Understanding empowerment and vulnerability through engagement with HIV self-testing among female sex workers in Blantyre, Malawi

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor in Philosophy

By

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Declaration

I, Wezzie Stephanie Lora, confirm that the work presented in this thesis is my own. I confirm that appropriate credit is indicated where information has been derived from other sources in this thesis.

Abstract

My thesis presents a discussion of the concepts of vulnerability and empowerment in research exploring female sex workers' (FSW) engagement with HIV Self-testing (HIVST). HIVST is regarded as an 'empowering innovative approach' to HIV testing; however, there are concerns that HIVST may generate unintended consequences, especially in the context of sex work. Despite optimism around HIVST, no studies exist to date exploring how HIVST 'empowers' FSW in settings constrained by political and structural barriers. There is a need to interrogate whether HIVST could increase vulnerability/empowerment among FSW given the existing barriers and the burden of responsibilities of HIV protection. I draw and reflect on a range of theoretical perspectives on sex work, power, vulnerabilities and empowerment and apply them to FSW's interaction with HIVST in the context of Blantyre, Malawi. I aimed to explore how FSW engage with HIVST and the extent to which this engagement contributes to their vulnerability or provide opportunities for empowerment.

I conducted my research in peri-urban Blantyre where HIVST was implemented as part of a large scale study. I used ethnography and participatory research methods to address the following three key research questions: 1) What constitutes FSW's vulnerability and empowerment, including perceptions of HIV risk in the sex work environment? 2) How does the sex work context shape FSW's experiences with HIVST and the meaning of empowerment? 3) How does HIVST impact on FSW's lives in relation to HIV prevention, treatment and care?

Overall, I found that FSW exercise limited power across their life course, although their narratives highlighted both their sense of agency and the societal structural forces shaping their decisions to engage and remain in sex work. Whilst FSW clearly exercised agency in entering sex work, this was done in a context of severely constrained choices shaped by gender relations and the global-local political economy. The delivery of HIVST has the potential to increase FSW's decision making power over when and where to test for HIV. However, the specific power relations and vulnerabilities vary in sex work contexts because, for some, the power to decide to test was not increased; for others, feelings of insecurity and a sense of the need for retesting were amplified. High (re)testing rates among FSW indicate that knowledge of the risk of HIV infection was high, though not translated into HIV prevention. These findings challenge the current narrative that HIVST alone will reduce the HIV testing gap or increase access, treatment and care, and prevent onward HIV transmission.

In conclusion, it is important to attend to the complexities of the political economy forces, public and public health discourses, gendered power relations, and FSW's voices at the site of the intervention. Therefore, implementers should strategically reconsider the delivery model for HIVST, as testing in some sex work locations creates power dynamics leading to coercive testing, and sometimes resulting in resistance from some FSW. As this is the case, HIVST should be implemented in the context of efforts to build wider trusting relationships between providers and FSW and to reduce widespread stigma and unequal power relations.

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Abbreviations

ABC	Abstinence, Be faithful and use Condom
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
ART	Antiretroviral Therapy
ARV	Antiretroviral
CBD	Central Business District
CINAHL	Cumulative Index of Nursing and Allied Health Literature
ESA	Eastern and Southern Africa
FSW	Female Sex Worker
FGD	Focus Group Discussion
GBV	Gender-based violence
HIV	Human Immunodeficiency Virus
HIVST	Human Immunodeficiency Virus Self-Testing
HTS	HIV Testing Services
ICE	Information, Communication and Education
IDI	In-Depth Interviews
KII	Key Informant Interviews
LMIC	Low- and Middle-Income Country
LSTM	Liverpool School of Tropical Medicine
LPD	Lead Peer Distributor
MEDLINE	Medical Literature Online
MLW	Malawi Liverpool Wellcome Trust-Clinical Research Programme
MSM	Men who have sex with men
NACP	National AIDS Commission Programme
NGO	Non-Governmental Organization
NSO	National Statistical Office
PD	Peer Distributor
PE	Peer Educator
PMTCT	Preventing mother-to-child transmission
PUBMED	National Library of Medicine
PrEP	Pre-Exposure Prophylaxis

PSI	Population Services International
RDT	Rapid Diagnostic Test
SSA	Sub-Saharan Africa
STAR	Self-testing Africa
STI	Sexually Transmitted Infection
UNAIDS	United Nations Program on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

Local language terms

Chichewa	**English**
Amayi	Mother
Ankolo	Uncle
Azachipatala	Health worker
Azimayi oyenda yenda	Highly mobile women
Bala	Bar
Chibuku	Local beer
Chibwenzi	Boyfriend/girlfriend
Chishango	Condom brand (widely used when referring to condom)
Choyezera mkamwa HIV	Oral HIVST kit
Hule/mahule	Prostitute(s)
Kuponda ponda	Very mobile
Madala	Father or older man
Mwamuna okhazikika	Stable partner
Nkhala kale	Veteran
Pompo pompo	Instant
Robale	Robber

1 Introduction

1.1 Introduction

This thesis explores the vulnerability and opportunities for empowerment of female sex workers (FSW) that arises from their engagement with human immunodeficiency virus (HIV) – testing technologies. It focuses on FSW and the use of HIV self-testing (HIVST) as a case study through which I consider the concepts of empowerment and vulnerability. The study originates from the widespread assumption that HIVST can be 'empowering' to key populations, including FSW, especially prevalent in public health discourses. It also originates from my personal interest in social justice issues, particularly health inequalities that affect marginalised populations, especially, women, in this case, FSW.

Perceived as a vulnerable and marginalised population, FSW often lack access to HIV testing services (HTS) due to stigma, violence and their working conditions, significantly increasing the risk of HIV transmission. Public health reports suggest that HIVST could 'empower' FSW to have regular testing to address their testing needs (World Health Organization, 2016a, 2019). This line of argument has gone uncontested in the literature. In this thesis, I engage with the concepts of vulnerability and empowerment to offer a critique of the implementation of HIV testing technologies - in this case, HIVST - and biomedicine more broadly, and the practices they engender in the context of sex work. I aim to interrogate the forms of power HIVST implementation produces and supports and how it affects agency in settings and populations characterised by structural vulnerabilities.

1.2 Background to the research

Global efforts, especially in testing and treatment, have brought about significant declines in HIV cases. Nearly 80% of people with HIV globally know their HIV status (World Health Organization, 2019). In Eastern and

Southern Africa (ESA) between 2010 and 2018, the proportion of adults with undiagnosed HIV decreased from 2.8% to 1.0%. These achievements have been possible primarily because of the substantial scale-up of effective HTS and antiretroviral therapy (ART) (World Health Organization, 2016b, 2019).

HIV testing is an essential gateway to the success of the HIV response and is central to achieving the 90–90–90 targets (World Health Organization and UNAIDS, 2017). The overarching goal of HIV testing is to deliver diagnoses and effectively facilitate access to and uptake of appropriate HIV prevention, treatment, care, and support (World Health Organization and UNAIDS, 2017; World Health Organization, 2016). HTS, treatment, and care interventions have the potential to reduce HIV transmission and HIV-related morbidity and mortality (UNAIDS, 2015; World Health Organization, 2016a).

Despite these achievements in HIV testing and ART, a substantial testing gap remains, and in many settings, HTS are not sufficiently focused and miss people who do not know their HIV status (World Health Organization, 2019). Men, adolescents and young people (15–24 years), sex workers, men who have sex with men (MSM), and people who inject drugs remain unreached despite being more affected by HIV than other groups and at high ongoing risk (World Health Organization, 2019). UNAIDS considers FSW to be one of the key population groups that are particularly vulnerable to HIV, have significantly lower access to HTS and are less likely to be linked to treatment and care (World Health Organization and UNAIDS, 2017). Recent data suggest that globally the risk of HIV acquisition among sex workers is 21 times higher than among other adults aged 15-49 years (UNAIDS, 2017a). Poor coverage and low uptake of HTS among FSW are related to the lack of availability and accessibility of the services. Various levels of socio-economic need, punitive laws, working circumstances, sex work typology, power and gender dynamics, stigmatisation and violence contribute to FSW’s vulnerability to HIV

(Chanda *et al.*, 2017; Nyblade *et al.*, 2017; Shannon *et al.*, 2015). These vulnerabilities affect FSW's agency and ability to respond to health interventions, including HIV testing. Furthermore, those programmes that address FSW's needs only offer small, fragmented projects with limited scope and coverage (Bekker *et al.*, 2015; UNAIDS, 2017a).

As FSW are at ongoing risk of HIV infection, maximising early HIV testing is a public health priority for this group (World Health Organization, 2016a). HIV testing coverage is relatively high; however, the rate of repeat testing among FSW continues to be low (UNAIDS, 2017b). Efforts to optimise the delivery of HIV testing are needed for FSW to protect their health. This HIV testing challenge among FSW requires a new focus and other approaches to reach women living with HIV who remain undiagnosed early in their infection. The availability of new HIV rapid diagnostic testing technologies (RDTs) such as HIVST may potentially address the needs of FSW. The critical aspect of HTS that target FSW is how these interventions pan out in settings characterised by structural vulnerabilities: how they address FSW's HIV testing needs; how FSW are engaged in planning and implementing such interventions, and; most importantly, how they are received or resisted.

1.2.1 HIV self-testing

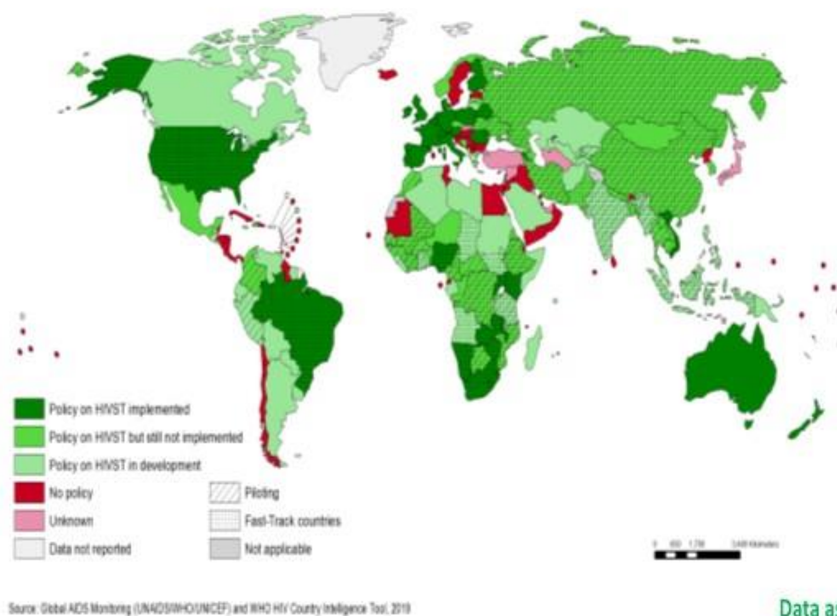
HIVST is "a process in which a person collects his or her own specimen (oral fluid or blood) and then performs a test and interprets the result, often in a private setting, either alone or with someone he or she trusts" (World Health Organization, 2016, p. 11). There are multiple ways of delivering HIVST, which vary according to the type of support, range of access and site of sale or distribution (see Figure 1) (World Health Organization, 2016a). As with any RDT, a single test is not sufficient to make an HIV-positive diagnosis. HIVST is a screening test that requires individuals with reactive test results to seek a confirmatory test from a facility using a validated national testing algorithm (World Health Organization, 2016a).

Globally, HIVST policy is at different stages of development and implementation (see Figure 2).

Figure 1: Models proposed by the World Health Organization (WHO) for HIVST according to support, distribution and access

Source: World Health Organization, 2016

Figure 2: Global HIVST policy and implementation map



Source: World Health Organization, 2019

Seventy-seven countries have policies, and 38 are implementing them; 47 countries' policies are under development; and 33 countries are piloting this initiative.

1.2.2 Assumptions about HIVST

HIVST can be "an empowering and innovative way" (World Health Organization, 2016, p. 11) to address the problems of facility-based testing by offering more choices, control and reaching first-time testers (Johnson *et al.*, 2014). In this case, 'empowerment' refers to an increased "sense of control, as the technology allows freedom of choice of when, where and with whom to use the test" (Oldenburg *et al.*, 2018, p. 646). Growing evidence shows that HIVST is acceptable, accurate and effective if used correctly (Choko *et al.*, 2011; Krause *et al.*, 2013; Ngure *et al.*, 2017). HIVST is acceptable among young people and MSM (Indravudh *et al.*, 2017; Witzel *et al.*, 2016) and facilitates serostatus disclosure among couples (Kumwenda *et al.*, 2014). In this way, HIVST represents another step in line with efforts to increase individual autonomy, decentralise services and create demand for HIV testing among those underserved by conventional methods (World Health Organization, 2016).

Despite the current discourse positioning HIVST as a highly acceptable community approach (MacPherson *et al.*, 2014; Choko *et al.*, 2017; Ngure et al., 2017; Choko *et al.*, 2019; Wulandari *et al.*, 2019), there is some evidence that decision-making processes around how self-testing kits that are used under non-trial conditions may generate adverse outcomes. For instance, relationships of unequal power and women's experiences of violence within intimate relationships can undermine this tool's potential to offer 'empowerment' to protect oneself (Kumwenda *et al.*, 2019; Njau et al., 2016). The benefits of HIVST described by participants across studies remain similar, even when analysed by country income, key population type, participant education level, type of specimen collection, whether an HIVST has been performed, and type of approach (Figueroa *et al.*, 2015).

However, research on social influences on the use and uptake of HIVST within the sex work context remains insufficient. In a review of attitudes towards and acceptability of HIVST among key populations, only three studies included FSW (Figueroa *et al.*, 2015). For key populations, the potential benefits of HIVST identified include the possibility of frequent testing (Bavinton *et al.*, 2013; Katz *et al.*, 2018) and reduced sexual risk behaviour (Carballo-Diéguez *et al.*, 2012). HIVST may have unintended consequences, including the inability to refuse to test when offered the chance to do so. Implementation of peer-led or community-based HIVST distribution models could alter people's autonomy and power relations in the community or peer groups (Indravudh *et al.*, 2017). For example, there are different players in sex work communities, including customers and venue owners. The power relations between these individuals and FSW may impact on how FSW respond to HIVST intervention.

In the context of ART, repeat testing is more likely to occur if there are few barriers to testing and the users directly control the process of testing themselves (Estem, Catania and Klausner, 2016). Increasingly, programmes are reporting retesting with HIVST among those on ART. For example, Kumwenda et al. (2014) found that couples who had not shared their past positive results were retesting to disclose their status. The reasons for retesting in other populations are unclear, and the consequences are poorly understood (Fuente-Soro *et al.*, 2018).

1.2.3 Context of the study

My study was nested in the HIV self-testing Africa (STAR) project in Malawi. The STAR project was a Unitaid grant to initiate HIVST implementation and research in different populations in Malawi, Zimbabwe and Zambia. The STAR Project's overall objective was to test and optimise distribution models of HIVST across the continuum of self-testing delivery. Across the three countries, the STAR project's implementer was

Population Services International (PSI), and in Malawi, Malawi Liverpool Wellcome Trust-Clinical Research Programme (MLW) conducted all the research activities.

The STAR project was a two-phase (2015–2019) initiative to catalyse the market for HIVST. In Malawi, as part of Phase 1 (2015–2017), approximately 10,000 HIVST (OraQuick ADVANCE Rapid HIV-1/2 Antibody Test) kits were to be delivered through a peer distribution model to FSW (age > 16 years old) in three districts (Blantyre, Mulanje and Chikhwawa). PSI subcontracted the Pakachere Institute for Health Development and Communication (Pakachere) to implement HIVST among FSW in Malawi. Pakachere was one of the organisations conducting ongoing HIV prevention, communication and advocacy work with FSW in Malawi, including in Blantyre.

1.3 Theoretical underpinnings of the study

In this thesis, I use the concepts of vulnerability, empowerment, agency, biopower and biocitizenship to offer a critique of HIVST. I aim to highlight how power operates in sex work communities and how new forms of power can affect those communities to facilitate change.

A key structural driver in the HIV epidemic is gender inequalities (power imbalances between men and women) because of how they can shape and constrain individuals in sexual interactions (Richardson *et al.*, 2014). Gender inequalities underpin power imbalances in society and can result in women's subordination and their interests in a manner that favours men. However, gender also interacts with other socio-cultural and economic structures to shape different community vulnerabilities. Understanding how these dynamics play out in sex work contexts is essential when developing new interventions.

In this thesis, I am drawing on a socio-ecological framework of understanding vulnerability arising from the relationship between

individuals and their structural and environmental contexts (Baral *et al.*, 2013; Tan *et al.*, 2014). This understanding draws attention to the role of extraneous factors in health outcomes and yet does not ignore the individual, whose sexual encounters constitute an HIV risk. Instead, individuals' choices and decisions, thus, their agency, and behaviours depend not only on their characteristics but also on a group- or community-level attributes and understandings, which together constitute other determinants of HIV risk. These factors, in turn, influence the structural and environmental contexts within which individuals live. The dynamic nature of vulnerability and its link to power and agency is essential to understanding the concept. Therefore, I also include agency, power, and political and cultural relationships in recognition of the fact that gender, age, ethnicity and values are also important features of differences in how environments change, and different people experience management strategies. These social differences may produce varying experiences in different contexts and populations.

My conceptualisation of empowerment in this thesis is concerned with presenting the limitations of public health discourses in examining change derived from biomedical HIV testing technologies. Different political economy contexts and populations offer contested spaces that reveal the barriers to realising emerging medical technologies' promise to improve health outcomes. The dynamic nature of social, economic and political structures constantly alters power balances in society, resulting in various empowerment dimensions to achieve better health outcomes. This creates societies in flux; the conceptualisation of empowerment needs to reflect this to achieve better health outcomes. As such, I have also looked at the concept of biopower to understand the practices of institutions and reflect the framing of policy and wider institutional discourses, as well as biomedical governance imperatives that shape the implementation of HIV interventions. I have used the concept of biocitizenship to explore how HIVST produce new forms of subjectivity, corporal realities and practices of those who use the technology.

1.4 Justification of the study

Although rights-based activism around HIVST development puts a high level of emphasis on ‘empowerment’ as individual autonomy and control, there have been no studies to explore how such technologies alter power relations or enable or constrain FSW’s agency in sex work environments. Scott (2014) argues that those settings characterised by high HIV prevalence and experience of social stigma may benefit less from HIVST. Therefore, HIVST may result in unintended consequences as its implementation unfolds in a complex sex work context characterised by unequal power relations, stigma and high HIV prevalence. In addition, there are concerns about the potential for coercion to test – for example, venue owners and customers forcing FSW to test (Scott, 2014). Therefore, bringing about a change in HIV testing coverage is not just about handing out test kits to a population but is instead about questioning how the intended users would use these kits.

The concept of empowerment poses essential questions about the translation of HIVST into different settings and its effect in those settings (Whittaker, 2015). The motivation to use the technology relates to social factors, HIVST rhetoric and imagined futures. To understand the process of empowerment, ideally, we need to scrutinise how the introduction of HIVST creates different forms of power in these communities and how HIVST alters the power inequalities that exist in FSW’s varied power relations. In this case, empowerment is a process of opening closed doors to engage FSW in dialogue around the issues that affect them, listen to the FSW’s voice by designing interventions, and allow FSW to drive these changes settings. We also need to understand how social networks can affect FSW’s positionality during the implementation of HIVST.

It is important to understand sex work settings, the power structures surrounding sex work, and FSW’s needs and how their experiences of vulnerabilities in these contexts translate into their desire for change, their

belief in the possibility of change, their subsequent agency and the choices they make to deal with their situation. FSW differ in terms of sex work type, marital status, geographical position, mobility, income levels, and the types of customers they solicit (Chizimba and Malera, 2011; Ngugi *et al.*, 2012). These differences also determine their differences in vulnerability and how they can respond to HIV prevention interventions. Given the complex nature of the vulnerability that FSW experience, Rogers, Mackenzie and Dodds (2012) argue that this inquiry requires a nuanced analysis of how they can be supported to improve their lives. A more nuanced understanding of vulnerability requires a careful disaggregation of the structure of the situation. Therefore, vulnerability analysis must include both sensitivity to both change and space and a recognition of how different groups in society experience risk.

1.5 Aim and objectives

1.5.1 Aim

To explore how FSW engage with HIVST and the extent to which this engagement contributes to their vulnerability and/or opportunities for empowerment in Blantyre, Malawi.

1.5.2 Specific objectives

1. To establish perceptions of HIV and wider vulnerabilities among FSW in different locales, contexts and interactions in Blantyre, Malawi.
2. To understand what empowerment means to FSW and how different locales, contexts and interactions shape this meaning in Blantyre, Malawi.
3. To explore how FSW engage with HIVST, and how different locales, contexts, interactions and positionalities shape this engagement in Blantyre, Malawi.

4. To explore how the use of HIVST impacts on FSW's lives, in relation to HIV prevention, vulnerability and opportunities for empowerment.
5. To examine the implications of the findings on future biomedical HIV prevention technology interventions among FSW in Blantyre, Malawi.

The following research questions have guided me in achieving these objectives:

1. What constitutes FSW's vulnerability and empowerment, including perceptions of HIV risk in the sex work environment?
2. How does the sex work context shape FSW's experiences with HIVST and the meaning of empowerment?
3. How does HIVST impact on FSW's lives in relation to HIV prevention, treatment and care?

1.6 Definitions of key concepts used in the thesis

In this section, I outline the definitions of the key concepts used in this thesis, and I provide a more detailed discussion of the concepts in Chapter 2.

- **Sex work** is the exchange of money or goods for the provision of sexual activities, performances or products, either regularly or occasionally (Baral *et al.*, 2012; World Health Organization, 2012).

- **Vulnerability** is the potential for harm as determined by the relationship between people and their social, political, economic and cultural environments and the lack of capacity to recover from this situation (Chambers, 1989; Blaikie *et al.*, 1994).

- **Empowerment** is the process through which individuals transform power relations within their environment and how they feel about

themselves while making decisions about their lives (Batliwala, 1994; Mayoux, 2000).

- **Power** refers to the ability to influence, dominate or control the actions, decisions and behaviours of others, and the capacity to change something, to be changed or to resist change; it is relative and dynamic and varies according to the situation or context in which it is being exercised (Read, 2012).

- **Agency** is “the ability to define one’s goals and act upon them” utilising available resources (material, human and social). The exercise of agency may be reflected in decision-making, but also in “bargaining and negotiation, deception and manipulation, subversion and resistance” (Kabeer, 1999, p. 438).

- **Biopower** “entails one or more truth discourses about the ‘vital’ character of living human beings; an array of authorities considered competent to speak that truth; strategies for intervention upon collective existence in the name of life and health; and modes of subjectification, in which individuals work on themselves in the name of individual or collective life or health” (Rabinow and Rose, 2006, p. 195).

- **Biocitizenship** is an active form of citizenship that produces new forms of belonging, claims to expertise and access to resources oriented around biological claims (Cooter, 2008; Novas, 2015).

- **Medicalisation** is the process by which some aspects of human conditions and problems come to be considered and treated as medical problems, when before they were not considered pathological (Maturo, 2012).

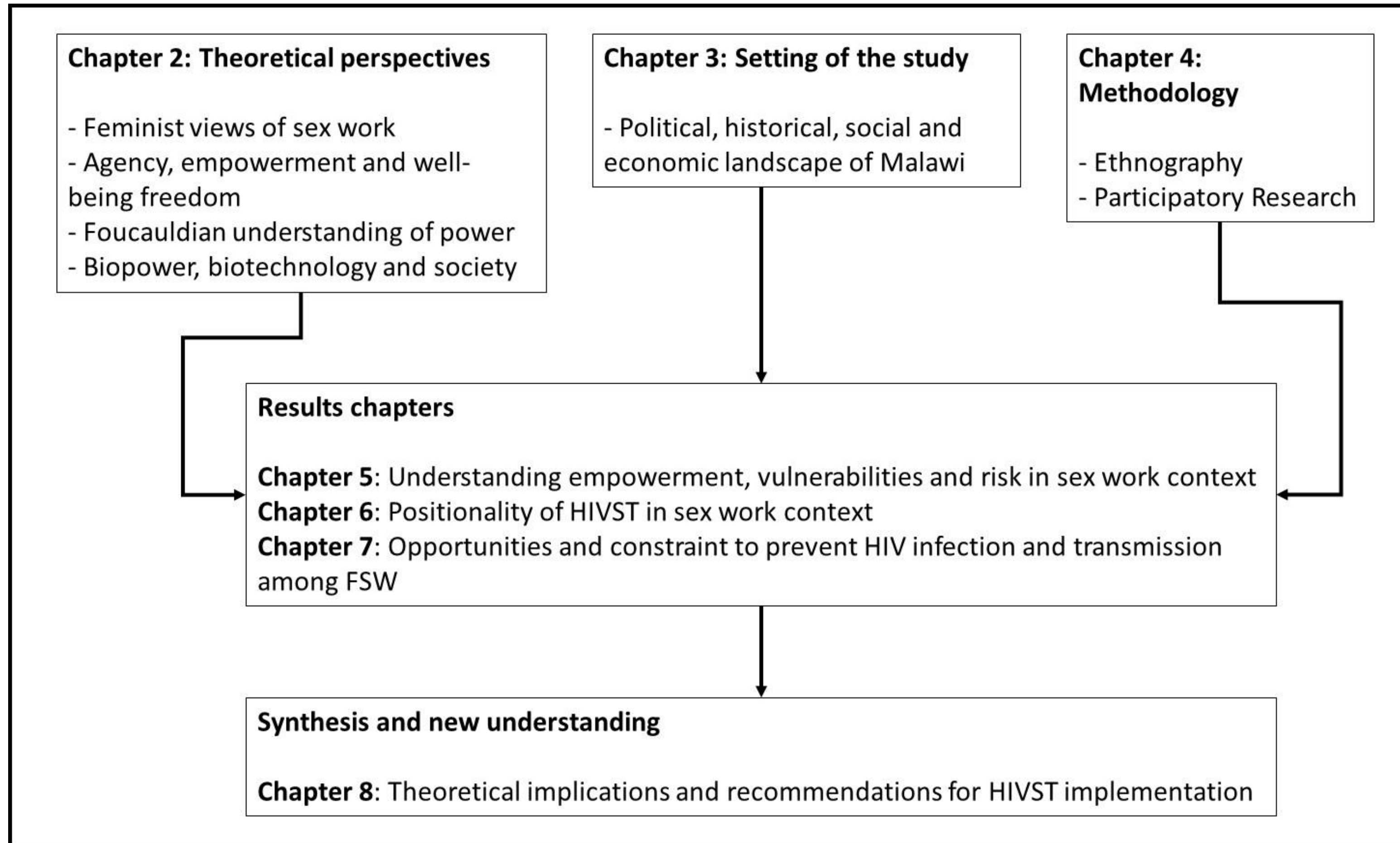
1.7 Outline of the thesis

I present this thesis in eight chapters. Following this introduction (**Chapter 1**), I review the literature to highlight the theoretical underpinnings of the concepts of vulnerability, power empowerment and sex work; I also present how these concepts are situated in HIV prevention programmes, particularly looking at the literature on HIVST as an emerging HIV technology (**Chapter 2**). In **Chapter 3**, I describe Malawi's context, specifically the historical, political, gendered power relations, the sex work legal framework, and the progress made in responding to the HIV prevention needs of FSW. In **Chapter 4**, I discuss the methodology and methods used in this study as well as the mechanisms used to assure the quality of data and address ethical issues. I divide the results and discussion into three chapters (**Chapter 5-7**), where I bring together findings and embed them in the literature, the context of sex work in Malawi and the broader context.

In **Chapter 5**, I discuss the power relations and vulnerabilities of FSW in the sex work context. Their narratives reveal that these women encounter a range of substantive difficulties and challenges in their lives. I highlight different dimensions of their perceived and experienced vulnerability and opportunities for empowerment. In **Chapter 6**, I move on to consider FSW’s engagement with HIVST, where I provide an overview of HIVST uptake and discuss power relations and vulnerabilities and how they have shaped experiences with HIVST among FSW. I also explore how HIVST increases the opportunities for some FSW to exercise agency in HIV testing, or constitutes new power relations and new practices of biocitizenship. I further explore how existing unequal power relationships, exploitation, and testing obligations were being perpetuated in new ways through HIVST. In **Chapter 7**, I discuss the experiences of FSW post-HIVST in relation to changes in their lives, their varied relationships after receiving their HIVST results, and their engagement with HIV prevention, treatment and care services and the impact on sex work. I explore how HIVST in this setting increase or reduce FSW agency to engage with HIV

prevention, treatment and care and their well-being freedom. I also explore the role of the health system in facilitating the creation of empowered therapeutic citizens. Finally, in **Chapter 8**, I provide implications, concluding remarks and recommendations for future HIVST interventions and consider how the thesis contributes to developing an understanding of vulnerability and empowerment.

Figure 3: Conceptual map of the thesis



2 Theoretical perspectives and literature review

2.1 Introduction

In this chapter, I review the existing evidence and arguments on sex work, vulnerability, agency and empowerment that frame the context of the study. I discuss different theoretical perspectives, including those drawn from the disciplines of anthropology, gender studies and sociology, to understand these concepts, highlighting the framing of sex work in sub-Saharan Africa (SSA). I give particular attention to instances where the concepts of vulnerability and empowerment relate to FSW, HIVST and public health. I first present a discussion on the concept of sex work and agency within it (section 2.3). In the second section (2.4), I explore the concept of vulnerability and its complexity and relational and dynamic nature. In the last section (2.5), I explore the multidimensionality and multidisciplinary nature of the concept of empowerment and its relation to agency.

2.2 Literature review search strategy

In this study, I used the following search strategy to find theoretical, empirical, practical and policy literature for the review. The database search included Africa-Wide Info, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Embase, Global Health, Medical Literature Online (MEDLINE), PsycINFO, National Library of Medicine (PUBMED), and Web of Science. I accessed the grey literature through the relevant world wide web pages to find technical reports and working papers. I search the reference lists of all identified reports and articles for additional studies. I considered studies in English for inclusion in this review because I am fluent in this language. There was no restriction in terms of the year of publication and geographical location. This decision was made to allow the inclusion of historical and contextual experiences of sex work and understand the foundations and the various ways of conceptualising empowerment and vulnerability. I used the following keywords in the search; female sex workers, sex work, gender,

agency, peer education, empowerment, vulnerability, HIVST, HIV, AIDS, prevention, technologies, power, biocitizenship and therapeutic citizenship.

2.3 Understanding sex work

In this section, I explore the meaning of sex work, focusing on gender theories, structural and individual factors and its theoretical issues.

Sex work is often used as an umbrella term to describe any type of sexual activity, performance or product exchanged for money or goods (Baral *et al.*, 2012). It is a recent term, coined by Carol Leigh (an FSW and advocate) in 1978 to replace the term prostitution (Global Network of Sex Work Projects, 2014). For a long time, the term prostitution has had negative connotations rooted in the patriarchal oppression of women and gender inequality (MacKinnon, 1993; O'Neil, 2000; Sutherland, 2004; Chizimba and Malera, 2011; Farley and Butler, 2012). The shift in terminology resulted from the sex work political movement, which debated views of sex work based on oppression and empowerment, offering conflicting ideas of agency experienced by FSW (Weitzer, 2010; Jean, 2015). This terminology shift reflects respect for individual, social, cultural, economic and human rights (McMillan et al., 2016).

Here, I simplify my arguments as binary to give an overview of the sex work paradigms. Within the oppression paradigm, FSW do not choose to enter or remain in sex work; instead, sex work is a way in which males can exert dominance and power over women (MacKinnon, 1993; Barry, Kathleen, 1996; Weitzer, 2009). In this manner, the oppression paradigm regards sex work as oppressive, regardless of an individual's choice to engage in sex work, thereby denying FSW agency. In contrast, the empowerment paradigm contends that sex work can exist as an alternative way of earning a living, and for some, it can bring substantial financial returns (Weitzer, 2010). Sex work is a space of potential agency for women, rather than necessary subordination: FSW are not victims – instead, it offers opportunities for empowerment (Ahmed, 2011). According to this paradigm, FSW have a choice to enter,

remain in or leave sex work; however, it is also acknowledged that agency is not uniformly exercised.

The term sex work has since been used widely in academic publications, official international briefings and policy and by sex work activists. The WHO (2012) defines sex work as the act of receiving money or goods in exchange for sexual services, either regularly or occasionally. Since the sex work term was coined, FSW rights organisations have sought to make a large-scale impact, often integrating local outreach and direct services to FSW with advocacy and policymaking agendas (Musto and College, 2015).

However, research across the globe shows that the lives and experiences of FSW transcend the simplistic binary arguments of victimhood and FSW's agency (Van Der Meulen, 2012). The studies conducted among FSW show that some women are capable of making independent decisions, making choices and taking actions based on the options available to them, but also highlight ways in which agency can be constrained (Fitzgerald-Husek *et al.*, 2011; MacPherson *et al.*, 2012; Swendeman *et al.*, 2015). Some women engage in sex work hoping for more than just money in exchange for sex: some are looking for long-term relationships and others for love (Stoebenau *et al.*, 2016; Wamoyi *et al.*, 2016). In SSA, sex for money often underlies most non-marital relationships based on love, emotional support or social expedience and is rarely perceived as sex work or immoral (Jewkes *et al.*, 2012; Wamoyi *et al.*, 2010). These views highlight the fact that there are myriad reasons why women engage in sex work, which challenges both the oppression and empowerment paradigms. Therefore, one needs to interrogate the underlying structural and individual factors to understand FSW's reasons for involvement in sex work depending on the context and circumstances.

2.3.1 Structure and agency

In this section, I discuss the relevance of the structural factors and agency understandings of sex work.

Drawing on Kabeer (1999, p. 438) definition of agency, agency is

> the ability to define one's goals and act upon them, utilising available resources (material, human and social). The exercise of agency may be reflected in decision-making, but also in bargaining and negotiation, deception and manipulation, subversion and resistance.

This definition reflects the individual's awareness and negotiation of different situations and the fact that agency and action are embedded within the larger social structure. The reciprocity between agency and structure offers a means of developing further understanding of sex work since it widens the way decision-making can be understood and how particular structures operate or drive actors to make particular decisions (Nkhoma and Charnley, 2018).

The structure and agency framework of sex work highlights sex work within structural economic, political and ideological contextual specificities that shape involvement in and experiences of sex work while acknowledging those involved as active agents. This is evident in sex work studies that document gendered power inequalities (Baleta, 2015), drugs (Miller *et al.*, 2011), pleasure (Almeida, 2011) and poverty as shaping decision-making processes in involvement in sex work. Despite some similarities of circumstances and conditions surrounding sex work, specific conditions and reasons for joining, continuing or leaving sex work vary widely within and between countries. Sex work in SSA is deeply rooted in historical and political events and gendered power relations that leave women in a disadvantaged position and have a direct effect on the kind of sexual relationships they enter and how they negotiate different issues in these sexual relationships (Desmond *et al.*, 2005; Baleta, 2015; Stoebenau *et al.*, 2016; Wamoyi *et al.*, 2016). In these highly patriarchal societies, socialisation processes that women undergo impact on the level of agency they can express when dealing with issues concerning their body, health and access to resources (Wamoyi *et al.*, 2016).

Once women join sex work, their experiences vary, as sex work is unevenly regulated regardless of whether it is criminalised, decriminalised or legalised.

Punitive laws play a central role in how individuals experience sex work and any corresponding violence and stigma they encounter (Musto *et al.*, 2015). Studies in Southern Africa conducted by FSW themselves show that sex work lowers the possibility of agency for some FSW (Hendricks and Woensdregt, 2018). High levels and multiple forms of violence, stigma and discrimination characterise the sex work experiences of some women. Punitive laws cement the cultural, religious and societal perceptions of FSW and have exacerbated the stigma associated with sex work.

2.4 Conceptualising vulnerability

In this thesis, I define vulnerability as the potential for harm as determined by the relationship between people and their social, political, economic and cultural environments and the lack of capacity to recover from this situation (Chambers, 1989; Blaikie *et a*l., 1994). This definition captures the key elements of understanding vulnerability; it focuses on the analysis of vulnerability on the relationships, power dynamics, and social and political circumstances of the particular population. Causes and phenomenon of vulnerability arising from the interaction between the physical and processes in the environment, thus, biological, social, political, economic and cultural factors that affect an individual or group of individuals (Scheibe, Drame and Shannon, 2012; Servin *et al.*, 2015). The dynamic nature of the social, economic, environmental and political factors usually alters power balances in a society (Andanda, 2009). Therefore, vulnerability cannot be defined as independent of the relationships, power dynamics, and social and political circumstances of the particular protocol. Vulnerability can be exacerbated through powerlessness, exploitation and discrimination.

In this section, I summarise the primary views on the concept of vulnerability in the literature. From my review of the literature, I have identified three significant themes that emerge as manifestations of vulnerability: (1) humans are vulnerable beings, (2) our experience of vulnerability matters, and (3) vulnerability is relative to the environment.

2.4.1 Universalist approach

According to the universalist approach, vulnerability is a universal shared risk; thus, everyone is vulnerable because everyone has an embodied, finite and socially contingent existence (Turner, 2006; Fineman, 2008; Rogers, Mackenzie and Dodds, 2012). According to this view, Turner argues, the state of vulnerability is a fundamental feature of humanity: it is inescapable (Turner, 2006). In relation to the oppression paradigm of sex work, Weitzer (2010) argues that FSW are inevitably vulnerable since sex work is part of patriarchal social structures and relations which exploit FSW. However, this inevitability fails to recognise the agency that FSW have within those social structures or the potential for resilience. It oversimplifies the complex experiences of FSW and fails to recognise their agency and the strategies they use to mitigate their circumstances.

The universalist view of vulnerability, therefore, does not offer opportunities for empowerment or for people to exercise their agency, nor does it recognise differential vulnerability. McLaughlin (2012) is critical of how ideas of universal vulnerability have risen to the forefront of individuals' relationships with social structures. He sees the rise of ‘vulnerable identities’ as characterising contemporary society, and as linked with a decline in the power of collective social movements and political activism. Coeckelbergh (2013) advances the notion of vulnerability to argue that vulnerability is a relational concept: that is, a condition (universal) as well as an experience (situational). Coeckelbergh (2013) contends that vulnerability is neither something we create nor something we perceive about a relationship between an object and a subject. Rather, vulnerability is a feature of the relation between us and the world and is primarily shaped by what we do. Further, vulnerability is a process and is dynamic: our desires and expectations change as our powers and abilities change.

2.4.2 Taxonomies approach

According to this approach, vulnerability is an increased risk of harm and wrongs in the lenses of three different and overlapping sources of

vulnerability: inherent (which is the same as universalist approach), situational or pathogenic (Hurst, 2008; Lange, Rogers and Dodds, 2013). This approach draws on the universalist perspective but goes beyond it to look at the complexity of the living environment to shape vulnerabilities and consequences. Individuals can experience each source as occurrent (immediate and present) or dispositional (latent or background) (Hurst, 2008). Inherent sources of vulnerability include sources that are inescapable to human nature and generate our neediness, our dependence on others and our social natures (Rogers, 1997). The extent of all these sources depends on age, health, gender and disability, as well as capacity for resilience, coping and available social support (Levine *et al.*, 2004).

The concept of vulnerability draws attention to the circumstances of people who find themselves at elevated risk. Situational vulnerability can be associated with forces that include the social, political, economic or environmental situations of an individual or group (Levine *et al.*, 2004), and how people respond to their environment. The pathogenic sources of vulnerability trickle down from situational sources due to dysfunctional social or personal relationships. Sometimes, responses to vulnerability may worsen vulnerabilities or generate new ones. Features of pathogenic sources of vulnerability include prejudice, abuse, injustice or political violence (Drame and Foley, 2015).

In relation to FSW, the pathogenic sources resonate with the universalist view of vulnerability and sex work, specifically looking at FSW as inevitably vulnerable or pathogenic because of the work they do and their biographies. There is an attempt to show that sex work is the result of a social, political and economic environment that forces women into sex work. This type of vulnerability involves elements of individual agency or choice as FSW are acting in response to their circumstances in life.

However, what is problematic about the taxonomies approach is that it does not provide a platform to analyse the complexity of society. Life situations cannot fit neatly into different taxonomies, without recognition that these

taxonomies tend to overlap, as suggested here (Luna, 2009). There is no superior taxonomy that can describe the layers of vulnerability in sex work. Luna (2015) argues that choosing one taxonomy is a means of silencing other voices.

2.4.3 Labelling approach

According to this view, vulnerability can be attributed to groups of individuals who show susceptibility to specific kinds of harm. Certain groups of individuals are associated with vulnerability due to being seen as people who have had a degree of misfortune and share certain characteristics (Underwood *et al.*, 2011). These groups are identified in the literature on support and management of vulnerable groups, but who is referred to within each category varies widely (Luna, 2014). Vulnerable groups may include persons who have limited capability or who have insufficient power, intelligence, education, resources, strength or other necessary attributes to protect their interests (Luna, 2009). This also relates to how public health frames problems. In public health, for instance, sex workers, women, older people and children are often labelled as vulnerable groups (World Health Organisation, 2012) due to their vulnerability to ill health.

My review of the literature also highlights the fact that some individuals are more vulnerable – those who are labelled ‘the most vulnerable’. The employment of the term ‘the most vulnerable’ sometimes carries with it a strong implied ethical responsibility to address the challenges of those labelled as most vulnerable by outsiders (Luna and Vanderpoel, 2013; Wrigley, 2015). In the same vein, while certain groups or individuals may be constructed officially as vulnerable and by implication deserving, their treatment in practice implies that they might also be considered a risk to society to some extent.

Benoit and Millar (2001) argue that FSW are labelled as vulnerable due to violence, stigma and discrimination and unsupportive legal frameworks. Both the oppression and the FSW agency paradigms view FSW as vulnerable in

the sense that the sex work environment prevents FSW from having any real control over their safety, but the FSW agency paradigm stresses that this vulnerability is not universal to all sex work in time and space (Benoit and Millar, 2001).

2.4.4 Layered approach

Luna (2015) suggests that the universalist approach to vulnerability can be utilised as a background condition because it is true that we are all vulnerable to ill health and death. The relational and contextual features of vulnerability, however, are the critical ones for facilitating the special protection of individuals who are inherently vulnerable. In criticising the taxonomies of vulnerability framing, Luna argues for a layered approach to vulnerability. There is a set of layers that render a person vulnerable. It is a way of understanding vulnerability by identifying different layers at the same time without providing a specific order (Hurst, 2008). Layers of vulnerability give flexibility to understanding vulnerability and allow for the unfolding of a variety of problems related to the circumstances under analysis (Hurst, 2008). The idea of a layered approach fosters the identification of different layers and shows how they are expressed and can interact with the environment. Luna's work, however, does not account for the necessary response or obligation to different layers of vulnerability (Luna and Vanderpoel, 2013).

According to this view, FSW have a range of vulnerabilities due to their multiple identities, power relations, biographies and sex work typologies. The layered approach is vital in looking at FSW as a heterogeneous group, and understanding different experiences, exploring vulnerabilities and opportunities for empowerment in more depth. Vulnerability needs a dynamic and contextual analysis that captures the multifaceted, multidimensional and relational aspects of the concept, where the layers of vulnerability may overlap. However, there is a danger that this approach underplays the structural influences of vulnerability by putting too much emphasis on the layers of vulnerability.

2.4.5 Vulnerability and biomedicine

The Ottawa Charter for Health Promotion (1986) mapped a landscape of health that emphasised the social determinants of health and led to a new framing of vulnerability to ill health (Rogers, Mackenzie and Dodds, 2012). The analysis of vulnerability in public health focuses on how health changes in response to changes in societal exposures, including addressing social inequalities in access to treatment options, prevention and health outcomes (Beroya-Eitner, 2016). Understanding the factors of such vulnerabilities in public health, such as age, gender and geographical location, may facilitate better policies and improve population health (Luna, 2009). Stephenson et al. (2014) argue that we need to interrogate how the concept of vulnerability is being appropriated in public health.

Public health looks at who is susceptible to ill health in order to control, prevent and treat diseases. Vulnerable persons are social groups that have an increased relative risk of or susceptibility to adverse health outcomes (Rogers, 1997; Luna, 2014). Evidence shows that people who experience more vulnerability drivers are likely to face greater health disparities (World Health Organization, 2012; Bates *et al.*, 2004). The importance of combining biological, social and structural factors in identifying vulnerable groups is that it shows commitment to the promotion of positive health outcomes by identifying and giving priority to those whose ill health is the result of systematic environmental and structural disadvantages (Bates *et al.*, 2004; Rogers, Mackenzie and Dodds, 2012).

2.4.6 Vulnerability and HIV

The concept of vulnerability in public health has received much attention in the context of the HIV epidemic. Previous approaches in responding to the HIV epidemic focused on high-risk groups, including FSW and MSM, whose sexual behaviour was considered risky (Kalipeni, 2000; Tallman, 2016). In recent years, interventions in response to HIV have shifted towards an understanding that HIV-related vulnerability evolves in complex socio-economic contexts (Stephenson *et al.*, 2014) to prompt action on structural

causes and social determinants of health and illness, advancing attempts to address health inequities and inequalities. In this section, I discuss how, gender power relation and poverty shape HIV risk and wider vulnerabilities.

Here, I use the term structural violence as conceptualised by Johan Galtung (1969) to highlight disparities and to identify socially constructed patterns of disease across population groups (Kleinman, 2000; Farmer 2004). Galtung (1975, p. 173) defined structural violence as “the indirect violence built into repressive social orders creating enormous differences between potential and actual human self-realisation”. Drawing on Galtung, Farmer et al. (2006) argued that structural violence is a way of describing social relationships that place individuals in a vulnerable state. These relationships are described as ‘structural’ because they are embedded in the political and economic organisation of our social world and ‘violent’ because they cause injury to individuals who are not responsible for perpetrating the inequalities (Farmer *et al.*, 2006).

Many analyses of structural violence include gendered power relations as an important driver of structural violence. These relations influence who has power and authority to make decisions both within the household and within wider society (Farmer *et al.*, 2006). Drawing on Connell, gender is understood as a materialist orientation of an individual, thus, in terms of practices, what people actually do, rather than what is expected of them (Connell, 1985). Gender power relation is considered as a structural construct since it originates from socially constructed gender norms and stereotypes that create a distinction on what are the roles and the rights of individuals in society.

From a public health perspective, it is these gender-based inequalities and disparities (for example, in women’s economic potential, control of resources, and their role in society) that generate the exposure or acquired risk that adversely shape women’s health (Wingwood, 2000). They determine whether people’s health needs are acknowledged, whether they have a voice or control over their lives and health and whether they can realize their rights (World Health Organization, 2007). Harmful dimensions of gender power

relations that emanate from the ideology of masculinity, such as gender-based violence have been linked to HIV vulnerability among women in SSA (Gupta, 2000; Jewkes *et al.*, 2010). Gender inequity in SSA contributes to the spread of HIV and impeding prevention efforts, and in the coping responses to the epidemic. All these interact to increase women's vulnerability to disease, including HIV.

Exploring the relationship between sex work and HIV reveals a gendered distribution of power that favours men and fuels the spread of HIV. Poverty and economic disparity are some of the driving forces of sex work, especially in SSA (Ampofo, 2001; Awungafac, Delvaux and Vuylsteke, 2017). Power dynamics also play a crucial role in the sex work environment and the lives of FSW, right from the scope of negotiation with customers and partners on condom use and sexual acts and managing the control and influence of stakeholders, such as venue owners (Ranebennur *et al.*, 2014). There is a vast literature that discusses negotiating power and its impact on agency among FSW in the context of HIV prevention, particularly condom use. Having the ability to communicate and negotiate condom use means having the confidence to bargain for safer sex in light of the social cost of such negotiations. FSW inability to negotiate condom use is one of the strongest correlates of poor condom use. Women's inability to negotiate safer sex may be particularly difficult due to perceived violence, alcohol and drug abuse and when the woman is in a committed relationship. Studies have established that a lack of negotiation skills has impacted how FSW relate to their customers when making decisions about condom use (Shannon *et al.*, 2009; Wirtz *et al.*, 2015).

A study in India found that a higher degree of mobility was associated with higher rates of inconsistent condom use with customers and stable partners (Bharat et al., 2013). Poverty and limited economic opportunities, particularly among women, are the key factors in entering sex work (Fielding-Miller *et al.*, 2014; Nkhoma and Charnley, 2018). Once in sex work, these factors exacerbate FSW's vulnerability because poverty and limited economic opportunities have been associated with limited FSW agency in decision-

making processes. Women with low education levels have higher HIV prevalence compared to their counterparts, and that education has protective tendencies on HIV prevalence, as literacy is positively associated with comprehensive knowledge about HIV/AIDS (UNAIDS, 2009; Scheibe, Drame and Shannon, 2012).

After defining FSW as a vulnerable group, the WHO (2014), for instance, has recommended that HIV programmes targeting this population should address the social and structural inequalities that exist among them. Given this, such interventions must be met with nuanced, multilevel responses suited to the multifaceted complexities of any given setting. However, the current empowerment-based approaches to HIV responses among FSW are rare in SSA, and, when available, they are often project-based and not integrated with or run in parallel with the national healthcare system (Kerrigan et al., 2013a). Stigma and lack of legal support in most SSA settings prevent FSW from seeking protection in the face of violence and has resulted in a lack of response from health sector, law enforcement institutions and social services to FSW's concerns (Abelson *et al.*, 2019; Huschke, 2019).

2.4.7 Vulnerability and technologies of the self

Culture has always evolved, and technological developments are instrumental to changes in society (Coeckelbergh, 2013). Historically, technologies have been developed to enhance human abilities and increase efficiency, and in the long run, how people use these technologies has also changed the broader social and political context (Coeckelbergh, 2013). This is a symbiotic relationship, as technology changes culture and in turn, culture changes how technology is used, appropriated and understood.

Foucault analyses technology as a way of revealing societal truths(Foucault, 1988). Foucault sets out a typology of four interrelated 'technologies' that shape, influence and define the self: (1) 'technologies of production' (2) 'technologies of sign systems' (3) 'technologies of power' and (4) 'technologies of the self'. 'Technologies of the self' grant individuals to change on their own or with the help of others to attain a particular state of satisfaction

or immortality (Foucault, 1988). Drawing on Foucault, Coeckelbergh calls the technologies of the self 'anti-vulnerability strategies; thus, we design and use technology to decrease our vulnerabilities (Coeckelbergh, 2013). The idea of modernity creates both personal and societal risks and vulnerabilities. To support this view, Beck (1992) states that the modern world is a "risk society" produced by modernisation. New technologies create new opportunities but also involve new risks. In the same vein, Coeckelbergh (2013) emphasises the paradox of technology; technology is at the same time the problem and the solution. Coeckelbergh (2013) argues that technology helps us in our struggle against risk and vulnerability but at the same time technology creates new risks, thus transforming vulnerabilities rather than reducing them. The new risks and vulnerabilities coexist with the old ones, and it is the response to the old ones that determine the performance and effect of the new technology. Then it is essential to explore not only new technologies and the new risks and vulnerabilities they may create but also their implications for the old ones, which are often reshaped by the new technologies (Coeckelbergh, 2013).

In this case, HIVST as a technology of the self assumed to address vulnerabilities and provide opportunities for 'empowerment', could be at the same time a solution and a problem. HIVST could help with waiting times at HIV testing facilities or the stigma that FSW face when they enter the medical setting, but at the same time, HIVST could create new risks, thereby worsening their vulnerabilities. As Luna (2009) argues, in the analysis of vulnerability, it becomes necessary to unpack different layers of vulnerability among diverse groups because engagement with the technology by different social groups can produce varied pathologies.

2.5 Conceptualising empowerment

Empowerment is rooted in development studies, and over the years, scholars have offered varied definitions of the concept. Empowerment can be defined as the process through which individuals transform power relations within their environment and how they feel about themselves while making decisions

about their lives (Batliwala, 1994; Mayoux, 2000). It is viewed as a multidimensional social process that enables people to gain control over their own lives by acting on issues that they consider as important through sharing in decision making and negotiation (Makoae and Mokomane, 2008). The concept assumes that empowered people develop a stronger sense of control or influence which gives them competence in daily life in the pursuit of their aspirations and goals. Central to the empowerment process are actions in which both individual and groups express their needs and concerns, engage in decision making and collective efforts to achieve those needs (Wallerstein, 2002).

Empowerment is a complex process of negotiation rather than a linear sequence of inputs and outcomes (Cornwall and Edwards, 2010). Cornwall and Edward (2010) argue that changes in people's lives, especially women, take place outside of conventional interventions, and these might include health interventions. They state that context is important in making sense of empowerment because context can shape the possibilities of women's empowerment by facilitating and enabling but also blocking and restricting possibilities. They further argue that empowerment is not just about enlarging the boundaries of action. Instead, it is also about increasing choices, but the choice is also context-specific as it depends on both the broader structural environment and circumstances of particular women (Cornwall and Edwards, 2010). Empowerment is also a dynamic negotiation process that revolves around both subtle and overt exercise of agency.

In the following sections, I discuss the relationship between agency and empowerment; the concept of power set out by VeneKlasen and Miller and by Foucault and how these theories contribute to studies of health and illness, and science, technology and society. I then discuss the concept of empowerment and how it has been interrogated and explored in public health. In the last part of this section, I further discuss the use of the concept of power in understanding empowerment in HIVST.

2.5.1 Agency and empowerment

I draw my understanding of the relationship between agency and empowerment from Kabeer and Drydyk. Kabeer (1999, p. 437) conceptualises empowerment as “the process by which those who have been denied the ability to make strategic life choices acquire such an ability” and this reduction or addition of choices explain one’s situation. Gender inequalities embedded in cultural and ideological spheres affect women’s empowerment as their choices are constrained (Das and Kundu, 2009). Therefore, one makes choices under certain preconditions or with resources that allow one to achieve new resources or more decision-making power over one’s well-being. Kabeer (1999) also highlights the relationship between poverty and disempowerment because the inability to meet one’s basic needs can often rule out the ability to exercise meaningful choice (Kabeer, 1999). Poverty may be a precondition for a woman demonstrating her financial situation, which may lead her into sex work. The income from sex work may give her the needed money to sustain her well-being. In this case, income from sex work adds new resources. Kabeer (1999) argues that the ability to exercise choice incorporates three inter-related dimensions to the ability to exercise choice: resources, process (agency), and achievements (outcomes).

She uses the term resources to include both access and future claims to a combination of materials (economic, human and social resources) that can improve the ability for individuals to exercise choice. However, access to resources does not mean control of resources. The second dimension of empowerment relates to agency, which stresses the important inequalities, including health, to make strategic decisions rather than just reflecting different choices. As per Kabeer’s definition of agency (in section 2.2.1), Kabeer (1999) highlights agency as encompassing decision-making power which goes beyond to include bargaining, and negotiation, deception and manipulation, subversion and resistance. Kabeer (1999) further argues that agency can have both positive and negative connotations. People can use agency to define their own life choices and goals or use it to control other people’s agency through domination or threat of violence. Both agency and resources constitute what Sen (1985) refers to as capabilities (the potential

that people have for living the lives they want). Achievement refers to changes in choices or inequalities in the ability to make choices.

The concept of ‘well-being freedom’ as conceptualised by Drydyk (2013) is very crucial to my work in expanding the understanding of the relationship between agency and empowerment. According to him, “while empowerment entails expanded agency, it is not reducible to ‘expanded agency’ (increase in a “person’s scope for achieving that person’s valued goal”), because empowerment has a conceptual link with well-being that agency cannot have” (Drydyk, 2013, p. 250). Agency is just one necessary component of empowerment, but empowerment also includes ‘well-being freedom (“the alternative combinations of functionings that a person can achieve”) (Drydyk, 2013, p. 251). Functioning refers to all possible ways of being and doing, which are valued by people in a given context (Drydyk, 2013). Drydyk (2013) sees agency as an active decision making and as a result of cooperation as social behaviour and practices are largely shaped by political, economic, and social factors (including ideologies and rhetoric). It is this context that determines how individuals exercise active decision-making.

Drydyk (2013) goes further to look at the relationship between power and empowerment and argues that we need to look beyond the individual since changes in systemic power relations cannot occur at an individual level. Cornwall and Edwards (2010) argue that mainstream conceptualization of empowerment tends to neglect relationships, to focus on individual women’s trajectories of self-improvement or economic change. Understanding of lived experiences of women of empowerment should incorporate social relationship because the social and intimate relations that women find themselves in can constrain or allow the possibility of their empowerment (Kabeer, 1999; Cornwall and Edwards, 2010).

Drawing on these theoretical grounds, therefore, “empowerment must be concerned not only with ‘expanded agency’ but also with removing the gaps and barriers between people’s agency and the expansion of their well-being freedom” (Drydyk, 2013, p. 254). Empowerment in this study may entail

having access and control of resources (including HIV prevention, treatment and care); having freedom from violence, stigma, abuse, coercion and exploitation; control of one's own body to be able to decide when and how to test for HIVST. Empowerment is transformative referring to gender and power relation and transformation of social relations (Drydyk, 2013).

2.5.2 The concept of power

Central to empowerment is the idea of power (Mayoux, 2010). Lukes (2005) argues that power remains a contested term. Power can be defined as the ability to influence, dominate or control the actions, decisions and behaviours of others, and the capacity to change something, to be changed or to resist change; it is relative and dynamic and varies according to the situation or context in which it is being exercised (Read, 2012).

VeneKlasen and Miller (2002) define power as the degree of control over the material, human, intellectual and financial resources exercised by different sections of society. Similar to vulnerability, it is a dynamic and relational concept, rather than absolute. Drawing on these definitions, power is manifested in social, economic and political relations between individuals and groups; it is repressive, or a source of inequality whereby some individuals and groups have greater control and others have little or no control, or it can create opportunities to gain more power to bring change. Power is spread at every level of society, including households, families and domestic units (Das and Kundu, 2009). It is sustained and perpetuated through social divisions such as gender, age, caste, class, ethnicity, race and geographical position, and through institutions such as the family, religion, education, the media and the law. VeneKlasen and Miller (2002) argue that power can also be resisted or challenged by those who are deemed powerless and marginalised in society. Below, I discuss some theories of power from VeneKlasen and Miller and Foucault.

2.5.3 Expressions of power

VeneKlasen and Miller (2002) emphasise that power can be defined as both negative and a form of dominion as well as a positive force to act for change. This conceptualisation of power resonates with Foucault's idea that power is localised because power 'diffuses' to micro-level relationships (Foucault, 1979). VeneKlasen and Miller (2002) describe four 'expressions of power':

1. *Power over*: This power is repressive and coercive and involves control over others in a win-lose relationship. It perpetuates inequality, injustice and poverty. It also trickles down to micro-level relationships if there are no alternative models.
2. *Power with*: It involves finding common ground among different interests and building collective strength. It is based on mutual support, solidarity and collaboration. It generally multiplies individual solidarity.
3. *Power to*: This power gives individuals a unique potential to shape their lives and world.
4. *Power within*: This power involves a person's self-worth and self-knowledge and involves recognising individual differences while respecting others.

Drawing on this understanding of power, these expressions of power can worsen vulnerabilities or offer opportunities for exercising agency, subject to the context-driven power relations in sex work environments and the ways individuals engage with an HIVST intervention. On the one hand, 'power over' in a sex work environment is exploitative and coercive and involves a variety of forms of violence. This expression of power can occur among FSW themselves, between FSW and pimps or queen mothers, or between FSW and their customers (Hendricks and Woensdregt, 2018). In some contexts, pimps or queen mothers, have 'power over' decisions about payments and customers, economically exploiting FSW (Marcus *et al.*, 2014). On the other hand, 'power with' can initiate social cohesion and enact change, offering FSW opportunities for collective empowerment (Kerrigan *et al.*, 2013; Huschke, 2019). FSW can find common ground to demand or initiate

interventions that would work for them, to be implemented in a way that is acceptable in their environment.

'Power to' is about individual or group capabilities and control over their situation (Kabeer, 1999). 'Power to' can offer FSW the opportunity to exercise agency and make choices to enact change. This expression of power can also enact individual and collective empowerment. This expression of power is ideally about freedom and choices. In the context of HIVST, ideally, FSW should be able to exercise agency in making decisions about whether to take part in HIVST interventions without feeling coerced by other FSW or test kit distributors. 'Power within' is about self-awareness and having confidence, making decisions while regarding other people's choices.

Therefore, empowerment of FSW could be viewed as a process that creates opportunities for FSW to gain 'power to' make life choices and be self-reliant (Das and Kundu, 2009) and increase their well-being freedom. This gain of power allows women to negotiate power relations in society and overcome the negative effects of cultural attitudes and prejudice. Empowerment is necessary to reflect the changes in the social-cultural context.

2.5.4 Foucauldian theory of power

According to Foucault, power is a relationship that is localised, dispersed and 'diffused' and is typically distinguished throughout the social system, operating at the micro, local and covert levels through acts of specific practices (Rabinow and Rose, 2006). It is exercised and naturalised in everyday practices simultaneously with resistance. Foucault further argues that power is a technique of actions that individuals can engage in. Drawing on Foucault's ideas, power relations rather than power itself should be the subject of analysis (Petersen and Bunton, 1997).

Foucault notes that health has become increasingly important politically as a significant point of contact between the government and the population (Foucault, 1979). The government has had to develop more advanced strategies in order to maintain control over the population while avoiding coercive action (Petersen and Bunton, 1997). Foucault made important

contributions to health and medicine. In the next section, I discuss the concept of biopower that describes the power relations between the state and population (Foucault, 1979).

2.5.4.1 Biopower

Foucault defines biopower as power employed to control individual bodies and populations and as a product of our practices and relationships, both with others and ourselves, and is therefore neutral (Foucault, 1979). However, in this thesis, I use the definition of biopower as conceptualised by (Rabinow and Rose, 2006, p. 195). They define biopower as:

> we suggest, entails one or more truth discourses about the ‘vital’ character of living human beings; an array of authorities considered competent to speak that truth; strategies for intervention upon collective existence in the name of life and health; and modes of subjectification, in which individuals work on themselves in the name of individual or collective life or health.

Regarding biopower, Lock and Nguyen (2018) argue that biomedical technologies are not neutral, nor do they operate in a vacuum. Biomedical innovations are socially produced and implemented by individuals or groups who are informed by social, political and medical interests that have practical and moral consequences. As Lock and Nguyen (2018) state, drawing on Foucault, they are technologies of the self, used to transform one’s own body and mind. The legitimisation of biotechnologies involves the dissemination of rhetoric about their purpose of contributing to scientific advances and satisfying human needs. The resistance that surrounds the introduction of biotechnologies makes it clear that new technologies are frequently assumed to be a threat to the moral order. Lock and Nguyen (2018) contend that the implementation of biotechnologies is often an example of medical imperialism (the extension of power and dominion of medicine over people’s social lives) and often meets with incomprehension, suspicion and outright resistance.

2.5.4.2 Biocitizenship

The concept of biocitizenship arises from long-established debates around the historical development of various conceptions of citizenship (Plows and Boddington, 2006). Adriana Petryna first introduced the concept of biocitizenship, however, the concept is now mobilised through patients' associations, disease advocacy organisations and self-help groups, from which new forms of subjectivities and collective actions are emerging (Heinemann and Lemke, 2014). In their essay on biocitizenship, Rose and Novas describe biocitizenship as a status where new connections between biology and self-identity are created (Cooter, 2008; Rose and Novas, 2014).

Rose and Novas (2014) argue that emerging biotechnologies open new discussions of what it means to be a human being. The human body is seen as a fragmented, biotechnologically exploitable consumer object that can be physically reshaped by technologies. They argue that biocitizenship departs from national citizenship by reconstituting citizens as biological consumers to place in a global marketplace of biotechnologies (Cooter, 2008). Rose and Novas (2014) also note that biocitizens are not solely constructed from above. The biocitizen appears to be actively involved in forming themselves from below, via self-education, self-care and collectivising action and thus, the extension of biopower (Heinemann and Lemke, 2014; Banda, 2015). In the same manner as Petryna, Rose and Novas (2014) characterise 'biological citizenship' as individualising to the extent that people shape how they relate to themselves regarding knowledge of their uniqueness, and as collectivising through biosocial groupings.

2.5.4.3 Biocitizenship and HIVST

In line with Foucault's view of power as productive and generative, Banda (2015) explores how self-diagnostics produce new forms of subjectivity, corporal realities and practices of biocitizenship. Banda (2015) argues that while HIVST has the potential to allow people to have more insight into their bodies outside the medical setting, the will to empower is neither liberatory nor repressive. Empowerment is a conditioned agency that can be enabling

and transformative while at the same time being shaped by discourses of medical authority, and it constitutes the operationalisation of biopower. While HIVST is an individual act, it entails responsibilities to others. HIV testing divides the HIV-negative from the -positive, the tested from the untested, both at individual and population levels (Banda, 2015), which forms part of self-governmentality.

HIVST is not neutral, but, rather, contributes to the moral and social fabric through which contemporary biocitizenship practices are produced (Banda, 2015). A biocitizen is not a passive recipient of HIVST biotechnology; uptake of HIVST technologies are contingent on how individuals negotiate them, even transforming them to meet their needs. The purpose of this transformation could be self-interest or the interest of the community in cases where people may use the kit as a tool to police others (Banda, 2015). Although manufacturers have not advertised this as a potential use of HIVST, some have advocated using the test to screen potential sexual partners. The argument is that HIVST could demonstrate that biotechnologies can provide an objective evaluation instead of relying on a partner's word, as is the case with conventional testing. A study among couples in Malawi found that women felt much more 'empowered' when they had a test that they could use to test their partner (Kumwenda *et a*l., 2014). Empowerment in this context is referred to the ability of women to initiate their partner's HIVST, an opportunity that was rare with conventional testing. In addition, they were able to rely on visual inspection of the HIVST test result to determine the HIV status of their partners reliably.

Given this background, implementation of HIVST among FSW could result in different dynamics, bearing in mind their typologies, whether or not they are involved in long-term partnerships and the sex work environment in general. HIVST constitutes a similar form of knowledge production, with the credibility that techno-scientific innovations provide.

2.5.4.4 HIV and therapeutic citizenship

Nguyen (2005) drawing on the concept of biocitizenship introduces the concept of therapeutic citizenship to draw our attention to the changes in people's identity resulting from their biological condition and their social interaction with HIV organisations. These organisations exert power through the resources they offer and accepted discourses about how to tackle and live with HIV. Through these interactions, particular subjects are fashioned (Nguyen, 2005); individuals are encouraged to assert their rights and make claims for treatment and behave as responsible citizens, including engagement with treatment.

Living with HIV is such a complex, dynamic and interactive process involving practical tasks as well as psychological and social adjustment (Sharpe and Curran, 2006; Russell and Seeley, 2010). These adjustments can broadly include incorporation of the new identity, illness, treatment and maintaining a positive view about the world in the face of a health condition. (Russell *et al.*, 2016) suggest that framing institutions such as health care providers can play a crucial role in shaping people's illness experiences. Health care providers have a position of authority which can be detrimental or productive. They can assist patients with treatment engagement, positive world views and cope and adjust more effectively or discourage patients from accessing such services (Russell *et al.*, 2016).

Cataldo (2008) argues that therapeutic citizenship can be empowering in the sense that people living with HIV are informed about their rights, disciplines and responsibilities and can claim them and be compliant with authorities. Here, context is also important as it plays a role in shaping the varied experiences of therapeutic citizens. In other cases, recovery while on ART can result in the transformation of subjectivities and create more empowered citizens (Nguyen, 2005).

In the context of sex work, FSW who are on ART need supportive health care systems that can facilitate an effective process of producing empowered citizens. The sex work environment can be challenging to incorporate

responsibilities such as drug routines and leading a positive lifestyle. Therefore, the understanding lived experiences of FSW with HIV should be context-specific.

2.5.4.5 HIVST as symbolic de-medicalisation

Banda further argues that HIVST testing is a symbolic form of de-medicalisation of HIV testing (Banda, 2015). Medicalisation is the process by which some aspects of human conditions and problems come to be considered and treated as medical problems, when before they were not considered pathological (Maturo, 2012). This concept is rooted in biopower as the role of doctors in deciding what was normal and what was pathological (Hancock, 2018). Medicalisation has traditionally been analysed as an issue of the authority of medical professionals to define, treat and control individuals (Figert, 2011), for example by reconstructing alcoholism and obesity as falling within the medical domain rather than the legal, religious or social domain. De-medicalisation is the opposite of medicalisation. It can mean the ending of medical jurisdiction over some activities or attributes (Clarke, 2009).

Its theory connects explicitly with the new and expanding techno-scientific advancements. Figert (2011) argues that the analysis of medicalisation is seemingly a top-down approach. The shift from medicalisation to biomedicalisation highlights a move away from micro- and meso-level approaches to the study of medicalisation processes and outcomes that focus on the individual patient, user or consumer. The argument is that it is insufficient to discuss new biomedical developments only in a top-down approach: new forms of agency, empowerment, and morality that emerge from dispersed social locations in response to such changes need to be considered in the analysis to understand how biomedicalisation informs and transforms knowledge and its users (Clarke, 2009; Figert, 2011). Figert (2011) further argues that the user is transformed from an object of professional medical surveillance into a more active and informed participant in the world. This transformation has also resulted in new forms of exclusion and domination, as stipulated by Rose and Novas (2014).

The shift to biomedicalisation has also intensified focus on and the elaboration of risk and surveillance biomedicines. In public health, the maintenance of health is now increasingly viewed as a moral obligation of bio-citizens (Hancock, 2018). Risk and surveillance concern shaping both the technologies and the discourses of biomedicalisation, as well as the spaces within which biomedicalisation processes occur. This shift also opens discussions around how users are actively engaging in these new biomedical potentialities individually, collectively and as populations (Clarke, 2009).

2.5.4.6 Biomedicalisation and risk

The current conceptualisation of risk as an outcome of human action impacts on processes of biomedicalisation and/or vice versa (Maturo, 2012). In health discourse, the concept of risk may be connected to the individualisation of social problems and the changing identities between normal and pathological (Clarke, 2009; Maturo, 2012). Illness is now perceived as an external risk due to this understanding, thus shifting the responsibility to the individual, despite illness and health being firmly connected to the environment (in the broader sense). Therefore, prevention is socially constructed as a specific duty. Moreover, considerable investments in diagnostics and genetics have led to the neglect of social causes of diseases and, again, to their being considered only in biological terms (Clarke, 2009; Maturo, 2012).

HIVST is part of a growing trend to identify the population that now poses the most at risk – ‘the untested bodies’; it is a tool not only for managing one's body but also for managing risk within intimate relationships and for society as a whole (Banda, 2015). Factors that limit good biocitizenship may include economic, legal, political and geographic locations. As in the case of HIV testing, individual bodies and identities are seen as needing technologies by virtue of their risky behaviours and lifestyles (Lakkimsetti, 2014).

Biocitizens are not uniform: while the general population has been identified as being at risk for HIV, the most at-risk bodies now are ‘the untested bodies’ (Banda, 2015). Lack of monitoring of one’s HIV status and abandonment of

the obligation to regularly assess and improve one's health translates into the risk to one's own body and those of other active citizens, informed biocitizens who are aware of their status. However, awareness of one's status is simply the beginning of a self-maintenance regime, for those who test negative and are 'risky bodies' are encouraged to conduct regular tests (Banda, 2015). One may test negative and then engage in a risky activity, thus returning to the status of untested, hence the status of 'tested body' is transitory.

These technologies of biopower emphasise the identification, classification and surveillance of bodies for disease prevention and require the active participation of FSW as individuals and as a community in the management of the epidemic. As indicated earlier, FSW are risky bodies due to their high HIV risk and are advised to have regular HIV tests. Therefore, new technologies may also strengthen state control of FSW and the creation of tested and untested FSW.

2.5.5 Interrogating the concept of empowerment in HIV prevention interventions

In this section, I discuss how the concept of empowerment has been appropriated in HIV prevention intervention.

From the beginning of the HIV epidemic in the early 1980s, the response to HIV was shaped by cognitive behavioural models of behaviour change and interventions that included information, communication and education (ICE) (Beeker, Guenther-grey and Raj, 1998). These approaches were attractive to researchers and HIV prevention providers, primarily biomedical and public health practitioners, who were interested in HIV transmission reduction (Czuba, 1999). For example, interventions targeting FSW had a three-pronged approach: peer education (PE), condom distribution and sexually transmitted infection (STI) screening. Interventions framed according to this approach proved to have a limited impact in reducing HIV risk among FSW and their customers (Kerrigan *et al.*, 2013). They were disease-based and individualistic approaches that failed to address the social, economic and political injustices that heighten the risk for HIV transmission, especially

among marginalised groups such as FSW (Fee and Krieger, 1993). The focus on individual behaviour change, particularly the focus on ‘abstinence, be faithful, use a condom (ABC) approach has been heavily critiqued for being individualistic (Murphy *et al.*, 2006).

Recognition of the limitations of such individualistic and disease-centred approaches among marginalised groups resulted in the empowerment concept becoming popular in HIV prevention interventions (Shannon and Montaner, 2012). In this framing, vulnerable groups have limited access to and participation in available HIV prevention services in many settings, hence the need for a more holistic approach that links HIV prevention to the broader mission of addressing social, economic, legal and political injustices (Kerrigan *et al*., 2015). In health promotion, the assumption is that empowerment increases the likelihood that people will engage in health-promoting behaviours (Tengland, 2007). The inclusion of empowerment in HIV prevention is based on three assumptions: greater buy-in from community leaders; community acceptance and relevance of the interventions; and the sustainability of activities and effects (Tengland, 2007).

An example of the empowerment initiative among FSW is the Sonagachi project in India (Kerrigan *et al.*, 2015). It promoted empowerment by increasing a sense of community, decreasing perceived powerlessness and insecurity, and increasing access and control over material resources and social participation (Kerrigan *et al*., 2015). Kerrigan *et al*., (2015) define empowerment as a process by which FSW take collective ownership of programmes and services to achieve the most effective HIV responses and address social and structural barriers to their health and human rights. Empowerment was found to be associated with decreased HIV and other STI infection rates. The results of this project ensured that community empowerment in FSW was recognised as UNAIDS best practice and it remains a theme in key UN policy documents regarding HIV in FSW (Kerrigan *et al.*, 2015; Rissel, 2017).

A systematic review assessing the effectiveness of empowerment in HIV prevention programmes implemented among FSW in low- and middle-income countries established that positive effects were documented for multiple HIV-related outcomes including HIV infection, STIs, and consistent condom use between FSW and their customers (Kerrigan *et al.*, 2013). Most studies were conducted in India and Africa with a few in Latin America and the Caribbean. However, a study in Brazil yielded no significant change in condom use when empowerment (as a process) was implemented in an ongoing intervention among FSW (Kerrigan *et al.*, 2013). A study in South Africa that examined FSW's participation in HIV interventions established that empowerment (according to Sonagachi's definition of empowerment) did not affect desired outcomes on condom use or economic development due to lack of trust in their peers and cooperation (Campbell and Mzaidume, 2001). Despite increasingly supportive evidence from India, studies from SSA have produced inconclusive results, especially when they have tried to replicate the Sonagachi empowerment approach (Cornish and Campbell, 2009; Kerrigan *et al.*, 2013). There is a consensus that interventions for FSW should be context-driven when translating the Sonagachi project to other settings (Evans and Lambert, 2008; Kerrigan *et al.*, 2008a).

2.5.6 Peer education (PE) in HIV prevention interventions among FSW

HIV prevention approaches among FSW emerged with PE as a strategy for implementation of the empowerment approach in HIV prevention. PE interventions initiate selection of individuals who share the same demographic characteristics (e.g. age or gender) or risk behaviour with a target group (Medley *et al.*, 2009). The selected individuals undergo training to raise awareness (e.g. regarding HIV transmission and prevention by using a condom consistently), impart knowledge and encourage behaviour change among members of that group. There are no strict modes of delivery for PE; it can be either formal or informal. PE methods vary, and they depend on intended outcomes, contexts and target group (Campbell and Mzaidume, 2001).

The conceptualisation of empowerment in this approach leans towards building capacity and skills as well as educating others. The rationale for PE interventions assumes that peers have a strong influence on individual behaviour (Campbell and Mzaidume, 2001). PE operates on levels of trust and access to peers. In public health, PE is assumed to be empowering to both the educator and target group (Campbell and Mzaidume, 2001).

Despite the popularity of PE, Turner and Shepherd (1999) argue that lay principles and assumptions inform PE; it is a method in search of theory and not an application of theory to practice. 'Empowering' interventions based on PE strategies have yielded inconclusive results across regions and countries (Campbell and Mzaidume, 2001). A meta-analysis carried out by Medley et al. (2009) on the effectiveness of PE interventions in changing HIV-related knowledge in developing countries established that these interventions are moderately effective at improving behavioural outcomes but show no significant impact on biological outcomes. Lack of critical consciousness and solidarity are some of the key factors that can undermine prospects for empowerment among FSW (Huschke, 2019).

Challenges to the effectiveness of empowerment through PE in changing HIV-related outcomes in developing countries, especially SSA, have been attributed to regressive international discourses and funding constraints; national laws criminalising sex work; and intersecting social stigmas, discrimination and violence (Medley *et al.*, 2009). Details of barriers to PE implementation are presented in Table 1.

Table 1: Challenges for peer education (PE) approaches in HIV prevention interventions among FSW in SSA (Medley *et al.*, 2009)

Cultural
• Limited involvement of FSW; they are viewed as a vulnerable group and not part and parcel of the intervention (ownership) • Challenges in establishing social cohesion to facilitate peer-led delivery • Challenges in defining FSW because of varying characteristics

• Stigma and discrimination leading to fragmentation of the group
Economic
• Dependence on donor funding • Lack of sustainability – most are embedded in research studies • Low coverage
Political
• Lack of accommodative policies for interventions targeting FSW • Legal and human rights challenges – the criminalisation of FSW • Public health interventions operating on moral grounds in relation to the implementation of interventions for FSW

2.6 Summary

In this chapter, I have offered a theoretical perspective of sex work by discussing a simplistic argument of two opposing perspectives of sex work, thus, the oppression and empowerment paradigms. I have argued that we should go beyond emphasising this simplistic binary because the lives and experiences of FSW demonstrate both FSW agency and victimhood, and there are varied reasons why women enter into sex work.

I have discussed the concept of vulnerability and its relation to sex work, biomedicine, HIV and HIVST. I have provided an overview of the different perspective of vulnerability. I have concluded that all humans are vulnerable beings but that our environment impinges on our experiences of vulnerability, and as a result, some people may be more vulnerable than others depending on context and time. I have also shown how HIVST has emerged as an 'anti-vulnerability technology' to address the HIV testing barriers faced in conventional HIV testing facilities. Here, I argue that HIVST could be at the same time a solution and a problem because the implementation of HIVST occurs in environments that may offer opportunities for empowerment or constrain people's choices.

I have also discussed the concept of empowerment and its relationship to agency, power and biocitizenship. I have argued that our understanding of empowerment should transcend the expansion of agency to incorporate a person's well-being freedom. This is achieved by addressing barriers between

people's agency and the expansion of their well-being and also addressing power inequalities. Drawing on the concepts of biopower and biocitizenship, I have identified the opportunities that can be realised from using HIVST, but also how HIVST can shape FSW's vulnerabilities. I have introduced the concept of therapeutic citizenship to address questions around opportunities and constraints to empowerment in relation to HIV prevention, treatment and care. Here, I consider the crucial role of the health care system in providing a conducive environment for producing empowered citizens.

Lastly, I have also raised questions around the incorporation of empowerment in HIV prevention interventions. I have provided evidence of how this concept has been used in different settings and also noted that the same empowerment intervention might work in one setting and not in others. Therefore, I agree that interventions should be context-driven, reflecting the lived realities of the target population.

In the next chapter, I provide an overview of Malawi to understand the study's cultural, socioeconomic and political context.

3 Understanding Malawi

3.1 Introduction

In this chapter, I introduce Malawi, the setting of this study. I discuss the historical and cultural background of Malawi, focusing on the topics relevant for this study: gender, poverty, sex work and HIV. I specifically focus on the position of women and of FSW, which provides a basis for situating the ethnographic analyses in Chapters 5–7.

3.2 Literature search strategy

3.3 Background

In this section, I give a brief impression of Malawi's geographical, democratic, political and economic characteristics to present the historical and current landscape of the country.

3.3.1 Geography and demography

Malawi is a relatively small but densely populated and landlocked country in the SSA region, located south of the equator (Briggs, 2016). The country shares borders with Zambia to the north west, Tanzania to the north east and Mozambique to the south, east and west. Malawi has a land area of approximately 119,000 km^2, and Lake Malawi makes up approximately 12% of the surface area of the country.

Administratively, Malawi is governed as three regions: the northern, southern and central regions, which are further divided into 28 districts – six in the north, nine in the central region and 13 in the south (see Figure 4). These districts are further divided into traditional authorities under the leadership of traditional chiefs. Villages rank as the smallest administrative unit and are presided over by village headmen/-women. Malawi has a diverse population of native peoples (including Chewa, Tumbuka and Yao), Asians and Europeans with several languages spoken (the official language is

English, and Chichewa is widely used as a local language) and an array of religious beliefs including Christianity and Islam.

Figure 4: Map of Malawi

Source: Worldometer

Malawi's current population size is estimated at 17.5 million, of whom 52% are women, and it ranks 63rd in the world (National Statistical Office (Malawi), 2019). The total population increased by 35% between 2008 and 2018, representing a growth rate of 2.9% per annum. The population is mostly young, with youth aged 15 years and below making up 45% of the population. This population size puts pressure on available land, productivity and environmental sustainability and has posed challenges for poverty reduction. Recently, Malawi has reduced the total fertility rate following campaign promoting the use of modern contraception (58% among married women), more than double the regional average (Schneidman et al., 2018). Life expectancy at birth (for both sexes) is low (64 years), and lower than the world average of 71 years.

3.3.2 Political history

Prior to colonialism, Malawi was part of the Maravi Empire (McCracken, 2012). Archaeological evidence suggests that Bantu people who originally inhabited present-day Malawi are said to have originally migrated from the Congo Basin between the 13th and 16th centuries (Newitt, 1982). Following the exploration of David Livingstone from Scotland in 1878, Malawi became a British protectorate under the name British Central Africa and later Nyasaland in 1891. Between 1951 and 1953, Malawi joined the colonies of Southern and Northern Rhodesia in the Federation of Rhodesia and Nyasaland (Pachai, 2007). Colonialism changed the socio-economic system in the country as the British were given land for coffee and sugar plantations, forcing Malawians to work under poor conditions (Pachai, 2007). Land ownership by the colonialists fundamentally altered the way land was used, and these legacies continue to be felt today. The colonial government failed to develop African people, and many men migrated to neighbouring countries to seek employment (Chirwa, 1997).

After almost a century of colonial rule, the federation was dissolved in 1963; the country achieved full political independence in 1964 and became a republic in 1966 (Englund, 2002). Dr Hastings Kamuzu Banda, a medical doctor, trained in Britain, led the campaign for decolonisation in the 1950s and won a popular vote to become the first prime minister in 1963 (McCracken, 2012). His government improved the railway and road networks, and there was much emphasis on cash crop production (tobacco, tea and sugar) and food security. Banda was heavily criticised for his autocratic rule, abuse of human rights and murders despite progress in infrastructure and agricultural development (Mwaungulu, 2006). He emphasised strict, conservative notions about sexuality and made sexuality a taboo subject in Malawi. He viewed women as having a very limited role in Malawian society, and this was reflected in the under-representation of women in decision-making positions after independence (Semu, 2002). After 30 years of dictatorial leadership, there was increasing internal opposition led by the Catholic bishops in 1992. This led to a referendum to reintroduce a multiparty democracy in 1993, and there was a general election in 1994 (Englund, 2002).

Bakili Muluzi succeeded Banda and served as president of Malawi between 1994 and 2004 (Englund, 2002). His government was tarnished with allegations of corruption and a lack of separation between government and party funds. His successor, Dr Bingu wa Mutharika, served Malawi from 2004 but died suddenly of a heart attack in 2012 before finishing his term. His first term was promising as there was an increase in agricultural production, but he was criticised for being an authoritative leader by civil societies in his second term (Chihana *et al.*, 2008). He was succeeded by Dr Joyce Banda, the first female president in Malawi and the second in Africa. She was in power for two years only, but during this time, corruption worsened. She lost the election to Bingu's brother Prof. Peter Mutharika in 2014 (Strasser, 2016). His first term (2014–May 2019) was marked by strong popular discontent due to corruption, food shortages and power cuts. The last elections, which put Prof. Mutharika back into power, were marred by controversy and claims of rigging by his party.

3.3.3 Economic history

The country remains vulnerable to external and internal shocks reinforced by weak governance and institutions, contributing to the cycle of economic crisis, corruption scandals and food insecurity (Schneidman *et al.*, 2018). Climate-related shocks, including droughts and floods, have threatened agricultural production. Economically, the country depends on substantial aid from the World Bank, the International Monetary Fund and other nations to meet development needs (World Bank Group, 2018). This dependence adds a further dimension to these cycles; for example, in 2013, donors suspended budget support in response to poor economic management and corruption. As a result, the government faces challenges in building and expanding the economy, improving education and healthcare. Currently, around 70% of the population live below the poverty line of US$1.90 per day (World Bank Group, 2018).

Despite a history of exceptionally low overall poverty reduction, slow and volatile growth and vulnerability to climate shocks, in recent years Malawi has made notable gains in macroeconomic stability, reduction in ultra-poverty rates and progress on key demographic indicators (World Bank Group, 2018). Malawi now ranks 171 of 188 countries in the 2018 Human Development Report (UNDP, 2015). The economy is heavily centred on agriculture, which drives livelihoods for two-thirds of the population yet accounts for only one-third of gross domestic product. With the reduction in the global demand for tobacco (the main export product), the Malawian economy has suffered a great deal recently.

3.4 Urbanisation in Malawi

Pre-colonialism, indigenous towns were established under the slave and ivory trade in Karonga, Makanjira and Nkhotakota, among others. However, these towns were later destroyed by colonialists during the anti-slave-trade campaigns (McCracken, 2012). Currently, in Malawi, urbanisation is concentrated in four cities: Lilongwe, the capital city and administrative centre; Mzuzu in the northern region; Zomba in the eastern region; and Blantyre, the

commercial hub. The rest of the urban population lives in municipalities, towns, districts and market centres. The current census report indicates that the urban population in Malawi has increased from about 2 million in 2008 to 2.8 million in 2018 (National Statistical Office (Malawi), 2019). The major drivers of urbanisation are high natural increase, rural-urban migration and immigration. Without effective urbanisation policies, this level of urbanisation can lead to urban poverty, which involves insecurity, vulnerability to shocks, violence, homelessness and unemployment.

3.4.1 Blantyre City

Blantyre has always been Malawi's financial and commercial centre and attracts populations from the neighbouring rural districts. Blantyre became the leading European settlement in the area by the late 1880s. It is one of the oldest cities in ESA, founded in 1876 under the Blantyre Mission and named after a small town in Scotland, the birthplace of Dr David Livingstone (McCracken, 2012). The development of Blantyre in the colonial era predates the establishment of Harare, Nairobi and Johannesburg. Trade, especially ivory, flourished in the city. This, together with Blantyre's easy accessibility and healthy climate, attracted further European and Asian settlers.
For this reason, Blantyre quickly became the most important settlement in Malawi and a trade crossroads for Southern Africa (McCracken, 2012). During the colonial period, Africans had limited economic opportunities. Most men engaged in estate labour, tailoring, butchery, and bicycle and gramophone repairs, among other occupations.

Currently, Blantyre City has a population of over 800,000 and, like many African cities, is composed of small islands of financially well-to-do people and increasingly impoverished people living in slums (National Statistical Office, 2019). These variations inevitably determine configurations of economic, employment and livelihood opportunities. Below, Photo 1 and Photo 2 show variations between the Blantyre central business district and peri-urban locations.

Photo 1: Blantyre central business district

Source: Flickr, taken by Ismael Mia, 2013

Photo 2: Peri-urban Blantyre

Photo by researcher

3.4.2 The selling of alcohol and emergence of bars

The history of beer brewing and drinking started before the Scottish missionaries came to Malawi. Beer brewed from maize, millet or sorghum was widely consumed. As early as 1883, Malawian chiefs were able to import

Brazilian whisky (McCracken, 2012). However, missionary work in places like Mzimba and Blantyre faced challenges because it was difficult to convince people to stop drinking beer. In response, in 1892, the colonial authorities banned imported alcohol to control alcohol intake. However, this gave rise to locally distilled *Kachasu* (a name derived from an old Brazilian brandy) (McCracken, 2012). With the spread of money in Blantyre, beer brewing became a commercial activity.

In Blantyre, some women were involved in the selling of *Kachasu*, mainly in their homes. In the early 1930s, it was estimated that beer brewers from villages close to Blantyre were making profits of around £8–£10 a year (McCracken, 2012). Following a campaign by Blantyre Mission, authorities banned beer brewing and drinking within townships, and it was later made illegal. The colonial authorities introduced a licensing system by which only certain men, and particularly village chiefs, were given rights to sell beer in designated places (McCracken, 2012). This led to the creation of local bars, run by women, who paid fees to the licence-holders. Blantyre became popular, with *Kachasu* attracting hundreds of young men drawn there to drink alcohol. This led to the emergence of bar-based sex work as men also came to the bars to dance with women, which sometimes led to casual sexual encounters as sex work was an alternative source of income for women.

3.5 Cultural context

Malawi has two lineage patterns, patrilineal and matrilineal, but cultural beliefs and norms largely revolve around a patriarchal system (Tiessen, 2008) and play a powerful role in influencing cultural practices. Malawi's cultural beliefs and norms continue to play a big role in shaping family practices that often link to sex work engagement among women. Below, I discuss the impact of unequal gender power relations on women's vulnerability and choices in life.

3.5.1 Unequal gender power relations

In Malawi, historically, both the colonial administration and post-colonial policies have contributed to the shifts in the power balance in both households and lineages in ways that generally weakened women's power, particularly

among matrilineal groups (Kaarhus, 2010). Both administrations intervened directly in ways that aimed to shift the power balance in matrilineal groups in favour of men, actively seeking to replace matrilineal practices with the more patriliny arrangements. The missionaries saw a challenge in how women held power and authority in the family structure of matrilineal groups, as such, they concentrated much of their effort in teaching that husbands were the head of the family and training young men to get paid jobs and take their wives with them when posted away from home (Phiri, 1983). In turn, this practice required the redefinition of male and female roles and responsibilities in the household. Peters' (1997, 2010) work in the southern region of Malawi on kinship provides proof of the viability of strong land rights for women in matrilineal groups; daughters are the rightful heirs of matrilineage's land, while sons use their wives' land or temporary use land belonging to their female matrikin. This matrilineal practice has historically been an issue of contention in both colonial and post-colonial administrations. According to Peters (2010), the land reform policy in Malawi contains provisions aimed at improving women's land rights and including both sons and daughters as heirs of land, however, where decision-making over land is shared with brothers, and local traditional leaders (predominantly male) threatens those very rights of women in Malawian context (Peters, 2010).

The most salient factor during the colonial era was the creation and reinforcement of dualistic understandings of social reality, with the effect that African women became associated with 'tradition' rather than 'modernity' and the 'rural' rather than the 'urban' (McFadden 2002). After colonialism, the notion of 'traditional' gender role was a key feature of Malawi's conservative political culture under Banda. For instance, the nation was conceived according to a metaphor of an idealised Chewa village. Banda was the *nkhoswe* – the head of the village which is also an older brother of the matrilineal sister group – and the women were his '*mbumba*' (clan) (Semu, 2002), therefore having an inferior role.

The new liberal democratic constitution of Malawi recognises economic, social and cultural rights and emphasises the state's obligation to provide people

with equal opportunities to access basic resources, education, health services, food, shelter, employment and infrastructure (Kanyongolo, 2009). Many studies conducted across different social groups in Malawi have documented that men possess power over women in different aspects of socio-economic activities (Kerr, 2005; Kululanga *et al.*, 2012). Men have a strong degree of control over the ways in which women can exercise agency. Due to these unequal power relations, in which women have little decision-making power or entitlement, there is a high risk of abuse, with very limited material or kin support, leaving women in a more vulnerable position than men. Interventions that aim to address gender inequalities and gender awareness still encounter challenges and often fail to acknowledge the local cultural practices that perpetuate gender inequality.

Together with economic factors and poverty contributing to limited choices and opportunities, long-held and deeply rooted gendered roles and behaviours limit women's access to key resources and perpetuate gender-based inequalities in the home, school or workplace (Tiessen, 2008). Historically, women in Malawi have been marginalised in terms of education, commerce and employment. Phiri (1997) argues that the introduction of slavery, the coming of patrilineal societies and the introduction of Christianity and colonisation have deprived Malawian women's status in society.

3.5.1.1 Malawi's literacy levels and gendered differences

Since 1994, the Malawian government has aimed to provide free primary education, but this is subject to the availability of resources, which are often in short supply. The National Statistical Office (NSO) of Malawi defines literacy as the ability to read and write a simple sentence in any language (National Statistical Office (Malawi), 2019). The literacy rate in Malawi is estimated at 68.6%, with notable gender, regional and residential differences. There are more literate men than women, 72% and 66% respectively. The southern and central regions have a low literacy rate, at 67%, compared to the northern region (79%). Although the free primary school education policy has contributed to an increase in the number of children attending school, the

quality of the teaching and learning environment has deteriorated in recent years (Kadzamira and Rose, 2003). This is because free primary education has not been accompanied by an increase in funding for more teachers or materials. The policy has contributed to the country's achievement of gender parity in primary and secondary school education enrolments; however, 62% of girls who enrol in standard one fail to continue to standard five due to pregnancy or the preference of parents to educate boys instead when resources are low (United States Agency for International Development, 2016).

Education is an important determinant of women's economic, health and social status in society. Studies have established that women who have a minimal level of secondary education are more likely to have better health outcomes, compared with women without formal education (Yaya *et al.*, 2016; Muula *et al.*, 2011). Education has the potential to empower women to take part in decision-making and the transformation of their lives and the population at large. It can also extend women's capabilities and develop their skills, including improving their negotiation skills, enabling them to demand better health services.

3.5.1.2 Employment and gendered differences

According to the NSO 2019 census report, of 17.5 million people, 9.1 million (52.3%) were people aged 15 to 64 years. Of these, 6,614,065 were economically active (72%) and 2,574,210 were economically inactive (28%) (National Statistical Office (Malawi), 2019). The working population comprises all persons aged 15 to 64 years. Of a labour force of 6.6 million people, 5.3 million (81.5%) were employed, and 1.2 million (18.5) were unemployed. According to the Centre for Social Concern's Basic Needs Basket June 2019 report, for a household with six people, the cost for basic food items and non-food items in Blantyre is MK219,040 per month (Center for Social Concern (Malawi), 2019). Given this, some people migrating from rural settings may be disadvantaged if they become unemployed or lose income-generating activities.

In Malawi, there is a strong division of labour along gender lines within households. Women often conduct domestic tasks, such as cooking and fetching firewood, whereas men explore more outdoor economic activities, usually in both formal and informal sectors. When women are employed in the wage economy, they are outnumbered by men. In the agricultural sector, women's participation is limited to growing food crops, while men produce cash crops. Additionally, women-owned businesses are less formal, less profitable and smaller than those owned by men (Campos, Goldstein and McKenzie, 2015; World Bank Group, 2018). These gender differences further marginalise women in economic activities and negatively affect their economic independence.

3.6 Sex work

In Malawi, like elsewhere, expanding mobility from rural to urban areas increases young women's vulnerability to engagement in sex work. Scholars who have conducted studies of FSW's risk of HIV have reported poverty, low educational levels and predisposing sociocultural practices for girls as the primary factors in the high rates of sex work in the country. Most FSW in Malawi are mobile and transitory (Tavory and Poulin, 2012). A study conducted by Nkhoma and Charnley (2018) in Malawi reported that most women enter sex work at a very young age – as young as 11 years old. Key drivers of sex work were the absence of family support through poverty or orphanhood; early marriages for girls, which limit opportunities for educational attainment and independent income generation; and gender-based violence (GBV) within marriage.

Currently, the Malawi PLACE 2018 report indicates, there are a total of 36,700 FSW in Malawi, working in different venues, and about 6,200 living in Blantyre (FHI 360, 2018). The highest numbers of FSW are documented in urban areas, significant cash crop farming districts and lakeshores. The most common venues are bars with sex work on-site; others include shabeens, rest houses and street venues.

3.6.1 The legal framework for sex work in Malawi

The legal framework for sex work in Malawi is complex and prompts confusion. Selling sexual services are not in itself illegal in Malawi, but various acts associated with sex work are prohibited. In terms of laws affecting customers, *Section 145* of the Penal Code (Government of Malawi, 1991, p 58) creates the offence of "a male person living on the earnings of prostitution or persistently soliciting". *Section 146* creates the offence of "a woman who lives on the earnings of prostitution or influencing others to engage in prostitution". Regarding brothel-keeping, *Section 147* criminalises the keeping of brothels (house, room, set of rooms or place of any kind whatsoever for purposes of sex work). Therefore, essentially the law criminalises the involvement of third parties in sex work, and not necessarily FSW, and it is there to protect FSW from exploiters.

However, misinterpretation of these sections is used to justify the prosecution of FSW under *Section 184(c)* of the Penal Code, which stipulates that

> Every person found in or upon or near any premises or in any road or highway or any place adjacent thereto or in any public place at such time and under such circumstances as to lead to the conclusion that such person is there for an illegal or disorderly purpose is deemed a rogue and vagabond (Government of Malawi, 1991, p. 75)

In practice, law enforcers carry out night raids and arrest any female found loitering in entertainment premises and public places. Those who are arrested are often charged with minor offences such as being found idle and disorderly or being a rogue and vagabond, which is covered in Penal Code *sections 180(a), 181 and 184* (Government of Malawi, 1991). Clearly, these arrests do not offer any form of safety and security to women, and instead violate the rights of women to dignity, respect or choice as regards freedom of association.

FSW also risk prosecution under *Section 192* of the Penal Code, which creates the offence of a negligent act likely to spread diseases dangerous to life (Government of Malawi, 1991). Although this clause may be perceived as

positive in preventing transmission and reducing the risks of infection, there is a risk of it exacerbating the violence that FSW can face at the hands of their customers or peers.

In January 2017, the high court in Blantyre, Malawi, ruled that the use of the rogue and vagabond law was unconstitutional (Government of Malawi, 2005). Theoretically, this translates into a weakening of police powers to arrest FSW under this law, therefore giving FSW a hopeful future. However, lack of clarity in laws around sex work and misinterpretation by law enforcers make FSW vulnerable to human right violations and discrimination, which also impacts on their access to health services when needed.

3.6.2 HIV in Malawi

As in many countries in SSA, the HIV prevalence rate in Malawi remains one of the highest in the world. HIV is a major public health, economic and social problem in Malawi (PEPFAR, 2018). The first HIV case in Malawi was reported in Lilongwe in 1985. HIV prevalence escalated between 1985 and 1993 due to an unsupportive political environment (Mwale, 2002). By 2012 approximately 10.8% of the population in Malawi was HIV-positive. The current estimated adult national prevalence is 10.6% among adults (15–64 years) but varies widely by region (UNAIDS, 2017). Prevalence is highest in the southern region and in the urban areas of Blantyre (17.7%) and Lilongwe (14.2%) (National Statistical Office (Malawi), 2017).

Men, women and children have all been affected by HIV, but incidence and prevalence are structured by gender and social inequalities. Women are more vulnerable to HIV because of power imbalances in sexual relationships, poverty and gender inequality (Anderson, 2012; Rosenthal, 2016). A national investigation of the impact of HIV on the population in 2015–2016, found HIV prevalence among adults in Malawi to be 10.6%, and among women (aged 15–64) to be 12.9%, compared to 8.1% among Malawian adult men (Ministry of Health and Population (Malawi), 2018). This disparity is especially prominent among young people, with 3.7% of young women aged 15–17

living with HIV compared to 0.4% of their male counterparts. Prevalence is higher among women in urban areas (22.7%) and lowest among men in rural areas (7.1%). HIV is also the leading cause of death in young adults, the most productive age group. HIV prevalence is nearly twice as high among females aged 15–24 years old (3.4%) than among males in the same age group (1.3%) (PEPFAR, 2019). There is evidence that HIV prevalence among FSW and their clients is about 10–20 times higher than among the general population. HIV prevalence among FSW remains unacceptably high, with an estimated 62.7% HIV prevalence (PEPFAR, 2019).

The Malawi Country Operational Plan (2019) indicates that Malawi is approaching epidemic control. Malawi has made good progress towards reaching the 90–90–90 UNAIDS goals. An estimated 90% of people living with HIV know their status, 84% of those are on ART, and 90% on ART are virally suppressed (UNAIDS, 2017).

3.6.3 Drivers of the Malawi epidemic

In Malawi and the rest of SSA, HIV is predominantly transmitted through unprotected heterosexual intercourse. Mobility is an important risk factor for HIV in Malawi (Chirwa, 1997) as labour migration was historically and still is a common strategy for men to try to improve their livelihood security. As workers leave their home for extended periods, many migrant workers engage in casual sexual encounters. The high incidence of concurrent partnerships is another underlying factor for the high rate of HIV incidents. Cross-cutting these factors, some reports emphasise the structural inequalities that people face daily (National AIDS Commission (Malawi), 2015). Gender constructs render women subordinate to men and make them culturally and economically dependent on men and so impact on negotiations of the conditions under which sex occurs (Anderson, 2012; MacPherson et al., 2012; National AIDS Commission (Malawi), 2014). Poverty is furthermore assumed to push men into migration and women into selling sex for money and so increase their risk of HIV infection.

3.6.4 The Malawian government response to HIV

Historical, political and economic factors characterise the HIV response in Malawi. The first case of HIV was reported during the dictatorship regime under the leadership of Banda (National AIDS Commission (Malawi), 2015). In response to the emerging HIV epidemic, the government implemented a short-term strategy, including blood screening and an HIV education programme. In 1988, the Malawian government created the National AIDS Control Programme (NACP) to coordinate education and prevention efforts (National AIDS Commission (Malawi) (2001). In 1989, the government implemented a five-year World Bank-supported intermediate plan, but this proved ineffective because HIV prevalence had already escalated; for example, HIV prevalence among pregnant women rose from 2% in 1989 to 30% in 1993 (Mwale, 2002).

After Malawi became democratised in 1994, freedom of speech was re-established, creating a more liberal environment in which HIV education could be carried out without fear of prosecution (National AIDS Commission (Malawi) (2001). In 2000, the government introduced yet another five-year plan: The National Strategic Framework. In 2001, the National AIDS Commission (NAC) replaced the NACP to develop an expanded HIV programme in Malawi (National AIDS Commission (Malawi), (2001).

In 2003, Malawi developed a national HIV/AIDS policy that served as an important milestone in the fight against the disease (Ministry of Health and Population (Malawi), 2003). It was informed by international policy principles and laid out an administrative and legal framework for all programmes and interventions, stating national goals to reduce HIV infection and provide care, treatment and support for people living with HIV. Antiretroviral drugs (ARVs) were first introduced in Malawi in 2003, and the country adopted a public health approach in 2004 to scale up access nationally (National AIDS Commission (Malawi), 2015). Currently, the National HIV and AIDS Strategic Plan 2015–2020 outlines some prevention policies and strategies for reducing HIV incidence. Some of these strategies include preventing mother-to-child transmission (PMTCT), voluntary medical male circumcision, condom

provision and programming, and ART (National AIDS Commission (Malawi), 2015). Malawi has made impressive progress in responding to its HIV epidemic, particularly regarding PMTCT; however, more efforts are needed that target key populations, including FSW (National AIDS Commission (Malawi), 2015).

3.6.4.1 HIVST in Malawi

Malawi pioneered population studies on HIVST, and between 2011 and 2017 a total of 175,683 HIVST kits were distributed. The studies in Malawi showed that there was a high level of HIVST uptake in the general population, and it was particularly attractive to men and young people (16–24), couples and partners (Kumwenda *et al.*, 2014; MacPherson *et al.*, 2014; Choko *et al.*, 2015; Indravudh, Sibanda, d'Elbée, *et al.*, 2017), it also increased demand for ART when combined with facilitated linkage strategies (Indravudh, Choko and Corbett, 2018). These studies reported low rates of social harms that included coercion to test and disclose. The Kumwenda et al. (2019, p. 54) defines social harm as "any intended or unintended cause of physical, economic, emotional or psychological injury or hurt from one person to another, a person to themselves, or an institution or a person, occurring before, during or after testing for HIV."

A study conducted in rural and urban Blantyre about HIVST perceptions among FSW found that FSW perceived HIVST as a strategy to address issues of inconvenience and irregularity of testing, although mistrust of distributors and lack of support after HIV-positive results were identified as some of the barriers. However, an HIVST study conducted in 2017 in Malawi, FSW reported coercive self-testing by employers, facility owners and Peer Distributors (PDs) (Kumwenda *et al.*, 2019).

It was only in 2018 that Malawi approved the use of HIVST for nationwide implementation (Ministry of Health and Population (Malawi), 2018). It is stated in the Malawian guidelines that HIVST can be distributed using facility-based and community (both community-led and community-based) approaches.

There is, however, no mention of FSW in the guidelines. The guidelines describe two target groups for HIVST: men and young people in the general population and prisoners.

3.6.5 The national response to the HIV burden among FSW

In settings where sex work is criminalised, governments often fail to effectively design, plan and implement national-level targeted HIV prevention interventions. Chizimba and Malera (2011) argue that this is largely because the government has no clear picture of the magnitude of the FSW population, including understanding the settings, social networks and behaviours that could inform effective programming

There are currently no specific nationwide government interventions targeting FSW in Malawi. There was an initiative from the HIV unit in the Ministry of Health to foster programmes targeting FSW; however, logistical challenges are delaying the National Action Plan that has been developed (National AIDS Commission (Malawi), 2014). HIV prevention, care and treatment are implemented through services targeting the general population, and the assumption has been that FSW would patronise these services as well. This approach has faced many challenges because FSW were not free to access these services due to the attitudes of health professionals, stigma and discrimination (Global Network of Sex Work Projects, 2015b). As such, HIV prevalence among FSW has escalated. However, as an increasing number of health service providers have come to understand the importance of providing HIV prevention, treatment, care and support to all sectors of the population, regardless of cultural norms or moral stances, the quality of services provided to FSW has improved. There are now several clinics providing non-biased services in STI treatment that are well attended by FSW and have thus helped to reduce the spread of HIV (National AIDS Commission (Malawi), 2015).

Many interventions that target FSW in Malawi have been implemented by non-governmental organisations (NGOs). NGOs including Theatre for Change and Médicins Sans Frontières have implemented interventions with a focus on HIV prevention messages, HIV testing, periodic STI screening and treatment,

condom distribution, skills and capacity-building (National Statistical Office (Malawi), 2019). There is also an FSW-led organisation advocating for sex workers' rights and mainly working with these NGOs to ensure that FSW's needs and problems are addressed (Global Network of Sex Work Project, 2014). However, greater effort is required to support FSW through comprehensive prevention programmes and campaigns that challenge the high levels of stigma and discrimination facing these populations. Unless this group's needs are properly addressed, significant gaps in Malawi's HIV response will remain.

3.7 Summary

This chapter aimed to provide an overview of the Malawian context in which the study is conducted. I have highlighted how pervasive poverty is in Malawi and how gendered inequalities favour men in accessing resources. The key drivers of sex work in Malawi include the absence of family support through poverty, orphanhood, early marriages for girls which limit their opportunities for educational attainment and independent income generation. I have also discussed that the legal system in Malawi is not clear on the laws that govern sex work, as such, law enforcement institutions take advantage of this ambiguity to prosecute FSW.

I also discussed the landscape of HIV in Malawi. In Malawi, like in other settings, HIV prevalence among FSW is high. Mobility, unprotected sex, and structural inequalities account for the heightened HIV incidents. I have highlighted how the health care system in Malawi offers limited support to HIV interventions that target women. Whilst Malawi has adopted HIVST in its health policy, the FSW population has not been considered in this development.

4 Methods

4.1 Introduction

This chapter describes the research methodology and design employed in this study. First, I give an account of how I conceptualised the study. I then discuss the methodological framework that shaped the research. I then present descriptions of the methods and their use in the field. After that, I discuss data analysis procedures. I also reflect on my position in the production of the research. Finally, I discuss the ethical issues that arose while conducting this research and how I addressed them *in situ*. I have used pseudonyms to replace participants' names and changed the names of research sites to address issues of confidentiality.

4.2 Situating the study

I joined MLW in 2013 as a research scientist soon after finishing my MSc in Medical Anthropology. I worked on a study to explore the social impacts of introducing HIVST in the general population in Blantyre, Malawi (ST Impacts study). The results from this study showed that HIVST could offer opportunities for individual autonomy and control; however, in some cases, HIVST exacerbated pre-existing violence. The concept of empowerment (as individual autonomy and control) was appearing in the growing literature around HIVST in the general population. It was evident that there was an opportunity to do more research on HIV prevention technologies, and there followed a series of meetings with my supervisor to talk about my PhD plans.

Before embarking on the PhD, I was fortunate to work with the STAR project (refer to **Chapter 1**, section 1.2.3) field team in 2016. I led the work in both rural and urban settings with FSW in the STAR project. I joined the team in Chikhwawa and Mulanje to conduct a formative study using rapid ethnographic assessment. We explored the needs of HIV prevention among FSW and their perceptions around HIVST. STAR used the results of the formative study to inform a peer-delivery method for HIVST among FSW.

The association between MLW and Pakachere was vital because I later used the existing project structures and rapport that were established by the STAR project in the communities. As a starting point, I consulted MLW STAR staff to gain an understanding of the sites and people in the settings. I used contacts from Pakachere to gain access to the PDs.

The interaction that I had with FSW and the learning I gained about their lives was critical in improving my PhD proposal and helpful in solving ethical issues – for instance, recognising the levels of consent available tor FSW that were residing at the bars. My experience of using ethnography prepared me to address some of the challenges in my PhD in the field. I had my first experience of going into a local bar in Malawi where every woman was perceived as an FSW and had my first encounter of being asked for sexual services.

4.3 Study site

Because limited funds and time were allocated to this study, I decided to situate this study in Blantyre. I selected two geographical locations in Blantyre after consulting Pakachere and reviewing their final distribution report. I then selected two bars (one for each area) based on the highest and lowest HIVST uptake to diversify the representation of the FSW. In Mpiko the PD worked from Aldo bar (high uptake), and the PD in Namachero from Rado bar (low uptake).

4.4 Justification of study design and methods used

I based my research study on an ontology that implies that all social research is subjective, and the researcher cannot detach themselves from the research context (Ritchie *et al.*, 2013). Epistemologically, I used a synthesis of two philosophical positions to guide my work: interpretivist and critical research perspectives (Ritchie *et al.*, 2013).

Interpretivism assumes that knowledge is socially constructed – people's interaction determines subjective meanings with others and through historical

and cultural norms that operate in individuals' lives – while critical research goes beyond revealing the interpretation of people's understanding of their world (Hammersley, 2013). The assumption is that all thought is mediated by power relations that are historically and socially constructed (Silverman, 2013; Bernard, 2014). The goal of critical research is to critique and challenge to transform and empower (Merriam, 2009). This approach gives power to the research participants to take the lead and represent their worldview and issues that are important to them. One of the objectives of this research was to explore varied views and subjective interpretations of HIVST and to understand power relations and how FSW viewed their world and experiences. Therefore, a combination of interpretivism and critical research allowed for an in-depth understanding of the subjective interpretation of HIVST and the manifestation of different forms of power relations in the sex work context.

Qualitative research methods were well suited as an approach to the research, given this philosophical foundation. Qualitative researchers assume that knowledge is socially constructed and influenced by the environment or context one lives in, and there is no one truth, as the truth of the phenomenon is based on multiple realities (Flick and Creswell, 2009; Silverman, 2013; Fletcher, 2015). The focus of qualitative research is to understand how people interpret their experiences, how they construct their world views and what meaning they attribute to their lives. Qualitative research finds its strength in providing opportunities for discovery, insights and an in-depth understanding of individuals' experiences of the world from the perspectives of the study participants (Flick and Creswell, 2009; Bryman, 2012).

This study aims to understand the vulnerability and empowerment of FSW in the context of HIVST in Blantyre, Malawi. I, therefore, framed this methodology to understand the meanings FSW had constructed around HIVST, how they make sense of this reality and the experiences they had had with HIVST as contextualised in the political, social and economic structures of sex work. Another strength of qualitative research is that research is carried out in ways that are sensitive to the nature of the topic and setting (Bryman,

2012); hence, qualitative research methods were the most appropriate with which to address the sensitivity of the research subject (HIV) and participants (FSW). Application of qualitative research within a critical and interpretive epistemology with groups such as FSW offers a platform for seeing the world from the perspectives of people marginalised in society as a means of giving voice to their point of view. The power that comes out of qualitative research, therefore, is a deepened understanding of the nature of a particular setting: what it means for participants to be in that setting, what their lives are like, what is going on for them and what their meanings are; this is the ‘emic’ understanding (the insider's perspective) versus the ‘etic’ (the outsider's view) (DeWalt and DeWalt, 2002).

4.4.1 Ethnography

Ethnography falls under qualitative research and within the interpretative paradigm. Definitions of ethnography vary. Spradley (1980) notes that it is the elicitation of cultural knowledge. Ethnography, according to Emerson (1995), is a study of groups and people as they go about their everyday life. Hammersley and Atkinson (2000) view ethnography as a broad field of study that drawing from various methods of collecting data or using any source of information to understand a phenomenon. What is common in the definitions is the immersion in other people’s worlds to understand their experiences. It was the ‘immersion’ element that drew me to ethnography since it allowed me to experience for myself and clarify both the routines and conditions under which FSW conduct their lives and the constraints and pressures of living in this setting. I needed to adopt this approach in the light of my position as an outsider attempting to further my understanding of sex work.

Through this experience, I was able to obtain first-hand information and an ‘up-close’ perspective on how meanings emerge through talk and collective action, and how understandings and interpretations change over time. Through ethnography, the researcher enters a social setting and gets to know the people involved in it, participating in the daily routines of the setting, forming ongoing relations with the people in it and observing all the while what

is going on (DeWalt and DeWalt, 2002). It is this process of letting actions, or behaviours, unfold in the natural setting that gives the researcher access to the fluidity of others' lives and enhances their sensitivity to interaction and process. Therefore, my task was to reveal the multiple truths constructed by the FSW's actions and interpretations of these actions.

Ethnographers assume that the individual learns, draws meaning and interprets meaning through social interaction, and can give an accurate account of their experiences in the interactive environment (Flick and Creswell, 2009). This approach facilitated the investigation of meaning that FSW attach to the vulnerabilities or opportunities that arise for them through access to HIVST technology. Ethnography allowed me to establish a rich source of data for assessing the meanings FSW connect to their experiences of life and the way they devise strategies for dealing with life challenges (DeWalt and DeWalt, 2002). In addition, ethnography allowed me to explore theoretical perspectives for understanding sex work (as discussed in Chapter 2) and FSW's needs, aspirations, expectations and motivations for using this technology and the choices they make, which may be shaped by social networks or peer groups and have the potential to support positive transformations in their lives. This research links with the work that I undertook in the STAR project, but because of the peri-urban setting, ethnography in this study provided a different dimension. The advantage of employing ethnography, therefore, is the focus on providing rich insights into people's lives and actions as well as the nature of the context the social actors inhabit (Atkinson and Hammersley, 1994).

4.4.2 Participatory research methods

The development of participatory methods has drawn on several sources and theoretical standpoints within a political framing that has increasingly opposed traditional power structures in research, particularly when situated within the critical research paradigm (Mason, 2015). Mason (2015) defines participatory research as a systematic, critical and reflective inquiry covering a wide variety of approaches grounded in people's shared experiences, struggles and local

knowledge, intending to improve their situations and having a commitment to social justice. In this thesis, I draw on the principles of participatory research approach as described by Lewin, Freire and gender theories.

The origins of participatory research can be traced to the movements that have shared a common vision of a society without domination (Maguire, 1987). Lewin (1946, cited in Maguire,1987) believes that people would be more motivated in their work if they were involved in the decision-making process of the issue at hand. His work focuses on addressing problems of segregation and discrimination to bring change, while Freire is critical of the dominance and power inherent in traditional education and believes that critical reflection is crucial for individual and social change (Maguire, 1987). He emphasises the development of critical consciousness through individual knowledge of political, economic and social contradictions, and the need to take action to change the oppressive elements of reality. The research approach also emerged from the desire of groups of researchers, such as feminists, to analyse power differences based on gender, and supported collaboration between researchers and participants (Maguire, 1987). Therefore, the research approach was developed as an alternative way to foster research that would treat local social actors as active rather than passive participants and give a voice to the most socially marginalised populations (Cornwall and Jewkes, 1995).

Central to this approach is the empowerment of marginalised populations to partner with researchers in social change, which encourages capacity-building and self-critical awareness by both the researchers and the participants (McTaggart, 1997). The overall goal of this approach is to bring about transformation and social change within local communities. In this approach, individuals are experts in their own lives, capable of reflexivity and self-change, and researchers are positioned as enablers and learners within a particular political and social context (Kindon, Pain and Kesby, 2007; Mason, 2015). In this way, it is possible to gain valid insights into subjective realms through direct and active negotiation, engagement and interaction with the

people concerned, while allowing the researcher to continuously reflect on the research process and communicate with the participants.

The term ‘participation’ evokes different meanings of shared common goals, a sense of togetherness and mutual understanding (Kindon, Pain, and Kesby, 2007). Arnstein (1969) defines participation as the distribution of power that enables socially marginalised populations, previously excluded from economic and political processes, to be deliberately included in the future. Arnstein, (1969, p. 216) argues that “participation without redistribution of power is an empty and frustrating process for the powerless” and it “maintains the status quo”. Arnstein (1969) introduced a ladder of citizen participation to measure the interaction between participation and power in order to illustrate the different extents of citizens’ power. According to this typology, citizens’ power ranges from non-participation (educating the marginalised) to tokenism (the marginalised hear and are heard by the powerful but lack the power to ensure that their lives will indeed change) to citizen power, where power is delegated to citizens and they act in partnership with previous power holders. In this case, therefore, full participation means a process in which the participants enter into partnerships with researchers to set the agenda with a particular aim in mind regarding social change and to ensure that this change is achieved.

In relation to the ‘ladder of citizen participation’, my study lands between placation (a higher-level tokenism) and partnership (Arnstein, 1969), as I retained the power of setting the aims and objectives of the study and representation of the findings in this thesis and publications. I did, however, conduct planning and decision-making processes collaboratively with the participants during data collection. This approach fitted well with this study, conducted by an outsider: the approach of giving power to the FSW, the insiders and the experts in their lives, to become active research participants and direct some aspects of data collection activities. Given my status as an outsider, I was reluctant to solely use techniques that were question-based and extractive and reinforced power differences. The aim of including participatory research methods was to provide a platform where FSW could

decide which story about themselves and their communities they wanted to tell, and how they wanted to be presented. Participation plays a significant role in sharing power and expertise and building the trust and confidence that enables the researcher to be accepted in the communities (Cooke and Kothari, 2001).

In the sections below, I discuss the various roles that the research assistant and I played in the study and how we supported each other during fieldwork.

4.5 Description of the research process

The sections below describe the fieldwork process: the roles of the researchers, entering the field and collecting data.

4.5.1 Researchers' roles and setting researchers' boundaries

Bowling (2002) argues that researchers conducting ethnography should have the ability to carry out their work in ways that are sensitive to the nature of the setting. The researcher should adopt an attitude of respect and appreciation for the social world. Drawing on these views, I had to consider our behaviours in the field and set some boundaries for conducting fieldwork. The sensitive nature of the study required consideration of the ethics of researching sex work communities. Given this, I had to carefully consider the gender of the research assistant, the researchers' roles and the logistics around the field sites, and to set boundaries for researchers during fieldwork.

During data collection, I was aware that gender would raise critical ethical issues, which posed the risk of excluding participants if not addressed continually throughout the process. During the STAR study, I was aware that some men and women were prejudiced against FSW. For women, there were concerns that they would be regarded as FSW, while men were concerned about being perceived as potential customers. For men, this attitude was reflected in their discussions with participants and led to some disagreements during data collection. I was made aware of this when one participant in the STAR study reported that she would not have been interviewed if it had been

with one of the researchers she had met the previous night. After reflecting on this issue, I had a discussion with my supervisors to address it, and we agreed to recruit a female research assistant for this project to minimise the potential for putting the FSW in an awkward position.

After recruiting a research assistant, we planned to set some boundaries for fieldwork. We evaluated our social behaviours and defined what we could or could not do. I was aware that in some instances the FSW would not behave as they on a normal basis because we were outsiders, but we hoped to be treated as insiders to some degree (gaining their trust and acceptance). We had to set boundaries on our clothing, make-up and behaviour when visiting the venues. We agreed that we could have a couple of alcoholic drinks, wear little/no make-up, and wear T-shirts and trousers, and we would avoid dancing (as this was the main activity by which FSW attracted customers) or solicit customers, but we could help the FSW do their chores or bar errands. Adapting to the sex work environment in this way enabled us to build rapport and trust with the participants.

I will now present the roles of the researchers in detail.

Barbra Chalulu

Barbra was 38 years old when she joined this study. She was a single mother of two children. Barbra had a certificate in Motor Vehicle Mechanics and an extensive research background working with the University of Malawi's College of Medicine doing qualitative fieldwork. At the time of her appointment, she had just completed her work with an MPhil student at University of Malawi's College of Medicine where she was facilitating focus group discussions (FGDs) and conducting structured observations and semi-structured interviews.

Barbra was very excited about this study even though she did not have a background working with FSW. She was more than willing to work with FSW and to be flexible with time, considering that data collection was sometimes to be carried out at night and over the weekend. Her primary role in the study

was to provide support on data collection activities, which included obtaining consent, taking notes during interviews, co-facilitating the group discussions and building rapport with the women. She was also responsible for conducting her participant observations and reflecting on the fieldwork days. Later, she led transcription of the audios supported by the transcription and translation team at MLW. She became instrumental in the initial analysis of this study by identifying different narratives that emerged during our field visits.

My role

I was 30 years old when I started my PhD, black, single, childless and living independently as a Malawian woman. I am very fluent in English (official language), Chichewa (national language) and Chitumbuka (mother tongue). Language is crucial in qualitative research, as it is the backbone of collecting and analysing data (Welch and Patton, 1992; Polkinghorne, 2005). So I was at an advantage in that I knew two languages in Malawi, and most people speak Chichewa in the settings I was working in. Knowing these two languages put me in a better position to undertake the research because I was an insider. However, I was also an outsider among FSW as most women were underprivileged, lacked formal jobs and had little education, and some FSW were younger than me but with two or more children. My insider/outsider position sometimes influenced how FSW responded to me, as you will see later in this thesis.

At MLW, I contributed to the Behaviour and Health group, specifically fostering qualitative and mixed research methods in health research but also looking at GBV. I had received training on how to conduct interviews with and support survivors of GBV, and I shared this knowledge with Barbra. This training was significant in this research as it prepared me for work with FSW, who face violence on an everyday basis.

During fieldwork, I was responsible for initiating a meeting with and sourcing documents from Pakachere. I was responsible for introducing the study to the gatekeepers, venue owners and FSW. I negotiated the consent process with the participants. I did participant observations every day I went to the field, co-

facilitated the photovoice training, conducted all the in-depth interviews (IDIs) and co-facilitated the FGDs. After fieldwork, I was responsible for organising all the data and securely storing it. In addition, I wrote the interview summaries for supervisors to review. After each day of fieldwork, Barbra and I shared reflections on the day, and later I would refine any study tools if necessary or bring any issues to supervisors for further review and guidance. I also supported Barbra with any problems that emerged during her stay at MLW. I quality-checked all transcripts for inconsistencies, accuracy and grammar and gave feedback to Barbra. Qualitative data analysis begins at the start of the study and is conducted at the same time as the data collection (Silverman and Marvasti, 2008). As part of my analysis, I produced preliminary results of the participant observations, the interviews and the photovoice process and shared them with the supervisors for review. After that, I was responsible for conducting the analysis: I coded the data, analysed it and produced the results.

4.5.2 Data collection

In this section, I describe how I collected the data using various data collection methods, detailing the researchers' relationships with the participants and the gatekeepers.

Table 2: Summary of data collection tools and target population

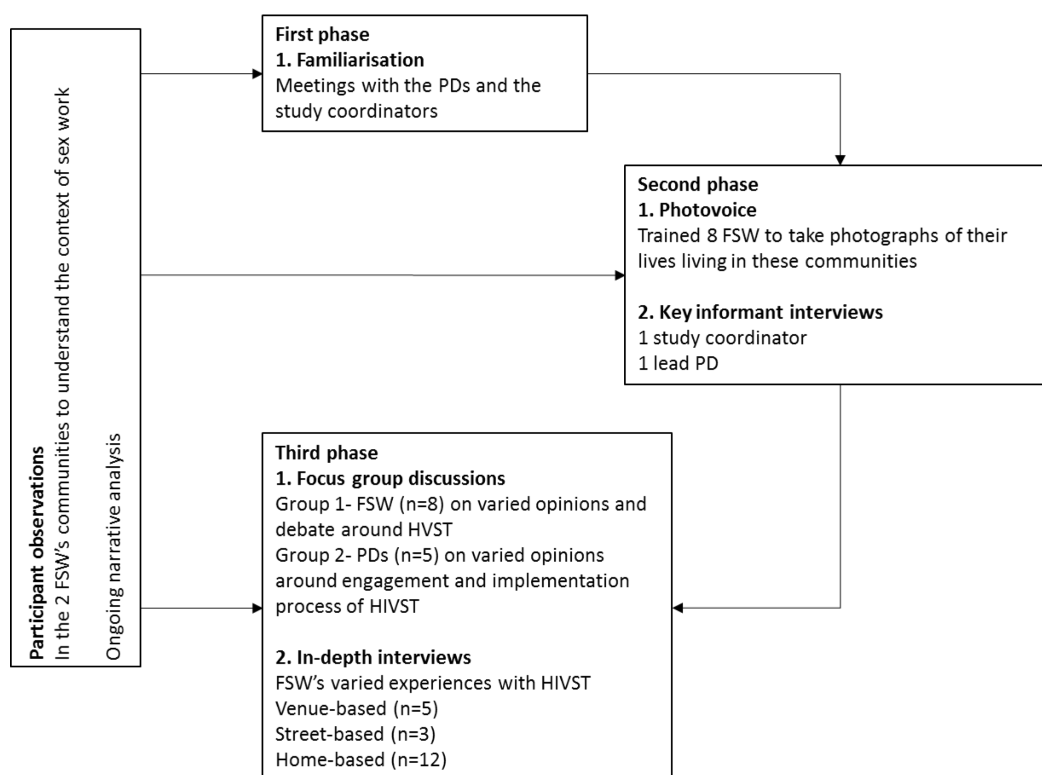
Data collection tool	Target population
Participant observation	FSW (home-, street- and venue-based), FSW social network (sex work customers, men in the bars and venue owners), and community where FSW lived.
Photovoice	FSW (home-, street- and venue-based)
In-depth interviews	FSW (home-, street- and venue-based)
Key informant interviews	Pakachere staff- Lead peer distributor and STAR project coordinator
Focus group discussion	Peer distributors and FSW (home-, street- and venue-based)

Phases of data collection

I initially planned to start fieldwork in the period October 2017–September 2018, but this was not possible due to the 'bloodsucker' issue in Malawi, which led to the suspension of all fieldwork activities at MLW. People were getting killed by vigilantes in many communities on suspicion of sucking other people's blood. However, I collected data for ten months (between December 2017 and September 2018).

I divided the data collection period into three phases, except participant observations, which were conducted in all the three phases (see Figure 6). In the first phase, I conducted participant observations and held meetings with the respective study coordinators and PDs as a process of introducing the study and familiarising myself with the research sites. In the second phase, I did more participant observations and included the photovoice method and key informant interviews with the study coordinator and the lead PD, which facilitated our learning about the experiences, behaviours and meanings of empowerment and vulnerability of FSW regarding HIVST at a relational and contextual level. I further conducted participant observations, FGDs and IDIs with participants during the third phase to learn more about the group- and individual-level experiences and narratives. I employed an iterative process: preliminary findings from one phase indicated themes to be explored in more depth and sampling guidelines in subsequent phases.

Figure 5: Data collection processes from December 2017–September 2018



The sections below will discuss the methodology in detail.

4.5.2.1 Participant observations

The foundation of the participant observation technique is the belief that it provides an opportunity to move beyond a single truth about a phenomenon (Spradley, 1980; Emerson, 1995; DeWalt and DeWalt, 2002). Data obtained can serve as a check on participants' subjective reporting of what they believe and do (Malmi, 2011). Participant observation is also useful for gaining an understanding of the structural context in which study participants live; the relationships among and between people, ideas, norms and events; and people's behaviours and activities (Spradley, 1980). The researcher who is engaged in participant observation tries to learn what life is like for an insider and make sense of people's lives and decisions while remaining an outsider (Atkinson and Hammersley, 1994; Hammersley and Atkinson, 2000). In addition, the quality of research depends on the quality of the researcher's relationship with the participants. Participant observation is important for this

development as the researcher builds rapport through a prolonged process of creating, engaging in and managing relationships with the participants (Kawulich, 2005). Observing and participating are integral to understanding the breadth and complexities of the human experience, and they give insights to the research study that were unforeseen (Weigl *et al.*, 2009). What I learnt from participant observation helped me to understand the methods but also to design questions for other data collection techniques to deepen understanding of the research problem further.

Gold (1958) describes four different types of participant observer roles:

(1) *the complete participant* – takes an insider role, is entirely part of the setting and often observes covertly

(2) *the participant as an observer* – the researcher gains access to an environment by having a non-research reason for being part of the setting

(3) *the observer as a participant* – the researcher or observer has only minimal involvement in the social environment; there is some connection to the context, but the observer is not naturally and typically part of the social context

(4) *the complete observer* – the researcher does not take part in the social setting at all.

From this typology, my role in this study was that of the observer as participant. I was not living in Mpiko or Namachero and had minimal involvement in the social environment, for example, by cutting *Chibuku* (opaque sorghum beer) cartons for customers. The beer is packed in cartons, and the carton (Tetra Pak) is cut using a knife before serving the customer.

Scarduzio, Giannini and Geist-Martin (2011) recommend that the researcher should be discreet (covert) enough about who they are and what they are doing to avoid disrupting regular activity, yet open (overt) enough for the people they observe and interact with not to feel that the researcher's presence compromises their privacy. In many situations, there was no reason to

announce my arrival at the scene (in the bar); in many others, however, it was essential that I openly stated my identity and purpose during conversations with certain people. These were individuals who specifically questioned my presence in the bars as an outsider (not looking like an FSW but someone who had a role not attached to the bar's activities). For example, I always provided the truthful response that I was a researcher interested in the experiences of women working in the bars, but I was also mindful that I should not leave my participants vulnerable by failing to disclose the project's focus on HIVST as this was a sensitive topic.

The first two months of ethnographic fieldwork mainly comprised the development of positive relationships with key informants and gatekeepers to get approvals and support during fieldwork (Morreira, 2015). These relationships were essential to the logistics of setting up the research and identifying potential study participants and how best to recruit them and gain access to them. I also conducted informal interviews (conversations) to build rapport with FSW, venue owners and customers, to broaden my understanding of the context (Bowling, 2002) and seek clarity on observed behaviours or situations from the perspectives of those involved.

Accessing the participants

In the section below, I discuss how I negotiated and maintained access to the participants in the study. In this case, access means seeking entry to an environment for primary research to generate data. Sanders (2006) uses the phrase 'layers of access' to describe the level of complexity involved in gaining access and acceptance into the sex work industry. In addition, these levels of access can influence who can/cannot participate in the research study. I had to seek approvals from several individuals to get to the potential participants because of the nature of the study, the way the study was situated, and the sites in which I was interested in conducting this research study.

The gatekeepers

Access to the field and research participants is often enabled by 'gatekeepers' in social research. A gatekeeper refers to an individual or an organisation who acts as an intermediary between researchers and participants and who has the power to withhold or grant access to participants for the study (O'Reilly, 2012). The role and influence of the gatekeeper in social research have been the subject of some debate and remains a challenge for many researchers (Singh and Wassenaar, 2016). On the one hand, a gatekeeper can ease access to study participants and save researchers' time and resources. On the other hand, gatekeeping can influence research proceedings by limiting access to participants (Sanders, 2006). In this study, the gatekeepers were as follows:

(1) *Pakachere staff*: HIVST intervention implementers in the study sites; they could assist with getting access to the PDs and intervention reports
(2) *PDs*: had a close connection to the group of FSW and the site were highly involved in the HIVST intervention and could support the identification of FSW who had participated in the intervention
(3) *Venue owners/managers*: could access FSW and those who had participated in the HIVST intervention.

Gaining access from gatekeepers does not guarantee cooperation, either from the gatekeepers themselves or prospective participants (Morreira, 2015). For example, in this study, all gatekeepers told me, when I met with them, that "*mahule ndiovuta*" ("prostitutes are a problem"). What gatekeepers meant by this statement is that FSW need money for their participation in any research study. The Pakachere director asked me if I had prepared reimbursements. I explained to all parties involved that I had prepared some monetary reimbursements for research participants. I explained further that these were not payments; rather, they were reimbursements for the time spent on the study.

During introductions, I explained to all the gatekeepers that I was a student researching with '*azimayi oyenda yenda*' ('highly mobile women'; this signifies their high mobility either from one location to another or from one sexual partner to another) to understand their engagement with HIVST. The term '*azimayi oyenda yenda*' was preferred to '*hule*' or '*mahule*' ('prostitute' or 'prostitutes') among FSW as this name was more dignifying than '*hule*'. I gave them information about why I had selected the site, what I would be doing during the data collection period, how much time I would be spending at the venues, what steps would be taken to maintain the status quo of the study setting, and how I proposed to present the results and benefits to the research participants (Creswell, 2009). I carried out these steps in every data collection component. The researchers showed respect to each other and the participants, and this helped to maintain good relationships.

I now introduce the gatekeepers, their role and my relationship with them during the study.

The PDs

I identified two PDs working in the research site. I will now explain their engagement with the study in detail.

Namurayi

Namurayi introduced herself as a PD for the Manto club in Blantyre central business district and in Mpiko. She was a street-based FSW, and a single parent of three children: two boys and a girl. Namurayi had been an FSW for most of her life, operating in the city centre on the high streets. She called herself a '*nkhala kale*' ('veteran') on the streets. Namurayi had completed standard 8 (the highest level of primary school) and was able to read and write.

Namurayi was very instrumental to this study as a street-based FSW. I spent the whole period of data collection working with Namurayi, learning a lot from her experience as an FSW on the streets, as a mother and an individual. Her primary role in the study was to refer me to other FSW who had participated in

the HIVST intervention. She was readily available on her phone or at home whenever I needed her. She knew many people in the area; most were her old peers and had started sex work around the same time. She identified most sex work venues in Mpiko, identified participants in each study component, and brought and introduced me to the participants. Her presence in the study was significant; she often gave me information about a potential participant beforehand, and I used this information carefully (not disclosing full details) as a way of probing for more detail about an issue. For instance, there was an older FSW who was one of the traditional chiefs in Mpiko. Her family and community were not aware of her engagement in sex work. Namurayi stressed the importance of maintaining this woman's confidentiality in the research. In order to address her concerns and maintain confidentiality, we conducted her interview at Namurayi's house instead of her own. At the time of data collection, Namurayi was still working with Pakachere on a different project. Her role in this study was a true reflection of her dedication and commitment to FSW's work in the community.

Miranda

Miranda was a PD in Mpiko. Miranda had two children, a boy and a girl. She moved around, taking the children with her wherever she went for sex work. Miranda was not living at the bar at the time of data collection because of her children, although the venue owner preferred all the girls to reside at the bar.

A few weeks after we introduced the study to her, the venue owner dismissed Miranda and a few other FSW because of their involvement with stable partners. The next time I called Miranda on the phone, I learnt that she had relocated to Twini bar in Namachero, working as a "*proper bar girl*" (sitting behind the counter and selling drinks to customers). Although new in Namachero, Miranda became very influential in the study, more than the original PD in Namachero, whom I did not meet during the period of recruitment not until the last FGD. Miranda's primary role in this study was to support the identification of potential participants. She was relatively new in Mpiko and had limited knowledge of the surroundings and home-based FSW, so her cohort was mainly venue-based FSW.

The venue owners

The role of the venue owners in this study was to give consent for us to conduct participant observations at the venue as well as access the FSW. In this case, the venue owners were either the owners of the bars or the people managing the bars. As data collection was an ongoing process, I obtained written consent from the owners of the bars and subsequent verbal consent to meet the FSW from whoever was available, whether the owner or the manager. The FSW worked at the bars in the daytime and night, so I intended to avoid any inconveniences that might have arisen for the women or the venue owners due to my presence at the venue.

At the bars, I introduced myself as a student working with both MLW and Pakachere who was interested in understanding the lives of FSW. In this introduction, I was an outsider (not involved in sex work) but also gave enough context to be treated as an insider because of my link with two organisations that were already known to the venue owners. Mainly, the venue owners were interested in learning more about the research activities at the venue, the timing of visits and the duration of the study. Otherwise, none of the venue owners presented any issues concerning the study.

I will now explain how I met the FSW and introduced the study to them.

Meeting the FSW

After receiving permission from the venue owners, I began visiting the bars to get familiar with the environment and build rapport with the FSW. I conducted participant observation in places where FSW spent their time, lived, solicited their clients and carried out their daily activities to understand their lives (see appendix 2A for participant observation details). I would visit the bars at any time of the day and on any day of the week, but at night it was usually around 7–9 pm because of security issues. I spent at least two to three days a week at each venue.

I capitalised on the groups set up at the venues to introduce the study to FSW. It was during these introductory sessions that I established how responsive FSW

were to activities that targeted them at their venues. For example, at Rado bar, the venue owner called the FSW to come and meet us. This responsiveness could be attributed to the relationship that the FSW had with the venue owners: they had to do whatever the owners asked them to.

I introduced myself as a student but also as working with MLW and Pakachere, and said that I was following up the FSW who had participated in the intervention to find out how they were doing and whether the intervention had had an impact in their lives. I also told them that I would be visiting them now and again to understand their lives as FSW. During the introduction, I made sure to stress the connection of my visit to HIVST intervention: '*zoyezera mkamwa HIV*' ('oral HIVST kit'). It was through this introduction that I discovered that there were only a few FSW who knew about HIVST; the rest had relocated to other venues post intervention.

During these introductions, I was asked some questions about how participant observation works. I explained to the FSW that I was there to learn from them about their way of life at the bar: they could do their regular chores or bar work, and we could help them. They were all surprised that I wanted to do this at the bar as a 'normal woman' – "*Ndiye muzibwera kubala kuno mtsikana wa bwino bwinowe?*" ("So you as a normal girl will be coming to the bar?") – and they all laughed. I did indeed feel like an outsider at this moment – this was not my first visit to a bar as a Malawian woman, but I was new to this type of bar, and that is when the reality hit me that I was probably very naïve about people's perceptions of women visiting bars in Malawi. However, they all seemed excited to have us around.

After these introductions, during the first few days of my visits to the bars as an outsider, I was quite nervous and anxious because I did not know what to expect – what people in the community would think of me, or how the men in the bars would respond to my presence. The women in the bars helped me to settle into their environment. I usually asked the women if I could accompany them as they were going for their night shifts because I was aiming to normalise my presence and address my anxieties. They even helped me to plan focused

observations as they knew the best time to observe certain behaviours. The women said that I would see changes in their behaviours at night; after a few drinks, they would dance and solicit men by winding their bodies against potential customers. The bars were usually busy at night from 8 pm as men were coming back from their jobs or businesses, and at the end of the month, as most of the men had their wages paid at that point. Given this, they told me to come around this time to get a feel for the local bars.

During the day, I would visit FSW to clarify things that had been observed the previous night because the bars were not busy during this time, and few men visited the bar during the daytime. Afternoons were the best time because most FSW rested in the morning because they had been working all night. During their free time, most FSW would do their laundry, cook meals on the veranda or sleep. I would chat with the FSW who were on a break and relaxing or help them with their chores.

I decided to conduct participant observation with Barbra for safety and methodological reasons during fieldwork, especially at night (Worley, Worley and Wood, 2016). Methodologically, conducting participant observations with Barbra allowed me to make comparisons of the fieldnotes, share experiences and discuss issues to observe further in subsequent sessions. We both went to the same places but would disperse in the room to spend time with different groups, doing focused observations to address particular questions. For instance, we would agree to observe and chat with men in the bars to understand how they interacted with the FSW. We would reconvene the next morning to compare fieldnotes, discuss commonalities and differences in our notes, and create a map of where to go next, at different times.

I gained acceptance and cooperation from the FSW as the fieldwork progressed. My presence at the bar started to mean something to them, and they started showing very loving and welcoming gestures, such as hugging me as a welcome or goodbye. At one point when Barbra and I visited Rado bar, we were invited straight into the bar by two FSW: "*Lero mumwe lero*" ("You should drink today"). We went into the bar, and they hugged us and grabbed us by our

hands, leading us to the bar counter, "*Mumwa chani?*" ("What are you drinking?") asked one of them. I could tell from her speech that she had had a few bottles of beer. Barbra chose *Chibuku*, and I chose Fanta. Of course, this meant that '*sindinamwe*' (I did not drink) because drinking meant consuming something alcoholic. I asked her if I could pay for the drinks, but she insisted that it was our treat from her. I wanted to find out if this is something that they do for their peers as well. I found out that it was not often the case, but they sometimes celebrated by drinking and buying their closest friends drinks after making a bit of extra money. Sometimes they would even buy drinks for their stable partners if the men did not have money.

It was a different experience with FSW who were home-based because of the nature of the setting. It was not easy to progress from being an outsider to being an insider as they were still treating me like a visitor in their homes. I made frequent visits to three sisters who lived in one house in Mpiko. Two of the sisters were divorced, each with one child, and one was single, having never married or had any children. They accepted me as a researcher and gave me an opportunity to collect data, but it was not easy to observe behaviour in the natural environment. We always sat inside the house even when I proposed that we could do something else. They would tell me that "*Kunjaku kulidzuwa, ndinu alendo mukhale m'nyumbamu*" ("It is too sunny, you are a visitor, you should sit in the house"). Inviting me into the house was their way of taking care of me as a visitor in their home. However, I did learn a lot from their stories about events on the streets or in the bars, from going to 'the field', and most of from all the relationships between the sisters, how they interacted with each other, and the support they gave to the children when one was in 'the field'.

One FSW in Mpiko who identified to us as Hailey allowed me to observe behaviour outside the home environment. We would walk together to the market or visit her friends in the community. Men, especially those selling charcoal at the market, said hello to us every time we passed by. Some would even stop Hailey to chat, and most men knew her by her real name, which signified their familiarity with her. She told me that Hailey was her daughter's

name, not hers, and she introduced herself to her regular customers by her real name.

Meeting the men in the bars

In the bars, I also observed what bar customers were doing, how they interacted with each other and the FSW, and their response to our presence in the bar. I discovered that some of the men in the bars had a clinical background, so they were quite familiar with MLW and the establishment of research structures in Blantyre. Others were business people selling various items at the local markets. During the first few days, many men seemed to notice that we were new at the bar and they were intrigued.

During the initial stages of participant observation, most men in the bars talked to Barbra and me as FSW. Some men told me that they liked me, but they could not afford me because of my appearance. This was very enlightening and reassuring that we had managed to attain the level of an insider (suspected FSW). As the study progressed, I got to know most of them, and they also became familiar with the purpose of my research at the venues. I discovered that the conversation with the men in the bars changed because of this. There was one man, a nurse at the local health centre, who told me that I was doing commendable work because "*these women are dangerous, they carry many diseases, and they are powerless*". This statement reflected the public discourse about sex work in this setting. They started asking me questions about HIV prevention. For instance, the men in the bars were concerned about why FSW were recipients of male condoms and not the men who wear them. They perceived this as unfair: the men did not get free condoms, and they had to buy them if they wanted to protect themselves from HIV.

Note-taking during participant observation

During participant observation, Barbra and I each had a field diary where we wrote notes about our observations and the informal interviews that we held in the communities (Emerson, 1995). I decided to make the process of writing notes covert to avoid making the people in the bars feel uncomfortable.

However, we realised that we could not write notes in the diary at night due to the nature of the settings: it was too dark, and there were people everywhere. We resorted to writing notes on our phones. Most people in the communities used mobile phones as a mode of communication. Therefore, we took advantage of the acceptability of appearing to text. In this case, nobody noticed that we were taking notes because it seemed as if we were texting.

We discovered that this could also work with daytime visits. The phone was better than a hard-copy notebook because I could easily synchronise my notes to my computer and type them in detail later. They were easily managed, kept in real time, tidy and securely saved on a password-locked phone. We made sure that we had full batteries on the phones before going into the field. Another option was to write the notes after bar visits, but we failed to keep up with what was going on in the bar and remember the details later. The notes were used to understand and interpret the conversations and observed FSW behaviours.

The sections below will discuss the data collection techniques that were conducted during and after participant observation. Conducting participant observation at these two sites facilitated the identification of potential study participants in the subsequent study components (Crang and Cook, 2007; Reeves, 2010). I was able to identify who had participated in the HIVST intervention and who had not. I purposively sampled FSW for the photovoice process, IDIs and FGDs.

4.5.2.2 Photovoice

Photovoice is a participatory research method that capitalises on photography as a research tool by asking participants to express their points of view through photographing experiences or contexts that have meaning to them (Wang, 1999). Photovoice is a “method by which people can identify, represent and enhance their communities” (Wang and Burris, 1994, p. 369) and draws on three theories: critical education, feminist theories and community photography. In Freire’s approach to education for critical

consciousness, visual tools are one tool enabling people to think critically about their community. Drawing from feminist theory, Maguire (1987) argues that power accrues to those who have a voice, set the language, make history and participate in decision-making. Photographs bring new ideas, conversations and voices into the public forum. Lastly, according to community photography theory, photography is a way of thinking about how ordinary people can appropriate cameras for social change (Maguire, 1987). Images provide immediate feedback for discussion, are aids for storytelling and reading, and make it possible to look at the world differently.

In this study, I chose photovoice because of the participants' ability to reframe things that are often taken for granted through the process of conscientisation, and their ability to enact insiders' perspectives and representations through the artistic medium of photography (Garvin *et al.*, 2008). Photovoice was well suited to establishing how FSW make sense of their sex work environment and HIV (Musoke *et al.*, 2015). Photovoice is intended to highlight participants' visual voices and their subjective experiences, and their critical awareness of their environment, identifying resources for social and political action. As the participatory aspect of the technique focuses on critical action, photovoice provided an opportunity for participants to direct part of the research (Wang, 1999). The key elements of photovoice include identification of participants, training of participants as co-researchers and photographers, selection of illustrative images, captioning of photographs, critical dialogue of the emerging themes, and dissemination.

The photovoice workshop was facilitated by Barbra and me and also by Rodrick Sambakunsi from MLW, who led the session on basic photography.

Recruitment of photovoice participants

The parameters for recruitment into the photovoice component were sex work typology and involvement/no involvement in a stable relationship. I believed that this would provide broader and diverse perspectives on the needs and aspirations of FSW. During my visits to the two bars, I introduced the photovoice

component to potential participants present at the venues that participated in the HIVST intervention. I also introduced the method to Namurayi and Miranda and asked them to identify FSW who had been involved in the HIVST intervention. During that initial meeting, I told the prospective participants what photovoice was, the length of the data collection and the role of the participants, and I explained the presence of their peers and the facilitators and my position during the activities. We identified nine potential participants, but I managed to recruit eight as one was not comfortable coming for the training. She had just arrived at the venue, and I had not developed a rapport with her. The recruited participants represented the initial sampling plan.

Training the photovoice participants

I invited the participants to a training workshop to learn about the photovoice method. This was a one-day workshop, and I planned to have sessions around the concept of power, ethics, basic photography and conducting photovoice in the field. On the day of the workshop, eight participants were present. We conducted the training in a private place outside the community, and we provided the participants with transport to and from the location.

After obtaining consent from the FSW, we conducted some exercises on basic photography and on using photographs to illuminate different themes. Also, during the workshop, I emphasised the ethics of taking photographs in the field (Wang and Redwood-Jones, 2001). Together with the participants, we established an understanding of the risks, the boundaries for taking photographs, confidentiality and safety when using the camera and sharing information based on the nature of the respective field settings.

Each participant received a camera and a journal to take home after the workshop. The journal was for writing down thoughts whenever desired, but it was not a requirement. I asked the participants to take photographs for five days in the following four areas:

1. A day in my life – I asked the participants to take photographs representing their typical day as an FSW

2. Dreams and realities – FSW's aspirations and needs in life
3. Abstract treasure hunt – FSW were asked to take pictures that represented their ideas about disappointment, perfection, happiness, absence, politics, danger and comfort
4. Ups and downs – things/people that make FSW happy or sad.

I encouraged the participants to take more than 50 photographs each to gain a wide variety of photos to explore the topics mentioned above.

Photovoice exercise week

During the photography exercise week, Barbra and I visited the participants at their venues or homes after arranging the time and place to provide support and discuss the photos they took. Each participant met individually with either Barbra or me to reflect on their photographs and/or journal entries. We guided the reflection about each photo using an adapted SHOWeD technique (see appendix 2C) (Wang, 1999). This method includes five questions that are asked to elicit thoughts from participants for discussion (Wheeler and Early, 2018):

1. What do you **s**ee here?
2. What is **h**appening here?
3. How does this relate to **o**ur lives?
4. **W**hy does this situation exist?
5. What can we **d**o about it?

We also asked the participants to share additional thoughts and feelings about their photographs.

During the follow-up visits, I found that participants at the Rado bar had difficulty operating the digital camera, so they formed a group to support each other to take photographs. Despite working in a group, each participant had an opportunity to choose which of her photographs to present to the group, and we conducted the photo elicitation exercise with each participant. By contrast, two participants at Alba bar competed to see who came up with

better photos, and each decided not to show their peer the photos taken because she feared that her friend would end up copying them.

Critical dialogue

At the end of the five days, I asked each participant to select photographs to discuss in group discussion. I printed the chosen photographs from each participant for the group discussions. I verbally obtained consent from the participants. I opened the session and asked participants to share their reflections on conducting data collection, to discuss what they found challenging or exciting. The participants used the SHOWeD technique to introduce many of their photographs. After that, each participant introduced her photograph, and other members of the group were encouraged to discuss the photographs. I also facilitated the discussions with prompts and probes to promote debate around each issue. Then, participants grouped the photographs into categories, and then themes developed. Some of the themes are highlighted in chapters 5–7.

In the following section, I discuss the interview component of the study.

4.5.2.3 Interviews

Interviews in qualitative research are essential in pursuing specific issues of concern that may lead to focused and constructive suggestions (Bernard, 2014). Interviews provide an opportunity for rich and detailed data. I conducted two sets of interviews from February to August. Interviews were useful to explore the lives of FSW to uncover issues that were not observable or could not be captured through the camera, but also to explore and make further sense of what I learnt during participant observation and the photovoice process. I used the IDIs in this study to interview implementers and FSW, and details for each set of interviews are below.

Key informant interviews

A key informant is an individual who has an instrumental role in the community and has access to information, ideas and insights required by the research (O'Reilly, 2012). The informants in this study were people from Pakachere who worked with FSW during the HIVST intervention. I purposefully selected participants who were well versed in study implementation and daily activities and had physical contact with FSW in the field. The key role of the key informants in this study was to provide information about the implementation process, facilitate access to gatekeepers (McKenna and Main, 2013) and help make connections between issues that were not obvious to me.

I conducted interviews with the Lead Peer Distributor (LPD) and the Project Coordinator. The LPD supervised the PDs during the distribution process and was always in the communities in proximity to the FSW and the PDs. The LPD's connection to the study population was invaluable because she had important links to the community: I would seek her advice whenever required, and she was able to clarify things when I could not make an objective judgement on experiences in the field. The Project Coordinator had a more managerial role in the intervention. He had been working with Pakachere since 2009 in various projects with young people and FSW.

After obtaining consent, and depending on the preferences of the interviewees, I conducted the interviews in English and some parts in Chichewa and audio-recorded them. The focus of these interviews was to explore FSW's engagement in the intervention and the approach to the implementation, including the peer-delivery model, mainly looking at organisational structure, the implementation of the intervention and the role of FSW in the intervention. Barbra took notes during the interviews (Creswell, 2007). Each interview lasted approximately one and a half hours.

Qualitative research that employs interview techniques is subject to social desirability bias (Bernard, 2014). I noticed that both interviewees were trying

to avoid embarrassment and often checked with me whether they had provided the desired response to a particular question. They would tell me to pause the recorder and ask if their responses were correct. Often, this related to questions about HIVST – they both knew that I had previously worked on the HIVST project, and they assumed that I was probably more knowledgeable on this topic than they were. In these scenarios, I reassured them that I was more interested in their experiences and that there were no right or wrong responses. In fact, the interviews were invaluable because I was in a better position to establish a comprehensive story about the implementation and decision-making around distribution and the challenges that the PDs and FSW faced (Reeves, 2010). I planned to use this information to situate responses from the FSW interviews to make a coherent and well-rounded story.

In-depth interviews (IDIs)

I conducted IDIs with FSW to understand their experiences and perceptions of their lives; how this influenced how they engaged with HIVST; what risk, vulnerability and empowerment meant to them; and how their engagement with the technologies and intervention processes impacted on these. IDIs were important in unravelling sensitive details about the FSW's experiences of vulnerability and opportunities for empowerment during the HIVST intervention (Dempsey *et al.*, 2016). Interviews were particularly helpful in allowing FSW to voice their feelings about their condition and to enable the researcher to obtain different views on experiences of this intervention (Bowling, 2002). I purposively sampled participants based on whether they were street- or venue-based, whether they used the HIVST tool after collection or not, and variation in other demographic characteristics and any interesting stories of merits and challenges of using the technology were also used to identify participants.

The interviews followed a life story approach, and Bryman (2012) describes a life story as an account someone gives of their life. This approach documents the experiences of individuals and how they interpret and define the world around them. Through FSW's life stories, I was able to determine significant

turning points in their lives (Bryman, 2012). I was particularly interested in FSW's assessments of their own lives – whether they saw improvement or deterioration since childhood, adolescence or young adulthood, and their self-evaluation of turning points, and their relationship to sex work – and in situating this in their participation in the HIVST intervention. To a large extent, the method stems from the growth of interest in the role and significance of agency in social life and allows typically marginalised people to make their positions visible (Bryman, 2012).

I conducted interviews with 20 FSW; each interview comprised two sessions to keep the interviews relatively short and allow more productive discussion (Bryman, 2012). The interviews lasted between one hour and one and a half hour. In the first part of the interview, I focused on exploring issues around FSW's background, adulthood and entry into sex work. The second part of the interview examined the challenges of being an FSW and FSW's participation and experiences in HIVST intervention.

I obtained written consent during the first part of the interview and verbal consent during the second part of the interview. Due to the high mobility of FSW, I intended to avoid any delay in conducting the second interviews. I, therefore, arranged a date, time and place for each second interview not long after the first, usually two days later. I did the interviews in FSW's homes, at the bars or at Namurayi's house (for those who did not feel comfortable doing the interviews in those places).

All the interviews were conducted in Chichewa and recorded using the digital voice recorder. I facilitated all the interviews and used the topic guide flexibly and iteratively by probing to get detailed data until I had covered all the topics in the topic guide. During interviews, I wrote down issues emerging from the responses that needed to be explored further so that I did not disrupt the flow of the interviews. I also allowed participants to ask questions and to provide feedback on the issues that emerged in the interviews. The decision to stop the interviews was made when the same themes and topics were emerging from

the participants, and new interviews did not yield any new insights (Bowling, 2014).

4.5.2.4 Focus group discussions (FGDs)

I conducted two FGDs, one with the PDs and another with the FSW, to examine different perspectives around the implementation of HIVST. FGDs are important in exploring ways in which participants share meanings and experiences of a particular reality (Bryman, 2012; Creswell, 2007). FGDs encourage debate and discussion around key issues and using them allowed me to explore varied views and seek explanations for differing opinions. During recruitment, I warned potential participants that they would be among other FSW and my colleagues, in case the issue of anonymity was going to be a source of concern.

I conducted both FGDs in a private hall in Mpiko. All FSW who participated in the FGDs consented. Each participant was assigned a number during the discussion to maximise the anonymity, and these numbers were used during transcription to track individual responses in the transcripts. I conducted the discussions in Chichewa. I facilitated the discussions and used the topic guides flexibly and iteratively by probing to get detailed data until I had covered all the topics in the topic guides. Two fieldworkers from MLW who had worked on STAR helped with note-taking during the FGD proceedings as Barbra could not make it.

I designed the FGD for the FSW to examine the role of the peer-delivery model in minimising or exacerbating vulnerability and empowerment; perceptions of HIVST; and the relevance of the peer-led model in HIV prevention among FSW. The topic guide was developed and used to facilitate the FGD's exploration of areas around FSW's experiences of being involved in the interventions, the benefits of the peer-delivery model and the challenges they encountered as participants. Eight participants attended the FGD, which lasted about 90 minutes.

I conducted the FGD with the PDs for Blantyre to explore areas around experiences of being a PD in the interventions, the benefits of being a PD, and the challenges they encountered and how this had affected how they identify themselves and how they interact with their peers and the community at large. Five PDs consented to participate in the FGD. I invited both Miranda and Namurayi to this FGD, and it also lasted about 90 minutes.

4.6 Management and analysis of data

In this section, I present the data management and analysis process.

4.6.1 Data management

All the interviews, FGDs and photo elicitations were audio-recorded and transcribed verbatim by the research team for accuracy and to retain the originality of what the participant said. Some researchers have emphasised that transcription, and analysis of transcripts, should be done by the same person (Lapadat and Lindsay, 1999) in order to understand the data entirely. I was not able to do the transcriptions myself due to time constraints. However, I quality-checked the transcripts against the audios for accuracy and completeness. I went through the transcripts carefully and gave the transcription team feedback until all queries were resolved.

Narrative data analysis

I used a narrative analysis approach informed by Polkinghorne (2005) to investigate the production and structure of FSW's stories about their lives and HIVST. He describes two analytical approaches to narrative inquiry: (1) narrative analysis that relies on paradigmatic cognition, and (2) narrative analysis informed by narrative cognition. The former is the process of identifying and classifying common or salient themes into different categories to fit into a larger pattern. He suggests that two types of paradigmatic analysis are possible: (1) ones informed by theory or logical possibilities that can be applied to data, and (2) ones inductively derived from the data (Polkinghorne, 2005). The emphasis of this approach is on the recognition of the differences between and diversity of people's behaviours and the reordering of

experiences, events and actions to produce coherent stories under themes. This process allows the use of both inductive and deductive approaches, which in this research was important for becoming immersed in the data as well as keeping in line with the objectives of the research study (Polkinghorne, 2005).

Drawing on Polkinghorne's approach, I printed out all the transcripts, read and reread each transcript and wrote key issues that were emerging on the transcripts (Polkinghorne, 2005). I then reread the transcripts to code the data on paper, line by line (Cohen, Glaser and Strauss, 1969). With the photovoice component, I read through the transcripts with the photos side by side to develop codes. I treated the photos as an integral form of data, not as supplementary material. During this time, I started developing a coding framework to identify more connections between critical issues (see appendix 5 for theme summaries). Simultaneously with the coding process, I wrote memos and annotations to develop categories and track emerging insights on the data or gaps for further exploration in subsequent data collection techniques. These memos aided interpretation and informed the findings of this study. I frequently discussed the analysis process and coding framework with the supervisors to ensure that I was capturing themes in the data.

I am aware that electronic coding is more organised than manual coding: the software keeps all files in one place and easy to manoeuvre. However, I started with manual coding; the choice of manual coding was more personal than technical. I find reading on screen mentally and physically draining, so I tend to later work on other aspects of the analysis process (developing patterns or making queries) on the screen.

After I had completed manual coding, all the transcripts and photographs and their accompanying narratives were uploaded into NVivo 11, and all the manual codes, annotations and memos were transposed. This seems like a tedious process and duplication of tasks; however, the act of transposing codes into NVivo (Edwards-Jones, 2014) enabled me to identify codes that I had missed out during the manual coding and to become more familiar with

the data. I then organised data sources and structured the key themes that were emerging into patterns across the data sets. I categorised the thematic issues into dominant categories. I then developed narratives describing similar and divergent views, developed explanations and found associations between them. I was triangulating the data in the process. The supervisors provided feedback on the narratives.

4.7 Quality assurance

Lincoln and Guba (1985) have coined 'trustworthiness' as an umbrella term to describe a set of criteria for judging the quality of qualitative research. There are four major trustworthiness criteria: credibility, transferability, dependability, and confirmability. In the sections below, I describe how I employed each of them to enhance trustworthiness in the study.

Credibility

- The study was conducted over ten months, and doing participant observation in the process enabled me to build trust and rapport with the research team and the participants. It also helped to reduce the 'Hawthorne Effect' (Hammersley, 1990). I was able to establish a detailed picture of the context of the study.

- The sample size followed the principle of saturation, whereby interviews and discussions continued until no new data emerged (Ritchie *et al.*, 2013). I was able to capture a wide range of views, meanings and understandings from the participants so that all perspectives relevant to the study were represented.

- Triangulation of sources (FSW and key informants) and methods (participant observation, photovoice, IDIs and FGDs) enabled me to cross-check the data and question the emerging themes.

- I had regular meetings with the research team and supervisors during data collection and analysis, which helped me uncover any gaps, biases and errors and do more probing.

Transferability

- I have provided a rich account of the context of the study, its setting in both text and photos and case studies to facilitate transferability judgement.

Dependability

- I have provided a detailed discussion of the data collection methods and analysis.
- Triangulation of the sources and meetings with the research team enabled cross-checking of the data.
- Training of the research team helped to ensure the quality of the data.
- All interviews were conducted in Chichewa with FSW to avoid problems of interpretation and to ensure accurate meaning. I continued to use the Chichewa language during the analysis process to ensure accurate meaning.
- I translated the quotations used in this thesis, and the research team checked these.
- I have written a transparent account of the research process, with the coding framework available in the appendices.

Confirmability

- I kept a diary throughout the research study to recall events and the reasons for any methodological decisions.
- I have provided a detailed account of my positionality in the research and how it might have impacted the methods, findings, analysis, and interpretation.
- Triangulation of sources enabled cross-checking of the data.

4.7.1 Reflexivity

Embarking on this research, I found myself continually reflecting on my position in the study, the interactions with the actors in the field, the response that I received from the community in my private (personal life) and public (work) spheres, and the tension of trying to balance these relationships without compromising my research. These relations that arise in the field may affect the whole research process in one way or another, and my experience was no exception. The main issue was that of insider/outsider relations and emerging identities and how these identities evolved as the study progressed.

I found myself operating in an environment where sex work had no clear legal framework and was usually judged on moral grounds in the communities. Sex work in Malawi was perceived as immoral, breaking up marriages and being the driver for high rates of HIV infection. FSW were constrained from accessing opportunities or a platform for giving their voice in society because of this structural background. My research was judged on these premises by many people that I interacted with at work and in my personal circles. My friends labelled me 'interesting' in the sense that one had to be 'wild' to work with this population. Some colleagues asked me why I decided to work with FSW rather than a more deserving population, such as children or young people, who are equally burdened by HIV. Although this was sometimes demotivating, I used this platform to reassess my intentions, judgements and justification for doing this work. As I reflected on people's opinions, I came to realise that it only reinforced my willingness to pursue this work as this exposed the need to do research with FSW and give them a platform to speak out about their experiences, especially in Malawi where stigmatisation of and discrimination against this group were persistent.

To FSW, on the one hand, I was an outsider and naïve about sex work life, and on the other hand, I was a sister/friend (a fellow woman, and hence an insider). The majority of the FSW that I interacted with had been widowed or divorced once or twice, and they had one or more children, although the majority of the women were much younger than I was. Most FSW were shocked when I told them that I was single, had never married and had no

children. One of the FSW said to me that I should pray to God to give me a man and children as at my age, the majority of women were married and had children. I took this as an opportunity to learn in-depth about the life of FSW in the community. It was interesting that some FSW would ask me for suggestions on prices to charge their potential customers. It was also refreshing to find a mutual grounding where sometimes the FSW were leading the discussions and teaching me more about their lives. The FSW openly discussed with me things that they typically do to attract men and what they learn during girls' initiation. I learnt a lot from my participants by capitalised on these various identities.

In the eyes of the venue owners, I was a special guest (an outsider). My role as a researcher and my link with MLW and Pakachere was the premise for this treatment. It was more pronounced when I visited the bars at night. The venue owners and bar managers would regularly check on Barbra and me throughout the night and give us free drinks of our choice. Although the benefits were excellent, this treatment made it more evident that I was an outsider. The rest of the people in the bar were buying their own drinks, and they were not receiving this much attention from the venue owners. Fortunately, although I was worried that it would disrupt my relationships with the people in the bar, this did not significantly impact how people in the bar interacted with me.

I saw my position evolving from ‘suspected sex worker’ to health worker as the study progressed in the bar. Some men approached me for a ‘short-time’ (sex work services that last less than an hour) or touched my buttocks to get my attention. In these moments, the venue owner would come to my rescue and chase them away. As the study progressed, I observed that many men in the bars started calling me ‘*azachipatala*’ (a health worker). This assumed role created a different relationship between the men and myself, and it was quite helpful because I was treated seriously and respected by men in the bar for once.

As human beings involved in studying a social world, researchers are inevitably emotionally involved with their participants (Johnson, 2009). Although this occurs throughout any research process, there is limited discussion of it in the literature. Evidence of researchers' emotional experiences, however, is often narrated in illness and health research. Gould and Nelson (2005) argue that qualitative researchers are not distant from their research participants and their stories; they are, in fact, embodied, subjective researchers who are passionate observers. Indeed, my fieldwork and analysis and the writing journey of this PhD have been largely an emotional one. Although I was aware of FSW's lived experiences through literature and, partly, the STAR project, it was inevitable I would get emotionally attached to the participants. As reported, I was well equipped to conduct the interviews by the GBV training; however, this was channelled more towards offering support to the participants and inclined more towards the interview process than the whole research process. Given this, my emotional response was fairly manageable during data collection; however, things became more challenging during the data analysis process when I had to read and reread the stories. The emotions resurfaced as I read the stories and recalled the interviews with the respective individuals. The limitations of the GBV training became apparent, but my supervisors became instrumental during this period as I was supported during our regular meetings. As Watts (2008) argues that such engagement with participants and data can facilitate a unique understanding and interpretation of data, I am aware that this experience inevitably influenced how I have represented the narratives from these women about their lives in this thesis.

4.8 Ethical considerations

I received ethical approvals from the Research Committee at the Liverpool School of Tropical Medicine and the University of Malawi's College of Medicine.

All participants provided consent confirming their voluntary participation. The consent sheet contained information about the purpose of the study, why participants had been selected, the data collection procedures, any benefits or

harms, their right to refuse or withdraw from the study at any time, and my contact details and those of the College of Medicine research committee. As the participants engaged with the study multiple times, initial consent was written, or thumb printed for illiterate ones and followed with verbal consent for subsequent meetings. Participants did not report any problems regarding the study's ethics throughout the data collection period or afterwards.

I extended this training to the gatekeepers because they were the ones who mainly identified the potential participants. I did, however, receive a complaint from one participant that Namurayi had told other FSW that some FSW had received money from this study, which of course, they did not like. Fortunately, Namurayi was there when the participant raised this complaint. Namurayi apologised and explained that other FSW had misinterpreted her story. After this meeting, I had a separate meeting with Namurayi to emphasise the importance of confidentiality in research and how best to introduce the study to other potential participants without mentioning reimbursements.

I also planned that any participants who reported any harm would be referred to a One Stop Centre (GBV support unit). I was also vigilant in noticing any existing tensions and risks during the recruitment process to minimise the possibility of putting participants at risk because of their involvement in the study. Participants did not report any harm relating to this study. FSW who showed distress during fieldwork were offered counselling support, which they all refused. I had anticipated that there would be some level of violence at the venues as these were high-risk places for violence. I only observed one incident in Namachero, but it did not involve FSW or Barbra and me.

In this thesis, I have anonymised names of research participants and locations by use of pseudonyms to avoid the identification of sources. I have removed any details of participants that are easily identified.

Reimbursements

I made sure that FSW were involved in the study during their free time and did not disrupt their work activities. I used participant observations to facilitate the process of identifying activities we could participate in, which mainly involved the normal routines of FSW outside work and determining reimbursement for participants. I reimbursed all study participants and gatekeepers for their time and any costs incurred in data collection activities.

4.9 Summary

In this chapter, I have presented a discussion of the research methodology that I used to explore how and why this research was conducted. I discussed the rationale of the epistemological foundations of the research and how this informed the data collection. I have provided the rationale for the choice of approaches, data collection techniques and data analysis processes. In addition, I have discussed the ethical challenges and how I addressed them during the research process. The research has generated rich data, co-constructed by FSW and myself, which I discuss in the next three chapters.

5 Power relations and vulnerabilities: exploring the context of sex work in Blantyre

5.1 Introduction

Sex work has been a topic of much discussion in the social and biomedical sciences (Romero-Daza, Weeks and Singer, 2003). There is a vast literature on how the HIV epidemic has impacted on sex work populations across the globe (Platt *et al.*, 2013; Awungafac, Delvaux and Vuylsteke, 2017). The evidence for the role of health and structural interventions in reducing the risk for HIV is currently inconclusive. There are examples in some contexts where intervention have reduced risk, but show little or no effect when replicated in most African contexts, as noted in Chapter 2. Little has been done to understand how social and structural factors construct and reconstruct power relations and vulnerabilities and the effect this has on HIV risk in Blantyre. Tavory and Poulin (2015) argue that, by locating sex work in its historical, social and cultural context, we can begin to map the interconnections and processes between sex work and HIV risk. Political, economic, social and cultural structures shape FSW's agency and understanding the meaning of their experiences.

In this chapter, I draw on the discussion on power and vulnerability in Chapter 2 to understand power relations and vulnerabilities in sex work, and FSW's HIV risk. Power relations and the context in which these powers are exercised shape the imperatives of the functionality of the sex work market. Sex work is not sustained simply by FSW's actions but also, importantly, by the socially constructed and culturally patterned behaviours, actions and inactions of people and practices in the sex work market. The structural and social arrangements in the sex work market may produce agency for FSW or diminish it and constrain them from exercising it. In this chapter, I discuss how the FSW agency exists simultaneously with violence and wider vulnerabilities. I also discuss how social, economic and political factors at both the macro and the micro levels shape the sex work industry and drive the HIV epidemic among FSW.

In the next sections (5.2-5.3), I set the scene by describing the context of sex work in Blantyre, specifically looking at the organisational structure of the sex work venues. In sections 5.4-5.4.3, I discuss the reasons for entry into sex work: the stories by FSW illuminate both each person's experience and the context (Murray, 2008). I then discuss the power dynamics and vulnerabilities in the sex work environment in sections 5.5-5.5.2. In sections 5.6-5.6.2, I discuss the experiences of vulnerabilities in sex work and how some women have resisted the notion of victimhood. In section 5.7, I discuss FSW's views concerning their sexuality. I examine the changes in sex work as embedded in the political and economic landscape in Malawi and the response from FSW in sections 5.8-5.8.2. Then I show the importance of understanding the impact of the heterogeneity, power relations and complexity of sex work on HIV risk in section 5.9 and provide a summary of the chapter in section 5.10.

5.2 Bars

In seeking to understand the context of sex work, it is useful first to consider the settings of sex work. Context helps build interpretations to facilitate understanding of the actions and experiences of FSW.

Photo 3: Typical local bar in peri-urban Blantyre

> *This is where we work; we meet our customers there, a lot of things happen at this place, you know; like people dancing, some playing*

pool, others just sitting on those benches enjoying their drinks- **Amelia, bar girl**

The history of urban migration and modernisation of transportation largely shaped the set-up of the local bars in Malawi (Tavory and Poulin, 2015). As young men from the surrounding rural areas came to Blantyre to work in the factories, they started constructing temporary shelters close to their workplaces, now slums. In addition, the development of the modern transport system during the Banda era facilitated internal migration. Small townships started to emerge along the roads and served the internal migrants with markets, rest houses and bars (Kishindo, 1995). As a result, these political and economic changes shaped the location of sex work venues in this setting.

Urbanisation, as discussed in Chapter 2, has had little effect on transforming modern-day sex work. The two study locations were slums in Blantyre, situated around the commercial and manufacturing centres and suburbs. The locations were about eight kilometres apart. The bars were strategically situated in marketplaces or busy roads to attract customers from the busy transport system or the market. The bar customers were ordinary people from around the community in salaried employment or informal business. Customers came to the bar for a drink or looking for a ‘short-time’ (sex work services lasting under an hour). The age range of the customers was 16–45. During fieldwork, I realised that women around the communities never visited the bars, and nor did men come to the bars accompanied by wives or partners with whom they have *chibwezi* (an intimate premarital relationship involving trust and love- boyfriend/girlfriend relationship) (Tavory and Poulin, 2015). As mentioned in Chapter 4, the communities perceive women who drink alcohol, especially in bars, negatively (Lancaster *et al.*, 2018).

These local bars were popularly known as ‘*kuchibuku*’ (literally, a *Chibuku* drinking joint). The bars often had inscriptions of the *Chibuku* trademark scribbled on their exterior for easy identification to attract *Chibuku* customers. The physical structure of each bar looked small at first glance, and I was surprised to discover that the whole structure would have three or more

sections: the bar, toilets, FSW's rooms and sometimes the venue owner's home. The design of the local bars accommodated those who wanted to have a drink or buy sex work and allowed venue owners to have easy access and control over the management of the venues' activities and employees.

The atmosphere in these bars arose from the combination of people dancing erotically to a mixture of Afro-pop music, usually Malawian, Zambian and Nigerian; people drinking beer, which included *Chibuku*, a variety of Carlsberg bottled beers, ciders and spirits in sachets; FSW cutting *Chibuku* cartons for customers; and people having a chat. The bars opened every day from 6 am until the last customer left, usually around midnight. It was usually busy at night, and people flocked in as they left their daily activities on their way home. The busiest days at the bar were weekends and paydays because people had more money and were more relaxed than other days of the week or month.

5.2.1 Mpiko

Mpiko had a big market where thousands of people earned their living through small-scale trade, and the majority of the work was informal. The traders were primarily men, but there were also a few women at the market selling vegetables or second-hand clothes. Most people who resided in Mpiko worked in the surrounding industries and suburbs as cooks, guards, drivers or nannies.

Alba bar was situated right in the middle of Mpiko township, close to people's homes and a small market. The physical structure of the bar made it look abandoned and uninhabitable; it had openings in the wall that allowed the passage of light and air, and the walls were also cracked in other places, and the bricks had weakened, and the paint had worn off and was coated in layers of dust.

Amayi (mother) and her husband opened the bar in the 1980s as a family business. After their divorce, her husband relocated and remarried. Their

eldest son, *Ankolo* (uncle), was the manager of the bar. *Ankolo* was a young man in his late twenties, married, with a son who was a few months old. The whole structure had three big sections:

1. **The bar area:**
    a. ***Pool table area*** – this was the first room of the bar as one entered through the main entrance door. The pool table was in the middle of the room. Customers in this section were usually teenagers playing pool. Across the room was a door leading to the room where the bar counter was situated, and the wall dividing these rooms had a big opening so one could see through to what was happening on the other side.
    b. ***The bar counter area*** – this room was slightly smaller than the pool area. The room was dark, only illuminated with blue and red disco lights. The bar counter was on the left side of the room, with seven bar stools surrounding it. The bar customers used this section as a dance floor as this is where the music was loudest.

2. ***Amayi*'s section** – *Amayi*'s house shared a wall with the bar counter side. I was stunned on the first day when the barman told us to go through the door next to the counter only to realise that I was in someone's sitting room. *Amayi*'s section had two bedrooms and a sitting room. During my visits, I used to find many people, mostly men, seated on the chairs eating *nsima* (a dish made from maize flour and water – a staple food in Malawi) or rice with some relish. Soon I realised that the sitting room was also serving as a restaurant. *Amayi* sold meals to FSW and bar customers who were usually in a home away from home at the bar; the customers would come to the bar to eat, chat with friends, listen to music, dance, drink a couple of beers and have a 'short-time'. *Amayi* limited the menu to *nsima*/rice with beef/chicken and vegetables. *Amayi*'s kitchen was on the veranda just outside the sitting room.

3. **FSW's rooms** – there was a little passageway outside *Amayi*'s house that led to the FSW's rooms. The first day I went there to see the FSW, I had a feeling that I was going into a dungeon. There were six rooms altogether, three rooms on each side of the corridor. Each room was roughly two metres by two metres in dimension and accommodated three to four FSW at a time. The room could only fit a single four-inch foam mattress; the mattress had no covers, was deflated in the middle, stank and had become brown with dirt.

5.2.2 Namachero

In contrast, Namachero was a small area with a small market where people sold food items and a few retail shops. A few women sold fresh vegetables along the streets, and men mostly worked as minibus drivers or conductors. Some people in Namachero worked in retail and wholesale shops in surrounding areas.

Rado bar: Being a local bar in Malawi, Rado bar had many similarities to Alba bar. Rado bar was well situated at a marketplace, close to the central bus station, and benefited from the minibus network along the main road going to the city centre. *Madala* (father), the owner of the bar, was a prominent businessman in the area. *Madala* had owned two bars and a small retail shop where he sold fabric, *zitenje* and snacks. He opened the bars in the 1990s as a family business with his first wife, but they later divorced, and *Madala* married Aunt. Aunt managed the shop while *Madala* focused on the bars. I found that the ex-wife had seized one bar because of *Madala*'s failure to repay her loan; however, Rado bar was the more popular of the two with FSW. As with Alba bar, at Rado bar, the physical structure was big, although it had only two sections because *Madala* did not live at the bar premises.

1. **The bar area** – the room seemed dark in the afternoon as there was little light coming from the open doors. The customers sat on the cement benches built around the walls. I never saw *Madala* at the

counter because a bar manager supervised the daily activities. The customers danced to Afro-pop music in the middle of the bar area.

2. **FSW's rooms** – there were three doors around the bar side: one entrance/exit door led to the bar section, one door led to FSW's room, and another led to the toilets but also another corridor leading to other FSW's rooms. There were 11 rooms, and each room was approximately two metres by two metres in dimension. There was a stench of urine and faeces in the FSW's rooms that were closest to the toilets. Unlike at Alba, the FSW had bamboo mats covered with thin blankets in the rooms. FSW prepared their meals outside their rooms, where I would usually find a *mbaula* (charcoal burner) that they used for cooking. I found about 23 FSW the first time I visited the bar, but the number eventually reduced as many of them relocated to other bars in the surrounding districts in the quest for greener pastures, as demand for sex work was high in the other districts. The numbers at Rado were likely to increase again when the demand for sex work in other locations was low.

Photo 4: Typical FSW room in peri-urban Blantyre

> *This is my room; I sleep here with two other FSW. This is where we bring our customers. You see the room is very filthy, the owner does not care about us, this is a very small room, but we keep all our belongings there*- **Madson, bar girl**

The settings of the local bars in these slums reflected the social and economic landscape in Malawi, highlighting poverty levels as manifested in the physical structures, in the accommodation for FSW and *Amayi* running the restaurant in the spaces of her home.

The following section highlights the relationship between the venue owners and FSW, which reflects expressions of control and manipulation. The power of the business location was critical to the venue owners as the location shaped the productivity and success of the business. The venue owners carefully constructed and situated the bars to balance bar business, sex work returns and family life.

5.3 FSW

During the inception of this study, I identified three categories of FSW through the host study sampling criteria: street-based, home-based and venue-based FSW, categories based on the location of sex work. During fieldwork, however, I established that these categories of FSW were not fixed, having a high level of fluidity: FSW moved from one category to another, or left sex work and then re-entered it after divorce, widowhood or lack of better economic opportunities.

In Malawi, FSW use terms such as *kuyenda yenda* or *kuponda ponda* (very mobile) metaphorically, to mean their geographical mobility as well as moving between partners (Tavory and Poulin, 2015). Similarly, in his literature review, Weitzer (2009) suggests that FSW do not confine themselves to one type of sex work in their career. In contrast, a study conducted by (Kishindo, 1995) found that most FSW did not see sex work as a permanent occupation because they expected to marry eventually and hoped to meet a man while still in sex work. The aspirations of marriage stated by some FSW in this study suggests that the integration or reintegration into culturally acceptable norms of the status of being a 'good woman' has remained constant. The motives for the fluidity of sex work included the search for better economic opportunities or love or relocation to other bars, streets or districts or even across national borders. Given this, an FSW could be operating as a home-based FSW in Blantyre and change to being a venue-based or street-based FSW when she relocated to another district.

Permanent moves from one type of sex work to another were rare. The venue-based FSW cited lack of safety, lack of money to sustain high status, and lack of support as barriers to moving to the streets. On the other hand, the home-based and street-based FSW stated that relocating to bars was a downward move in the social strata of sex work, and therefore embarrassing and diminishing. Weitzer (2009) confirms that mobility across social strata seldom occurs among FSW, and FSW tend to maintain their position in their work for much of their life. Therefore, I re-categorised the three groups into

two, the bar girls and the freelancers (Kishindo,1995), but I took into consideration the fact that the definitions of these groups may also change depending on the context and time. I acknowledge that the term ‘bar girl’ is degrading, however, this term is widely used among FSW in this context to refer to venue-based FSW. Bar girls were FSW tied to venue owners, and they worked and lived at the bars (Tavory and Poulin, 2015), while the freelancers were FSW not tied to any venue owners, and they operated from home or went on the streets or to nightclubs or bars. These categories were analytical terms to describe the relationship between the FSW and the venue owners.

The overall level of education among the participants was low. Most of FSW’s education in this study had been interrupted, mostly because of lack of fees, early marriages and pregnancies. All women reported having received some primary education, only a few had some secondary school experience, and none had tertiary education. As in many studies conducted in this setting, the women in this group were generally from a rural background (Kishindo, 1995; Lancaster *et al.*, 2018; Chirwa, 1997).

Most women migrated from neighbouring districts of Blantyre looking for greener pastures in the city and were identified and recruited by friends who introduced them to bar work. The duration of periods spent at the bar was approximately between one month and two years (but they could leave and come back during this period). Ages varied between 16 and late 40s. Most freelancers were older (35 years and older), single women, sometimes living with a partner, or their children or siblings, in their own or rented houses without a visible (to the wider community) source of income. Most freelancers were born and bred in peri-urban locations in Blantyre and surrounding areas, with a much higher social status in the FSW’s community than the bar girls because of their higher income. This type of mobility provides a contrast with the Anglo-American settings, where the street-based FSW are at the bottom of the sex industry ranking, and women involved in this type of sex work often come from a background of drug addiction, which impairs their price negotiating power (Dalla, 2001).

5.4 Mapping divergences in sex work narratives

There is limited research in the literature describing sex work in colonial Nyasaland (Tavory and Poulin, 2015); however, there is some evidence on how colonial structures reconfigured unequal gendered power relations in Africa (Ogbomo, 2005), and in Malawi in particular (Power,1995), which pushed many women into sex work. During the colonial period, men migrated to neighbouring countries for work, leaving women in home countries without economic support and largely dependent on subsistence farming (Chirwa, 1997). As shown in Chapter 2, during the postcolonial period, the position of women further weakened due to unsupportive structures (land rights and education), which marginalised women in economic activities.

International migration patterns changed after independence when President Banda implemented a policy to build a modern economic infrastructure to stimulate Malawi’s cash crop estate agriculture (Tavory and Poulin, 2015). This change resulted in a decrease in international migration and an increase in internal migration as people moved from villages to cities and was accompanied by an emphasis on men as wage earners. These changes in the postcolonial period further weakened women’s economic position, education opportunities and bargaining power (Tavory and Poulin, 2015). The government did little to address gender inequalities in economic activities. The constellation of sustained rural–rural migration, increased urbanisation, and continued restriction of income-generating opportunities for women encouraged a greater move into sex work for women.

Malawi, as a landlocked country, has limited connectivity to the SSA region and the rest of the world, resulting in poor economic performance on a global level. Recently, governance structures and political limitations were compounded by natural shocks; the 2001–2002 and 2008 famines in southern Malawi (Tostensen, 2017) both exacerbated women's need to sell their labour in trading centres and drew them increasingly to sex work.

In the section below, I show how power arises out of the interactions of individuals within political, economic and social structures that push women into sex work and shape the uneven distribution of agency among FSW. I discuss how poverty, unequal gendered power relations and violence undermine women's agency by limiting their choices in life. There were varied reasons for entry into sex work, none dominant over the other, which affirm, challenge or contrast with the dominant narratives of sex work, as discussed in Chapter 2.

5.4.1 Life is hard: sex work resulting from economic pressures

> *I needed money at that time to support my family, so I found that I could do that through sex work. I then decided to stay in sex work for as long as there was money coming in. –* ***Alina, bar girl***

> *I didn't want my children to suffer, and I did not want to lack anything, like food or soap. –* ***Malika, freelancer***

> *If a person drops out of school, what else can they do? They are just doing sex work. In my situation, can I get a job? They [employers] would tell me that they need a form four certificate, whereas I dropped out of primary school, so where will I get a form four certificate? Life is hard. –* ***Nova, freelancer***

Case study 1: Hailey

Hailey was a bar girl working in Mpiko, and she had been working at the bar for more than two years. Hailey came from a neighbouring district of Blantyre (Mulanje). Her father was a church pastor back in her village, and her mother relied on farm produce for her income. Hailey had been married for almost 18 months but left her husband because of the ridicule she went through due to the failure to conceive a baby. Her parents could not take her in because of food insecurity, and they had other responsibilities in taking care of her siblings. In addition, she later realised that she was

pregnant, which also brought more responsibility. Hailey moved in with her grandparents on her father's side, but they did not have the best relationship because they regularly had physical fights. The grandmother often told Hailey that she would never inherit the family house because of her rudeness, and they would later argue, and this ended in bouts of fighting. She grew tired of this relationship and decided to leave and move in with her cousin who lived in Mayiro, one of the townships in Blantyre. She found a job in one of the factories but was later made redundant. After Hailey had lived with her cousin for a few months, the cousin approached her about household finances. Hailey was told to leave or contribute to the household finances. She tried selling charcoal at the local market, but this was not profitable. The cousin then introduced her to some women in the neighbourhood who were involved in sex work. Hailey was at first shocked at the suggestion and decided not to join, but she later succumbed to the idea because there was nothing else to do in town. She joined the women and went to Mpiko at one of the bars. She started as a bar girl but later decided to leave the bar rooms because of the bar managers' cruelty. The bar managers refused to let FSW prepare their meals at the bar premises. Then she rented a room at an older FSW's house. She was still working at the same bar but now as a freelancer. After joining sex work, Hailey's life changed: in her previous job she earned MK12,000 a month, but during the first week of sex work, she made more than MK100,000. She decided to save the money so that she could find another source of income and leave sex work. In less than a month, she made more than MK240,000 and then left, rented a house in the neighbourhood, bought essential household materials and used the other money to start a small business. She started selling charcoal again, but this was not profitable, as before, and within two months the money was gone and she was back at the bar. She then decided that she was going to be a full-time FSW and things had changed for the better for Hailey since she became an FSW.

To a large extent, limited material or social opportunities contributed to women's economic vulnerability and pushed them into sex work. There was uniform agreement among FSW that by far, the most critical driver into sex

work was poverty. These findings support other studies in other settings on the role of poverty as a key driver into sex work (Van Blerk, 2008; Udoh *et al.*, 2009; Elmes *et al.*, 2017; Ganju and Saggurti, 2017).

In this context, however, these women understood poverty as both a material and a social condition. The FSW like Hailey reported that they engaged in sex work due to food insecurity and to meet the necessary costs of everyday living. There were obvious financial rewards in sex work for women marginalised from mainstream employment structures. Here, Hailey stated that sex work was their only option, with fewer paid jobs available and a saturated market for small businesses, to meet the ever-increasing cost of living. FSW's poor educational background, as well as a lack of training and qualifications, reduced their chances of finding alternative forms of employment and constrained their life choices. The material drive to engage in sex work to survive was strong as some FSW indicated that sex work offered better opportunities for *pompo pompo* (instant) money. The high levels of inflation further impacted on standards of living and women's economic vulnerability.

Despite collective agreement on sex work as a source of income, there were a few notable differences regarding the association between sex work type and level of income generation. These disparities included sex work prices and clientele. The following quotation from an interview with Hailey is illustrative of experiences and perceptions of being in a 'cheap' bar compared to an 'expensive' bar or different sex work type.

> *Our bar is cheap; cheap bars also entail little money, for example, people who walk around the streets [street-based sex workers] are paid more money because they are close to the expensive bars, but the customers in our bars are not rich. –* ***Hailey, freelancer***

In this context, the cheap bars that Hailey stated were the C*hibuku* bars, and prices there for a 'short-time' exchange (about 30 minutes) ranged between MK1,000 and MK3,500, and for overnight between MK4,000 and MK7,000.

Freelancers operated around bars in the suburbs and the streets in central business areas and were usually patronised by middle-class men. The difference in payment was significant: ‘short-time’ prices ranged between MK8,000 and MK10,000, and prices for overnight between MK15,000 and MK20,000. However, FSW agreed that sometimes the customers would pay extra money based on performance during sex, physical appearance and duration of the service. In this case, poverty constrained some women’s sexual agency as economic pressures influenced sex work decisions.

The power inequalities between men and women affect members of the community at different ages and life stages and hence affect one’s capacity to be secure and supported. Among the participants, there was a link between poverty and a lack of social capital. A history of childhood and adulthood abuse, neglect and rejection characterised the pathway into sex work. Most women had come from broken and economically poor backgrounds, raised by single parents, especially mothers. A few had experienced physical or emotional abuse during childhood. Most women reported that they had dropped out of school by the age of 12 and had been married off by parents. They indicated that pregnancy was a significant factor in parents’ decision-making because it was considered shameful for a daughter to be pregnant outside of wedlock. In some instances, poverty compelled the parents to arrange a marriage for their daughters. The belief was that there would be “*one less mouth to feed*” or that the child’s husband would also economically support the family. Research in Malawi has established that 50% of adolescent girls get married before the age of 18, compared to 9% of boys (Plan International, 2016). Although the minimum age of marriage is 18 years for both boys and girls (Government of Malawi, 2015), the Constitution of the Republic of Malawi (1994) still allows individuals between 15 and 18 years to get married with parental consent, which undermines the efforts of the Act to end child marriages. Apart from resulting from parental shame due to pregnancy, child marriages are also the result of cultural practices and beliefs (Mwambene and Mawodza, 2017). For example, initiation ceremonies expose adolescents to sexual activities that sometimes lead them to early marriages (Scott, 2017).

After being married for a few years, most women like Hailey were then divorced or widowed, and a few were on their second or third marriages. There was only one woman who did not have children; the rest had an average of three children. The women mentioned physical, economic or emotional abuse and husbands' infidelity as reasons for divorce. After their divorces, most women reported having a challenging time meeting the basic needs of their families, particularly due to limited financial support. However, they experienced more freedom from abuse. Hence, a combination of poverty and marital breakdown were big pushes for these women and drove their involvement in sex work, for example, the case of Hailey. These findings are consistent a study conducted by family and marriage scholars who have established a dramatic decrease in the standard of living for women with low socioeconomic status after divorce, separation or widowhood (Hayes and Trafford, 1997). The women described early childhood histories characterised by the experiences identified in the literature as 'push/pull' factors into sex work.

Sex work studies demonstrate that a sense of powerlessness and lack of self-worth among some women often precipitate them into sex work involvement (Melrose and Pearce, 2013). Loss of economic support and social capital, combined with a lack of economic opportunities and the need to provide for dependents, led women in this context into sex work. Women in Blantyre embedded the meanings of entry into sex work in their significant relationships, critical life events and broader social and economic factors. This attitude, compounded with adverse childhood experiences, in turn, it reinforced a negative self-image and a sense of inevitability about lack of life choices.

There were some responses to women's involvement in sex work that were constructed differently but had the same meaning: *nanga ndipanga bwanji?* (what else can I do?) or *kusowa chochita* (there is nothing else I can do). Both terms refer to a lack of choice or options and a feeling of helplessness and hopelessness. In this context, these responses signify an emphasis on the

deterioration of living conditions. These feelings in these narratives result in FSW assuming that sex work is their destiny and that they are powerless to change their situation. It is all they feel they have and who they are. This response may be considered a result of the cumulative impact of adverse experiences and losses, which reduce perceptions of self-worth, while others who have not had such experiences and losses may have resilience. Abusive experiences may impact on their cognitive and emotional processes and distort their sense of self-worth. It appears that the FSW have internalised and interpreted negative experiences as an expression of their worth and destiny.

5.4.2 Agency and sex work

Case study 2: Willow

Willow was a 39-year-old FSW born into a family of 24 children from a single mother. The mother had twins, triplets and quadruplets. However, only five children were living at that time. The mother died after giving birth to her last twins due to a haemorrhage. Willow's late father had remarried after the mother's death, and there was no support for the children when this happened. Willow got married when she was only 15; unfortunately, her partner later died of TB. They had two children together: a boy and a girl, now both teenagers. After the death of her husband, Willow decided not to remarry because she wanted to take care of her children. Luckily, her late father had been a prominent political leader in Mpiko, and he had had enough money and influence to buy a lot of lands, which his children inherited after his death. However, despite owning a house, living in proximity to her siblings and having a small business, things started getting hard for Willow and her children financially. She decided to join some women's microloan groups in the community to invest in a bigger business (selling second-hand clothes). It was through these fellow women that she was introduced to the concept of sex work. Although sex work is not as profitable for her as it used to be, it remains her main source of income. The excerpt below explains more about how she became an FSW.

“I was troubled when my husband died because of the children … and sometimes we would sleep on an empty stomach. I found myself in women's groups in the community, and they told me that “aah you, you are fine, you have US [dollars], pounds, Malawi kwacha … you can exchange if for Malawi kwacha” … and then they would tell me, “you can sell your body and exchange it for money to feed your children”.

It is evident from this quotation that Willow’s friends advised her to take control of her situation, stop being passive and think unconventionally about her body as a commodity on the exchange market. Materially, her case was not different from the women described in the last section as forced into sex work by poverty, however, Willow’s narrative is different. Some of the FSW perceived their bodies as something that was highly marketable, using the notion of currency as an example of how they could use their bodies as a special commodity. It suggests that in this context, these women considered sex work to be an option for women who saw their bodies as a commodity that men sought after, in order for these women to support their families. The women reported that support from their families was insufficient after divorce or death. As indicated in Chapter 2, in Malawi, culturally, the children belong to/are the responsibility (both socially and economically) of a senior male member on the mother’s side (Sear, 2008). After a divorce or the death of the husband, the children did indeed remain with the woman. However, in many cases, due to the financial hardship that was widespread in the communities, economic support from the family or mechanisms to enforce the father’s support for his offspring were barely sufficient. As a result, this situation further shaped and constrained the woman’s economic position in the communities.

There were different forms of capital that FSW were able to exploit, even in impoverished conditions, as a form of economic empowerment. Some FSW reported that they became FSW because sex work is work. They did acknowledge that they were indeed living in poverty, and they entered sex work for money to alleviate this state. However, they emphasised their agency in their decision-making, as stated by Stailey in the case study below.

Case study 3: Stailey

Stailey was a 38-year-old FSW working as a freelancer. Stailey shared a house with her sister (introduced later as **Rylee** and an FSW) and a three-year-old niece. Stailey had another sister, **Nova**, an FSW as well. Stailey dropped out of school when she was in standard eight because she was pregnant; unfortunately, she miscarried, but she decided not to go back to school. She never married but had multiple stable partners. Stailey had an abusive father who cheated on her mother with an FSW, and the father later decided to divorce the mother and marry the FSW. This meant that the mother had to take care of all the children and things became hard for them. Due to the dire levels of poverty that the family were going through, Stailey decided to help herself financially, and she started sleeping with married men for money. After doing this for some time, she realised that there was a risk of this transactional sex being discovered by the community. She decided to join her peers, who were FSW at the local bars. She was 17 years old when she started going to the bars. Stailey saw sex work as a way to survive but felt that she was making that choice. Her decision to join sex work involved a choice in a context where there are very few other available options for earning money. Sex work remains her primary source of income. *"If I say that there was someone or something [who forced her], it would seem like someone held my hand and told me to go there, but it was me, I made that decision myself."*

Some FSW like Hailey had tried to run small businesses but had not succeeded. Others argued that selling charcoal or working as a maid did not bring in substantial income to sustain their livelihoods. Most maids received the minimum wage (MK35,000) or less per month, while FSW could make this money in a week or two. Just like Stailey, some FSW maintained that sex work was an individual choice out of the limited options available in their community and the best option as the payment was better than that of other available work. FSW, therefore, do not lack rationality when entering sex work or become passive victims of men's sexual power (Jean, 2015). Indeed, they

exercised situated rationality, strength and resilience in oppressive conditions to help improve their situation.

5.4.3 Sex work as temporary work

This narrative emphasises the values shared between FSW and other community members, and thus FSW's perception of sex work as a temporary deviation from social values and plans for reintegration into mainstream society through marriage. Although the money factor was relevant, other FSW argued that they were generally looking for *mwamuna okhazikika* (stable partners) *or partners with whom they have chibwenzi*. The FSW were aware of the negative connotations of the identity of sex work and the repercussions of subscribing to this identity, as their self-concept is so reliant on the approval of society. Their families and communities called FSW the "*lost daughters*", "*the lions who were roaming the cities to devour any man*" or "*vectors of STIs*". In Malawi, society values marriage for varied reasons. Marriage gives men and women status to start reproducing and a sense of stability. Singlehood at their age (>20 years) meant being viewed as promiscuous, not respected by society and not legitimate for procreation. For FSW in this study, it was almost impossible to sustain relationships with significant others alongside sex work, hence their emphasis on the temporary nature of the work. Sex work was, therefore, a means to an end: they felt they had the agency to make a choice, and that choice was to find a man and exit sex work; however, these choices were still shaped by patriarchal norms.

Case study 4: Peyton

Peyton was a 34-year-old freelancer, a widow with three children. She was a sister to **Willow** and one of the last pair of twins born to their mother. Unfortunately, her twin died a couple of years after their birth. She was raised by her older siblings and partly by their stepmother. Due to lack of support at home, she was married off to a man in his 20s by her father when she was only 12 years old, to ease his responsibilities in the household. Although she resisted this decision, she could see no other choice; she had to choose either poverty or the man who was

going to give her food daily. It was a rough start because of her young age, and she was naïve regarding wife and in-law roles, and sex; however, she had enough support from her partner, and things got better after that. Unfortunately, her husband died in 2010, and she was left to take care of their children alone. Despite having her siblings around, things were hard for her and the children. She started selling second hand clothes, but the proceeds could not meet all her needs. She had some acquaintances who were FSW, operating as freelancers, and she decided to join them. It was, unfortunately, the case that she did not have a close relationship with **Willow** and they never went to the same locations for sex work. During their interviews, they both explained that they never trusted each other because each thought the other had a 'big mouth'. Peyton was able to send her children to private schools and build a house from sex work proceeds. She emphasised that she joined sex work to find a stable partner who would help her financially because she was not comfortable with the idea of going to the bars every day. Indeed, during the interviews, she was living with her stable partner in her house. Unfortunately, he became jobless a few months after moving in. Peyton has been an FSW since 2010.

I found that most FSW aspired to be married just like Peyton. Having a stable family was key to FSW, and it appeared to be a crucial aspect of their self-worth. Dodsworth (2015) argues that this is evidence of the need to balancing life challenges (poverty, deprivation and other adverse social and material conditions) and management of multiple identities (mother, wife, daughter). The women express agency through the decision to finance, through sex work, a lifestyle that would otherwise be impossible, but also have a strong sense that this is a job to support life, and not one's whole life or identity, and retain their life's pathway. This sense of agency promotes resilience by developing problem-solving abilities and a belief that one's efforts might make a difference.

The fluidity of sex work, the exit and re-entry into sex work, has reinforced perceptions of sex work as transitory. For example, Luna, a bar girl in Rado,

was in a stable relationship when I first visited the bar. She participated in the photovoice component, but I later learnt that she had left the bar to cohabit with her stable partner. It was surprising to see her back at the bar after five months when I started conducting interviews. Negative experiences after leaving sex work would, however, push these women back into sex work. Their reasons for re-entering sex work, which included various forms of violence perpetrated by partners or significant others, economic pressures and the deaths of partners, were similar to the reasons that initially pushed them into sex work. Luna stated that her partner was financially dependent and living with his parents when they decided to cohabit. This move translated into her being dependent on the partner's family and a lack of economic independence. Also, his family scolded her after learning about her involvement in sex work. She could not handle this pressure from the partner's family and later decided to go back to selling sex.

In my study, the heterogeneity of FSW based on age and duration in sex work shaped the complexity of the temporary narrative of sex work. On average, the older FSW in this study had been in sex work for a decade. Indeed, the concerns from some older women included the younger FSW rebuking them because of their age and their prolonged involvement in sex work. The younger FSW (below the age of 34) described the older women as grandmothers who should have retired from sex work and should be looking after their grandchildren. The older women argued that they were also seeking money since they had children in secondary schools and needed school fees, and there were still a few customers who preferred older to younger women. Some customers perceived the older women as more respectful than younger women, so this created demand for their services. Despite these polarised arguments between younger and older women, their arguments have in common the fact that they show the economic hardships and stagnant poverty in the community. For both older and younger women, their rationale for remaining in sex work was the need for money to meet their daily needs. This situation suggests that although FSW initially thought their involvement in sex work was temporary, broader circumstances and

experiences inside and outside sex work have made it impossible for many FSW to leave sex work permanently.

5.5 Power dynamics in the sex work market

After FSW enter sex work, the combination of occupational arrangements (whether as a freelancer or bar girl) and power relations in the sex work market shape their experiences. Exploring the nature of FSW is central to HIV prevention programmes because different sex work environments are associated with differential HIV risks (Buzdugan *et al.*, 2012). A critical component in this discussion is an understanding of both subtle power relations and the overt behaviours of both venue owners and FSW, and the effect of these power relations on individualised notions of vulnerability and opportunities for empowerment.

5.5.1 The bar girls

Weitzer (2009) argues that bar norms, roles and expectations are a strong predictor of FSW's experiences in many contexts of venue-based sex work. Venue owners establish roles, social norms, values and expectations, systematically establishing their own power to determine whether FSW are accepted and expected in the bar environment. In this study, the involvement of venue owners in the activities of the bar girls was varied, ranging from exploitative and manipulative to protective and supportive. These tactics that venue owners used to exploit, discipline or support FSW were their actual instruments of power.

The bar girls combined dual roles while working at these bars. The venue owners officially employed the bar girls to serve drinks to customers and clean the bar area. The bar girls also sold sex at the same time as fulfilling their official role at the premises, with the full knowledge of the venue owners. At the start of the bar role, the bar girl and the venue owner would agree on a wage for their work in the bar, ranging between MK5,000 and MK7,000 per month. This wage supplemented earnings from sex work. The venue owner would typically not charge rent for FSW's rooms, a fact used by the venue

owners to justify low wages. The venue owners often presented their relationship with FSW as a ‘business partnership’, where FSW were a means of attracting bar customers and in return, the venue owner provided accommodation for the FSW so they could conduct their sex work and earn money from bar work. In agreement with other studies among FSW in Malawi (Kishindo, 1995; Tavory and Poulin, 2015; Chirwa, 1997), the dual role of FSW translated into competing priorities. The venue owners expected the bar girls to combine sex work with chatting and serving customers and cleaning the bar area.

The combination of bar work and sex work was beneficial to the venue owners. The venue owners of both Rado and Alba bars gained monetary benefits from sex work. They charged K100 per sex work customer just because they provided free accommodation. The collection of money from FSW was an underground activity, as ‘pimping’ is illegal in Malawi, as in many other countries. It was a common belief that this sex work charge was extremely unfair to FSW because it was the venue owners who were benefiting from all the bars’ activities.

> *A guard stands at the entrance to our rooms every night to collect money when we go to the rooms with a customer. There is no way of escaping this, we give them K100, and they let us pass. This is very unfair, though – they can’t be collecting money from us while they are also making a lot of money from selling beer in the bar … they don’t even pay our salaries in full. Each month they come with excuses. This means that they are the ones benefiting and not us.* – ***Madison, bar girl***

Both the FSW and the venue owners sometimes presented their relationship as similar to a child–parent relationship. Some venue owners provided FSW with protection from physical violence from customers or their peers or provided transport to seek healthcare in times of ill health, and opportunities for advance payments. This relationship presented FSW as situationally dependent on venue owners, highlighting the situational vulnerability of FSW. Some FSW believed that venue owners should be actively playing a parental

role because it was their responsibility to make sure that FSW at their respective bars were well taken care of.

However, there were economic consequences if the bar girls did not meet these expectations. Often the venue owner or the bar manager would monitor bar activities and knew who was on duty or not. The venue owner would deduct a certain amount of money from the salary if an FSW committed an offence at the bar. For example, sleeping outside the venue would incur a cost of K1,500 for FSW. At the end of the month, the venue owner would then deduct the money from the respective FSW. This example of monetary repercussions implies that control and surveillance by venue owners over FSW impacted on their freedom of movement and economic independence.

Kearins (1996, p.6) argues that “power relations are not fixed, nor are they consistent across all issues; power has useful means in the context in which it is exercised”. Highlighting these power relations does not mean that the FSW experienced one relationship or another: the manifestation of these power relations was dependent on the varying degrees of control that venue owners had over these women within particular situations. Structurally, the level of association with the venue owners influenced the nexuses of power and control between the venue owners and the FSW. The more tied an FSW was to a venue owner, the higher the level of control and power the venue owner had over her. For instance, FSW had different experiences when they moved to different bars where they had to pay a daily rate for their rooms and received full payment from bar work. Most FSW preferred to work at venues where they were more independent and rented their room in return for a fuller salary as this arrangement provided them with more opportunities for economic independence. The more familial protectionist bars were only convenient when sex demand was very low because the women were assured of free accommodation. These results suggest that being tethered to a venue owner can be disempowering to varying degrees and can result in different experiences among bar girls.

5.5.2 Freelancers

The experiences of bar girls differed fundamentally from those of freelancers: the freelancers were self-employed and self-reliant and enjoyed some level of autonomy. They managed their income and enjoyed free mobility. The FSW identity among freelancers was relatively invisible in the community and to their peers because the values and social norms of a ‘good woman’ subtly affected their practices and behaviours.

The acceptability and expectations of the values of a ‘good woman’ created a surveillance system that motivated the freelancers to regulate their behaviours and act as though society was watching them. To conceal their sex work identity, the freelancers usually travelled to the bars or the streets to solicit their customers at night, and seldom during the day. They would find a venue for sex work in the local rest houses, abandoned cars, car parks or bathrooms (shed-like outhouses at the back of houses).

> ***Interviewer****: So how does this happen?*
> ***Participant****: We sometimes go to the market. You know those benches where vendors lay their items for sale, right? … We just lean on the bench, and the customers enter from behind. They just do a quickie, pay us and off they go. –* ***Stailey, freelancer***

However, this invisibility did not translate into the reduced stigma. Although the FSW were not living at the bars, and even though there was no proof of sex work, the communities had the perception that the freelancers were ‘suspected’ FSW. Their age, marital and economic statuses, and household structure betrayed them. There was widespread speculation in the community that selling sex was common among single women who had no visible income-generating activities. These perceptions present a different interpretation from the widespread belief that sex for money is considered acceptable; it appears that the acceptability of sex for money was somewhat situational at this particular time. The practice of explicit or implicit exchange of sex for money is a normalised historical phenomenon in *chibwenzi*, which are transactional relationships in nature and persist in contemporary Malawi

(Forster, 2000). A man is socialised and expected to be a provider, and these roles, expectations and social norms shape acceptability and discourses around sex for money and reinforce the practice of sex work during economic hardships.

However, risks in the home or street environment affected the freedom enjoyed by the freelancers. Sex work conditions, risks of violence and levels of satisfaction with their financial earnings influenced the varied experiences of the FSW. The quotations below illustrate the differences in risks between the freelancers and the bar workers:

> *Aah, I have never been on the streets because it is dangerous. You stand on the street; you don't know the men you end up sleeping with, not even your peers know him. However, in the bar, the men buy you drinks, you dance with them, if you go missing or something happens, the peers will give you support, and they can say that "Aaah she was with a certain man, who looks like this", you hear me? Unlike on the streets, you just jump into the cars, and no one knows where you are going.* – ***Beckie, freelancer, mainly home-based but a bar girl when she was working outside Blantyre***

> *Sometimes, FSW who are home-based must solicit their customers from the bars in town, and there is a specific time for this kind of sex work, we leave home at night only. We wait for the neighbours in the community to go to sleep, and we try to come back before dawn; that is where the danger is [travelling at night]. That's where the difference is with venue-based sex work, FSW reside at the bar, and the customers find them there.* – ***Taylor, freelancer, mainly a street-based FSW but sometimes operating from home***

> *Venue-based sex work is better than home-based sex work because if you are operating from home, the community can attack you when they find out that you are sleeping with someone else's husband … when*

you are a venue-based FSW, people are aware that you are an FSW. –
Malika, freelancer

FSW linked their interpretations of vulnerabilities to a relative lack of protection in sex work conditions. There were obvious reasons why the violence rates were different between the freelancers and the bar girls. The freelancers lacked the institutional setting that defined the working experiences of the bar girls. The freelancers mainly operated in isolation, outdoors and in open spaces, and hence lacked peer and venue owner support regarding protection from physical harm. It was, therefore, not surprising that some participants referred to the freelancers as '*magobo*'. '*Magobo*' is a slang word used in Malawi to describe hard work, especially work that is associated with several risks. These spaces exposed the women to unknown men who posed as potential customers, getting stranded in unfamiliar places or at risk of meeting '*arobale*' (robbers), who were often pickpockets and purse/phone snatchers loitering around the communities or streets. In addition, freelancers were also at risk of being raped by 'street kids' or the police during their street raids, whereas the bar girls had the advantage of operating in more enclosed and indoor spaces where they had peers, venue owners or security guards for support. Due to the ongoing economic problems in Malawi, crime remains a fundamental problem, especially at night. In this context, if poverty pushes women into sex work, then one wonders what becomes of men. FSW stated that most unemployed men who had limited education and no visible source of income-generating activities were *arobale*, and men did indeed perpetrate most of the criminal offences that occur at night.

5.6 A space of vulnerability

In this section, I present a selection of the positions and identities of the FSW's personal and sexual relationships, which often indicated commonalities in their narratives of how social, economic, cultural and political contexts shaped the different kinds of harms they were exposed to. Sometimes the exposure to harm appeared to impact more on one group of

FSW than on others. Although discourses of vulnerability existed among this group, there was also evidence of the FSW resisting narratives of victimhood.

Photo 5: The paradox of money

This photograph is telling us that FSW can be vulnerable because of this money. – ***Mia, bar girl.***

Money was one of the motivations of FSW's individual freedom; conversely, it became a potential instrument of vulnerability.

The term 'space of vulnerability' has been investigated by some scholars to illustrate the causal factors of vulnerability (Watts & Bohle, 1993; Sanders, 2016) and to focus on the institutional and environmental determinants of vulnerabilities. Emmel and Hughes (2014) use the term to explore the nuances of lived experiences of deprivation. Sanders and Campbell (2007) state that the environment in which sex work happens has an intrinsic bearing on the safety of those who work there. Central to their argument is the idea that vulnerability involves relations between individuals and households, government institutions and services that address basic needs (Emmel and Hughes, 2010). A wide range of research has shown important diversity and differences of sex work vulnerabilities across sex work environments.

The FSW in this study portrayed a shared sense of vulnerability, although their accounts diverged in how they interpreted universalist vulnerability. The following excerpts paint a picture of FSW's expressions of their experiences in

sex work in Blantyre, with violence being a strong component of these narratives:

> *We don't know where we are going, we don't know the men we are going to meet, but we go to the streets to find the money. We meet the men, but we are not aware what kind of men we are exposing ourselves to, they can kill you while you are asleep, stab you with a knife, or even spike your drink. We are happy when we come back home alive, and we just say "Eee thank you, Lord, you have favoured me". –* ***Brielle, freelancer***

> *We meet violent men, we also meet men who just want to sleep with us and give us less money than agreed, and others who don't even pay, and some who beat us, we can even get infections. There are many things that we experience in sex work. –* ***Kim, bar girl***

5.6.1 Violence

Instances of physical, emotional, economic or sexual violence featured heavily in FSW's stories, as shown in the excerpts. Most commonly, violence was referred to in connection with the relationship between FSW and their customers, as well as feelings of uncertainty, fear and anxiety about the sex work environment. There were different forms of violence, resulting in FSW describing sex work as a high-risk business and describing their experiences of violence and ill health. In this case, sex work as a risky behaviour was a path that involved a challenge to obtain economic and social benefits even though there was an element of uncertainty involved in the outcome (Waterstone, 2012). There was a widespread expectation that FSW would experience one form of violence or another, but what was significant was that violence remained an everyday concern for FSW. Given the prevalence of violent incidents among FSW, some FSW believed that violence was intrinsic to the sex work environment.

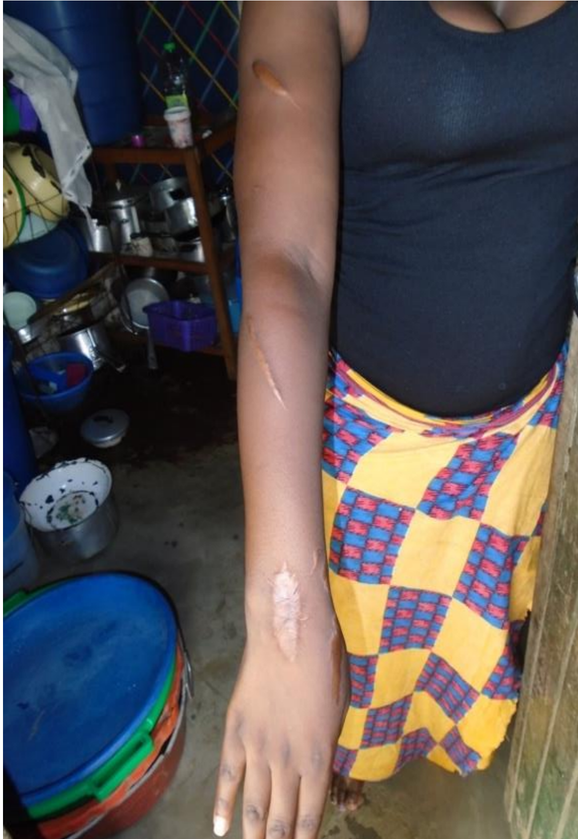
Some of the women's stories of violence perpetrated by customers were particularly brutal.

Case study 5: Ava

Ava was 24 years old, divorced, with one child. She had been a bar girl for about three years. Her mother and siblings lived in Suzo, a township in Blantyre, and her father was working in South Africa and barely came home or provided any financial support. He would occasionally call if there were critical family social issues, to give guidance. Ava invited me to her mother's house several times during the data collection period.
I first found her in Alba bar, but she later moved to Namachero as she was one of the FSW who were dismissed from work. She dropped out of school after getting pregnant by her ex-partner. They agreed to live together despite resistance from Ava's mother. The mother decided to give them a small house within their compound to keep an eye on Ava. Everything was going well during the first few months, but later the husband started drinking, sleeping outside the home, beating Ava after his drinking sprees and to an extent scolding his in-laws. Ava later divorced her husband, and she decided not to go back to live with her mother. Instead, she joined her friends who were working as FSW in the local bars. She started as a freelancer but later decided that this was not profitable because she was supposed to be paying rent. She left her daughter with her mother in Suzo and visited her every week when she was off duty.

Ava's experience of violence did not stop with marriage; like many FSW, this was one of her greatest fears. During the photovoice process Ava asked her friend to take a photo of her scars, shown below:

Photo 6: Each scar has a story



I went to a bar and met a man who requested a short-time. I slept with him and charged him K1,500 for the short-time. After that, we began drinking beer together in the bottle store. I got extremely drunk, I don't recall what happened, but we argued and fought. He cut me here with a bottle. I think I blacked out and woke up only to realise that I was in pain and the man had fled. I initially went to the clinic; however, they wouldn't help me without a police report, so I went to the police to collect the required letter. I returned to the clinic and this time they could treat me. The doctor gave me a report to pass to the man who assaulted me, but he was nowhere to be found. Later his friend informed me that he had migrated to South Africa. I told my mother about this; she knew the man and told me not to pursue the case any further since the man had fled the country, so I didn't. – ***Ava, bar girl***

FSW work in places where alcohol use is highly normalised (Lancaster *et al.*, 2018). Both FSW and their customers use alcohol as a strategy to facilitate sex work by reducing insecurities or to make them more comfortable when approaching each other (Li, Li and Stanton, 2010). Hazardous use of alcohol increases the risk of violence, as shown in Ava's case. Consensus largely exists in the literature regarding FSW's vulnerability to violence and its association with alcohol. A study in Kenya established that alcohol use among FSW and their customers increased violence and sexual risk behaviours (Chersich *et al.*, 2014). A study conducted by Lancaster et al. (2018) in

Malawi among FSW found that there was a direct link between drinking alcohol and risk of impaired cognition and violence, for both perpetrators and victims.

FSW also reported sexual and economic violence that they were fearful of and detested in their work. These included contractual disagreement such as men "*removing or puncturing condoms*" or refusing to pay or paying less than agreed for sex work. Knowledge of availability and accessibility of condoms was uniform among FSW. All the women understood the protective effects of condoms against STIs, HIV and pregnancy. Those who were HIV-positive knew about the risk of retransmission through condomless sex. In addition, non-payments threatened the very purpose of being in sex work because they translated into offering free sexual services. Fear and hate of this violence resulted from FSW's feelings of powerlessness and helplessness in challenging their customers to give them what they deserved or negotiating condom use as this could result in physical violence.

Violence occurs against the backdrop of a broader social context (Government of Malawi, 2014). These violent incidents do not target FSW only; rather, physical violence was a common feature in this context. As described in section 5.2, I found that there was a cycle of violence that FSW experienced throughout their lives as children or wives. In Malawi like most contexts in the world, both men and women are victims of GBV, but women bear the brunt of the practice, especially physical violence (12.4% versus 24.5%) (Bisika, 2008). Gendered power dynamics have normalised violence against women, and this is exacerbated by sex work. For instance, although women typically accept more active responsibility for negotiating safer sex, men are more likely to resist these efforts (Kaler, 2004; Chimbiri, 2007). This gender inequality indicates a level of powerlessness in safe sex negotiations and a lack of control in how women would like to protect their bodies from HIV infection.

However, FSW experienced a disproportionate burden of GBV compared to women outside sex work due to their marginalised status in society and

unsupportive laws in Malawi. Communities' perceptions of FSW as deviants and bad women for selling sex made them even greater targets of violence by men. The customers expected FSW to do more than a 'good woman' does to a man to prove the customers their wealth – that is, performing better in bed and being more submissive and subordinate to a man. Further, Malawi's complex and confusing laws on sex work render FSW second-class citizens, a position that reinforces the inequalities that FSW face, and men know they can act with impunity.

The literature on the challenges of disclosing and reporting GBV cases in Malawi is vast (Mkandawire, 2012; Chepuka *et al.*, 2014; Government of Malawi, 2014). In Malawi, as in most SSA countries, a culture of silence and structural violence impedes disclosure and reporting of violent incidents (Mkandawire, 2009). Perceptions of GBV as a family and domestic matter or an embarrassment and source of stigma also ensure non-disclosure and non-reporting of GBV for women outside sex work. In addition, the acceptability of GBV seems to be institutionalised as legal authorities rarely take appropriate action to protect women against GBV, and many women are victimised through insensitive and accusatory lines of questioning by police (Mkandawire, 2009). The failure of healthcare and police facilities also constrains FSW from reporting GBV incidents. Ava's case provides an example of the relationship between health and law enforcement systems and the procedures that can prevent FSW from reporting cases and receiving treatment after being assaulted. Sending Ava back to the community to identify a person who assaulted her would have endangered Ava's life. In addition, it is worrying to see that health clinics would not attend to her until she had been to the police, despite the severity of her injuries.

5.6.2 Stigma and discrimination

In my study, there was no indication of a cultural shift in how communities view sex work. In FSW's narratives, their interpretation of their sexual behaviour differed from those of the community around them. The communities judged FSW on moral grounds, as indicated in the previous

sections. However, FSW believed that there was a rational justification for why they took the risk of being an FSW. For FSW, sex work was a way of conforming to the social responsibility of taking care of their families in situations of limited economic opportunities.

The association between the invisibility of a freelancer's identity and stigma reduction proved to be complex in this context. Although the freelancers valued this invisibility, they were vulnerable to community attacks once it was discovered that they were sleeping with someone else's partner, whereas for bar girls, people in the communities were aware of their sexual behaviour because of their visibility at the bars so they would not face the same punishment. Sex work or sleeping with someone else's husband was more acceptable in the bar context on the basis that "*mu bar mulibe mkazi wa mwini kapena mwamuna wamwini*" ("in the bar there is no such thing as my girlfriend/wife or boyfriend/husband"). This phrase was a bar rule scribbled on the walls to mitigate any relationship conflicts or violence. The venue owners would verbally discipline an FSW if she was the culprit in a violent incident or restrict a customer's entry to the bar if he was the culprit. For instance, *Madala* reported others to the community police for punishment if the violence involved fights. However, this was relative because not all venue owners offered protection to bar girls, as indicated earlier.

However, some freelancers resisted the negative connotations of sex work. They maintained private and public identities: a private, sex work life and a public 'housewife' image. These identities were ideal; they were respectable women or mothers during the day just like any other housewife and switched to an FSW identity at night. They had to walk, get a taxi or risk taking a lift from a stranger, and pack a change of clothes or wear *chitenje* (cloth wrapper) when going to or coming from the bars. This strategy allowed them to assert a specific favourable identity in the community to adhere to behavioural prescriptions and morals, but not necessarily to change the position of FSW. Drawing on Foucault, Kearins (1996) argues that power does not necessarily produce conformity; instead, it produces individuality. Society as a governing body of knowledge produces values, beliefs and

norms that result in a discourse of norms and normality, to which individuals desire to conform. Individuals control themselves by conforming to cultural norms through self-surveillance and self-disciplinary practices. The concealment of sex work by some FSW, by remaining discreet and invisible and distancing themselves from the FSW identity, shows greater efficiency and acceptance of the normalisation of a 'good woman'. They referred to this as conducting "*respectable sex work*".

Case study 6: Beckie

Beckie was 37 years old and working as a freelancer. She classified herself as one of the high-earning FSW because she targeted "*the biggies*" for her sex work clientele. She had three children from her previous marriage. She joined sex work after the death of both parents. The relatives who took her and her siblings did not provide adequate support. She got married when she was 16 years old, then divorced. She remarried and divorced again. Both divorces were due to experiences of violence in the relationships. She was introduced to sex work through friends who were already working as FSW. She was doing very well: she sent her children to school looked after her siblings and their children and was able to pay rent and buy food for her household. Beckie was living with a new partner whom she had met through sex work, but this did not stop her from going for sex work, although the partner despised it. Unfortunately, the new partner had no job, and so Beckie could only meet her needs and those of her family through sex work.

Like many freelancers in the community, Beckie experienced stigma and discrimination from her neighbours when she tried to secure a house in the community:

For example, when the landlord gave me the house where I live now, some neighbours went to the landlord to tell him "don't give her the house, she is going to break our marriages here, she also has a partner,

that means your house will be destroyed as well because her customers will be fighting when they find out that she has a stable partner.

Beckie's quotation further highlights how the fact that she had recently found a partner did not automatically offset her position as a 'suspected FSW'; instead, the community perceived it as a cause of more threat and a warrant for her exclusion in the community. FSW deviate from the ideal woman as constructed in this context and are considered unable to restrain their sexuality like other women and to be based in spaces where women are not supposed to be in the community. Social norms about sexuality reinforce the shaming of women who visibly show their active sexual lives more than that of men who exhibit similar behaviour. Some FSW reported that they were socialised from their childhood to think about sex as something terrible and risky. They were taught to fear men and not to engage in sex because they could get pregnant and get STIs (Stoebenau *et al.*, 2016), whereas other studies report that men are usually socialised to explore their sexuality (Swidler and Watkins, 2007). Arguably, gendered norms in these communities exacerbated the FSW's physical, social and economic vulnerabilities.

Here, the narratives of vulnerability have accommodated diverse understandings and interpretations in which safety, protection and social support have remained an everyday concern for the FSW. The findings suggest that ideas about 'inevitability of their vulnerability' are shared by FSW to some extent. FSW's experiences of vulnerability and their choices were contingent on the social context and the geographical location of their workspace. Over time, as FSW gained experience in their job, they learnt about the risks involved in sex work.

There is an indication in these narratives that some of the counter-responses to vulnerability or anti-vulnerability regulated FSW's behaviours in ways that conformed to particular norms about the correct or appropriate behaviour of a good social citizen. However, these efforts were insufficient to challenge the dominant, stigmatising representation of sex work. Rather, these narratives suggest that the normative representation of sex work prevails among FSW,

yet some FSW find ways through self-governmentality to exercise their agency.

5.7 Sex work and pleasure

Some FSW resisted the notion of victimhood in their sexual expressions. They maintained that there were times when they combined sex work and pleasure. Women admitted that health promotion messages compelled them to always use a condom with all their sexual partners due to high STI risk. However, most FSW perceived protected sex as unexciting and argued that there was pleasure in 'plain sex' and that they sometimes needed it.

> *We need vitamin K, and everyone needs it. You can't be eating sweets in the wrapper every day. Sometimes we need to take off the wrapper to have a better taste of the sweet. The vitamin is necessary for strength.* – ***Lindani, bar girl***

Sexual pleasure and beliefs around the nutritional value of semen, and that it was necessary for a woman's body, justified the longing for 'plain sex'. There was a heated debate around condom use in sex work during the FSW's FGD, where some FSW argued for consistent use of condoms, raising pregnancy and STI infections as potential risks, while others stated that sometimes FSW had to enjoy their sexuality. They concluded the discussion with the agreement that sex work should be able to accommodate both work and pleasure but that other contraceptive methods should be used to prevent pregnancy because they could not afford to have babies by strangers.

The customer who was "*privileged*" to receive 'plain sex' would not necessarily be a regular or stable partner, but someone they consciously chose. The FSW targeted younger men for these pleasurable encounters because they were assumed to have "*magazi a fresh*" (fresh blood) or uncontaminated blood. The critical aspect of this discussion was the visibility of FSW's agency in condom use decision-making, which contradicted the normative perception of condom use. Some studies have represented FSW

as inevitably succumbing to the pressures of masculinity needs in the context of condom use (Simengwa, 2016; Twizelimana and Muula, 2015). In Lindani's case, the point is not to ignore the risk of having unprotected sex but to understand the context of how FSW negotiate condom use in sex work and their expressions of agency regarding their own sexuality.

Despite this discourse, Hailey (in Case study 1) exercised agency in negotiating condom use, which translated into her consistent use with all partners. Knowledge of her HIV-negative status and the efficacy of condoms in protecting HIV infection and other STIs largely informed her decision to maintain 'self-discipline'. Her narrative of agency can also be attributed to her strong personality and the fact that she was not afraid to say no to men if she disagreed with them – for example, she was the only one who had had a late sexual debut at the age of 21 years. Her long-term goal was to maintain a body image that was desirable to maintain her sex work position. However, this did not affect her sex work earnings as there was no observable difference from those of her peers who offered unprotected sex.

I previously reported, in section 5.6.1, that FSW were concerned about men who pierced condoms, thus exacerbating their risk for HIV and other STIs. I explored the actions that women employed when they found themselves in this situation. Some indicated that they demanded extra money from the customer because they were aware of the risk for STIs and the need for treatment if they were infected. Some reported that they had developed strategies of using female condoms as a discreet method of preventing HIV infection from men who refused to wear condoms. However, the female condoms were not readily accessible in their communities. There were a few women who reported that they did not like the appearance of the female condom so they would not use it.

5.8 "*Sex work is not like it used to be before*": factors influencing changes in sex work

The exercise of power is not limited to the functions and behaviours that make power relations immediately observable, as illuminated in the relationships between FSW and venue owners or communities. In this section, I discuss how social, political and economic structures have directly and indirectly reconfigured sex work discourses and practices in the sex work market in Blantyre.

5.8.1 Changes in the economic and political landscape in Malawi

> ***Participant****: Although I am still doing sex work, things are not the same, it is terrible … it is different from the past when we had money.*
> ***Interviewer****: What do you mean?*
> ***Participant****: Problems … you can stay for four days without a single tambala, and sometimes you come back with K1,000. –* ***Willow, freelancer for more than 20 years***

> *Aaaaah things are not going well now compared to the past, people used to buy land or build a house, as I said, my children are attending excellent schools, but now there is no money, everyone [the customers] is saying that they would rather take care of their wives than spend their money on sex work.* ***– Peyton, freelancer for more than 20 years.***

It was evident that economic conditions in the country had directly affected the demand for and pricing of sex work. While women acknowledged that they were involved in sex work for varied reasons, including money and partnerships, they lamented the changes in conditions since the time they started sex work. They referred to the fact that they used to have relative economic independence compared to now. As stated in Chapter 3, in Malawi high rates of poverty have persisted due to volatile and weak economic growth, compounded by high population growth, environmental degradation

and policies that profoundly impact on Malawi's predominantly agricultural economy (Tostensen, 2017). Between 2011 and 2017, drought and famine increased rural poverty, while national poverty remained stagnant. Poverty (using the international poverty line: $1.90) reduced marginally from 69.2% in 2017 to 69.0% in 2018 (World Bank Group, 2018). These economic changes had an impact on the experience of sex work and reflect broader economic experiences.

This revelation of changes in sex work also illuminates stagnant sex work prices and reduced frequency of sex work. Prices over the years have not kept pace with increasing inflation in Malawi. Here, Willow, highlights how sex work prices had fluctuated and price negotiation had become even more challenging:

> ***Interviewer****: How much do you make per day?*
> ***Participant****: As I said, things are different now, like now, I come back with MK1,000 or MK2,000, so what can you buy with this MK2,000 considering the high prices of goods?*
> ***Interviewer****: Mmmh.*
> ***Participant****: What can you buy? Sugar and bread, that's it … that is why we go out on Monday, Friday …*
> ***Interviewer****: Uh-huh.*
> ***Participant****: Saturday to Monday without rest.*
> ***Interviewer****: Uh-huh.*
> ***Participant****: Before, when you say MK3,000 they [customers] wouldn't complain, MK4,000 they wouldn't complain, but now you will hear "eeh woman … [laughter] … this stinky thing [indicating a woman's genitals] …"*
> ***Interviewer****: [laughter]*
> ***Participant****: "… even if you used ten Lifebuoys [type of soap] it would still stink" [laughter].* – ***Willow, freelancer***

For Willow and Peyton, this was a stark contrast for women who had previously profited from sex work; not only had prices changed, but so had

timing and frequency of demand. Past experience of sex work demand, which had previously fluctuated in a predictable manner (peaking at weekends and around payday), informed the construction of this narrative. Economic decline, however, had reduced opportunities for regular sex work, because local men did not have disposable income to buy drinks or to pay for sex, hence they purchased sex on an ad hoc basis. This situation can be typical of informal employment, which lacks formal structures for adjustment to macroeconomic changes. Older women were able to analyse economic and political trends due to their longer experience of sex work.

> *… there are money issues; it's simply that things are not functioning admirably with this present government, eh, things are not functioning admirably since this administration came into power. It was better during 'aChair's' (a name given to Bakili Muluzi by communities) [time] … individuals would go to town and they would sometimes meet the president who might throw a sack loaded with money, however it was counterfeit MK50, yet despite everything, we got something … this implied we would likewise get something even if we were not there.* – ***Peyton, freelancer***

Peyton's statement referred to the time when Malawi attained political liberalism and Bakili Muluzi was the president. Political and economic analysts describe this regime as "a period of decentralised, short-horizon rent management and a further deterioration of the state bureaucracy" (Cammack and Kelsall, 2011, p. 88). This was the period that older FSW referred to as productive years for FSW. Peyton was aware of the fake money and corruption rumours that were circulating but ignored the implications of the president's actions. The acceptability of the fake money in the community highlights the self-interested reasoning of happenings in the political, economic and social spheres, which then trickled down to sex work operations. The women were not passive agents in all these situations; over time, they developed methods of vetting potentially dangerous acts, exploitation and manipulation. Peyton also reflected on the changes in government and the limited circulation of money, which meant that sex work

customers did not have disposable money to pay for sex work. This situation highlights the critical role of the interplay of political and economic influences with other structural, relational and individual factors (Månsson and Hedin, 1999).

5.8.2 Beliefs and social relationships

In addition to the deteriorating local economy, other social changes have impacted on the demand for sex work. FSW believed that their current difficult predicament was due to the rise of prosperity and prophetic gospel among Christians. Their churches preached about accumulation through miracles and prophecies. Despite many FSW admitting that they were irregular churchgoers, they remained religious, and were mainly Christians. They believed that prayer changed things, things outside of themselves, and held the potential to change the course of history. In addition, prophetic messages were always considered accurate by believers. Some FSW believed that some of their customers' partners were taking part in these prosperity and prophetic gospel churches and were, therefore, praying for their partners to stop drinking alcohol or sleeping with FSW. The FSW stated that these prayers were working as there was a decrease in the number of men in the bars; the few who came would drink a few cartons of *Chibuku* and leave without requesting sex work. In addition, alcohol cessation by some customers translated into their not visiting the bars and hence reduced sex work demand and income for FSW.

Competition for customers was common in the sex work market and constrained FSW's ability to discuss better sex work prices among themselves amicably. Physical appearance, age and sex performance were some of the important factors in how an FSW identified herself and how she could sustain her position in sex work compared to her peers. The women strived to look their best to attract customers by using make-up, altering their body parts (by elongating their labia), and in some cases using traditional medicine to enhance their beauty. Competition between older and younger FSW was apparent. Some FSW's reports showed that younger and older

groups rarely reached consensus on anything and they maintained a blame game. For instance, their discussions about increasing prices proved futile because the younger FSW argued that older women were comfortable with the prices. It was more viable for older women to accept low prices during periods of economic decline because it made more sense for older women to make money for the day than to increase the price and have no customers.

In contrast, older FSW argued that younger FSW were not entirely aware of sex pricing processes and were fine with the low prices because they were new in the field of sex work. As a result, it was a challenge for them to establish social cohesion among themselves to enact proper negotiation for changes in sex work prices. Social cohesion in this context occurred in small group settings determined by a sense of belonging to the same age group or place of origin. Social cohesion is essential for social change. There was no consensus on this issue, and it is evident that most of the decisions made by either younger or older women were very individualistic. The relationship between the younger and older FSW illuminates the heterogeneity of FSW and the complexity of social cohesion, and it is one factor in the lack of social change among FSW. This feud between younger and older FSW, combined with the poor economy, resulted in stagnant sex work prices. These narratives also highlight how complex it would be for FSW to take collective action in the context of these relationships. As noted here, progressive actions are fragmented and sometimes constrained by power relations in various sex work environments.

5.9 HIV risk

In this section, I discuss the cultural logic that lies behind FSW's decisions on safe sex and perceptions of HIV risk.

Knowledge of sexual risk behaviour in sex work prompted FSW to have fatalistic ideas about HIV risk. Fatalism is the belief that there is a superior power controlling people's lives (Hess and McKinney, 2007). They knew that sex is part of the job they do. Women based HIV risk perceptions on the belief

that those involved in sex work had sufficient information about the risks of having "*multiple partners*" or "*challenges in negotiating condom use with customers*".

Photo 7: HIV risk

Eeh, it is difficult to avoid these [STIs], how can I say that I am going to protect myself from these [STIs and HIV] yet I am still going to these places? – ***Brielle, freelancer***

In some cases, women used metaphors such as "*ukufa lero safamawa"* ("one who is supposed to die today will not die tomorrow") or "*matenda anabwelera anthu"* ("illnesses have come for people") to explain their world view around HIV risk: that disease is inescapable for humanity and therefore vulnerability is universal and unavoidable.

This photo, selected by a bar girl, depicts seven condoms used in one night by one FSW. This photograph generated discussion about FSW's HIV risk perception. They discussed how, as FSW, they recognised their vulnerability to HIV infection but thought "*it is inevitable for an FSW to get HIV*" due to issues around poverty and lack of trustworthiness in stable partnerships, which limit their ability to protect themselves against HIV infection.

One participant in the discussion said

> *it is sad, but we have bigger things to worry about. I have two children to look after, even my mother looks up to me.* - **Mia, bar girl**

This perception instilled the idea of the inevitability of HIV infection. Many studies similar setting have established the link between fatalism and belief in the inevitability of HIV infection (Twizelimana and Muula, 2015; Sileo *et al.*, 2019). A study in Nigeria found that fatalism was a typical response to the discrepancies between knowledge of HV risk and risky sexual behaviours (Ankomah *et al.*, 2011). In my study, FSW knew about the risks of their sexual behaviours and were aware of their feelings of powerlessness in negotiating safe sex, and hence they became fatalistic because they felt that they were doomed irrespective of what they did. Hence, this type of fatalism is the ultimate vulnerability: vulnerablility to their own inevitable fate. Meyer-Weitz (2005, p. 75) argues that people who show “low self-efficacy to effect change, a low living standard, and feelings of hopelessness were more likely to express a fatalistic attitude towards HIV protection than others”.

Despite FSW having knowledge of condom efficacy, there were conspiracy theories and mistrust over the use of condoms circulating in their communities. In relation to biopower, FSW in this study considered condoms to carry a form of institutionalised power to infect the wider local communities with a new epidemic. I discovered that there were rumours in the communities that the lubricant in the condoms was causing fibroids in women. Scientifically, the aetiology of fibroids is generally unknown (Ernest, Mwakalebela and Mpondo, 2016). The myths around condom use were a cause of anxiety among older FSW and would sometimes cast doubt on the efficacy and effects of condom use. Indeed, the interpretation of these rumours about the association of fibroids with condoms discouraged some FSW from choosing to use condoms consistently. Also, there was a lack of clarity on condom technology, which led to the spread of rumours influencing decision-making in condom use.

Another significant factor that was viewed by many FSW as increasing vulnerability concerned periods of transition that were closely linked to partnerships and geographical location. They were aware of the dangers of mixing sex work with love and trust, which they believed transitioned to plain sex. FSW’s vulnerability was considered to vary over time and throughout an

FSW's life course. Being with *chibwenzi* was considered high risk for HIV infection. As stated earlier, remarriages were common among this group of women and *chibwenzi* was the courtship process leading to marriage. The association between inconsistent condom use and types of partners among FSW is well established in the literature *chibwenzi* (Tan and Melendez-Torres, 2016). Through sex work experience, women were aware of how regular sex work partnerships transitioned to *chibwenzi* that involved trust and intimacy, and how hard it was to negotiate protected sex in such relationships, exacerbating their risk for HIV infection.

5.10 Summary

This chapter has demonstrated that FSW exercised limited power across their life course although their stories highlighted both a sense of agency and societal constraints shaping their decisions to engage and remain in sex work. The economic vulnerability of FSW was created by an intersection of local gender power relations and the global political economy. The main reason for engaging in sex work was lack of access to male income through a father or husband. Rather than relying on a husband, partner or male relatives, sex work allowed FSW to make choices free from this pressure. Sometimes sex work offered FSW increased opportunities to exercise agency towards promoting their well-being, through both greater access to resources and relative decision making in how their money was spent. However, sex work renders women less powerful in other spheres of their lives, which creates new vulnerabilities to violence and ill-health.

FSW perceived their vulnerability as both inevitable and situational. Inevitable because of their exposure to HIV infection and violence, and situational because FSW's experiences of vulnerability differed according to sex work type and location. Unequal power relations between venue owners and bar girls increased bar girls' vulnerability to economic exploitation. Whereas, the freelancers had more autonomy and economic independence than the bar girls because they were not tethered to venue owners. GBV was pervasive in the sex work environment, and lack of social and legal support after an

assault in the sex work context affected GBV reporting. FSW interpretation of HIV risk were largely informed by their cultural and individual frameworks, and partially by biomedical understandings of risk of HIV transmission.

Although sex work increased FSW's 'well-being (though in limited ways), none of the participants hoped to engage in sex work in the long term due to social stigma attached to sex work, violence experienced in sex work, and need to (re)integrate into a societally acceptable social identity.

6 The impact of HIVST on FSW's experiences of vulnerability and agency

6.1 Introduction

In the previous chapter, I discussed power relations and vulnerabilities of FSW in their social environment. Given this background, in this chapter, I focus on the impact of HIVST in addressing, reinforcing or producing forms of power in the sex work environment. I discuss both the peer-led delivery model of HIVST implementation and HIVST technology and the vulnerabilities or opportunities it offers to FSW. I highlight the experiences of FSW with HIVST and how HIVST, with its multiple uses and transformations, has shaped FSW's identities and subjectivities. HIVST has mediated new ways of FSW relating to their peers and their community and evoked new ways of feeling and being in the world in the context of HIV prevention.

Following this introduction, I provide a description of the HIVST implementation process in section 6.2; in sections 6.3–6.3.4, I explore the PDs' positionality in the implementation and how different contexts and positionalities shape FSW's engagement. I also explore power relations and resistance and how these factors shaped the uptake of HIVST among FSW. In sections 6.4–6.4.4.2, I discuss the effect of the HIVST distribution model on FSW's agency and vulnerability. Then, in sections 6.5–6.5.4, I discuss the rationales for HIVST uptake, and I give a summary of the chapter in section 6.6.

6.2 Description of the HIVST implementation process

The motive for the peer-led delivery model was to increase the acceptability of the intervention and create demand for HIVST. Before the implementation, Pakachere created a list of targeted venues that they believed accommodated both freelancers and bar girls. They also created criteria for the ideal PD for the distribution of kits. Attributes of the ideal PD were "trustworthiness, willingness to work as a volunteer with her peers, and literacy". During

recruitment, the intervention coordinators from Pakachere visited sex work venues and mobilised FSW with the support of the venue owners to elect an FSW who would represent her peers in the intervention based on the prescribed criteria. Through this process, FSW elected 12 PDs in Blantyre. The results from the HIVST formative studies with FSW in Blantyre, Chikhwawa and Mulanje informed the development of training materials for distribution, which centred on the introduction to HIVST, distribution of HIVST to their peers, ethical issues and how to mitigate them during distribution, interpersonal skills and HIV prevention, and treatment referral procedures once a person has tested HIV-positive.

In the intervention, the key responsibilities of the PDs were to

1. create demand for HIVST
2. distribute self-testing kits to FSW and their partners
3. follow up FSW and their partners who accessed HIVST to
    a. establish self-testing kit usage
    b. organise the return of self-testing kits
    c. report social harms related to HIVST
4. link FSW to care.

Through a formal recruitment process of job advertisements and interviews, Pakachere recruited three LPDs, one for each district. The key role of the LPDs was to supervise, support and mentor the PDs, and conduct monthly meetings to ensure optimal performance.

After three months of implementation, during the monthly meetings between Pakachere and the PDs it was established that the number of HIVST kits distributed was suboptimal. It soon became apparent that the PDs had reached a saturation point within their communities (almost everyone had self-tested). In response to the suboptimal performance, Pakachere introduced an ‘acceleration plan’ (a plan designed to speed up the distribution process), which included monetary incentives for the PDs to achieve distribution targets. Each PD from Blantyre was required to distribute at least 100 HIVST kits per

month. The introduction of incentives in the ‘acceleration plan’ had a significant impact on the distribution process: some PDs achieved or even beat their targets. However, the organisation still did not meet its target. At the end of the five months of distribution, the PDs had distributed a total of 5,281 out of 10,022 kits in the three districts. In Blantyre, they distributed a total of 2,001 kits, representing 38%. Despite Blantyre being a city with more sex work venues than Mulanje or Chikhwawa, it was Mulanje that had the highest HIVST uptake.

Table 3: Overall distribution of HIVST kits among FSW in Blantyre, Chikhwawa and Mulanje

District	**Total**	**%**
Mulanje	2,043	39
Chikhwawa	1,237	23
Blantyre	2,001	38
Total	**5,281**	**100**

Pakachere attributed the low HIVST uptake to logistical challenges during HIVST implementation. This limitation was due to the high mobility of FSW at the time of implementation and the short time frame for implementation. In the Family Planning Association of Malawi (FPAM) 2016 report (FPAM, 2016), it was estimated that there were approximately 3,000 FSW living in Blantyre and, as reported in Chapter 5, FSW are highly mobile so they might have relocated to other areas where sex work demand was high. The LPD confirmed that most FSW had relocated to Mulanje due to the high demand for sex work in this area. Mulanje attracted FSW during tea harvesting season, which led to the lower numbers of FSW living in Blantyre at the time of HIVST implementation. In addition, Pakachere only had five months to deliver HIVST distribution so, they argued, this was not enough to meet the target. This suggests that there is a need to carefully map FSW mobility around the agricultural season, for example, in this setting, and to plan implementation programmes that target FSW in appropriate seasons and locations. This also indicates a problem with focusing on the target of test

distribution rather than linkage to care, which is the ultimate intended outcome. This created a perverse incentive just to get tests out, regardless of need.

6.3 PDs' positionality in the HIVST intervention

A prerequisite for HIVST implementation among FSW was the active involvement of FSW for effective delivery of HIVST to increase testing coverage and testing frequency among women in Blantyre. As I explained in Chapter 2, the peer-led delivery model is implemented on the premise that individuals make changes based not only on what they know but also on the opinions and actions of their peers. In this section, I discuss the positionality of the PDs, which was important in both the implementation of and the response to HIVST.

6.3.1 Perceptions of common background

In this study, the PDs saw their role as important because they interacted with their peers, those of similar background, interests and social expectations, in a way that outsiders would lack.

> *Do they [implementers] know where to find FSW? No, it is us, we know each other and where we hang out. They knew that they would not manage to do this work without us, that is why we were involved, and indeed we managed to achieve the targets. –* ***Kim, freelancer***

The PDs offered a feasible way of doing surveillance in sex work communities. The PDs reported that they possessed knowledge of their context – the sex work venues – and FSW's social activities and were familiar with FSW's mobility and language. The PDs even mapped sex work venues that were not previously listed by Pakachere worked out strategies to reach out to their peers and ensured that their peers made links with care services.

6.3.2 PDs as agents of the implementation process

The PDs believed they were valued not only for their acceptability and credibility in the peer community but also as Pakachere's best means of generating accurate information, usable data and programmatic evidence. This role was not contingent on their existing level of health awareness, but on the access they had to local communities; reaching out to these communities is understood to be the riskiest and challenging aspect of HIV work. The role of the PDs, therefore, reconfigures the power relations between the implementers and FSW (as agents of the implementers and a means of dispersing power in their localities), as well as the power relations between the PDs and their peers.

The PDs also played a critical role in psychosocial support among their peers. As indicated in Chapter 4, most PDs were born and bred in the respective communities that they were designated during the intervention. Familiarity with their environment equipped them with negotiating power during HIVST delivery as they had a good rapport with most FSW in their locations. The levels of trust and comfort between the PDs and their peers facilitated more open discussions on sensitive topics and reduced anxieties about testing.

6.4 Peer-led distribution model as empowering

During the implementation of HIVST, it was crucial to understand the effect of the mode of delivery on HIVST uptake among a highly stigmatised population. Access to sex work communities in contexts where HIV is highly stigmatised remains a challenge for public health programmes (Kerrigan *et al.*, 2013). To run an intervention programme, there was a need to know a lot about the community and their perspectives, and issues within the sex trade and its relationship with wider society – thus, to be an insider.

While the engagement of FSW was a prerequisite during implementation, I wondered what effect this had on relationships between Pakachere, PDs and FSW. I explored the expectations of these groups, from their participation to the kinds of power that were produced in their relationships during

implementation, which also accounted for how well each group tolerated other groups' failures.

6.4.1 Communication

The PDs cited a lack of communication of the important aspects of implementation as one of the challenges during implementation. I noted that the responses from the PDs reflected a lack of clarity on the information they had received on their role from the beginning of implementation. The PDs stated lack of transparency on the distribution plan and shared goals, which negatively affected the distribution process. The intervention coordinator admitted that some issues were not clarified during of the initiation of the PDs to the HIVST intervention, which included issues of targets for distribution; however, the intervention coordinator argued that this was not intentional, and this was why the acceleration plan was introduced. The lack of information meant that the PDs had the opportunity to control the pace of distribution and commit as little time as possible to distribution; however, this negatively affected the distribution numbers.

Apart from the distribution role, there was also a disconnection between Pakachere and the needs of the PDs that were to be prioritised during the implementation. While it was common for the PDs to be in the communities to monitor the uptake of kits and act as 'whistle-blowers' about any harms resulting from HIVST, the key informants raised two key concerns about the PDs: high mobility during the implementation and inefficiency in providing reports, which resulted in the untimely analysis of data and the failure to make timely decisions on implementation as they arose. The PDs reported that the PD role was too demanding, and impacted on their sex work role and family life, and impacted more on those PDs who were bar girls:

> *I can't lie that it was easy – imagine, I had to think about getting customers for the night, distribution of kits and even the venue owners wanted us to do our shifts as well. We prioritised where we received more money … from the men … because you know they [Pakachere]*

> *started giving us money when we complained that the work was demanding.* – ***Alefa, PD, bar girl***

This quotation suggests that the PDs appreciated the value of HIVST distribution, and tried to balance sex work, HIVST kit distribution and bar work even though they had personal financial needs to address. Given this, they were exercising their agency and acting in response to these circumstances. This finding confirms the experiences of FSW in peer-led intervention in other settings where FSW have expressed challenges in combining different roles in light of their involvement in FSW interventions (Kerrigan *et al.*, 2013).

The PDs felt that Pakachere did not meet their needs concerning financial incentives. Most PDs reported that, as agreed at the intervention initiation, they expected a substantial financial incentive at the end of distribution as a token of appreciation, but Pakachere did not provide this.

> *They really disappointed us with this issue [about the incentives]. They promised us something that they could not keep. But you know, we are children, and they are our elders. When they want us to do this job again, we will do it because we want to help our friends. There was nothing else we could have done to persuade them to give us the money.* – ***Jando, PD, freelancer***

Although there was still visible anger and disappointment during the discussions, the PDs felt powerless and too inferior to influence Pakachere's decision on incentives. There was a clear power imbalance indicated in likening the PDs and Pakachere to children and parents. Even after the implementation, the PDs described themselves as children and Pakachere as adults, suggesting the long-term impact of the relationship that Pakachere had with the PDs. This section gives a clear indication that involvement of FSW in the intervention did not completely offset the power imbalances that exist between implementers and target populations, hence reinforcing the vulnerabilities of FSW about feelings of powerlessness and hopelessness in such types of relationships.

6.4.2 Knowledge and skills

A common view among the PDs was that, initially, it was difficult to internalise HIVST information and communicate it to ensure uptake of HIVST among their peers. The PDs indicated that the information was new and that the responsibility of the PDs was not merely HIVST distribution and information dissemination; rather, it included behaviour change and behaviour monitoring.

> *Given that this thing [HIVST] was new, we needed much support in the beginning. This was for us to comprehend the information to allow us to perform our roles better in the communities when distributing the kits. Eeeh, it was challenging though, our friends needed much information about why we were targeting FSW only, some were asking why we were the ones distributing the kits instead of healthcare workers, but it became easier in due course as we developed ways of approaching our friends.* – ***Joy, PD, freelancer***

In this context, legitimacy, credibility and trust were essential beacons when approaching a marginalised population to create and sustain demand for HIVST. This initiative called for creative ways of constructing and framing HIVST messages, as HIV testing, per se, was not a novel idea. However, as HIVST was a new intervention among FSW, the technology prompted rumours that inevitably could have influenced the use of the test. Mainly, these rumours concerned individual financial benefits from the intervention or the belief that the PDs were using the used HIVST kits for satanic rituals. In response, the PDs had to create messages to mitigate these rumours and anxieties about HIV testing. They framed HIVST using the following:

1. the innovative non-invasive nature of the technology – something new and modern, unlike the traditional methods of conducting an HIV test (finger pricking)
2. the results from HIVST being comparable to those of conventional HIV testing technologies

3. encouraging those who doubted the credibility of the technology to confirm their results at health centres with traditional HIV testing methods
4. specifying that the ‘government’ was an authoritative body of implementation of HIVST among FSW.

For the FSW to trust and use the kit, the PDs had to construct a message around the legitimacy of the HIVST technology to increase uptake. They stated that the government had considered improving the lives of FSW in their communities with the use of the new HIV testing technology to address their HIV testing needs.

> *“Ahh you are one of the bloodsuckers” – I used to say no, the government has approved these tools and they have favoured us, after their HIV testing uptake analysis they found that FSW work all night, and they get tired so they don’t test. So, they have given us this opportunity for us to test ourselves and know our status. –* ***Namurayi, PD, freelancer***

This quotation emphasises the relationship between the state and its citizens regarding public health intervention. In Malawi, historically, public health interventions and campaigns have been understood as endorsed by the government. Hence, the PDs took advantage of this rhetoric to legitimise the introduction of HIVST. From this relationship between the state and FSW stem new regimes of governmentality and disciplinary power to transform the stigma of risk and define risk management as a shared value of the state and FSW (Lakkimsetti, 2014). This approach disperses state power and makes FSW responsible for regulating and monitoring their HIV risk and articulating these new forms of governance. The mechanisms of discipline and regulation are not directly repressive, but they facilitate new modes of accountability through the technologies of legitimate risk reduction as a biopower intervention. The inclusion of FSW into these programmes as both implementers and targets, therefore, bridges the moral distinction between the state and its citizens.

The PDs' knowledge of HIVST accounted for the reconfigured power relations between the PDs and their peers. Knowledge and skills acquired from this intervention brought new forms of governmentality where the PDs had credibility separate from that of the state or an NGO to govern and enforce uptake of HIVST among their peers. It was common among the PDs to describe empowerment as having access to information about HIVST and ethical issues; the availability of a support system; and the advantage of being familiar with the sex work communities, which gave the PDs power to influence their peers to engage with HIVST. In this case, empowerment meant the ability to influence their peers and offer support to make positive choices (as defined in health promotion messages, for example, treatment initiation and using condoms with all customers) regarding HIV testing, treatment and prevention.

Knowledge and skills obtained during the training were also applicable to their everyday lives and interactions with various groups. Some PDs admitted to changing their behaviours on attaining this role:

> *Like me, I was never like this, I used to beat people. Most girls never got close to me, they were so afraid of me. But when I started this job, it all changed. That training changed me a lot, I became a better person. I now relate to people better than before.* – ***Miranda, PD, freelancer.***

The PDs had to maintain self-discipline in their communities in order to be exemplary among their peers. They were to remain calm and respectful at all times. What most FSW found more important during their training was the depiction of FSW's self-image and HIV prevention and care. Most PDs stated that they knew the importance of "*good body image*" in sex work to maintain their FSW position and the relationship with their customers but that attending the training reinforced this understanding. For the PDs, this led to increased agency and self-esteem in decision-making about their health. They had to "*love their body more than money*" – that is, adhere to ART to maintain a

healthy lifestyle and use condoms all the time. If they adhered to these messages, then they would be able to lead a healthy life and create a high demand for sex work. This meant that they had to be assertive in making decisions about condom use with all their customers. This was valuable information that they shared with their peers to foster positive change regarding HIV prevention, care and treatment, and understanding of FSW's personhood. This illustrates the opportunities for FSW empowerment, which were mainly expressed about their perceptions of their future opportunities in sex work. However, the application of this approach was sometimes challenging in this context, as some women needed the extra money they received from having condomless sex. This indicates the limitations of public health interventions in shaping power relations regarding HIV prevention.

The knowledge and skills attained in training were two-faceted: they were enough to make the PDs feel valued in the intervention, and create changes in HIV testing among their peers and themselves, but not sufficient to initiate changes in power relations between the PDs and the implementation body. Overall, in line with their definition above, the PDs felt empowered by the knowledge and skills that Pakachere imparted to them during their training. Despite having knowledge of the sex work context in their communities, the PDs believed that they needed technical knowledge of HIVST, ways of addressing ethical issues, and interpersonal and teamwork skills to succeed in this role.

6.4.3 Power relations in the HIVST intervention

In this section, I discuss the relationships between the PDs and venue owners, and between the PDs and their peers.

6.4.3.1 Power relations between PDs and venue owners

Given the nature of the intervention, the PDs felt the need to inform the venue owners of the intervention procedures before engaging with the bar girls to improve the uptake of HIVST. They explained that it was important to observe the existing social structure protocols and seek venue owners' approval to

mobilise and distribute kits to the FSW residing at the bars. The PDs assumed that if the venue owners were given information prior to implementation, they would become supportive of the intervention by offering advice relevant to their specific context and mobilising the bar girls residing at their respective venues. Since the venue owners were owners of the venues, they were perceived as key to advancing the uptake of HIVST. The PDs expressed a variety of perspectives relating to the introduction of HIVST at different venues.

Some PDs described the introduction sessions as going relatively smoothly. Before HIVST intervention, venue owners had always been interested in HIV interventions targeting FSW at their bars. Venue owners saw this as an opportunity to boost their businesses indirectly: having healthy FSW at a bar meant more customers for both sex work and beer and hence more money for venue owners. Therefore, some venue owners also assisted the PDs in identifying and mobilising FSW – even those who lived close to the venues but did not reside there.

Case study 7: Aldo Bar

Aldo bar – venue with FSW's residence: Miranda's experience

It was not easy for Miranda to get permission from *Amayi* (the venue owner) to distribute HIVST kits; throughout the distribution period, Miranda had to negotiate her relationship with her:

Amayi *was a difficult person to work with. She initially agreed with Pakachere for me to distribute the kits at the bar, but she sat me down before I started the distribution.* Amayi *thought that I had a salary from Pakachere, and she asked to be given a share if I was going to work at the bar. I told her that this was just voluntary work, but she thought that I was lying to her. Although she reluctantly agreed for the distribution to happen, often she would comment in passing that she knew I cheated her about the money; at one time she even threatened me that she*

would stop me from distribution if I didn't give her any money … but I stuck to my story that the distribution role was voluntary.

Case study 8: Manto club

Manto club – close to the street, where some freelancers operated from: Namurayi's experience

This venue was very popular with FSW operating along its street and was a place where Namurayi also operated from, which meant that she was very familiar with the relationship between the venue owner and FSW:

I did not even try to talk to the venue owner. You know he doesn't allow FSW to stand on that street. He often sent his guards to chase us off the street. His argument was that sex work was affecting his business. The customers leave the venue early to look for sex work services instead of buying beer for a prolonged time. I was one of the FSW who were banned from entering the venue, so there was no way the owner was going to listen to me, so I asked the coordinator to intervene. She negotiated for us to distribute at the venue based on the condition that we would not stand on the streets for sex work. Well, we agreed, but you know we didn't forget our roots, we would sneak out to get a few customers. And the guards would occasionally chase us away from the streets.

The quotations above show the experiences of some PDs of introducing themselves to venue owners. Miranda's experience highlights the venue owner's perception of the intervention as a transactional opportunity. However, this was an extension of the typical relationship between the venue owners and bar girls (for example, 'pimping') where venues owners saw monetary opportunities in other bar girls' relationships that emerged from the venues. By contrast, Namurayi was aware of her past relationship with the venue owner of the need to seek intervention from the project coordinator.

In other cases, venue owners created barriers during the HIVST distribution process:

> *It was challenging to get approval from the venue owners because we were also distributing condoms to the women to attract their attention during the dissemination of HIVST information. The women would come to us to collect free condoms, when they used to buy from venue owners in the past, so venue owners thought the condom service was disrupting their business. –* ***Elube, PD, bar girl***

Condom distribution was not a welcome idea at some venues, and initially, a few venue owners blocked the self-testing kit distribution. Venue owners saw the intervention as a competing strategy due to the pre-existing supply of condoms at the venues. Through all this, PDs used their negotiating skills to obtain permission to distribute at the venues by convincing the venue owners of the importance of HIVST intervention to both the FSW and the venue owners by reiterating the sex work/bar business strategy. Sometimes a third party (usually a family member of the venue owner) had to intervene in the negotiation process. This suggests that the PDs had developed a consciousness of their role in the community and the ability to influence the decision-making of the venue owners. It seems that a new power relation has been developed that enables some PDs to be listened to by venue owners but without changing the underlying wider power relations.

6.4.3.2 Power relations and trust between PDs and FSW

Despite the PDs being recruited from a range of venues, there were visibly unequal power relations during HIVST implementation process. In theory, it is easier for an FSW to approach another FSW, but in reality, the work is challenging, and relationships in the context of sex work are fragile (Lakkimsetti, 2014). In this section, I show the complex power relations and dynamics between the PDs and their peers, which sometimes highlighted some form of ‘power to’ influence their peers and peers’ resistance.

PDs found bar girls to be easily accessed, approachable and very open to HIV discussion, which eased their distribution work. I observed that bar girls would always congregate to greet and chat with me whenever I visited their venues. In Malawi, this is a way of welcoming a visitor into the home and to hear the intent of the visit. Although I did not observe this behaviour during implementation as distribution had finished before I started fieldwork, I believe it is possible that it happened when mobilising the bar girls. Therefore, it was convenient for the PDs to share HIV information, demonstrate how to use the self-testing kits and share the interpretation of the results in a group format rather than on an individual basis. This was also partly due to support from the venue owners in mobilising the FSW who resided at or close to the bar. This suggests that the norms and behaviours of bar girls combined with the power of venue owners over bar girls to facilitate a relatively smooth process of introducing HIVST in this context. In section 6.6, I discuss in detail how this initial relationship between the PDs and bar girls led to complex decision-making processes around HIVST uptake and how bar girls were subjected to disciplinary power by the PDs and venue owners.

Case study 9: Vulnerability in HIVST among bar girls

Hailey was still residing at the bar when HIVST was being implemented. She has always been positive about HIV testing interventions, especially those targeting FSW, but she noticed that something was slightly strange in how HIVST was being delivered in the community in this case. The first PD who came to the bar obtained permission from the venue owner to conduct HIVST, and then went to the FSW and told them that she was testing all FSW in the community. After a few weeks, a different PD came to conduct the same procedure; although the FSW told them that they had been recently tested, she still insisted that "*the government wants all FSW to be tested*". After a few more weeks, a different PD came with the same rhetoric and tested the girls for the third time. Unfortunately, there was no support from the venue owner when this was happening. Although Hailey had no problem with testing, she thought this was unethical because everything seemed to be rushed and

they did not receive adequate or convincing information about the purpose of frequent HIVST.

However, the PDs stated that they did not believe this happened to anyone, and they were no issues raised by their peers concerning frequent testing. One interpretation for frequent HIVST could have been the need to meet the distribution target after the introduction of the “acceleration plan.”

The PDs further mentioned that one challenge in their work was identifying home-based freelancers. Some freelancers (home-based) were somewhat assimilated in the communities as housewives or single parents but also involved in sex work. As Pakachere instructed the PDs to distribute the kits only to FSW living at bars or working on the street, the PDs did not believe that some home-based freelancers were indeed FSW and were concerned that they would be distributing to the wrong group. This demonstrates that although PDs were recruited based on their familiarity with the sex work localities and because they were insiders, they inevitably had limited knowledge of some of the FSW living in their communities.

The nature of freelance sex work, particularly street-based, and the timing of HIVST kit distribution affected the introduction of HIVST. Freelancers were discreet about their residences, and the only time to access them was at night when they were on duty. This was not well received by some FSW, as some PDs were turned away. The phrasing that FSW used when refusing the HIVST kit was “*Don’t waste your time, let me do what I am here for*”*.* In this instance, freelancers were portrayed as having a more active role in negotiating engagement with HIVST on their own terms. The freelancers were able to control their engagement themselves using a variety of techniques and forms of resistance. The response by the freelancers shows that individuals do not instinctively accept and use the technology or respond to the responsibility of their biocitizenship. Working independently as FSW offered freelancers the opportunities and freedom to choose whether to use or to resist HIVST. In addition, some freelancers were not approachable because they were perceived as high-class and knowledgeable about HIV-related

issues. Freelancers based on the streets or nightclubs came from a wide range of backgrounds; some came from informal settlements like Mpiko and Namachero, while others came from the suburbs around Blantyre. Selection of the PDs did not account for this heterogeneity, resulting in challenges to introducing HIVST to FSW who did not socially identify with the PDs.

> *You know the women on the streets are different, sometimes you meet the women who work the streets … you know they have come there for money, but they don't want to show it off to you, you go and meet them, but you will be surprised at what they would say to you. They used to tell me that "you are not my kind [reported in English during the discussion].* – ***Namurayi, PD, freelancer***

These unequal power relations affected the distribution process as some of them expressed outright refusal to listen to HIVST information. This reflected a gap in PD recruitment as there was no PD to reach out to this particular group of FSW. As discussed in Chapter 5, the freelancers (street-based) were regarded as high-class FSW; as a result, some PDs felt inferior when engaging with these women although some of them were street-based PDs. According to some freelancers, as reported by the LPD, they were not FSW; rather, they were just '*hooking up*' *with men*, and an FSW was someone who was based at and working at a bar. 'Hooking up' is a vague phrase that often referred to sexual activities. It can be argued that these groups used this phrase to protect their identity as they felt at risk of being exposed as FSW – or, indeed, they did not identify with the term 'FSW' in general. Having access to HIVST, in this case, did not seem to sufficiently increase PDs' status to enable them to engage these women with HIVST.

6.4.3.3 Power relations between the PDs and the wider community

In the wider community, PDs transformed their identity from that of suspected FSW (as described in Chapter 5) to community health workers working in bars to implement HIV interventions. The PD role provided evidence for the visible job that they required to conform to societal norms.

> *You don't know what it meant for us to have that ID card and carry those files … whenever my neighbours asked me about what I was, I used to tell them that I was a healthcare worker distributing test kits to FSW. So, imagine this time I was working at night in the bars, I would pack my sex work clothes in my bag, carry my ID card and the files and off I went to work, that's sex work and distribution. I was very proud of myself and happy to show off my new job.* – ***Malita, PD, freelancer***

The PDs then argued that this role reduced the level of community stigma that they previously experienced. This demonstrates that a new power relation has been developed that enables some PDs to elevate their status but without changing the underlying wider power relations. In the next section, I make a stronger case that the new identities that emerge for PDs are part of biopower in that they create a new form of self-governance for PDs.

In the next section I discuss the role of the PDs, their relationship with Pakachere and others, and how it shaped their vulnerabilities and opportunities for empowerment.

6.4.4 Social identity

PD narratives suggest that being an FSW and having the role of a PD facilitated the emergence of a new social identity. The PDs identified themselves as FSW and as agents of change with an important role in influencing behaviour change among their peers. Without direct intervention from Pakachere, the PDs developed small teams in their localities to increase demand for HIVST. They helped each other mobilise FSW and used a snowballing approach to add other sex work venues when the uptake was low. They knew the importance of linking their peers to care after testing HIV-positive so they could start treatment early and hence maintain a healthy body. The PDs stated that the knowledge and skills acquired from this project would be transferable to other interventions if they were given similar opportunities. The PDs argued that the biggest challenge in their work was to

link newly diagnosed FSW to care. They used information about treatment and care to persuade individuals with anxieties and resistance to link to care. However, for their peers, this was viewed as something suspicious because of the PDs' frequent visits to their homes or bars.

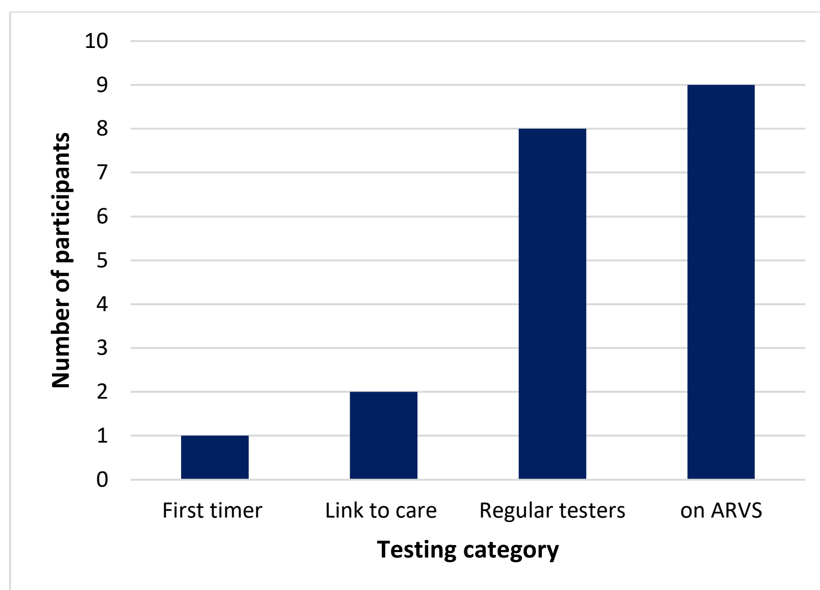
In addition, with their peers, the PDs became unofficial community health workers whom FSW could relate to based on sex work affiliation. They had someone in their community they could open up to about their general health issues, collect condoms from and seek sex work advice from whenever required and without being judged. This work required the in-depth and detailed management of bodies, which can only happen with the involvement of insiders. However, these changes did not transform power relations between the PDs as FSW and the community. PDs emerging new social identities are part of the operation of biopower. The peer-led model was a means of increasing the state's power to survey FSW who were subjected to HIVST. Because of the health system and biopower concerns, FSW became more integral to the state's own success (in better health policies) and became subjects and extensions of transactional governmentality through the intervention.

6.5 Rationales supporting the adoption of HIVST

It is evident that the implementation of HIVST brought about diverse changes among FSW and did not impact on FSW and their communities uniformly. The FSW's choices about the use of HIVST and the ways they interpreted the results were shaped by broader societal values, beliefs and constraints.

The graph below is drawn from the IDI participants and highlights the reasons for testing using the self-test kit. Of 20 FSW who were interviewed, 11 FSW retested while already knowing they were HIV-positive. Of the 11, nine were on ART, and two used the kit to link to care. Eight were HIV-negative, and only one was testing for HIV for the first time. Overall, the graph demonstrates that there was a high level of retesting among FSW who had prior knowledge of their HIV-positive status.

Figure 6: Summary of motivations for participants testing and retesting using HIVST



Throughout the data collection period, I observed the enthusiasm for HIVST among the women who participated in the interventions. This enthusiasm was exhibited through frequent questions about the scaling up of HIVST, and especially for FSW. However, the narratives of HIVST from FSW highlighted experiences of coercion to test, anxiety after testing and using HIVST whilst on ART. as understood in the context of power relations between FSW, the PDs and the venue owners.

This section discusses the narratives of HIVST from FSW as understood in the context of power relations between FSW, the PDs and the venue owners.

6.5.1 Stigma and social respect

> *The reason I did not test before is because of stigma. I remember vividly that there was a time that I attempted to go for testing. I went to Queens at the VCT office, that was in room 9 …I was timid because of the people present there so I came back home. But I accepted testing when I found that Malawi Liverpool Trust has a door-to-door testing intervention. This was my first time testing for HIV, I thought that I was already dead, I am a sex worker, and HIV acquisition is inevitable … but I was happy with this kit because it gives one some respect, that is*

why I used it. I would not have tested if they didn't have this intervention because of stigma– ***Stailey, 39 years old, freelancer for 20 years***

Some FSW reported that HIVST "*inali yopasa ulemu*" (enabled one to be respected). According to these women, 'respect' was demonstrated by offering them access to an appropriate way of addressing their HIV testing needs. Beach et al. (2007) note the limitations of bioethics in defining the scope of the concept of respect. She argues that bioethics offers a distorted view of respect for autonomy and respect for persons. The former focuses on goals and preferences, whereas the latter requires an acknowledgement of the patient as a person if they exhibit some level of autonomy. Beach maintains that all living human beings are persons and, consequently, deserving of respect.

Through the life stories conveyed by FSW, women like Stailey reflected on their perceptions and experiences of HIV testing, which allowed them to observe the differences between the existing HIV testing service structures and HIVST. This reflection then enabled these women to justify differential value judgements and levels of engagement with HIVST in comparison with conventional HTS. FSW face multilevel barriers to accessing conventional healthcare services, which can limit HIV testing coverage (Chanda *et al.*, 2017). A systematic review that explored barriers and facilitators in HIV testing among FSW found that the two barriers to HIV testing most commonly reported were costs and stigma (Tokar *et al.*, 2018). These results resonate with what some women in this study stated as barriers to HIV testing. Stigma complicates decisions about testing and impacts on disclosure of status and ability to negotiate prevention behaviours. It is established that people who experience high levels of stigma are over four times more likely to report poor access to care (Sayles *et al.*, 2009). This contributes to the expansion of the global HIV epidemic and a higher number of AIDS-related deaths. An unwillingness to take an HIV test means that more FSW are diagnosed late, when the virus may have already progressed to AIDS.

There was a close association between going for HIV testing and the need to sustain the sex work market. For these women, a key barrier to testing was the perceptions of inevitability of HIV infection as reported in Chapter 4 and as confirmed by Stailey above, and fear of being noticed by customers or potential customers at the HIV testing facilities. A common perception in this context is that one's presence at an HIV testing facility is an involuntary or unintended disclosure of HIV-positive status. In these communities, health centres were located around marketplaces and HIV testing facilities and had a designated building or room where people queued to receive the services, and onlookers would notice who was going into or out of a facility.

In addition, I also observed that the male clinicians and nurses working at the local health centres were regular bar customers or sex work customers. The interface with these professionals in these two places (bars and health centres) was also a cause for concern for FSW. The FSW were concerned about confidentiality issues if they tested HIV-positive and the effect on their sex work business. Consequently, stigma affected how FSW felt about themselves, their confidence and their individual agency to engage with HTS. Therefore, FSW were increasingly marginalised, not only from society, but also from the HIV testing and treatment services.

According to Stailey, when HIVST was introduced to FSW, they felt that HIVST resonated with their HIV testing needs and was a departure from the conventional testing methods. The notion of the 'clinical gaze' as stipulated by Foucault became relevant. Many felt that the dislocation of HIV testing from the gaze of clinicians (in healthcare professionals' interactions) and social customers and the wider community to the privacy of their homes prompted these women to engage with HIVST. In this context, some FSW reported making an informed autonomous choice to use the kit without feeling any pressure or coercion from PDs, peers or family, and dealing peacefully with their HIV testing anxieties in the comfort of their home or wherever they deemed more private.

Usually, PDs would demonstrate the procedure for self-testing and leave the kits with FSW and encourage them to conduct the tests themselves. FSW chose whether they wanted to test in the presence of PDs or peers or not. In addition, HIVST was convenient for FSW as it accommodated their busy schedule. During the fieldwork, as explained in Chapter 4, I noted that bar girls were more likely to work most of the day, while freelancers worked all night and came home at dawn to rest. Throughout the study, they argued that their mobility while at the bars or after work was limited due to the pressure of their work schedule and need for rest. Given this, the flexibility of HIVST offered them an opportunity to test in their own time.

However, these notions of HIVST as enabling autonomy mostly emerged from freelancers (home-based FSW). I suggest that this was the case because HIVST was introduced in the privacy of their home rather than a bar or street, and they were working independently and, therefore, more inclined to make a more autonomous decision. In addition, the freelancers were able to make this decision in the context of their private home and free from the influence of venue owners and peers. Based on this narrative, demand for HIVST came from FSW, who perceived existing service provision as insufficient to meet their immediate needs based on structural or perhaps personal barriers to testing. Freedom to choose where, when and with whom to test and a belief that HIVST was better than conventional HTS were some of the aspects that factored in their decision-making process.

The next section explores the narrative that describes the process of making the decision to self-test that was common among the bar girls.

6.5.2 HIVST as a self-monitoring tool

In the sections below, I discuss how FSW used to self-monitor their HIVST status, and in some cases their actions indicate the intended use of HIVST. Majority of FSW (**Figure 6**) were monitoring their HIV status for varied reasons, which included distrust in the conventional technology and to find out if their status had changed after being on ART for a long time.

6.5.2.1 HIVST as a response to HIV risk

HIVST as a self-monitoring tool was a response to the recognition of an ongoing higher risk of HIV in the FSW's community and of a pluralistic belief system about health and illness. Obligations of biocitizenship are central to FSW's understanding of the utility of HIVST. In the context of discourses of biocitizenship, FSW perceived HIVST as a tool to manage anxiety around one's HIV status based on an acknowledgement of HIV vulnerability arising from being an FSW, and on knowledge of HIV prevention and treatment or complying with social norms and meeting the demands of biomedicine. Under notions of biocitizenship, individuals are expected to take an active role in their health, including managing and monitoring HIV risk. FSW demonstrated good biocitizenship by complying with the HIV testing behaviours that are expected of them by the healthcare system. In adopting such an approach, individuals are expected to develop strategies of self-discipline.

The need for reassurance about continued seronegative status was constantly reinforced by interaction with peers and by health promotion messages. This was reported by HIV-negative FSW. For some FSW like Hailey, being an active FSW brought a requirement to respond to popular narratives of HIV testing and engage with the process of surveillance of one's HIV status. Social contacts were key in providing motivation and support for testing. The understanding of oneself as belonging to a risk group was one of the developing norms surrounding HIV testing; there was a distinctly social process, which had a psychological impact.

There was a heated debate during an FGD with FSW around FSW who were 'HIV-negative' and whether a negative result could be trusted. Strong sentiments about "*the inevitability of HIV*" emerged again during this discussion. Some believed that there was something wrong with the conventional HIV testing technologies but were surprised to receive the same negative result from HIVST. Others stated that they could not wait to receive the positive result to get it over and done with, so that they could have peace

of mind. They strongly believed that there could never be an HIV-negative result for a FSW, or believed that perhaps those FSW who tested negative fell into a population of people with 'special blood group O'. There is wide speculation in the communities that the technology used in Malawi for HIV testing could not detect HIV in people with blood group O because this blood is rare. A participant in the FGD stated that

> *People believe that "aah, that means my blood group is O [they are carriers], I will just be spreading the virus".* – ***Zione, bar girl***

Currently, there is no scientific evidence for these speculations. A study by Siransy et al. (2015) that aimed to examine the association between ABO and rhesus blood groups and susceptibility to HIV infection and hepatitis B found that the highest frequency of infections was observed in blood group O. Other FSW countered this by saying that there was no such thing, that anyone can get sick, but this also became complicated when they justified this with religious notions, saying that those who were now HIV-negative had been favoured by God, and they warned others to always use condoms.

Nevertheless, HIVST offered FSW the opportunity for regular testing, and the lack of counselling within a clinical setting was generally perceived as less problematic because PDs had sufficient skills to offer this support. The WHO (2016) recommends that key populations including FSW test every three months. Some women confirmed that HIVST was what they needed for regular testing to respond to the constant HIV risk, and that it was useful in managing and monitoring one's own HIV risk and providing confirmation of their HIV-negative status. In lived experience, managing one's HIV risk was actually complex, and this will be explored in the next chapter. This was particularly common among those who described a growing anxiety between tests due to their persistent exposure to HIV risk through sex work and inconsistent condom use. Testing negative was framed as a source of anxiety, so being a good bio-citizen also came with a psychological price, thereby reducing their well-being freedom.

6.5.2.2 Trust in PDs and HIVST diagnostic accuracy

While individuals were often already aware of their HIV-positive status, ongoing trust issues with HIV test results were a key factor in their decision to seek further HIV testing. Trust in a relationship or interaction is either present or not and this has implications for service delivery and how people respond to it. Issues of trust in the technology, the process of testing and the person performing the test on FSW's behalf were evident here. There were a few women who reported that they self-tested because they did not trust their previous HIV test results. This lack of trust was connected to how HIV testing was introduced and executed. There were concerns from women who tested through Antenatal Care (ANC) that the providers forced pregnant women to test. The case of Rylee illustrates some of the limitations with conventional HIV testing procedures and the psychological impact they produce.

> *I was forced to test for HIV when I went to deliver my baby, they were forcing everyone to test before delivery. They tested me and they told me that I was found HIV-positive and they gave me Nevirapine. But I did not accept this result because you know they forced me to do it, so I did not believe them until when Namurayi came with self-testing kits, she tested me and I was still found HIV-positive…this was the time I made a decision to accept the result. My child was often had pneumonia and I went to see Namurayi, unfortunately, she had run out of the kits, so I went to Congo* [a health centre in the location] *…my daughter was also found HIV-positive and she started treatment straight away. -* **Rylee, freelancer for more than eight years**

Case study 10: Rylee

Rylee was a sister to Stailey, 35 years old, divorced, and had one daughter. Unlike Stailey, Rylee dropped out of school while she was in standard 8 because their mother could not afford to pay her school fees. When Rylee was 15, she started sleeping with older men for money due to economic hardship at home and she got pregnant with one of her

partners. Unfortunately, the baby died eight months later because of malnutrition. Rylee later became involved in sex work due to peer pressure. She found a stable partner and later got married, however, the man divorced her after a few years because "*she had lent her neighbour a knife*". She went on and off sex work after a couple of remarriages. She was first diagnosed with HIV in 2011 (when she was pregnant) and followed all the PMTCT procedures until the baby was six months old. However, she decided not to continue with treatment because she felt coerced to test and therefore, failed to accept the result. This ultimately resulted in her daughter becoming HIV positive.

With the introduction of HIVST, some FSW stated that they trusted their PDs because they were friends and had grown up together in the communities. They trusted that their friends would not betray them or provide them with a technology that would harm them or give them fake results. This rendered the self-test kits credible.

However, these sentiments towards PDs contradict what women reported. The personalities of the PDs had an impact on the uptake of HIVST. Some peers did not trust the PDs with their test results, which resulted in low uptake of the kits in some venues. The LPD argued that some FSW decided not to accept the kits from familiar faces, and they asked to receive the kits from other PDs whom they regarded as 'strangers' in their community. The LPD said this:

> *[HIVST] was well received and it was easy for her [the PD] to approach them [her peers] … but at the same time it would backfire because if they knew you and your bad habits, your big mouth, it would also blow the project up.* – ***LPD for Blantyre***

The quotation above is an illustration of how the role of PD did not offset preconceived ideas of a PD's personality even in the presence of HIVST. Although the PDs perceived their position as a means of mitigating the stigma that FSW previously experienced with HTS, issues of trust in PDs determined

the uptake of kits. This contradiction concerning trust in PDs leads to the interpretation that 'trust among FSW' was situational and determined by the previous relationship between a PD and an FSW. The newer the relationship, the longer it would take to trust the PDs, and the worse the attitude, the more challenging it was to develop trust, and vice versa.

6.5.2.3 Trust in HIV testing technologies

FSW who retested while on ART reported that they wanted to monitor whether their HIV-positive status had changed after being on ART for a long time. There were rumours that being on ARVs for a long time would cure a person of their HIV. Also, some people in the communities were testifying that they were free from HIV after being prayed for by religious leaders or being cured after taking traditional medicine. This backdrop of misinformation influenced these women's choices and engagement with HIVST. Some reported that they conducted HIVST with full knowledge of their HIV-positive status and were on treatment. Below is a quotation from Taylor:

> *… some people say that a person can be cured if they have been on the drugs for a long time. I started taking these drugs a long time ago. I wanted evidence [that her status had changed] so that's why I tested … when you follow the treatment as advised by healthcare workers and you go for testing again, they find that you don't have the virus any more.* – ***Taylor, 40 years old, FSW for more than 10 years, HIV-positive since 2002, been on ART since 2016***

Case study 11: Taylor

Taylor *was a 40-year-old FSW born and bred in Mpiko, working as a freelancer. She had four children and her husband had recently died on a road accident. Taylor had very abusive parents. They owned a restaurant in the CBD and they forced Taylor to drop out of school when she was in standard 8 to help them run the restaurants. Her parents used to beat her when she was disobedient to them. She became tired of the treatment she received from her parents and moved in with her*

friends in a neighbouring township to Mpiko. She later joined her friends in sex work because that is how they could meet their daily needs. She married a couple of times with partners from sex work, unfortunately, all the relationships did not work out well. In 2002, Taylor got pregnant and she was found HIV-positive through ANC HIV testing routine, however, her CD4 count was high so she did not start treatment. She started taking ARVs in 2013 when she got pregnant. She had been on treatment for more than three years.

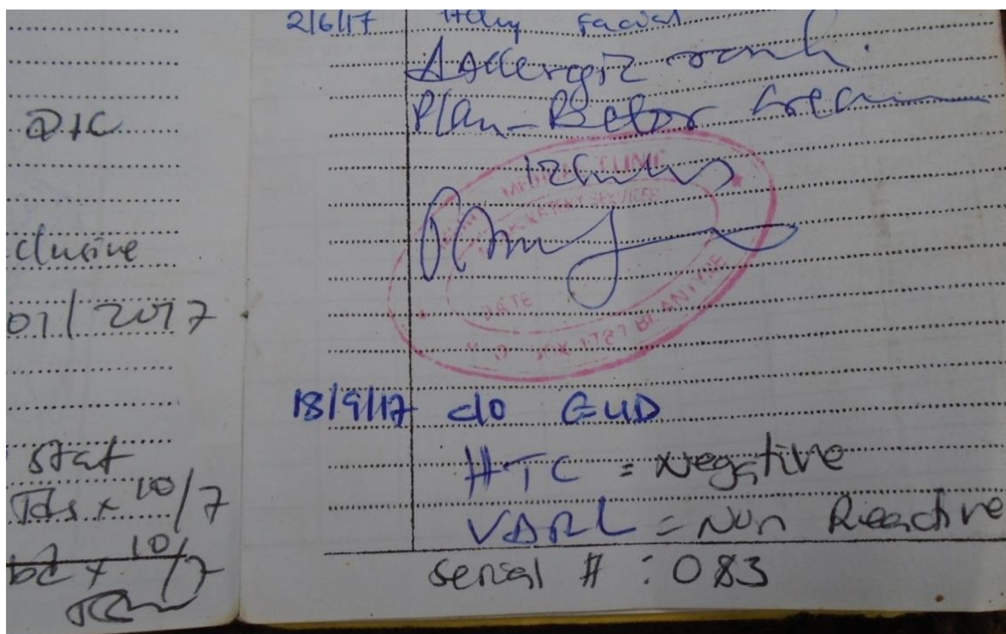
Malawi has made great strides in HIV prevention, care and treatment, and introduced the Test-and-Treat initiative in all government hospitals, previously prescription of ARVs was based on a threshold level of CD4 count (Dovel *et al.*, 2020). This explains Mabel's case and the gap between the initial HIV-positive result test and ART initiation. Taylor argued that her CD4 count was still high but started ART because of the Test-and-Treat initiative.

I explored what participants meant by 'cure' to understand their rationale for retesting. There were varied responses on the meaning of 'cure', which were at times vague. Some stated that they meant viral load suppression, the virus as dormant or the virus hiding or sleeping. However, a contradiction emerged when they all denied that HIV can die and yet asserted that the decision to test was to find out whether they were cured of HIV, lending further confusion to what they meant by 'cure' in this narrative. These responses indicate that there was some level of understanding of the efficacy of ARV drugs in the body, eventually leading to HIV being undetectable, but a knowledge gap still remains on what 'undetectable' actually means.

I, therefore, suggest that the discussion around trust in the test and in the service provider is also valid here. As the self-test kit was a novel technology, I assume that some FSW wanted to see whether the test kit would bring a different result. These women were acting on a perception of their positionality of being 'high-risk women' and of the inevitability of HIV infection. Consequently, it would have been easy for some of them to accept any earlier positive result on this basis.

Several studies have reported retesting among those who have been identified through conventional HIV testing programmes as living with HIV, and also reported that some people have multiple testing episodes before accepting their status (Hanna, Tsoi and Begier, 2009; Duffus *et al.*, 2012; Fuente-Soro *et al.*, 2018). The national policy guidelines (Ministry of Health and Population, 2018) and HIVST kit instructions for use both discourage use of the HIVST kit by those on ART (Ministry of Health and Population (Malawi), 2017*)*. Use of oral fluid tests can lead to false-negative test results for those on ART, given their lower sensitivity than blood-based tests (Guanira *et al.*, 2015; Ngure *et al.*, 2017). As mentioned in Chapter 1, increasingly, however, programmes are reporting retesting among those on ART. For example, Kumwenda et al. (2014) found that couples that had not shared their past positive results were retesting in order to disclose their status.

Photo 8: FSW showing an HIV-negative test result after HIV testing using a conventional method



This photo was taken by Ava to depict her frustration with HIV testing. Her initial test was positive, and she was put on treatment. Her subsequent tests have all been negative, including HIVST. The photo here shows a

conventional test she took after HIVST, which still shows a negative result, and she said this:

> *It is confusing, you know. Every time I test for HIV they find me negative so I wanted to try self-testing. I am still negative, and I don't know what to do now but I don't want to stop taking my medicine, I am afraid of untimely death. –* ***Ava, FSW for over four years, diagnosed with HIV in 2013, on ART since then***

Ava's case makes the actions of these women in retesting somewhat valid but also suggests a lack of discussion around false negatives/positives. On the one hand, the initial test might have been a false positive, and she acted based on her high HIV risk perception as an FSW when she accepted the test result and started treatment. On the other hand, the test could have been a true positive, and she is now testing negative because of viral load suppression since she is on treatment. In this context, this scenario illuminates the reality of anxieties about HIV testing, and HIVST, as an emerging technology, has the potential to increase retesting among those who are HIV-positive regardless of whether they are on treatment or not. Arguably, such technologies have the potential to bring about such unintended consequences.

I also investigated the actions taken after testing 'negative'. I found that social contacts between FSW and their peers and the social environment were key for producing knowledge about both retesting behaviours and treatment. The participants who had had false negatives after previous tests reported that they had the desire to continue with treatment, mentioning the fear of serious illness and untimely death after stopping treatment as their motivating factors. This fear stemmed from rumours and experiences of other people in the wider local communities. They shared examples of friends or relatives who died a short time after stopping treatment because they believed that they had been healed by religious leaders or by being on ART for a long time.

The knowledge of the risk of getting a false-negative result from HIVST was not uniform among FSW. The instructions on the OraQuick package do not recommend the use of the kit by individuals on ART because of the risk of false negatives. The majority were aware of the instruction not to use the kit while on ART, but not why the recommendation was made. The role of the PDs in monitoring and screening individuals who received the kit was important, but the challenge was finding the means of identifying those on ART. Both the PDs and the FSW initiated the decision to retest while on ART. Some FSW disclosed to the PDs that they were on ART but still collected the self-test kit, and others concealed this from the PDs due to their fear that the PDs would refuse to give them the kit. On the one hand, the reports from FSW suggest that the PDs were possibly acting in response to the pressure to reach their distribution targets. On the other hand, it was also due to a lack of understanding of the implications of self-testing while on ART and issues around false-negative results among FSW.

6.5.3 HIV testing as a normative behaviour

The history of targeted HIV interventions among FSW is long, as with other key populations, such as MSM, they have occurred since the emergence of HIV. The implication of targeted HIV interventions is the reinforcement of the notions of victimhood and deservingness among key populations. These interventions, as biopower, emphasise the identification, classification and surveillance of at-risk bodies for disease prevention and require active participation of FSW in the management of the epidemic. The accrued experiences of FSW's engagement with these interventions have produced normalisation of their subjectivities in HIV prevention, treatment and care interventions.

Some bar girls indicated that they participated in the HIVST intervention because there was no reason to refuse the self-test kit even when they were given a chance to exercise their autonomy: "*it is just the way it is*". HIVST was just like any other HIV test they had previously taken and intervention that they were subjected to frequently. As stated earlier, the bar girls had easier

access to interventions than the freelancers, and this accounted for their experiences with several targeted HIV interventions. I also observed from the interviews and reports that Pakachere invested more time at the bars than in identifying freelancers because the bar girls were easily accessed and more receptive to HIV interventions. The bar girls also reported that during the HIVST intervention, two or three other organisations came to the venues with HIV testing that used conventional methods. Pakachere also had other programmes that encouraged these women to test using this method or others in the communities. These interventions indicated increased surveillance of this population regarding HIV testing. One might infer that a variety of interventions would provide these women with choices; however, if there is no engagement prior to the implementation of these interventions, this would generate suspicions around the implementers' motives and moral values. The bar girls' engagement with the interventions produced bodies that were subjected continuously, used, monitored and improved as a way of disciplining and controlling the FSW population in managing the epidemic.

6.5.4 Social networks and privacy

The assumption about HIVST is that individuals will be able to make an autonomous decision to test themselves and interpret the results whenever they wish and wherever they deem private. HIVST, however, is not an autonomous entity: its development and implementation are inevitably embedded in political and social environments that have practical and moral consequences for well-being (Lock and Nguyen, 2018). The implementation of HIVST in this context transformed the relationships of the targeted population with their peers, their partners and the venue owners. Although there were no reports of any overt physical harm resulting from their decision to self-test, as with any form of HIV testing, potential social harms must be anticipated and mitigated.

Can true privacy be attained in the context of the bar environment and the power relations that exist there? Some bar girls reported that they were not given space to make an independent decision to collect and use the self-test kit. They reported being coerced to self-test by the venue owners and the

PDs. The venue owners had an interest in keeping "healthy FSW" at their bar, which meant frequent HIV testing and uptake of treatment if found positive. Consequently, the venue owners verbally coerced FSW who were resisting self-testing and instilled fear in these women that they were going to lose their jobs as bar girls. The PDs took advantage of the existing relationship between the bar girls and the venue owners by verbally threatening their peers that they would report those who were refusing to self-test to the venue owner. The quote below is from Hailey, who reported that the PDs made them feel that HIVST was compulsory for all FSW in their community. The reports from the PDs, however, differed from these expressions of lack of agency. The PDs stated that their peers were given a chance to decide whether or not they wanted the self-test kit.

> *They [the PDs] just told us that every girl at the bar should test whether we wanted to or not, we wondered why this was happening, they just told us that they had been sent to test all the FSW in the community and that it was compulsory. –* ***Hailey, FSW for two years, bar girl and sometimes a freelancer***

> *The venue owner ordered us all to test, and he would dismiss everyone who decided not to from work, I believed that I was being forced to test, so I decided to test in order for me to secure my job at the bar.* - **Alina, FSW for more than four years, bar girl**

Case study 12: Alina

Alina was a 21-year-old bar girl, divorced with one child. Alina was the 8th born in a family of 11 children. She was born and bred in Blantyre. Alina dropped out of school in standard 2 because of poverty. She got married when she was 15 years old, unfortunately, her husband was a robber, and he also started sleeping with Alina's sister, as this was the case, Alina decided to divorce him. She later joined sex work from the influence of her friends. She had worked for *ankolo* and *amayi* for four years. Unfortunately, she was among the FSW who were dismissed by *ankolo.* Alina was one of the bar girls who were HIV-negative.

Some women reported that venue owners coerced some bar girls to sleep with them in exchange for the self-test kits. The bar girls preferred to keep the kits, along with other valuable items, with the venue owners, due to security issues affecting bar girls in their social environment at the bars. However, when they requested the kits from the venue owners, some venue owners gave the FSW the condition of sleeping with them in exchange for the kits. Although they did not sleep with the venue owners, this case highlights the complexity of the context where HIVST was implemented and how the venue owners could easily use their power as owners to control women's actions at their premises.

As stated earlier, FSW are a heterogeneous group, and the pathway to sex work differs across settings and in various groups of sex workers. In the previous chapter, I stated that some women joined sex work in their adolescence and when they were underage. The adolescent sex workers become hard to reach in these contexts because of their age and because of perceptions in the sex work industry that they are illegal and therefore, should be excluded in interventions targeting FSW. These girls were 13–15 years old and usually neglected in the conventional HTS due to their age and the perception that they were not eligible to be FSW or to be involved in sexual reproductive health discussions. Nevertheless, the peer-led delivery model using the door-to-door method facilitated the identification of some adolescents in sex work venues. The PDs were caught in a dilemma when they met adolescents because the age range for HIVST in this intervention was 16–49 years old; as the LPD stated,

> *We had no option … we should not ignore these young FSW, they are out there and it's real. They are taken advantage of by older men because they think they are young and they are powerless … but they need to know their status as well.* – ***LPD for Blantyre***

The PDs reported that they encountered young girls who were sexually exploited by older men to use self-testing kits. The HIVST intervention enabled the PDs to have contact with these adolescents, whose HIV risk is

neglected even though they are also exchanging sex for money with multiple partners and sometimes living at the venues.

6.6 Summary

This chapter shows that while HIVST seems to increase the opportunities for some FSW to exercise agency in HIV testing, it simultaneously constitutes new power relations and new practices of biocitizenship. The study has demonstrated that there was only one FSW who was testing for the first time, and the majority were using the kit due to perceived HIV risk, or because of normalisation of HIV testing in a sex work context; or to find out that if their HIV-positive status had changed after being on ART for a long time.

HIVST did not result in empowerment; although for some, HIVST created new opportunities for FSW to test for HIV, it did not create any sustained expansion of freedom in the lives of FSW. Some bar girls reported being coerced to test by venue owners. High levels of retesting for HIV among FSW living with HIV, with nearly half of my sample on ART in this study

Peer-led model in HIVST implementation did not address the asymmetrical vulnerabilities that existed between FSW and the implementing organisation. The issues of distribution targets, incentives, and communication account for asymmetrical power relationship between PDs and the implementers.

In the next chapter, I discuss FSW's experiences after HIVST, which included HIV testing disclosure and the realities of being on ART.

7 Realities of living with HIV as an FSW in Blantyre

7.1 Introduction

The discourse about the HIV/AIDS epidemic began with illness, fear and death as the world faced a new and unknown virus. Scientists have identified the pathogen, developed diagnostics, prevention methods and treatments capable of turning what had been a death sentence into what is now framed as a chronic and manageable disease, and subsequently public perceptions of HIV have shifted (Beaudin and Chambré, 1996). However, the transition and the promises of scientific breakthroughs have not unfolded at the same rate or in the same way in all populations.

The context of sex work presents a setting characterised by high levels of stigma and limited freedoms and choices. I have explored the context of sex work and the engagement of FSW in the HIVST intervention in the two previous chapters. The critical point discussed in these chapters is how the sex work environment has shaped FSW's vulnerabilities, and how the introduction of HIVST in this setting and this particular group resulted in varied and complex experiences. The focus of this chapter is to understand FSW's experiences of ART after HIVST. The narratives of these women reflect the meanings FSW attach to HIV discussions, the effect of HIV on their lives, and the meaning of sex work as embedded in settings characterised by high levels of stigma and discrimination.

In the first section (7.1–7.1.2), I explore the factors that facilitate or limit disclosure and the implications for HIV prevention, treatment and care. In the second section (7.2–7.2.2.3), I discuss the factors shaping engagement with or disengagement from treatment and care. I explore how the complexity of the sex work environment shapes the perceptions and experiences of FSW on ART treatment. In the last section (7.3), I then present FSW's dreams and aspirations despite the struggles of sex work and living on ART.

7.2 Managing HIV status disclosure in the context of sex work

HIV status disclosure is a critical gateway to prevention and is used as a strategy for negotiating safe sex with partners and encouraging testing among sexual partners. HIV status disclosure, however, remains an ongoing challenge for many people living with HIV. Various theories inform disclosure; the consequence theory of HIV disclosure proposes that individuals living with HIV disclose their status when the rewards for disclosure outweigh the associated costs (Serovich, 2005). Seorovich (2005) argues that perceived potential rewards for disclosure include improved psychological well-being, feelings of peace of mind, being able to seek care openly and positive feelings after disclosure. The costs of the disclosure may entail abuse, rejection, stigma and anxiety. The management of HIV, however, requires the mobilisation of a social network to provide resources, which may require disclosure of HIV status (Winchester, 2015).

As per ART initiation procedures, all individuals newly diagnosed in the HIVST intervention were mandated to attend some initiation sessions to prepare them for their new life experiences.

> *They [healthcare workers] told me to find a guardian, preferably a relative or friend. I don't trust my sister in this house, so I went and asked an older lady who lives a few houses away to come with me to the health centre for ART initiation. –* ***Stailey, newly diagnosed, on ART***

The women reported that healthcare providers in the communities as well as in the facilities encouraged newly HIV diagnosed individuals to disclose their HIV status to at least one person they felt comfortable and open with within their social network before they were initiated into ART. The assumption was that this disclosure might have benefits for HIV-positive individuals because of the social support and encouragement they could potentially receive from their network members after sharing the news of their HIV status. The recipients of the news were called 'guardians', and their key role was to

ensure adherence to treatment, a healthy lifestyle, and the collection of drugs if the women were ill or had travelled. A newly diagnosed individual was to bring this guardian to their first ART initiation class or risk not getting initiated into ART if they failed to do so. On the day, they were taught about drug routines, drug efficacy, drug side effects, diet and nutrition. However, this meant that a woman had to disclose her HIV status to a third person even when she did not want to. Some women indicated that they found the process of identifying a guardian psychologically challenging. The women were also worried about being stigmatised, as some expressed fears that some guardians talk to other people in the communities about their status. This tendency of identifying and recruiting guardians can be perceived as a way of extending the control or maintaining the disciplinary power of the clinic by performing surveillance on populations. The requirement from the healthcare workers to recruit guardians was a way of extending their power to disseminate HIV treatment and care surveillance more widely in the communities and to ensure that the individuals remained good therapeutic citizens.

Some FSW, however, stated their reluctance to disclose their HIV status to anyone. They often cited concerns around confidentiality and stigma as the reasons for this reluctance, but the need to start treatment forced them to do so. HIV disclosure was a mechanism of empowerment for some FSW in this study and only in limited ways. Although FSW managed to talk to selected people about their HIV status, HIV status disclosure was a process of weighing the role of the recipient and the proximity of that recipient, and sometimes there were circumstances that prohibited disclosure to certain individuals. These issues have been explored further in the following sections.

7.2.1 HIV status disclosure and social support

There were both benefits and risks associated with the disclosure by FSW of their HIV status to their peers. When I was applying for ethical approval, I agreed with my supervisors not to include any questions that would prompt participants to disclose their HIV status in a group setting, especially when

conducting FGDs, to protect their privacy. Conversely, my experience with these women in the field was different from what we anticipated, but it greatly illuminated how HIV status disclosure was managed in the sex work context. I found that selective disclosure appeared to be the norm among FSW since they only disclosed their status when they did not fear the threat of undermining their sex work markets.

Most bar girls overtly expressed their seropositive status in their rooms with their peers or venue owners. From my experience talking with these women and conducting participant observations at the bars, I established that the majority of the bar girls were living with HIV. For example, during the study introductions at Rado, some bar girls would just announce that they were HIV-positive without being prompted. Some FSW disclosed their HIV status to emphasise a point they were making about HIV testing.

> *For example, my partner knows my HIV status. We tested together as a couple; he is negative, and I was found HIV-positive, and we are happy about our situation.* - **Lipa, PD, bar girl**

As FSW, they made a ‘point-blank disclosure’ of their HIV-positive status based on their perceptions of a shared HIV-positive identity. Point-blank disclosure refers to “direct disclosures where there is an overt expression of one’s seropositivity” (Serovich, 2005, p. 4). Talking about their status in my presence and my colleague’s might have occurred because of their perception that there was a low risk that we as researchers were a threat to them in their environment. We were outsiders; we were not their customers, peers or relatives and nor did we come from their sex work community. Also, partly, the good rapport that we had developed with these women and the duration of our stay in the sex work communities led to their openness.

At the bars, the peers were their closest allies, second to their families, so they became instrumental in offering care during illness and episodes of food shortage, hence the openness in talking about their HIV status in their rooms.

For example, studies have established the inverse association between food insecurity and ART engagement (Kalichman *et al.*, 2010; Weiser *et al.*, 2011).

> ***Interviewer**: Are you not shy?*
> ***Participant**: It's my life, why should I be shy? In a situation where I run out of food, and I cannot take those drugs on an empty stomach, I can faint because the drugs are very strong.*
> ***Interviewer**: The drugs?*
> ***Participant**: Eeeh, for example, all my peers at Mpiko know that I am HIV-positive, I told them, in cases when I don't have money, I tell them, for example, in the evening [when she is supposed to take medicine] "Eeeh* aise *[mate], I don't have money, why should I fail to take my drugs when you have food?" I wash my hands, sit down with them and eat the* nsima*, and then take my drugs. –* ***Ava, bar girl***

Some bar girls felt comfortable to disclose their HIV-positive status to their peers because they knew that they would need their support in case of ill health or food shortage.

Disclosure of HIV status to the venue owners was complex as power relations informed the process of disclosure. There were some FSW who voluntarily disclosed their status to the venue owners. The imperatives of disclosing to the venue owners were framed around the need for support, thus, in the event of an illness or storage of ARVs. The venue owners were the ARVs custodians because of the limited privacy at the bars (this point is explored in section 6.2). As such, FSW on ART needed to disclose their HIV-positive status for safekeeping of their ARVs.

As discussed in Chapter 5, the venue owners had an interest in promoting the health and well-being of the FSW living at their bars as a way of extending their control over the activities and personnel at the bars. The venue owners often subjected the bar girls to regular HIV testing at the bars through HIV testing programmes that target FSW. Although the venue owners portrayed disclosure as optional, it was the pressure put on those who tested positive to

link to care that inevitably created the division of HIV-negatives and -positives, leading to implicit disclosure. The venue owners told the bar girls that they would dismiss anyone who tested positive but refused to link to care.

> ***Interviewer****: Why would the bar owners force you to test?*
> ***Participant****: Aah because he wants all the girls who are positive to be taking medicine. He says that those who refuse to test would get sick eventually and the men would start saying terrible things about the bar – "aah the girls at that bar have the disease" – he would then lose customers because of that. And if the girls get very sick, they also go to him to ask for transport to go to the hospital. He gives us the money and deducts it from our wages. So he doesn't want this to happen at his bar.*

However, this also meant that FSW who were linking to care were unintentionally disclosing to their peers even when they did not want to. As stated before, FSW were always in competition with each other for customers; this being the case, there was always a risk in disclosing HIV-positive status to a peer. If they disclosed to a peer who was HIV-negative, they could risk damaging their reputation through gossip and potentially face rejection from customers. Given this, some FSW reported fear of losing customers and income due to HIV-positive disclosure.

7.2.2 The responsibility of HIV status disclosure to partners

For FSW, the process of HIV-positive status disclosure to their sexual partners (whether stable or casual) is very complex and those who are living with HIV bear a unique burden and responsibility for disclosing their HIV status to their partners. In their systematic review, O'Leary and Wolitski (2013) found that concern about infecting others is central to the sexual decision-making of people living with HIV. A randomised controlled trial among FSW in Uganda found that the majority (75%) of women disclosed their status to their partners but seldom asked customers their HIV status before sex (Musoke, 2017) or disclosed their own to customers. A study in

South Africa found that there were differences among FSW between HIV status disclosure to paying sexual partners and to long-term sexual partners (Wells, 2018). With those who were in long-term relationships, the levels of disclosure to their stable partners or boyfriends were particularly high. Intimacy levels are higher with long-term partners and regular customers, but as intimacy increases condom use tends to decrease. FSW felt socially obligated to disclose to their stable boyfriends out of love and affection but also to have sex with them without using condoms. FSW believed that they could build a future with these partners. The benefits of disclosing to partners included reinforcement of trust in their relationships, and they would also encourage their partners to disclose their status to them or to go for testing if they had not done so already. Sometimes, initial reactions from partners after disclosure included anger, violence, rejection and confusion, but some partners gradually accepted the situation. Some FSW discussed their personal experiences of disclosing their status to their partner for the first time:

> *I think it did us right eventually because he was initially furious when I first told him, and he stopped coming to my house. I was tired of taking my ARVs in secret when he was around, and sometimes I would skip a week without taking them because he sometimes comes to stay with me for a week or so. I started feeling like my immunity was being compromised; I started having diarrhoea. I gathered enough courage on this day, and I was prepared to take it whether he was going to leave me or not. So I left the ARV bottle on a stool when he was away. When he came back, he asked me, "What's that?" I said, "They are my pills." "Why didn't you tell me all this time?" he asked me. "I was afraid, I am now not able to take these drugs consistently because I skip them when you are around," I told him. He was incredibly angry, and he left. He came back after a few days. He told me that we should both go for testing, so we went to the DIC [drop-in centre] together for testing. He was negative, and my results came out positive. I still take my medicine, but it is not like he would accept using a condom, no, he refuses, and we are still together. –* ***Miranda, PD, freelancer***

This experience highlights how difficult and challenging disclosure is in sexual partnerships, especially when relationships are relatively new and FSW largely depends on these partnerships for financial support. Miranda's experience also illuminates the effects of non-disclosure on HIV prevention and engagement with treatment. I have discussed the issues of experiences with ART in-depth in section 7.3. Her experience also highlights the strategies that FSW use to initiate discussion around HIV with their partners and the emotional processes that individuals experience when initiating this discussion. In this case, Miranda used the ARV bottle as a cue. This is a subtle way of communicating with partners but provides real evidence that the person is indeed HIV-positive and on treatment. Individuals use cues because they are easier to recognise, interpret and draw conclusions from. Miranda said that she used the ARV bottle as an icebreaker to avoid direct disclosure. The partner's response to her HIV-positive disclosure shows a typical pattern in HIV studies (Wells *et al.*, 2018).

However, some FSW found it unnecessary to disclose their HIV-positive status to their sexual partners. There were varied reasons for non-disclosure, particularly to sex work customers. Relations with customers were ad hoc, or one-off sexual encounters and the FSW were not emotionally attached. Some women felt that customers never tell FSW that they are HIV-positive if they know it, so they would also withhold their status.

Case study 13: Nova

Nova was a 26-year-old FSW, a freelancer, divorced, and the youngest among the three sisters. She had two children, but only one was dependent on her, the older child lived with her ex-husband. Like **Stailey** and **Rylee**, Nova was born and bred in Mpiko. She dropped out of school in form 3. She got married when she was 17 years old but later divorced her husband because the ex-husband was a drunkard and often spent nights out. She decided to do the same; she started going to the bars, drinking alcohol and sleeping with other men. She later

decided to leave him in order to do sex work. She stated that sometimes she goes to the bars to steal from men that she slept with. She was found HIV-positive through ANC HIV routine testing, and she has been on ART since then. She believes that it was her ex-husband who infected her because he used to sleep with FSW.

> *I didn't place an order for HIV, I was just given it. No one told me that they were HIV-positive so why should I tell them? –* ***Nova, freelancer***

The quotation shows that Nova felt no obligation to disclose her status to customers. Nova metaphorically compares getting infected with placing an order to depict the complexity of disclosure in these relationships. No FSW consciously chose or 'ordered' HIV: their sexual partners infected them, so they did not see any problem with reciprocating the action. However, this is not surprising because these relationships are only transactional.

Some women felt that they were economically vulnerable if they disclosed their status. This is because their HIV-positive status could lead to relationship conflict and the potential risk of losing customers, eventually leading to the loss of social and financial support. Elevated levels of poverty and economic dependence on sex work were persisted, and therefore non-disclosure to customers was needed for financial and relational security.

> *I don't look anywhere else when I am with these customers, I look in their pockets. Then they ask me "the way you are looking, why should I use* chishango *[condom]?" That means they have money and I will receive more if* chishango *isn't used. –* ***Madison, bar girl on ART***

HIV status disclosure has serious implications for HIV prevention since most partners of FSW are HIV-negative or of unknown HIV status. Some FSW stated that HIV status disclosure should be a shared responsibility, so if a man refused to wear a condom, it meant he was also HIV-positive or had STIs. Unsafe sex would occur despite knowledge of HIV-positive status or

disclosure to customers or partners, as the decision on whether to use condoms rested with the male partner. In some instances, some women who were HIV positive insisted on condom use for fear of ‘reinfection’ and not necessarily fear of infecting the partner.

> *I refuse to sleep with a man without using a condom, even when they tell me that they would give me more money. I tell them to keep their money. See, I have the money right here K1,500.00 (shows me the money which is coming from her bra) the man refused to use a condom, so I just left. I do this because I don’t want to get re-infected.* – **Rylee, freelancer**

They believed that they would get ‘more HIV viruses’ if they slept with someone living with HIV without a condom. Others followed the customers’ demands if the customers preferred not to use a condom, to receive more money.

7.2.3 HIV status disclosure to family members

In Malawi, family continues to be an important human social unit, although family size, structure and functions are evolving. Kin or blood connects a network of people, whether nuclear or extended, and this kinship system informs treatment and care patterns (Ankrah, 1993). On a functional level, in all family types, family caregiving for people with HIV brings about role reconfiguration and financial and other impacts. Households affected by the pandemic access various forms of support mechanisms to mitigate this impact.

Most FSW felt comfortable disclosing to a family member who was instrumental in providing social and emotional support and readily available, and to those who were usually responsible for caring for family members who assumed a sick role. Often mothers or mother figures were perceived to be better at handling this sensitive topic, but FSW felt nervous and cautious about disclosing to male family members, siblings and young children.

Siblings were perceived as inquisitive and gossipy so they could not be trusted with such information, as the case of the three sisters in Mpiko.

> *My big sister has a big mouth, even when you call her now and tell her this story, she will leave and tell it all to the concerned person, and even tells the person that you can go ask my sister if you think that I am lying. We don't tell her anything. –* ***Nova, freelancer***

> *I can't tell my son about my status because I don't want him to be worried about me. I tell my older sister if I am not feeling well.* ***– Willow, freelancer***

FSW viewed their children as fragile and potentially devastated about the news, since it concerned their own mother. Rather than using symbolic hints or cues, FSW preferred a face-to-face discussion with their family to eliminate any confusion and answer any questions that emerged. FSW also considered the environment where this discussion occurred; instead of disclosing in a public place, they preferred to have this conversation in a more secluded place like their bedroom, or when other household members were out and about.

7.2.4 HIV status disclosure and linkage to care

There were conflicting reports from the FSW and the PDs about HIV status disclosure. Some PDs reported that one of the challenges in their role was linkage to care. The PDs argued that many of their peers decided not to disclose their HIV test results so they could not determine whether they needed the PDs' support with linkage or not. The PDs said that sometimes they would make several visits to one client in the hope that they would one day start the discussion but to no avail. In some instances, the PDs, as stated in the previous chapter, were not trusted by the FSW. This was due to their unpopularity before becoming PDs, which meant they were viewed as posing a risk in managing HIV status disclosure. Due to the high retesting rate in this study, the majority of those who were HIV-positive knew about their status

prior to HIVST and therefore might not have felt the need to disclose their status because they were already on ART.

In contrast, some peers reported that during HIVST implementation, most women who had a reactive HIV test result disclosed their status to the PDs. They believed that the PDs would link them to an FSW-friendly facility to get them initiated/re-initiated into ART. However, some women reported that they waited for the PDs to come and discuss their HIV test result with them and link them to care, but the PDs never came back after distributing the kits. These FSW then linked themselves to the community health centres.

> *I did not see the benefit of telling Namurayi about my status. When she came here, she told me about the clinic that their organisation runs and she told me that she would take me there to start treatment. That was on Friday. I waited until Tuesday the other week, but she did not come. I just believed that she was not coming back and she was going to delay me. I then decided to go to Queens [Queen Elizabeth Central Hospital in Blantyre]. I told the doctor that I had self-tested and found I was positive, but he told me that they had to test me again because the HIVST was not hospital-based. –* ***Stailey, freelancer, first-time tester and now on ART***

However, during my interactions with Namurayi, she narrated that she was very supportive of her peers and would escort them to the FSW's clinic after they tested positive and if they showed a willingness to be linked to care. Drawing on Stailey's report, it seems as if some PDs disappointed some FSW by not keeping the promises they made to their peers. Most women said that they preferred these clinics to the government facilities because they provided opportunities for shorter waiting times, and because the potential for meeting customers was very low. Despite this disappointment, Stailey had the agency to initiate herself into care after assessing the need for treatment following her HIV-positive result. It is possible that the pressures of kit distribution and the personal commitment of the PDs could have affected linkage to care.

The next section discusses the factors that shape engagement with or disengagement from ART.

7.3 ART experiences

HIV treatment is inevitably a social process and dependent on patient engagement. Discourses of HIV care and treatment imply certain kinds of patient expectations and responsibilities. The WHO recommends that people living with HIV and on ART should adhere to both treatment and clinical appointments for optimal treatment outcomes and prolonged life (World Health Organization, 2016). Disengagement could seriously undermine the benefits of ART and increase drug resistance.

In the context of ART, the social and economic vulnerabilities of FSW with ART engagement indicate that some FSW had challenges in managing their HIV-positive status. There is a considerable body of literature that emphasises the importance of social and environmental factors in shaping HIV treatment provision and engagement (Cormier McSwiggin, 2017; Ho & Goh, 2017; Russell et al., 2016). HIV care is situated in complex health practices, identities and subjectivities with implications for different social and political contexts (Paparini and Rhodes, 2016). FSW's engagement in HIV care was situated in a specific sex work context, which shaped the multiple and competing meanings of HIV risk, including how biomedical treatment opportunities were negotiated in everyday social life. Engagement may be affected by individual, medication-related and health system factors (World Health Organization, 2015).

All participants in my study who were HIV-positive reported that they were on treatment (though sporadically). On average, participants had been on treatment for more than a year. All participants recognised the benefits of ART as they recalled the dramatic difference before and after the treatment of an illness episode. Descriptions of returning to sex work accompanied this discussion. Although some shared positive stories of ART when probed further others indicated they had experienced early challenges

accommodating their drug routine in their everyday activities. These experiences increased the likelihood of poor engagement with ART.

Living with HIV and on ART is a domain of self-discipline involving work to adjust to a new condition. Two main themes emerged from the ART experiences of FSW. The first theme concerns the notion that HIV is a manageable disease due to the availability of ART, which has managed to conceal the previously stigmatised identity of people living with HIV. After this topic was explored further, the second theme emerged. The second theme concerned the complexity of efforts to remain on ART and how poverty, stigma and other forms of vulnerabilities continue to shape treatment experiences. What these narratives reflect, however, is the limitation of subscribing to a single story of the success of ART and the shift of HIV/AIDS from an acute to a chronic and manageable disease (McGrath et al., 2014; Sangaramoorthy, 2018).

7.3.1 Factors shaping engagement with HIV treatment and care among FSW

7.3.1.1 Meaning of HIV risk in the context of ART

The perceived need for treatment was an important motivation among FSW for starting ART. This was concerning their feelings about their personhood: how they viewed themselves in relation to others and their sex work identity. Some participants described the embodied signs of HIV, which served to warn them of the potential risk of deteriorating health:

> ***Participant***: *I decided to go for testing because I had a big ringworm that was on my bum, eeh, that was the time I went to the hospital. The ringworm disappeared after I started taking medicine. My bum is as clear as it was before.*
> ***Interviewer***: *So why didn't you go for testing before the ringworm appeared?*

> ***Participant**: I previously didn't go for testing because I was fine, there were no symptoms of any illness. People say that you can go for testing if you are coughing or if you have body sores. Now they are even testing people who are presenting with a headache before starting treatment. –* ***Malika, freelancer***

For some, receiving an HIV diagnosis was itself an indication of the need for treatment. Some individuals believed that treatment would prolong their lives.

> *Syphilis and gonorrhoea are nasty, but now people can take this medicine (that is for HIV), and I don't see a problem with it, but these two, eeeeeh, if they diagnose you with these, you cannot sleep with anyone, how can someone do that? It is very painful, and they give you injections, but AIDS, you take your medicine and that's it. –**Lira, bar girl and occasional freelancer***

When I asked the women specifically about their ART experiences, FSW who related stories of their experiences of ART embarked on an emotional journey of reminiscing about the peers, relatives and children who had died of AIDS-related causes and how "*favoured*" and "*lucky*" they were to be alive because of the treatment available. Some older women in the study reported having witnessed the progress of major scientific discoveries in HIV/AIDS treatment. They talked about the period when people living with HIV slowly wasted away and died because there was no available treatment; the period when people living with HIV were a laughing stock in communities because of the effects on physical appearance that were a side effect of the early regimens of ART; and the current status, where the available ART regimens were so advanced that "*the naked eye*" was no longer trusted to identify a person living with HIV. Overall, this reflected the changes in HIV/AIDS over time, which had a bearing on how FSW perceived HIV risk after the introduction and experience of ART and the meaning of living with HIV as embedded in an FSW's life.

The narrative that was emerging in the FSW communities was that HIV appeared to have lost its sting; the HIV/AIDS discourse was shifting from

viewing it as a death sentence to viewing it as a disease that was manageable in the communities. Access to ART has increased at a remarkable pace and saved millions of lives over the last decade in SSA (McGrath *et al.*, 2014; Sangaramoorthy, 2018). For example, Malawi has demonstrated an unprecedented commitment to HIV prevention, treatment and care. Major achievements include preventing transmission from mothers living with HIV to their infants, and 2011 Malawi became the first country to implement the Option B+ approach, irrespective of CD4 count (National AIDS Commission Malawi, 2014). The FSW had hope for the future because of the treatment available.

The emergence of ARVs has brought new ways in which people exercise self-discipline, resulting in changes in the epidemics in public health. From these experiences, some FSW recognised HIV as a disease that was stable and manageable. Several FSW living with HIV described experiencing physical changes after starting ART, such as increased weight and energy, and feeling healthier, including the continuation of sex work. This reinforced a sense of the value of the treatment and motivation to continue taking treatment. The first regimen that was introduced had side effects, which resulted in some people living with HIV developing lipodystrophy (a condition in which the body is unable to produce and maintain fat tissue) (Phan and Reue, 2005), which was a source of stigma and discrimination for people living with HIV. Some FSW talked about the effects of showing AIDS-related signs, and reduced sex work demand, and experiences of stigma within the sex work environment and the wider community. The current regimen has produced positive results as it has reduced side effects and prolonged life. Mia, a bar girl who was sick for a year, had had a positive experience with ART:

> *I felt that my peers were pushing me away because of the way I was looking before [with a rash all over her body]. I felt rejected by customers. It was quite serious. I know that my health deteriorated because I delayed treatment, I was afraid to test. I had to leave sex work and went back home to receive proper care from my family. I was free from this stigma after being on treatment for a year and a half. My*

body and health were restored, and I did not have any deformities and I came back to the bars. Actually, some of my peers do not believe me when I tell them about that illness but those who saw me at that time know exactly what I am talking about and they know the benefits and the side effects of these drugs. – ***Mia, bar girl on ART***

The quotation above reflects the effect of HIV/AIDS on social relationships, its impact on sex work and the reframed risk. These historical accounts of fear and death combined with existing feelings of hope and a long, healthy life influenced reconstructions of risk among FSW. Mia describes a scenario whereby de-stigmatisation was predicated on the successful treatment that allowed her to resume sex work activities and to live without physical markers of illness. Mia was able to live a 'normal' FSW life because she had managed to 'avoid stigma'. ART made it possible for her to look healthy, thereby concealing the diagnosis from her peers and customers. To her dismay, she did not receive support from her peers when she became sick, contrary to the experiences others narrated in section 7.1.1, which indicates a variation in the support that peers can offer to each other.

Some women reported that the information that was circulating in the local communities was that "*cancer is more dangerous than HIV*". This may be due to the rise in cancer diagnoses in the communities as a result of improved cancer diagnosis in Malawi (Gopal *et al.*, 2013). In their study, Ho and Goh, (2017) found that participants felt that cancer was better than HIV because cancer patients were not stigmatised. These women, however, believed that cancer was deadly and that the cure for cancer remained elusive. Those who could afford to receive treatment travelled to Tanzania or India. This understanding was framed in the context of sex work. Women argued that they could still carry on with their activities despite living with HIV, unlike with cancer, where a patient assumes a sick role, is relieved of their duties and cannot manage to maintain their sex work role, and hence it could interrupt their economic activities.

However, for others, HIV risk was not a reduced risk *per se* but the product of multiple risks generated from the response to ART. The women who held a belief in multiple risks believed that some of the incidents of cancer and other non-communicable diseases were related to HIV. These women argued that although HIV/AIDS was no longer a death sentence, people should be aware of other risks associated with the disease. Indeed, a study by Horner et al. (2018) found a high cancer burden among ART users in Malawi.

The changes experienced by these women regarding HIV/AIDS were a product of both scientific and social efforts in response to the epidemic and had a profound effect on the social construction of HIV risk and biology. Knowledge of HIV risk among the FSW was a cumulative process, in which new ideas of risk were built on the old. This process is an example of a combination of history and people's experiences as active agents of change producing new knowledge. This construction provides opportunities to identify the creation of new practices – specifically, how FSW as subjects of change interrogate and give meaning to this new knowledge and apply it in their lives.

This reflection resonates with Foucault's ideas on knowledge. Foucault states that knowledge is not neutral; it produces particular perspectives and motivations that shape our behaviours and have a controlling effect on our bodies (Pylypa, 1998). Technologies can play a crucial role in formulating identities related to the personal experience of risk and illnesses and in how a population becomes focused on the regulation of life. Scientific discourses around ART have produced new knowledge about HIV prevention, treatment and care, resulting in a new form of governmentality for those living with HIV. This production of scientific knowledge is an instance of biopower in that it creates positive reasons for FSW to engage with biomedical systems. It simultaneously creates a new obligation to conform to what is desirable, thus to engage with ART to maintain their social bodies and changing identifies.

7.3.2 Factors shaping disengagement from HIV treatment and care among FSW

Drawing on the success stories, the narrative of lifesaving and health-restoring treatment for HIV is now common, including in some countries in SSA. The prescribed drug routines, however, are extremely complex and frequently require some lifestyle changes (Erlen *et al.*, 2001). In addition, understanding and perception of how the medication works in the body impact the experiences of taking the medication. The FSW's views show that other forms of vulnerabilities related to the sheer complexity of the regimens - including taking medications at assigned times, with or without food - shape treatment experiences. For some women, it was the physical environment of the bar, the nature of their work, the packaging of the drugs and experiences of intrusive customers that affected their engagement with treatment.

7.3.2.1 The struggle of accommodating an ART drugs routine in an FSW's life

Photo 9: Taking ARVs in the sex work context

No one here takes these medicines daily; it is impossible, and it can never happen. At the hospital, they tell us to take medicine and sleep but here we don't sleep. We sometimes feel dizzy when working in the bar. – ***Melody, bar girl***

The bar environment affected drug routines, leading to disengagement from treatment. There were three things that the FSW were concerned about when taking ARV drugs: food, alcohol and sex work. The messages about ART that some women reported were sometimes conflicting. In an ideal situation, the

drugs were supposed to be taken every day at a specific time that they felt comfortable with, and they were to remain consistent in that routine.

Drug routine and sex work

Some FSW stated that they needed to take their drugs with food, as advised by the healthcare workers because the drugs were strong. Others believed that they were given a specific time to take the drugs, for example, many mentioned 8 pm. There were a few who reported that they were given the freedom to choose a suitable time to accommodate their daily activities.

These drugs, however, were reported to have side effects. The women reported feeling dizzy, talking in their sleep, having nightmares and experiencing nausea, which compromised sex work because the scheduled time for taking drugs coincided with the time when sex work demand was high. They said that the side effects affected their ability to solicit customers for sex work, which meant no money. Some FSW reported that healthcare workers told them that there were clinically recognised side effects that warranted medical consultation. Other side effects, including those experienced by these women, were framed as tolerable. What providers perceived as tolerable side effects, however, contrasted with what FSW found it possible to manage every day. Given this, they could not afford to permit these side effects to interfere with sex work.

Due to these side effects and disruptions, the FSW devised ways of accommodating drug routines in their sex work life. Some preferred to take the drugs during the day when sex work demand was low. The bar girls, however, raised concerns that they could not sleep during the day because of the loud music that played in the bar. Others preferred to take the drugs when the bar was closed when it was quiet. However, sometimes alcohol and drug use affected memory, and often women forgot to take their drugs, or the presence of overnight customers would affect drug intake.

Alcohol and drug routine

Alcohol affected drug routine in two ways. On the one hand, some FSW believed that they were supposed to abstain from alcohol when they wanted to take the drugs. Most of the FSW were worried about drug contamination with alcohol and noted that alcohol abuse was a key issue in engagement with treatment. Some women highlighted that they did not like to stop drinking or abstain from alcohol, and therefore they sometimes decided not to take their drugs to accommodate alcohol consumption: "*I don't take my medicine when I want to drink [alcohol].*" On the other hand, some of the women were not worried about contamination but stated that the effect of alcohol on their memory meant they missed doses. In the bar settings, alcohol was often accessible through customers who bought the girls drinks.

The FSW adapted their drug routines to meet the demands of sex work. Their approach to treatment was neither an ongoing, self-disciplined routine nor outright resistance and complete disengagement. FSW, rather, employed 'situated rationality' (Schmid, 1988) where the perceived risk of disengagement from ART was managed simultaneously with the maintenance of their sex work position.

7.3.2.2 Lack of individual space and privacy

Another important feature of the FSW's experiences of ART was the ongoing vigilance needed to protect their privacy, and stigma management in a crowded place, especially for the bar girls. The social and physical environment in which the FSW in the study took their ART medication shaped their engagement with ART experiences. Even in the absence of the side effects and challenges of drug routines, the immediate problems of space and individual privacy reduced engagement with ART and increased fear of stigma and loss of economic support. When I visited the bars during the day, I saw that they were always busy, and customers were present in FSW's rooms, although traffic increased at night. Luna took a photograph below during photovoice to show the environment and the condition of their rooms in relation to ART experiences:

Photo 10: FSW's room

We usually don't keep our medicine in our rooms. The customers are very nosy, they go through our bags when we go out; let's say I go out to the toilet, then a customer finds the medicine in there. And those pills rattle when they are in the bottle [laughter] so they can easily tell that I have ARVs and that I am positive. – ***Luna, bar girl***

Some FSW, mostly those who were bar-based, said that they were not comfortable taking their medicine in places where they met their customers. At the bars, the FSW lacked personal space and individual privacy as the rooms were small and shared among the FSW. The FSW feared public humiliation, especially as they considered the pills to be something private. The women expressed concerns about unintentionally disclosing their HIV-positive status to their sex work customers and about the stigma. The presence of ARV drugs was a potential means of involuntary or unintended disclosure of their HIV-positive status. In addition, as Luna said, some customers were intrusive and would usually go through their personal belongings without permission and they could easily find the drugs. There were also concerns that the drugs rattled when they were in the bottle, which sometimes brought unnecessarily social curiosity and prompted customers to ask uncomfortable questions about ARVs and HIV status. Given this, some bar girls were not comfortable with keeping their drugs in their rooms. They feared that they could lose customers if customers knew about their HIV-positive status and that they were on treatment.

Instead, these women resorted to having drug custodians to avoid this stigma and humiliation. The drug custodians were individuals who were living at or near the bar who agreed to keep ARVs for FSW for the duration they were working at a particular bar. The drug custodians were often the venue owners or their peers who lived close to the bars. Sometimes, some FSW could temporarily move the drugs to the room of a peer who lived at the same bar if they were expecting a customer at a particular time. This initiative of having drug custodians, however, eventually undermined engagement with treatment. Most drug custodians were not always available or accessible when the pills were needed, due to travelling or having company.

7.3.2.3 Pills on loan

For many women living at the bars who were HIV-positive and on treatment, sharing ARVs was the norm. Due to some women disengaging from treatment there were leftover drugs. Ideally, there are enough drugs in a bottle for one month, which meant that if they skipped two or three days they had an overflow of drugs for the subsequent month. Consequently, there were always pills available for loan among the bar girls. In some cases, some FSW were not able to go for clinic appointments for drug collection due to transport costs, and they potentially risked disengagement from treatment. Some studies have established that many people living with HIV in many parts of SSA express challenges in adhering to clinical appointments due to costs or a fear of unintended HIV-positive status disclosure to neighbours (McSwiggin, 2017). In this situation some FSW felt the need to take pills on loan, with an agreement that they would return the pills from their own batch after collecting it from the clinic.

Drug sharing often occurred among FSW who had long-term relationships. Luna and Madison come from the same village from a district neighbouring Blantyre. They both work at the same bar and are both HIV-positive and on treatment but they collect their drugs at different times. Although they both admitted to being inconsistent with treatment, they tried their best to remain on treatment and supported each other with drugs if one of them needed

them. However, they were on different regimens; Madison was on the 'white drugs' and Luna was on the 'yellow drugs'.

The knowledge of the risks of drug sharing was common among these women, however, Madison said "*there is no difference between the white or the yellow medicine*". Madison meant that there was no difference between the white and the yellow drugs regarding their efficacy. However, they reported notable differences in the side effects – 'yellow pills' had more side effects than the 'white ones': "*The yellow ones make us go crazy, we can't function in the bar; sometimes the customers also notice that there is something wrong with us.*"

This scenario reflects the openness about HIV-positive disclosure among the bar girls, which prompted discussions around HIV treatment and encouraged social support among them. Farmer et al. (2001) however, argue that initiating ART without ensuring full engagement through adequate support systems is likely to lead to treatment failure and the emergence of drug resistance. Studies on ART engagement show that even minor disengagement from the prescribed regimen can result in subsequent treatment failure (Orrell, 2005; Bezabih, Beyene and Bezabhe, 2019).

There were consequences, however, to drug overflow and sharing among my participants. I further explain this point in the next section.

7.3.2.4 Juggling rewards, discipline and punishments

The FSW reported that the health system in Malawi had developed ways of sanctioning disengagement and rewarding those who were consistent with their drug routine. The FSW explained that at the start of ART, the women were prescribed drugs to last them a month.

This was a first step to test the individuals' commitment to treatment. If the women managed to finish the drugs as expected, they were rewarded with two bottles to last two months on their next clinic appointment. If individuals

satisfied this expectation, then they were given three bottles to last three months. The three bottles were given to reduce clinic visits for drug collection. The health system 'punished' those who disengaged from ART by reverting to one bottle, which would require more frequent visits to the hospital. Sometimes it got even worse. When there were anomalies with engagement, and an individual was showing signs of illness, they were told to go for a refresher initiation class. Then they would start with one bottle again. Although these measures were put into effect to persuade the individuals to follow their drug routine consistently and remain on treatment, the socio-economic status of the participants sometimes impeded their ability to remain on treatment. During fieldwork, a couple of times FSW reported that they had missed their clinic appointments because they did not have money for transport. I gathered that this was the case for many FSW during times when sex work demand was low, which meant no income.

> *They give us a punishment if we do not consistently follow the drug routine. Next time you go to the clinic they give you one bottle instead of three so that you learn from your mistakes, you then have to go every month to the clinic to collect your batch until they are satisfied that you can commit to the routine. –* ***Luna, bar girl***

Practices of perceived 'rewards' and 'punishment' effectively categorised those who consistently engaged with treatment as 'good' and those who did not as 'bad'. This categorisation conveyed ideas of the social and moral currency (McSwiggin, 2017) of treatment engagement, self-blame, and stigmatisation of those who often disengaged from treatment. Biomedical discourses charge individuals with the responsibility of self-discipline and maintenance of a healthy lifestyle to maximise the benefits of treatment. These discourses, therefore, frame responsible therapeutic citizenship as a choice and cast individuals who engage poorly with treatment as choosing poor health over well-being (Marsland and Prince, 2012). The logic of disengagement due to side effects or food insecurity are framed as 'personal, moral shortcomings' (McSwiggin, 2017). Since disengagement was considered a moral shortcoming, there was much gossip among the FSW

about the ‘bad therapeutic citizens’, and they often talked about individuals’ physiological health. Hailey said this about a peer who lived at the same bar: “*Stimela stopped taking her medicine a long time ago. Have you seen the way she is looking now? She is skinny and sickly; she was not like that before.*”

Engagement with treatment can be a challenge to some FSW because of their mobility, especially to freelancers. FSW discussed the flexibility of the healthcare system to accommodate people’s mobility and relocation. Common perceptions and experiences reflect the fact that the system allows a change of drug collection point as long as one has requested it. Some FSW reported that they usually get a transfer when they are relocating to a different venue in another district. Some FSW reported that they were able to collect two to three bottles if they anticipated any temporary relocation to a different venue, and they would ensure that they came back home before finishing the last bottle. There were, however, others who still travelled back to their home village to collect batches and those who chose to refill ART medication from a facility far from their communities to avoid stigma in the communities. Their efforts, however, were sometimes impeded by a lack of money to travel back to their drug collection points, leading to disengagement.

7.4 Life must go on

Despite the discussion around struggles to remain consistently on ART and wider vulnerabilities in the sex work environment, FSW were getting on with their lives and had aspirations for the future, with a focus on themselves and their families. FSW took photographs that depicted their aspirations and dreams. The photographs below present a richly layered understanding of their aspirations, opportunities, dignity and purpose in life. These women bore the burden of providing social and economic support for their children, siblings and other dependants.

Photo 11: My dream house

I want to own a house, and I know it is going to be possible, I want to have a house like this one. I have already started assembling building materials; I have already bought iron sheets, doors, windows, windowpanes, I now have to buy bricks and wood poles only. You know I am using the same money that I get from sex work to buy these materials. – ***Ava, bar girl***

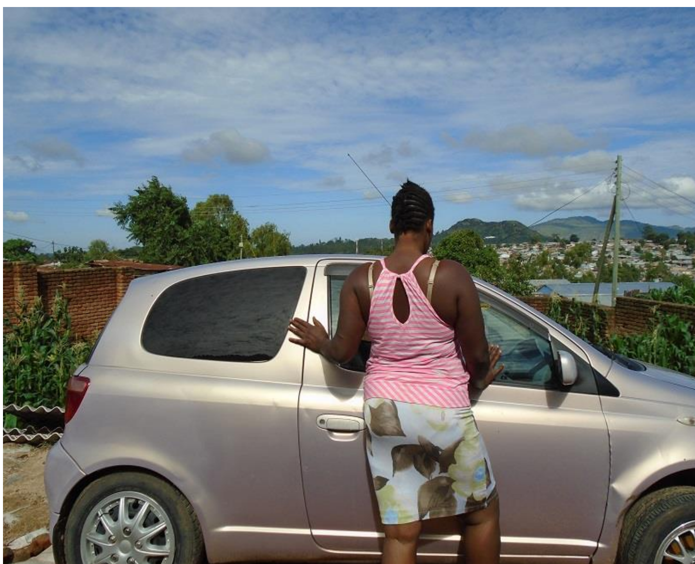
Photo 12: Food security

I want to go home to see how my maize crop is faring, but I am unable to do so because I am here and I don't have money for transport. I photographed this to show that I have the desire to have maize to have food security. It is telling us that even highly mobile women have that desire to have food in their household. – ***Amelia, bar girl***

Photo 13: Big investment

I want one day to be there, leaving my house and going to my shop. It is giving me courage that FSW, we also need to think about our future. Business is like an investment, and we won't lack a thing if we have something like this. As FSW, we also need to save money and not spend it all. – ***Zoe, freelancer***

Photo 14: Plan for exiting sex work



I want three things in life: a house, a car and a respectable marriage, and then I will leave sex work for good … This is telling us that I have plans to leave this place and be independent. – ***Miranda, freelancer***

The analysis of these aspirations should not be limited to their rationality or feasibility, as Hart (2016) argues that aspirations depict an individual's pathway and can be consciously or unconsciously motivated. These photographs show aspirations and also in some cases, the FSW talk about how they are in the process of realising these, showing that they can exercise strategic agency in identifying

goals and pursuing them. These aspirations emerged from both the individual and the dominant discourses that shape particular aspirations in the communities.

I observed many similarities between the two groups in Mpiko and Namachero; there were many photographs taken of maize and houses. As aspirations can either be short, medium or long term (Hart, 2016), these photographs depicted both the short- and long-term needs of FSW. They need food in their households daily, as Amelia said. The aspiration to own a house was framed around, creating wealth that their children could inherit in the future. For example, owning a house in this community was perceived as honourable. And FSW would say that "*every wise parent wants to leave a house for their children as their inheritance*". These two aspirations indicate the conscious decisions these women have made based on their current needs and are mainly focused on the normative identity of being a single parent. The FSW viewed themselves as both mother and father: they were responsible for both providing for and nurturing their children and other dependants.

There were also notable differences among the FSW about what photographs they could or could not take. A few of them took photographs of a car, especially the freelancers. Some Freelancers stated that a car could ease their mobility and raise their status in their communities, whereas others argued that they could not take photographs of a car although they wanted one because cars were expensive, they did not have driving licences and they did not even know the price range for cars in Malawi.

The photographs also highlight the commitment these women had to achieve their aspirations. The buying and assembling of building materials or realising the need to save money for a shop (Miranda) show their determination and commitment to the cause. These women were working towards breaking the cycle of generational poverty, and towards offering solutions to their problems. This indicates that although they were FSW and on ART, their experiences did not constrain them from having aspirations they wished to fulfil.

7.5 Summary

This chapter has demonstrated that HIVST failed to increase FSW agency to engage with HIV prevention, treatment and care thereby reducing their well-being freedom. Sex work demands, alcohol abuse, need for sexual pleasure and gendered power relations reduced FSW agency to practice safe sex consistently. Experiences of stigma were still persistent among the FSW as a barrier to both HIV status disclosure and access and adherence to treatment.

Knowledge of the benefits of ART was common among FSW, and all FSW who tested HIV positive reported to have been linked to care at some point. However, FSW reported that sex work daily routines, economic pressures and drug side-effects constrained FSW agency to engage with ART continuously. Sex work demands and drug side effects played a critical role in the expression of their therapeutic citizenship. “A sense of being healthy, and responsible, including appropriate use” of (Young *et al.*, 2019, p.1) drugs, conflicted with sex and bar work demands.

Support from the health system was insufficient to facilitate the creation of an empowered and informed therapeutic citizens, instead disciplinary power was used to ‘punish’, control and discipline those who failed to adhere to ART.

8 Implications, conclusions and recommendations

8.1 Introduction

In this final chapter, I draw on key literature to contextualise the research findings that emerged from the various strands of the study to provide an understanding of the implications of the work. I also lay out the key arguments in response to the research questions. In section 8.2, I begin by giving an overview of the research study: the research questions and the discussion of the key findings. I then describe the contribution the study makes to the theories (8.3). Following this discussion, I state the limitations of the current work (8.4) and provide recommendations for HIVST interventions (8.5) and final reflections (8.6).

8.2 Implications of the research study

The idea of this thesis arose out of a concern about empowerment, the rhetoric that surrounds HIVST and remains unchallenged in the public health sphere. In this ethnographic study, I used qualitative and participatory research methods to understand how the sex work environment shapes FSW's experiences with HIVST and the ways in which this engagement contributed to their vulnerability or opportunities for empowerment. FSW have often been treated as a homogenous "key population" with prevailing discourses around FSW as being victims/vectors of disease rather than women with agency. The choice of FSW as a study sample in my thesis has made a strong case for the justification of this concern.

In this thesis, I argue that HIVST can be empowering to FSW but in very limited ways; FSW can sometimes have 'expanded agency' as a result of the implementation of HIVST, but this only revolves around making decision about when and where to test. However, this 'expanded agency' does not result in an increase in well-being freedom due to a myriad of vulnerabilities that FSW experienced in the sex work environment and were not addressed by the technology and the way it was implemented. There were no clear examples of FSW experiencing an enhanced ability to prevent HIV or access

to care due to many limits of their well-being freedom. Considering empowerment from biopower and biocitizenship alerts us to the way in which we are not all equal in relation to biotechnology (Plows and Boddington, 2006). Plows and Boddington (2006) contend that opening up attention to these contested relations is important to facilitate discussion about duties and responsibilities that place disproportionate burdens and distribute benefits of biotechnology unevenly.

In **Chapter 1,** I presented key research questions to be addressed in the research study:

1. What constitutes FSW's vulnerability and empowerment, including perceptions of HIV risk in the sex work environment?
2. How does the sex work context shape FSW's experiences with HIVST and the meaning of empowerment?
3. How does HIVST impact on FSW's lives in relation to HIV prevention, treatment and care?

In the next sections, I address these three questions and provide a discussion of the key findings of this research study.

8.2.1 Power relations, vulnerabilities and risk in sex work environment

In **Chapter 5**, I address the first research question that aimed to elicit an in-depth and nuanced understanding of women's biographies and sex work context in which HIVST was implemented, in order to situate the understandings of vulnerability and empowerment in sex work environment.

Gendered power relations and political economy

This study has demonstrated that overall, FSW exercise limited power across their life course although their narratives highlighted both their sense of agency and the societal structural forces shaping their decisions to engage and remain in sex work.

In my study, the lack of access to male income through a father or husbands was the key reason for engaging in sex work. Meeting their own and their families' basic needs was paramount to many of their decisions. These findings are similar to other settings where gendered power relations also shaped women's access to income (Flowers, 2001; Hunter, 2002). I found that FSW were coming from poor backgrounds, raised by their mothers or siblings, limited education, and unstable access to relative economic and social security, and sex work offered them greater economic power. FSW's narratives revealed how gender roles and relations, including differential access to resources, benefit men more than women in Malawian society. The gendered hegemonic culture afforded underprivileged women few options for economic survival, constraining women's life choices, including their opportunities for economic independence and the complete lack of safety nets and government support. The inability to meet one's basic needs, and the resulting dependence on male gender to do so rules out the capacity for meaningful choice. In particular, women felt the adverse effects of these inequities after separation or divorce or the death of a spouse. Women's weaker socio-economic positions and economic vulnerability constrain their choices in society, resulting in their disempowered status. Within these constraints, women exercised agency by engaging in sex work to meet their daily needs to support themselves and their families.

I found that after joining sex work, power relations inherent in global and local political economies influenced the patterns and practices of sex work in Blantyre. FSW, especially the older FSW, showed concern about the profitability of sex work after the introduction of democracy in Malawi. Due to increased poverty levels and high inflation, men lacked disposable cash for sex work, which translated into reduced demand for sex work and stagnant sex work prices. This increased women's economic vulnerability within sex work but also limited alternative income generating options, so they remained in sex work, though with little pay. They also became highly mobile in search of new sex work markets which reduced the possibilities of trust and solidarity among them. These findings support evidence from other studies that broader

political economy structures influence decisions and patterns in sex work (Fielding-Miller *et al*., 2014; Beckham *et al*., 2015; Warria, 2018). Hence, the economic vulnerability of women in this setting was created by an intersection of local gender power relations and the global political economy. Whilst increasing their capacities for survival and economic independence, sex work renders women less powerful in other spheres of their lives, which creates new vulnerabilities to violence and ill-health. FSW's agency in joining sex work is an indication of 'situated rationality' (Schmid, 1988) made within constrained circumstances of structural violence. In this study, however, patriarchy, violence and subordination of women were not inherent to sex work; instead, they embodied the life of a woman in general.

Economic independence and empowerment

There are views among some feminists that sex work not only empowers particularly by providing them with greater opportunities for economic power (Weitzer, 2009; Beran, 2012). For my participants, sex work was a means for becoming better able to shape one's life through economic gains that would be otherwise unattainable. In my study, I found that sometimes sex work offered FSW increased opportunities to exercise agency towards promoting their well-being, through both greater access to resources and relative decision making in how their money was spent. Although part of their money went to venue owners (employment agreement as for the bar girls), FSW valued the greater sense of independence. Rather than relying on a husband, partner or male relatives, sex work allowed FSW to make choices free from this pressure or influence.

Sex work increased FSW's 'well-being freedom' in limited ways that revolved only around positive changes in women's personal and household circumstances. FSW's access to income from sex work brought positive changes in women's own perceptions of themselves and an increase in women's assets. Some FSW owned property; others had savings, with a plan to construct their family home; and others were saving money for the next agricultural season or educating their dependants. Individual differences

existed in how FSW set their goals, and expenditure was usually determined by personal and family needs.

However, none of the participants showed an interest to engage in sex work in the long term. Social stigma attached to sex work, violence experienced in sex work, and need to (re)integrate into a societally acceptable social identity (wife) influenced this decision. Narratives from FSW in this study demonstrated that although sex work was not a reliable route to economic independence, attempts to leave sex work often failed since alternative livelihoods were less stable or profitable. This suggests that sex work was the most stable of the options available to women. In this case, I argue that many FSW face a contradictory reality: whilst sex work offers few economically viable alternatives for survival without access to resources through a male partner, life in sex work offers many social and physical vulnerabilities. To some extent there is a trade -off between economic independence, or even survival, and physical and emotional safety, including the possibility of an acceptable and desirable social identity. Therefore, meaningful FSW empowerment should not only focus on economic empowerment, but should also encompass changing the power relations responsible for causing FSW's vulnerabilities; address the social values that leave women stigmatised and unprotected from abuse and violence if they sell sex; and address the gendered power relations that mean that selling sex is one of the only viable livelihood options they face. However, public health interventions rarely grapple with these complexities.

Power relations in sex work

The FSW's narratives also highlighted the exploitative conditions of sex work in which FSW were generally found. After joining sex work, I found that FSW experienced a range of vulnerabilities due to power relations with venue owners and customers and these experiences differed according to sex work type and location. In this section, I argue that it is the interaction of various social, economic factors and aspects of sex work itself that together contribute toward making FSW vulnerable, and some FSW more than others.

Unequal power relations between venue owners and bar girls increased bar girls' vulnerability to economic exploitation and coercion which limited women's agency in decision making over their sex work earnings and participation in HIV interventions. In this study, the 'power over' FSW of the venue owners was key in the sex work environment and contributed to the 'bar girls' experiences of sex work. For bar girls (who were tethered to the venue owners), the venue owners used their power to control sex work income and to directly or indirectly coerce FSW to participate in HIV prevention, treatment and care interventions. Venue owners' social and economic power intersect with the public health discourses (which meant that HIV testing, in general, was advantageous to the venue owners as they could present the FSW working there as 'clean') to create specific vulnerabilities to coercion for bar girls. In addition, venue owners had set strict rules for FSW, and employed guards to monitor FSW's mobility and actions, so there was direct coercive use of their underlying power as employers. This finding highlights the disempowering sex work environment as demonstrated by the dominant 'power over' exercised by the venue owners on FSW, and reinforcement of public health discourses.

However, the freelancers had more autonomy in their daily lives and economic independence than the bar girls because they were not tethered to venue owners, so they demonstrated 'power to' manage and control their income. The freelancers were, however, described as more vulnerable to physical and sexual harm than the bar girls because they operated in isolation, and therefore lacked social power because they did not have peers' and venue owners' support, and physical protection through men employed at the bars to break up fights. Therefore, treating all FSW as a homogeneous group may, therefore, resulting in failure to see their complex lives. We need to pay attention to the different layers of vulnerabilities that are experienced by different groups of FSW (Luna, 2014).

Normalisation of GBV

I found that GBV was deeply rooted and defended on cultural grounds (Nkhoma and Charnley, 2018), and it was not surprising that all FSW reported

their vulnerabilities to physical violence. Other studies in the Malawian context have found that, GBV was experienced by both men and women although women bear the burden more than men (Kathewera-Banda *et al.*, 2005; Mandal and Hindin, 2013; Chepuka *et al.*, 2014). FSW in this study stated that they had experienced GBV before, during and after periods of sex work and that it mostly had a strong impact on their decisions to engage in sex work (for instance, when leaving an abusive partner). Socio-cultural factors including societal cultural norms, stigma and alcohol abuse reinforced GBV (Davison, 2007) experiences among FSW. Alcohol abuse in the bar setting often increased impairment of cognition and triggered violent behaviours. Research studies have consistently indicated that alcohol abuse is often associated with violent crimes against women (Setlalentoa *et al.*, 2010; Heylen *et al.*, 2019). Davison (2007) found that alcohol abuse among women was an expression of oppression and a coping mechanism which reflected the distribution of violence and powerlessness throughout their lives. This could be true for this population because of FSW's experiences of violence in their life course.

Lack of social and legal support after an assault in the sex work context affected GBV reporting. In this study, the relationship between FSW and venue owners, type of sex work and broad legal structures determined the level of support in mitigating GBV in the sex work environment. As in many settings (Mkandawire, 2012), FSW rarely have support from the police when violent acts are reported, and so FSW rarely report these cases. The failure to address the problems that FSW face daily in their work can be associated with patriarchal institutional power relations in the legislature and police institutions. The legal framework in Malawi does not recognise sex work as work resulting in the lack of supportive sex work laws which made it possible for men to act with impunity. Clearly these institutions are unwilling to change the unjust practices that FSW face. It is well established that violence has destructive impact on somatic and mental health as well as quality of life women (Anczewska *et al.*, 2007). FSW with violence experience often reported feelings of helplessness and powerlessness which reduces their agency in seeking help or support after an assault. FSW vulnerability to violence derives from gender power relations in society in general, which both

often precipitated their move into sex work, and underlie the exacerbated vulnerability they face as FSW due to societal gendered norms that stigmatise sex work.

The power of social norms on inevitability of HIV infection

In this thesis, the complex power relations in the sex work environment increased FSW's vulnerabilities to heightened HIV risk infection and shaped perceptions of risk. It is well established that FSW demonstrate a good understanding of HIV risk and transmission (Lakkimsetti, 2014); however, social and economic forces in the communities impact on their opportunities for and constraints on acting in ways that would prevent transmission (Borne, 2003; Nnko *et al.*, 2019). A combination of violence, alcohol abuse, and simultaneous practices of *zibwenzi* (boyfriend relationship) and sex work increase FSW's HIV risk. The normative power relations of both *zibwenzi* (long- or short-term) and sex work increased FSW's HIV risk (Bukenya *et al.*, 2013; Tavory and Swidler, 2009; Wirtz *et al.*, 2015). It was typical that FSW had stable and trusted relationships simultaneously with sex work, sometimes for prospects of marriage or as a 'buffer' to sex work. The threats of violence and gendered power imbalances experienced in both sex work and *zibwenzi*, combined with alcohol abuse, impacted on FSW's ability to negotiate condom use and decision-making during sex work, thereby increasing their vulnerability to HIV infection.

FSW interpreted their HIV risk subjectively through their own cultural and individual frameworks, which were partially informed by biomedical understandings of risk of HIV infection. Many FSW's narratives revealed their sense of themselves as inevitably vulnerable to HIV, which they internalised as part of being an FSW. FSW's perceptions of HIV vulnerability as inevitable emerged from the hidden dimensions of biopower and power relations in the sex work environment. Expressions of inevitability of HIV infection were also reported in another study among FSW in Malawi (Twizelimana and Muula, 2015). FSW's experiences show that power exercised in the form of ideology the public and public health discourses that frame FSW as deviant (and therefore deserving harm) and as an 'at-risk population' respectively - shaped

FSW's subjectivities about their HIV vulnerability. These discourses have an effect on how FSW exercise their agency in managing their health and their interactions with health systems.

In summary, the discourses that surround sex work are varied and pluralistic. Understanding the historical and contextual analysis of sex work is important in order to attend to the complexities of the political economy forces, public and public health discourses, gendered power relations, and FSW's voices at the site of the intervention. Whilst FSW exercised agency in entering sex work, this was done in a context of severely constrained choices shaped by gender relations and the global-local political economy. Some emphasised their agency in their narratives whilst others emphasised their lack of choice. Sex work did increase women's individual 'power to' in the sense of economic survival and sometimes independence and relative autonomy, but in a wider sense women were still subject to (in varying ways) intersections of wider gender power relations (including GBV and stigma), the limitations of the economic environment and the work relations of sex work environments. Women's access to sex work may have given them a sense of agency and purchasing power, but working conditions simultaneously eroded their health and exploited their labour. Sex work was the best of the available alternatives to improve their situation and achieve economic independence. Therefore, despite limited individual increases in power, involvement in sex work cannot be seen as empowering since it did little to address the gaps and barriers between these women's agency and a sustained expansion of their well-being freedom (Drydyk, 2013).

8.2.2 Positioning HIVST within systems and networks of power in the sex work environment

In **Chapter 6**, I addressed the second question which asks how the sex work environment shapes FSW's experiences with HIVST. My analysis suggests that whilst HIVST seems to increase the opportunities for some FSW to exercise agency in HIV testing, it simultaneously constitutes new power relations and new practices of biocitizenship. Existing unequal power

relationships, exploitation, and testing obligations were being perpetuated in new ways through the new technology. The following sections explain how implementation of HIVST in sex work context increased FSW agency only in limited ways.

Obligations of monitoring HIV status

A range of studies have attributed HIVST uptake to increased autonomy and control over their decision to test by users (Burke *et al.*, 2017; Estem *et al.*, 2016; Indravudh *et al.*, 2017). In my study, HIVST increased FSW's autonomy to test in fairly limited ways. For example, because it meant that they did not have to navigate potential stigma by going to a facility to test for HIV and gave FSW freedom to test when and wherever they felt comfortable to perform the test. However, there was only one FSW who reported HIV testing for the first time, challenging the evidence that FSW underutilise HTS. The majority of FSW in my sample reported that they had tested two to three times before HIVST implementation and many of them already knew they were HIV positive.

There are two possible explanations for this; firstly, routine HIV testing of pregnant women at ANC and secondly, FSW-targeted HIV testing by different organisations may have resulted in increased HIV testing reports among FSW. This means that low access to HIV testing is not actually a significant problem for these FSW, so arguably, HIVST does not address a priority for them. Even within a limited definition of empowerment as an increase in individual power, HIVST is not offering this. HIVST, along with other HIV testing approaches created a new obligation (regular self-monitoring) for FSW as biocitizens, without actually increasing their power to use the information it gives them (Anderson, 2015). HIV testing imperatives disseminated through varied public health actors has reinforced FSW's sense of their obligation for regular self-monitoring.

Although HIVST created new opportunities for FSW to test for HIV and therefore offered limited increases in individual 'power to' for some, it did not create any sustained expansion of freedom in the lives of FSW to be able to

make choices that align with what they value in the pursuit of their well-being as an oppressed group, and therefore did not result in empowerment in this sex work environment (Govindasamy and Malhotra, 1996; Kabeer, 1999b). In addition, positive views about HIVST were not uniform; working for venue owners appeared to reduce FSW's agency to engage with HIVST. For some venue-based FSW, HIVST decision-making processes constitute an ongoing navigation of power relations and vigilance about keeping their jobs in the bars. The narrative that HIVST is 'empowering' assumes that individuals engaging with the technology do not have to navigate potential pressure or influence from other people, which is not the case for bar girls in the Malawian sex work environment. The delivery of HIVST in this intervention did not attempt to alter the broader power structures in sex work environment that my study has shown are the underlying forces shaping FSW vulnerability and disempowerment.

I argue that decision making in HIVST reflects the HIV testing imperatives disseminated through varied public health actors in combination with individual, social and economic vulnerabilities in the sex work environment (Anderson *et al.*, 2015), which in my study reinforced FSW's sense of their social obligations for regular self-monitoring. Specific forms of use of HIVST technology channel existing forms of power in new ways and create new power forms and relations. HIVST creates new forms of biocitizenship located in existing systems of power that frame the social meanings and experiences of the technology for FSW. The obligation to test is part of the 'positive power' that the tests produce, as it is linked to the desirable attributes of an increased sense of autonomy. Such 'positive power' however, may not be interpreted as empowerment.

Increased coercive HIVST in the bar context

My study shows that implementation of HIVST in a bar context in urban Malawi has the potential to increase coercive HIVST among bar girls. Coercive HIVST has also been reported in the general population (Kumwenda *et al.*, 2019). Coercion and mandatory testing are not recommended in the context of HIVST (World Health Organization, 2016), however, HIVST was

introduced in a sex work environment where unequal power relations persisted between FSW and venue owners. Some FSW reported coercive HIVST perpetrated by venue owners and the PDs, which reflected the complexity of consent in the bar context. Venue owners were able to override the agency of FSW through the use of verbal coercion. FSW's reports of coercion to self-test should be understood in the historical context. Venue owners were involved in decision-making around health and well-being as a means of extending their control of the FSW who resided at the bars, and indirectly benefiting FSW due to supporting demand. But this could not be interpreted as empowering in this context, since the asymmetrical relationship between FSW and venue owners remained unchanged, and arguably deepened.

Other studies have reported an escalation of other forms of harm following HIVST (Kumwenda *et al.*, 2019). In my study, FSW viewed coercive HIVST as unacceptable and increased negative psychological experiences. It left some FSW feeling powerless and confused about the utility of HIV testing, in general and the rationale of targeting FSW in the bars. Coercive HIVST clearly constrains active exercise of choice (to refuse the test) and as such HIVST implemented in this way could be seen as disempowering for these FSW.

High levels of retesting for HIV while on ART

As Drydyk (2013) notes, people can also exercise agency in ways which create negative outcomes for their well-being minimising their opportunities for empowerment. Here, although some FSW's exercised agency in testing, this did not necessarily promote their well-being freedom. I found high levels of retesting for HIV among FSW living with HIV, with nearly half of my sample on ART in this study. This is consistent with other HIVST studies among diverse populations (Choko *et al.*, 2015; Harichund *et al.*, 2019; Moore *et al.*, 2019). There were high expectations of a positive HIV status among the FSW; which were shaped by an awareness of high prevalence of HIV among FSW and past experiences with public health interventions highlighting 'at-risk groups' and targeting FSW. However, these practices are not merely examples of

pervasive biopower; women are not passive recipients of biopower (Banda, 2015) because they negotiate the use of these tests and sometimes in contradiction to their intended use. Their decision to retest reflects knowledge construction about HIV treatment developing in response to the ideas from multiple belief systems, often offering different interpretations with biomedicine. Although the Malawian government has expanded its programmes in HIV prevention, care and treatment (Dovel *et al.*, 2020), a gap remains in communities around the interpretation of what being 'undetectable' actually means, as evident in this study. This behaviour reflects a strong need for support in interpreting the test results in a population with high HIV prevalence rates and where individuals are encouraged to re-test if negative.

HIVST could be an important means of contributing towards empowerment through prevention, treatment and care, thus, increased well-being freedom. However, using HIVST to retest for HIV while on ART can have negative effects on women's well-being freedom. Retesting for HIV can cause psychological harm to individuals as it creates anxiety and uncertainty among those affected. Retesting of those with negative status is encouraged (World Health Organization, 2016) and highly acceptable among those on pre-exposure prophylaxis (PrEP) (World Health Organization, 2016; Ngure *et al.*, 2017). However, among those who are on ART, HIVST can result in a false-negative. A false-negative result can lead to misinterpretation, the potential for negative psychological impacts and disengagement from care (Olaru *et al.*, 2017). Although we found no evidence of 'total' disengagement from care (engagement with care for FSW was complex, as discussed in section 1.2.3, the FSW who tested negative were left confused and without support when they needed it. A study in South Africa also found no evidence of disengagement in the event of false-negative results after using HIVST (Moore et al., 2019).

Using HIVST for retesting for HIV while on ART demonstrates that HIVST does not in itself change the trust issues associated with HIV testing. The use of HIVST by some FSW reflected mistrust and uncertainty regarding their previous HIV diagnoses and discrepancies in viral load interpretation between

the community and biomedical framings. The slippage between ‘undetectable’ and ‘negative’ appears to be an effect of FSW active engagement with discourses on their health and identity. Potential increased agency or autonomy in testing does not necessarily translate into FSW’s agency to pursue their own well-being due to information asymmetry and syncretic understandings of health and technology.

(Re)production of power relations in HIVST interventions

As discussed above, in this study, HIVST increased pre-existing forms of unequal gendered power relations between FSW and venue owners. It also produced new forms of power between FSW and their peers, the implementers and the wider community.

The introduction of HIVST through the peer distribution model brought about changes in the lives of those designated PDs and in their relationships with other FSW. PDs received training for their roles, which has the potential to offer opportunities for new knowledge and skills, as well as cognitive abilities, which could increase their agency. In this study, the knowledge and skills attained from the training seemed to be beneficial to the PDs; however, these were specific to how to effectively deliver the self-testing kits. PDs experienced the training and their role as positive; in addition to increased knowledge, it also encouraged them to reflect on their own HIV status and risk. In this sense, it could be argued that their scope for agency was expanded. They also demonstrated a sense of pride in their work having been given responsibilities in the intervention.

However, whether this sense of expanded agency is empowering for these individuals also depends on the kinds of actions it enables. Further, whether it is empowering for FSW as a group depends on the social relationships that it creates and promotes. My study found that engagement of FSW as PDs in HIVST implementation did not address the asymmetrical vulnerabilities (power over) that existed between FSW and the implementers (Drydyk, 2013). The issues of distribution targets, incentives, and communication discussed in

Chapter 6 indicate that the relationship was not reciprocal. The knowledge and skills attained from this intervention did little to equip PDs to question the decision making power of implementers and PDs' subordinate status, without power to shape the intervention even in the longer-term (Drydyk, 2013). This problematizes the focus on the distribution of tests rather than linkage to care; a focus on test distribution created a perverse incentive for the implanting organisation to just get tests out, regardless of the needs and priorities of FSW. Thus, the sense of expanded agency for PDs could not be interpreted as empowerment, given the reproduction of power relations with the implementing agency, which limited the extent to which HIVST implementation addressed their barriers to linking to care.

In addition, although PD's sense of agency was expanded in their roles (in limited ways), this change simultaneously reproduced and strengthened power relationships between PDs and their peers based on the types of sex work they engaged in. I observed that social inequalities in sex work were reproduced during the intervention. The PDs presented the bar girls as 'modest' and receptive to HIV information and testing; in line with pressure and incentives from the implementing organisation to meet targets for the distribution of tests, they took advantage of the power relations of their sex work context to distribute tests to these FSW, resulting in coercive HIVST. In contrast, freelancers were seen as 'high status', assertive and brave by PDs, which they viewed as a challenge in introducing HIVST and meeting the project goals. The complexity of freelancers' sex work location and time for sex work continued to make it difficult for PDs to introduce HIVST and to support them with linkage to care. Attitudes of PDs and the implementing institution reinforced these existing power relations and therefore, bar girls' sense of inferiority and lack of autonomy; as such, it created forms of disempowerment for them as a group.

In summary, the delivery of HIVST has the potential to increase FSW decision making power over when and where to test for HIV. This control over HIV testing can provide information to FSW, which has the potential to inform decisions to act to prevent HIV, and to access treatment, care and support

(World Health Organization, 2016). However, the specific power relations and vulnerabilities in the varying sex work contexts mean that in my study for some, the power to decide to test was not actually increased; for others, feelings of insecurity and a sense of the need for retesting were amplified, and the multiple constraints on FSW exercising their agency to prevent HIV infection or access and adhere to care remained unchanged, as were the wider vulnerabilities experienced by FSW. The problems that FSW have expressed in this study are deeply rooted in individual, social, economic and political structures that HIVST cannot, in itself, address. These findings challenge the discourses which tend to represent biomedical technology as neutral. This representation is clear from the manufacturers and global health discourses surrounding HIVST (World Health Organization, 2016). However, based on my study, I would support those who argue that HIVST as a biomedical technology is not neutral (Banda, 2015): HIVST both contributes to and draws its meaning from the social fabric of citizen practices - what FSW do - and from the discourses of biopower that create certain forms of governmentality - in this case the public health surveillance regime.

8.2.3 Power of FSW to prevent HIV infection and transmission after HIVST

In **Chapter 7,** I addressed the third and last question which asks how HIVST impacts on FSW's lives in relation to HIV prevention, treatment and care. I aimed to highlight the experiences of FSW post HIVST in relation to changes in their lives, their relationship with their families, customers, peers and venue owners after receiving their HIVST results, and their engagement with HIV prevention, treatment and care services and the impact on sex work. A lot of the reality of what HIVST means and whether it can function in the sex work environment depends on how far implementation processes are shaped around FSW's constraints and priorities. In this section, I argue that implementation of HIVST in this setting failed to increase FSW agency to engage with HIV prevention, treatment and care thereby reducing their well-being freedom. The health system did very little to facilitate the creation of an empowered and informed therapeutic citizens, instead disciplinary power was

used to ‘punish’ those who failed to adhere to biomedical information about ART. In the sections below, I explore how HIVST peer-led delivery failed to increase FSW’s participation in HIV prevention, treatment and care.

The complexity of HIV status disclosure decision-making processes

The assumption of the public health discourse underlying testing is that testing or knowing one's status begins with a process of the responsible therapeutic citizen taking action, which leads to uptake of preventive measures including abstinence, condom use, disclosure and linkage to care (Mazanderani and Paparini, 2015; Russell, Zalwango, *et al.*, 2016). FSW understood that changes to sexual behaviour were important to protect their own health and those of others. Constraints around sexual behavior change faced by people living with HIV in the general population are well documented (Sri Krishnan *et al.*, 2007; Allen *et al.*, 2011; Mbonye *et al.*, 2013). However, for FSW in my study, sex work demands, alcohol abuse and need for sexual pleasure were some of the specific ways that their working environment and its power relations reduced FSW agency to consistently practice safe sex.

While stigma has lessened with the roll-out of ART, it was still persistent among the FSW as a barrier to both HIV status disclosure and access and adherence to treatment. HIV status disclosure to venue owners and peers at the bar seemed to be a normal behaviour among bar girls, but this was interpreted in the context of the imperative of supportive/coercive power relations between venue owners and FSW, rather than FSW having an increased sense of agency to do so. HIV status disclosure between FSW and their customers was rare because of fear of reduced economic income while it was common to disclose to partners in trusted relationships. This increased practices of condomless sex thereby reducing their well-being freedom by increasing risk for HIV transmission, and re-infection in the longer term.

HIV positive status disclosure has the potential to create an atmosphere of instability which is unsettling to both sexual partners (Kumwenda *et al.*, 2018). In contrast to the general population (Kumwenda *et al.*, 2018), HIV-discordant relationships did not lead to abandonment of the HIV infected partners in the

more stable, intimate relationships of FSW. The biomedical concept of discordancy was hardly understood by FSW and their interpretations of discordant status were linked to perceived associations between having blood group O and low risk of HIV acquisition (Siransy *et al.*, 2015).

Utility of ART in sex work context

Access to HIV treatment has long been framed as a right (Robins and von Lieres, 2004). In my study, knowledge of both the benefits and imperatives to take ART was common among FSW: they understood that with HIV treatment, they could manage HIV in their bodies and prevent onward transmission. All FSW in this study sample who tested HIV positive had linked to care at some point. The dramatic transition highlighted in this thesis connects HIV therapeutic citizenship with the historical and biological shifts and changes in HIV treatment (Russell *et al.*, 2016). FSW talked about their embodied experiences of living with HIV and how this related to understandings and expressions of their HIV identities. Some FSW exercised their agency to enact forms of good HIV therapeutic citizenship by complying with their ARV prescription (though sporadically) to manage their HIV infection. However, doing so in a disempowering sex work environment was challenging. Sex work demands and drug side effects played a critical role in the expression of this therapeutic citizenship. A sense of being healthy, and responsible, including appropriate use of drugs, conflicted with sex and bar work demands.

High ART disengagement and disciplinary power

High levels of ART sporadic engagement were reported in this study risking drug resistance in the longer-term. FSW who are not initiated into care early have a higher risk of clinical progression and ongoing transmission (Lancaster *et al.*, 2016). Although knowledge of importance of ART was common among FSW, sex work daily routines, economic pressures and drug side effects constrained FSW agency to continuously engage with ART. Economic pressures and drug side effects are common problems in linkage and adherence to care in various populations and not exclusive to HIVST or FSW (Losina *et al.*, 2010; Rosen and Fox, 2011; Choko *et al.*, 2015). For instance,

in Malawi, linkage to care was 56% among community-based self-testers (Choko *et al*, 2015). However, what was revealing from FSW narratives was that the problem was with adherence rather than engagement. FSW perhaps had particular incentives to link to care due to the need to present a 'healthy body' as part of their livelihoods. For them, their main challenge was the hard struggle of poverty, sex work routines and lack of privacy in the sex work environment.

The responsibilities of FSW living with HIV to live as 'good therapeutic citizens' in relation to ARVs were shaped by complexities within the framing of ART and the practices of health care providers. I argue here that histories of FSW community response to HIV, cultural practices, stigma, power relations and gender shape how clinical information about the management of HIV will be accessed, understood and incorporated into everyday practice (Chinouya and Davidson, 2003). The emphasis on the 'healthy FSW' reinforces the idea that ARV is ideological as patients are encouraged to focus more on the benefits on ARVs and less on the challenges, in this case, the drug side effects. However, as reported by my participants, drug side effects were a critical factor in ART disengagement. I have highlighted that in my study, practices in the health care system, particularly in ART delivery, were characterized by the exercise of 'power over' FSW, who were controlled and disciplined by health workers using overt or covert threats to shape a subordinated therapeutic citizen. However, practices of institutions arguably extend beyond the actions of individual health workers and reflect the framing of policy and wider institutional discourses, which also tend to reflect wider social discourses on FSW for example, as well as biomedical governance imperatives.

In summary, I argue that as long as HIV remains a stigmatised disease, disclosure of HIV-positive status will always be an issue for those infected and affected with HIV, and impact on creating empowered therapeutic citizens who are active agents in their engagement with HIV prevention, treatment and care and can do so in ways that promote their well-being. These findings do not support the current narrative that HIVST alone will reduce the HIV testing

gap, or increase access to treatment and care and through this prevent onward HIV transmission. High (re)testing rates among FSW indicate that knowledge of the risk of HIV infection was high, though not translated into HIV prevention. I have argued that power relations, the sex work environment and the level of stigmatisation of and discrimination against people living with HIV influenced how FSW opened up with their partners, families, friends and healthcare workers about their HIV status, and relatedly their engagement with treatment, care and prevention.

8.3 Research contributions

This section focuses on the significant and original contributions of the thesis. The section is divided into three subsections addressing empirical, theoretical and methodological contributions.

8.3.1 Empirical contributions

The unique contribution of this thesis is the combination of gender, political economy and Foucauldian analysis to consider power and empowerment regarding biomedical technologies and FSW. To my knowledge, this is the first study to have this focus across the globe. It differs in its focus and methodology from other published studies focusing on sex work and HIVST in other settings. By drawing on a range of theoretical perspectives on sex work, power, vulnerabilities and empowerment and applying them to FSW's interaction with HIVST in a specific socio-political, geographic and disease context, this thesis provides new learning on how the interaction of FSW agency and the power relations within which they are situated produces both vulnerabilities and opportunities for empowerment. What these insights demonstrate is that there are some commonalities in terms of the underlying power relations that intersect to produce vulnerabilities among FSW with HIVST.

8.3.2 Methodological contributions

The study differs from other studies of FSW's engagement with HIVST across the world that primarily use surveys and IDIs, rarely engaging with

ethnographic and participatory approaches that privilege FSW's own frames of reference (Chanda, Ortblad, *et al.*, 2017; Oduetse *et al.*, 2019; Wulandari *et al.*, 2019). The main methodological contribution of the research lies in the experience gained through the application of interpretivist epistemology, emic approach and participatory techniques applied for data collection. This approach made it possible to access and examine the different meanings FSW attach to their live, HIVST and health-related practices. This approach not only strengthened the authenticity and triangulation of study findings but was welcomed by FSW as a sign of respect in contrast to an approach with prescribed assumptions about FSW. This approach may be useful for other studies among FSW in similar settings.

Another methodological contribution was the amount of time spent in sex work venues talking to FSW about issues and concerns that matter most to them. This approach was valuable for its potential FSW's emic views. It is the combination of these processes that enhanced the depth and quality of data generated. It also opened possibilities for examining more diverse and nuanced aspects of empowerment and vulnerability of FSW.

8.3.3 Theoretical contributions

My study has illuminated that vulnerability is not a phenomenon that occurs suddenly. I have shown the importance of studying the historical, political and social context as vulnerability often stems from historical exclusion, cultural practices and social norms. In the context of sex work in this setting, vulnerability is a dynamic process influenced by diverse factors such as dependency on male/husband's income, historical patterns of male domination and unequal access and distribution of power and resources. The amount of time spent talking to FSW about issues and concerns that matter most to them allowed me to understand that vulnerability is a phenomenon that changes over an FSW's life course as FSW transitioned in and out of sex work, and through seasons of risks that usually heighten their HIV risk.

This thesis provides new learning on how FSW agency is exhibited in very subtle but important ways in the context of sex work. Often studies implemented in the context like Malawi fail to recognise such aspects as high levels of vulnerabilities that FSW experience tend to inhibit instances of the nature of agency. In addition, individualistic views of sex work focus on the FSW's mental capabilities for 'agency' (Jean, 2015), instead of providing an understanding of the social, cultural, political and economic situations that reduce the possibility of agency and enhance well-being freedom.

My application of different concepts of power and empowerment to the specific context of sex work in Blantyre, Malawi has explored how power relations are produced and maintained in sex work in this context and made it possible to identify the sources of power and its manifestations, to determine who benefits, who suffers and how power can be shared. The emphasis on power analysis has enabled discussion of how power has been institutionalised in the routine discursive practices of the everyday lives of FSW, and in particular how norms and practices function in both more overt and subtle and discreet ways through techniques of discipline and normalisation to constitute particular subject positions. Drawing on this understanding, it is important to go beyond looking at individual FSW differences if FSW are to have more sustainable empowerment since changes in the systematic power relations that enable or constrain well-being freedom cannot occur at an individual level (Drydyk, 2013).

The successful use of theories of gender, power and political economy contributes, and the methodology in my study contributes towards providing examples of the interpretation of FSW's engagement with HIV prevention technologies in countries like Malawi.

8.4 Limitations of the study

In the sections below, I discuss the limitations of the study.

Research design – Since I carried out data collection a few months after HIVST implementation had been completed, and this could have resulted in biases in recall and social desirability. This limitation also led to a lack of discussion of real-time HIVST experiences and observations. However, data collection still offered valuable information on sex work life, HIV prevention, treatment and care, especially on ART experiences.

Sampling framework –The study did not cover the experiences of all types of FSW, for example, more highly educated FSW. Also, I collected data from venue owners and men in bars only through chats and observations.

Limited use of photo-voice – a core aim of the photo-voice method is to facilitate social change informed by the research findings and participants themselves. However, in this study, I used the method for research purposes only. However, in the time of the thesis, I could not involve participants in all parts of the project cycle, especially the dissemination of the results. Potentially, FSW and their stakeholders, including policymakers, could use photovoice to identify needs and how best to address them. I did, however, capitalise on various forums to reach policymakers. I presented the photovoice findings at several international conferences, including the 5th Global Symposium on Health Systems Research and HIV Research for Prevention, and I plan to do this now that I am back in Malawi.

8.5 Study recommendations

The complex phenomenon of sex work and HIVST demonstrates a need for HIVST intervention efforts to be formulated in a way that reflects and responds to the varied and multifaceted dimensions of sex work that in turn produce and reproduce experiences of biomedical interventions.

The thesis raises important implications, which include the following:

HIVST delivery – slowly, implementers are recognising the importance of engaging with FSW in planning, implementation and evaluation of research

studies and interventions outside a research context (Cowan et al., 2017; Global Network of Sex work Projects, 2015). The aim of HIVST implementation, as shown in this thesis should not simply be behaviour change but also a positive change in the wider vulnerabilities faced by FSW and the attainment of more opportunities and capacities for empowerment, including, but not limited to autonomy in decision making around testing. The incorporation of an empowerment focus in such interventions could lead to more activities aimed at strengthening FSW agency, addressing power imbalances in the sex work environment, and building skills to achieve healthier and more sustainable lives. Implementers should, therefore, strategically reconsider the delivery model for HIVST, as testing at the bars created new power relations often resulted in coercive testing, and delivery on the streets resulted in resistance from some FSW. As this is the case, HIVST should be implemented in the context of efforts to build wider trusting relationships between providers and FSW and to reduce widespread stigma and unequal power relations. HIV testing campaigns that are user-initiated and sex worker-friendly clinics seem to work for FSW in other settings (Cowan *et al.*, 2017) because they increase FSW's control and choice. In Zimbabwe, HIV testing is conducted in FSW's clinics and not door-to-door; the role of the PEs is to form a support group and encourage each other to access HTS.

The issue of retesting while on ART indicates the need for robust training and follow-up strategies for participants in order to reduce retesting while on ART. There is a need for implementers to invest in efforts to manage and support those on ART who receive false-negative results as HIVST is scaled up and address FSW concerns and anxieties about the accuracy of their HIV-positive test result.

HIV prevention, treatment and care –Given the burden of HIV among FSW and the need for support to engage with ART, there is a need for low-cost interventions that encourage FSW living with HIV to share their experiences. The health institutions should give FSW information to understand the biomedical framing of HIV that underpins treatment and testing to help their psychological adjustment. Positive messages are important for many people

living with HIV in resource-limited settings and the success of ART programs (Ware *et al.*, 2009). ART providers can play a role in shaping FWS's experiences with treatment. They can help FSW living with HIV realise that they could control their condition, provide useful concepts and language for emotional coping and give advice about treatment experiences (Russell *et al.*, 2016) as well as behave in ways that accord dignity to patients and avoid stigmatisation. Trusting and productive relationships with providers, which create this motivation, are likely to be beneficial (Ware *et al.*, 2009) and stop judging and punishing FSW for non-adherence.

Consolidated FSW HIV prevention intervention- In this thesis, FSW reported being targeted for HIV prevention interventions by different implementers resulting in confusion and questioning the utility of HIV testing in general. Currently, the efforts targeting FSW are fragmented, and this is reinforced by the influx of NGO funding and lack of coordination, which means that efforts become duplicated, creating challenges in assessing, measuring and consolidating impact, and concerns of treating HIV interventions as an enterprise. I suggest a need to harmonise the behavioural, biomedical and structural approaches for FSW in order to improve their well-being, including individual and collective empowerment and reduction of poverty levels. A sister with a Voice, a Zimbabwe's national HIV programme for FSW is an ideal example of a consolidated FSW programme that has significantly increased HIV testing, treatment and viral suppression among FSW. It promotes FSW community empowerment by prioritising FSW ownership of the programme and training of providers to treat FSW with respect and dignity (Cowan *et al.*, 2017). These programmes need to be modified to ensure they reflect the context and lived experiences of FSW in Malawi.

Addressing wider determinants of sex work conditions – GBV – in Malawi, democracy is embedded in a highly conservative society that constrains some human rights freedoms (e.g. of sexuality) and displays rigidity in response to change. Changing the attitudes, norms, policies and practices that affect women in society is a long and challenging process. Policymakers, researchers and practitioners agree that both men and women

should be involved in GBV interventions (Gaynor and Cronin, 2019). Community engagement is crucial to learning about the context as significant differences in norms and gender relations appear in different geographical areas of Malawi, and this would impact on opportunities for and approaches to enacting social change collectively. However, in Malawi, the evidence is scant for what does and does not work regarding changes to harmful attitudes about GBV, stopping the different forms of violence and getting the survivors the help they want and need (Mellish, Settergren and Sapuwa, 2015). There is a need to prioritise funding and implementation of more research and evaluation that focus on the impact and costs of GBV programmes and services.

Improving economic opportunities for women – In my study, gendered poverty was a major push for women to engage in sex work. It was also evident that sex work remained the only viable choice for women to improve their economic status. Economic empowerment programmes play an important role in supporting women's economic status and influencing gender norms. Malawi should do better in implementing economic empowerment programmes for FSW. The intervention in Malawi that was implemented by FPAM aimed to rehabilitate FSW through training FSW in tailoring, salon management, mushroom production and restaurant management to give them an alternative to sex work (Global Network of Sex Work Projects, 2015a). However, this intervention was unsustainable because no one actually benefited from the initiative as the implementer focused more on rehabilitation and failed to consult FSW during the initiation and implementation stages. As such, it is important to focus on keeping women safe within sex work (including working on policy and policing) and developing solidarity between sex workers to negotiate decent working conditions better. If sex work is actually one of the best options economically then arguably constant attempts to 'rehabilitate' FSW perpetuate stigma against them, which just compounds their vulnerabilities.

One intervention in Kenya, Survivors, an FSW-led organisation worked with FSW to successfully improved their economic opportunities (Global Network of Sex Work Projects, 2015a). The organisation used social mobilisation to

raise the standard of living and improve the quality of life for FSW through income-generating activities alternative to sex work. The initiative played a major role in harm reduction as many FSW condom negotiation skills had improved. This approach can be adapted to a Malawian setting. Funding for these organisations should be sustained for a reasonable period to maximise the benefits for participants of projects and the capacity of FSW-led organisations in general. It is important to point out that individual-focused efforts, such as negotiation skills will only get so far. Developing sustainable economic opportunities for FSW will need to go beyond income-generating projects (which often fail because they do not address the many constraints in the political economy) to address the laws and policies that underpin current inequalities. These include education policies, inheritance and divorce laws and efforts to address violence against women. It is also important to develop leadership by creating space for equal decision making by FSW; otherwise, projects/interventions themselves inadvertently reinforce existing power relations as argued in this thesis.

8.6 Final reflections

This study has personally challenged me in so many ways: as a human being, a woman and a researcher. The research work that I carried out before this study prepared me with an understanding of the underlying factors that drive sex work but not enough to support me on this long academic journey. Reading about, interacting with and inevitably having an emotional attachment with my participants, and then writing about and representing them, has humbled me. I have a better understanding of the privilege of being more educated and financially stable than most women in Malawi. I have respect for women who become involved in sex work to meet their basic needs.

In this study, my participants showed resilience in a sex work environment that was characterised by unequal power relations between FSW and venue owners, self- and community stigma, high levels of violence, economic instability and high HIV prevalence. Sex work did not define their whole being; it is what they did to meet their daily needs; apart from that, FSW were

mothers, sisters, daughters and ‘trying’ to fit in in the community that they lived in. Unfortunately, unlike other women in the general population, they had to find ways of navigating different types of relationships in the most challenging circumstances due to the stigma that was associated with sex work. In all these difficult circumstances, FSW moved on with their lives and had plans for their future and the future of their families.

The most significant issue raised in this thesis is that sex work and the implementation of biomedical technologies take place in a very complex context characterised by gendered power relations, poverty and violence. In the context of Malawi, where there is no explicit political will to implement structural interventions for FSW, the fragmented research endeavours that researchers undertake have limited capacity to alter the underlying political and economic structures that underpin sex work, and may consequently be framed as an enterprise carrying out research on FSW rather than serving their interests.

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10 Appendices

10.1 Ethical approvals

UNIVERSITY OF MALAWI

CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.09/17/2282 – Understanding vulnerability and empowerment through engagement with biomedical HIV prevention technologies amongst female sex workers in Malawi version 1.0 dated 220817 by Wezzie Stephanie Lora

On 26th September 2017

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

Dr. L. Alfazema-Chiuzeni- Vice_Chairperson (COMREC)

Approved by College of Medicine 26 SEP 2017 (COMREC) Research and Ethics Committee

Date 26 Sep 2017

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Monday, 23 October 2017

Dear Ms. Lora,

Research Protocol (17-026RS) Understanding vulnerability and empowerment through engagement with home-based bio-medical HIV prevention technologies amongst highly mobile women in Malawi

Thank you for your correspondence of 23 October 2017 providing the necessary in-country approvals for this project. I can confirm that the protocol now has formal ethical approval from the LSTM Research Ethics Committee.

The approval is for a fixed period of three years and will therefore expire on 22 October 2020.The Committee may suspend or withdraw ethical approval at any time if appropriate.

Approval is conditional upon:

- Continued adherence to all in-country ethical requirements.
- Notification of all amendments to the protocol for approval before implementation.
- Notification of when the project actually starts.
- Provision of an annual update to the Committee.
  Failure to do so could result in suspension of the study without further notice.
- Reporting of new information relevant to patient safety to the Committee
- Provision of Data Monitoring Committee reports (if applicable) to the Committee

Failure to comply with these requirements is a breach of the LSTM Research Code of Conduct and will result in withdrawal of approval and may lead to disciplinary action. The Committee would also like to receive copies of the final report once the study is completed. Please quote your Ethics Reference number with all correspondence.

Yours sincerely

Dr Jamie Rylance
Co-Chair
LSTM Research Ethics Committee

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RECTEM010 v1.0
Release date: 14/07/2017 Issued by: RGEO

10.2 Study tools

Appendix 2A: Participant Observation Form

<table>
<tr><td colspan="3">Descriptive observations
Mapping-description of the relationships between behaviours and the physical environment
Drawing maps</td></tr>
<tr><th>Category</th><th>Includes</th><th>Duty of the researcher</th></tr>
<tr><td>Physical environment</td><td>Bars, streets, Female Sex worker’s home, rest houses, clubs, lodges, hotels</td><td>What kind of space is this? Is it typical of this sort or unusual? How is the space organized? What kinds of things are in this space or building? How is the space organized?</td></tr>
<tr><td>People</td><td>Gender, race, clothing, physical appearance</td><td>How many people are there? What are their ages? genders? ethnicity? How are they dressed? Anything unusual about these people?</td></tr>
<tr><td>Services</td><td>Hospital/health centres, police, schools</td><td>Availability, access, forms, target population</td></tr>
<tr><td>Events or activities</td><td>Meetings, parties, bridal showers, hen parties, local banking</td><td>What are people doing? What kind of gathering is it? Is this state of affairs somehow typical? Or is it discernibly unusual in some way? What feelings about this activity?</td></tr>
</table>

Behaviours	What people do, who does what, who interacts with whom, who is not interacting	How people use their bodies and voices to communicate different emotions; what individuals' behaviours indicate about their feelings toward one another, their social rank, or their profession
	Who speaks to whom and for how long; who initiates interaction; languages or dialects spoken; tone of voice **(Verbal behaviours and interactions)**	Gender, age, ethnicity, dynamics of interaction, what they talk about services in the community
Focused observations • Focused on matters of interest • Systematic details of emerging problems/gaps from descriptive observations and issues of the study • Informal interviews and casual questioning		
Category	**Includes**	**Duty of the researcher**
Physical environment	Two streets and two venues	How often has this space been visited? What is interesting/unusual about this space? Has anything changed about the space since the last visit?
People	FSW and people they interact with	How many FSW are there? What are their ages? How are they dressed? What is particular/unusual about FSW? Is there anything

		unusual or striking about these FSW?
Services	HIVST study	Availability and access to FSW, who is delivering these services to FSW, time of delivery, place of delivery, cost of these services
Events/situations	Sex worker's meetings and other social events they participate in	What kind of meetings/activities do FSW participate in? what are these meeting/activities about? What is particular/unusual about these meeting/activities? Who leads these events/activities?
Behaviours	What FSW do, who does what, who interacts FSW with, which FSW are not interacting **(Physical behaviour and gestures)**	How FSW use their bodies and voices to communicate different emotions; what FSW's behaviours indicate about their feelings toward their clients, their social rank. Any violence activities?
	Who speaks to whom and for how long; who initiates interaction; languages or dialects spoken; tone of voice **(Verbal behaviours and interactions)**	Age of sex worker, what do they talk about HIVST or (vulnerability or empowerment?), dynamics of interaction, what type of sex work?

Selective observations • Selected individuals and themes • Systematic details of emerging problems/gaps from descriptive/focused observations and issues of the study • Informal interviews and casual questioning		
Category	**Includes**	**Duty of the researcher**
Physical environment	Selective places with the two streets and two venues	How often has this space been visited? What is interesting/unusual about this space? Has anything changed about the space since the last visit?
People	Selected FSW and people they interact with	How many FSW are there? What are their ages? How are they dressed? What is particular/unusual about FSW? Is there anything unusual or striking about these FSW? What is their background?
Services	HIVST and studies, sex	Availability and access to these FSW, who delivered these services to these FSW, time of delivery, place of delivery, cost of these services
Events	Activities/events that the selected participants participate in	What kind of meetings/activities do these FSW participate in? what are these meeting/activities about? What is particular/unusual about these meeting/activities?

		Who leads these events/activities?
Behaviours	What FSW do, who does what, who interacts FSW with, which FSW are not interacting **(Physical behaviour and gestures)**	How FSW use their bodies and voices to communicate different emotions; what FSW' behaviours indicate about their feelings toward their clients, their social rank. Any violence activities?
	Who speaks to whom and for how long; who initiates interaction; languages or dialects spoken; tone of voice **(Verbal behaviours and interactions)**	Age of sex worker, what do they talk about HIVST or (vulnerability or empowerment?), dynamics of interaction, what type of sex work?

CROSSCUTTING and ITERATIVE

- Date and time
- Duration of activities
- Frequency
- Impressions (five senses concept)

Things to look out for

- Objective and subjective meaning
- Levels: community, group, individual
- Dimensions: social, cultural, economic, political, legal factors

Informed by: (Weigl *et al.*, 2009)

Appendix 2B: Photovoice training plan

Understanding vulnerability and empowerment through engagement with home-based bio-medical HIV prevention technologies in female sex workers in Malawi

Photovoice training plan

Time	Activity	Objective	Description	Exercise	Materials
10 minutes	**Welcome**	• To welcome everyone • To introduce the research team • To give a quick reflection on all the participants in the training • To create a positive environment in which the training can start	Facilitators' names, the organisation and work we are doing General information on the backgrounds of the participants and why they are at the workshop Ask the participants to write a name badge	Writing a name badge	Badges Markers
30 minutes	**Getting acquainted**	• To provide an opportunity for the participants and the facilitators to briefly introduce themselves and get to know each other's names • To create an open attitude • To get familiar with fellow participants and facilitators	Participants mention their name and where they are coming from. A game will be used in this activity	Notable name game: participants mention a positive adjective that starts with the first letter of	A ball

				their own name	
30 minutes	**Ground rules & expectations**	• To share and agree on common conditions • To feel safe and confident in openly discussing sensitive issues • To establish clear expectations of what will and will not be accomplished in the training	All rules will be developed and agreed by all participants. Basic ground rules: • Confidentiality in case of sharing sensitive or personal issues • Never disclose who said what, outside the training room • Listen to each other and give each other enough time to speak up • Respect differences in opinions • Time management • Active participation • Learn from each other Emphasise that Photovoice is about telling a personal story supported by visuals, rather than becoming a professional photographer. We are more interested in specific expectations to photovoice.	Group contract game: The group contract can be put together using the hopes and fears identified by the participants	Post it notes Marker Flipchart
30 minutes	**Objectives of the workshop**	• To explain workshop and study objectives to the participants • To receive feedback from participants on the objectives that have	Explaining the reasons for the training, the learning method and what will be done with the results.	Brainstorming ideas about the objective	Photos# Photovoice participant

		been presented **Workshop objectives:** • To introduce research study to the photovoice participants • To obtain consent from the participants who are willing to participate in the photovoice component • To introduce photovoice as a data collection method • To review ethics of taking photographs in the community • To introduce basic camera skills to photovoice participants	The information sheet will be read out to the participant and facilitators will address any questions.		information sheets and consent forms
20 minutes	**Introduction to photovoice**	• To define photovoice • To explain why photovoice is being used in the research study • To explain the benefits and challenges of using photovoice	Defining photovoice, its benefits and challenges. Photos will be used during explanation	Brainstorm why conducting photovoice might be important with this group	Photos Flipchart Markers
Coffee/tea break (30 minutes)					
30 minutes	**Introduction to basic photography**	• To understand how we 'read' images • To think about the different possible meanings of pictures	Explanation and discussion about how images can be perceived:	Group work: using photos to understand	Photos

		• To understand that there are different ways of visualising what you want to say	pictures can be misleading and not everyone sees the same things. Explanation that pictures can be interpreted in different ways by different people and how groups of pictures can tell a story. Explanation and discussion about how certain photography techniques can take a picture more interesting to the viewer. Introduction to the concept of symbolism to the group.	perception and arranging scenes to illustrate concept of symbolism	
30 minutes	**Power of the camera**	• Discuss the concept of power when using the camera	Cameras as tools for exploration, passports to private places, and instruments for change The limits and the dangers of photos and representing “ourselves” and “others”	Group work: using photos to discuss the power of the camera	Photos
60 minutes	**Ethics**	• To review ethics of taking pictures in the field	Establishing a space of understanding, boundaries, information and trust. In relation to each other, as a group, in the		Community information sheet and

			community, confidentiality and safety when using the camera. • Avoid taking pictures of other people/yourself-convey a concept without photographing a person-capitalise on symbolism. • Avoid taking photos in public places • Do not take photos of illegal activities, e.g. drug use, sexually explicit photos, photos of clients, violence • Take pictures during normal daily routines • Always obtain consent from others if you want to take pictures about them (objects, shadows, surroundings). Respect their decision when they refuse-respect other people's rights and privacy • Relinquish camera if someone wants to steal the equipment. • Work where you can take pictures safely without being harassed in any way. • Report any violence during photovoice exercise.		consent forms Photo release form
Lunch break (60 minutes)					

30 minutes	**The research question**	• To discuss the research question • To enable participants to reflect on their own ideas and opinions related to the research question • To think of possibilities of symbolism to represent the answers • To think about possibilities to arrange a scene to create the image	Participants understand the research question they are going to answer through Participants understand the key concepts of the research question Participants understand why the question has been selected	Brainstorm meanings of concepts in the research question	Flipchart Markers Study objective relevant to photovoice
45 minutes	**How to work a camera**	• To have the basic technical knowledge about using the camera; focus, light, using the flash, movement, replacing batteries • To feel comfortable using the camera • To practice using the camera's and get the desired results • To experience a photography exercise • To get familiar with the functions and buttons on the camera • To get used to photographing other people	Demonstration and exercises of how to handle and take photos. In these activities participants learn about the options on the camera and they learn how to use them. NB: • Camera is not theirs to keep • They are custodians of the same camera for the duration of the exercise	Individual exercise: taking random pictures and trying out different camera options	Cameras Batteries

45 minutes	**Photography exercises**	• To experience putting abstract themes into pictures • To experience telling a story with pictures • To be able to communicate and express yourself visually	Demonstration and exercises of how to handle and take photos through themes. Participants can practise working with the camera, shooting and composing of photos and putting concepts or ideas into images.	Treasure hunt game (grouped in pairs): participants to take five photos of a portrait, their favourite colour, something natural and a detail that no one else will see.	Camera Markers Papers
			Coffee/tea break (30 minutes)		
60 minutes	**Photography exercises…conti**	• To experience putting abstract themes into pictures • To experience telling a story with pictures • To be able to communicate and express yourself visually	Demonstration and exercises of how to handle and take photos through themes. Participants can practise working with the camera, shooting and composing of photos and putting concepts or ideas into images.	Treasure hunt game (grouped in pairs): participants to take five photos of a portrait, their favourite colour,	Camera Markers Papers

				something natural and a detail that no one else will	
30 minutes	**Practicalities of fieldwork**	• To give tips of creating safe space for taking pictures in the field	**Fieldwork practicalities:** • Always focus on the question when taking photos. • How to answer when people ask participants why they are taking pictures- "I am part of a Photovoice project in which we use photography to show our everyday life" • Check the weather when you plan to take photos • Remember to change batteries when the camera is showing one bar of battery life	Brainstorm about challenges that they can foresee during this fieldwork. Participants to brainstorm variety of places where they can take photos safely	Flipchart Markers
END					

Instructions for the photovoice exercise

Participants will have 5 days to collect 50 images showing:

- A day in my life- participants will be asked to take photos of their typical day
- Dreams and realities-photos about their aspiration and needs

- Abstract treasure hunt-photos that represent their ideas about disappointment, perfection, happiness, absence, politics, danger and comfort
- Up and downs- things or people that make them happy or sad

    - Participants will be asked to explain what these images show, that is, the story behind the image at a later group discussion
    - Each participant can take an additional 20 images of other scenes, for example their family and friends for personal use

    Informed by: (Cheung, 2010)

Appendix 2C: Photovoice SHOWeD

Understanding vulnerability and empowerment through engagement with home-based bio-medical HIV prevention technologies in female sex workers in Malawi

Photo ID □□□/□

Question	Notes
Can you describe your photo?	
What is happening in your photo?	
Why did you take this photo?	
What does this photo tell us about your life and your community	

What does this photo tell us about your exposure to HIVST/microbicides?	
Why does this happen?	

Appendix 2D: Key Informant Interviews

Beneficiaries/highly mobile women

1. Can you describe the types of highly mobile women that you target for HIVST? *Probes: typology, age, where they live, marital status, economic status.*

2. How does Pakachere (PK) select its beneficiaries of HIVST? *Probes: What are the characteristics -location, age, marital status.*

HIV Self-testing (HIVST) implementation

3. How are highly mobile women involved in the implementation of the HIVST?
Probes: Decision making, planning, promotion

4. How does PK deliver HIVST information to highly mobile women? *Probes: What kind of message? How was this decision made?*

5. How are the needs specific to highly mobile women articulated in your organisation's service delivery?

Peer distributor

6. What is the role of peer education in HIVST intervention? How is the approach structured?

7. How are peer distributor (PDs) recruited?
Probes: How is the post advertised amongst highly mobile women? Who participates in the recruitment process?

8. What are the attributes of a PD?
Probes: Influence among peers, leadership role in the community?

9. What are the responsibilities of PD in the context of HIVST?

Probes: HIVST information? Distributing tools? Promoting HIVST to increase demand-how?

10. What kind of training do the PD receive? And in the context of HIVST?

11. What kind of support are you giving PD in the process of delivering HIVST? Refresher training on using HIVST tool?

12. How are they reimbursed for their time? Incentives?

13. What are your views in relation to how PD in their communities are experiencing regarding their role as PD?
Probes: Negative or positive experiences. What are the opportunities? What are the challenges? Trust, jealous or social support?

14. How does the PD role affect their position as highly mobile women? Relationships with their peers-community health workers-?

15. What are PK experiences in using this method to deliver HIVST?

16. How does PK deliberate on issues affect highly mobile women regarding HIVST?

17. Apart from delivering HIVST, how else are highly mobile women involved in the intervention. *Probes: prevention technologies, Monitoring and evaluation*

18. How does this delivery model address needs specific to highly mobile women?

Effect of HIVST delivery approach on highly mobile women

19. What is the uptake of HIVST in highly mobile women you target?
    Probes: What are the differences in terms of location, age, marital status, education levels, economic status? Why these differences?

20. How has this delivery model affected highly mobile women? In relation to HIV prevention management?
    Probes: Negative or positive experiences. What are the opportunities? What are the challenges? Trust, jealous or social support?

21. What are the strategies in place to increase highly mobile women's participation in HIVST intervention?

22. How does PK address these HIV prevention challenges facing highly mobile women?

Appendix 2E: In-depth Interviews

Part one

Prompt: I am now going to ask some questions about your childhood and adult hood experiences which may elicit some unpleasant and traumatic emotions. If you do not want to talk about any particular incident, answer any question, or stop the interview, please feel free to let me know and I will skip to the next question or end the interview.

Background and Origin:

1. Where were you born?
2. Tell me about your mother and father. What memories do you have of them?
3. How did your family earn money? How did your family compare to others in the neighbourhood – richer, poorer, the same?
4. How many brothers and sisters do you have? What memories do you have of each of them from when you were growing up?

Childhood and growing up:

5. Please explain what you were like as a child? What's your happiest memory growing up?
6. Please explain responsibilities you had at home when you were young?
7. Can you please tell me what kind of formal education you received? What did you dream about doing with your life? Did you have any role models?
8. What big events can you remember when you were growing up? Coming of age or rite of passage?
9. When you became a teenager, how did your responsibilities change?
10. Can you remember how it was like to have a first boyfriend?
11. How old were you when you had your first sexual experience? How was the decision made?

12. Can you please explain what you learnt about sex when you were growing up?

Adulthood:

1. As an adult, what was your first job like? What did you like or not like about the job?
2. Have you ever exchanged sex for employment, job security, or promotion before you became a highly mobile woman?
3. Can you please tell me your current relationship status? (***skip a and b if never been married before and skip c and d if participant does not have any children***)
    a. How is married life like? What are the best moments? What are the worst moments?
    b. If separated/divorced, can you please explain why you divorced or separated?
    c. How many children do you have? How many people including your children are currently dependent on you?
    d. How are you like a mother? What is the best thing of being a mother? What is the hardest thing of being a mother?
4. Can you please explain the one thing you've always wanted but still don't have?
5. How different do you feel about yourself now from how you felt when you were younger?
6. What do you think has stayed the same about you throughout life? What do you think has changed?

Sex work entry and daily life:

7. How did you become a highly mobile woman?
   Probes: What was going on in your life? What made you decide to become a highly mobile woman?
8. Please tell me about your experience when you first exchanged sex for money? How did you feel?
9. How long have you been a highly mobile woman?

Probes: How many clients do you have per day? Week? Estimate how many clients you've had.

10. How do you feel about exchanging sex for money? How has your feeling about exchanging sex for money changed since the first time you sold sex?
11. Do you enjoy sex with clients?
12. What makes a "successful" or "unsuccessful" highly mobile woman? What type of person do you have to be to succeed as a highly mobile woman?
13. What makes a "good" or "bad" client?
14. What do you have in common with other highly mobile women? What makes you unique?
15. Describe your typical workday.

    Probes: Where do you work from? When do you work? Where do you live? When do you bring clients home? When do you not bring clients home? How do you get ready for a client? How much do you charge? How do you meet clients? What are your strategies? Does anyone help you?
16. Describe your clientele.

    Probes: Who are your typical clients? Only men? Are there types of clients you want more than others? How much do you earn in a typical day? What do you do with this money?
17. What kind of skills have you learned as a highly mobile woman?
18. What things do you like to do when you're not working? Do you have another job apart from being a highly mobile woman?

PART TWO

Sex work challenges:

Prompt: I am now going to ask some questions about your experiences of violence which may elicit some unpleasant and traumatic emotions. If you do not want to talk about any particular incident or answer any question, please feel free to let me know and I will skip to the next question or end the interview.

19. Can you please describe any physical dangers from your job.
    Probes: where? peers, clients, community
20. Can you please describe any sexually harassment from your job?
    Probes: By who? Community, family, service providers? How many times in the last week? Month? Year?
21. Do you get any protection from your job? If so, in what way and by who? *Creating safe space, police, payment?*
22. What things do clients pay extra for? Do they make you feel uncomfortable or unsafe? How often are you requested to do things you don't want to do?
23. Describe any arrests from your job? Why were you arrested?
24. How does being a highly mobile woman make you feel emotionally? How do you cope with any negative feelings?
25. Have you ever tried getting out of this job? What do you like most about sex work? Hate most?
26. Where do you go when you are sick or have a health problem?
27. How do you think being a highly mobile woman has affected you experiences at health facilities? Positive or negative experiences?
28. Please can you tell me about any health risks of being a highly mobile woman? How easy or difficult is it to prevent these risks?
29. Can you please explain how you prevent yourself from HIV risk? What do you think about condoms as a prevention method?
30. Have you ever been tested for HIV?
    Probes: How was your last experience when you tested for HIV? How did you feel after taking the test? Challenges/opportunities? Relationship with health providers?

Highly mobile women participation in HIVST

31. Can you tell me how you knew about HIVST study? What is the intervention about?
32. How was HIVST service provided to you?
    Probes: How was your decision to participate in the intervention made? Did you discuss with anyone? Who influenced you? How different would you have preferred the tools be delivered to you?

33. What did you think about HIVST tool when it was presented to you? What are your views about the technology of the tool?
34. What were your expectation from the service that you received? Were your expectations met? If not, how did you cope?

For HIVST participants

35. If this was your first time you tested for HIV, can you describe the feeling of knowing your status? If you knew your HIV status already, how different is it from the last time you tested for HIV? Is this what you expected? Why?
36. What did you do after you knew your HIV status? What kind of support did you get from the PD, peers, friends or family?
    Probes: counselling, confirmatory test, linkage to care- was this your decision, how do you feel about taking these steps?
37. What is the response from people that you disclosed your status to? How do you feel about disclosing your status to them? Social exclusion or social support?

Impact of HIVST on highly mobile women

38. What are your views about targeted intervention?
    Probes: What opportunities have been created- convenience, *HIV risk and prevention? What risks and challenges have you faced-stigma and discrimination, coercion, violence?*
39. What are your views about how highly mobile women are involved in the HIVST intervention?
    Probes: What are the opportunities/challenges? Decision making, training, information giving
40. What are your views about how HIVST were delivered? What opportunities have been created? What risks and challenges have you faced-violence, coercion?
41. Describe your relationship with the peer educator before service delivery? During service delivery? After service delivery? Trust, jealous, social support

42. What things are most important to you now? Why? How important is it that you participated in HIVST? Why?
43. What are your plans regarding managing your HIV risk?

Appendix 2F: Focus Group Discussion with peer distributors

Highly mobile women community

1. Can you please give me a picture of your experiences of being highly mobile women in this community? What do people in the community say about highly mobile women? How does this make you feel?
2. What kind of health issues are common amongst highly mobile women in this community? How capable are highly mobile women of making decisions that concern their health? What are the challenges? How are these challenges addressed?

Understanding of HIVST

3. Can you please explain what the STAR study is about? What is/are the aim(s) of the STAR study? Target groups, sites
4. In your view, what do you think about HIVST technology?
5. How are highly mobile women involved in the HIVST intervention? Planning the intervention, implementation, promotion, monitoring and evaluation
6. In your view, why do you think HIVST interventions are targeting highly mobile women?

Peer-delivery model

7. Can you tell us the meaning of a peer distributor?
    a. What qualities should peer distributor have?
    b. What skills should peer distributor have?
8. In your view, what is the role of a peer distributor? What are the responsibilities of peer distributor?
9. Can you describe how peer distributor are recruitment in this community? What are your views on how these peer distributors are recruited? Who was in involved in the recruitment process? how are decisions made in this process?
10. Can you describe how your group of peer distributors were recruitment in HIV intervention? What are your views on the

recruitment process? Who was in involved in the recruitment process? How were decisions made in the recruitment process?

11. What is your role in HIVST intervention? What are your responsibilities in HIVST intervention?
12. What kind of training did you receive? What were you expecting from the training? Were your expectations met? If yes, how? If no, why?
13. Apart from your responsibilities in HIVST intervention, what other services do you provide to highly mobile women? Condom distribution; information dissemination?

Experiences of peer distributor in relation to HIVST intervention

14. How important is your position of peer distributor in the community-HIVST? Why?
15. What has been your experience working with peers in this community? In this intervention? Positive or negative experiences? Why?
    a. What opportunities has the role of peer distributor created for your group?
    Probes: income, independence, influence, trust, leadership
    Interaction with peers, friends, family or community?
    Probes: power relations, trust, decision making, social support
    b. What challenges and risks do you face as peer distributor?
    Probes: power relations, trust, decision making, jealousy
    c. Interaction with peers, friends, family or community?
    Probes: power relations, trust, decision making, jealousy, stigma, social exclusion

Relationship with implementers

16. What remuneration are you entitled to as a peer distributor for doing your job? How is this remuneration packaged? What are your views on this remuneration? Positive or negative? Why?
17. relationship with HIVST implementers? Negative or positive? Why? What kind of support do you receive from implementers?
    i. Do HIVST implementers offer any form of support? If yes, what kind? If not, why do you think this is so?
18. Who is your contact person at Pakachere? How do you communicate with them? How often?
19. Are you involved in decision making processes that affect you as Peer distributor? If so, in what way? How often?

    Probes: power relations and trust

Appendix 2G: Focus group discussion with highly mobile women

Highly mobile women community

1. Can you describe the highly mobile women community found in this area? Typology, age, sex, location.
2. Can you describe the experiences of highly mobile women in this community in relation to exchanging sex for money? Violence, arrests, mobility.
3. What strategies are in place to cope with these experiences? Skills? Knowledge? What kind of support do you receive to address these problems? Where does this support come from?
4. Can you describe the experiences of highly mobile women in this community in relation to HIV prevention? HIV testing, treatment and care and safe sex. What are the opportunities/challenges? How are these challenges addressed? Where do highly mobile women access HIV prevention services?

Understanding of HIVST

5. Can you please explain what the STAR study is about? What is/are the aim(s) of the STAR study? Target groups, sites
6. In your view, what do you think about HIVST technology?
7. How are highly mobile women involved in the HIVST intervention? Planning the intervention, implementation, promotion, monitoring and evaluation
8. In your view, why do you think HIVST interventions are targeting highly mobile women?

Understanding the implementation approach

9. How were HIVST tools delivered to highly mobile women? Accessibility-availability of providers, time, travel
10. What are your views on how HIVST tools were delivered to highly mobile women? How important was this approach in HIVST intervention?

11. Do you report any concerns regarding HIVST intervention? How do you report any concerns regarding HIVST?

Peer-delivery model

12. Can you tell us the meaning of a peer distributor?
    a. What qualities should a peer distributor have?
    b. What skills should peer distributor have?
13. In your view, what is the role of a peer distributor? What are the responsibilities of peer distributors?
14. Can you describe how peer distributors are recruitment in this community? What are your views on how these peer distributors are recruited? Who was in involved in the recruitment process? how are decisions made in this process?
15. What has been your experience working with peer distributors in this community-in this intervention? Positive or negative experiences? Why?
16. Apart from HIVST, what other services does this intervention provide to highly mobile women? Condom distribution; information dissemination?

Experiences of highly mobile women in relation to HIVST intervention

17. As highly mobile women, what are your experiences in participating in HIVST intervention?
    i. What opportunities does HIVST interventions create for highly mobile women in the community? Interaction with peer distributors, peers, family community?
       Probes: power relations, trust, decision making, jealousy, stigma, social exclusion
    ii. What challenges and risks does HIVST interventions create for highly mobile women? Interaction with peer distributors, peers, family community?
       Probes: power relations, trust, decision making, jealousy, stigma, social exclusion

b. What kind of support is there in response to challenges faced by highly mobile women?
    i. Do HIVST providers offer any form of support? If yes, what kind? If not, why do you think this is so?
    ii. Does the community offer any form of support? If yes, what kind? If not, why do you think this is so?
    iii. Do peer distributor offer any form of support? If yes, what kind? If not, why do you think this is so?

10.3 Information sheets

Appendix 3A: Participant observations_venue owners

The research study

This study is being conducted as part of a research project from Liverpool School of Tropical Medicine, UK in collaboration with Malawi Liverpool Wellcome Trust-Clinical Research Program, Blantyre, Malawi. The project explores experiences of highly mobile women* when they are exposed to HIV self-testing and in Malawi. This will help us understand the best approaches for HIV prevention programs targeting highly mobile women in Malawi.

What are we trying to learn

In this component, we are interested to make observations in places where highly mobile women hang out or live. We are going to make observations on gender, age, clothing, how people speak to each other, how and how many people enter or leave the space, identification of people who receive a lot of attention from others. In addition, participant observations will include observing how the venue is laid out and its surrounding features.

Your participation in the study

You have been selected because you have been identified as someone who owns or oversees a venue that hosts highly mobile women. Venue owners who are interested in the study have linked us to other owners within their networks. Agreement to participate in this research will not compromise your legal rights. If you withdraw from the study any information gathered from you will be destroyed.

What are we asking you to do

You will not be directly involved in the study if you decide to let us conduct participant observations at your venue. However, you will be asked about

your contact details for future communication. After obtaining consent, we will make observations within the venue about the topics we have listed above. There will be two researchers available to make these observations, myself and a colleague and I may come alone at times. During observations, we will write down short phrases about events, behaviors or interactions that we observe. We would like to record the observations to have an accurate record of things observed so that we can review later. These notes will not be written in public to avoid making people uncomfortable. We are also interested to take photos of the venue. We are going to follow ethical procedures when taking these photos and no photos will be taken of the public unless there is consent to do so. Participant observations will mainly be carried out in the afternoon or at night when most activities take place and sometimes in the morning to see if there any variations. Maximum time that will be spent at each session will be two hours, twice a week. Participant observations will be carried out for approximately 12 months.

Steps we take to protect your privacy

All information obtained from the participant observations and equipment used will be stored securely in a lockable bag when not in use in the field and in a lockable drawer in the office and only researchers in this study will have access to them. When we publish information from these observations and pictures we will not identify you by your name so that your venue cannot be linked to your identity. We will show you any reports using information from this interview before we use it in any published materials (e.g. reports or scientific publications) and we will not use it without your approval. Pseudonyms will be used for all reports and all characteristics that link to your identity will be edited to maximise anonymity.

Will this study help you or others

Giving consent for observations at your venue will not benefit you personally. However, observations will help establish context in which highly mobile women live, work, or hang out and identify challenges or

opportunities for effective HIV prevention programs for highly mobile women in Malawi.

What are the risks or harms

We believe that the risks are minimal. We assure you that anything that will be observed and photos taken during this process will remain confidential. You are free to tell us to stop making observations at your venue at any time.

Are there any costs to you if you participate in the study

It will not cost you anything to participate and you will not receive payment for your giving consent to make observations at your venue.

Information about your rights

Please know that your participation in this component of the study is your choice. You can decide at any time to stop us from making observations and taking pictures at your venue.

Questions

Do you have any questions you want to ask me before you decide whether or not to participate in the study? I will give you a copy of this form to keep, if you wish.

Who to contact if you have any questions

If you have any questions about this study please feel free to ask them. If you think of any questions after we have gone please feel free to contact us by calling the following number and asking for:

Wezzie Lora
Principle Investigator
+265 995 351 611

Please contact the COMREC Secretariat should you wish further information about your rights, safety, and wellbeing in research:

COMREC Secretariat
College of Medicine Research and Ethics Committee
P/Bag 360, Chichiri, Blantyre 3, Malawi
Telephone: 01877245/01877291

Participant's statement

I will now read you a brief statement. After I have read it please let me know if you would like to participate in this interview:

This activity has been explained to me and I agree to allow researchers to make observations at my venue. I have had the opportunity to ask questions. I understand that I can choose not to answer some questions and can stop them from making observations at my venue at any time. I understand that I can contact the investigators if I have questions about the study. I can contact the person named above if I have questions about my rights as a participant.

Appendix 3B: Participant observations_Female sex workers

The research study

This study is being conducted as part of a research project from Liverpool School of Tropical Medicine, UK in collaboration with Malawi Liverpool Wellcome Trust-Clinical Research Program, Blantyre, Malawi. The project explores experiences of highly mobile women* when they are exposed to HIV self-testing and in Malawi. This will help us understand the best approaches for HIV prevention programs targeting highly mobile women in Malawi.

What are we trying to learn

In this component, we are interested to learn about your everyday life. We will make observations of places where you live, the community that you live in, places where you hang out; how you interact with your peers, friends, potential clients, Peer Educators and community at large; things that you do daily, like shopping and your participation in community activities, like meetings or any leisure activities.

Your participation in the study

Malawi Liverpool Wellcome Trust has been providing HIV self-testing in urban Blantyre and it is likely that you have participated as someone who has decided to self-test. You may also have participated in other aspects of other studies carried out by these institutions. We are asking people who have recently received HIV self-testing kits. You have been selected because you are between the ages of 16 and 49 and identified as highly mobile woman. Agreement to participate in this research will not compromise your legal rights. If you withdraw from the study any information gathered from you will be destroyed, unless you want us to use the data.

What are we asking you to do

If you decide to participate in the study, we will take your contact details for communication in future, your age, marital status, education background

and occupation. We will be visiting you at home and accompany you when you are doing activities or going places after obtaining your verbal consent. During observations, we will write down short phrases about events, behaviors or interactions that we observe in a notebook. We would like to record the observations to have an accurate record of the things observed so that we can review later. These notes will not be written in public to avoid making people uncomfortable. We will also hold informal interviews with you if we would like to seek clarity on some themes. We are also interested to take photos during the observation period. We are going to follow ethical procedures when taking these photos and no photos will be taken of the things that you are not comfortable with unless you have given us consent to do so. With your permission, we are going to make these observations in the morning, afternoon or at night but without interfering with your work schedule or private activities. Each session will focus on an activity like accompanying you to the market or doing some household chores. Observations will stop after activity completion but up to the maximum of four hours, twice a week. The observations will be carried out for approximately 12 months.

Steps we take to protect your privacy

All information obtained from the observations and equipment used will be stored securely in a lockable bag when not in use in the field and in a lockable drawer in the office, and only researchers in this study will have access to them. When we publish information from these observations and pictures we will not identify you by your name so that data presented cannot be linked to your identity. We will show you any reports using information from these observations to you before we use it in any published materials (e.g. reports or scientific publications) and will not use it without your approval. Pseudonyms will be used for all reports and all characteristics that link your identity will be edited to maximise anonymity.

Will this study help you or others

Giving consent to be part of the observations will not benefit you personally. However, observations will help establish context in which

highly mobile women live, work, or hang out and identify challenges or opportunities for effective HIV prevention programs for highly mobile women in Malawi.

What are the risks or harms

We believe that the risks are minimal. You are free to inform us If you feel like our presence is putting you at greater risk. You are free to inform us if you would like to continue participating in the study or not. We assure you that anything that will be observed and photos taken during this process will remain confidential.

Are there any costs to you if you participate in the study

It will not cost you anything to participate and you will not receive payment for your giving consent to make observations at your venue.

Information about your rights

Please know that your participation in this component of the study is your choice. You can decide at any time to stop us from making observations and taking pictures at your venue.

Questions

Do you have any questions you want to ask me before you decide whether to participate in the study? I will give you a copy of this form to keep, if you wish.

Who to contact if you have any questions

If you have any questions about this study please feel free to ask them. If you think of any questions after we have gone please feel free to contact us by calling the following number and asking for:

Wezzie Lora

Principle Investigator

+265 995 351 611

Please contact the COMREC Secretariat should you wish further information about your rights, safety, and wellbeing in research:

COMREC Secretariat
College of Medicine Research and Ethics Committee
P/Bag 360, Chichiri, Blantyre 3, Malawi
Telephone: 01877245/01877291

Participant's statement

I will now read you a brief statement. After I have read it please let me know if you would like to participate in this interview:

This activity has been explained to me and I agree to participate in the participant observations. I have had the opportunity to ask questions. I understand that I can choose not to answer some questions and can stop participating in the interview at any time. I understand that I can contact the investigators if I have questions about the study. I can contact the person named above if I have questions about my rights as a participant.

Appendix 3C: Photovoice_Female sex workers

The research study

This study is being conducted as part of a research project from Liverpool School of Tropical Medicine, UK in collaboration with Malawi Liverpool Wellcome Trust-Clinical Research Program, Blantyre, Malawi. The project explores experiences of highly mobile women* when they are exposed to HIV self-testing in Malawi. This will help us understand the best approaches for HIV prevention programs targeting highly mobile women in Malawi.

What are we trying to learn

We are interested to learn about your everyday life, your needs and aspirations through photos. Specifically, we are interested to explore themes relating to your reflections, fears, feelings, hopes and aspirations in your life and in relation to use of HIVST.

Your participation in the study

We are asking people who have recently received HIV self-testing kits. You have been selected because you are between the ages of 16 and 49 and identified as highly mobile woman. Agreement to participate in this research will not compromise your legal rights. If you withdraw from the study any information gathered from you will be destroyed.

What are we asking you to do

If you decide to participate in the study, we will take your contact details for communication in future, your age, marital status, education, and occupation. We will ask you to come to a workshop to learn how to take photos in the field. You will be given enough support to allow you to carry out this activity on your own in your communities. You will be given a camera to take photos at your own time. You will be asked to take photos of indirect reflections of your everyday life, needs and aspirations using objects nature or shadows rather than people to minimise risk of pointers of your identity or other people. We will be visiting you at a place your convenience and

time just to see how you are getting on with the exercise and for any support when required. You will be asked to follow ethical procedures when taking these photos and no photos will be taken of the things that people are not comfortable with unless they have given you consent to do so. This exercise will be carried out for approximately 7 days. If possible, we will ask you to participate in both the workshop and photography week, and sharing experiences with other highly mobile women during discussions but it is not a must.

Steps we take to protect your privacy

All information obtained from this study component will be stored securely in a lockable bag when not in use in the field and in a lockable drawer in the office, and all electronic copies will be saved on a password protected computer. Only researchers in this study will have access to these materials. You will be given an opportunity to determine what photos will be used for public consumption. Photos that identify you, your friends, work places, family will be edited with you. When we publish information from these photos, we will show you any reports before we use it in any published materials (e.g. reports or scientific publications) and will not use it without your approval. Pseudonyms will be used for all captions and narratives and all characteristics that link to the identity of a particular individual will be edited to maximise anonymity.

Will this study help you or others

Giving consent to be part of the photography exercise will not benefit you personally. However, the photos will help us reflect more on everyday life of highly mobile women in Malawi.

What are the risks or harms

We believe that the risks are minimal. You are free to inform us If you feel like our presence is putting you at greater risk. You are free to inform us if you would like to continue participating in the study or not.

Are there any costs to you if you participate in the study

It will not cost you anything to participate and you will receive K5000 for the workshop and K2500 per day for the period you be required to take photos in the community.

Information about your rights

Please know that your participation in this component of the study is your choice. You can decide at any time to stop us from making observations and taking pictures at your venue.

Questions

Do you have any questions you want to ask me before you decide whether to participate in the study? I will give you a copy of this form to keep, if you wish.

Who to contact if you have any questions

If you have any questions about this study please feel free to ask them. If you think of any questions after we have gone please feel free to contact us by calling the following number and asking for:

Wezzie Lora
Principle Investigator
+265 995 351 611

Please contact the COMREC Secretariat should you wish further information about your rights, safety, and wellbeing in research:

COMREC Secretariat
College of Medicine Research and Ethics Committee
P/Bag 360, Chichiri, Blantyre 3, Malawi
Telephone: 01877245/01877291

Participant’s statement

I will now read you a brief statement. After I have read it please let me know if you would like to participate in this interview:

This activity has been explained to me and I agree to participate in the photography exercise. I have had the opportunity to ask questions. I understand that I can choose not to take part in other components of the study and can stop participating in this exercise at any time. I understand that I can contact the investigators if I have questions about the study. I can contact the person named above if I have questions about my rights as a participant.

Appendix 3D: Photovoice_Community

The research study

This study is being conducted as part of a research project from Liverpool School of Tropical Medicine, UK in collaboration with Malawi Liverpool Wellcome Trust-Clinical Research Program, Blantyre, Malawi. The project explores experiences of highly mobile women* when they are exposed to HIV self-testing in Malawi. This will help us understand the best approaches for HIV prevention programs targeting highly mobile women in Malawi.

What are we trying to learn

We are interested to learn about everyday life of highly mobile women, their needs and aspirations through photos. Specifically, we are interested to explore themes relating to highly mobile women's reflections, fears, feelings, hopes and aspirations in their lives and in relation to use of HIVST.

Your participation in the study

You have been approached because you are within the circles of the of highly mobile women in this community. If at any point, you would like to withdraw your photo(s) from the study, you may contact us and we will withdraw any photo(s) from the study that is linked to you.

What are we asking you to do

If you decide to participate in the study, we are going to take photos of any objects, shadows, nature or something related to you to use in this study. We are going to follow ethical procedures when taking these photos and no photos will be taken of the things that will make you feel uncomfortable unless you have given us consent to do so. This exercise will be carried out for approximately 10 minutes.

Steps we take to protect your privacy

All information obtained from this study component will be stored securely

in a lockable bag when not in use in the field, in a lockable drawer while in the office, and the electronic copies will be saved on a password secured computer, and only researchers in this study will have access to these photos. You will be given an opportunity to determine what photos will be used for public consumption. Photos that identify you, your friends, work places, family will be edited with you to maintain confidentiality. When we publish information from these photos, we will show you any reports before we use it in any published materials (e.g. reports or scientific publications) and will not use it without your approval. You will be given permission to ask that your photos not be used, shared or distributed. If you request it, photos will be destroyed, deleted or returned to you. Pseudonyms will be used for all captions and narratives and all characteristics that link to you will be edited to maximise anonymity.

Will this study help you or others

Giving consent to be part of this photography exercise will not benefit you personally. However, the photos will help us reflect more on everyday life of highly mobile women in Malawi.

What are the risks or harms

We believe that the risks are minimal. You are free to inform us If you feel like our participation in the study is putting you at greater risk. You are free to inform us if you would like to continue participating in the study or not.

Are there any costs to you if you participate in the study

It will not cost you anything to participate and you will not receive any form of payment for your consent to take a photo of you.

Information about your rights

Please know that your participation in this component of the study is your choice. You can decide at any time to stop us from using your pictures in the reports

Questions

Do you have any questions you want to ask me before you decide whether to participate in the study? I will give you a copy of this form to keep, if you wish.

Who to contact if you have any questions

If you have any questions about this study please feel free to ask them. If you think of any questions after we have gone please feel free to contact us by calling the following number and asking for:

Wezzie Lora
Principle Investigator
+265 995 351 611

Please contact the COMREC Secretariat should you wish further information about your rights, safety, and wellbeing in research:

COMREC Secretariat
College of Medicine Research and Ethics Committee
P/Bag 360, Chichiri, Blantyre 3, Malawi
Telephone: 01877245/01877291

Participant's statement

I will now read you a brief statement. After I have read it please let me know if you would like to participate in this interview:

This activity has been explained to me and I agree to participate in the photography exercise. I have had the opportunity to ask questions. I understand that I can choose not to take part in other components of the study and can stop participating in this exercise at any time. I understand that I can contact the investigators if I have questions about the study. I can contact the person named above if I have questions about my rights as a participant.

Appendix 3F: Key informant interviews

The research study

This study is being conducted as part of a research project from Liverpool School of Tropical Medicine, UK in collaboration with Malawi Liverpool Wellcome Trust-Clinical Research Program, Blantyre, Malawi. The project explores experiences of highly mobile women* when they are exposed to HIV self-testing in Malawi. This will help us understand the best approaches for HIV prevention programs targeting highly mobile women in Malawi.

What are we trying to learn

In this component of the study we would like to hear your views of how you engaged highly mobile women and the approach you took in implementing HIVST intervention. We are interested to understand the problems you have faced, choices made, opportunities created, lessons learnt as implementers.

Why have you been asked to participate in the study

You have been asked to participate in the study because you work with highly mobile women in the organisation that you work with. The study coordinator has referred us to you because you have detailed information of HIV self-testing intervention and how these interventions were implemented amongst highly mobile women.

What are we asking you to do

If you decide to participate in the study, we will ask about where your contact information, your age, occupation, and education background. You will then be asked to take part in an interview where we will ask you questions about the themes discussed above. You will be given an opportunity to choose a private and safe place where you will be able to express yourself freely. I will be the only one present during the interview. After this interview, we will keep in touch with you and may visit you again for any clarification regarding this interview. This interview will

approximately take 30-45 minutes of your time.

Steps we take to protect your privacy

All information obtained from this discussion or equipment used will be stored securely in a lockable bag when not in use in the field, in a lockable drawer while in the office, and electronic copies will be saved on a password protected computer. Only researchers in this study will have access to these sources. When we publish information from these data, we will show you any reports before we use it in any published materials (e.g. reports or scientific publications) and will not use it without your approval. Pseudonyms will be used for all reports and all characteristics that link your identity will be edited to maximise anonymity.

Will this study help you or others

Giving consent to take part in this discussion will not benefit you personally. However, information that will be collected will help us establish an account of experiences of highly mobile women and their engagement with HIV self-testing.

What are the risks or harms

We believe that the risks are minimal. You are free to inform us if you would like to continue participating in the study or not.

Are there any costs to you if you participate in the study

It will not cost you anything to participate and you will not receive any payment for your participation.

Information about your rights

Please know that your participation in this component of the study is your choice. You can decide at any time to stop us during this interview.

Questions

Do you have any questions you want to ask me before you decide whether to participate in the study? I will give you a copy of this form to keep, if you wish.

Who to contact if you have any questions

If you have any questions about this study please feel free to ask them. If you think of any questions after we have gone please feel free to contact us by calling the following number and asking for:

Wezzie Lora
Principle Investigator
+265 995 351 611

Please contact the COMREC Secretariat should you wish further information about your rights, safety, and wellbeing in research:

COMREC Secretariat
College of Medicine Research and Ethics Committee
P/Bag 360, Chichiri, Blantyre 3, Malawi
Telephone: 01877245/01877291

Participant's statement

I will now read you a brief statement. After I have read it please let me know if you would like to participate in this interview:

This activity has been explained to me and I agree to participate in this interview. I have had the opportunity to ask questions. I understand that I can choose not to answer some questions and can stop participating in the interview at any time. I understand that I can contact the investigators if I have questions about the study. I can contact the person named above if I have questions about my rights as a participant.

Appendix 3G: In-depth interviews

The research study

This study is being conducted as part of a research project from Liverpool School of Tropical Medicine, UK in collaboration with Malawi Liverpool Wellcome Trust-Clinical Research Program, Blantyre, Malawi. The project explores experiences of highly mobile women* when they are exposed to HIV self-testing in Malawi. This will help us understand the best approaches for HIV prevention programs targeting highly mobile women in Malawi.

What are we trying to learn

In this component of the study we would like to understand your experiences of participating in HIV self-testing study. We are interested to understand the problems you have faced, choices made, opportunities created as an individual, a group of highly mobile women and your community at large.

Your participation in the study

Malawi Liverpool Wellcome Trust has been providing HIV self-testing in urban Blantyre and it is likely that you have participated as someone who has decided to self-test. You may also have participated in other aspects of other studies carried out by these institutions. We are asking people who have recently received HIV self-testing kits. You have been selected because you are between the ages of 16 and 49 and identified as highly mobile woman. If you withdraw from the study any information gathered from you will be destroyed. Agreement to participate in this research will not compromise your legal rights.

What are we asking you to do

If you decide to participate in the study, we are going ask you for your contact details for future communication, your age marital status, education level, and occupation. You will participate in an interview where we will ask you questions about the themes discussed. You will be given

an opportunity to choose a private and safe place where you will be able to express yourself freely. I will be the only one present during the interview. After this interview, we will keep in touch with you and may visit you again for any clarification regarding this interview. This interview will approximately take 120 minutes of your time.

Steps we take to protect your privacy

All information obtained from this interview or equipment used will be stored securely in a lockable bag when not in use in the field, in a lockable drawer while in the office, and electronic copies will be saved on a password protected computer. Only researchers in this study will have access to these sources. When we publish information from these data, we will show you any reports before we use it in any published materials (e.g. reports or scientific publications) and will not use it without your approval. Pseudonyms will be used for all reports and all characteristics that link your identity will be edited to maximise anonymity.

Will this study help you or others

Giving consent to part in this interview will not benefit you personally. However, information that will be collected will help us establish an account of experiences of highly mobile women and their engagement with HIV self-testing.

What are the risks or harms

We believe that the risks are minimal. You are free to inform us If you feel like our participation in the study is putting you at greater risk. You are free to inform us if you would like to continue participating in the study or not.

Are there any costs to you if you participate in the study

It will not cost you anything to participate and you will receive K2,500 as a compensation for your time

Information about your rights

Please know that your participation in this component of the study is your choice. You can decide at any time to stop participating in this interview.

Questions

Do you have any questions you want to ask me before you decide whether to participate in the study? I will give you a copy of this form to keep, if you wish.

Who to contact if you have any questions

If you have any questions about this study please feel free to ask them. If you think of any questions after we have gone please feel free to contact us by calling the following number and asking for:

Wezzie Lora
Principle Investigator
+265 995 351 611

Please contact the COMREC Secretariat should you wish further information about your rights, safety, and wellbeing in research:

COMREC Secretariat
College of Medicine Research and Ethics Committee
P/Bag 360, Chichiri, Blantyre 3, Malawi
Telephone: 01877245/01877291

Participant's statement

I will now read you a brief statement. After I have read it please let me know if you would like to participate in this interview:

This activity has been explained to me and I agree to participate in this interview. I have had the opportunity to ask questions. I understand that I can choose not to answer some questions and can stop participating in the interview at any time. I understand that I can contact the investigators if I have questions about the study. I can contact the person named above if I have questions about my rights as a participant.

Appendix 3H: Focus group discussion: Peer distributors

The research study

This study is being conducted as part of a research project from Liverpool School of Tropical Medicine, UK in collaboration with Malawi Liverpool Wellcome Trust-Clinical Research Program, Blantyre, Malawi. The project explores experiences of highly mobile women* when they are exposed to HIV self-testing in Malawi. This will help us understand the best approaches for HIV prevention programs targeting highly mobile women in Malawi.

What are we trying to learn

In this component of the study we would like to understand your experiences of participating in HIV self-testing study. We would to hear your views of using Peer Educators as distributors in the intervention and whether and how it led to more problems or created opportunities regarding engagement with HIV self-testing. We are interested to understand the problems you have faced, choices made, opportunities created as Peer Educators, a group of highly mobile women and your community at large.

Your participation in the study

Malawi Liverpool Wellcome Trust has been providing HIV self-testing in Blantyre and it is likely that you have participated as someone who distributed HIV self-testing kits to your peers. You have been selected to participate by chance and there is no other reason why we have chosen you instead of others. Agreement to participate in this research will not compromise your legal rights.

What are we asking you to do

If you decide to take part in the study, we will ask about where you live, your contact information, and your age and occupation. You will then be taking part in a group discussion with your peers and it is likely that you will know some of the people in the group. There will be two researchers

during the discussion, myself and a colleague. One of us will be facilitating the discussion and another person will be taking notes of the discussion of the issues being discussed and observing group dynamics. The discussion will take place here in Blantyre, and the group will be given an opportunity to choose a private and safe place where the discussion can take place. This will allow group members to express themselves freely. The focus group discussion will be recorded using a digital recorder to avoid losing important data and minimise recall bias. The discussion will approximately take 120 minutes of your time.

Steps we take to protect your privacy

All information obtained from this discussion or equipment used will be stored securely in a lockable bag when not in use in the field, in a lockable drawer while in the office, and electronic copies will be saved on a password protected computer. Only researchers in this study will have access to these sources. When we publish information from these data, we will show you any reports before we use it in any published materials (e.g. reports or scientific publications) and will not use it without your approval. Pseudonyms will be used for all reports and all characteristics that link your identity will be edited to maximise anonymity.

Will this study help you or others

Giving consent to part in this discussion will not benefit you personally. However, information that will be collected will help us establish an account of experiences of highly mobile women and their engagement with HIV self-testing.

What are the risks or harms

We believe that the risks are minimal. You are free to inform us If you feel like our participation in the study is putting you at greater risk. You are free to inform us if you would like to continue participating in the study or not.

Are there any costs to you if you participate in the study

It will not cost you anything to participate and you will receive K2,500 as a compensation for your time

Information about your rights

Please know that your participation in this component of the study is your choice. You can decide at any time to stop participating in the discussions.

Questions

Do you have any questions you want to ask me before you decide whether to participate in the study? I will give you a copy of this form to keep, if you wish.

Who to contact if you have any questions

If you have any questions about this study please feel free to ask them. If you think of any questions after we have gone please feel free to contact us by calling the following number and asking for:

Wezzie Lora
Principle Investigator
+265 995 351 611

Please contact the COMREC Secretariat should you wish further information about your rights, safety, and wellbeing in research:

COMREC Secretariat
College of Medicine Research and Ethics Committee
P/Bag 360, Chichiri, Blantyre 3, Malawi
Telephone: 01877245/01877291

Participant's statement

I will now read you a brief statement. After I have read it please let me know if you would like to participate in this interview:

This activity has been explained to me and I agree to participate in this discussion. I have had the opportunity to ask questions. I understand that I can choose not to answer some questions and can stop participating in the discussion at any time. I understand that I can contact the investigators if I have questions about the study. I can contact the person named above if I have questions about my rights as a participant.

Appendix 3I: Focus group discussion: Female sex workers

The research study

This study is being conducted as part of a research project from Liverpool School of Tropical Medicine, UK in collaboration with Malawi Liverpool Wellcome Trust-Clinical Research Program, Blantyre, Malawi. The project explores experiences of highly mobile women* when they are exposed to HIV self-testing in Malawi. This will help us understand the best approaches for HIV prevention programs targeting highly mobile women in Malawi.

What are we trying to learn

In this component of the study we would like to hear your views of using Peer Educators as distributors in the intervention led to more problems or created opportunities for you as an individual, your group of highly mobile women regarding engagement with HIV self-testing. We are interested to understand the problems you have faced, choices made, opportunities created as a group of highly mobile women and your community at large.

Why have you been asked to participate in the study

Malawi Liverpool Wellcome Trust has been providing HIV self-testing in urban Blantyre and it is likely that you have participated as someone who has decided to self-test. You may also have participated in other aspects of other studies carried out by these institutions. We are asking people who have recently received HIV self-testing kits. You have been selected because you are between the ages of 16 and 49 and identified as a highly mobile woman. If you withdraw from the study any information gathered from you will be destroyed. Agreement to participate in this research will not compromise your legal rights.

What are we asking you to do

If you decide to participate in the study, we will ask about where you live, your contact information, your age, occupation, marital status and education background. You will then be asked to take part in a group

discussion with your peerswherewe will ask you questions about the themes discussed above. It is likely that you will know some of the people in the group. There will be two researchers during the discussion, myself and a colleague. One of us will be facilitating the discussion and another person will be taking notes of the issues being discussed and observing group dynamics. The discussion will take place here in Blantyre, and the group members will be given an opportunity to choose a private and safe place where the discussion can take place. This will allow group members to express themselves freely and maximise your privacy. The focus group discussion will be recorded using a digital recorder to avoid losing important data and minimise recall bias. The discussion will approximately take 60-90 minutes of your time.

Steps we take to protect your privacy

All information obtained from this discussion or equipment used will be stored securely in a lockable bag when not in use in the field, in a lockable drawer while in the office, and electronic copies will be saved on a password protected computer. Only researchers in this study will have access to these sources. When we publish information from these data, we will show you any reports before we use it in any published materials (e.g. reports or scientific publications) and will not use it without your approval. Pseudonyms will be used for all reports and all characteristics that link your identity will be edited to maximise anonymity.

Will this study help you or others

Giving consent to part in this discussion will not benefit you personally. However, information that will be collected will help us establish an account of experiences of highly mobile women and their engagement with HIV self-testing.

What are the risks or harms

We believe that the risks are minimal. You are free to inform us If you feel like our participation in the study is putting you at greater risk. You are free to inform us if you would like to continue participating in the study or not.

Are there any costs to you if you participate in the study

It will not cost you anything to participate and you will receive K2, 500 as a compensation for your time.

Information about your rights

Please know that your participation in this component of the study is your choice. You can decide at any time to stop us from using your pictures in the reports

Questions

Do you have any questions you want to ask me before you decide whether to participate in the study? I will give you a copy of this form to keep, if you wish.

Who to contact if you have any questions

If you have any questions about this study please feel free to ask them. If you think of any questions after we have gone please feel free to contact us by calling the following number and asking for:

Wezzie Lora
Principle Investigator
+265 995 351 611

Please contact the COMREC Secretariat should you wish further information about your rights, safety, and wellbeing in research:

COMREC Secretariat
College of Medicine Research and Ethics Committee
P/Bag 360, Chichiri, Blantyre 3, Malawi
Telephone: 01877245/01877291

Participant's statement

I will now read you a brief statement. After I have read it please let me know if you would like to participate in this interview:

This activity has been explained to me and I agree to participate in this interview. I have had the opportunity to ask questions. I understand that I can choose not to answer some questions and can stop participating in the interview at any time. I understand that I can contact the investigators if I have questions about the study. I can contact the person named above if I have questions about my rights as a participant.

10.4 Consent forms

Appendix 4A: Photo release form

I allow…………………………………………………….…to use photos of/about me…………………………………………..…taken during the research study named above in Blantyre, Malawi for any purpose, and in any media, throughout the world and without time limit. I understand that the photographer may use images for any purpose they choose and that this may include use:

a) On websites, available to anyone with internet access worldwide
b) In printed materials including leaflets, books, reports and postcards
c) In public exhibitions
d) In the printed and online press and journals, nationality and internationally
e) On television
f) On posters and billboards

I understand that I will not be paid for any such use

I agree that I have no rights to the images including to inspect or approve the researcher's/ use of the images, and that all rights to the images belong to the researcher.

I agree that the images may be combined with the images, text, and graphics and could be cropped, altered or modified as the researcher wishes.

I agree that the researcher may assign this permission to another person

PLEASE FILL IN YOUR FULL CONTACT DETAILS BELOW:

Full name:

Address:

Location:

Phone number:

Signature/thumbprint:

Signature of witness:

Date:

Appendix 4A Consent form

Understanding vulnerability and empowerment through engagement with home-based bio-medical HIV prevention technologies in female sex workers in Malawi

Principal investigator: Wezzie Lora
Study site: Blantyre, Malawi

	Please initial box/thumbprint
1. I confirm I have read and understood the information sheet dated......... (Version.......) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2. I understand that participation in this study is voluntary and I am free to withdraw consent at any time, without giving a reason, without any penalties.	
3. I understand that data collected during the study, may be looked at by individuals from LSTM/MLW and from regulatory authorities. I give permission for these individuals to have access to my records.	
4. I hereby declare that I have not been subjected to any form of coercion in giving this consent.	
5. I agree to the data about me collected in this study being stored for further use in the future.	
6. I agree to take part in this study.	

Signing this declaration does not affect your right to decline to take part in any future study.

Name of participant Date Signature/thumbprint

Name of witness Date Signature/thumbprint

Name of person taking Date Signature Consent

When complete: 1 copy for participant; 1 copy (original) for research

10.5 Theme summaries

Summaries	Free nodes	Categories	Themes
Coming from big families: 4-24 siblings Some experience death of parents or siblings at a very young age Most FSW came from broken families Wage labour as a source of income for parents, mother were usually housewives or conducting small businesses Children raised not to question parents Parents expected children to support in economic activities Conditionally separated families	Siblings Death Divorce/separated Income Poverty Expectations Relocation	Personal and social relationships Life events Labour and investment structure	**History, culture and gender: the context of sex work in Blantyre**

Lack of economic opportunities after divorce/partner's death No support at home Followed friends Searching for a husband/stable partner Abuse from family Sex work for; • a house • food • Agriculture • Family support- school fees There is nothing else to do	Poverty Money Peer pressure Marriage Violence Economic opportunities Husband Parents Divorce/separation Death Helplessness	Labour and investment structure Personal and social relationships Life events Power as a state of being Sex work entry	

	Powerlessness Support		
FSW get beaten by customers/stable partners/street kids Customers sometimes do not pay FSW for sex work Name calling “hule” by community FSW get raped by customers/police/street kids Police brutality Older FSW are mocked by younger FSW Cold weather and rain on the streets- a challenge to street-based FSW	Physical violence Economic violence Emotional violence Stigma Sexual violence Customer Stable partner Street kids Police officer	Violence Personal and social relationships	

Attacks by robbers on the way home from bars Unlawful arrests FSW steal money from customers FSW showing each other scars- violence is inevitable	Risks		
"There is nothing we can do about it" Difficult to get support from police officers because they are corrupt Police officers receive money from culprits when we report cases and the cases never get investigated Sometimes FSW do not report violence because they are unable to identify the offender	Support FSW Police Venue owners Evidence Helplessness Powerlessness	Personal and social relationship Violence Support Violence management Knowledge	

Sometimes FSW accept the situation and go on with their lives Sometimes venue supporters support FSW- ban violent customers from visiting the bar- In Ndirande Some venue owners do not intervene in issues of violence concerning FSW- Manje, and FSW who do not reside at a particular bar Sometimes FSW relocate due to violence experiences			
FSW residing at a venue: • Not allowed to go to other bars in the communities • Not allowed to cook their own food in Ndirande • But found women cooking in Manje • Not allowed to have /boyfriends • Six girls were fired because they had boyfriends • No long skirts or dresses when working in the bar	Mobility Nutrition Work shifts HIV testing	Power as restrictive Power as enabling Power as a state of being Power as oppressive	

• Told to be dancing or serving customers when in the bar • Some were just sitting even at night when customers were in the bar dancing on their own • Pay money to venue owner for every client • Pay money to venue owner when they want to go out of the bar with a client • "unfixed salaries" for bar work Venue owners conducted routine testing in Ndirande those who refuse were fired from bar work • Found all FSW had gone for testing at FSW clinic in Ndirande	Emotional attachments Payments Control Rules Powerlessness Helplessness "Pimping" Exploitation Coercion	Sexual related behaviour Opposition	
Venue-based FSW; • Venue owners support FSW when ill in Ndirande • Venue owners support FSW when arrested in Ndirande	Venue owners Support	Rules and regulations at the bars	

• FSW can visit family/home: illness, funerals • FSW support each other- food, money, basic necessities • Community police support FSW • Trust in the venue owner-keeping of ARVs/valuable items Home-based FSW better living standards than the venue-based Parents perceive FSW as “prodigal daughters” Some FSW were disowned by parents Changing identities based on place and person FSW interact with Old friends (that is before sex work) not comfortable to interact with FSW Sex work is not a reliable job	Violence management Stigma Identity Trust Poverty Reliability Sex work	Power as restrictive Power as a state of being Opposition Personality traits of FSW Sex work initiation	

FSW’s perception of enhanced HIV risk because of their position -FSW fear knowing their HIV status -self-declaration of their positive status -past experience with health workers at health facilities To know one’s HIV status Re-confirming one’s HIV positive status after being on ART for a long time Able to do everything themselves and seek support where ever they wanted “You can choose to self-test or not” “self-testing as something respectful” Addressed issues of FSW’s busy schedule	Stigma Identity Agency Choice Autonomy Privacy Confidentiality Convenience Technology Citizenship	Power as enabling Conditions/state of self-testing Power as legit (authority)	**Female FSW’ motivations for HIVST**

It was good because self-testing was done at home No queues HIVST as something new No pricking hence no pain (vs conventional HTC) The kit was easy to use History of participation in health interventions targeting FSW			

Using test kit to disclose HIV status to partners/venue owners Presence of self-test kits at the venue perceived as unintended disclosure of HIV positive status Venue owners asking for sex in return of self-test kit Venue owners asked all FSW at the venue in Ndirande to self-test or they would risk losing their jobs at the bar Peer distributors told FSW that HIVST was “compulsory” Encouraged to link to care/unmet expectations related to linkage to care	Technology Venue owners Sexual violence Coercion Choice Identity Control Powerlessness Peer distributor Stable partner Husband	Personal and social relationships Power as oppression Power as enabling Power as a state of being	**Risk perception and the power in the context of HIVST**

Assumed advocate role of PDs- Encouraged others to stop sex work after testing HIV negative FSW' partners interested in HIVST FSW introduced HIVST to partners PDs told women that HIVST was meant for FSW FSW' identification of married women in the community as a high-risk group hence the ones who needed self-testing more than them Self-testing was attractive to adolescents who face stigma because of their age- at the health facilities as well as at the bar Testing negative while on ART- leading to confusion	Risk		

FSW forcing partners to disclose HIV status after self-testing Partners forcing FSW to disclose HIV status after self-testing			
Home-based had challenges in accessing HIVST- by design the PDs were distributing in bars or streets Home-based thought that PDs did not believe that they were FSW Frequent visits and HIVST procedure done by some PDs led to mistrust of the intervention Perceptions that PD was just like a health worker Some FSW had problems in interpreting self-testing results	Accessibility HIVST procedure Identity Home-based FSW Peer distributor Fear Expectations Support		**Power relation between PDs and their peers**

PDs not providing enough information on interpreting results PDs feared by FSW because of behaviour before they became PDs Expectation that PDs would link them to the FSW' clinic Selective distribution putting FSW at risk of violence from stable partners The belief that HIV virus cannot infect individuals with "blood group O"	Risk		

Peer distributors valued the training that they received PD thought they empowered their peers with the HIV prevention information Monetary incentives were appreciated Concerns around time and distance to venues Losing on sex work- prioritised distribution Venue-based FSW were the easiest to access Challenges in introducing HIVST to street-based FSW	Peer distributors Money Support Information Venue-based FSW Street-based FSW Commitment Expectations Mobility	Personal and social relationships Power as enabling	

Identified home-based FSW through their old sex work networks PDs knew the language of how to convince their peers to self-test PD important in identifying new hotspots in Blantyre HIVST delivered as a package of self-testing kit and a pack of condoms Venue owners helped PDs in identifying and mobilising FSW during the intervention PDs were proud to have saved someone's life PDs perceived their role as voluntary position PDs made a lot of friendships with FSW PDs were managing social harms after HIVST			

PDs lack of information on discordant results PDs changed their sexual and social behaviour because of the role of PD KIIs'concern: coordinating PDs due to mobility during the distribution period KII managing expectations; distribution targets vs incentives			
Need for regular testing Name calling after choices made, testing HIV positive after HIVST HIV prevention- limited choices/knowledge Helpless after condoms burst	Condom Preferences Alcohol Peer distributor Customers	HIV prevention Personal and social relationships	**HIV prevention in the context of HIVST**

Promotion of male condoms vs female condoms Self-declaration that all FSW are HIV positive-hard to believe their HIV negative status “Feeling the need to have plain sex to feed the virus” Condom negotiation with customers still a challenge Belief that one cannot have sex with a stable partner using a condom Difficult to monitor linkage to care PDs proud that some FSW linked to care through them-empowering their peers	Linkage to care Support Risk		

<table>
<tr>
<td>ARVs are in fashion

Hiding ARVs bottles from participants with friends or venue owner

Leaving ARVs bottles in the open for partners to see as a way of disclosing HIV status

Concerns that ARVs when in a bottle make a lot of noise hence leading to unintended disclosure

Self-awareness- accessing and managing ARVs bottles

Side effects of ARV drugs affecting sex work

Body image- looking good after being on ART for a long time

HIV/AIDS more manageable than cancer and other STIs

Being on ART for a long time as curing AIDS

Shy to go to health facility because of its geographical location in Ndirande</td>
<td>Hope

Immunity

Disclosure

Stigma

Dizzy

Nightmares

Appearance

Shy

Convenience

Alcohol

Drug use</td>
<td></td>
<td></td>
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</table>

Waiting room at ART clinic not conducive Medicine routing affected by alcohol and drug use Fear of disease progression if one stops taking ARVs Peers/health professionals as a source of information around managing life on ART Sharing ARVs amongst peers Waiting time for drug collection PD using themselves as role models to encourage peers to go to the health facility to start treatment	Fear Role models		