, age 27).*

### 9.2.2.2 Freedom from HIV scars

Two participants viewed PrEP as providing them an opportunity to engage in sex work without being infected or ‘scared’ by HIV. PrEP ensures that they can one day walk away from sex work without acquiring HIV, which will serve as a constant reminder of their engagement in sex work:

*Once I decide to stop doing sex work, I don't want to look back at my past and see scars that I was once a sex worker in life, but I want to know that I have been through this and that but I left everything there (FSW, age 27).*

*So, you will not be infected and there will be no scars to remind you that you were once a sex worker, you will be left with no scars, hence it is easy to move on with your life when you did something and left with no scars. Can you imagine you have just started practicing sex work, you are a student and HIV negative, coming from the village and you are new in the city then you get infected by HIV from someone you do not know, and you will have to deal with your new status to disclose (FSW, age 28).*

### 9.2.2.3 Infection is an inevitable outcome

There were, however, some participants who felt a sense of hopelessness. This sense of despondency that they experienced was as a result of the risks and the unpredictability that comes with living life as a sex worker. They mentioned the uncertainty they have about making it back home safely because of having to meet different clients, and not knowing whether after a sexual encounter, they will make it out alive. Others even went as far as referring to themselves as walking graves. The emotional numbing and the physical and sexual violations they experienced made them feel like they were no longer living but merely waiting to die. It is worth mentioning that the participants who felt this way were not on PrEP:

*It's all about losing hope, you lose hope when you are doing sex work. You just realise that it is the last option in life, after that you are dead. There is no marriage, there is no career, there is nothing, and there is no serious boyfriend. Yes, that too can be a problem, Nosipho, because if you can think that I have been in this industry for 20 years, so if I can tell another person that there is hope, she can just laugh at me (FSW, age 38).*

*All you are waiting for is RIP [Rest in Peace] death (FSW, age 35).*

*And you expect RIP every single day. As soon as you leave your house, you will just pray and ask the Lord to be with you wherever you are going (FSW, age 26).*

Under this theme there were mixed emotions towards PrEP. The majority of the participants on PrEP felt that PrEP was a source of hope because it provided them with the freedom to protect themselves from HIV. It also gave them the confidence to engage in sex work without fear that they will contract HIV; however, others felt as though the fear of contracting HIV was minor, compared to some of the dangers that they experienced in sex work which could render them dead at any point in time.

### **9.2.3 Life beyond sex work**

The two themes discussed under this main theme are studies as preparation for a better life, and prospects of entrepreneurship.

#### **9.2.3.1 Studies as preparation for a better life**

There were two participants who were involved in sex work while studying further for their college diplomas and another participant who had aspirations to become a caregiver and eventually get a driving license. These participants were very enthusiastic about the future, and taking PrEP was another way in which they felt they could eventually walk away from sex work, physically unscathed. They used sex work as a means to get money to pay for their studies and livelihood:

*I am doing my final year at university and I have a child. The fact that I am doing sex work, I might be infected by HIV which can be something I have to live with for the rest of my life, unless there would be a way of curing HIV in future (FSW, age, 27).*

*I am negative and I am a student, therefore I have a future to take care of. Whatever I do now I take PrEP so that I will not be HIV infected and whenever I decide to stop, my status will be HIV negative (FSW, age, 28).*

*So, right now as I am here, I am trying to save money. I didn't go to school, I am not that much educated, so when I just came here, I saved money and did my driver's license, and now I am doing a course that is for the old age people, whereby you will be looking after old people at homes, where you will have to take them to hospitals. So, when I started, they said I must have a driver's license, that is why I did it, and now I am saving money so that I will do that course and it cost R8 000. My sister has finished doing it and she is working right now, so that is the thing I want, and I feel it will be easier for me to do it (FSW, age 32).*

### 9.2.3.2 Entrepreneurship

Some participants on PrEP expressed that they had entrepreneurial goals, these dreams were as a result of knowing that through PrEP they were guaranteed a longer life free from HIV. PrEP gave them the courage to see beyond their immediate reality:

*I see myself going back home to Zimbabwe after sex work to go open a business for myself and my children (FSW age 38).*

*I see myself owning a mobile kitchen and selling food to people, making money in a different way (FSW age 32).*

The effects of PrEP among some FSWs were that it gave them the confidence to plan for the future and to envision a life beyond sex work. The prospects of remaining HIV-free ignited in some participants excitement for life and an ability to plan ahead and beyond their current circumstances.

## 9.3 Discussion

The FSWs in this study who were consistently taking PrEP, mentioned the personal motivations that inspire them to engage in HIV prevention. They were not solely focused on taking PrEP to prevent risk out of fear of HIV infection, but had found an added benefit to taking PrEP that changed their outlook on life. PrEP gave them the autonomy and self-determination to take control of their sexual health. Remaining HIV negative was more important than pleasing a sexual partner or client by engaging in risky sex. PrEP also afforded the FSWs in this study the ability to privately take HIV prevention measures without having to request permission from their partners and they no longer needed to rely on the fidelity of their partners to remain HIV negative. These findings coincide with results from Grant and Koester's (2016) study among MSM in the USA who expressed that PrEP gave them a feeling of empowerment which emanated from the sense of control they felt when on PrEP because of not having to solely rely on their sexual partners to use condoms; thus, they can be proactive in preventing HIV.

For the FSWs in this study, taking PrEP was also an expression of self-love. The participants were adamant that they no longer relegated the responsibility of loving oneself to intimate partners, but had taken ownership of themselves and PrEP aligned with this purpose. This finding is similar to a finding from a study on the use of PrEP among gay men. Some participants equated the use of PrEP with the love for self and the love for the partner, while

some in the same study viewed the use of PrEP as a sign of mistrust between partners (Quinn, Zarwell, John, Christenson, & Walsh, 2020).

The concept of self-love in this study is related to another finding that is unique to this study, which was the body being seen as a source of livelihood. Some participants felt that the body of a sex worker is like a business that should be taken care of and, therefore, taking PrEP and preventing HIV, was one way of taking care of the body and maintaining the business. Viewing the body in this way helped some FSWs to face up to internalised stigma and push against notions that associate sex workers with diseased bodies and HIV.

Some participants were motivated to take PrEP because of the important role they play in providing for their dependents. The identity of motherhood was cited by some participants as inspiring them to take PrEP so that they can live longer to take care of their children. The fear was that they did not want to leave their children in an impoverished state that would also lead them into sex work, which was what most of them had experienced. This finding pertaining to PrEP use and the specific identity of motherhood is unique to this study. Other studies simply highlight women's entry into sex work as a means to care for their dependents and not because they ascribe value to a specific identity such as motherhood (Oliveira, 2017; Sinha, 2015).

A vision of a life beyond sex work played an important role in motivating some participants to maintain their PrEP use. The prospects of not acquiring HIV, ignited the ability to dream further and work towards a better life. Some participants were students and were using sex work as a means to pay towards their studies and, as a result, they were adamant that PrEP would assist them to one day walk away from sex work without HIV scars. Other participants envisioned themselves running their own businesses. PrEP represented a possibility of being able to start over without HIV as a reminder of former years in sex work. A multinational study was conducted among 1 790 potential PrEP user groups in seven countries, including South Africa. This study looked at attitudes and acceptance of oral PrEP and found that 54% of the participants expressed that PrEP gave them hope of new possibilities in their lives (Eisingerich et al., 2012).

In essence, it is important to note that even though the participants were cognisant of their risk to HIV acquisition, their reasons for taking PrEP went beyond risk reduction, to a need for a holistic lifestyle change fuelled by goals and aspirations that included longevity, self-control, wellness, and self-love. In their commentary, Haberer et al. (2019) suggested ways for effective

PrEP delivery among adolescent girls and young women and emphasised that PrEP should be presented as a lifestyle choice as opposed to a biomedical HIV prevention tool. This means that instead of focusing on PrEP mainly as a risk reduction tool, the focus needs to be on the benefits of PrEP for those who take it. PrEP should be messaged in a way that appeals to young people's aspirations. The focus should be on young women's need to stay healthy so that they can lead productive lives. Likewise, the same can be said for FSWs, who need to view PrEP from a gain-framed perspective. According to Amico and Bekker (2019), the majority of PrEP interventions have adopted the loss-framed perspective which emphasises risk, whereas a gain-framed approach focuses on health and its benefits. Furthermore, Amico and Bekker (2019) believed that messages emphasising risk reduction could potentially alienate the majority of people who could benefit from PrEP because they may not perceive themselves to be at risk. Inversely, this risk-focused approach can stigmatise those who are willing to take PrEP as belonging to a high risk infection group, thus likely to be misconstrued as promiscuous or hypersexual. The positive framing of PrEP as offering additional safety and sexual health through overall wellness is therefore a compelling and empowering approach to prevention (O'Malley et al., 2019).

As a recommendation to encourage long-term retention on PrEP, it will be beneficial to utilise methods or awareness messages that focus on PrEP and the promotion of sexual wellness, as well as engaging with client motivations to encourage retention which can be explored with psycho-behavioural approaches. Cowan et al. (2016) highlighted the importance of combining the biomedical prevention approach with behavioural interventions that build self-efficacy, empowerment, and social cohesion.

#### **9.4 Conclusion**

This chapter has considered the personal motivations of FSWs who were consistently taking PrEP. Even though HIV prevention was a strong underlying motivation for PrEP use, the participants in this study mentioned other compelling reasons for prolonged engagement with PrEP, such as PrEP being a mechanism to gain control over one's body through engaging in prevention without the pressure of involving male partners in the decision. Taking PrEP was seen as an expression of self-love and prioritising wellness of the body that was viewed as a source of livelihood that needs to be cared for and protected. FSWs expressed feeling a sense of power and agency in being able to decide and take matters of prevention into their own hands, and with PrEP they felt less vulnerable to infection. HIV was no longer viewed as an

occupational hazard, which gave some FSWs hope for a HIV-free future where they can aspire to envision a life beyond sex work and working towards future goals. FSWs were motivated to take PrEP to live longer for their children's sake and provide them with better opportunities to break the cycle of poverty and sex work. Evidence has shown that prevention interventions are most likely to be effective when coupled with psychosocial elements. Thus, messages encouraging PrEP uptake aimed at FSWs, should not be premised on a negative risk reduction framework, but to rather promote positive sexual health and personal well-being. Understanding the personal motivating factors to uptake and retention could inform PrEP behavioural intervention approaches to focus on PrEP for longevity and lessen PrEP stigma associated with high risk and promiscuity.

## Chapter 10

# Developing a Sex Worker-led Community Intervention Plan to Improve Pre-exposure Prophylaxis Uptake and Retention in South Africa: An Intervention Mapping Approach

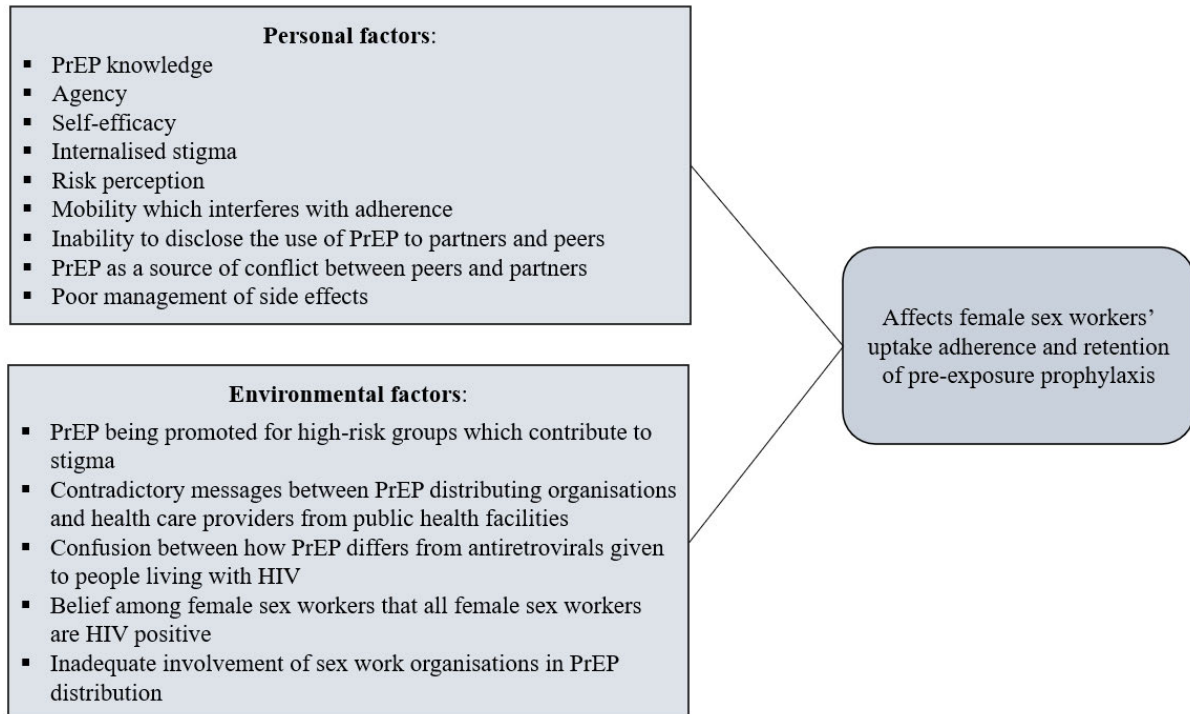
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The purpose of intervention design in health promotion is to design programmes aimed at bringing about change to the environmental and behavioural factors related to health. Intervention mapping is based on planning a programme informed by theory and evidence, taking into account the social, physical, and environmental factors contributing to health problems and risk behaviour. Intervention mapping in health promotion provides health promoters, programme managers and policymakers with a blueprint or framework for effective decision-making with regard to each step of the intervention – from planning, implementation to evaluation (Bartholomew et al., 2006; Durks et al., 2017). As discussed in Chapter 5, intervention mapping consists of six steps. For the purpose of this thesis, the intervention working group mapped out Steps 1 to 4. Steps 5 and 6 have been drafted and are attached as appendices to be further developed at a later stage.

### 10.1 Intervention mapping – Step 1: Summary of the needs analysis conducted in Phase 1

The needs analysis conducted in Phase 1 was a systematic investigation of the differences between the existing circumstances that prevail versus the ideal circumstances. True to the views of Eldredge et al. (2016), this phase presented the views and opinions of stakeholders who have a vested interest in the problem, and possess insider information to provide a factual description of the problem and its causes as well as being interested in finding relevant solutions to challenges. Chapters 7 to 9 of this thesis reports the findings from the needs analysis, and Figure 11 provides a synopsis of the individual and environmental factors impacting on PrEP uptake among FSWs. As mentioned in the methodology section (Chapter 5), this phase of the study included 39 participants of which 11 were FSW peer educators, one health care provider and one researcher, and 26 FSWs of which 20 were PrEP users and six were non-PrEP users (see Table 2, Chapter 7). All participants were best equipped to inform the needs analysis because they worked with and were part of the target population and they understood the challenges of uptake and retention of FSWs on PrEP. Intervention mapping

guidelines stipulate that the needs analysis is a problem identification phase which should be based on the following principles: avoid blaming the victim, involve community participants, and examine the environmental causes of problems (Bartholomew et al., 2006).



**Figure 11. Synopsis of personal and environmental factors affecting pre-exposure prophylaxis uptake, adherence and retention among female sex workers (Chapters 7 and 8)**

## 10.2 Intervention mapping – Step 2: Matrices of change objectives

In light of the participatory paradigm and the participatory action research approach in developing the intervention programme, a working group was established, comprising FSWs for whom the programme was intended. (See Chapter 5, research methodology on the detailed account of the working group formation.) The demographic information of the intervention working group is provided in Table 3. The peer educators (FSWs) from Sisonke and TB HIV Care formed part of the working group. It is important to note that these peer educators also participated in the needs analysis phase of the intervention. Steps 2 to 4 of the intervention mapping process were conducted in collaboration with the working group. The working group was involved in formulating the performance and change objectives of the intervention as captured in the matrices (Step 2) and intervention activities (Step 3), as well as to assist in the designing of the intervention programme (Step 4). The intention was that they would also be

the main intervention implementers at the initial stages of the programme with a view to train other facilitators from the FSW community at a later stage as a way to encourage sustainability.

**Table 3**

*Demographic information of intervention working group*

<b>Participant</b>	<b>Age</b>	<b>Marital status</b>	<b>Language(s)</b>	<b>Educational level</b>	<b>Place of origin</b>
1. C M	28	Single	isiZulu	Matric	Ndwedwe (KZN)
2. N H	40	Married	isiZulu	Matric	South Coast
3. T M	47	Single	isiZulu	Grade 7	Ndwedwe (KZN)
4. N J	51	Single	isiZulu /Xhosa	Grade 7	Bizana (Eastern Cape)
5. L K	32	Single	isiZulu	Matric	South Coast (KZN)
6. S N	47	Married	Xhosa	Grade 11	East London (Eastern Cape)
7. N G	25	Single	isiZulu	Tertiary	South Coast (KZN)
8. S Z	44	Single	isiZulu	Grade 12	KZN

The matrices of change are key tools to intervention mapping because they provide the implementers with intervention deliverables or performance objectives, which will enable changes in behaviour and the environment that in turn will improve the health and quality of life of those targeted by the intervention. As mentioned earlier, change objectives are derived from the **needs analysis** that provided evidence of the behavioural and environmental factors that need to be changed in order for the intervention to have any real impact. To ensure impact, the change needs to occur at multiple ecological levels, namely the individual characteristics that influence behaviour such as knowledge, attitudes, and beliefs. The interpersonal levels refer to family, friends, and partners, as all of these are the social networks that the FSWs are a part of. The organisational level includes rules and regulations, formal and informal structures that may constrain or support the recommended behaviours. Community level influences encompass social norms and practices of the particular community that promote or constrain the desired healthy behaviours (Fernandez et al., 2019; Kok, Gottlieb, Commers, & Smerecnik, 2008). The public policy level influences refer to the state and its laws that regulate or support healthy actions, providing resources for early detection, control and management of diseases (Carl et al., 2010). However, the priority for this intervention was to focus on change at the individual and interpersonal level and not the policy and state laws. However, recommendations were made to government on what needs to change at policy level to improve PrEP uptake among FSWs.

Each performance objective provides a detailed description of what needs to be done at each level to improve health outcomes. The matrices of change are created by an intersection of performance objectives with behavioural and environmental determinants. These matrices form the basis of health promotion intervention design and provide immediate objectives to be accomplished through health education and promotion (Bartholomew et al., 2006).

### **10.2.1 Behavioural outcomes**

Behavioural outcomes should be stated in terms of the behaviours to be accomplished as a result of the health education or promotion programme. In this programme, the broad behavioural outcomes are the following:

- To assist FSWs to identify ways that will enable them to take PrEP consistently to improve adherence and retention of FSWs on PrEP.
- To assist FSWs to develop agency and self-efficacy regarding the use of PrEP.
- To assist them in being able to disclose their use of PrEP as an antiretroviral to prevent HIV both to their partners and friends to avoid conflict and misunderstanding.
- To assist FSWs to address internalised stigma as a result of engaging in sex work as well as the stigma that comes with PrEP use.
- To effectively manage side effects.

### **10.2.2 The broad social and environmental outcomes**

- To challenge the misconception that all FSWs are HIV positive, which leads to a fatalistic attitude of despondency, as well as assisting them to understand that being HIV positive is not a death sentence.
- To tackle the stigmatising messages around PrEP, for instance PrEP being for high-risk groups; thus, engaging FSWs in the design of positive awareness messages about PrEP that resonate with them.
- To make recommendations to government to provide PrEP education to public health services providers to empower them in offering quality service and avoiding mixed messages.

- To assist FSWs to understand why PrEP is not being widely distributed to curb suspicion with regard to its credibility.

### 10.2.3 Performance objectives

Once the behavioural and environmental outcomes have been outlined, it is important to formulate performance objectives for each desired outcome. The purpose of performance objectives is to clarify the actions or performances expected from intervention recipients. Performance objectives enable planners to transition from broad behavioural and environmental conditions into producing detailed descriptions of sub-behaviours that make up the broader desired healthy behaviours. These sub-behaviours, expressed in the form of action words, become the performance objectives (Eldredge et al., 2016). Tables 4 to 6 consist of both performance and change objectives.

**Table 4**

#### *Matrices of individual change objectives*

Determinants	Self-efficacy	Agency	Hope	Future aspirations	Side effects management
Performance objectives	Assist FSWs to acquire the confidence to be able to use PrEP.	Encourage FSWs to make an independent decision to take PrEP.	Develop hope through focusing on positive aspects of the FSWs' lives.	Encourage FSWs to articulate their future aspirations.	Provide PrEP users with practical suggestions on how to manage side effects.
Change objectives	Encourage FSWs to engage with other FSWs who are taking PrEP when they need motivation. Ask FSWs to imagine how PrEP can change their lives and how life will change should they be diagnosed with HIV. Have FSWs monitor their progress in terms of PrEP adherence to build self-belief. Develop persuasive awareness messages about PrEP that encourage hope, pride and confidence in PrEP.	Assist FSWs to have an intention as to why they choose PrEP. Assist them to articulate their goals and the action plans needed for them to realise their goals. They need to have forethought about their future and be reflective about their lives, and to examine whether they are living a life contrary to their life goals or whether they are making choices that support their vision.	Goal setting and developing pathways to achieving those goals. Encouraging FSWs to list the things about their lives that they are grateful for and to keep a gratitude journal. List the hardships they were able to overcome. This will help nurture a sense of hope.	Instead of focusing solely on the past and the present, engage FSWs in how they view their future and what they would like to see happening in their lives. The changes they would like to make and why. Engage with FSWs in terms of where they see themselves in a year, within two years, five years and ten years. This is to create a time perspective of their lives.	It is important for FSWs to understand that side effects are short lived, and to have practical ways and advice on how to deal with side effects. For example, they can take their pills at night instead of in the morning, make their way to the clinic to see a nurse, or speak to a peer educator.

**Table 5**

*Matrices of interpersonal change objectives*

Determinants	Stigma	Encourage support from intimate partners	Address conflicts between FSWs on PrEP and those on antiretrovirals
Performance objective	Destigmatise PrEP through knowledge	Equip FSWs to engage in PrEP negotiation with their partners	Equip FSWs to be able to handle conflict and confrontation from their friends about PrEP legitimacy
Change objectives	<p>The taking of PrEP among FSWs should be destigmatised through PrEP education and promotion.</p> <p>Also, PrEP being an antiretroviral, should be explained to FSWs that it is an antiretroviral that prevents HIV before transmission takes place.</p> <p>It is important to fight the stigma through the use of positive messages about PrEP, as well as not framing messaging around high-risk groups but present PrEP as a pill that promotes sexual agency and wellness – change the predominant discourses.</p>	<p>FSWs need to be taught and prepared on how to negotiate PrEP use with their partners, as well as be taught on how to explain the benefits of using PrEP as an additional HIV prevention method and encourage their partners to take PrEP. This could be done through role play.</p>	<p>It is important to address the conflict happening among FSWs on PrEP and those taking antiretrovirals. The conflict exists because of a lack of knowledge and the belief that all FSWs are HIV positive, which is also a myth that needs to be challenged through dialogue.</p> <p>This is related to the fierce competition that exists in the FSW community. As well as the jealousy that all should suffer the same fate of contracting HIV because they are all sex workers. This could also be due to a high HIV prevalence in the community which renders being HIV negative an achievement.</p>

**Table 6**

*Matrices of environmental change objectives*

Determinants	PrEP ambassadors	PrEP normalisation	PrEP education	PrEP access	Mobility
Performance objectives	Train FSWs who are PrEP enthusiasts to educate their friends and peers about PrEP.	Promote PrEP to the wider community so that it becomes a normalised way of preventing HIV	Health care providers and peer educators must show and explain the similarities between PrEP for prevention and antiretrovirals in simple everyday language.	Make PrEP available in other government clinics and not only in specific NGOs.	Provide FSWs with options on how to manage their pill supply when away from their primary residence
Change objectives	Through the intervention programme, peer educators will train FSWs who are interested in taking PrEP. Those who have been trained will be given an opportunity to volunteer as PrEP ambassadors, who are willing to motivate and encourage their friends to take PrEP for prevention. These will provide further PrEP awareness at localised contexts.	According to FSWs, the government and health care providers need to create PrEP awareness through mass messaging, not only to high-risk groups but also to the wider population. This will curb stigma and the taking of PrEP will be normalised as another way to prevent to prevent HIV.	FSWs need to be able to understand the similarities between PrEP and antiretrovirals. When explaining PrEP, peer educators and health care providers need to show and illustrate how the pills differ. They should not use medical jargon. They need to know how the regimens differ and in which aspects they are similar.	FSWs need a wider access of PrEP and not just from specific clinics and research NGOs. FSWs living outside the cities do not have access to PrEP.	FSWs should be able to access PrEP in other parts of South Africa at other distributing centres. They should be able to receive an extra quantity of pills to cater for their time away.

#### 10.2.4 Theory of change logic framework

The process of intervention design involved formulating a theory of change. In its early conceptualisation by Weiss (1995), a theory of change is meant to provide an explanation of how and why an initiative works. A set of assumptions or necessary conditions for change are proposed and cumulative steps are formulated to show how the goals and changes can be achieved. There is a strong connection between activities and outcomes (Steing & Valters, 2012). The logic model is used to demonstrate the logic flow of the intervention to implementers (Mills, Lawton, & Sheard, 2019). It is important to take all the objectives generated in Step 2 and depict the pathways of change to guide the thinking and direction of the intervention, as suggested by Funnell and Rodgers (2011). The intervention theory of change logic framework depicts the goals, activities, inputs, and outcomes informed by the matrices of change. Furthermore, the logic framework depicts the priorities of the intervention.

The W.K. Kellogg Foundation developed a logic model development guide which was updated in 2004. According to this guide, a logic model is a visual representation of the systematic depiction of the intervention and its components. It consists of the problem, goal of the intervention, the inputs needed that will lead to the intervention activities, as well as outcomes which can be classified as short-term, intermediate, and distal outcomes which eventually contribute to the overall impact of the intervention. Logic models are important because they ensure that programme developers depict a systematic way of thinking and adjusting the programme based on what is feasible. In this case, the logic model was incorporated into Step 2 of the intervention mapping process to assist the stakeholders to have a shared understanding of how the programme will be implemented, how change will be achieved through the intervention and the various detailed activities that need to take place for that change to be realised, as outlined by Breuer et al. (2014). Each component of the logic model is important and leads to another step in a systematic way.

The logic model can be broken down into five main components, namely the **problem** which has been identified in the needs analysis; **inputs**, which are the resources needed to carry out the intervention in the form of human capital, finances, stakeholders, and community resources. The fourth component is **programme activities** that consist of the processes, tools, events, technology, and actions that need to be applied to facilitate change. **Outcomes** refer to the specific changes to be achieved, such as behaviour, knowledge, skills, and status (Funnell & Rogers, 2011; Alderman, 2014; Breuer, Lee, De Silva, & Lund, 2015).

The W.K. Kellogg Foundation (2004) recommended that short-term outcomes should be attainable within one to two years, while the longer or intermediate outcomes can take three to five years. Thus, the measuring and evaluation of impact of an intervention should be done within four to ten years of the intervention, because behavioural change is a process that happens over a longer period of time; however, programmes should be monitored closely to ensure fidelity of delivery in order to achieve the intended outcomes. The logic model in Figure 12 provides stakeholders and potential programme implementers with an intervention blueprint or road map for implementation and evaluation.

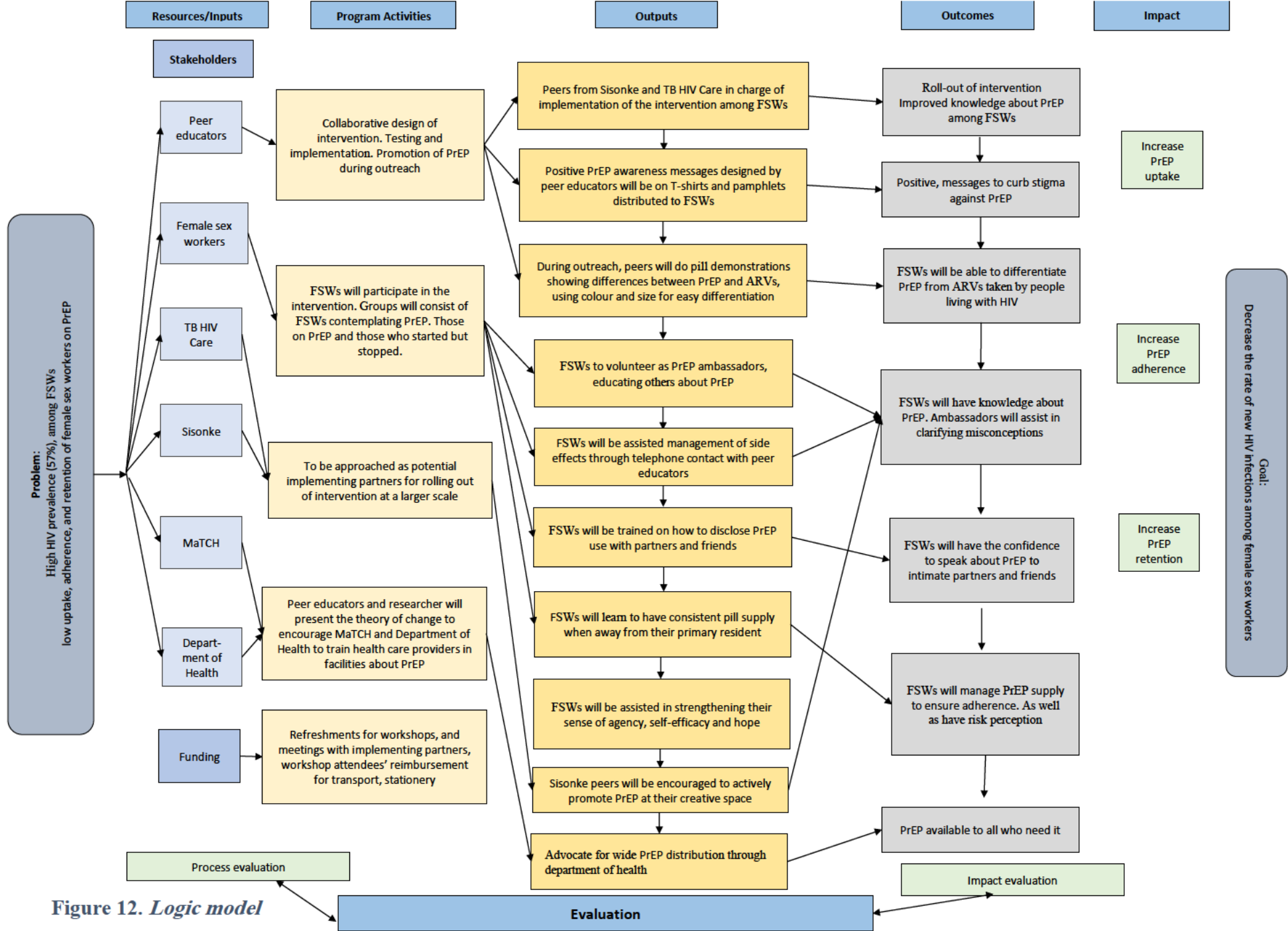


Figure 12. Logic model

### 10.3 Intervention mapping – Step 3: Theory-based methods and practical strategies

The engagement of FSWs peer educators in formulating the performance objectives, as well as the change objectives in Step 2 above, leads to the identification of appropriate theory-based methods and strategies. These theory-based methods are techniques and processes that are applied to achieve the intended individual and environmental changes. Theoretical methods intended to facilitate change at individual level, need to be applied differently when seeking to effect change at an ecological or environmental level. While the determinants may be the same, the techniques or delivery mode of the theoretical method may differ to achieve the intended change. Theory-based methods also inform the intervention activities of the intervention programme (Kok, 2018).

Relevant theories are linked to the key determinants and change objectives as outlined in Table 7. During the intervention design stage, specific activities (strategies) are designed for the specific change objectives grounded in the respective theories. (See the shaded column in Table 7.)

**Table 7**

#### *Theory-based methods*

Determinants and change objectives	Theory-based methods	Examples of strategies and practical applications	Examples of activities and materials
Promote PrEP to wider community (organisational)	Systems change (systems theory) (Best et al., 2012)	Engage Department of Health to discuss the benefits of widening PrEP distribution.	Have meetings with Department of Health, present theory of change.
PrEP access: PrEP must be accessible to the wider community	Systems change (Best et al., 2012)	FSWs need a wider access of PrEP and not just from special clinics and NGOs. FSWs living outside the cities where the PrEP distributing NGOs do not operate may not have access to PrEP.	Engage Department of Health to promote and distribute PrEP at clinics and hospitals.
PrEP education: Health care providers and peer educators must show and explain the differences and similarities between PrEP and antiretrovirals in simple everyday language	Using imagery (Theories of information processing) (Wright, 2011)	Educate FSWs about the similarities and differences between PrEP and antiretrovirals.	Take both the antiretroviral container and PrEP container and show how the two containers differ and how the regimens differ. Then take out the actual pills and show the differences.
Engage FSWs in the development of awareness messages	Framing (Protection motivation theory) (Van 't Riet et al., 2014)	Engage FSWs in the design of gain-frame/positive messages and loss-frame messages (HIV risk) about PrEP.	FSW peer educators will each brainstorm two to three messages that outline the positive aspects of PrEP use. According to the participants, the current message about PrEP is vague and says nothing specific about PrEP preventing HIV.

Determinants and change objectives	Theory-based methods	Examples of strategies and practical applications	Examples of activities and materials
PrEP ambassadors	Use of lay health workers; peer education (Theories of social networks and social support) (Tolli, 2012) Ambassadors are change agents (diffusion of innovation theory) (Dearing, 2009)	PrEP ambassadors will be asked to volunteer. These volunteers will come from the groups of FSWs who would have participated in the intervention programme. Ambassadors will promote the use of PrEP at their brothels and streets where they work.	Peer educators will use this intervention programme to train FSWs; those willing will be PrEP ambassadors. Ambassadors will be assisted by peer educators on verbal persuasion and will be role models for other FSWs with regards to adherence on PrEP.
Side effects management	Planning coping responses (Theories of self-regulation) (Marlatt & Donovan, 2005)	FSWs will be encouraged to list possible PrEP side effects and coping mechanisms.	FSW peer educators will provide a step-by-step process on how PrEP users can cope with side effects.
Planning for access and adherence to PrEP for eventualities	Planning coping responses and self-efficacy and self-regulation (Bandura, 1991)	Suggestions will be provided on how to ensure a steady supply of pills when one is away from their primary residence.	FSW peer educators suggest that if FSWs know that they will be away, they need to approach the PrEP distributing organisation for an extra supply of pills. They should also keep a small pill box in the bag that helps to ensure that they have some supply of their pills should they decide to overnight with their client.
Stigma (Destigmatise PrEP through knowledge)	Shifting perspectives (Theories of stigma and discrimination) (Batson, Chang, Orr, & Rowland, 2002; Goffman 2003)	Through PrEP education and promotion.	Using scenarios and role play to equip participants on how they can deal with stigma, as well as how they can respond to the stigma they experience from friends and partners.
Ability to disclose the use of PrEP to intimate partners	Guided practice (Social cognitive theory and theories of self-regulation) (Bandura, 1991; Kelder, Hoelscher, & Perry, 2015)	FSWs will be encouraged to disclose the use of PrEP to their partners.	Through scenarios and role play, FSWs will be equipped on how to disclose the use of PrEP to their partners so that they can promote trust and openness in their relationships.
Self-efficacy	Modelling (Theories of learning) (Bandura, 1999; McAlister, Perry, & Parcel, 2008)	FSWs need to express confidence in their ability to take PrEP and adhere to it.	FSWs will be exposed to their peers who are PrEP enthusiasts (PrEP ambassadors) and will engage with role-model scenarios.
Agency	Goal setting and self-affirmations (Goal setting theory, theories of self-regulation) (Bandura 1999; Latham & Locke, 2007)	FSWs will be encouraged to focus on the power of making decisions and taking positive action.	FSWs will engage in a reflective exercise on how they have used their agency in the past to make decisions and how they could have made better choices. They will also reflect on how having the power of choice can have an effect on their ability to prevent HIV and bring them closer to their personal goals.
Hope	Self-affirmation Goal setting (Goal setting theory, theories of self-regulation) Positive thinking and emotions (Fredrickson, 2001; Latham & Locke, 2007)	FSWs will be encouraged to focus on those aspects of their lives that give them hope and meaning.	Keep a gratitude journal, as well as reflect on how they have managed to overcome adversity through resourcefulness. List all the people who benefit from their existence and ways in which they provide hope to others.
Future aspirations	Motivational interviewing Goal setting (theories of self-regulation) (Deci & Ryan, 2010; Miller & Rollnick, 2012)	FSWs will be engaged on personal goals.	FSWs will be asked about their goals for taking PrEP. They will engage in an exercise where they will provide a visual representation of their goals and will be asked to provide a plan on how they will accomplish those goals.

#### **10.4 Intervention mapping – Step 4: Programme design**

In an effort to address the low uptake and adherence of PrEP among FSWs, the working group felt that it is important to formulate a programme in the form of workshops that align with the change objectives established in Step 2 and the theory-based activities in Step 3. These workshops will be facilitated by peer educators among small groups of FSWs to empower and educate them about PrEP, and to motivate for and encourage the uptake of PrEP. These workshops consist of eight modules. The development and refinement of these modules were done by the working group, with my assistance, through a participatory action formative evaluation process with the working group. Through the needs analysis we were able to understand the context of PrEP programming, the strengths and the challenges and thus the need for the intervention. The working group and I engaged critically with the insights generated through Steps 1 to 3 of the intervention mapping as these were the foundation for the assembling or design of the programme in Step 4. The activities informed by the theory, and highlighted in Table 7, were incorporated into the programme.

A series of meetings were held during the programme design phase for participatory deliberations and dialogue. (See Chapter 5 for more detail.) Formative evaluation as a cyclical process that allowed multiple opportunities to modify components of the proposed intervention programme to ensure fit for purpose and relevance with the ultimate goal of optimal outcome success, as stated by Stetler et al. (2006). This implied that members of the working group piloted some programme components, for example, suggestions made during the planning meetings verified how these will be received by FSWs during their PrEP outreach sessions. Regular feedback was provided about their respected field experiences, and amendments were made to the programme where relevant. As mentioned in Chapter 5, the workshop meetings with the peer educators were transformational in the sense that they were provided with opportunities to share ideas, strengthen and consolidate their approach to PrEP outreach from working in silos within their respective organisations, to partnership with other organisations and stakeholders in promoting PrEP.

The formative evaluation is also an opportunity to ascertain dose, consistency, usefulness and quality of the intended intervention. Through the formative evaluation process, causal events leading to change are established and related to specific components of the intervention. Furthermore, the formative evaluation establishes intervention accessibility and relevance to the target audience (Bauman, & Nutbeam, 2013; Evans, Raines, & Owen, 1989). An example

was the use of the pill differentiation method where a peer educator demonstrated the differences between PrEP and antiretrovirals for HIV-positive people. The feedback from the peer educator was that this teaching method was received well and thus it was incorporated into the programme. Another example was the use of the PrEP awareness slogans designed by the working group during the intervention mapping. These messages – *Taking the power of HIV prevention with PrEP; Stay PrEPared and HIV protected with PrEP; My body, my HIV negative status is my inspiration for taking PrEP* – were printed on T-shirts worn by the peer educators during outreach/ The feedback was that the T-shirts sparked curiosity among FSWs and were good conversation starters about PrEP. Thus, the formative process embarked upon in the development of the intervention was beneficial in that peer educators refined their ideas for the programme drawing on their experiences from the field.

The formative evaluation, therefore, assists implementers to be able to ascertain weaknesses in the intervention design and proposed implementation process. Data collection that occurs in this process, has occurred before, during and after implementation so as to optimise success as well as to have a detailed understanding of the nature of the intervention, while making room for refinements before and during the implementation phase (Dehar, Casswell, & Duignan, 1993; Evans, Raines, & Owen, 1989; McClintock, 1984).

Formative evaluation, furthermore, provides an opportunity for implementers to analyse complexities that may influence the progress and effectiveness of the implementation process, questions are asked to ascertain feasibility, context and adaptation as well as response towards the intervention among the target audience. This takes place during the design and pretesting of the programme to guide the intervention process (Dixon-Ibarra, Driver, VanVolkenburg, & Humphries, 2017; Vella, 2019).

The *Walk in Hope* PrEP workshop programme consists of two sections: The first part focuses on promoting personal growth and introspection among FSWs and relates this with HIV prevention through the use of PrEP. The second part focuses on promoting PrEP knowledge and stigma.

The **first part** of the programme was informed by the results from the situational analysis, which showed that the FSWs who adhered and were retained on PrEP, did so in part due to their personal motivations which stemmed from self-love, having developed their own sense of agency, as well as the inspiration they received from taking care of their children. Some also had aspirations of studying further with the hope of finding other forms of employment or

starting up businesses. The working group felt that the majority of health care interventions tend to focus on the act of taking pills daily, without regard to the human element of treatment. They also felt that FSWs have to cope with various intersecting issues such as societal stigma, discrimination and human rights violations, which render them marginalised and to an extent dehumanised, which contribute to a sense of apathy and a fatalistic as well as a hopeless approach to life. It was therefore important for the programme to start with the process of personal development to ignite hope, encourage growth and introspection before addressing the technical aspects of prevention. The group felt that FSWs would most likely engage effectively in preventing HIV if they have a strong sense of personal agency, purpose, and mastery over their own lives. This empowerment of the self was thus the foundation to create receptiveness for the information and motivational content of the intervention.

The process of personal development encompassed activities to promote self-examination and critical reflexivity. The programme starts with a tree of life activity, which is a process imbedded in the narrative methodology. The purpose of the tree of life is to encourage the telling of life stories, which encourage experiential and observational learning (Graaf, Sanders, & Hoeken, 2016; Hinyard, & Kreuter, 2007). It is in the understanding of a person's life story that one can begin to see the values they hold, how they have been socialised and what led to the current problems they are experiencing. In listening intently to someone's life story, it is then that they can be helped to create an alternative story (Morgan, 2000). During the process of telling their stories, the facilitators/peer educators will listen for accounts that focus on that particular FSW's personal strengths and triumphs, as well as moments where they demonstrate personal agency. The participant will be encouraged to write it down so that they can focus on the positive aspects of their personal experiences. They will then be encouraged to outline their personal goals and future aspirations, and also outline tangible ways on how they can reach those goals to create a sense of hope. In these workshops, FSWs will be assisted with cultivating self-love amidst a society that condemns them. This will be done through a process of self-affirmations where FSWs will be encouraged to list all the good personal qualities they possess as well as the different roles they occupy in society and in the lives of the people they influence, be it their children, family members or friends. The purpose of this exercise will be to tackle internalised stigma and the shame that some women may feel because of their engagement in sex work.

The **second part** of the *Walk in Hope* workshop programme was designed with the purpose of encouraging adherence and self-management behaviours in relation to PrEP. To achieve this, the needs analysis showed that client education is important to help individuals who take PrEP

or those contemplating to take it. This is important for the purpose of adherence to the prescribed daily pill, as well as to understand the treatment process inclusive of the related physiological side effects and other social challenges they may face in taking PrEP, such as stigma. Data from the needs analysis, including several other empirical studies of various authors (Enriquez & McKinsey, 2011; Melchior, Nemes, Alencar, & Buchalla, 2007; Stirratt & Gordon, 2008;), have shown that adherence to a prescribed treatment regimen that a patient has to take over a period of time is challenging. To engage effectively with long-term medication use, this necessitates that the client makes adjustments to take consistent action by changing physiological conditions and life situations. This is also known as self-management that implies self-regulation where clients need to make decisions and take action independently of health care providers (Gibson, Ram, & Powell, 2003). The ultimate goal of self-management includes consistency in performing a health behaviour as well as improving the quality of the behaviour, whereby the client is able to engage effectively in problem-solving as well as to overcome barriers (Cameron & Leventhal, 2003). Encouraging self-management to improve adherence is an integral part of this intervention because for PrEP to be effective in preventing HIV, it needs to be taken consistently. Evidence from the needs analysis showed that FSWs are faced with complex behavioural and environmental challenges that make engaging with this prevention method challenging. It is therefore imperative that they make adjustments to their everyday life situations so that they will be able to take PrEP consistently. These adjustments include FSWs knowing how to perceive risk so that they can start PrEP as well as to take PrEP consistently, manage side effects as well as how to disclose to their partners and friends and also to manage pill supply when away from their primary residence.

The framework for the *Walk in Hope* intervention workshop programme is discussed below followed by the full programme.

# Walk in Hope Intervention Programme Framework and Objectives

## Programme Part One Personal Awareness and Development

### *Dialogue 1: Tree of life*

Activity	Objectives
<b>1</b> Building trust among participants	<ul style="list-style-type: none"><li>• To create a safe and supportive space to openly share feelings and experiences.</li><li>• To build rapport among participants.</li><li>• To explore issues of mutual respect and positive regard for each other.</li><li>• To create an understanding that trust implies mutual respect for each other and show sensitivity to each other's life stories.</li></ul>
<b>2</b> Drawing the tree of life	<ul style="list-style-type: none"><li>• To use the tree of life as a metaphor to tell FSWs' life stories.</li><li>• To draw the roots to represent their early life and childhood experiences.</li><li>• To draw the trunk to represent their teenage life before their entry into sex work.</li><li>• To draw the branches to represent their current life and adult experiences.</li><li>• To draw broken branches to represent their broken dreams and painful experiences.</li><li>• To draw leaves and fruit to represent the good aspects of their lives, hopes and dreams.</li></ul>

Activity	Objectives
3 Sharing of life stories	<ul style="list-style-type: none"> <li>• To tell their life stories – this gives FSWs an opportunity to share intimate details about themselves and their lives.</li> <li>• To assist the FSW to refocus on the positive aspect of their life story where they display positive qualities of agency, self-efficacy, hope and resilience.</li> <li>• To list their triumphs and all the challenges they have managed to overcome.</li> <li>• To use their own past experiences of resilience and coping, when faced with current difficulties</li> </ul>

*Dialogue 2: Who am I? and Who are We?*

Activities	Objectives
1 Reflecting on personal values, beliefs and identity	<ul style="list-style-type: none"> <li>• To reflect on different parts of themselves that are separate from being a sex worker.</li> <li>• To engage with their multiple roles and identities.</li> <li>• To list the people in their lives that benefit from their multiple identities and roles.</li> <li>• To reflect on their goals in life.</li> <li>• To develop action plans for achieving those goals.</li> </ul>
2 Clarification of values	<ul style="list-style-type: none"> <li>• To engage with their beliefs about who they are.</li> <li>• To explore and identify the values that are important to them.</li> <li>• To relate their values to everyday life and HIV prevention.</li> </ul>
3 Collective identity	<ul style="list-style-type: none"> <li>• To reflect about the self in relation to the larger sex worker community.</li> <li>• To explore how they view each other.</li> <li>• To explore shared values to foster collective identity.</li> <li>• To engage with aspects related to a collective identity and responsibility and how this relates to HIV prevention.</li> <li>• To explore the likely outcomes of a united community of FSWs to gain insight into the positive outcomes, for example, source of support and strength to draw from.</li> </ul>

### *Dialogue 3: Power from within and power with others*

<b>Activity</b>	<b>Objectives</b>
<b>1</b> Understanding power and power relations	<ul style="list-style-type: none"><li>• To engage participants in a conversation about how they understand power and how power influences their lives.</li><li>• To explore ways in which they deal with power relations in their intimate relationships.</li><li>• To explore how they deal with power relations in their relationships with their peers and friends.</li><li>• To understand their power relationships with their clients.</li><li>• To identify ways in which they can reclaim some of their own power.</li><li>• To explore the role of power in HIV prevention.</li></ul>

### *Dialogue 4: My actions; my responsibility*

<b>Activity</b>	<b>Objectives</b>
<b>1</b> Making difficult choices and lessons learnt	<ul style="list-style-type: none"><li>• To identify the difficult choices they had to make in life.</li><li>• To explore the aspects that helped them make those choices.</li><li>• To reflect on the good and bad choices they made.</li><li>• To identify the good choices they can make in relation to HIV prevention.</li><li>• To foster a personal sense of responsibility to prevent HIV.</li><li>• To explore their views about a personal responsibility to prevent HIV among their intimate partners and clients.</li></ul>

### *Dialogue 5: Hope*

<b>Activity</b>	<b>Objectives</b>
<b>1</b> Fostering gratitude and hope	<ul style="list-style-type: none"><li>• To identify aspects that give them hope.</li></ul>

- To reflect on their hopes for the future.

### *Dialogue 6: Walking the Talk – Performativity*

Activity	Objectives
<b>1</b> Holistic health care behaviour	<ul style="list-style-type: none"> <li>• To develop insight into holistic health care (sexual, physical, spiritual and mental health).</li> <li>• To explore barriers and facilitating factors in health seeking behaviours that is required by an individual and by the FSW community.</li> <li>• To build skills and self-efficacy to adhere to healthy behaviours.</li> <li>• To explore strategies to encourage and keep one accountable in engaging in healthy lifestyles, also at a community level.</li> </ul>



## **Programme Part Two Pre-exposure Prophylaxis Education and Promotion**

Discussion	Objectives
<b>1</b> HIV prevention	<ul style="list-style-type: none"> <li>• To give participants an opportunity to explain why preventing HIV is important to them.</li> <li>• To engage participants on the methods they currently use to prevent HIV.</li> <li>• To ascertain awareness of PrEP.</li> </ul>
<b>2</b> What is PrEP?	<ul style="list-style-type: none"> <li>• To explore current knowledge and understandings about PrEP.</li> <li>• To equip participants with accurate factual information about PrEP, for example, how it works and reasons why PrEP is referred to as an antiretroviral.</li> <li>• To develop understanding of why condom use is important when using PrEP.</li> </ul>

## Discussion

## Objectives

- 
- To explore acceptability and accessibility of PrEP and the processes involved to be initiated on PrEP.
  - To develop insight into possible side effects of PrEP and actions to take when side effects are experienced.
  - To explore the differences between PrEP and PEP and appropriate use.
- 
- 3 PrEP stigma**
- Explore facilitating factors and barriers to the use of PrEP and strategies to overcome barriers.
  - Gain insight into the stigma surrounding PrEP and best ways to cope with challenges pertaining to its use.
  - Develop self-efficacy and skills to disclose their use of PrEP to their intimate partners and friends, as well as how to deal with negative feedback.
- 



## Programme Conclusion Knowledge Gained and Feedback

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- Assessing knowledge gained about PrEP through an interactive game.
  - Seek feedback on participants' experiences with the programme, for example:
    - programme highlights; and
    - ways to improve the programme.

# Draft Walk in Hope Intervention Full Workshop Programme

## Section One Personal Awareness and Development

### *Dialogue 1: Tree of Life*

Activity	Exercise
<p><b>1 Building trust:</b> In order to ensure that participants feel free to share their thoughts and experiences it is important that rapport and trust are established, and that group confidentiality is emphasised.</p>	<p><b>Building a Nest:</b> Divide participants into groups of three or four, depending on the number of participants in attendance. Ask them to go outside to look for various materials that they can use to build a nest. Once each group has a nest, give each group an egg and ask them to choose one person who will stand on a chair and drop the egg into the nest on the floor. If the egg breaks, then the nest will be considered as unsafe; however, if the egg does not break, the nest will be considered safe and protective.</p> <p>After this exercise, the facilitator should liken trust to a safe and soft nest to demonstrate the importance of mutual respect and trust that should characterise the dialogical space.</p>
<p><b>2 Tree of Life:</b> The purpose of a tree of life is to facilitate the narrative methodology of working with life stories. Throughout the programme, FSWs will be required to reflect on their lived experiences and given the space to envision the future and relate it to HIV prevention.</p>	<p>Divide FSWs into groups and ask them to draw a tree on chart paper. The roots of the tree represent their early life, where they grew up and their childhood experiences. The trunk represents their teenage life, before their entry into sex work. The broken branches next to the tree represent their dashed hopes and dreams. The firm branches on the tree represent their current experiences in the sex trade. Encourage FSWs to reflect on the good aspects of the trade to encourage a positive mindset for dialogue. The leaves represent their current hopes and dreams and what they want to achieve in their lives as mothers, sisters, partners and citizens of South Africa, as well as what they can do to protect themselves from HIV to achieve their goals.</p>

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The facilitator then asks the following questions:

- What factors led you into sex work?
- How has selling sex benefited you?
- Which part of your story shows strength and courage?
- Which part of your story shows your hopes and dreams?
- How do you think actively protecting yourself from HIV will help you reach your goals?

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**3** Write down all the things you have been able to overcome.

What does overcoming these challenges say about you and the kind of person you are?  
Have other people noticed these abilities before?  
Remind yourself of these achievements whenever you are faced with challenges.

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## *Dialogue 2: Values and Identity*

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### **Activity**

### **Exercise**

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**1** Pictures from a magazine

Ask FSWs to draw or cut out four pictures from a magazine that represent their values and identity. Ask them to paste the pictures on the chart provided. Ask them to share what spoke to them in the pictures that they have chosen. Allow the discussion to evolve beyond the pictures.

The pictures only serve as a tool to increase visibility about values and long-term goals. The pictures should represent the following:

- Who you are, or who do you aspire to be? (Apart from identifying as a sex worker, how else do you identify yourself?)
- Your goals in life.
- Your beliefs.

---

**2** Choose one example of a value or belief that is important to you as an individual and state why that value or belief is important?

The facilitator should ask the following questions:

- Do you think your beliefs make you a good and loveable person? How so?
  - How do you think that value or belief help you to engage effectively with HIV prevention?
  - Apart from identifying as a sex worker, what other roles do you identify with?
-

- 
- How important is this identity to you?
  - What are the things that you feel are important about you that add to your identity?
  - List the people in your life who benefit from you being here and having these multiple identities.
  - How are you planning to achieve your goals?
- 



## Section Two Collective Identity

The facilitator asks the following questions

- How would you as FSWs define a community?
- Do you see yourself as part of a community of sex workers? (If yes, why? If not, why not?)
- What can you do together to create a sense of community as FSWs?
- What are the things that make you similar as a group? And what are the things that make you different?
- What strengths do you all possess as FSWs?
- What weaknesses exist within the community? (Probe – and how can you overcome those weaknesses?)
- What can you all do to protect each other as a group?
- What are the collective values that you all share as a group?
- How can you use those collective values to help you as a group/community to prevent HIV?

### Dialogue 3: Power

#### Activity

#### Exercise

- 1 The facilitator asks participants to read the following scenario:

**Scenario 1:**

*Candi is a 30-year-old woman who is also a sex worker. She has been selling sex since she was 25 years old. She knows that because she sees different clients, it is important for her to use a condom with all her clients. However, she also has five clients who are now becoming regular and one of them is even starting to insist that they not use a condom*

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*because he claims to trust her, and she should also trust him. Candi likes this client because he is kind and gentle towards her and pays her generously, but she also knows the importance of condom use. Candi has tested for HIV and is HIV negative but feels tempted to sleep with this regular client without a condom because she doesn't want to lose him. Candi feels powerless and confused. What should she do?*

(Group discussion follows).

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- |   |   |
|---|---|
| <b>2</b> The facilitator asks the following questions | <ul style="list-style-type: none"><li>• What do you understand by the word 'power'?</li><li>• What power do you have as an FSW?</li><li>• What are the positive ways in which you can use your power?</li><li>• What power do you think you all have as an FSW community and how can that change the way business is conducted?</li><li>• How do you think you can use that power to improve sexual relationships with clients?</li><li>• How do you think you can use that power to engage effectively with HIV prevention?</li><li>• What added power do you think using PrEP can provide to HIV-negative FSWs?</li></ul> |
|---|---|
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### ***Dialogue 4: Agency and Responsibilities***

#### **Activity**

#### **Exercise**

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|---|---|
| <b>1</b> Think of a time that you had to make difficult choices in your life. | <ul style="list-style-type: none"><li>• What were those choices? (list them) and what helped you to decide?</li><li>• What have you learned from having made those difficult choices?</li></ul> |
|---|---|
- 

The facilitator asks the following questions:

- After having reflected on the choices you have made, what could you have done differently?
  - If you could, which of those choices could you rectify and why?
  - What kind of choices do you think will benefit your life and bring you closer to your goals?  
(Refer to the goals outlined in Dialogue 2.)
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- What responsibilities do you think you have when it comes to yourself and HIV prevention?
  - What responsibilities do you have when it comes to clients and HIV prevention?
  - Are there any situations in your life relating to sexual risk behaviour?
- 

Probe further:

- If you take a moment to reflect on those situations, what could you have done differently?
  - If you have an opportunity to go back into that moment, what would you like to change and why?
  - List the positive choices related to your personal health goals that you are willing to make going forward.
  - Show how you are going to achieve those goals.
- 

### *Dialogue 3: Developing Hope*

#### **Activity**

#### **Exercise**

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|---|--|
| <p><b>1</b> Provide each participant with a notebook to use during this session and beyond.<br/>Ask them to do the following:</p>   | <ul style="list-style-type: none"> <li>• List or draw five things that you are currently grateful for or appreciate in your life.</li> <li>• Why are you grateful for these things?</li> <li>• List five other things that you believe could happen that you would be grateful for.</li> <li>• Share how you are going to try and make these things happen?</li> <li>• Provide feedback to the group based on their gratitude lists.</li> <li>• List three things that are a success in your life (these could range from relationships, achievements, etc.).</li> <li>• List the resources you have or have access to via others (these could be food, a roof over their heads, being able to provide for their children, etc.).</li> </ul> |
| <p><b>2.</b> The purpose of this activity is to help participants to realise that they have the ability to achieve success and that they have the resources they need to survive.</p> | <ul style="list-style-type: none"> <li>• List the positive contributions that you make in other people's lives.</li> <li>• Choose three to five people that you feel that have made a positive contribution towards your life.</li> <li>• How do you feel about the contributions they made?</li> <li>• List the people who need you and state how you think you provide hope to these people.</li> </ul>  |
-

This will bring to the fore their level of resilience and ability to survive against all odds.

(This will assist the FSWs to see that their presence matter in other people's lives.)

- Ask each participant to speak to their list.

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### *Dialogue 4: Walking-the-talk Performativity*

#### **Activity**

#### **Exercise**

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|--|---|
| <p><b>1</b> Break FSWs into groups. Let the whole group design a poster that creates awareness about the different health care behaviours.</p> | <ul style="list-style-type: none"><li>• List holistic health care behaviours (sexual health, physical health, spiritual health, mental health) that you would like to live by.</li></ul> <p>Let each group report back.</p>   |
| <p><b>2</b> The facilitator asks the following questions:</p>  | <ul style="list-style-type: none"><li>• As a group, what are the health-seeking or life enhancing behaviours you can recommend for yourselves and other FSWs?</li><li>• How can you ensure that you live by those healthy behaviours?</li><li>• How can you encourage other FSWs to adopt those healthy behaviours?</li></ul> |
-

# Pre-exposure Prophylaxis Education and Promotion

## HIV Prevention

The facilitator asks the following questions to stimulate discussion:

- Why is HIV prevention important to you?
- What methods of HIV prevention are you currently using?
- Have you heard of PrEP?

The facilitator first poses each question listed below and wait for the participants' responses:

After the group engagement the facilitator provides participants with the knowledge provided:

### Question & Activity

### Answer

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#### **What is PrEP?**

PrEP is an HIV prevention method that was introduced in South Africa in 2016. It is a pill that is given to HIV-negative people to reduce their risk of getting infected with HIV.

PrEP can reduce the risk of infection by 90%.

PrEP prevents HIV infection even if the virus enters the body through the exchange of sexual fluids or from an injection.

Research has been conducted in various parts of the world to test the effectiveness of PrEP, and PrEP was found efficient to protect against HIV.

Furthermore, according to Reid (n.d.: Online), PrEP was approved by the Centers for Disease Control in 2014.

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#### **How does PrEP work?**

Upon initiation, it was estimated that PrEP has to be taken daily for a total of 21 days before it can be effective in the body. Thereafter, PrEP needs to be taken daily like one would take an oral contraceptive. PrEP can be taken with or without food.

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It is important to adhere to the daily dosage to ensure HIV prevention. Missing doses may increase the risk of HIV infection.

People on PrEP need to get tested for HIV every three months when on PrEP to ensure that a person has not seroconverted, and that they are still eligible for PrEP. Should a person contract HIV, it is important that they stop taking PrEP and are initiated on antiretrovirals.

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**Why do we say that PrEP is an antiretroviral?**

PrEP is referred to as an antiretroviral because it consists of tenofovir (TDF) and tenofovir/emtricitabine (TDF-TFC) in a single tablet fixed dose (PrEPwatch, 2017).

TDF-TFC make up Truvada, which is an antiretroviral used to suppress the virus in people living with HIV.

However, through research it has been discovered that Truvada can also prevent the virus from infecting people if taken consistently by HIV-negative people to prevent HIV (CDC, 2020a: Online).

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**Demonstration:**

Take the container pills for PrEP and antiretroviral treatment using pill size and colour differentiation, take out the two pills and explain the differences and similarities to the participants.

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**Should a person use condoms when on PrEP?**

PrEP has been issued as part of combination prevention, meaning that PrEP does not replace other methods of HIV prevention such as condoms, but should be used in addition to condoms.

PrEP does not protect a person from other STIs or pregnancy; thus, it is important to use condoms while taking PrEP (PrEPwatch, 2017).

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**Where can one get PrEP?**

PrEP is distributed at specific implementation sites and is not yet widely available.

PrEP can be purchased over the counter; however, it is costly for FSWs to buy.

The FSWs in Durban receive PrEP from TB HIV Care who provide mobile medical facilities that go out to areas where FSWs sell sex.

Through peer educators, FSWs are educated about PrEP and initiated on PrEP.

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**How does a person get initiated on PrEP?**

First, an FSW interested in PrEP is tested for HIV and if the test is negative, they are encouraged to start PrEP.

However, before PrEP can be issued, the person is also tested for kidney function because PrEP should not be taken by persons with renal impairment.

At three months after PrEP initiation, it is important that a person is tested again for HIV and is also tested for creatinine clearance associated with kidney function, as well as screened for pregnancy because the effects of Truvada on unborn babies is not yet known (CDC, 2020a: Online).

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**Does PrEP have side effects? If so, what kind of side effects can a person taking PrEP expect?**

The facilitator should ask the group if anyone has experienced side effects and how they dealt with them.

PrEP does come with side effects which vary between individuals. The common side effects that one can experience are nausea, dizziness, headaches, fatigue, and stomach cramps.

There are ways in which these side effects can be alleviated, for instance some patients have found that the side effects were less when taking PrEP after they have eaten, and some scheduled their doses taking the pill at night time instead of daytime to avoid it interfering with their daily activities (Acon Health Limited, 2016: Online).

---

**What is the best possible way to deal with side effects?**

Call or speak to a peer educator via WhatsApp.

Make it a point to go to the clinic to see a health care provider.

Depending on the side effect, take a pain killer and plan to see a health care provider as soon as you can.

If you tend to experience side effects in the morning, you can start taking your pill in the evenings consistently so that the side effects do not interfere with your day.

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**What is the difference between PrEP and PEP?**

PEP stands for post-exposure prophylaxis, which is treatment taken after potential exposure to HIV.

PEP, like PrEP, works to prevent the virus from creating an infection; however, PEP has to be taken within 72 hours of exposure and is not intended for prolonged use.

PEP is mainly given to rape survivors (Acon Health Limited, 2018: Online).

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## Scenarios presenting various options of prevention (post-exposure prophylaxis, pre-exposure prophylaxis, condoms)

Activity	Exercise
Facilitator should ask participants to read the scenarios and then answer the question.	
<b>Scenario 1</b>	<i>Thuli is a 35-year-old sex worker. She has just started taking PrEP and is anxious about the need to take a pill every day at the same time. This is challenging for Thuli because she has decided to take her pill in the evenings and that is also the time for work. At times she meets clients who want to spend a few days with her, particularly her regular clients who are truck drivers who want to drive out of town with her. Thuli also does not like carrying her big bottle of pills with her because they make a noise in her bag and she is also afraid that she may lose them. It was during those moments that Thuli tends to miss her daily dosage. What can Thuli do to deal with this problem?</i>
Possible solutions for Thuli	Thuli can buy herself a pill box to ensure that she can have her pills with her should she go out of town. Thuli can also take her daily dose in the mornings rather than the evenings.
<b>Scenario 2</b>	<i>Ntombi is a 40-year-old sex worker having been selling sex since she was 20 years old. She is grateful to be HIV negative. Ntombi is on PrEP and is convinced that PrEP works. However, she will be going home for a long Christmas break and is afraid her pills are going to run out before she is back in the city. She is going to visit her children in the rural areas of the Eastern Cape and is sure that the village clinic does not yet provide PrEP. Ntombi does not want to miss her dosage when on holiday. How do you think Ntombi can handle this problem?</i>
Possible solutions for Ntombi	Ntombi can approach TB HIV Care and ask for an extra supply of pills to use while on holiday.
Discuss the solutions	Divide participants into groups and let one group discuss solution for Scenario 1 and another group discuss the solutions for Scenario 2. Let each group report back to the larger group.

## Activity

## Exercise

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### Scenario 3

*Bongi is a 20-year-old sex worker. She has just climbed out of a client's car and was walking home. It was midnight and she was done with her shift, when a group of five men approached her. They started calling her names like magosha (prostitute) and saying that she should give them a service for free. One of them grabbed Bongi by the arm and when she tried to get away, another one tripped her. Bongi fell to the ground and all of a sudden, she felt her dress being ripped apart and the boys gang raped her. After what felt like forever the boys left her lying there and took her bag that had her money and phone. Bongi slowly managed to gather some strength and walked to her flat. She was scared that she may have contracted HIV from this incident, because she knew her status to be negative having been tested recently.*

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Question posed to the group

What do you think should be Bongi's first plan of action and what is her option regarding HIV prevention?

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### Scenario 4

*Charity is a 22-year-old FSW. She has been selling sex now for the past six months. She got introduced into sex work by her friends from the same township she lives in. Charity has been struggling to make ends meet, especially because she has a child and is a single mother. Charity has since realised that selling sex is risky because of multiple partners. She has also come across those clients who are willing to pay more for sex without a condom. She has also noticed that even though condoms are safe they also burst. She is worried about maintaining her negative status. She also believes that one day she will walk away from sex work but does not want to get HIV as a reminder of this lifestyle.*

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Question posed to the group

How can Charity ensure that she stays negative?

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### Disclosing the use of pre-exposure prophylaxis to a partner and close friend

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Role plays

Divide participants into groups of two each and ask them to practice disclosing their use of PrEP to their partners.

Let the participants change roles and act out disclosing their use of PrEP to close friends.

Let each group play out their roles to the larger group and allow for critique and feedback from participants.

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**Curbing pre-exposure prophylaxis stigma and conflict**


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**Scenario 1**

*Ayanda is a 39-year-old sex worker. She works in a brothel. Ayanda has been working in this particular brothel for two years. Ayanda and her colleagues know one another well, they pick up clients downstairs at a bar and service the clients upstairs in their rented rooms. The sex workers in this establishment see similar clients and provide services to each other's clients depending on who the client picks. Ayanda has a close friend whose name is Mbali. Mbali recently tested HIV positive and was surprised when Ayanda said she was HIV negative and on PrEP. Mbali became instantly defensive and told Ayanda that it was not possible that she was HIV negative when they share clients and Mbali knows of one particular client who likes both of them who is HIV positive. Mbali started accusing Ayanda of being in denial of her HIV status as well as lying about PrEP preventing HIV while it looks similar to the antiretrovirals that Mbali takes.*

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 Question posed to the group

What do you think Ayanda should do as she also does not want to lose her friendship with Mbali, but is not sure how to tell Mbali about PrEP in a way that Mbali can understand?

**Scenario 2**

*Yolanda lives with her husband and is a sex worker. Yolanda's husband does not know that she is a sex worker; all he knows is that she works at a restaurant in the evenings. Yolanda is a 36-year-old woman who loves her children and husband. She entered sex work three years ago when her husband got retrenched as a factory worker. Yolanda struggled to find work and heard about sex work from her friend who is also a sex worker. Yolanda is careful to use condoms when servicing clients because she does not want to infect her husband with HIV as this would make her feel bad. However, Yolanda is not sure whether to trust her husband because whenever she goes to work in the evenings the kids have told her that he also leaves the house and she's not sure where he goes. Yolanda has decided to start taking PrEP; however, she is afraid to tell her husband about it because he is going to get suspicious of her taking a pill daily and she is also not sure how to explain her use of PrEP without raising suspicion about her identity as a sex*

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## Activity

## Exercise

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*worker, since PrEP is given to people considered to be at high risk of HIV.*

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Question posed to the group      How do you think Yolanda can approach this situation?

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Engaging participants in a true of false game to test their knowledge of PrEP levels      Facilitator asks participants the following true of false questions. The participant that gets the most correct answers wins a small prize, for example, a voucher or stuffed animal.

True or false:

- Is it true or false that all sex workers are HIV positive?
  - Is it true or false that sex workers taking PrEP are blood type O?
  - Is it true or false that HIV is hiding in the blood of sex workers taking PrEP?
  - Is it true or false that PrEP is taken before or after intercourse?
  - Is it true or false that PrEP is effective on the first day of initiation?
  - Is it true or false that PrEP is an antiretroviral?
  - Is it true or false that a person can stop taking PrEP when they no longer feel at high risk for HIV?
  - Is it true or false that stopping to take PrEP may lead to drug resistance?
  - Is it true or false that PrEP can affect kidney function?
-

## Chapter 11

### Synthesis, Limitations and Recommendations

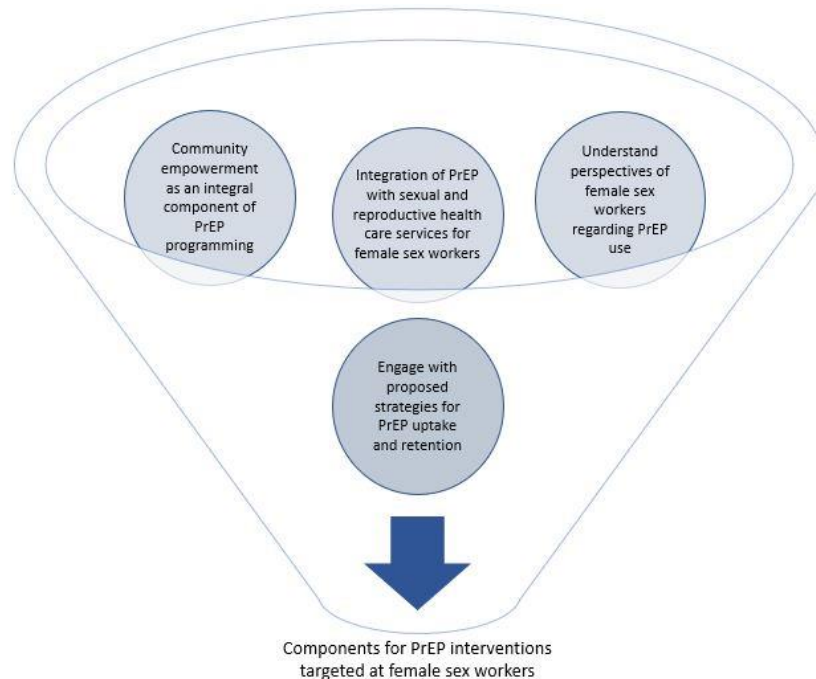
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This chapter is a synthesis of the study and a critical analysis of the findings in relation to the research objectives of the study. It is an attempt to demonstrate to the reader the contribution that this research has made and the significance of the findings in relation to the theoretical frameworks. The limitations of the study and recommendations for future research are also outlined.

#### **11.1 Objective 1: To outline the strategies that have been recommended in the literature to inform pre-exposure prophylaxis interventions for female sex workers**

This objective was addressed through a scoping review of the empirical literature to locate the design of the intervention programme within the broader literature on PrEP for FSWs, as well as to justify the need for a community-based PrEP intervention plan and workshop programme as a strategy to encourage PrEP uptake among this population. The recommendations for PrEP interventions from the literature called for an integration of PrEP with sexual and reproductive health care services to create a comprehensive health care system suitable to the needs of FSWs, as a way to encourage PrEP uptake (Becquet et al., 2020, Bowring et al., 2020). Community empowerment was recommended as a component of PrEP programming. This means involving FSWs in the design and implementation of structural, behavioural and biological interventions with the aim to empower FSWs to engage effectively in HIV prevention (Bekker et al., 2015; Cowan & Delany-Moretlwe, 2016). Programmes need to understand the perceptions of FSWs regarding PrEP use. This means that programmes need to address the concerns FSWs have, such as challenges to daily pill intake, drug resistance, doubts of PrEP efficacy, and the fear of disclosing the use of PrEP to intimate partners and friends within the sex trade (Eakle, Bourne et al., 2018; Emmanuel et al, 2020). Programmes need to incorporate various strategies to promote PrEP uptake and retention among FSWs. The strategies recommended from the literature are PrEP education, for PrEP to be positioned within the current knowledge on antiretroviral therapy through combining both PrEP and antiretroviral therapy services, as well as using the popular oral contraception as an example to explain daily pill intake. Studies also call for a wider distribution of PrEP to curb stigma, as well as monitoring pill intake among PrEP clients through the use of electronic bottle caps that

track pill withdrawals. Training of health care staff about PrEP initiation and management is crucial to ensure PrEP uptake among FSWs (Eakle, Mutanha, 2018; Mayer & Allan-Blitz, 2019; Mayer et al., 2016; Ortblad et al., 2018). Figure 13 provides a summary of scoping review findings.



**Figure 13. Summary of recommendations from the literature for effective PrEP programming**

## **11.2 Objective 2: To understand the barriers and facilitators of pre-exposure prophylaxis use among female sex workers**

### **11.2.1 Barriers**

The second objective of this study was to understand the barriers and facilitators of PrEP use among FSWs in Durban. The needs analysis conducted in Phase 1 of the overall intervention research addressed this particular aspect.

#### **11.2.1.1 Sex workers as vectors of disease**

This study has found that, according to the participants, PrEP was introduced as an HIV prevention drug for high-risk groups which included sex workers. This approach reinforced the notion of sex workers being vectors of disease and centred them as solely responsible for HIV transmission, which perpetuates both internal and external stigma among sex workers (Nova, 2016). When designing a programme for marginalised groups, it is important to ensure that the

programme is not framed in an accusatory manner that makes the constituents of the programme feel solely responsible for their own high-risk behaviour. This study identified various factors that contribute to sex workers' exposure to risk, namely clients, the law, and the health care system (Scorgie et al., 2012). Power relations are skewed in the favour of clients who enjoy anonymity and invisibility, and they can violate a FSW's rights with little or no consequence, particularly in a context such as South Africa where sex work is criminalised (Huysamen & Richter, 2020). Sex workers have limited room to negotiate power relations in a system that fails to protect their basic human rights. It is therefore important to take all of these factors into consideration to avoid focusing on sex workers in a way that fuels negative stereotypes, placing the responsibility of the high HIV prevalence solely on them.

#### **11.2.1.2 Getting lost in translation**

Another barrier to PrEP use found in this study was the inability to differentiate PrEP as an antiretroviral for HIV negative people and antiretrovirals given to people living with HIV. This implies that the understanding of PrEP and its physiological functions were not properly explained nor understood. Since the start of the nationwide antiretroviral programme, the message has always been clear that antiretrovirals are taken by persons testing HIV positive to suppress the virus from multiplying in the system and progressing to AIDS (Meyer-Rath, 2017). The scientific notion that antiretrovirals are now able to prevent HIV infection, provided that they are taken consistently, has been lost in translation (Günthard, 2016; Saag, 2020). It is only through rigorous campaigning and educating that we can begin to reconfigure people's understanding of antiretrovirals as not only a suppressant but as a prevention tool. A simplistic assumption was made that PrEP would be readily accepted among high-risk groups. Little consideration was given to the cognitive dissonance that would result when introducing an antiretroviral treatment as a prevention method for HIV. The study highlights the importance that prior to roll-out, awareness and spaces for dialogue need to be created to engage the population and provide guidance regarding how this new prevention technology can be promoted and explained to users in a manner that is compelling and contextually relevant.

#### **11.2.1.3 Contradictory messages about pre-exposure prophylaxis**

This study found that there were contradictory messages from PrEP distributing organisations and public health facilities, which was another barrier to PrEP use. NGOs that provide health care to key populations, as well as public health care providers are not disseminating the same

information. The lack of coordination between the two systems has created confusion for FSWs who access both services. In most cases, primary health care clinics are the first line of contact for FSWs seeking health care; thus, when a new HIV prevention tool is not being rolled out at public health clinics, this creates suspicion among FSWs. Some of the participants in this study mentioned that upon receiving PrEP, they went to their local clinics to seek clarity and confirmation as to whether PrEP prevented HIV. The knowledge that the NGOs are also engaging in research created suspicion and fear among some FSWs that they are being experimented on without their knowledge nor consent. The resistance of government to roll out PrEP to the wider community has created a sense that they are being singled out, resulting in isolation and confusion. The nurses in public clinics are said to be dismissive of PrEP and simply labelling it as an antiretroviral without providing further information. This points to the urgent need to train public health care providers about PrEP (Carter, Aaron, Nassau, & Brady, 2019; Krakower & Mayer, 2016; Petroll, Walsh, Owczarzak, McAuliffe, Bogart, & Kelly, 2017). It seems that currently, sex workers are caught in the middle of these two fragmented health delivery systems that coexist, but do not communicate effectively. This negatively impacts PrEP retention because nurses with limited understanding of PrEP as a preventive antiretroviral have presumably told participants to stop taking the drug. Health care workers occupy a position of legitimate medical power which, when used incorrectly or ignorantly, can have long-lasting implications of prevention intervention success. Thus, it is important to have support from the national Department of Health to formulate a unified standard message for PrEP.

#### **11.2.1.4 HIV positive by association**

It was evident from this study that FSWs are a community with their own characteristics and beliefs. One of the common assumptions among this particular group of FSWs was the idea that all FSWs are HIV positive. The diagnosis was through association because FSWs shared clients. These assumptions emanate from the idea that selling sex is high risk and it is unlikely that a sex worker will not get infected. The expectation of becoming infected with HIV could contribute to feelings of apathy, hopelessness and fatalism, which has been reported by some studies (Sileo, Bogart, Wagner, Musoke, Naigino, Mukasa, & Wanyenze, 2019). Within this context, it seemed very difficult for HIV-negative FSWs taking PrEP, to explain to their peers that they were taking tenofovir for prevention. This misunderstanding resulted in interpersonal conflict, and those on PrEP were viewed as HIV denialists. Theoretically, it is important to

recognise the shared identity among FSWs, its unintended consequences and the impact this has on prevention efforts. If FSWs feel that acquiring HIV is the price one pays for selling sex, then it becomes difficult for them to engage in prevention in a way that is meaningful. Those who tested negative did not believe that they were negative, and they kept expecting the HIV to eventually ‘show itself in the blood’. Therefore, having a programme that addresses these misconceptions is important and this could be done through the use of PrEP ambassadors – sex workers who have been able to stay negative, who will act as change agents to promote HIV prevention through PrEP.

#### **11.2.1.5 Pre-exposure prophylaxis as a source of conflict**

The lack of understanding about PrEP as mentioned in the preceding paragraphs, has caused conflict. Taking an antiretroviral to prevent HIV might add salt to injury to someone who is taking antiretrovirals because they are positive. FSWs are highly competitive and compare themselves to their peers. Thus, being HIV negative while engaging in sex work leads to mixed feelings of envy, disbelief and even admiration from peers who are HIV positive. An intimate partner discovering that their female partner takes tenofovir as PrEP will most likely suspect her to be HIV positive. Therefore, the lack of widespread PrEP awareness puts FSWs taking PrEP in awkward situations that are difficult to navigate, particularly when they are not equipped with the knowledge and confidence to explain how PrEP works to prevent infection. Most FSWs have opted to exercise their individual agency and discretion and take PrEP secretly. Some FSWs desired to tell their partners about PrEP with the hope that they too could be encouraged to take PrEP. They were, however, reluctant to do so because PrEP was being offered to FSWs by private mobile health care facilities, and feared that this could potentially expose the identity of the partner as a sex worker.

#### **11.2.2 Facilitators of pre-exposure prophylaxis use**

##### **11.2.2.1 Awareness raising and pre-exposure prophylaxis distribution**

At the time of this study, TB HIV Care was the only organisation distributing PrEP to FSWs. They used the peer education approach and engaged in outreach activities as well as inviting FSWs to monthly community advisory board meeting to educate them about new PrEP research. This approach had limitations, because not all FSWs were prepared to attend meetings, while their outreach efforts seemed more effective because it meant targeting FSWs where they work. Another limitation was that TB HIV Care functioned independent of other

sex work organisations such as Sisonke, who also has peer educators who engage in outreach activities. The Sisonke peer educators, at the time of this study, did not feel knowledgeable enough about PrEP and therefore lacked the confidence to talk about it. This was indicative of the general consensus among sex work organisations that they were not given space to engage with PrEP as a new prevention method. This resulted in a lost opportunity because, had Sisonke been included in awareness processes, the peer educators would have felt more comfortable to promote PrEP at their events that target FSWs from different networks. Another weakness was that the distribution of PrEP only covered areas in and around the Durban inner city; thus, rural KZN may not have PrEP programmes targeted at FSWs.

#### **11.2.2.2 Peer educators take charge of pre-exposure prophylaxis messaging**

The study found that the majority of peer educators felt that FSWs still needed knowledge about PrEP. The peer educators mentioned that they were confronted with various questions from FSWs, such as why they should take a pill when they are not HIV positive. Others asked why PrEP was not made into an injectable, which would be more convenient. The peer educators simply focused on promoting PrEP, based on how they have been trained by their organisation (TB HIV Care), even when they could see that these messages did not resonate with the people they met on the ground. During the engagement of the peer educators in the framing of their authentic but correct messages during the intervention mapping phase, they expressed their frustrations regarding the existing awareness message about PrEP – *We are the generation that will end HIV*. They described this message as vague and that it did not get the point across about PrEP preventing HIV. The messages that the peer educators formulated during the intervention mapping process, indicated that PrEP is a prevention tool, but it also appeals to aspects of self-love, agency, power, and general wellness. The messages were as follows: *Taking the power of HIV prevention with PrEP* (Figure 14a); *Stay PrEPared and HIV protected with PrEP* (Figure 14b); *My body, my HIV negative status is my inspiration for taking PrEP* (Figure 14c). These messages were also devoid of stigma because they do not allude to risk or sex work but were positive and self-affirming. The peer educators also felt that during outreach they needed to find an easier way to differentiate PrEP from antiretrovirals given to people living with HIV. They therefore agreed on using simple identifiers such as size and colour since PrEP is blue and each pill is labelled PrEP. In that way they felt that FSWs would be better equipped to differentiate the two regimens.



**Figure 14. T-shirt messages formulated by peer educators**

### **11.2.2.3 Keeping a client on pre-exposure prophylaxis**

Peer educators assist FSWs on PrEP to manage side effects through advising them to come to the mobile clinic to see a health care provider (Andrew Scheibe, Richter, et al., 2016; Webel, Okonsky, Trompeta, & Holzemer, 2010). FSWs have access to peer educators via WhatsApp instant messaging and are at liberty to ask for advice on how to manage side effects. However, through the process of intervention mapping and design, peer educators further proposed that

it was important to provide FSWs with practical solutions on how they can cope while not being able to see a health care provider. This could be through taking a painkiller should a patient experience a headache or changing the time of taking the pill from morning to night-time to manage side effects such as nausea, which are common. Peer educators also go the extra mile to deliver PrEP and send reminders to those who have not picked up their pills.

It is evident that peer educators are dedicated to their work and do all they can to ensure the success of the existing TB HIV Care PrEP programme. It was therefore important to engage these peer educators at a higher level of intervention design and implementation since they knew what the barriers were and how best to overcome them. Should they only have been involved in the latter parts of the programme development, their deeper insights and well-informed ideas embedded in the everyday life experiences of FSWs would have been lost for the intervention.

### **11.3 Objective 3: To explore the intrinsic personal motivations for pre-exposure prophylaxis use among female sex workers**

This objective was explored through understanding the personal motivations of FSWs for preventing HIV, particularly those who, at the time of this study, were taking PrEP consistently. The first motivation found was self-love; the participants felt that it is important to cultivate self-love because it determines the decisions that they make pertaining to prevention. PrEP is a great tool that give FSWs control over preventing HIV, similar to the birth control pill. FSWs can make decisions about their bodies and sexual health, independently of their clients or partner's knowledge or approval. Self-love was also connected to the concept of power where FSWs felt that PrEP gave them the agency to determine their sexual health and not seek permission and validation from a partner. The ability to prevent HIV has long been in the power of male partners because of the general availability of male condoms, and the scarcity of female condoms being further made worse by their non-user-friendly manufacturing, which has contributed to men not wanting women to wear them. Thus, women have to constantly cope with issues of condom negotiation and being on the receiving end of partner cooperation or conflict. With PrEP, however, an FSW has the power to make a choice that serves and protects her. This is linked to individual agency and the confidence that comes with feeling a sense of control.

The FSWs mentioned that PrEP gave them peace of mind of not having to be obsessed over their partner's fidelity, but to focus more on themselves and keeping themselves HIV free. They no longer felt a sense of helplessness when it comes to prevention, and HIV was no longer seen as an eventuality. This fosters a sense of hope and a drive to plan for the future. The FSWs on PrEP viewed sex work as a means to an end, a steppingstone to their goals. Those who had no hope, on the other hand, were fatalistic and did not see a life beyond sex work. Some saw themselves as more than just sex workers, but assumed other identities such as mothers, which they felt was another motivating factor to ensure that they remain HIV free for the sake of their children. They valued their role of motherhood so much that it inspired them to take on PrEP as a prevention tool. It is important for programmes to recognise that FSWs are not one homogenous group but are a group of women who practice agency, who have a sense of self-worth and have chosen to navigate this patriarchal system in a way that works for them and helps them to survive. It is important to help FSWs tap into their inner power and agency through the articulation of their values.

#### **11.4 Objective 4: To outline the methodological processes and outcomes of a pre-exposure prophylaxis intervention plan designed by female sex worker peer educators**

During Phase 2 of this study, the role of planning frameworks in the design of complex interventions was demonstrated. For this study, it was vital to design an intervention that intervened at various stages of human influence. With the guide of Bronfenbrenner's (1994) bioecological framework, it was possible to see the underlying processes that influence human behaviour. These processes can be divided into proximal and distal processes (Bronfenbrenner, 1994). Proximal processes involve a reciprocal interaction between the individual and the environment. Distal processes are those factors that occur away from the centre of the individual but have a significant effect on the life of the individual. Thus, interventions have to address both the proximal and distal processes.

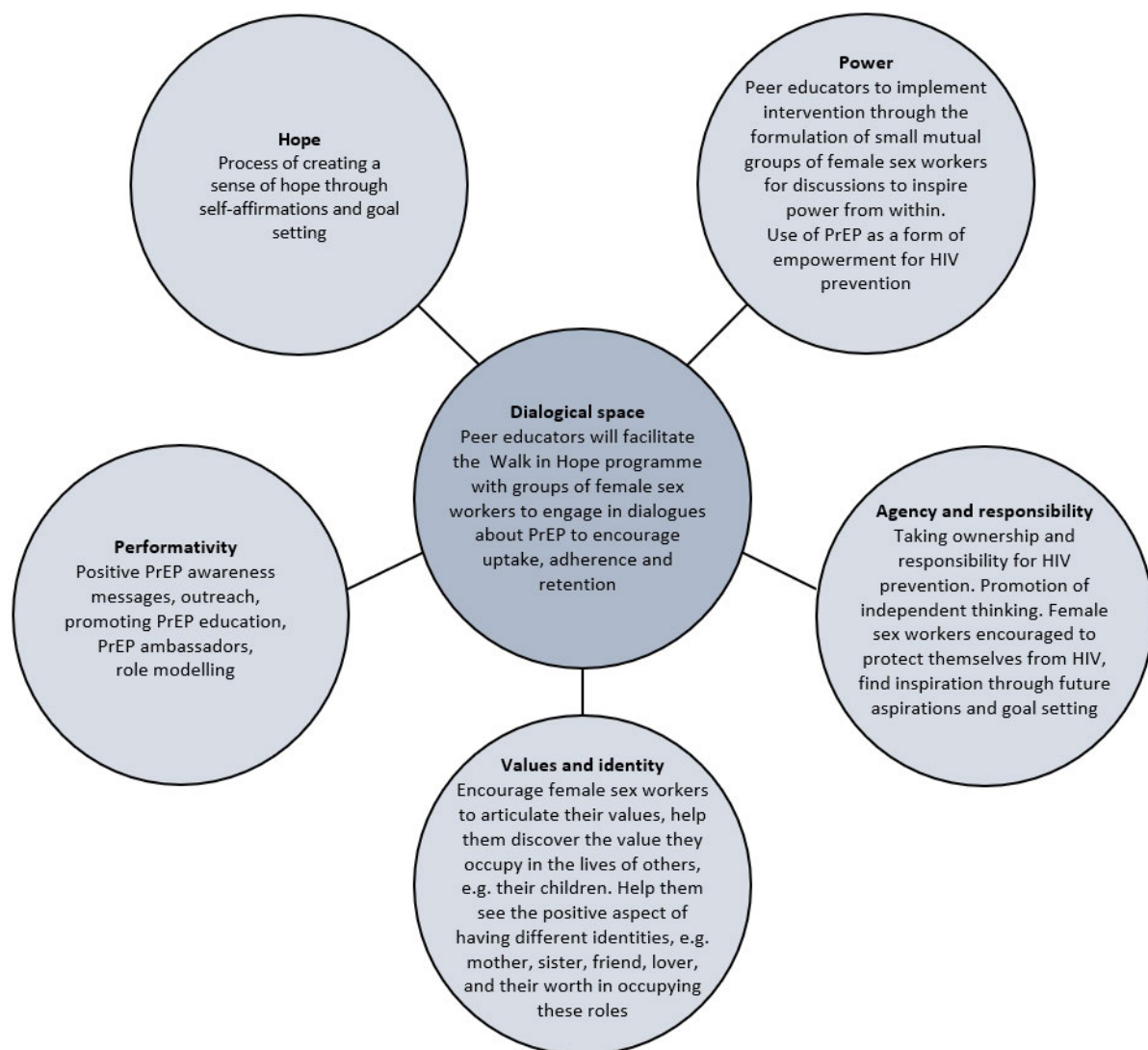
The personal component of this model emphasises the exploration of the biological and genetic aspects of an individual. These are subdivided into demand, resources, and force. Demand characteristics are an individual's physical characteristics which have a bearing on how they are perceived in the world. Certain physical attributes can mean access to resources or deprivation, depending on the sociopolitical dominant discourses prevalent in that environment. Resources characteristics are related to the mental and emotional resources such

as intelligence, skills, and material access. Force characteristics have to do with differences in temperament, motivation, and persistence (Bronfenbrenner, 1994)

Individuals are embedded within a context. This sphere consists of various layers of a social system that have a direct or indirect influence on the individual. Bronfenbrenner (1994) referred to these layers as the micro-, meso-, exo-, and macrosystems. Thus, interventions have to consider these different layers of influence and how they can intervene to ensure a conducive environment, starting with the individual's mental and emotional well-being, their interaction with family, partners and friends, as well as the community at large, including the health care systems and laws to facilitate protective factors for sustainable behavioural change. This study has demonstrated that in the case of PrEP, it is necessary to identify various personal and environmental challenges that hinder uptake and make retention difficult. Through the intervention plan designed by FSW peer educators, this plan addresses the various challenges that FSWs experience in their ecological context and show the types of changes that need to take place in the personal and environmental sphere to assist FSWs in preventing HIV.

This study utilised a participatory approach for the intervention plan and found that it is important for programmes and interventions to place FSWs at the centre of knowledge sharing and creating solutions to the problems they face. This was facilitated by the critical reflexive process of dialogue and the shifting of power from the researcher to the working group (Sliep & Kotze, 2011; Laverack, 2007). Through dialogue, a working group of FSW peer educators were able to address the problems associated with PrEP uptake, adherence, and retention. This intervention mapping process was guided by the principles of community empowerment whereby FSWs were engaged in developing and informing an intervention plan, which resulted in the *Walk in Hope* PrEP workshop programme. This programme consists of a personal development section informed by the critical reflexivity framework which utilises the narrative methodology to establish FSWs power relations, values and identity, agency and responsibility. The intervention workshop was designed by FSW peer educators which they will implement. This was also done in the hope of creating a sense of ownership to foster sustainability and possibly transferability of the programme. From the discussions, a theory of change was developed which is a detailed depiction of how the intervention will achieve its short-term and long-term outcomes. What was evident from this process was that FSWs are capable of thinking through complex problems and formulating meaningful and contextually relevant solutions. Other research (Moore et al., 2014) has shown that in most studies FSWs are at the

periphery, they are usually involved as informants, and the far end of the spectrum has been peer education which has been the golden standard of participation in the African context. However, the involvement of FSWs at the outset of the design and implementation of interventions is something that has not been adequately explored, and as shown in this study, it is feasible for FSWs to be part of complex processes and they are better suited to inform those processes because they possess a deep insider perspective. Figure 15 depicts the summarised application of critical reflexivity in informing the *Walk in Hope* PrEP intervention plan with FSWs.



**Figure 15. Critical reflexivity framework and its role in the *Walk in Hope* intervention**

### 11.5 Contribution to knowledge

The introduction of oral PrEP for HIV prevention in South Africa is still fairly new and uptake is unexpectedly low. It was thus imperative to understand the barriers and facilitators of PrEP

use among FSWs. This study was conducted among FSWs in Durban in KZN, a province with the highest HIV prevalence in South Africa. To my knowledge, no studies have so far been done on the acceptability and uptake of oral PrEP among FSWs in this part of South Africa. Studies conducted among women in the region have looked at PrEP in the form of microbicides such as tenofovir vaginal gels and intravaginal rings (Abdool Karim et al., 2015; Govender, Mansoor, MacQueen, & Abdool Karim, 2017; Govender, Mansoor, & Abdool Karim, 2017; Nota, Govender, & Vukapi, 2020), as well as acceptability of oral PrEP among men and women in the general population (Govender & Abdool Karim, 2018; Mbewe & Govender, 2020). Studies that have focused on the acceptability of oral PrEP among FSWs were conducted in the Gauteng province (Eakle, Gomez, Naicker, Bothma, Mbogua, Cabrera Escobar, et al., 2017; Eakle, Mutanha, et al., 2018).

To my knowledge thus far as a researcher, this is one of a few studies in South Africa that has explored the deeper personal motivations for PrEP use among FSWs going beyond the assumption of the need to prevent HIV to demonstrating that the drive to HIV prevention is intertwined with factors such as human agency, identity, power and values. This study has also utilised a participatory action research methodology through working collaboratively with FSW peer educators to design a community-based PrEP intervention programme. This process was achieved through the engagement of FSWs from two organisations – Sisonke and TB HIV Care – in a PrEP intervention mapping, which has not been done before in the Durban area. Furthermore, a theory of change was developed in collaboration with peer educators to demonstrate the changes that need to take place to improve PrEP uptake. No intervention plan has to date been designed with this level of collaboration by FSWs in Durban focusing on the process of improving PrEP uptake and retention, particularly with a focus on addressing the behavioural and social aspects of prevention, using the critical reflexivity approach to HIV prevention, understanding prevention by engaging participants on agency, power relations, their values and identity through community dialogues.

## **11.6 Limitations of the study**

This study was subject to the following limitations, but by virtue of this being a qualitative study, the results of this study cannot be generalised to FSW populations in other parts of South Africa. This study utilised the framework of intervention mapping, which has been criticised as a time-consuming exercise. Therefore, due to the limited duration of a doctoral study I could only thoroughly cover Steps 1 to 4 of intervention mapping. The intervention workshop

programme developed in collaboration with FSW peer educators has not yet been piloted; therefore, its implementation ability has not yet been tested and this will be conducted at a later stage. Intervention mapping is highly theoretical and, therefore, working at grassroots level means that a researcher needs to use the theoretical underpinnings in such a way that participants can comprehend. The steps of intervention mapping may need to be adapted to suite the context and population for which the intervention is intended, as well as research budget constraints.

## 11.7 Recommendations

This study recommends the following:

- Engage FSWs in the design and implementation of interventions and not simply as tail-end service users.
- For a new HIV prevention technology to be effective, buying in of the target population is important and in the case of PrEP, sex work organisations need to be at the forefront and driving the PrEP uptake initiatives.
- PrEP education needs to be clear and filtered through to the awareness messages. South Africa had one generic message for PrEP – *We are the generation that will end HIV*. FSWs did not connect with this slogan and did not understand the message behind it because it did not explain the preventative nature of PrEP. It is vital for programmes to allow each population group to design their own awareness messages (gain-frame messages) that focus on the benefits of PrEP.
- PrEP education should be clear about side effects, their tolerability and how they can be managed.
- PrEP education should emphasise the intermittent use of PrEP during periods of high risk and the ability to stop PrEP during periods of low risk.
- It is important to engage FSWs on what their perceptions of risk are and how they can gauge risk, based on their personal circumstances.
- It is important to contextualise PrEP within the existing current antiretroviral treatment knowledge to avoid confusion; antiretrovirals for both treatment and prevention; explain the physiological effects of the use of antiretrovirals for treatment and prevention in simple terms.
- Combine both PrEP and antiretroviral therapy services to normalise the use of antiretroviral therapy for prevention purposes.

- To curb the stigma of using PrEP, government needs to consider a wider population roll-out of PrEP to avoid targeting it at high-risk groups which cause resistance to uptake because of its association with marginalised populations, fuelling internalised stigma within those populations.
- The Department of Health should ensure that public health care providers have adequate knowledge about new prevention methods, as well as how to sensitively engage with high-risk groups.
- Future research should focus on developing injectable forms of PrEP to curb the need and the challenges that accompany daily pill intake.
- Furthermore, more research is needed to see whether incorporating HIV self-testing with PrEP use would be feasible.

## 11.8 Conclusion

This doctoral study has established that the introduction of PrEP as an additional HIV prevention method for high risk groups in South Africa was not well executed. The distribution of PrEP to high risk groups was as per WHO 2015 guidelines. These guidelines were adopted by the South African government without taking into consideration the context of HIV/AIDS and sex work in South Africa. This is the limitation of universal guidelines introduced by international agencies; they are adopted with little consideration for their relevance to local contexts. Despite rigorous campaigning and education about HIV/AIDS, South Africa has not succeeded in eradicating HIV stigma. There are multiple studies that have reported on the stigma associated with the taking of antiretrovirals. Introducing PrEP in this environment meant that PrEP has been subjected to the existing stigma associated with antiretrovirals and daily pill taking, which exposes one to scrutiny by family members, friends and romantic partners.

Sex work in South Africa is criminalised, resulting in added stigma and discrimination, which is evident at health care facilities. Sex workers receive health care services through donor-funded research organisations that operate mobile clinics. These research organisations are PrEP distributors that function parallel to the public health care system. FSWs have to navigate these two fragmented systems for health care. A mistake by government was not providing adequate orientation and education about PrEP among public health care service providers. Thus, when some FSWs received PrEP from research organisations, they later confirmed PrEP eligibility at public health care clinics, where health care providers dismissed PrEP as an

antiretroviral taken by HIV-positive people. This created confusion among FSWs and caused some to stop taking PrEP, while others were suspicious of the motives of the research organisations as testing PrEP on FSWs. This thinking was not completely unfounded since there have been trials a few years ago on testing microbicides (vaginal and anal) PrEP among this group. These products were never distributed to the general public. Furthermore, FSWs did not understand why government would not distribute PrEP to the wider population since South Africa generally has a high HIV prevalence among various sectors of the population.

When PrEP was introduced, there was little awareness and advocacy around its composition and effectiveness; therefore, the majority of FSWs did not know much about PrEP. The confusion was compounded by the fact that PrEP is Truvada, which is an antiretroviral. The message was not clear that antiretrovirals can be used both as prevention against HIV and as a virus suppressant for HIV-positive people. Another problem was that sex work advocacy groups were not at the forefront of PrEP promotion and programming. Donor-funded research organisations at the outset of PrEP distribution were functioning independently of sex work organisations instead of joining forces to ensure PrEP promotion through peer education. This fragmentation contributed to further confusion about PrEP.

The biomedical approach for PrEP meant the focus was on testing FSWs for HIV and initiating PrEP as well as the management of side effects. However, these interventions did not factor in the psychosocial behavioural and environmental obstacles that FSWs face that would make it difficult for FSWs to be retained on PrEP. As a result, various studies reported on the low PrEP retention rates among FSWs. It is therefore important that biomedical interventions be accompanied by raising awareness and knowledge sharing, as well as psychosocial behavioural change approaches to ensure sustainable health-related behaviour, risk assessment and prevention through PrEP and condom use. It is also important to involve the beneficiaries of these interventions in the design and implementation processes of the intervention to help inform strategies and find solutions to their own challenges. There is an intentional need to not only view FSWs as tail end service users or as peer educators who recruit participants for research and service engagement, but to position them as knowledge producers, experts in their environment and lived experiences. FSWs are capable of designing implementing programmes alongside researchers as this will increase confidence in prevention interventions as well as ensure relevance, ownership and sustainability. It is also important for researchers to involve sex work organisations as pioneers of new prevention technologies and as information disseminators to convince FSWs. It is also important to engage with various networks of FSWs

who may not have access to donor-funded mobile health care facilities. These are FSWs who trade along transport routes and highways, targeting truck drivers as well as FSWs in rural areas.

It is important to understand that FSWs are not a homogenous group, but the community of sex workers is made up of different people with varying circumstances. Street-based FSWs face different challenges from indoor sex workers. Therefore, street-based FSWs will need an intervention tailored to their needs, likewise with indoor-based FSWs. Therefore, it is necessary to create solutions to ensure daily pill taking. These solutions require a lot of premeditated advice and intentional action; therefore, it is important to engage FSWs in their agency, how they negotiate power relations, as well as their values. All of these human attributes are determining factors in how one engages in pro-social or antisocial behaviour and it is important for interventions to explore a human centred approach to HIV prevention.

The intervention developed in this study has a transformative agenda. It was also an empowering process for the FSW peer educators who created a programme that seeks to build self confidence among FSWs, restore human dignity and hope, as well as freeing FSWs from a life of fear and apathy brought on by HIV. This programme is a tool to assist FSWs to discover their deeper selves hidden under layers of shame through societal judgement. FSWs are given a moment to reflect on their choices and their complex identities as well as the dynamic roles they play in other people's lives, This is done so that a woman sees herself as more than just her occupation, which is simply sex work. Importantly, FSWs are helped to grapple with their agency, how to negotiate their power and self-manage to walk the talk in the process of effective HIV prevention.

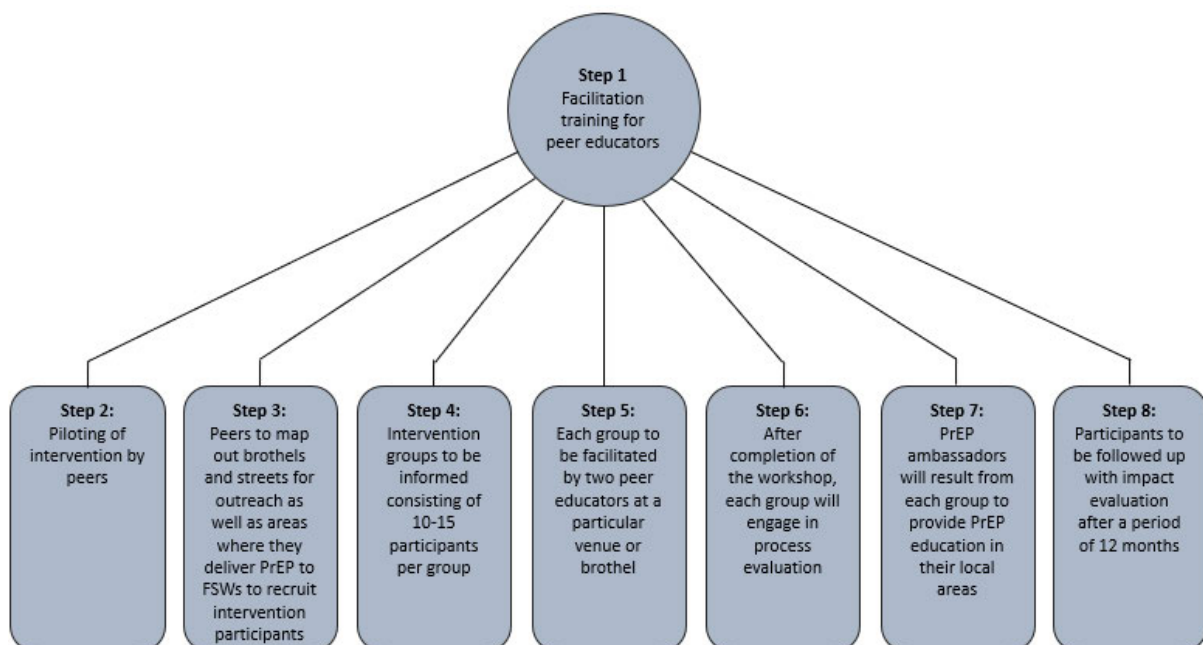
## Appendix A

### Intervention Mapping – Step 5: Planning Programme Adoption, Implementation and Sustainability

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As the implementation phase was not part of the scope of the thesis, a planning outline for implementation is provided. It is envisaged that the intervention will be rolled out first among inner-city FSWs. Existing organisations, such as Sisonke, TB HIV Care, MaTCH, and the national and provincial Departments of Health will be engaged as potential implementing partners. The peer educators will present the programme outline to the representatives of these organisations to demonstrate a sense of ownership. These organisations will be approached as potential implementing partners because MaTCH already runs a PrEP programme for adolescents at public health facilities in Durban. They utilise the peer navigation approach whereby peer educators approach young people within the facilities to inform them about PrEP. The Department of Health will also be approached to provide PrEP training to public health care staff. Prior to implementation, the intervention will be piloted. The steps of the implementation plan are depicted in Figure 16.



**Figure 16. Pilot study – Implementation and Evaluation Plan**

### **Step 1 – Training of Walk in Hope Programme facilitators**

Prior to the piloting phase, there will be a training of peer educators. This training will include facilitation skills as well as how to work with life stories through the use of the narrative methodology. Even though narrative methodology is a specialised skill, peer educators will be trained on the basics of life story work to cater to their level of comprehension and practice. Many of the activities in the intervention programme are practical to suit the needs and competencies of the recipients and facilitators of the programme. The programme will be translated into isiZulu since it is the main language spoken in Durban.

### **Step 2 – Pilot phase**

The pilot phase will be conducted by the peer educators. One group of volunteers (10–15) will be recruited, and two facilitators will run the programme and the other peer educators will observe and provide comments and feedback. At the end of the sessions, a process evaluation will be conducted by the peers as well as an impact evaluation to test the evaluation tools. The evaluation tools will be tested and assessed for clarity and possibility for self-administration.

### **Step 3 – Implementation phase**

This step consist of planning to prepare for implementation. Peer educators will conduct a community mapping process to plan for recruitment. Some of the sex work venues will include those that peer educators already have access to and are conducting PrEP outreach or delivering PrEP to FSWs in those areas through TB HIV Care and Sisonke. The intervention will target FSWs who tested negative and are contemplating using PrEP, as well as those who are taking it regularly and those who have defaulted or have completely stopped.

### **Step 4**

Participants recruited to participate in the workshops will be placed in groups of 10 to 15 participants per group.

### **Step 5**

Peer educators will be divided into two facilitators per group. A peer educator with strong facilitation skills will be paired with another individual who may have strong organisational skills so that they can complement one another. Numerous groups will be running concurrently at different venues. Brothel-based FSWs will have groups running at the brothels, provided that there are rooms where they can be accommodated and that the brothel owners are agreeable. However, if this will not be possible, a venue located in the city centre will be booked. The programme is designed so that it can be run for eight days with the same group,

thus the participants will be expected to avail themselves for a minimum of eight days to complete the whole programme for about four hours a day. The exact duration of the programme will be firmly established during the piloting phase.

It is anticipated that one of the main challenges in running this programme will be attendance. Having a consistent group of FSWs attending the workshop for all eight days will be a challenge due to the pressure to make a daily income; thus, the participant reimbursement of R100 (\$6.50) per day will ensure that they have some money to cover their daily expenses. This amount is not too high to coerce participation and it is not too low either, but it is what an average FSW would have made in those hours should they have been working. The reimbursement of FSWs for participation in research has been listed as an ethical practice of beneficence (Bloomquist, 2020). Refreshments will also be served to ensure that participants feel comfortable and valued.

### **Step 6**

At the end of the workshops, participants will be engaged in a process evaluation to ascertain whether the intervention has been implemented as intended. (See Impact Evaluation, Appendix B.)

### **Step 7**

Among the group of participants, those who have shown enthusiasm for the programme and have attended all eight days and have shown a willingness to take PrEP consistently, will be encouraged to volunteer as ambassadors or PrEP enthusiasts. Ambassadors will promote PrEP in their respective work areas. They will be incentivised with grocery vouchers for each FSW they refer to the programme.

### **Step 8**

The goal of this intervention is to have 100 FSWs who have participated in the study over a period of one year. Participants will be followed up to participate in an impact evaluation which will be conducted pre and post participation at intervals (comparative interrupted time series design) to monitor whether the intervention had an impact on their choices regarding PrEP use and whether participants have remained HIV negative. (See appendix B for the impact evaluation process.)

## **Appendix B**

### **Intervention Mapping – Step 6: Evaluation Plan**

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The purpose of developing a public health intervention is to respond to health concerns and improve the health of at-risk population groups. Interventions that respond to various health concerns are multifaceted and respond at different ecological levels, for example, individual, interpersonal, and organisational levels (Moore et al., 2014). Interventions are also embedded and delivered in a social system and specific environment that may determine whether the intervention succeeded or not. Complex interventions are multidimensional in nature in that they seek to address a health issue at various societal levels (O'Cathain et al., 2019). The list of factors that qualify an intervention as complex refers to its multidimensional nature, in other words, addressing both personal and environmental factors to influence change; the number and difficulty of behaviours required by those delivering or receiving the intervention; the number of groups or organisations targeted by the intervention and the degree of flexibility or tailoring of the intervention (Craig et al., 2008). To evaluate these types of interventions requires evaluators to tackle the various levels of complexity and move beyond asking questions of whether the intervention works, to looking at both outcomes and processes (Moore et al., 2014).

#### **Process evaluation**

Before embarking on process evaluation, it is important for the researcher to consult the literature regarding the various interventions that have been done in the specific field of study. In doing so, the researcher will be able to ascertain what has been done and how those studies have been evaluated in relation to what they sought to do (Weir, Sabin, Abdul-Quader, Au, Bok, & Butler, 2014). In the case of this study, a systematic scoping review has been conducted and various HIV prevention interventions among FSWs have been considered; however, what made this particular intervention unique is that it was designed by FSWs for FSWs utilising the method of intervention mapping in a participatory manner, with FSWs as the main implementers of the intervention in the pilot study and beyond. It is, however, envisaged that other facilitators would be trained should the programme be extended to the KZN province. It is important to monitor whether the intervention is being implemented as planned in relation to the quality and scale required to achieve the intended outcomes.

Process evaluation is used to monitor the input, quality, and output of an intervention. It entails documenting and collecting information about the way in which the programme was implemented and received by the target population (Richards & Hallberg, 2015). Furthermore, process evaluation captures details around accessibility of the service or intervention, whether the intervention reached the intended population, how the services were delivered, participant or user satisfaction, and perceptions regarding needs and management practices (Murdoch, 2016). This information is collected at the intervention sites and should be collected during the process of the intervention to make the necessary improvements and adjustments as the intervention is being rolled out.

To achieve the intervention activities, it is important to identify the resources needed. Process evaluation therefore offers planners an opportunity to appraise the available resources as well as to ascertain whether there is a resource gap. Planners need to ask themselves the following questions: What is the gap between the amount of funds needed to meet the targets and the amount available? What is the gap between other resources needed to meet the targets and resources available? The funds can be captured on a Microsoft Excel spreadsheet. An inventory of inputs will consist of a number of peer educators/programme staff, number of workshops conducted, number of people who attended workshops, number of FSWs who volunteered as PrEP ambassadors, educational materials, funds needed for venues, stationery, transport and remuneration for peer educators, refreshments, participant reimbursement to cover time and transport, and number of implementing partners:

*Inventory of inputs*

<b>Resources</b>	<b>Service delivery level</b>
Venue rental	Sex worker-friendly space
Car rental	Transportation of peer educators to various brothels
Remuneration	Peer educators Drivers
Participant reimbursement	Participant’s time and transportation Monthly vouchers for PrEP ambassadors (vouchers given are based on the number of people referred on PrEP and initiated)
Personnel	Eight peer educators as implementers PrEP ambassadors
Supplies	T-shirts Information education communication materials Training equipment Stationery

Resources	Service delivery level
Skills	Facilitation training Training on working with life stories (narrative therapy) Basic report writing Basic data capturing
Funding	Budget for each intervention item The gap between the amount of funds needed to meet targets subtracted from the funds available $\text{Funds received} - \text{Funds expended} = \text{Funds available}$ Monthly monitoring of costs

### Quality monitoring

It is important to monitor the quality of the programme and the services provided. For instance, the implementation staff should be well trained on communication and facilitation skills. Quality is concerned with the availability, acceptability, and accessibility of services. In practical terms, this can be broken down into services being offered, the need to be available at all times, the venue where the services are provided, needs to be safe and easily accessible, as well as ensuring that the supplies and equipment needed are available. Quality is measurable, provided that there are existing standards that have been approved at national level; however, it is important to gain input from experts, providers, and the people being served. Furthermore, quality encompasses the scope of the intervention, safety measures, consistency, and appropriateness of the service for the population being served, as well as to ensure user satisfaction.

It is also important to ascertain whether services are being implemented as planned. This refers to the fidelity of the intervention (CDC, 2020b). This involves access to services, whether these services reach the intended population, in this case sex workers, and how services are delivered. This intervention is designed in such a way that the implementers should be FSWs. It is also important to assess the intensity of the programme exposure for participants. In the case of this programme, it is important that participants attended all eight days of the workshop. A process evaluation enables implementers to understand the socio-economic, legal, and cultural factors that affect the programme. Methods used to gather data for process evaluation are mainly interviews, observations, focus groups, and facility audits (Bess, King, & LeMaster, 2004).

Interviews with intervention participants can provide insights on their experiences, perceptions, and satisfaction with the services received. The following table gives a list of questions that can be posed to participants.

*Questions to be posed to participants*

Process evaluation questions	Indicators
Was the intervention delivered as intended?	<p>Did the programme consist of FSWs?</p> <p>Was the programme implemented by FSW peer educators and delivered to FSWs?</p> <p>Were groups of 10–15 FSWs created and facilitated by two peer educators?</p> <p>Did FSWs participate in all eight workshops? (Participants need to sign an attendance register.)</p> <p>How many sex workers did the intervention reach in a month? (The target is 100 per year.)</p>
Were the implementers of this intervention welcoming and respectful?	<p>Were FSWs comfortable with interacting with the facilitators?</p> <p>Were they comfortable to voice their concerns regarding the intervention?</p>
Was the intervention programme relevant?	<p>Was the intervention programme culturally appropriate and relatable to FSWs?</p> <p>Has the programme been translated into the relevant languages?</p> <p>Was the programme easy to follow?</p> <p>Were the activities simple and comprehensible?</p> <p>Did the programme goals and objectives of the intervention address the needs identified and will they eventually contribute to the quality of life among FSWs?</p>
Was the intervention venue safe and easily accessible?	<p>Were FSWs comfortable with coming to the venue?</p> <p>Did they feel that the venue is discreet and psychologically safe? (In the sense that they will not be subjected to stigma and discrimination or unnecessary exposure)</p>
Assessing knowledge about PrEP	<p>Were FSWs able to explain the difference between PrEP being an antiretroviral that prevents HIV vs antiretrovirals for HIV-positive people?</p>
Have the selected theoretical methods been applied and operationalised appropriately through the activities?	<p>Were FSWs able to express confidence in taking PrEP (self-efficacy)?</p> <p>Were FSWs able to explain their use of PrEP to partners and peer educators?</p> <p>Were FSWs able to express a sense of personal agency in taking PrEP?</p> <p>Were they able to associate PrEP with the power to prevent HIV?</p> <p>Were they able to connect their future aspirations and goals with PrEP?</p> <p>Did PrEP provide FSWs with a sense of hope?</p> <p>Were FSWs able to identify with PrEP role models?</p> <p>Participants and facilitators to keep a field diary to record these transitions.</p>
Did the intervention result in PrEP ambassadors?	<p>Each session should result in a minimum of two volunteer PrEP ambassadors from different sex work venues and streets.</p> <p>Peer educators need to generate an ambassador list.</p>

## Appendix C

### Impact evaluation

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The role of the impact evaluation is to ascertain the causal effect of an intervention. The impact evaluation looks at the changes in the outcome that can be directly attributed to the programme. The focus is on causality and various methods that can be used to investigate this causality or impact of the intervention (Gertler, Martinez, Premand, Rawlings, & Vermeersch, 2016; White, 2010). The way in which impact or change can be measured is by ascertaining what that change looks like among those exposed to the intervention, and also have a comparison group with those who were not part of the intervention to analyse the differences between the two groups. Impact evaluations are important because implementers can ascertain the effectiveness of a programme and, if established, that programme can be rolled out at a much larger scale (Imas & Rist, 2009); the results can inform policy and improve health care approaches. For the purpose of this thesis, a possible impact evaluation plan is however provided; since the implementation of this intervention is beyond the scope of this thesis, the proposed evaluation plan has not been tested.

Randomised control trials (RCTs) are considered the ultimate golden standard as an impact evaluation design because of their internal validity and efficacy (Hariton & Locascio, 2018). Randomisation and a large sample are important in RTCs because they ensure that anyone in the population has a fair chance of being sampled to mitigate against bias. This is what makes RCTs reliable as they provide the most accurate estimate of what the outcome is if one were exposed to the intervention, or if they were not (Cartwright, 2010). In the light of the intervention designed in this thesis, an RCT may not be feasible, first, because RCTs are time-consuming and costly; and second, randomisation may not be feasible with this population of FSWs because of their hidden nature and the need to purposively sample FSWs who are HIV negative and are on PrEP (Tomlinson, Ward, & Marlow, 2015). Therefore a quasi-experimental controlled or comparative interrupted time series (CITS) design is proposed. The CITS is a type of design that includes a control group that is observed during the same time as the treatment group but does not receive treatment (Sage Publications, 2019; St. Clair, Hallberg, & Cook, 2016). This will provide evidence to establish a causal relationship between the intervention and the outcome. Conversely, the presence of a control group may provide alternate effects not related to the intervention that may influence the outcomes. Both the

intervention group and the control group need to be analysed at the same point in time so that other time-sensitive factors, such as other interventions that would affect both populations, can be accounted for. However, it is important to note that observed effects could be attributed to other confounding factors, either than the intervention, which may be unknown or difficult to measure. Randomisation addresses this issue in other RCTs; however, randomisation may not be favourable or practical in some public health studies, particularly in this study with FSWs. The CITS design employs multiple pre-intervention and post-intervention analysis so as to account for underlying trends and changes. It is important that the selected control group shares similar characteristics as the intervention group; the only difference being non-exposure to the intervention (Bernal, Cummins, & Gasparrini, 2018; Biglan, Ary, & Wagenaar, 2000). In the case of this study, FSWs who are HIV negative will be selected based on their exposure to the TB HIV Care PrEP services which both groups are exposed to; however, the control group will not be exposed to the Walk in Hope PrEP programme designed in this doctoral thesis.

The CITS design is suitable to track changes of behaviour over time and to measure progress. Through a series of repeated measures pre and post intervention, it becomes evident how change is taking place. This type of design has been used in behavioural change interventions to track changes in behaviour over time and it has also been used to track the adoption and effects of policies. It is important to outline that the challenge with this design is that change could be caused by numerous other factors in the social world that co-occur with the intervention and it is important to account for these. Therefore, it is important to have multiple measurements of change over time so as to track the impact attributable to the intervention.

This intervention will consist of two groups: the intervention group and the control group. This will be FSWs residing in the Ethekwini municipality in Durban and both these groups would have been exposed to the TB HIV Care PrEP programme. The eligibility criteria will be FSWs who have sold sex for money for the last six months, who have tested HIV negative and have been made aware of PrEP or had been initiated on PrEP. One group will undergo the Walk in Hope eight-week intervention programme and the other group will be a control group. Prior to participation in the intervention, both groups will undergo a pre-test survey questionnaire. This questionnaire will test their levels of PrEP knowledge, their sense of motivation to take PrEP and self-efficacy. The intervention group will undergo the intervention for eight weeks, thereafter a post-test survey questionnaire will be administered to both groups. That preliminary data will be analysed. The first follow-ups will be conducted three months after the initial survey where participants will be asked to fill in another survey questionnaire, and

the last follow-up will be done within another three months; thus, there will be a total of three follow-ups, excluding the initial pre-test survey questionnaire. Participants records will be accessed through TB HIV Care who are responsible for HIV testing and PrEP initiation among FSWs.

The survey questionnaire will consist of demographic information; the rest of the questionnaire will be informed by the information motivation behavioural skills model (IMB). The assumptions that the IMB framework makes are that to the extent that risk groups are well informed about PrEP, motivated by their knowledge and also equipped with the necessary skills to seek out and initiate PrEP, they will successfully overcome obstacles to initiate and adhere to PrEP (Fisher & Fisher, 2002). The adaptation of IMB for this study is because the intervention seeks to understand levels of PrEP education, measure motivation, agency and self-efficacy in relation to PrEP use as well as willingness to change behaviour. Only a few studies have used IMB in the design of PrEP survey questionnaires among other high risk groups (Fisher, Fisher, Bryan, & Misovich, 2002; Qu, Zhong, Lai, Dai, Liang, & Huang, 2019). The use of the IMB framework for the design of survey questionnaires is that it does not focus on a single issue but draws on various complex issues that relate to one another to form a web that influences the user’s engagement with PrEP (Shrestha, Altice, Huedo-Medina, Karki, & Copenhaver, 2017). The impact evaluation survey questionnaire follows below. This questionnaire will be administered during the pre-test with both the intervention group and the control group; it will also be administered to both groups as a post-test, as well as in three-months intervals after the intervention so as to monitor changes in behaviour as well as in PrEP retention.

**Please fill in the following information**

Information	Responses
Gender	
Age	
Nationality	
Race	
Home language	
Educational level	
Marital status	
Have a live-in sexual partner	
Sold sex in the last 6 months	
Have tested for HIV in the last 6 months?	
HIV status?	
Taking PrEP?	
Contemplating to take PrEP?	

Information	Responses
Have you heard of the TB HIV Care PrEP programme?	
Are you part of the TB HIV Care PrEP programme?	
Have you heard of the Walk in Hope PrEP programme?	
Have you participated in the Walk in Hope PrEP programme?	

**Tick ‘yes’ or ‘no’ or ‘maybe’**

PrEP Information	Yes	No	Maybe
Have you heard about pre-exposure prophylaxis (PrEP)?			
Is PrEP easily accessible for you?			
Are PrEP providers friendly?			
Have you been exposed to information about PrEP through TB HIV Care?			
Have you been exposed to information about PrEP through any other organisation?			
PrEP provides protection against HIV			
PrEP is the same as post exposure prophylaxis (PEP)			
PrEP provides protection against other sexually transmitted infections			
PrEP should be taken for a minimum of 28 days before it can be effective in protecting against HIV			
While on PrEP I don’t need to use condoms			
Condoms are a replacement for PrEP			
Can I engage in unprotected sex on the day I initiate PrEP?			
I need to take PrEP once every day at a specific time			
I need to take PrEP the day before I engage in unprotected sex			
I need to take PrEP a few hours or minutes before I engage in unprotected sex			
PrEP is an antiretroviral taken by HIV-negative people			
While on PrEP I have to get tested for HIV regularly			
The short-term side effects of PrEP include nausea and dizziness, weight loss and others			
I need to take PrEP during periods of high risk			
I can take PrEP while pregnant			
I need to take PrEP all my life			
I can continue to take PrEP even when my HIV status is no longer negative			
I believe that all female sex workers are HIV positive			
Taking PrEP will cause drug resistance			
Sex workers that are blood type O cannot get infected with HIV			

**Please tick under the appropriate response**

PrEP motivation	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I would be less worried about contracting HIV if I was on PrEP					
If I was on PrEP, I would be less concerned about side effects					
If I disclose that I am on PrEP to my sex partner, he/she would be comfortable with it					
If I disclose that I am on PrEP to my friends, they would be comfortable with it					
I have a responsibility to contribute to HIV prevention efforts by taking PrEP					
I have aspirations for the future that motivate me to take PrEP					
I have people in my life that need me to live longer and prevent HIV, hence I take PrEP					
I have family members or friends that encourage me to take PrEP consistently					
PrEP is my source of hope for preventing HIV					
Preventing HIV is part of my personal responsibility to myself and others					
PrEP is in line with my personal values					
Taking PrEP is related to who I am as a person					
Taking PrEP is in line with my personal goals					
Taking PrEP shows that I value my life					
Taking PrEP is an expression of self-love					

PrEP behavioural skills	Not at all confident	Slightly confident	Somewhat confident	Fairly confident	Completely confident
How confident are you that you will routinely take PrEP daily?					
How confident are you that you will continue to take PrEP even when you experience side effects?					
How confident are you that you will contact a peer educator or health care provider to assist you in managing side effects?					
How confident are you that you can get PrEP refills before you run out?					
How confident are you that you will make sure you have PrEP with you when travelling to another province?					
How confident are you that you can take time to get a PrEP refill even when your working schedule is busy?					
How confident are you that you will have your PrEP medication with you when spending time with clients overnight?					
How confident are you that you can take PrEP while spending the night with a client?					

PrEP behavioural skills	Not at all confident	Slightly confident	Somewhat confident	Fairly confident	Completely confident
How confident are you that you can take PrEP while living with your intimate sexual partner?					
How confident are you that you can disclose taking PrEP to your intimate sexual partner?					
How confident are you that you will continue to take PrEP even if your intimate sexual partner does not agree?					
How confident are you that you will continue to take PrEP even if your intimate sexual partner threatens to end the relationship?					
How confident are you that you will continue to take PrEP even if your partner labels you HIV positive?					
How confident are you that you will disclose taking PrEP to your friends?					
How confident are you that you will continue to take PrEP even if your friends do not agree?					
How confident are you that you will continue to take PrEP even when you friends label you as HIV positive?					
How confident are you that you will continue to take PrEP even when you experience PrEP stigma?					
How confident are you that you continue to use condoms while you take PrEP?					
How confident are you that you will be able to assess your exposure to HIV risk and take PrEP during those periods?					
How confident are you that you will remember take PrEP even under the influence of alcohol?					
How confident are you that you will remember to take PrEP even under the influence of drugs?					
How confident are you that you will not stop taking PrEP?					
How confident are you that you will remain on PrEP for as long as you are practicing sex work?					

## Appendix D

# Ethics Approval Letter

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15 May 2018

Ms Nosipho Makhake 214580306  
School of Applied Human Sciences  
Howard College

Dear Ms Makhakhe

**Protocol reference number: HSS/0203/018D**

**Project title:** Let's talk about PrEP: A diagonal space on sex work and HIV prevention for FSWs in Durban South Africa.

#### Full Approval – Full Committee Reviewed Application

With regards to your response received on 11 May 2018 to our letter of 19 April 2018, the Humanities and Social Sciences Research Ethics Committee has considered the abovementioned application and the protocol have been granted FULL APPROVAL.

**Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number.**

**Please note: Research data should be securely stored in the discipline/department for a period of 5 years.**

**The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.**

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

.....  
Dr Shamila Naidoo (Deputy Chair)

/px

cc Supervisor: Prof Anna Meyer-Weitz and Prof Yvonne Sliep  
cc Academic Leader Research: Dr Lauren Dyll  
cc School Administrator: Ms Ayanda Ntuli

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Humanities & Social Sciences Research Ethics Committee

Professor Shenuka Singh (Chair)

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Website: [www.ukzn.ac.za](http://www.ukzn.ac.za)



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## Appendix E

### Gatekeepers Letter

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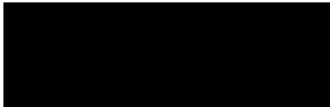
DATE : 18 APRIL 2018

Dear Ms Makhakhe

#### RE: PERMISSION TO CONDUCT RESEARCH

Coordinator and Members of Mother for the Future hereby grants permission for you to conduct research in partnership with SWEAT and Sisonke towards your PhD research entitled *Let's talk about PrEP: A dialogical space on sex work and HIV prevention for female sex workers in Durban*. You can proceed with your study provided that ethical clearance has been obtained. Data collected must be treated with due confidentiality and anonymity.

Kind Regards



EMILY CRAVEN  
DIRECTOR  
SWEAT

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Vincent  
East London  
Tel: 074 124 0547

## **Appendix F**

### **Informed Consent**

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#### **Information sheet for participants**

Dear Participant

Good Morning/afternoon, my name is Nosipho Faith Makhakhe. I am a student in the School of Applied Human Sciences. I am doing my PhD in Health Promotion and Communication (Student number: 214580306) at the University of Kwa-Zulu Natal, 4041, Durban, South Africa. I am conducting research on the use of pre-exposure prophylaxis (PrEP) among female sex workers. I would like to speak to you only if you agree to speak to me.

This discussion will take about 40 minutes to 1 hour. I will ask you to talk about the use of PrEP among FSWs in relation to their knowledge, acceptability, accessibility of PrEP for FSWs in Durban. I will also ask you about your experiences in distributing PrEP to this population. I will need your permission to use audio-tape recorders to capture our discussion. All information that you give will be kept confidential. The information collected will be stored in my office and only my supervisor and research assistants working with me on this project will have access to it. Information will be used for research purposes alone and raw data will be destroyed as soon as the study is completely over. Also, we will not use your actual name or designation in reporting the findings of the study but will use disguised name to make sure that no one links the information you have given us to you.

You will not be given any monetary payments for participating in the study, but your department/ organisations/ community/ the government will benefit from this study immensely. The results will help us ascertain whether FSWs are accessing PrEP and whether they are willing to use it, and how we can improve knowledge and distribution. Your participation in this study is voluntary and you have the right not talk to us if you do not want to. If you agree to take part in the study, we will ask you to sign a form as an indication that we did not force you to participate in the study. Please note that you will not be at any disadvantage if you choose not to participate in the study. You may also refuse to answer particular questions if you do not feel comfortable answering them. You may also end the discussion at any-time if you feel uncomfortable with the interview. In case you want to withdraw information given after the interview, you can call me on 084 478 4090.

## **Information sheet for female sex workers (Intervention mapping phase)**

Dear Participant

Good Morning/afternoon, my name is Nosipho Faith Makhakhe. I am a student in the School of Applied Human Sciences. I am doing my PhD in Health Promotion and Communication (Student number: 214580306) at the University of Kwa-Zulu Natal, 4041, Durban, South Africa. I am conducting research on the use of pre-exposure prophylaxis (PrEP) among female sex workers. I would like to speak to you only if you agree to speak to me.

This discussion will take about 1 to 2 hours. In this dialogical space you will be asked to talk about your experiences in relation to sex work and HIV prevention, particularly PrEP. In this space, you will be encouraged to reflect on how you have positioned yourself in relation to your power, decisions, as well as your values and responsibilities when it comes to HIV prevention. In this discussion you will be encouraged to think of alternative ways in which you can deal with some of the personal, structural, and social challenges you face, which make it difficult for you to engage effectively in HIV prevention. I will need your permission to use audio-tape recorders to capture our discussion. All information that you give will be kept confidential. The information collected will be stored in my office and only my supervisor and research assistants working with me on this project will have access to it. Information will be used for research purposes alone and raw data will be destroyed as soon as the study is completely over. Also, we will not use your actual name or designation in reporting the findings of the study but will use disguised name to make sure that no one links the information you have given us to you.

You will be reimbursed for your time and transport costs that you have incurred in participating in this study. This study has the following possible risks; participants may risk being discriminated against for participating in this study or risk being exposed by other participants to those who are not part of the study. Your participation in this study is voluntary and you have the right not talk to us if you do not want to. If you agree to take part in the study, we will ask you to sign a form as an indication that we did not force you to participate in the study. Please note that you will not be at any disadvantage if you choose not to participate in the study. You may also refuse to answer particular questions if you do not feel comfortable answering them. You may also end the discussion at any-time if you feel uncomfortable with the interview. In case you want to withdraw information given after the interview, you can call me on 084 478 4090.

School of Applied Human Science, College of Humanities, University of KwaZulu Natal,  
Howard College Campus

Dear Participant

### INFORMED CONSENT LETTER

My name is Nosipho Faith Makhakhe. I am a Health Promotion PhD student, studying at the University of Kwa-Zulu Natal, Durban, South Africa. I am conducting research on the use of pre-exposure prophylaxis (PrEP) among female sex workers. To gather the information, I will ask you some questions only if you agree to speak to me.

Please note that:

- Your confidentiality is guaranteed as your inputs will not be attributed to you in person but reported only as a population member opinion.
- Any information given by you cannot be used against you, and the collected data will be used for purposes of this research only.
- Data will be stored in secure storage and destroyed after five years. Only me, the research assistants and supervisor will have access to the data.
- You have a choice to participate, not participate or stop participating in the research. You will not be penalised for taking such an action.
- If you are willing to be interviewed, please indicate (by ticking as applicable), whether or not you are willing to allow the interview to be recorded by the following equipment:

	willing	Not willing
Audio recording		

I can be contacted at:

Cell Phone: 084 478 4090

Email: Makhakhe945@gmail.com

My supervisor is Anna Meyer-Weitz who is located at the School of Applied Human Science, Durban at the University of KwaZulu Natal.

Contact Details:

Phone number: 031 260 7618

Email: [Meyerweitza@ukzn.ac.za](mailto:Meyerweitza@ukzn.ac.za)

You may also contact the Research Office through:

HSSREC Research Office

P. Mohun

Contact Details:

Phone number: +27 31 260 4557

Email: [mohunp@ukzn.ac.za](mailto:mohunp@ukzn.ac.za)

INFORMED CONSENT FORM

I..... (full names of participant) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire without any negative consequences.

SIGNATURE OF PARTICIPANT

DATE

.....

.....

## Appendix G

### Interview Guides

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#### **Semi-structured interview guide for participants**

Before we begin, please tell me your name, age, educational level, occupation and your involvement with FSWs

- 1.) What is PrEP?
- 2.) Who qualifies for PrEP in South Africa?
- 3.) How is PrEP prescribed and under what circumstances?
- 4.) Do you think health care providers have enough knowledge and know how to prescribe PrEP? (Probe do they have to attend any special training?)
- 5.) How does it work? (Probe how soon does it become effective when one starts taking it? Can one stop using it anytime? What about drug resistance?)
- 6.) Is it safe to take PrEP while drinking alcohol or on recreational drugs?
- 7.) Is it necessary for one to still use a condom while on PrEP?
- 8.) Are there any side effects that potential users should worry about?
- 9.) Is PrEP safe to use during pregnancy or when breastfeeding?
- 10.) Do you think the current provision of PrEP in South Africa is economically sustainable?
- 11.) Where can FSWs access PrEP?
- 12.) Has your organisation faced any challenges in providing PrEP to FSWs?  
How long are you planning to provide PrEP to FSWs?
- 13.) In your experience what do you think FSWs know about PrEP?
- 14.) What do you think is their level of understanding in terms of how it works?
- 15.) Are FSWs aware of where they can access PrEP? (If they are where is it being prescribed? If not, how can we create awareness?)
- 16.) What are your thoughts about the acceptability of PrEP among FSWs?
- 17.) FSWs will have to take PrEP daily for it to be effective, how feasible do you think this will be for them?
- 18.) What challenges do you think FSWs will face in taking PrEP?
- 19.) In what way do you think the provision of PrEP will affect sexual relations between FSWs and their clients?
- 20.) Is PrEP a change factor for female sex workers regarding HIV prevention/ Will it help to make a difference in their prevention of HIV?
- 21.) How do you think the introduction of PrEP among FSWs affect condom use?
- 22.) How do you think FSWs will deal with the issue of adherence to PrEP?
- 23.) How has the use of PrEP been communicated or advertised to FSWs?
- 24.) Are FSWs organisations involved in the distribution of PrEP or creating awareness about it?
- 25.) In what ways do you distribute PrEP to FSWs?
- 26.) Have you been able to reach FSWs working in various contexts? (Probe for streets, brothels/hotels/escort agencies)
- 27.) At the moment is the uptake and use of PrEP among FSWs divided through racial and socio-economic lines?
- 28.) In what age groups are the FSWs accessing PrEP?

- 29.) Would you say that the FSWs accessing PrEP are women who are in their early stages of sex work or is it women who have been doing sex work for some time more than a year for instance?
- 30.) In your opinion what do you think can be done to reach sex workers with PrEP early to ensure that we lessen the rise of new HIV infections?
- 31.) Do you think sex workers are aware of their risk to HIV (Probe does that awareness develop over time in the industry or is it something they are aware of as soon as they enter sex work?)
- 32.) How do you think the government and civil society including sex work organisations can stimulate social action for PrEP?

### **Topic guide for dialogical space intervention**

Before we begin, please tell me your age, race, nationality, marital status, educational level, language, current place of residence, and period of time in sex work.

#### **Section A: HIV prevention-PrEP**

Activity: Start the session by welcoming FSWs to the dialogical space, provide a report back from the data gathered during the social assessment. Go through the proposed topics for dialogue and ask FSWs to provide input and suggestions. Proceed to questions below.

What do you as FSWs understand about HIV prevention?

How do FSWs engage in HIV prevention?

Why do they engage with it in that way?

What has influenced their decision to engage in HIV prevention in that way?

Are FSWs aware of PrEP as another strategy to HIV prevention? (Probe- if so how did they learn about it?)

Is PrEP accessible to FSWs? (Probe-are they willing to use it?)

Can they explain how it works?

How can the use of PrEP be advertised or communicated to FSWs?

What are some of the reasons that could cause FSWs not to use PrEP?

In your opinion do you think PrEP is easily accessible? (Probe if not why and how can access be improved? if it is, where do they access it?)

Do you think that FSWs working in different settings will find it easy to access PrEP? (Probe-How can access be improve?)

## References

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- Abdool Karim, S. S., Abdool Karim, Q., Kharsany, A. B., Baxter, C., Grobler, A. C., Werner, L., ... Mindel, A. (2015). Tenofovir gel for the prevention of herpes simplex virus type 2 infection. *New England Journal of Medicine*, 373(6), 530–539.
- Acon Health Limited. (2016a). PREP side effects – What do I do if they happen? [Online] <https://endinghiv.org.au/blog/prep-side-effects/#>
- Acon Health Limited. 2016b. Prepped for PrEP. Understanding PrEP, PEP & Truvada. [Online]. <https://endinghiv.org.au/blog/understanding-prep-pep-truvada/>
- Acon Health Limited. (2018). Prepped for PREP: Understanding PrEP, PEP & Truvada. Everything you need to know in one easy location to keep you informed. [Online] <https://endinghiv.org.au/blog/understanding-prep-pep-truvada/#>
- Agha, S., & Van Rossem, R. (2004). Impact of a school-based peer sexual health intervention on normative beliefs, risk perceptions, and sexual behavior of Zambian adolescents. *Journal of Adolescent Health*, 34(5), 441–452.
- AIDS.gov. (2020). *A timeline of HIV/AIDS*. U.S. Department of Health & Human Services. Retrieved from <https://www.hiv.gov/sites/default/files/aidsgov-timeline.pdf>
- Albright, E., & D'Adamo, K. (2017). Decreasing human trafficking through sex work decriminalization. *AMA Journal of Ethics*, 19(1), 122–126.
- Alderman, L. (2014). Purposeful program theory: Effective use of theories of change and logic models [Book Review]. *Evaluation Journal of Australasia*, 14(1), 46–47. <https://eprints.qut.edu.au/76537/>
- Amico, K. R., & Bekker, L.-G. (2019). Global PrEP roll-out: Recommendations for programmatic success. *The Lancet HIV*, 6(2), e137–e140.
- Amico, K. R., Mansoor, L. E., Corneli, A., Torjesen, K., & Van der Straten, A. (2013). Adherence support approaches in biomedical HIV prevention trials: Experiences, insights and future directions from four multisite prevention trials. *AIDS and Behaviour*, 17, 2143–2155. doi:10.1007/s10461-013-0429-9

- Anderson, E. S., Wagstaff, D. A., Heckman, T. G., Winett, R. A., Roffman, R. A., Solomon, L. J., ... Sikkema, K. J. (2006). Information-motivation-behavioral skills (IMB) model: Testing direct and mediated treatment effects on condom use among women in low-income housing. *Annals of Behavioral Medicine*, *31*(1), 70–79.
- Anderson, P., Glidden, D. V., Liu, A., Buchbinder, S., Lama, J. R., Guanira, J. V., ... Grant, R. M. (2012). Emtricitabine-tenofovir concentrations and pre-exposure prophylaxis efficacy in men who have sex with men. *Science Translational Medicine*, *4*(151), 151ra125. doi:10.1126/scitranslmed.3004006
- Anderson, S., Allen, P., Peckham, S., & Goodwin, N. (2008). Asking the right questions: Scoping studies in the commissioning of research on the organisation and delivery of health services. *Health Research Policy and Systems*, *6*, 7. doi:10.1186/1478-4505-6-7
- Andrews, M., Squire, C., & Tamboukou, M. (2013). *Doing narrative research*: Thousand Oaks, CA: Sage.
- Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32.
- Armstrong, L. (2017). From law enforcement to protection? Interactions between sex workers and police in a decriminalized street-based sex industry. *British Journal of Criminology*, *57*(3), 570–588.
- Au, K. H. (1998). Social constructivism and the school literacy learning of students of diverse backgrounds. *Journal of Literacy Research*, *30*(2), 297–319.
- Avert. (2019a). HIV prevention programmes overview. Retrieved from <https://www.avert.org/professionals/hiv-programming/prevention/overview>
- Avert. (2019b). Treatment as prevention (TASP) for HIV. Retrieved from <https://www.avert.org/professionals/hiv-programming/prevention/treatment-as-prevention>
- Avert. (2020). Global information and education on HIV and AIDS. Retrieved from <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/south-africa>
- Awungafac, G., Delvaux, T., & Vuylsteke, B. (2017). Systematic review of sex work interventions in sub-Saharan Africa: Examining combination prevention approaches. *Tropical Medicine & International Health*, *22*(8), 971–993. doi:10.1111/tmi.12890

- Baeten, J. M., Donnell, D., Ndase, P., Mugo, N. R., Campbell, J. D., Wangisi, J., ... Celum, C. (2012). Antiretroviral prophylaxis for HIV prevention in heterosexual men and women. *The New England Journal of Medicine*, 367(5), 399–410.
- Bak, M., Van Dam, A., & Janssens, R. (2018). Awareness and acceptability of pre-exposure prophylaxis (PrEP) among men who have sex with men in Kazakhstan: A mixed methods study. *Central Asian Journal of Medical Sciences*, 4(2), 102–115.
- Bauman, A., & Nutbeam, D. (2013). Evaluation in a nutshell: A practical guide to the evaluation of health promotion programs. McGraw-Hill.
- Bandura, A. (1991). Social cognitive theory of self-regulation. *Organizational behavior and human decision processes*, 50(2), 248–287.
- Bandura, A. (1999). Social cognitive theory: An agentic perspective. *Asian Journal of Social Psychology*, 2(1), 21–41.
- Bandura, A. (1994). Social cognitive theory and exercise of control over HIV infection. In: R. J. DiClemente & J. L. Peterson (Eds.), *Preventing AIDS: Theories and methods of behavioral interventions*. New York: Springer.
- Bandura, A. (2006). Toward a psychology of human agency. *Perspectives on Psychological Science*, 1(2), 164–180.
- Baral, S., Beyrer, C., Muessig, K., Poteat, T., Wirtz, A. L., Decker, M. R., ... Kerrigan, D. (2012). Burden of HIV among female sex workers in low-income and middle-income countries: A systematic review and meta-analysis. *The Lancet, Infectious Diseases*, 12(7), 538–549.
- Barron, P., Pillay, Y., Doherty, T., Sherman, G., Jackson, D., Bhardwaj, S., ... Goga, A. (2013). Eliminating mother-to-child HIV transmission in South Africa. *Bulletin of the World Health Organization*, 91(1), 70–74.
- Bartholomew, L. K., Parcel, G. S., & Kok, G. (1998). Intervention mapping: A process for developing theory and evidence-based health education programs. *Health Education & Behavior*, 25(5), 545–563.
- Bartholomew, L. K., Parcel, G. S., Kok, G., Gottlieb, N. H., Schaalma, H. C., Markham, C. C., ... Mullen, P. D. C. (2006). *Planning health promotion programs: An intervention mapping approach*. Jossey-Bass.

- Basu, A., & Dutta, M. J. (2009). Sex workers and HIV/AIDS: Analyzing participatory culture-centered health communication strategies. *Human Communication Research, 35*(1), 86–114.
- Basu, I., Jana, S., Rotheram-Borus, M. J., Swendeman, D., Lee, S.-J., Newman, P., & Weiss, R. (2004). HIV prevention among sex workers in India. *Journal of Acquired Immune Deficiency Syndrome, 36*(3), 845.
- Batson, C. D., Chang, J., Orr, R., & Rowland, J. (2002). Empathy, attitudes, and action: Can feeling for a member of a stigmatized group motivate one to help the group? *Personality and Social Psychology Bulletin, 28*(12), 1656–1666.
- Baughner, A. R., Beer, L., Fagan, J. L., Mattson, C. L., Freedman, M., Skarbinski, J., & Shouse, R. L. (2017). Prevalence of internalized HIV-related stigma among HIV-infected adults in care, United States, 2011–2013. *AIDS Behaviour, 21*(9), 2600–2608.
- Baum, F., MacDougall, C., & Smith, D. (2006). Participatory action research. *Journal of Epidemiology and Community Health, 60*(10), 854.
- Baxter, P., & Jack, S. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report, 13*(4), 544–559.
- Becquet, V., Nouaman, M., Plazy, M., Masumbuko, J. M., Anoma, C., Kouame, S., ... Larmarange, J. (2020). Sexual health needs of female sex workers in Côte d'Ivoire: A mixed-methods study to prepare the future implementation of pre-exposure prophylaxis (PrEP) for HIV prevention. *BMJ Open, 10*(1). doi:10.1136/bmjopen-2018-028508
- Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research, 15*(2), 219–234.
- Bekker, L.-G., Johnson, L., Cowan, F., Overs, C., Besada, D., Hillier, S., & Cates, W., Jr. (2015). Combination HIV prevention for female sex workers: What is the evidence? *The Lancet, 385*(9962), 72–87. doi:10.1016/S0140-6736(14)60974-0
- Berman, S. (1997). Children's social consciousness and the development of social responsibility. SUNY Press.
- Bess, G., King, M., & LeMaster, P. L. (2004). Process evaluation: How it works. *American Indian and Alaska Native Mental Health Research The Journal of the National Center, 11*(2), 109–120.

- Best, A., Greenhalgh, T., Lewis, S., Saul, J. E., Carroll, S., & Bitz, J. (2012). Large-system transformation in health care: A realist review. *The Milbank Quarterly*, *90*(3), 421–456.
- Branson, B. M., Handsfield, H. H., Lampe, M. A., Janssen, R. S., Taylor, A. W., Lyss, S. B., & Clark, J. E. (2006). Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings. *Morbidity and Mortality Weekly Report: Recommendations and Reports*, *55*(14), 1-CE.
- Breuer, E., Lee, L., De Silva, M., & Lund, C. (2015). Using theory of change to design and evaluate public health interventions: A systematic review. *Implementation Science*, *11*(1), 63.
- Breuer, E., De Silva, M. J., Fekadu, A., Luitel, N. P., Murhar, V., Nakku, J., ... & Lund, C. (2014). Using workshops to develop theories of change in five low and middle income countries: lessons from the programme for improving mental health care (PRIME). *International Journal of Mental Health Systems*, *8*(1), 15.
- Beyrer, C., Crago, A.-L., Bekker, L.-G., Butler, J., Shannon, K., Kerrigan, D., ... Strathdee, S. A. (2015). An action agenda for HIV and sex workers. *The Lancet*, *385*(9964), 287–301. doi:10.1016/S0140-6736(14)60933-8
- Bhattacharjee, P., Campbell, L., Thalinja, R., Nair, S., Doddamane, M., Ramanaik, S., ... Beattie, T. S. (2018). Understanding the relationship between female sex workers and their intimate partners: Lessons and initial findings from participatory research in North Karnataka, South India. *Health Education & Behavior*, *45*(5), 824–835.
- Biello, K. B., Hosek, S., Drucker, M. T., Belzer, M., Mimiaga, M. J., Marrow, E., ... Mayer, K. H. (2018). Preferences for injectable PrEP among young US cisgender men and transgender women and men who have sex with men. *Archives of Sexual Behavior*, *47*(7), 2101–2107.
- Biello, K. B., Oldenburg, C. E., Mitty, J. A., Closson, E. F., Mayer, K. H., Safren, S. A., & Mimiaga, M. J. (2017). The “safe sex” conundrum: Anticipated stigma from sexual partners as a barrier to PrEP use among substance using MSM engaging in transactional sex. *AIDS Behavior*, *21*(1), 300–306.
- Biglan, A., Ary, D., & Wagenaar, A. C. (2000). The value of interrupted time-series experiments for community intervention research. *Prevention Science*, *1*(1), 31–49.

- Black History Editorial Team. (2015). *The history of AIDS in Africa*. [Online] <https://www.blackhistorymonth.org.uk/article/section/real-stories/the-history-of-aids-in-africa/>
- Blas, E., Gilson, L., Kelly, M. P., Labonté, R., Lapitan, J., Muntaner, C., ... Sen, G. (2008). Addressing social determinants of health inequities: What can the state and civil society do? *The Lancet*, 372(9650), 1684–1689.
- Bloomquist, K. (2020). Sex work research hub: Ethical guidelines. Retrieved from <https://www.swrh.co.uk/ethical-guidelines.html>
- Bourdieu, P. (1989). Social space and symbolic power. *Sociological Theory*, 7(1), 14–25.
- Bowring, A. L., Ampt, F. H., Schwartz, S., Stoové, M. A., Luchters, S., Baral, S., & Hellard, M. (2020). HIV pre-exposure prophylaxis for female sex workers: Ensuring women's family planning needs are not left behind. *Journal of the International AIDS Society*, 23(2), e25442. doi:10.1002/jia2.25442
- Boyes, M. E., Pantelic, M., Casale, M., Toska, E., Newnham, E., & Cluver, L. D. (2020). Prospective associations between bullying victimisation, internalised stigma, and mental health in South African adolescents living with HIV. *Journal of Affective Disorders*, 276, 418–423.
- Bradbury, H., & Reason, P. (2003). Action research: An opportunity for revitalizing research purpose and practices. *Qualitative Social Work*, 2(2), 155–175.
- Branson, B. M., Handsfield, H. H., Lampe, M. A., Janssen, R. S., Taylor, A. W. ... Clark, J. E. (2006). *Revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings*. Centers for Disease Control and Prevention. Retrieved from <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brewer, J., & Hunter, A. (1989). *Multimethod research: A synthesis of styles*. Thousand Oaks, CA: Sage.
- Broadhead, R. S., Volkanovsky, V. L., Rydanova, T., Ryabkova, M., Borch, C., Van Hulst, Y., ... Heckathorn, D. D. (2006). Peer-driven HIV interventions for drug injectors in

- Russia: First year impact results of a field experiment. *International Journal of Drug Policy*, 17(5), 379–392.
- Bronfenbrenner, U. (1994). Ecological models of human development. *Readings on the development of children*, 2(1), 37–43.
- Bronfenbrenner, U., & Morris, P. A. (2007). The bioecological model of human development. *Handbook of Child Psychology*, 1.
- Brundage, J. A. (2009). *Law, sex, and Christian society in medieval Europe*. Chicago: University of Chicago Press.
- Butler, J., & Butler, K. C. (1997). *Excitable speech: A politics of the performative*. Psychology Press.
- Butler, J., & Trouble, G. (1990). Feminism and the subversion of identity. *Gender Trouble*, 3, 1–25.
- Cáceres, C. F., Borquez, A., Klausner, J. D., Baggaley, R., & Beyrer, C. (2016). Implementation of pre-exposure prophylaxis for human immunodeficiency virus infection: Progress and emerging issues in research and policy. *Journal of the International AIDS Society*, 19, 21108.
- Cáceres, C. F., O'Reilly, K. R., Mayer, K. H., & Baggaley, R. (2015). PrEP implementation: Moving from trials to policy and practice. *Journal of the International AIDS Society*, 18, 20222.
- Cameron, L. D., & Leventhal, H. (2003). Self-regulation, health, and illness: An overview. In L. D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 1–14). London: Routledge.
- Campbell, C., & Mzaidume, Z. (2001). Grassroots participation, peer education, and HIV prevention by sex workers in South Africa. *American Journal of Public Health*, 91(12), 1978–1986.
- Carey, M. P., & Lewis, B. P. (1999). Motivational strategies can enhance HIV risk reduction programs. *AIDS Behavior*, 3(4), 269–276.
- Carney, T., Petersen Williams, P. M., Plüddemann, A., & Parry, C. D. H. (2015). Sexual HIV risk among substance-using female commercial sex workers in Durban, South Africa.

*African Journal of AIDS Research*, 14(2), 153–158.

doi:10.2989/16085906.2015.1040811

Carter, M. R., Aaron, E., Nassau, T., & Brady, K. A. (2019). Knowledge, attitudes, and PrEP prescribing practices of health care providers in Philadelphia, PA. *Journal of Primary Care & Community Health*, 10. doi:10.1177/2150132719878526

Cartwright, N. (2010). What are randomised controlled trials good for? *Philosophical Studies*, 147(1), 59.

Centers for Disease Control and Prevention. (2017). *HIV and AIDS timeline*. [Online] Retrieved from <https://npin.cdc.gov/pages/hiv-and-aids-timeline>

Centers for Disease Control and Prevention. (2020a). Pre-exposure prophylaxis (PrEP). [Online] <https://www.cdc.gov/hiv/clinicians/prevention/prep.html>

Centers for Disease Control and Prevention. (2020b) Process evaluation. Retrieved from [https://www.cdc.gov/teenpregnancy/practitioner-tools-resources/psba-gto-guide/pdf/chapters/PSBA\\_GTO\\_Step7\\_508tagged.pdf](https://www.cdc.gov/teenpregnancy/practitioner-tools-resources/psba-gto-guide/pdf/chapters/PSBA_GTO_Step7_508tagged.pdf)

Chakrapani, V., Newman, P. A., Shunmugam, M., Mengle, S., Varghese, J., Nelson, R., & Bharat, S. (2015). Acceptability of HIV pre-exposure prophylaxis (PrEP) and implementation challenges among men who have sex with men in India: a qualitative investigation. *AIDS Patient Care STDs*, 29(10), 569–577.

Chanzu, N. M., Mwanda, W., Oyugi, J., & Anzala, O. (2015). Mucosal blood group antigen expression profiles and HIV infections: a study among female sex workers in Kenya. *PloS One*, 10(7), e0133049.

Chersich, M. F., Luchters, S., Ntaganira, I., Gerbase, A., Lo, Y.-R., Scorgie, F., & Steen, R. (2013). Priority interventions to reduce HIV transmission in sex work settings in sub-Saharan Africa and delivery of these services. *Journal of the International AIDS Society*, 16, 17980–17980. doi:10.7448/IAS.16.1.17980

Coates, T. J., Richter, L., & Caceres, C. (2008). Behavioural strategies to reduce HIV transmission: how to make them work better. *The Lancet*, 372(9639), 669–684.

Cohen, D., & Crabtree, B. (2006). Qualitative research guidelines project. Robert Wood Johnson Foundation. [Online] <http://www.qualres.org/HomeEval-3664.html>

- Connell, R. W., & Messerschmidt, J. W. (2005). Hegemonic masculinity: Rethinking the concept. *Gender & Society, 19*(6), 829–859.
- Conquergood, D. (1998). Beyond the text: Toward a performative cultural politics. *The future of performance studies: Visions and Revisions, 25–36*.
- Coovadia, H., Jewkes, R., Barron, P., Sanders, D., & McIntyre, D. (2009). The health and health system of South Africa: Historical roots of current public health challenges. *The Lancet, 374*(9692), 817–834.
- Cornish, F., & Campbell, C. (2009). The social conditions for successful peer education: A comparison of two HIV prevention programs run by sex workers in India and South Africa. *American Journal of Community Psychology, 44*(1–2), 123–135. doi:10.1007/s10464-009-9254-8
- Cowan, F. M., & Delany-Moretlwe, S. (2016). Promise and pitfalls of pre-exposure prophylaxis for female sex workers. *Current Opinion in HIV and AIDS, 11*(1), 27–34. doi:10.1097/coh.0000000000000215
- Cowan, F. M., Delany-Moretlwe, S., Sanders, E. J., Mugo, N. R., Guedou, F. A., Alary, M., ... Bekker, L. G. (2016). PrEP implementation research in Africa: What is new? *Journal of the International AIDS Society, 19*(7Suppl 6), 21101. doi:10.7448/ias.19.7.21101
- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ, 337*, a1655. doi:10.1136/bmj.a1655
- Creswell, J. W., & Creswell, J. D. (2017). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Creswell, J. W. (2014). *A concise introduction to mixed methods research*. Thousand Oaks, CA: Sage.
- Cuca, Y. P., Onono, M., Bukusi, E., & Turan, J. M. (2012). Factors associated with pregnant women's anticipations and experiences of HIV-related stigma in rural Kenya. *AIDS Care, 24*(9), 1173–1180.
- Cuthill, M. (2002). Exploratory research: citizen participation, local government and sustainable development in Australia. *Sustainable Development, 10*(2), 79–89.

- Das, P., & Horton, R. (2015). Bringing sex workers to the centre of the HIV response. *The Lancet*, 385(9962), 3–4. doi:https://doi.org/10.1016/S0140-6736(14)61064-3
- Davis, K., Drey, N., & Gould, D. (2009). What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies*, 46(10), 1386–1400.
- Dearing, J. W. (2009). Applying diffusion of innovation theory to intervention development. *Research on Social Work Practice*, 19(5), 503–518.
- Deci, E. L., & Ryan, R. M. (2002). Overview of self-determination theory: An organismic dialectical perspective. *Handbook of Self-determination Research*, 3–33.
- Deci, E. L., & Ryan, R. M. (2010). Intrinsic motivation. *The Corsini Encyclopedia of Psychology*, 1–2.
- Decker, M. R., Park, J. N., Allen, S. T., Silberzahn, B., Footer, K., Huettner, S., ... Sherman, S. G. (2020). Inconsistent condom use among female sex workers: Partner-specific influences of substance use, violence, and condom coercion. *AIDS Behavior*, 24(3), 762–774.
- Dehar, M. A., Casswell, S., & Duignan, P. (1993). Formative and process evaluation of health promotion and disease prevention programs. *Evaluation Review*, 17(2), 204–220.
- Dehne, K. L., Dallabetta, G., Wilson, D., Garnett, G. P., Laga, M., Benomar, E., ... Kasedde, S. (2016). HIV Prevention 2020: A framework for delivery and a call for action. *The Lancet HIV*, 3(7), e323–e332.
- Denzin, N. K. (2001). *Interpretive interactionism* (Vol. 16). Thousand Oaks, CA: Sage.
- Denzin, N. K., & Lincoln, Y. S. (Eds.) (2005). *The Sage handbook of qualitative research*. 3rd edition. Thousand Oaks: Sage.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education*, 40(4), 314–321.
- Dixon-Ibarra, A., Driver, S., VanVolkenburg, H., & Humphries, K. (2017). Formative evaluation on a physical activity health promotion program for the group home setting. *Evaluation and Program Planning*, 60, 81–90.

- Door, V. M. (2014). Critical pedagogy and reflexivity: The issue of ethical consistency. *The International Journal of Critical Pedagogy*, 5(2), 88–99. Retrieved from <http://libjournal.uncg.edu/ijcp/article/view/419/656>
- Durks, D., Fernandez-Llimos, F., Hossain, L. N., Franco-Trigo, L., Benrimoj, S. I., & Sabater-Hernández, D. (2017). Use of intervention mapping to enhance health care professional practice: a systematic review. *Health Education & Behavior*, 44(4), 524–535.
- Eakle, R., Venter, F., & Rees, H. (2018). Pre-exposure prophylaxis (PrEP) in an era of stalled HIV prevention: Can it change the game? *Retrovirology*, 15, 29. doi:10.1186/s12977-018-0408-3
- Eakle, R., Bourne, A., Mbogua, J., Mutanha, N., & Rees, H. (2018). Exploring acceptability of oral PrEP prior to implementation among female sex workers in South Africa. *Journal of the International AIDS Society*, 21(2), e25081. doi:10.1002/jia2.25081
- Eakle, R., Bothma, R., Bourne, A., Gumede, S., Motsosi, K., & Rees, H. (2019). "I am still negative": Female sex workers' perspectives on uptake and use of daily pre-exposure prophylaxis for HIV prevention in South Africa. *PloS One*, 14(4), e0212271–e0212271. doi:10.1371/journal.pone.0212271
- Eakle, R., Gomez, G. B., Naicker, N., Bothma, R., Mbogua, J., Cabrera Escobar, M. A., ... Rees, H. (2017). HIV pre-exposure prophylaxis and early antiretroviral treatment among female sex workers in South Africa: Results from a prospective observational demonstration project. *PLoS Med*, 14(11), e1002444. doi:10.1371/journal.pmed.1002444
- Eakle, R., Mutanha, N., Mbogua, J., Sibanyoni, M., Bourne, A., Gomez, G., ... Rees, H. (2018). Designing PrEP and early HIV treatment interventions for implementation among female sex workers in South Africa: Developing and learning from a formative research process. *BMJ open*, 8(6). doi:10.1136/bmjopen-2017-019292
- Eisingerich, A. B., Wheelock, A., Gomez, G. B., Garnett, G. P., Dybul, M. R., & Piot, P. K. (2012). Attitudes and acceptance of oral and parenteral HIV preexposure prophylaxis among potential user groups: a multinational study. *PLoS One*, 7(1), e28238. doi:10.1371/journal.pone.0028238

- Eldredge, L. K. B., Markham, C. M., Ruiters, R. A., Ferni, M. E., Kok, G., & Parcel, G. S. (2016). *Planning health promotion programs: An intervention mapping approach*. New Jersey: Wiley.
- Emmanuel, G., Folayan, M., Undelikwe, G., Ochonye, B., Jayeoba, T., Yusuf, A., ... Kalaiwo, A. (2020). Community perspectives on barriers and challenges to HIV pre-exposure prophylaxis access by men who have sex with men and female sex workers access in Nigeria. *BMC Public Health*, 20(1). doi:10.1186/s12889-020-8195-x
- Enriquez, M., & McKinsey, D. S. (2011). Strategies to improve HIV treatment adherence in developed countries: clinical management at the individual level. *HIV/Aids (Auckland, NZ)*, 3, 45.
- Errington, L. (2015). Using dialogical space to create therapy enhancing possibilities with adolescents in family therapy. *Australian and New Zealand Journal of Family Therapy*, 36(1), 20–32.
- Etikan, I., Musa, S. A., & Alkassim, R. S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), 1–4.
- eThekwini Municipality (2020). About eThekwini Municipality. Retrieved from [http://www.durban.gov.za/Discover\\_Durban/Pages/AboutEM.aspx](http://www.durban.gov.za/Discover_Durban/Pages/AboutEM.aspx)
- Evangelini, M., Pady, K., & Wroe, A. L. (2016). Which psychological factors are related to HIV testing? A quantitative systematic review of global studies. *AIDS Behavior*, 20(4), 880–918.
- Evangelini, M., Baker, L. L., Pady, K., Jones, B., & Wroe, A. L. (2016). What leads some people to think they are HIV-positive before knowing their diagnosis? A systematic review of psychological and behavioural correlates of HIV-risk perception. *AIDS Care*, 28(8), 943–953.
- Evans, R. I., Raines, B. E., & Owen, A. E. (1989). Formative evaluation in school-based health promotion investigations. *Preventive Medicine*, 18(2), 229–234.
- Falcao, J., Ahoua, L., Zerbe, A., di Mattei, P., Baggaley, R., Chivurre, V., ... El-Sadr, W. (2017). Willingness to use short-term oral pre-exposure prophylaxis (PrEP) by migrant

- miners and female partners of migrant miners in Mozambique. *Culture, Health & Sexuality*, 19(12), 1389–1403. doi:10.1080/13691058.2017.1316424
- Fals-Borda, O., & Rahman, M. A. (1991). *Action and knowledge: Breaking the monopoly with participatory action-research* (No. 300.720172 A2).
- Fearon, E., Phillips, A., Mtetwa, S., Chabata, S. T., Mushati, P., Cambiano, V., ... Hargreaves, J. R. (2019). How Can programs better support female sex workers to avoid HIV infection in Zimbabwe? A prevention cascade analysis. *Jaids-Journal of Acquired Immune Deficiency Syndromes*, 81(1), 24–35. doi:10.1097/qai.0000000000001980
- Feild, L., Pruchno, R. A., Bewley, J., Lemay Jr, E. P., & Levinsky, N. G. (2006). Using probability vs. nonprobability sampling to identify hard-to-access participants for health-related research: Costs and contrasts. *Journal of Aging and Health*, 18(4), 565-583.
- Felsher, M., Szep, Z., Krakower, D., Martinez-Donate, A., Tran, N., & Roth, A. M. (2018). "I Don't Need PrEP Right Now": A qualitative exploration of the barriers to PrEP care engagement through the application of the health belief model. *AIDS Education and Prevention*, 30(5), 369–381. Official publication of the International Society for AIDS Education. doi:10.1521/aeap.2018.30.5.369
- Fernandez, M. E., Ten Hoor, G. A., Van Lieshout, S., Rodriguez, S. A., Beidas, R. S., Parcel, G., ... Kok, G. (2019). Implementation mapping: Using intervention mapping to develop implementation strategies. *Frontiers in Public Health*, 7, 158. doi:10.3389/fpubh.2019.00158
- Fisher, J. D., & Fisher, W. A. (2002). The information-motivation-behavioral skills model. *Emerging theories in health promotion practice and research: Strategies for Improving Public Health*, 1, 40–70.
- Fisher, J. D., Fisher, W. A., Bryan, A. D., & Misovich, S. J. (2002). Information-motivation-behavioral skills model-based HIV risk behavior change intervention for inner-city high school youth. *Health Psychology*, 21(2), 177.

- Flanagan, C. A., Cumsille, P., Gill, S., & Gallay, L. S. (2007). School and community climates and civic commitments: Patterns for ethnic minority and majority students. *Journal of Educational Psychology, 99*(2), 421.
- Fonner, V. A., Dalglish, S. L., Kennedy, C. E., Baggaley, R., O'Reilly, K. R., Koechlin, F. M., ... Grant, R. M. (2016). Effectiveness and safety of oral HIV preexposure prophylaxis for all populations. *Aids, 30*(12), 1973–1983. doi:10.1097/QAD.0000000000001145
- Ford, K., Wirawan, D., Suastina, W., Reed, B., & Muliawan, P. (2000). Evaluation of a peer education programme for female sex workers in Bali, Indonesia. *International Journal of STD & AIDS, 11*(11), 731–733.
- Foucault, M. (1982). The subject and power. *Critical Inquiry, 8*(4), 777–795.
- Fraser, M. W., & Galinsky, M. J. (2010). Steps in intervention research: Designing and developing social programs. *Research on Social Work Practice, 20*(5), 459–466.
- Fraser, M. W., Richman, J. M., Galinsky, M. J., & Day, S. H. (2009). *Intervention research: Developing social programs*. Oxford University Press.
- Fredrickson, B. L. (2001). The role of positive emotions in positive psychology. *American Psychologist, 56*(3):218–226.
- Funnell, S. C., & Rogers, P. J. (2011). *Purposeful program theory: Effective use of theories of change and logic models* (Vol. 31). New Jersey: Wiley.
- Fusch, P. I., & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report, 20*(9), 1408.
- Gaventa, J. (2003). *Power after Lukes: An overview of theories of power since Lukes and their application to development*. Brighton: Participation Group, Institute of Development Studies.
- Gazimbi, M. M., Magadi, M. A., & Kruger, C. (2019). The Association between Male Circumcision and HIV Infection in Sub-Saharan Africa: A Systematic Review of the Literature. *International Archives of Public Health Community Medicine, 3*(1), 1–11.
- Gecas, V. (2000). Value identities, self-motives, and social movements. In S. Stryker, T. J. Owens, & R. W. White (Eds.), *Social movements, protest, and contention; v. 13. Self, identity, and social movements* (p. 93–109). University of Minnesota Press.

- Gecas, V., & Burke, P. J. (1995). Self and identity. In K. S. Cook, G. A. Fine, & J. S. House (Eds.), *Sociological perspectives on social psychology* (pp. 41–67). Boston: Pearson.
- Gengiah, T. N., Moosa, A., Naidoo, A., & Mansoor, L. E. (2014). Adherence challenges with drugs for pre-exposure prophylaxis to prevent HIV infection. *International journal of clinical pharmacy*, *36*(1), 70–85.
- Gergen, K. J. (1999). *An invitation to social construction*. Thousand Oaks, CA: Thousand Oaks, CA: Sage.
- Gergen, K. J., & Gergen, M. M. (1991). Toward reflexive methodologies. In F. Steier (Ed.), *Inquiries in social construction. Research and reflexivity* (pp. 76–95). Thousand Oaks, CA: Sage.
- Gertler, P. J., Martinez, S., Premand, P., Rawlings, L. B., & Vermeersch, C. M. (2016). *Impact evaluation in practice*. The World Bank.
- Gibson, P. G., Ram, F. S., & Powell, H. (2003). Asthma education. *Respiratory Medicine*, *97*(9), 1036–1044.
- Gilbert, A., & Sliap, Y. (2009). Reflexivity in the practice of social action: From self-to inter-relational reflexivity. *South African Journal of Psychology*, *39*(4), 468–479.
- Gilbert, L., & Walker, L. (2002). HIV/AIDS in South Africa: An overview. *Cadernos de Saude Publica*, *18*, 651–660.
- Goodman, L. A. (2011). Comment: On respondent-driven sampling and snowball sampling in hard-to-reach populations and snowball sampling not in hard-to-reach populations. *Sociological Methodology*, *41*(1), 347–353.
- Goodman, L. A. (1961). Snowball sampling. *The Annals of Mathematical Statistics*, 148–170.
- Goffman, E. (2003). *Stigma*. Praha: Sociologické nakladatelství (SLON).
- Goldenberg, S. M., Duff, P., & Krusi, A. (2015). Work environments and HIV prevention: A qualitative review and meta-synthesis of sex worker narratives. *BMC Public Health*, *15*, 1241. doi:10.1186/s12889-015-2491-x
- Golub, S. A. (2018). PrEP stigma: Implicit and explicit drivers of disparity. *Current HIV/AIDS Reports*, *15*(2), 190–197.

- Gomez, G. B., Eakle, R., Mbogua, J., Akpomiemie, G., Venter, W. F., & Rees, H. (2016). Treatment and prevention for female sex workers in South Africa: protocol for the TAPS demonstration project. *BMJ Open*, *6*(9).
- Gomez, G. B., Eakle, R., Mbogua, J., Akpomiemie, G., Venter, W. F., & Rees, H. (2017). Sex workers in South Africa: protocol for the TAPS Demonstration Project.
- Govender, E., & Abdool Karim, Q. (2018). Understanding women and men's acceptability of current and new HIV prevention technologies in KwaZulu-Natal, South Africa. *AIDS Care*, *30*(10), 1311–1314.
- Govender, E. M., Mansoor, L. E., & Abdool Karim, Q. (2017). Influences of geo-spatial location on pre-exposure prophylaxis use in South Africa: positioning microbicides for better product uptake. *AIDS Care*, *29*(6), 734–740.
- Govender, E., Mansoor, L., MacQueen, K., & Abdool Karim, Q. (2017). Secrecy, empowerment and protection: positioning PrEP in KwaZulu-Natal, South Africa. *Cult Health Sex*, *19*(11), 1268–1285.
- Gould, C., & Fick, N. (2008). *Selling sex in Cape Town: Sex work and human trafficking in a South African city*: Institute for Security Studies.
- Graaf, A. D., Sanders, J., & Hoeken, H. (2016). Characteristics of narrative interventions and health effects: A review of the content, form, and context of narratives in health-related narrative persuasion research. *Review of Communication Research*, *4*, 88–131.
- Grant, C., & Osanloo, A. (2016). Understanding, selecting, and integrating a theoretical framework in dissertation research: Creating the blueprint for your “house”. *Administrative Issues Journal: Connecting Education, Practice, and Research*, *4*(2), 12–26. <https://files.eric.ed.gov/fulltext/EJ1058505.pdf>
- Grant, M. J., & Booth, A. (2009). A typology of reviews: An analysis of 14 review types and associated methodologies. *Health Information & Libraries Journal*, *26*(2), 91–108.
- Grant, R. M., & Koester, K. A. (2016). What people want from sex and PrEP. *Current Opinion in HIV and AIDS*, *11*(1), 3.
- Grasso, M. A., Manyuchi, A. E., Sibanyoni, M., Marr, A., Osmand, T., Isdahl, Z., ... Rees, H. V. (2018). Estimating the population size of female sex workers in three South African cities: Results and recommendations from the 2013–2014 South Africa Health

- Monitoring Survey and Stakeholder Consensus. *Journal of Medical Internet Research Public Health Surveillance*, 4(3), e10188.
- Greene, W. C. (2007). A history of AIDS: Looking back to see ahead. *European Journal of Immunology*, 37(S1), S94–S102.
- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*, 10(2), 261–280.
- Günthard, H. F., Saag, M. S., Benson, C. A., Del Rio, C., Eron, J. J., Gallant, J. E., ... & Volberding, P. A. (2016). Antiretroviral drugs for treatment and prevention of HIV infection in adults: 2016 recommendations of the International Antiviral Society–USA panel. *Jama*, 316(2), 191–210.
- Haberer, J. E., Mugo, N., Baeten, J. M., Pyra, M., Bukusi, E., & Bekker, L.-G. (2019). PrEP as a lifestyle and investment for adolescent girls and young women in sub-Saharan Africa. *Journal of the International Association of Providers of AIDS Care*, 18. doi:10.1177/2325958219831011.
- Hampana, K. M. (2013). The social dynamics of selling sex in Mombasa, Kenya: A qualitative study contextualizing high risk sexual behaviour. *African Journal of Reproductive Health*, 17(2), 141–149.
- Han, J., Bouey, J. Z., Wang, L., Mi, G., Chen, Z., He, Y., ... Zhang, F. (2019). PrEP uptake preferences among men who have sex with men in China: results from a National Internet Survey. *Journal of the International AIDS Society*, 22(2), e25242.
- Hankins, C. (2013). Overview of the current state of the epidemic. *Current HIV/Aids reports*, 10(2), 113–123.
- Hankins, C. A., & De Zaluondo, B. O. (2010). Combination prevention: A deeper understanding of effective HIV prevention. *Aids*, 24(Suppl 4), S70–80. doi: 10.1097/01.aids.0000390709.04255.fd
- Hapunda, G., Abubakar, A., & Van de Vijver, F. (2017). Applying the bioecological model to understand factors contributing to psychosocial well-being and healthcare of children and adolescents with diabetes mellitus. *South African Journal of Diabetes and Vascular Disease*, 14(1), 11–17.

- Harrell, M. C., & Bradley, M. A. (2009). *Data collection methods. Semi-structured interviews and focus groups*. Training Manual. Santa Monica, CA: Rand National Security Research Division. Retrieved from [https://www.rand.org/content/dam/rand/pubs/technical\\_reports/2009/RAND\\_TR718.pdf](https://www.rand.org/content/dam/rand/pubs/technical_reports/2009/RAND_TR718.pdf)
- Hariton, E., & Locascio, J. J. (2018). Randomised controlled trials – The gold standard for effectiveness research. *BJOG: An international Journal of Obstetrics and Gynaecology*, *125*(13), 1716.
- Hawe, P. (1994). Capturing the meaning of ‘community’ in community intervention evaluation: Some contributions from community psychology. *Health Promotion International*, *9*(3), 199–210.
- He, J., Wang, Y., Du, Z., Liao, J., He, N., & Hao, Y. (2020). Peer education for HIV prevention among high-risk groups: a systematic review and meta-analysis. *BMC Infectious Diseases*, *20*, 1–20.
- Heckathorn, D. (2011). Snowball versus respondent-driven sampling. *Sociological Methodology*, *41*(1), 355–366.
- Hennink, M., Hutter, I., & Bailey, A. (2020). *Qualitative research methods*. Thousand Oaks, CA: Sage.
- Hewitt, J. P., & Shulman, D. (1979). *Self and society: A symbolic interactionist social psychology*. Boston: Allyn and Bacon.
- Hinyard, L. J., & Kreuter, M. W. (2007). Using narrative communication as a tool for health behavior change: a conceptual, theoretical, and empirical overview. *Health Education & Behavior*, *34*(5), 777–792.
- Hitlin, S. (2003). Values as the core of personal identity: Drawing links between two theories of self. *Social Psychology Quarterly*, *66*(2), 118–137. doi:10.2307/1519843
- Holmes, D. (2012). FDA paves the way for pre-exposure HIV prophylaxis. *The Lancet*, *380*(9839), 325.
- Hopman-Rock, M., & Westhoff, M. H. (2000). The effects of a health educational and exercise program for older adults with osteoarthritis for the hip or knee. *The Journal of Rheumatology*, *27*(8), 1947–1954.

- Hosek, S., & Pettifor, A. (2019). HIV prevention interventions for adolescents. *Current HIV/AIDS Reports*, 16(1), 120–128.
- Hosek, S., Celum, C., Wilson, C. M., Kapogiannis, B., Delany-Moretlwe, S., & Bekker, L. G. (2016). Preventing HIV among adolescents with oral PrEP: observations and challenges in the United States and South Africa. *Journal of the International AIDS Society*, 19, 21107.
- Howard, S. (2019). Sex workers' health: International evidence on the law's impact. *The BMJ*, 364, 1343.
- Hunt, T., Lalley-Chareczko, L., Daughtridge, G., Swyryn, M., & Koenig, H. (2019). Challenges to PrEP use and perceptions of urine tenofovir adherence monitoring reported by individuals on PrEP. *AIDS care*, 31(10), 1203–1206.
- Huysamen, M., & Richter, M. (2020). Towards harm reduction programmes with sex worker clients in South Africa. Sonke Gender Justice, May 2020.
- Iiffe, J. (2005). *The African AIDS epidemic: A history*: Ohio University Press.
- International Treatment Preparedness Coalition. (2017). What's out there on PrEP. Retrieved from <https://itpcglobal.org/wp-content/uploads/2018/02/ITPC-PrEP-Literature-Review-2017.pdf>
- Jackson, A. Y. (2004). Performativity identified. *Qualitative Inquiry*, 10(5), 673–690.
- Jana, S., Basu, I., Rotheram-Borus, M. J., & Newman, P. A. (2004). The Sonagachi project: A sustainable community intervention program. *AIDS Education and Prevention*, 16(5), 405–414.
- Joint United Nations Programme on HIV/AIDS. (2008). *2008 report on the global AIDS epidemic*. Unaid.
- Joint United Nations Programme on HIV/AIDS. (2016a). *Global AIDS update 2016*. Geneva, Switzerland. Retrieved from [https://www.unaids.org/sites/default/files/media\\_asset/global-AIDS-update-2016\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/global-AIDS-update-2016_en.pdf)

- Joint United Nations Programme on HIV/AIDS. (2016b). *Prevention gap report*. Geneva, Switzerland. Retrieved from [https://www.unaids.org/sites/default/files/media\\_asset/2016-prevention-gap-report\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/2016-prevention-gap-report_en.pdf)
- Joint United Nations Programme on HIV/AIDS. (2017). HIV prevention 2020 road map. *Accelerating HIV prevention to reduce new infections by 75*. Retrieved from [https://www.unaids.org/sites/default/files/media\\_asset/hiv-prevention-2020-road-map\\_en.pdf](https://www.unaids.org/sites/default/files/media_asset/hiv-prevention-2020-road-map_en.pdf)
- Joint United Nations Programme on HIV/AIDS. (2018). *UNAIDS data 2018*. Geneva, Switzerland. Retrieved from [http://www.unaids.org/sites/default/files/media\\_asset/unaids-data-2018\\_en.pdf](http://www.unaids.org/sites/default/files/media_asset/unaids-data-2018_en.pdf)
- Kalichman, S. C., Sikkema, K. J., Kelly, J. A., & Bulto, M. (1995). Use of a brief behavioral skills intervention to prevent HIV infection among chronic mentally ill adults. *Psychiatric Services*, 46(3), 275–280. doi:10.1176/ps.46.3.275.
- Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, 72(12), 2954–2965.
- Kelder, S. H., Hoelscher, D., & Perry, C. L. (2015). How individuals, environments, and health behaviors interact: Social cognitive theory. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior: Theory, research, and practice* (pp. 159–181). Jossey-Bass.
- Kempadoo, K., & Doezema, J. (2018). *Global sex workers: Rights, resistance, and redefinition*. Routledge.
- Kerrigan, D., Moreno, L., Rosario, S., & Sweat, M. (2001). Adapting the Thai 100% condom programme: Developing a culturally appropriate model for the Dominican Republic. *Culture, Health and Sexuality*, 3(2), 221–240.
- Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *BMJ*, 311(7000), 299–302.
- Klatt, N. R., Cheu, R., Birse, K., Zevin, A. S., Perner, M., Noël-Romas, L., ... & Mansoor, L. (2017). Vaginal bacteria modify HIV tenofovir microbicide efficacy in African women. *Science*, 356(6341), 938–945.

- Knight, L. (2008). *The first 10 years, 1996-2006*. Geneva, Switzerland: UNAIDS. Retrieved from [https://data.unaids.org/pub/report/2008/jc1579\\_first\\_10\\_years\\_en.pdf](https://data.unaids.org/pub/report/2008/jc1579_first_10_years_en.pdf)
- Kok, G. (2018). A practical guide to effective behavior change: How to apply theory- and evidence-based behavior change methods in an intervention. *The European Health Psychologist*, 16(5), 156–170. Retrieved from <https://www.ehps.net/ehp/index.php/contents/article/download/ehp.v16.i5.p156/8>
- Kok, G., Gottlieb, N. H., Commers, M., & Smerecnik, C. (2008). The ecological approach in health promotion programs: A decade later. *American Journal of Health Promotion*, 22(6), 437–442.
- Kok, G., Peters, L. W. H., & Ruiter, R. A. C. (2017). Planning theory- and evidence-based behavior change interventions: A conceptual review of the intervention mapping protocol. *Psicologia: Reflexão e Crítica*, 30, article 19.
- Konstant, T., Rangasami, J., Stacey, M., Stewart, M., & Nogoduka, C. (2015). Estimating the number of sex workers in South Africa: Rapid population size estimation. *AIDS & Behavior*, 19, 3–15. doi:10.1007/s10461-014-0981-y
- Krueger, R. A., & Casey, M. A. (2014). *Focus groups: A practical guide for applied health research*. (5<sup>th</sup> ed.) Singapore: Sage.
- Kurth, A. E., Celum, C., Baeten, J. M., Vermund, S. H., & Wasserheit, J. N. (2011). Combination HIV prevention: Significance, challenges, and opportunities. *Current HIV/AIDS Reports*, 8(1), 62–72.
- Lafort, Y., Lessitala, F., Candrinho, B., Greener, L., Greener, R., Beksinska, M., ... Delva, W. (2016). Barriers to HIV and sexual and reproductive health care for female sex workers in Tete, Mozambique: Results from a cross-sectional survey and focus group discussions. *BMC Public Health*, 16, 608–608. doi:10.1186/s12889-016-3305-5
- Lancaster, K. E., Cernigliaro, D., Zulliger, R., & Fleming, P. F. (2016). HIV care and treatment experiences among female sex workers living with HIV in sub-Saharan Africa: a systematic review. *African Journal of AIDS Research*, 15(4), 377–386.
- Lancaster, K. E., Lungu, T., Bula, A., Shea, J. M., Shoben, A., Hosseinipour, M. C., ... Miller, W. C. (2019). Preferences for pre-exposure prophylaxis service delivery among female

sex workers in Malawi: A discrete choice experiment. *AIDS and Behavior*, 24, 1294–1303. . doi:10.1007/s10461-019-02705-3

Landovitz, R.J., Donnel, D., Clement, M., Hanscom B., Cottle, L., Coelho L., ... Grinsztejn B. (2020). HPTN083 interim results: Pre-exposure prophylaxis (PrEP) containing long-acting injectable cabotegravir (CAB-LA) is safe and highly effective for cisgender men and transgender women who have sex with men (MSM,TGW). 23rd International HIV Conference (AIDS 2020: Virtual), abstract OAXLB0101, <https://aids2020.org/wp-content/uploads/2020/07/HIV-Highlights-Press-Conference-Abstracts.pdf>

Landovitz, R. J., Kofron, R., & McCauley, M. (2016). The promise and pitfalls of long acting injectable agents for HIV prevention. *Current Opinion in HIV and AIDS*, 11(1), 122.

Langellier, K. M. (1999). Personal narrative, performance, performativity: Two or three things I know for sure. *Text and performance quarterly*, 19(2), 125-144.

Latham, G. P., & Locke, E. A. (2007). New developments in and directions for goal-setting research. *European Psychologist*, 12(4), 290–300.

Laverack, G. (2004). *Health promotion practice: Power and empowerment*. Thousand Oaks, CA: Sage.

Laverack, G. (2007). *Health promotion practice: Building empowered communities*. McGraw-Hill Education (UK).

Laverack, G., & Labonte, R. (2000). A planning framework for community empowerment goals within health promotion. *Health Policy and Planning*, 15(3), 255–262.

Laverack, G., & Wallerstein, N. (2001). Measuring community empowerment: A fresh look at organizational domains. *Health Promotion International*, 16(2), 179–185.

Leonard, L., Ndiaye, I., Kapadia, A., & Eisen, G. (2000). HIV prevention among male clients of female sex workers in Kaolack, Senegal: Results of a peer education program. *AIDS Education and Prevention*, 12(1), 21.

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5(1), 69.

- Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic Inquiry*, 289(331), 289–327.
- Lopez Bernal, J., Cummins, S., & Gasparrini, A. (2018). The use of controls in interrupted time series studies of public health interventions. *International Journal of Epidemiology*, 47(6), 2082–2093.
- MacDonald, C. (2012). Understanding participatory action research: A qualitative research methodology option. *The Canadian Journal of Action Research*, 13(2), 34–50.
- Mack, N., Odhiambo, J., Wong, C. M., & Agot, K. (2014). Barriers and facilitators to pre-exposure prophylaxis (PrEP) eligibility screening and ongoing HIV testing among target populations in Bondo and Rarieda, Kenya: Results of a consultation with community stakeholders. *BMC Health Services Research*, 14, 231. doi:10.1186/1472-6963-14-231
- Makhakhe, N. F., Meyer-Weitz, A., Struthers, H., & McIntyre, J. (2019). The role of health and advocacy organisations in assisting female sex workers to gain access to health care in South Africa. *BMC Health Services Research*, 19(1), 1–9.
- Mansoor, L. E., Karim, Q. A., Yende-Zuma, N., MacQueen, K. M., Baxter, C., Madlala, B. T., ... & Karim, S. S. A. (2014). Adherence in the CAPRISA 004 tenofovir gel microbicide trial. *AIDS and Behavior*, 18(5), 811–819.
- Marcus, J., Buisker, T., Horvath, T., Amico, K., Fuchs, J., Buchbinder, S., ... Liu, A. (2014). Helping our patients take HIV pre-exposure prophylaxis (PrEP): A systematic review of adherence interventions. *HIV Medicine*, 15(7), 385–395.
- Marlatt, G. A., & Donovan, D. M. (2005). *Relapse prevention: Maintenance strategies in the treatment of addictive behaviors*. New York: Guilford.
- Marshall, C., & Rossman, G. B. (1999). *Designing qualitative research*. Thousand Oaks, CA: Sage.
- Masyuko, S., Mukui, I., Njathi, O., Kimani, M., Oluoch, P., Wamicwe, J., ... Muchiri, P. (2018). Pre-exposure prophylaxis rollout in a national public sector program: The Kenyan case study. *Sex Health*, 15(6), 578–586. doi:10.1071/SH18090
- Mathenjwa, T., & Maharaj, P. (2012). ‘Female condoms give women greater control’: A qualitative assessment of the experiences of commercial sex workers in Swaziland. *The*

*European Journal of Contraception & Reproductive Health Care*, 17(5), 383–392.  
doi:10.3109/13625187.2012.694147

- Mayer, K. H., & Allan-Blitz, L.-T. (2019). PrEP 1.0 and beyond: Optimizing a biobehavioral intervention. *Journal of Acquired Immune Deficiency Syndromes*, 82 Suppl 2(2), S113–S117. doi:10.1097/QAI.0000000000002169
- Mayer, K. H., Chandhiok, N., & Thomas, B. (2016). Antiretroviral pre-exposure prophylaxis: A new opportunity to slow HIV spread in India. *Indian Journal of Medical Research*, 143(2), 125–128. doi:10.4103/0971-5916.180194
- Mbewe, L., & Govender, E. (2020). Male partners' influence on women's acceptance and use of PrEP products across two high HIV-burdened districts in South Africa. *African Journal of AIDS Research*, 1–8.
- Mboup, A., Béhanzin, L., Guédou, F. A., Geraldo, N., Goma-Matsétsé, E., Giguère, K., ... Kêkê, R. K. (2018). Early antiretroviral therapy and daily pre-exposure prophylaxis for HIV prevention among female sex workers in Cotonou, Benin: A prospective observational demonstration study. *Journal of the International AIDS Society*, 21(11), e25208.
- McAlister, A. L., Perry, C. L., & Parcel, G. S. (2008). How individuals, environments, and health behaviors interact: Social cognitive theory. In K. Glanz, B.K. Rimer, & K. Viswanath (Eds.), *Health behavior: Theory, research, and practice* (pp. 169–188). Jossey-Bass.
- McClintock, C. (1984). Toward a theory of formative program evaluation. *New Directions for Adult and Continuing Education*, 1984(24), 77–95.
- McClure, L., & Faraone, C. A. (2006). *Prostitutes and courtesans in the Ancient World (Wisconsin Studies in Classics)*. Wisconsin: University of Wisconsin Press.
- McCormack, S., Dunn, D. T., Desai, M., Dolling, D. I., Gafos, M., Gilson, R., ... Schembri, G. (2016). Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection (PROUD): Effectiveness results from the pilot phase of a pragmatic open-label randomised trial. *The Lancet*, 387(10013), 53–60.

- Medley, A., Kennedy, C., O'Reilly, K., & Sweat, M. (2009). Effectiveness of peer education interventions for HIV prevention in developing countries: A systematic review and meta-analysis. *AIDS Education and Prevention, 21*(3), 181–206.
- Melchior, R., Nemes, M. I. B., Alencar, T. M. D., & Buchalla, C. M. (2007). Challenges of treatment adherence by people living with HIV/AIDS in Brazil. *Revista de Saúde Pública, 41*, 87–93.
- Merson, M., Padian, N., Coates, T. J., Gupta, G. R., Bertozzi, S. M., Piot, P., ... Bartos, M. (2008). Combination HIV prevention. *The Lancet, 372*(9652), 1805–1806.
- Meyers, K., Wu, Y., Qian, H., Sandfort, T., Huang, X., Xu, J., ... Wu, H. (2018). Interest in long-acting injectable PrEP in a cohort of men who have sex with men in China. *AIDS Behavior, 22*(4), 1217–1227.
- Meyer-Rath, G., Johnson, L. F., Pillay, Y., Blecher, M., Brennan, A. T., Long, L., ... & Rosen, S. (2017). Changing the South African national antiretroviral therapy guidelines: the role of cost modelling. *PLoS One, 12*(10), e0186557.
- Mgbako, C., & Smith, L. A. (2009). Sex work and human rights in Africa. *Fordham International Law Journal, 33*, 1178. <https://ir.lawnet.fordham.edu/ilj/vol33/iss4/2>
- Mhodes, M., & Nyamhanga, T. (2016). Experiences and impact of stigma and discrimination among people on antiretroviral therapy in Dar es Salaam: A qualitative perspective. *AIDS Research and Treatment, 2016*, art. 7925052. doi:10.1155/2016/7925052
- Miller, W. R., & Rollnick, S. (2012). *Motivational interviewing: Helping people change*. New York: Guilford.
- Mills, T., Lawton, R., & Sheard, L. (2019). Advancing complexity science in healthcare research: the logic of logic models. *BMC Medical Research Methodology, 19*(1), 1–11.
- Mkhize, G., & Njawala, L. (2016). Rethinking hegemonic masculinity and patriarchal privilege within heterosexual interpersonal relationships. *The Oriental Anthropologist, 16*(2), 379–397.
- Molina, J.-M., Capitant, C., Spire, B., Pialoux, G., Cotte, L., Charreau, I., ... Delfraissy, J. (2015). On-demand preexposure prophylaxis in men at high risk for HIV-1 infection. *New England Journal of Medicine, 373*(23), 2237–2246. doi:10.1056/NEJMoa1506273

- Mongkuo, M. Y., Lucas, N., & Taylor, A. (2012). The effects of motivation and knowledge on HIV prevention behavior among historically black college students: An application of the Information-Motivation-Behavioral Skills Model. *Greener Journal of Medical Sciences*, 2(2), 1–7.
- Moore, G., Audrey, S., Barker, M., Bond, L., Bonell, C., Cooper, C., ... Baird, J. (2014). Process evaluation in complex public health intervention studies: The need for guidance. *Journal of Epidemiology and Community Health*, 68(2), 101–102. doi:10.1136/jech-2013-202869
- Moore, L., Chersich, M. F., Steen, R., Reza-Paul, S., Dhana, A., Vuylsteke, B., ... Scorgie, F. (2014). Community empowerment and involvement of female sex workers in targeted sexual and reproductive health interventions in Africa: A systematic review. *Global Health*, 10, 47. doi:10.1186/1744-8603-10-47
- Morgan, A. (2000). *What is narrative therapy?* Adelaide: Dulwich Centre Publications.
- Morgan, D. L., & Krueger, R. A. (1993). When to use focus groups and why. In D.L. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 3–19). A Sage Focus Edition. Thousand Oaks, CA: Sage. doi:10.4135/9781483349008
- Morra Imas, L. G., & Rist, R. (2009). *The road to results: Designing and conducting effective development evaluations*. The World Bank.
- Mudzviti, T., Dhliwayo, A., Chingombe, B., Ngara, B., Monera-Penduka, T., Maponga, C., & Morse, G. (2019). Female sex workers and their attitude towards oral pre-exposure prophylaxis. *Sexually Transmitted Infections*, 95, A360-A360. doi:10.1136/sextrans-2019-sti.903
- Mudzviti, T., Dhliwayo, A., Chingombe, B., Ngara, B., Monera-Penduka, T. G., Maponga, C. C., & Morse, G. D. (2020). Perspectives on oral pre-exposure prophylaxis use amongst female sex workers in Harare, Zimbabwe. *Southern African Journal of HIV Medicine*, 21(1), 1–6.
- Mugo, N. R., Ngunjiri, K., Kiragu, M., Irungu, E., & Kilonzo, N. (2016). The preexposure prophylaxis revolution: From clinical trials to programmatic implementation. *Current Opinion in HIV and AIDS*, 11(1), 80–86.

- Murdoch, J. (2016). Process evaluation for complex interventions in health services research: analysing context, text trajectories and disruptions. *BMC health services research*, 16(1), 407. doi:10.1186/s12913-016-1651-8
- Naidu, T., Sliap, Y., & Dageid, W. (2012). The social construction of identity in HIV/AIDS home-based care volunteers in rural KwaZulu-Natal, South Africa. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 9(2), 113–126.
- Ndugwa Kabwama, S., & Berg-Beckhoff, G. (2015). The association between HIV/AIDS-related knowledge and perception of risk for infection: A systematic review. *Perspectives in Public Health*, 135(6), 299–308. doi:10.1177/1757913915595831
- Nealon, J. T. (1994). Theory that matters. *Postmodern Culture*, 5(1).
- Needle, R., Kroeger, K., Belani, H., Achrekar, A., Parry, C. D., & Dewing, S. (2008). Sex, drugs, and HIV: Rapid assessment of HIV risk behaviors among street-based drug using sex workers in Durban, South Africa. *Social Science & Medicine*, 67(9), 1447–1455. doi:10.1016/j.socscimed.2008.06.031
- Neuman, L. W. (2007). *Social research methods* (6<sup>th</sup> ed.) India: Pearson Education.
- Neuman, L. W. (2014). *Social research methods: Qualitative and quantitative approaches*. Essex: Pearson Education.
- Norum, K. E. (2008). *Natural setting*. *The Sage Encyclopedia of Qualitative Research Methods*. California, US: Sage. Retrieved from <http://knowledge.sagepub.com/view/research/SAGE.xml>.
- Norton, L., & Sliap, Y. (2018). A critical reflexive model: Working with life stories in health promotion education. *South African Journal of Higher Education*, 32(3), 45–63.
- Norton, L., & Sliap, Y. (2019). #WE SPEAK: Exploring the experience of refugee youth through participatory research and poetry. *Journal of Youth Studies*, 22(7), 873–890.
- Norton, L., & Sliap, Y. (2020). Performing life stories: Hindsight and foresight for better insight. *Learning Landscapes*, 13(1), 173–188.
- Nota, P., Govender, E., & Vukapi, Y. (2020). “Male-supported, female-initiated”: Exploring a cultural message for communicating around new HIV prevention technologies for

- women in KwaZulu-Natal, South Africa. *Communicare: Journal for Communication Sciences in Southern Africa*, 39(1), 18–32.
- Nova, C. (2016). Vectors of disease: Sex workers as bodies to be managed. *QED: A Journal in GLBTQ Worldmaking*, 3(3), 196–200.
- O’Cathain, A., Croot, L., Duncan, E., Rousseau, N., Sworn, K., Turner, K. M., ... & Hoddinott, P. (2019). Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open*, 9(8), e029954.
- Oliveira, E. (2017). ‘I am more than just a sex worker but you have to also know that I sell sex and it’s okay’: Lived Experiences of Migrant Sex Workers in Inner-City Johannesburg, South Africa. In *Urban Forum*, 28(1), 43–57.
- O’Malley, G., Barnabee, G., & Mugwanya, K. (2019). Scaling-up PrEP delivery in sub-Saharan Africa: What can we learn from the scale-up of ART? *Current HIV/AIDS Reports*, 16(2), 141–150.
- Odek, W. O., Busza, J., Morris, C. N., Cleland, J., Ngugi, E. N., & Ferguson, A. G. (2009). Effects of micro-enterprise services on HIV risk behaviour among female sex workers in Kenya’s urban slums. *AIDS Behavior*, 13(3), 449.
- Ogunbajo, A., Kang, A., Shangani, S., Wade, R. M., Onyango, D. P., Odero, W. W., & Harper, G. W. (2019). Awareness and acceptability of pre-exposure prophylaxis (PrEP) among gay, bisexual and other men who have sex with men (GBMSM) in Kenya. *AIDS Care*, 10, 1185–1192. doi:10.1080/09540121.2019.1612023
- Ogunbajo, A., Leblanc, N. M., Kushwaha, S., Boakye, F., Hanson, S., Smith, M. D., & Nelson, L. E. (2019). Knowledge and acceptability of HIV pre-exposure prophylaxis (PrEP) among men who have sex with men (MSM) in Ghana. *AIDS Care*, 32(3), 330–336. doi:10.1080/09540121.2019.1675858
- Okorie, H. M., Ifeany, O. E., Vincent, C. C. N., & Prayer, N. (2020). Association of ABO blood group with HIV infection. *Canadian Journal of Infectious Diseases and Medical Microbiology*, 1(1), 1–7.
- Oldenburg, C. E., Biello, K. B., Colby, D., Closson, E. F., Nguyen, T., Trang, N. N., ... Mimiaga, M. J. (2014). Engagement with peer health educators is associated with

- willingness to use pre-exposure prophylaxis among male sex workers in Ho Chi Minh City, Vietnam. *AIDS Patient Care and STDs*, 28(3), 109–112.
- O'Malley, G., Barnabee, G., & Mugwanya, K. (2019). Correction to: Scaling-up PrEP Delivery in Sub-Saharan Africa: What Can We Learn from the Scale-up of ART?. *Current HIV/AIDS Reports*, 16(3), 257-257.
- Open Society Foundations. (2015). Ten reasons to decriminalize sex work. <https://www.opensocietyfoundations.org/publications/ten-reasons-decriminalize-sex-work>
- Ortblad, K. F., & Oldenburg, C. E. (2018). Tailoring combination HIV prevention for female sex workers. *Lancet HIV*, 5(8), e406.
- Ortblad, K. F., Chanda, M. M., Musoke, D. K., Ngabirano, T., Mwale, M., Nakitende, A., ... Oldenburg, C. E. (2018). Acceptability of HIV self-testing to support pre-exposure prophylaxis among female sex workers in Uganda and Zambia: Results from two randomized controlled trials. *BMC Infectious Diseases*, 18(1). doi:10.1186/s12879-018-3415-z
- Padian, N. S., Buvé, A., Balkus, J., Serwadda, D., & Cates Jr, W. (2008). Biomedical interventions to prevent HIV infection: Evidence, challenges, and way forward. *The Lancet*, 372(9638), 585–599. doi:10.1016/S0140-6736(08)60885-5
- Pantelic, M., Shenderovich, Y., Cluver, L., & Boyes, M. (2015). Predictors of internalised HIV-related stigma: A systematic review of studies in sub-Saharan Africa. *Health Psychology Review*, 9(4), 469–490.
- Parker, R. (2011). Grassroots activism, civil society mobilization, and the politics of the global HIV/AIDS epidemic. *The Brown Journal of World Affairs*, 17(2), 21–37.
- Parker, S., Chan, P. A., Oldenburg, C. E., Hoffmann, M., Poceta, J., Harvey, J., ... Nunn, A. (2015). Patient experiences of men who have sex with men using pre-exposure prophylaxis to prevent HIV infection. *AIDS Patient Care and STDs*, 29(12), 639–642.
- Parry, C. D., Dewing, S., Petersen, P., Carney, T., Needle, R., Kroeger, K., & Treger, L. (2009). Rapid assessment of HIV risk behavior in drug using sex workers in three cities in South Africa. *AIDS Behavior*, 13(5), 849–859. doi:10.1007/s10461-008-9367-3

- Parsons, J. T., Rendina, H. J., Whitfield, T. H., & Grov, C. (2016). Familiarity with and preferences for oral and long-acting injectable HIV pre-exposure prophylaxis (PrEP) in a national sample of gay and bisexual men in the US. *AIDS Behavior*, *20*(7), 1390–1399.
- Pauw, I., & Brener, L. (2003). ‘You are just whores—you can’t be raped’: Barriers to safer sex practices among women street sex workers in Cape Town. *Culture, Health and Sexuality*, *5*(6), 465–481. doi:10.1080/136910501185198
- Pelletier, S. J., Gagnon, M.-P., Diabaté, S., Kra, O., Biékoua, Y. J., Osso, G. D., ... Alary, M. (2019). Pre-exposure prophylaxis (PrEP) in men who have sex with men in Bouaké, Côte d’Ivoire: A qualitative evaluation of acceptability. *Open AIDS Journal*, *13*(1), 49–58. doi:10.2174/1874613601913010049
- Petroll, A. E., Walsh, J. L., Owczarzak, J. L., McAuliffe, T. L., Bogart, L. M., & Kelly, J. A. (2017). PrEP awareness, familiarity, comfort, and prescribing experience among US primary care providers and HIV specialists. *AIDS and Behavior*, *21*(5), 1256–1267.
- Pettifor, A., Nguyen, N. L., Celum, C., Cowan, F. M., Go, V., & Hightow-Weidman, L. (2015). Tailored combination prevention packages and PrEP for young key populations. *Journal of the International AIDS Society*, *18*, 19434.
- Pillay, D., Stankevitz, K., Lanham, M., Ridgeway, K., Murire, M., Briedenhann, E., ... Mullick, S. (2020). Factors influencing uptake, continuation, and discontinuation of oral PrEP among clients at sex worker and MSM facilities in South Africa. *PLoS One*, *15*(4), e0228620.
- Pladevall, M., Brotons, C., Gabriel, R., Arnau, A., Suarez, C., de la Figuera, M., ... Divine, G. (2010). Multicenter cluster-randomized trial of a multifactorial intervention to improve antihypertensive medication adherence and blood pressure control among patients at high cardiovascular risk (the COM99 study). *Circulation*, *122*(12), 1183–1191.
- PrEPwatch. (2017). PrEP implementation pack: South Africa 2016-2017. Retrieved from [https://www.prepwatch.org/wp-content/uploads/2017/07/SA\\_ImplementationPack.pdf](https://www.prepwatch.org/wp-content/uploads/2017/07/SA_ImplementationPack.pdf)
- Prodger, J. L., & Kaul, R. (2017). The biology of how circumcision reduces HIV susceptibility: Broader implications for the prevention field. *AIDS Research and Therapy*, *14*(1), 49. doi:10.1186/s12981-017-0167-6

- Potter, J. (1996). *Representing reality: Discourse, rhetoric and social construction*. Thousand Oaks, CA: Sage.
- Quaife, M., Vickerman, P., Manian, S., Eakle, R., Cabrera-Escobar, M. A., Delany-Moretlwe, S., & Terris-Prestholt, F. (2018). The effect of HIV prevention products on incentives to supply condomless commercial sex among female sex workers in South Africa. *Health Economics*, *27*(10), 1550–1566.
- Qu, D., Zhong, X., Lai, M., Dai, J., Liang, H., & Huang, A. (2019). Influencing factors of pre-exposure prophylaxis self-efficacy among men who have sex with men. *American journal of men's health*, *13*(2), 1557988319847088.
- Quinn, K. G., Zarwell, M., John, S. A., Christenson, E., & Walsh, J. L. (2020). Perceptions of PrEP use within primary relationships among young black gay, bisexual, and other men who have sex with men. *Archives of Sexual Behavior*, *49*(6), 2117–2128. doi:10.1007/s10508-020-01683-1
- Quinn, T. C., Mann, J. M., Curran, J. W., & Piot, P. (1986). AIDS in Africa: An epidemiologic paradigm. *Science*, *234*(4779), 955–963.
- Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition Society*, *63*(4), 655–660. doi:10.1079/PNS2004399
- Rangasami, J., & Konstant, T. (2019). *Evaluation of peer education in the Global Fund Sex Work Programme April 2016 to March 2019*. Report to the Networking HIV and AIDS Community of Southern Africa (NACOSA). Retrieved from [https://www.nacosa.org.za/wp-content/uploads/2019/05/FINAL-report\\_Sex-Work-peer-educator-evaluation-2019.pdf](https://www.nacosa.org.za/wp-content/uploads/2019/05/FINAL-report_Sex-Work-peer-educator-evaluation-2019.pdf)
- Ransome, Y., Zarwell, M., & Robinson, W. T. (2019). Participation in community groups increases the likelihood of PrEP awareness: New Orleans NHBS-MSM Cycle, 2014. *PLoS One*, *14*(3), e0213022.
- Reason, P. (1994). Co-operative inquiry, participatory action research & action inquiry: Three approaches to participative inquiry. In N K. Denzin & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (pp. 324–339). Thousand Oaks: Sage. Retrieved from <https://pdf4pro.com/cdn/three-approaches-to-participative-inquiry-peter-2e0a52.pdf>

- Reid, C. (n.d.) *PrEP: Your guide to this HIV prevention drug*. [Online] [https://desmondutuhivfoundation.org.za/blog\\_post/prep-your-guide-to-this-hiv-prevention-drug/](https://desmondutuhivfoundation.org.za/blog_post/prep-your-guide-to-this-hiv-prevention-drug/)
- Rekart, M. L. (2005). Sex-work harm reduction. *The Lancet*, 366(9503), 2123–2134.
- Reza-Paul, S., Lazarus, L., Doshi, M., Hafeez Ur Rahman, S., Ramaiah, M., Maiya, R., ... Lorway, R. (2016). Prioritizing risk in preparation for a demonstration project: A mixed methods feasibility study of oral pre-exposure prophylaxis (PrEP) among female sex workers in South India. *PloS One*, 11(11), 1–20. doi:10.1371/journal.pone.0166889
- Reza-Paul, S., Lazarus, L., Jana, S., Ray, P., Mugo, N., Ngure, K., ... Lorway, R. (2019). Community inclusion in PrEP demonstration projects: Lessons for scaling up. *Gates Open Research*, 5(3), 1504. doi:10.12688/gatesopenres.13042.2
- Richards, D. A., & Hallberg, I. R. (Eds.). (2015). *Complex interventions in health: an overview of research methods*. Routledge.
- Ritchie, J., & Spencer, L. (2002). Qualitative data analysis for applied policy research. *The qualitative researcher's companion*, 573(2002), 305–329.
- Richter, M. (2008). Sex work, reform initiatives and HIV/AIDS in inner-city Johannesburg. *African Journal of AIDS Research*, 7(3), 323–333. doi:10.2989/AJAR.2008.7.3.9.656
- Ringdal, N. J. (2007). *Love for sale: A world history of prostitution*. (Kindle edition). New York, NY: Grove Press.
- Rissel, C. (1994). Empowerment: the holy grail of health promotion? *Health Promotion International*, 9(1), 39–47.
- Rober, P. (2005). The therapist's self in dialogical family therapy: some ideas about not-knowing and the therapist's inner conversation. *Family Process*, 44(4), 477–495.
- Rojas Castro, D., Delabre, R. M., & Molina, J. M. (2019). Give PrEP a chance: Moving on from the “risk compensation” concept. *Journal of the International AIDS Society*, 22, e25351.
- Rosa, E. M., & Tudge, J. (2013). Urie Bronfenbrenner's theory of human development: Its evolution from ecology to bioecology. *Journal of Family Theory & Review*, 5(4), 243–258.

- Rubin, H. J., & Rubin, I. S. (2011). *Qualitative interviewing: The art of hearing data*. Thousand aks, CA: Sage.
- Rule, P. (2004). Dialogic spaces, adult education projects and social engagement. *International Journal of Lifelong Education*, 23(4), 319–334.
- Ruppar, T. M. (2010). Randomized pilot study of a behavioral feedback intervention to improve medication adherence in older adults with hypertension. *Journal of Cardiovascular Nursing*, 25(6), 470–479.
- Saag, M. S., Gandhi, R. T., Hoy, J. F., Landovitz, R. J., Thompson, M. A., Sax, P. E., ... & Volberding, P. A. (2020). Antiretroviral drugs for treatment and prevention of HIV infection in adults: 2020 Recommendations of the International Antiviral Society–USA Panel. *Jama*, 324(16), 1651–1669.
- SAGE Publications (2019) Quasi-experimental and single-case experimental designs. Retrieved from [https://us.sagepub.com/sites/default/files/upm-binaries/89876\\_Chapter\\_13\\_Quasi\\_Experimental\\_and\\_Single\\_Case\\_Designs.pdf](https://us.sagepub.com/sites/default/files/upm-binaries/89876_Chapter_13_Quasi_Experimental_and_Single_Case_Designs.pdf)
- Sarafian, I. (2012). Process assessment of a peer education programme for HIV prevention among sex workers in Dhaka, Bangladesh: A social support framework. *Social Science & Medicine*, 75(4), 668–675.
- Sarbu, I., Matei, C., Benea, V., & Georgescu, S. (2014). Brief history of syphilis. *Journal of Medicine and Life*, 7(1), 4.
- Scambler, G., & Paoli, F. (2008). Health work, female sex workers and HIV/AIDS: Global and local dimensions of stigma and deviance as barriers to effective interventions. *Social Science & Medicine*, 66(8), 1848–1862.
- Schauer, M., Schauer, M., Neuner, F., & Elbert, T. (2011). *Narrative exposure therapy: A short-term treatment for traumatic stress disorders*. Hogrefe Publishing.
- Scheibe, A., Drame, F. M., & Shannon, K. (2012). HIV prevention among female sex workers in Africa. *Sahara-J: Journal of Social Aspects of HIV/AIDS*, 9(3), 167–172. doi:10.1080/17290376.2012.743809
- Scheibe, A., Richter, M., & Vearey, J. (2016). Sex work and South Africa's health system: Addressing the needs of the underserved. *South African Health Review*, 2016(1), 165–178.

- Scheibe, A., Brown, B., Duby, Z., & Bekker, L.-G. (2011). Key populations, key responses. A gap analysis for key populations and HIV in South Africa, and recommendations for the National Strategic Plan for HIV/AIDS, STIs and TB (2012–2016). Cape Town: Desmond Tutu HIV Foundation, Joint UN Team on HIV and AIDS.
- Scheibe, A., Howell, S., Müller, A., Katumba, M., Langen, B., Artz, L., & Marks, M. (2016). Finding solid ground: law enforcement, key populations and their health and rights in South Africa. *Journal of the International AIDS Society*, 19(4 Suppl 3), 20872–20872. doi:10.7448/IAS.19.4.20872
- Schwartz, S. H. (1992). Universals in the content and structure of values: Theoretical advances and empirical tests in 20 countries. *Advances in Experimental Social Psychology*, 25(1), 1–65.
- Schwartz, S. H. (1994). Are there universal aspects in the structure and contents of human values? *Journal of Social Issues*, 50(4), 19–45.
- Schwartz, S., Lambert, A., Phaswana-Mafuya, N., Kose, Z., McIngana, M., Holland, C., ... Baral, S. (2017). Engagement in the HIV care cascade and barriers to antiretroviral therapy uptake among female sex workers in Port Elizabeth, South Africa: Findings from a respondent-driven sampling study. *Sexually Transm Infections*, 93(4), 290–296. doi:10.1136/sextrans-2016-052773
- Scorgie, F., Chersich, M. F., Ntaganira, I., Gerbase, A., Lule, F., & Lo, Y. R. (2012). Socio-demographic characteristics and behavioral risk factors of female sex workers in sub-Saharan Africa: A systematic review. *AIDS Behavior*, 16(4), 920–933. doi:10.1007/s10461-011-9985-z
- Scorgie, F., Nakato, D., Harper, E., Richter, M., Maseko, S., Nare, P., ... Chersich, M. (2013). ‘We are despised in the hospitals’: SEX workers' experiences of accessing health care in four African countries. *Culture, Health and Sexuality*, 15(4), 450–465. doi:10.1080/13691058.2012.763187
- Seale, C. (1999). Quality in qualitative research. *Qualitative Inquiry*, 5(4), 465–478.
- Shannon, K., Strathdee, S. A., Goldenberg, S. M., Duff, P., Mwangi, P., Rusakova, M., ... & Boily, M. C. (2015). Global epidemiology of HIV among female sex workers: influence of structural determinants. *The Lancet*, 385(9962), 55–71.

- Shea, J., Bula, A., Dunda, W., Hosseinipour, M. C., Golin, C. E., Hoffman, I. F., ... Lancaster, K. E. (2019). "The drug will help protect my tomorrow": Perceptions of integrating PrEP into HIV prevention behaviours among FSWs in Lilongwe Malawi. *AIDS Education and Prevention*, 31(5), 421–432. doi:10.1521/aeap.2019.31.5.421
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63–75.
- Shrestha, R., Altice, F. L., Huedo-Medina, T. B., Karki, P., & Copenhaver, M. (2017). Willingness to use pre-exposure prophylaxis (PrEP): An empirical test of the information-motivation-behavioral skills (IMB) model among high-risk drug users in treatment. *AIDS and Behavior*, 21(5), 1299–1308.
- Shotter, J. (1993). *Conversational realities: Constructing life through language* (Vol. 11). Thousand Oaks, CA: Sage.
- ShowMe. (2020). Maps of South Africa. Retrieved from <https://showme.co.za/facts-about-south-africa/the-maps-of-south-africa/>
- Sidani, S. (2014). *Health intervention research: Understanding research design and methods*. Thousand Oaks, CA: Sage.
- Simelela, N., & Venter, W. D. F. (2014). A brief history of South Africa's response to AIDS. *South African Medical Journal*, 104(3), 249–251.
- Simelela, N., Venter, W. F., Pillay, Y., & Barron, P. (2015). A political and social history of HIV in South Africa. *Current HIV/AIDS Reports*, 12(2), 256–261.
- Simoni, J. M., Nelson, K. M., Franks, J. C., Yard, S. S., & Lehavot, K. (2011). Are peer interventions for HIV efficacious? A systematic review. *AIDS and Behavior*, 15(8), 1589–1595.
- Sinha, S. (2015). Reasons for women's entry into sex work: A case study of Kolkata, India. *Sexuality & Culture*, 19(1), 216–235.
- Siransy, L. K., Nanga, Z. Y., Zaba, F. S., Tufa, N. Y., & Dasse, S. R. (2015). ABO/Rh blood groups and risk of HIV infection and Hepatitis B among blood donors of Abidjan, Côte D'ivoire. *European Journal of Microbiology and Immunology*, 5(3), 205–209.

- Sliep, Y., & Kotze, E. (2011). Weaving a learning community by the telling, deconstructing and re-telling of life stories. In K. Maree (Ed.), *Shaping the story: A guide to facilitating narrative career counselling* (pp. 138–151). Brill, Sense. doi:10.1163/9789004406162\_013
- Sliep, Y., & Gilbert, A. (2006). Promoting inter-relational reflexivity with psychosocial workers in community work: A case study from Burundi. *Journal of Psychology in Africa, 16*(2), 293–302.
- Smith, J. H., & Whiteside, A. (2010). The history of AIDS exceptionalism. *Journal of the International AIDS Society, 13*(1), 47–47.
- Sokal, D. C., Abdool Karim, Q., Sibeko, S., Yende Zuma, N., Mansoor, L. E., Baxter, C., ... Karim, S. S. A. (2012). Safety of tenofovir gel, a vaginal microbicide, in South African women: Results of the CAPRISA 004 Trial. doi:10.3851/imp2311
- South, J. (2014). Health promotion by communities and in communities: Current issues for research and practice. *Scandinavian Journal of Public Health, 42*(15\_suppl), 82–87. doi:10.1177/1403494814545341
- South Africa. 1996. Constitution of the Republic of South Africa. Cape Town: Government Gazette.
- South Africa. 1957. Sexual Offences Act, Act 23 of 1957. Cape Town: Government Gazette.
- South Africa. Department of Health. (2016). *Guidelines for expanding combination prevention and treatment options: Oral pre-exposure prophylaxis (PrEP) and test and treat (T&T)*. Retrieved from <https://www.nicd.ac.za/assets/files/PrEP%20and%20TT%20Guidelines%20-%20Final%20Draft%20-%202011%20May%202016.pdf>
- South African Law Reform Commission. (2009). Discussion paper 001/2009, Project 107. Sexual offences. Adult prostitution. Retrieved from [https://www.justice.gov.za/salrc/dpapers/dp0001-2009\\_prj107\\_2009.pdf](https://www.justice.gov.za/salrc/dpapers/dp0001-2009_prj107_2009.pdf)
- South African National Aids Council. (2016). The South African National Sex Worker HIV Plan, 2016–2019. Pretoria. Retrieved from <https://sanac.org.za/download/721/sex-worker/3857/south-african-national-sex-worker-hiv-plan-2016-2019.pdf>

- Sileo, K. M., Bogart, L. M., Wagner, G. J., Musoke, W., Naigino, R., Mukasa, B., & Wanyenze, R. K. (2019). HIV fatalism and engagement in transactional sex among Ugandan fisherfolk living with HIV. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *16*(1), 1–9.
- Spinelli, M., Scott, H., Vittinghoff, E., Liu, A. Y., Gonzalez, R., Morehead-Gee, A., ... Buchbinder, S. P. (2018). *Examining PrEP interruptions in a safety-net primary care network: Missed opportunities to re-engage PrEP users accessing non-PrEP services*. Paper presented at the Aids Research and Human Retroviruses, 21-25 October, Madrid.
- St. Clair, T., Hallberg, K., & Cook, T. D. (2016). The validity and precision of the comparative interrupted time-series design: three within-study comparisons. *Journal of Educational and Behavioral Statistics*, *41*(3), 269–299.
- Stadler, J., & Delany, S. (2006). The 'healthy brothel': The context of clinical services for sex workers in Hillbrow, South Africa. *Culture, Health and Sexuality*, *8*(5), 451–464. doi:10.1080/13691050600872107
- Stein, D., & Valters, C. (2012). Understanding theory of change in international development. <http://eprints.lse.ac.uk/56359/>
- Stetler, C. B., Legro, M. W., Wallace, C. M., Bowman, C., Guihan, M., Hagedorn, H., ... & Smith, J. L. (2006). The role of formative evaluation in implementation research and the QUERI experience. *Journal of General Internal Medicine*, *21*(2), S1.
- Strathdee, S. A., Wechsberg, W. M., Kerrigan, D. L., & Patterson, T. L. (2013). HIV prevention among women in low- and middle-income countries: Intervening upon contexts of heightened HIV risk. *Annual Review of Public Health*, *34*, 301–316. doi:10.1146/annurev-publhealth-031912-114411
- Stirratt, M. J., & Gordon, C. M. (2008). Adherence to biomedical HIV prevention methods: considerations drawn from HIV treatment adherence research. *Current HIV/AIDS Reports*, *5*(4), 186.
- Suen, L. J. W., Huang, H. M., & Lee, H. H. (2014). A comparison of convenience sampling and purposive sampling. *Hu Li Za Zhi*, *61*(3), 105–111. doi: 10.6224/JN.61.3.105
- Sutton, J., & Austin, Z. (2015). Qualitative research: Data collection, analysis, and management. *The Canadian Journal of Hospital Pharmacy*, *68*(3), 226.

- Syvvertsen, A. (2006). Youth activism: An international encyclopedia. In: Westport, CT: Greenwood.
- Thigpen, M. C., Kebaabetswe, P. M., Paxton, L. A., Smith, D. K., Rose, C. E., Segolodi, T. M., ... Chillag, K. L. (2012). Antiretroviral preexposure prophylaxis for heterosexual HIV transmission in Botswana. *New England Journal of Medicine*, *367*(5), 423–434.
- Thomas, I. (2015). The history of AIDS in Africa. Retrieved from <https://www.blackhistorymonth.org.uk/article/section/real-stories/the-history-of-aids-in-africa/>
- Tolli, M. V. (2012). Effectiveness of peer education interventions for HIV prevention, adolescent pregnancy prevention and sexual health promotion for young people: A systematic review of European studies. *Health Education Research*, *27*(5), 904–913.
- Tomlinson, M., Ward, C. L., & Marlow, M. (2015). Improving the efficiency of evidence-based interventions: The strengths and limitations of randomised controlled trials. *South African Crime Quarterly*, *51*, 43–52.
- Tongco, M. D. C. (2007). Purposive sampling as a tool for informant selection. *Ethnobotany Research and applications*, *5*, 147–158.
- University of California, San Francisco, Anova Health Institute & Wits Reproductive Health and HIV Institute (2015). *South African Health Monitoring Survey (SAHMS): An integrated biological and behavioural survey among female sex workers, South Africa 2013–2014. Final Report*. San Francisco: UCSF. Retrieved from <http://www.anovahealth.co.za/wp-content/uploads/2016/03/SAHMS-Report.pdf>
- Van Damme, L., Corneli, A., Ahmed, K., Agot, K., Lombaard, J., Kapiga, S., ... Onyango, J. (2012). Preexposure prophylaxis for HIV infection among African women. *New England Journal of Medicine*, *367*(5), 411–422.
- Van der Elst, E. M., Mbogua, J., Operario, D., Mutua, G., Kuo, C., Mugo, P., ... Priddy, F. (2013). High acceptability of HIV pre-exposure prophylaxis but challenges in adherence and use: Qualitative insights from a Phase I trial of intermittent and daily PrEP in at-risk populations in Kenya. *AIDS Behavior*, *17*(6), 2162–2172.
- Van't Riet, J., Cox, A. D., Cox, D., Zimet, G. D., De Bruijn, G.-J., Van den Putte, B., ... Ruiter, R. A. (2014). Does perceived risk influence the effects of message framing? A new investigation of a widely held notion. *Psychology & Health*, *29*(8), 933.

- Vanwesenbeeck, I. (2017). Sex work criminalization is barking up the wrong tree. *Archives of sexual behavior*, 46(6), 1631–1640.
- Venter, W. (2014). A South African decade of antiretrovirals. *South African Medical Journal*, 104(1), 3. doi:10.7196/SAMJ.778
- Venter, W. D. F., Cowan, F., Black, V., Rebe, K., & Bekker, L.-G. (2015). Pre-exposure prophylaxis in Southern Africa: Feasible or not? *Journal of the International AIDS Society*, 18(4Supp 3), 1–7. doi:10.7448/IAS.18.4.19979
- Visser, M., & Sipsma, H. (2013). The experience of HIV-related stigma in South Africa. In Liamputtong, P. (Ed.), *Stigma, discrimination and living with HIV/AIDS: A cross-cultural perspective* (pp. 205–227). Springer.
- Visser, M. J., Kershaw, T., Makin, J. D., & Forsyth, B. W. (2008). Development of parallel scales to measure HIV-related stigma. *AIDS Behavior*, 12(5), 759–771.
- Voeten, H. A., Egesah, O. B., Ondiege, M. Y., Varkevisser, C. M., & Habbema, J. D. F. (2002). Clients of female sex workers in Nyanza province, Kenya: A core group in STD/HIV transmission. *Sexually Transmitted Diseases*, 29(8), 444–452.
- Waa, A., Holibar, F., Spinola, C., Runanga, W., Me te Paekaka, H., Huijbers, K., ... & Te Hauora, O. (1998). *Planning and doing programme evaluation: An introductory guide for health promotion*. Alcohol & Public Health Research Unit, University of Auckland.
- Walker, C. A. (2015). Social constructionism and qualitative research. *Journal of Theory Construction and Testing*, 19(2), 37.
- Wanyenze, R. K., Musinguzi, G., Kiguli, J., Nuwaha, F., Mujisha, G., Musinguzi, J., ... Matovu, J. K. B. (2017). “When they know that you are a sex worker, you will be the last person to be treated”: Perceptions and experiences of female sex workers in accessing HIV services in Uganda. *BMC International Health and Human Rights*, 17(1), 11–11. doi:10.1186/s12914-017-0119-1
- Watkins-Hayes, C. (2014). Intersectionality and the sociology of HIV/AIDS: Past, present, and future research directions. *Annual Review of Sociology*, 40, 431–457.
- Watt, D. (2007). On becoming a qualitative researcher: The value of reflexivity. *Qualitative Report*, 12(1), 82–101.

- Webel, A. R. (2010). Testing a peer-based symptom management intervention for women living with HIV/AIDS. *AIDS Care*, 22(9), 1029–1040.
- Webel, A. R., Okonsky, J., Trompeta, J., & Holzemer, W. L. (2010). A systematic review of the effectiveness of peer-based interventions on health-related behaviors in adults. *American Journal of Public Health*, 100(2), 247–253.
- Weiss, C. H. (1995). Nothing as practical as good theory: Exploring theory-based evaluation for comprehensive community initiatives for children and families. *New approaches to evaluating community initiatives: Concepts, methods, and contexts*, 1, 65–92.
- Weir, S., Sabin, K., Abdul-Quader, A., Au, M., Bok, L., & Butler, J. (2014). Operational guidelines for monitoring and evaluation of HIV Programmes for sex workers, men who have sex with men, and transgender people. Volume I, National and Sub-National Levels. MEASURE Evaluation.
- Werner, C. M. (1998). Strategies for service-learning: internalization and empowerment. In R. G. Bringle, & D. K. Duffy (Eds.), *With service in mind: Concepts and models for service-learning in psychology* (pp. 119–127). Stylus Publishing.
- White, H. (2010). A contribution to current debates in impact evaluation. *Evaluation*, 16(2), 153–164.
- White, S., Fook, J., & Gardner, F. (2006). Critical reflection: A review of contemporary literature and understandings. In S. White, J. Fook, & F. Gardner (Eds.), *Critical reflection in health and social care* (pp. 3–20). Open University Press.
- Williams, C. (2007). Research methods. *Journal of Business & Economics Research*, 5(3). doi:10.19030/jber.v5i3.2532
- W.K. Kellogg Foundation. (2004). *Using logic models to bring together planning, evaluation, and action: logic model development guide*. Michigan: Kellogg Foundation.
- World Health Organization. (2012a). *Guidance on pre-exposure oral prophylaxis (PrEP) for serodiscordant couples, men who have sex with men and transgender women at high risk of HIV in implementation research, Annexes*. World Health Organization, Geneva, Switzerland. <https://apps.who.int/iris/handle/10665/75191>
- World Health Organization. (2012b). *Prevention and treatment of HIV and other sexually transmitted infections for sex workers in low-and middle-income countries:*

- Recommendations for a public health approach.* World Health Organization, Geneva, Switzerland. Retrieved from:  
[https://apps.who.int/iris/bitstream/handle/10665/77745/9789241504744\\_eng.pdf?sequence=1](https://apps.who.int/iris/bitstream/handle/10665/77745/9789241504744_eng.pdf?sequence=1)
- World Health Organization. (2015). *Policy brief: Pre-exposure prophylaxis (PrEP): WHO expands recommendation on oral pre-exposure prophylaxis of HIV infection (PrEP).* World Health Organization, Geneva, Switzerland.  
<https://apps.who.int/iris/handle/10665/197906>
- World Health Organization. (2016). *Progress report 2016: Prevent HIV, test and treat all: WHO support for country impact* (No. WHO/HIV/2016.24). World Health Organization.
- World Health Organization. (2017). *Policy brief: Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations.* World Health Organization, Geneva, Switzerland. <https://apps.who.int/iris/handle/10665/258967>
- Wray-Lake, L., & Syvertsen, A. K. (2011). The developmental roots of social responsibility in childhood and adolescence. *New Directions for Child and Adolescent Development*, 2011(134), 11–25.
- Wright, P. (2012). Using graphics effectively in text. In C. Abraham, & M. Kools (Eds.), *Writing health communication: An evidence-based guide* (pp. 63–82). Thousand Oaks, CA: Sage. doi:10.4135/9781446288054
- Yi, S., Tuot, S., Mwai, G. W., Ngin, C., Chhim, K., Pal, K., ... Mburu, G. (2017). Awareness and willingness to use HIV pre-exposure prophylaxis among men who have sex with men in low-and middle-income countries: A systematic review and meta-analysis. *Journal of the International AIDS Society*, 20(1), 21580.
- Zablotska, I., Grulich, A. E., Phanuphak, N., Anand, T., Janyam, S., Poonkasetwattana, M. ... Lo, Y.-R. (2016). PrEP implementation in the Asia-Pacific region: opportunities, implementation and barriers. *Journal of the International AIDS Society*, 19(Suppl 6), 30–38. doi:<https://doi.org/10.7448/IAS.19.7.21119>