

A Thesis Submitted for the Degree of PhD at the University of Warwick

Permanent WRAP URL:

<http://wrap.warwick.ac.uk/162176>

Copyright and reuse:

This thesis is made available online and is protected by original copyright.

Please scroll down to view the document itself.

Please refer to the repository record for this item for information to help you to cite it.

Our policy information is available from the repository home page.

For more information, please contact the WRAP Team at: wrap@warwick.ac.uk

Exploration of Female Sex Workers' experiences and Perceptions with Accessing
Healthcare in Malawi: A Qualitative Study

By

Hilda Lexa Makoti Kabambe

A thesis submitted in partial fulfilment of the requirements for

the degree

of Doctor of Philosophy in Health Sciences

University of Warwick, Warwick Medical School

26th April 2021

Contents

Library Declaration and Deposit Agreement.....	i
List of Tables	xiv
List of Figures	xv
Acronyms and Abbreviations	xvi
Acknowledgement	xx
Declaration of Authorship.....	xxi
Abstract	xxii
Chapter One: Introduction.....	1
1.0 An Overview	1
1.1 Background Information	1
1.2 Developing Understanding of Female Sex Workers in Malawi	2
1.2.1 The laws regarding sex work at global level	3
1.2.1.1 The Law and sex work in Malawi.....	4
1.2.2 Malawi's HIV progress and public health implication for prevention and treatment of HIV.....	6
1.2.2.1 Female Sex Workers and HIV prevalence.....	8
1.3 Description of the Family Planning Association of Malawi.....	9
1.4 Description of Theatre for a Change	9
1.5 Background Information of Malawi.....	11
1.5.1 The country's profile.....	11
1.5.2 Administrative and political distribution.....	13
1.5.3 The country's economic context.....	13
1.5.4 The country's social context	13
1.5.5 Education context.....	14
1.5.6 Healthcare system in Malawi.....	15
1.5.6.1 Community level.....	17
1.5.6.2 Primary level	17
1.5.6.3 Secondary level.....	18
1.5.6.4 Tertiary level	18

1.5.6.5 Health sector reforms	18
1.5.6.6 Health sector-wide approach, essential health package, and programme of work	20
1.6 Aim and Objectives of the Study	21
1.7 The Research Questions.....	22
1.8 Rationale of the Study.....	22
1.9 Description of Proposed Study and Sample.....	23
1.10 The Significance of the Study.....	24
1.11 Organisation of Thesis.....	25
1.12 Summary.....	27
Chapter Two: Literature Review of the Factors Affecting Female Sex Workers’ Experiences and Perceptions with Accessing Healthcare	28
2.0 Introduction.....	28
2.1 Systematic Literature Review Strategies	28
2.1.1 Data sources.....	29
2.1.2 Study selection.....	29
2.1.3 Quality assessment.....	32
2.1.4 Data extraction.....	32
2.2 Thematic Literature Review for Study 2.....	33
2.2.1 Data sources.....	33
2.2.2 Inclusion criteria	34
2.3 Definition of Terms Used.....	35
2.4 Socio-cultural Factors Affecting Female Sex Workers’ Experiences	36
2.5 Taboos Regarding Sex.....	37
2.6 Stigma and Discrimination	39
2.7 Violence Among Female Sex Workers and its Implication on Public Health	41
2.8 Health-Sector Responses to Female Sex Workers’ Health Needs in Malawi.....	43
2.9 Summary of Literature Review	44
Chapter Three: Theoretical Perspectives of Health Service Utilisation.....	46
3.0 Introduction.....	46

3.1 Theories and Models.....	47
3.1.1 The health belief model.....	47
3.1.1.1 Perceived threat	48
3.1.1.2 Perceived benefits	49
3.1.1.3 Perceived barriers.....	49
3.1.1.4 Cues to action.....	49
3.1.1.5 Other variables	50
3.1.2 The empowerment theory	50
3.1.2.1 At individual level	50
3.1.2.2 At intrapersonal level.....	51
3.1.2.3 At the organisational level.....	51
3.1.3 The socio-economic model	52
3.1.4 A conceptual framework of access healthcare	53
3.1.4.1 Approachability.....	54
3.1.4.2 Acceptability.....	55
3.1.4.3 Availability and accommodation	55
3.1.4.4 Affordability	55
3.1.4.5 Appropriateness	56
3.1.5 Dahlgren and Whitehead’s social model of health.....	56
3.1.6 The socio-ecological framework models.....	58
3.1.6.1 Intrapersonal factors.....	59
3.1.6.2 Interpersonal factors.....	59
3.1.6.3 Organisational factors	59
3.1.6.4 Community factors.....	60
3.1.6.5 Public policy	60
3.2 Conclusion Remarks	61
Chapter Four: Methods and Methodology	62
4.0 Introduction.....	62
4.1 Ontology.....	63

4.2 Epistemology.....	63
4.3 Philosophical Tenets.....	64
4.4 Study Setting for Study 1 and Study 2.....	65
4.5 The aim and the research questions of Study 1.....	66
4.6 Research Method for Study 1.....	66
4.6.1 Rationale for choosing a qualitative study in Study 1.....	66
4.7 Research Method for Study 1.....	67
4.7.1 Accessing participants for Study 1.....	67
4.7.2 Sample for Study 1.....	69
4.7.2.1 Sampling criteria of Study 1.....	70
4.7.2.2 Inclusion and exclusion criteria in Study 1.....	70
4.7.2.3 Sample size in Study 1.....	70
4.8 Methods of Data Collection.....	71
4.8.1 Data collection in Study 1.....	71
4.9 Data Storage and Management in Study 1.....	72
4.9.1 Data analysis and interpretation.....	72
4.9.2 Transcription and translation in Study 1.....	73
4.9.3 Data analysis.....	73
4.9.3.1 Data analysis in Study 1.....	73
4.10 Aim of the Study, Objectives, and the Research Questions for Study 2.....	75
4.10.1 Research questions for Study 2.....	75
4.10.2 Research objectives for Study 2.....	75
4.11 Methodology for Study 2.....	76
4.11.1 Phenomenology.....	76
4.11.2 Rationale for using phenomenological approaches.....	77
4.12 Research Method for Study 2.....	79
4.12.1 Access to participants during Study 2.....	79
4.12.2 Sample in Study 2.....	80
4.12.3 Sampling criteria in Study 2.....	80
4.12.4 Inclusion and exclusion criteria in Study 2.....	80

4.13 Data Collection for Study 2	81
4.14 Data Storage and Management in Study 2	82
4.14.1 Transcription and translation for Study 2	82
4.14.2 Data analysis in Study 2	83
4.15 Ethical Approval (Study 1 and Study 2)	86
4.15.1 Ethical consideration for Study 1 and Study 2	86
4.15.2 Reimbursement of Expenses for Study 1 and Study 2	88
4.15.3 Tokens of appreciation for participation for Study 1 and Study 2	88
4.16 Trustworthiness of the Study	88
4.16.1 Credibility	89
4.16.2 Reflexivity	90
4.17 Summary	94
Chapter Five: Findings of Study 1	96
5.0 Introduction	96
5.1 Characteristics of Participants	96
5.2 Factors Contributing to Female Sex Workers' Positive Experiences	97
5.2.1 Approaches to improving access to care	97
5.2.1.1 Outreach services	97
5.2.1.2 Home-Based care services	98
5.2.1.3 Convenient location of a health facility	100
5.2.1.4 Available of resources	101
5.2.2 Effects of non-governmental organisations on provision of services to female sex workers	102
5.2.2.1 Engaging all stakeholders on provision of services	102
5.2.2.2 Sexual and reproductive health services including HIV/STI management	104
5.2.2.3 Empowerment	105
5.2.3 Healthcare professionals' awareness of female sex workers' needs	105
5.2.3.1 Breaking down barriers and healthcare professionals' attitudes towards female sex workers	106

5.2.3.2 Leadership	108
5.3 Summary.....	108
Chapter Six: Research Findings of Study 2.....	110
6.0 Introduction.....	110
6.1 Participants Characteristics.....	112
6.2 Enduring Structural Violence	112
6.2.1 Stigma from community	113
6.2.2 Stigma from healthcare professionals	114
6.2.2.1 Healthcare professionals' attitudes toward female sex workers.....	116
6.2.2.2 Unconsented HIV Testing.....	117
6.2.2.3 Denial/withhold/delay of services	118
6.2.2.4 Breach of confidentiality	120
6.2.3 Unfavourable policies and laws	121
6.3 Enduring Direct Violence.....	122
6.3.1 Violence from clients	123
6.3.2 Violence from law enforcers/police.....	124
6.3.3 Violence from healthcare professionals.....	125
6.4 Combating Structural Violence.....	126
6.4.1 Improving service delivery and access	126
6.4.2 The role of non-governmental organisations	128
6.4.2.1 Promotion of HIV/STI prevention/testing/treatment.....	129
6.4.2.2 Health and advocacy.....	129
6.4.2.3 Empowerment of FSWs	132
6.4.2.4 The role of social networks.....	133
6.4.3 Understanding female sex workers' health needs and their perception of a good service	134
6.4.3.1 Equality of care.....	136
6.4.3.2 Bringing services near to female sex workers' 'Hot spots'	137
6.4.3.3 Establishing specific clinics for female sex workers	138
6.5 Summary.....	140

Chapter Seven: Discussion.....	142
7.0 Introduction.....	142
7.1 Female Sex Workers' Positive Experiences with Accessing Healthcare.....	142
7.2 Issues Related to Service Delivery and Access	143
7.2.1 Outreach and Home-Based Services	144
7.2.2 Location of HIV/STI facilities	145
7.3 Healthcare Professionals' Awareness of Female Sex Workers' Healthcare Needs.....	145
7.4 Structural Violence	147
7.4.1 Direct violence from community	147
7.4.2 Direct structural violence from clients	148
7.4.3 Direct violence from healthcare professionals	149
7.4.3.1 Unconsented HIV testing	151
7.4.3.2 Denial or withhold of treatment.....	152
7.4.3.3 Breach of confidentiality.....	152
7.4.3.4 Unfavourable policies and laws	153
7.5 Combating Structural Violence.....	154
7.5.1 The role of social networks.....	155
7.5.2 Establishment of special health facility or 'Hotspot'	156
7.6 Contribution to New Knowledge.....	156
7.7 Summary.....	158
Chapter Eight: Researcher's Positionality and Lessons Learnt	160
8.0 Introduction.....	160
8.1 Researcher's Positionality.....	160
8.2 What Has Been Learnt?	162
8.2.1 What and how I have learnt.....	162
8.3 Summary.....	166
Chapter Nine: Conclusions and Recommendations	167
9.0 Introduction.....	167
9.1 Strength and Limitations of both Studies	167

9.1.1 Strengths of the Study.....	168
9.1.2 Limitations of the study	169
9.2 Key Conclusions and Recommendations of Study 1 and Study 2.....	171
9.2.1 Improving health service delivery in public health facilities	171
9.2.2 Developing services specifically for female sex workers.....	173
9.2.3 Cultural norms and beliefs as determinants of FSWs' experiences	173
9.3 Recommendations.....	174
9.3.1 Implications for service delivery.....	175
9.3.1.1 Implications for healthcare policy and planners	175
9.3.2 Implication for practice	176
9.3.3 Implications for future research	177
9.4 Summary.....	177
References	178
Appendices.....	210

List of Tables

Table N°	Table Name	Page N°
1.1	Number of Health facilities offering services in Malawi	16
2.1	Criteria for inclusion of studies	30
4.1	The six stages followed in the thematic analysis undertaken in Study 1.	74

List of Figures

Figure N°	Figure Name	Page N°
1.1	Malawi's HIV progress towards 90-90-90	6
1.2	Map of Malawi demarcations its neighbouring countries	11
1.3	Lilongwe city where most sex work is conducted.	13
1.4	Lilongwe Urban poor in Chatata settlement near Kanengo in Lilongwe.	14
1.5	The health delivery system in Malawi adapted from Health Sector Strategic Plan (HSSP) 2011-2016 Moving towards equity and quality.	20
2.1	The process of screening the studies	31
3.1	Key variables of the Health Belief Model	48
3.2	A conceptual framework of access to healthcare	54
3.3	Dahlgren and Whitehead's social model of health	57
3.4	The social ecological model	58
4.1	An example of a residential area where most FSWs live.	65
4.2	overview of the two studies design and methods undertaken and how the findings of the studies are integrated in the discussion.	85
6.1	The main themes, sub-themes and codes identified in Study 2.	111

Acronyms and Abbreviations

AIDS: Acquired Immune Deficiency Syndrome

ANC: Antenatal Care

ART: Antiretroviral Therapy

BSREC: Biomedical & Scientific Research Ethics Committee

CBDAs: Community-Based Distributing Agents

CBO: Community-Based Organisation

CBS: community-Based Services

CEDAM: Convention on Elimination of all forms of Discrimination Against Women

CEDEP: Centre for the Development of People

CHAM: Christian Health Association of Malawi

CPD: Continuous Professional Development.

CRH: Centre for Reproductive Health

CRHP: Community Reproductive Health Promoters

CSOs: Civil Society Organisations

CSR: Centre for Social Research

DC: District Commissioner

DHMTs: District Health Management Teams

DHOs: District Health Officers

DIP: District Implementation Plans

DHMT: District Health Management Team

DHO: District Health Officer

EHP: Essential Health Package

FPAM: Family Planning Association of Malawi

FSWs: Female Sex Workers

GDP: Gross Domestic Product

GNSWP: Global Network of Sex Work Projects

GOM: Government of Malawi

GPs: General Practitioner Surgeries

GTZ: German Technical Cooperation Agency

HAART: Highly Active Antiretroviral Therapy

HBM: Health Belief Model

HCPs: Healthcare Professionals

HCT: HIV Testing and Counselling

HIV: Human Immunodeficiency Virus

HMIS: Health Management Information System

HSAs: Health Surveillance Assistants

HSSP: Health Sector Strategic Plan

ID: Identification Number

IMF: International Monetary Fund

IPPF: International Planned Parenthood Federation

JHPIEGO: John Hopkins Program for International Education in Gynaecology and Obstetrics

MDG: Millennium Development Goals

MDHS: Malawi Demographic Health Survey

MW/FSW: Malawi Female Sex Workers

MHRC: Malawi Human Rights Commission

MHSSP: Malawi Health Sector Strategic Plan

MoLGRD: Ministry of Local Government

MoH: Ministry of Health

MPs: Members of Parliament

MSF: Médecins Sans Frontières

NAC: National AIDS Commission

NBHW: National Board of Health and Welfare

NGO: Non-Governmental Organisation

NHSREC: National Health Research Council

NSO: National Statistics Office

NAPSWs: National Action Plan for Sex Workers

NSWP: Network for Sex Work Projects

OHCHR: Office of the High Commissioner for Human Rights

PLWHIV: People Living With HIV

POW: Programme of Work

PFP: Private For Profit

PNFP: Private Not For Profit

PEP: Post-Exposure Prophylaxis

PTC: Pre-Test Counselling

SRH: Sexual and Reproductive Health

STIs: Sexually Transmitted Infections

SWAP: Sector Wide Approach

TAs: Traditional Authorities

TB: Tuberculosis

TfaC: Theatre for a Change

UHC: Universal Health Coverage

UK: United Kingdom

UN: United Nations

UHC: Universal Health Coverage

UNAIDS: United Nations Programme on HIV/AIDS

UNC: The University of North Carolina at Chapel Hill

UNFPA: United Nations Food Programme Agency

UNICEF: United Nations for Population Agency

USA: United States of America

USD: United States Dollar

VCT: Voluntary Counselling and Testing (of HIV/AIDS)

VHC: Village Health Committee

WHO: World Health Organisation.

Acknowledgement

I would like to thank my academic supervisors Professor Sophie Staniszezwska and Professor Kate Seers. Thank you for your patience, inspiration, and guidance without which this study would not have been possible. Thank you, not only for the PhD supervision but for the many skills and knowledge I have acquired through your supervision. The journey was not easy but with your support and encouragement when things could have gone either way during the Covid-19 pandemic, you were there for me and you still believed in my abilities and encouraged me to achieve my goals.

I am so grateful for the support and encouragement from my two beloved children, Tyanjana and Mwapatsa. You have been my greatest strength and always made me believe my goals are achievable. Yes! I wish my mother and father were alive to witness this.

Many thanks to Martin Nthakomwa, lecturer in International Disaster Relief and Community Reconstruction at Coventry University, UK, you have been a rock. I really could not have done this without your invaluable advice and support when I was made to feel that this path was not for me, you were there, encouraging me not to give up and to take any action that would see me through the tough time that was ahead of me.

I also extend my appreciation to the managers of Family Planning Association of Malawi (FPAM) and Theatre for a Change (TfaC) for allowing me to access the study participants through their organisations.

I would like to thank the then Director (Mr Tannach Masache) and all the staff of Malawi College of Health Sciences for the support they gave me during my fieldwork.

Last but not least, my sincere appreciation to all female sex workers, healthcare professionals and service providers who gave their time to be interviewed, without whom this study would not have been possible.

Declaration of Authorship

This thesis is my own work and has not been submitted for a degree at another university.

Abstract

Female sex workers (FSWs) in Malawi, like other similar settings, face major challenges accessing healthcare services including those provided by public and non-governmental organisations (NGOs). Understanding FSWs' experiences and perceptions of accessing healthcare could improve service delivery to this vulnerable group of women by enhancing service utilisation and reducing their potential of being infected with Human Immunodeficiency Virus (HIV) and sexual transmitted infections (STIs) thus reducing transmission.

Study 1 explored FSWs' positive experiences with access to healthcare and Study 2 explored a wider range of FSWs' experiences and perceptions of accessing healthcare services provided by public and non-governmental organisations in Malawi. Qualitative methods were employed to explore FSWs' experiences and perceptions of accessing healthcare services in Malawi.

Study 1 collected data, using face-to-face semi-structured interviews from 45 FSWs, 10 healthcare professionals (HCPs) and six service providers from Theatre for a Change and Family Planning Association of Malawi.

Three main themes emerged from data of Study 1: (1) Approaches to improving access to healthcare, (2) Effects of the NGOs on provision of healthcare services to FSWs, and (3) Professionals' awareness of FSWs' needs. Three main themes also emerged from the data of Study 2: (1) Enduring structural violence; (2) Enduring direct violence; (3) Combating structural violence.

The empirical evidence derived from these studies about positive experiences with access to healthcare and structural determinants of negative experiences and perceptions of accessing healthcare, particularly in public health facilities and the preference for provision of services in 'Hotspots' could be used, along with other evidence to review current policy and inform future plans. Development should be aimed at improving HCPs' awareness of the needs of FSWs while making services more acceptable and approachable in Malawi for this high risk population.

Chapter One: Introduction

1.0 An Overview

This thesis documents a study which addressed a key global health challenge: how we understand FSWs experiences of healthcare and how this knowledge informs the types of services that should be provided. The study has provided a learning journey for me as I document the key points of learning throughout the thesis and bring them together after the discussion chapter. Furthermore, this thesis presents two studies, Study 1 which was conducted between 2014-2017 and Study 2 which was conducted between 2018-2021.

To provide a context for the thesis, the first part of this section introduces the key issues, drawing briefly on the literature presented in more detail in Chapter Two. This literature helped identify knowledge about FSWs' experiences and perceptions of healthcare services. It then provides a brief overview on what is currently known about FSWs including the laws affecting sex work and a brief description of Malawi's HIV Progress and public health implications for prevention and treatment of HIV. This is followed by a description of "Family Planning Association of Malawi" and "Theatre for a Change" (these are NGOs that were utilised to access participants for both studies). The country's profile including the healthcare systems is also presented. All these factors have an important influence on the study and, indeed, influence FSWs' experiences with healthcare systems. The chapter further presents a brief description of the process of recruiting participants (both FSWs and service providers), which is fully described in Chapter Four. Furthermore, this chapter outlines the study's aim, objectives, the research questions, the rationale, and the significance of the study. The chapter ends with a summary.

1.1 Background Information

FSWs have been reported to be at high risk of HIV infection in nearly every setting where they have been studied (Baral *et al.*, 2012; Matovu & Ssebadduka, 2012; Zachariah *et al.*, 2003), yet studies have shown that structural risk factors indirectly heighten this risk by restricting access to preventive health, HIV and STIs services and treatment (Chakrapani *et al.*, 2009; Rosenheck *et al.*, 2010; World Health Organization, 2012). Structural

factors include poverty, discrimination, and gender inequality as well as the damaging effects of physical and sexual violence, stigma, and social exclusion (United Nations Programme on HIV/AIDS, 2007). Also, structural factors such as the organisation and power dynamics of sex work, being identified as a FSW, and the legal and regulatory policies regarding sex work have also been shown to contribute to sex workers' increased risk of HIV infection by limiting their ability to negotiate safer sex (Erausquin *et al.*, 2011; Fonner *et al.*, 2014; Munkhbaatar *et al.*, 2014; Shannon *et al.*, 2008).

Despite the WHO's recommendation that FSWs and other high-risk groups undergo HIV testing at least once a year (World Health Organization, 2012), there are still few interventions specifically focusing on increasing access to HIV testing for FSWs in sub-Saharan countries (Baral *et al.*, 2012).

To understand FSWs' experiences and perceptions towards healthcare systems, both FSWs' and service providers' (such as healthcare providers and service providers from Family Planning Association of Malawi and Theatre for a Change) perspectives are important to include. Family Planning Association of Malawi and Theatre for a Change objectives and aims for providing health-related services are described below in sections 1.3 and 1.4, respectively.

This qualitative study aimed to explore FSWs' experiences and perceptions of access to healthcare in Malawi. The next section presents a brief description of the current status of FSWs in Malawi.

1.2 Developing Understanding of Female Sex Workers in Malawi

Most FSWs in Malawi are mobile and transitory (Family Planning Association of Malawi, 2011) and so, are a hard to reach group, thus, it is challenging to understand their experiences and perspectives which has implications in designing services targeted at this population. A survey conducted by Family Planning Association of Malawi in ten randomly selected districts of Malawi in 2011, estimated that about 20,000 FSWs work in different venues (e.g., entertainment venues, bars, in homes and on the streets (Family Planning Association of Malawi, 2011). Previous studies have revealed that the highest numbers of FSWs are in urban and in significant commercial farming areas of

the country (Chikaphupha *et al.*, 2009; Family Planning Association of Malawi, 2011).

Evidence reveals that poverty, low educational levels, socio-cultural and inadequate legal support for girls are the reasons most women join the sex industry in Malawi (Baird *et al.*, 2012; Underwood *et al.*, 2011; Van de Borne, 2003). FSWs also experience high levels of violence, discrimination and abuse from police, intimate partners, clients and members of the public (Global Networks for Sex Workers Project, 2020). Frequently, the police are involved in the exploitation of women's vulnerability, by rounding them up and pressurising them into having sex in exchange for release without prosecution (Theatre for a Change, 2012).

These ecological factors increase FSWs' vulnerability to HIV/STI, violence and sexual exploitation (MacPherson *et al.*, 2012; Rushing *et al.*, 2005). FSWs have the highest prevalence of HIV in Malawi. This evidence is also supported by findings from a nationwide survey which revealed that FSWs have the highest prevalence rate of HIV among the general population (Government of the Republic of Malawi, 2015a). In 2018, 55% of sex workers were estimated to be living with HIV (United Nations Programme on HIV/AIDS, 2018). In order to provide a context for considering experiences, it is important to recognise the laws in Malawi and in other countries regarding sex work.

1.2.1 The laws regarding sex work at global level

Sex work and the law is complicated because criminal laws cover different activities, people and settings associated with sex work (Overs, 2017). Understanding the laws that govern sex work can be complicated and confusing, especially because those laws are not uniform globally, or even within each country. For instance, in Colombia, Cambodia, Indonesia and in some parts of the United States, it is legal to operate a sex business if it is licensed (Overs, 2017). However, in countries such as Russia, Bosnia and Herzegovina, Malawi and Guyana, only selling and organising prostitution are illegal (Family Planning Association of Malawi, 2011; Overs, 2017). Countries such as Nepal and Sri Lanka prohibit all aspects of sex work by defining them as human trafficking, even when the sex worker consents (Overs, 2017). In

San Francisco and most of the United States, the law clearly states that the purchasing and selling of sexual services and associated activities are criminal offences (Lutnick & Cohan, 2009; Overs, 2017). In the United Kingdom (England, Wales, Scotland and Northern Ireland), exchanging sex for money is legal (UK Legislation, 2003), but a number of activities for example, soliciting in public space or running a brothel business is a crime (UK Legislation, 2003). Evidence suggests that, to understand sex work law, we must consider of both the 'law on the books' and the 'law on the street' (Overs, 2017). The next section describes the laws affecting FSWs in Malawi.

1.2.1.1 The Law and sex work in Malawi

Sex work in Malawi, like many other countries, is a 'criminal offence' (Family Planning Association of Malawi, 2011). This criminalisation of sex work limits the amount of available data on this key population, as well as the support and services sex workers are able to access. The laws regarding sex work in Malawi lacks clarity compared with other nations. In Malawi, purchasing of sex is not criminalised but living on earnings from sex work is a criminal offence (Government of the Republic of Malawi, 1999). While prostitution or sex work is 'illegal' in Malawi, the law does not criminalise sex work outright. This legal uncertainty, coupled with the societal norms, has implications for public perception of sex workers in Malawi. For instance, Section 146 of the penal code does not criminalise FSWs but seeks to protect these women from any sort of exploitation. The legal misinterpretations and lack of clarity exacerbate discrimination against FSWs and the experiences FSWs have with access to services (World Health Organization & UNAIDS, 2015).

A better understanding of what laws there are, what the laws mean and how they affect FSWs' lives is necessary when exploring FSWs' experiences with access to healthcare services. The law regarding FSWs in Malawi is contained in the Penal Code (Cap 7:01) of the Laws of Malawi (Sections 146, 147, 180(a), 181, 184 and 194), in which sex work is defined as 'prostitution'. For example, Section 146 delineates the crime of a woman living on the earnings of prostitution or influencing others to engage in prostitution.

Section 147 criminalises the keeping of brothels (house, room/rooms, or places of any kind whatsoever used for prostitution). Sex workers are at risk of

prosecution under Section 192 of the Penal Code, which defines the offence of a negligent act likely to spread disease dangerous to life. However, according to the Southern Africa Litigation Centre, there is no provision in the Malawi Penal Code which criminalises the selling of sexual services by a sex worker (Global Networks for Sex Workers Project, 2018). It is, accordingly, unlawful to apply sections of the Penal Code to a sex worker that were originally aimed at protecting sex workers from exploitation.

Despite the Southern Africa Litigation Centre describing the arrest of FSWs as unlawful, police officers continue to arrest FSWs in Malawi. Police officers incorrectly interpret Section 146 of the Malawi Penal Code to mean that sex work is illegal in Malawi. They use this incorrect interpretation to justify the arrest of FSWs under Section 184 of the Penal Code and to charge them as 'Rogues and Vagabonds', which are also offences covered in Penal Codes 180(a) 181. These sections cover idle and disorderly persons and their conduct that is likely to cause a breach of peace, respectively. For example, 14 FSWs were arrested on a single day in Blantyre in April 2009 and forced to undergo HIV tests. Eleven FSWs from Mwanza district were arrested in 2009 and 23 FSWs were arrested in Kasungu district on 5 June 2014 (Mywage, 2004). The eleven FSWs arrested in Mwanza filed an application in 2009 to the High Court seeking judicial review challenging their subjection to HIV test without their consent and the public disclosure of their HIV status. They won the case and were compensated (Malikwa, 2015). However, these are isolated cases, sex workers often do not have the means, the knowledge, or the power to make use of the remedies that may be available.

Current laws regarding sex work in countries like Malawi where sex work is 'illegal,' increase FSWs' vulnerability towards HIV/AIDS, violence and, consequently, affect their experiences and perception of the services. The single most powerful strategy in improving FSWs' experiences and perception of services as well as reducing violence against sex workers, is to recognise sex work as viable work and to protect those who are doing it by decriminalising the sex industry (The World AIDS Campaign, Undated).

The next section sets the context of the study and presents a brief description of Malawi's HIV Progress and public health implications for prevention and treatment of HIV.

1.2.2 Malawi's HIV progress and public health implication for prevention and treatment of HIV

Malawi has one of the highest HIV prevalence in the world, with 9.2% of the adult population (aged 15-49) living with HIV, despite the impressive progress the country has made in controlling its HIV epidemic in recent years (Avert, 2019). Malawi's HIV epidemic is generalised, which means it affects the general population as well as certain high-risk groups (Avert, 2019). The first case of HIV/AIDS in Malawi was reported in 1985 (Government of Malawi, 2012). HIV/AIDS increased drastically between 1985 and 1993 when HIV prevalence rates was estimated to be as high as 30% among pregnant women (Government of the Republic of Malawi, 2015b). However, the President (Dr Hastings Kamuzu Banda) who was in power at the time, responded with several small-scale prevention initiatives and created the National AIDS Control Programme, a division of the Ministry of Health, to manage the growing epidemic (Avert, 2012; Government of Malawi, 2012). Since then, impressive efforts to reduce the HIV epidemic have been made at both national and local levels (Avert, 2019). The efforts include raising awareness about how to prevent HIV, provision of free condoms, HIV testing and counselling (HTC) services provided in two ways: through client-initiated HTC (also known as 'voluntary counselling and testing'), and provider-initiated HTC. Provider-initiated testing, which is when a health worker offers an HIV test to a patient and a 'test-and-treat' strategy, which calls for all people living with HIV to begin antiretroviral treatment (ART) as soon as possible, irrespective of their CD4 count (Government of the Republic of Malawi, 2015a).

Hence, in 2019, 90% of people living with HIV in Malawi were aware of their status, of whom 88% were on treatment. Of these people, 92% were virally suppressed, meaning the country was close to achieving the UNAIDS 90-90-90 targets, which include 90% of people with HIV knowing their status, 90% of these accessing ARVs and 90% of those on treatment being virally suppressed (See Figure 1.1).

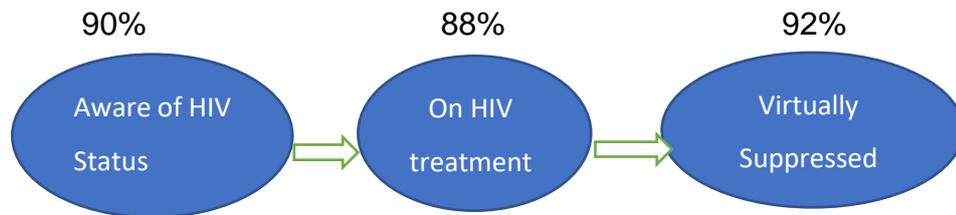


Figure 1.1 Malawi's HIV progress towards 90-90-90. Source: (Avert, 2019).

Also, Malawi has demonstrated a remarkable commitment to preventing transmission from mothers living with HIV to their child in recent years (Avert, 2019). Prevention of Mother to Child Transmission (PMTCT) is an intervention which aims to ensure that no child is born with HIV and it is an essential step to ensuring an AIDS free generation (Avert, 2019). The PMTCT initiative provides drugs, counselling and psychological support to help mothers safeguard their infants against the virus (United Nations Programme on HIV/AIDS, 2014). Malawi became the first country to implement the Option B+ approach to HIV management and treatment in 2011. This meant that all pregnant women living with HIV are offered antiretroviral treatment for life, irrespective of CD4 count (Avert, 2019). This has had a huge impact on the proportion of women living with HIV. Those who were diagnosed went from 49% to 94% between 2011 and 2018 (UNAIDS, 2019). This resulted in more than 95% of pregnant women being tested for HIV and more than 95% of those tested positive, were on ART.

There is evidence of growing positive trends in the adoption of safer behaviours by FSWs that may help to reduce HIV transmission further in Malawi. The aim of the HIV prevention programme is to change the individual behaviours of those at risk of infection to less risky behaviour by adopting consistent condom use (World Health Organization, 2012). For example, in 2018, 65% FSWs reported using a condom with their most recent client and 91% of FSWs diagnosed with HIV were on treatment (Avert, 2019). The HIV/AIDS prevention programmes in Malawi have included media, poster/pamphlets campaign and billboards (National AIDS Commission and Ministry of Health, 2003). The main government agency responsible for HIV/AIDS and STD is under the Ministry of Health and National AIDS Commission (UNAIDS, 2019).

Although Malawi has made impressive progress in responding to its HIV epidemic, several gaps in the country's response may lessen its ability to reach these goals (90-90-90). For instance, Malawi faces challenges regarding adequate funding for both its HIV response and its healthcare system in general, a challenge shared by many countries across sub-Saharan Africa (Avert, 2019). Greater effort is also required to support sex workers through comprehensive prevention programmes and campaigns that challenge stigma and discrimination. HIV-related stigma significantly impacts on the uptake of HIV testing, adherence to HIV treatment and follow-up (O'Brien *et al.*, 2009). Unless these groups' needs are properly addressed, significant gaps in Malawi's HIV response will remain. This study contributes to understanding the perception of FSWs and how these perceptions affected their access to healthcare.

1.2.2.1 Female Sex Workers and HIV prevalence

The proportion of FSWs with HIV in Malawi remains disproportionately high, globally, despite decades of prevention interventions (Lancaster *et al.*, 2016). This evidence is also supported by findings from a nationwide survey which revealed that FSWs have the highest prevalence rate of HIV among the general population (Government of the Republic of Malawi, 2015a). In 2018, 55% of sex workers were estimated to be living with HIV (United Nations Programme on HIV/AIDS, 2018).

Most of these women do not use condoms, especially with regular clients and, in cases where transactional sex or sex for gifts or for favours occur, because of power differences (MacPherson *et al.*, 2012). Power differences between FSWs and their clients creates an environment where FSWs are subjected to violence and sexual exploitation (MacPherson *et al.*, 2012; Rushing *et al.*, 2005). Other evidence reveals that, in some cases, the police officers are involved in the exploitation of these women by rounding them up and pressurising them into having sex in exchange for release without prosecution (Family Planning Association of Malawi, 2011; Theatre for a Change, 2012). The next section presents the description of the organisations. First is Family Planning Association of Malawi and the next is the Theatre for a Change, used as gatekeepers to accessing participants for both the first and second studies.

1.3 Description of the Family Planning Association of Malawi

Family Planning Association of Malawi is a prominent NGO in Malawi, implementing a variety of interventions aimed at sex workers and their clients. The main aim of the organisation is to give the population of Malawi, particularly young people, enhanced access to a wide range of SRH services. Its mission is to provide high quality and affordable, comprehensive, sexual and reproductive health rights (SRHR) information and services to young people, both women and men, regardless of their social status (FPAM, 1999). One of its key target populations are People Living with HIV and female sex workers in the 16 districts of Karonga, Nkhatabay, Mzimba North, Kasungu, Salima, Dowa, Mchinji, Lilongwe, Dedza, Balaka, Ntcheu, Neno, Machinga, Mangochi, Mulanje and Thyolo.

Furthermore, the organisation targets young people and reaches out to under-served rural communities, including sex workers. Family Planning Association of Malawi operates 53 mobile SRH facilities and 4 static clinics. Its community-based distributors/services (CBDs/CBSs) profile is also strong, with 65 additional delivery points. Family Planning Association of Malawi also networks with other SRH-focused groups, particularly in the fields of HIV and AIDS and youth issues. The vision of Family Planning Association of Malawi is for a healthy Malawian society, free of poverty, where young people, women and men enjoy basic sexual and reproductive health and rights. Moreover, the organisation aims to promote and protect sexual and reproductive health rights, prevent, and mitigate against HIV and AIDS and advocate for the elimination of all barriers to access to and provision of SRHS and information, with a special focus on young people, the hard to reach and under-served communities.

1.4 Description of Theatre for a Change

Theatre for a Change is an international organisation promoting the rights of women and girls in Ghana, Malawi, the UK, the USA, the Democratic Republic of Congo (DRC) and Bangladesh (Kapindu, 2015). Theatre for a Change was established in Malawi in 2007. Its headquarters are in Lilongwe and the organisation runs two main types of programmes: education programmes and

community programmes. Theatre for a Change also works alongside other organisations within Malawi and worldwide to promote behaviour and policy change to protect the most vulnerable and marginalised women and girls. Theatre for a Change has seven values, which include: creating a more equal society, serving the most marginalised people, equal participation in everything the organisation does, telling the truth and being honest about the strengths and weaknesses of its programmes, being true to all of its values (integrity) and encouraging people to take responsibility for their behaviour (Theatre for a Change, 2012).

Theatre for a Change uses a unique combination of drama and participatory learning to empower vulnerable and marginalised groups of women and girls. This is aimed at changing behaviour and policy. Theatre for a Change has two core objectives which focus mainly on behaviour change and advocacy. Theatre for a Change uses participants' experiences as the starting point for the process of change. Furthermore, Theatre for a Change equips the most marginalised and vulnerable people (e.g., sex workers and sexually abused girls) with the tools they need to make positive changes to their sexual and reproductive health. With regard to changing social attitudes through advocacy, Theatre for a Change uses interactive and legislative types of theatre to allow marginalised groups to tell their stories, in their own words, to people with whom they would never normally interact. It is through this approach that Theatre for a Change has helped marginalised people to have a voice and enabled those in power to find out what struggles are faced by vulnerable groups. The Theatre for a Change vision is to see vulnerable and marginalised groups empowered with the knowledge, awareness, and skills to transform their lives positively and to inform the lives of others at local, national, and international levels. The Theatre for a Change mission is to disseminate uniquely active and participatory tools that promote sexual and reproductive health and gender rights. The goal of the organisation is to improve the SRH of vulnerable and marginalised people.

Women and girls in Malawi (as in other countries across the sub-Saharan African region) face multiple barriers to good sexual and reproductive health services and gender equality (Baral *et al.*, 2012; Baral *et al.*, 2014; Ghosh & Kalipeni, 2005). Malawi demonstrates a significant need for this unique

combination of drama and participatory learning and the sustainable change that it seeks to bring about, which can positively transform the lives of vulnerable and marginalised women. Theatre for a Change provides both static and mobile health clinics to most of the 'hotspot' areas in Lilongwe and other parts of Malawi. Services provided include HIV counselling and testing, sexual and reproductive health services, and essential medication to the most at-risk people. Those benefitting from these services include FSWs, sexually exploited girls and their families, clients, brothel owners, the police, and the wider community in which they work. In order to provide a context for considering experiences, it is important to understand the laws of Malawi and in other countries regarding sex work. The next section presents the Malawi's wider context.

1.5 Background Information of Malawi

To understand the issues, that affect FSWs' experiences with access to healthcare in Malawi, it is important to understand the country's wider context including political and administrative distribution aspects. The economic, social, and education contexts as well as the healthcare system in Malawi are presented.

1.5.1 The country's profile

Malawi is a sub-Saharan country. It is landlocked and bordered to the north by Tanzania; to the east, south, and southwest by Mozambique; and to the west and northwest by Zambia (Figure 1.2). The country is 901 kilometres long and ranges in width from 80 to 161 kilometres. The country's total area is 118,484 km², of which 94,276 km² is made of land and about 475 km² is water (Government of the Republic of Malawi, 2012). The country has an estimated population of 18.6 million which is expected to double by 2038 (The World Bank, 2021).

Malawi is predominantly rural with only about 19% of the population in urban areas and 81% in rural areas (National Statistics Office, 2017). The Malawian people are of Bantu origin and are said to have migrated from the Congo basin between the 13th and 16th centuries (Kayambazinthu, 1998). The country is ethnically and linguistically heterogeneous, with 13 languages and varied

spoken dialects. The indigenous languages co-exist alongside the English language, which is regarded as the official language. The 'Chewa' are a dominant group and the 'Chewa' language has been used as the national language since 1968 (Kayambazinthu, 1998).



Figure 1.2 Map of Malawi demarcating its neighbouring countries (Adapted from World Map).

Source: www.nationsonline.org/oneworld/go/google: Map of Lilongwe- Nations Online Project.

Lilongwe is the capital city of Malawi with a population of just over one million and most of the residents in the city have come from neighbouring districts in search of jobs or to run small scale business. Figure 1.3 illustrates where most sex work is conducted in Lilongwe.



Figure 1.3 Lilongwe city where most sex work is conducted.

1.5.2 Administrative and political distribution

Administratively, the country is divided into three regions, the Northern, Central and Southern Regions, which are further divided into 28 districts (six in the North Region, nine in the Central Region, and 13 in the South Region). The districts are sub-divided into Traditional Authorities (TAs) presided over by chiefs. Each TA is made up of villages (the smallest administrative units) presided over by village headmen/women (Lowe *et al.*, 2010). Politically, Malawi is a generally peaceful country and has had stable governments since independence in 1964. One-party rule ended in 1993; since then multi-party presidential and parliamentary elections have been held every five years (The World Bank, 2021). The country is divided into four political regions: North, Central, South, and Eastern. Each district is divided into constituencies that are represented by Members of Parliament (MPs) in the National Assembly. The constituencies are divided into wards, which are represented by local councillors in District Councils (Lowe *et al.*, 2010).

1.5.3 The country's economic context

Malawi is one of the poorest countries in the world, despite making significant economic and structural reforms to sustain economic growth (The World Bank, 2021). The economy is heavily dependent on agriculture, employing nearly 80% of the population and is vulnerable to external shocks, particularly climatic shocks. In 2019, Malawi's economy grew by 4.4% in, a marked increase from 3.5% in 2018. This was a result of a rebound in agriculture production, as maize and key crops (apart from Tobacco) increased (The World Bank, 2021). Real gross domestic product (GDP) growth for 2020 was projected in September 2019 at 4.8% due to an expectation of the second consecutive year of strong harvests. However, fast economic growth has been interrupted by the COVID-19 (coronavirus) pandemic and continuing political uncertainty weighing on business activity and investment (The World Bank, 2021).

1.5.4 The country's social context

Poverty and inequality remains very high in Malawi with the figures showing that the national poverty rate increased slightly from 50.7% in 2010 to 51.5% in 2016 (The World Bank, 2021). According to the World Bank, poverty in

Malawi is driven by low productivity in the agriculture sector, limited opportunities in non-farming activities, volatile economic growth, rapid population growth, limited coverage of safety net programmes and targeting challenges (The World Bank, 2021). Most people live in very poorly structured temporary housing as seen in Figure 1.4.



Figure. 1.4 Lilongwe Urban poor in Chatata settlement near Kanengo in Lilongwe.

Despite the poverty and inequalities faced by the country's population, Malawi has made progress in building its human capital -the knowledge, skills, and health that people accumulate over their lives - in recent years. Life expectancy at birth is 63.7 years (National Statistics Office, 2019). The total fertility rate in 2015/16 was 4.4 children per woman, down from 6.7 in 1992.

1.5.5 Education context

The average literacy rate in Malawi is 64%, with notable gender, regional and residential differences (National Statistics Office, 2016). Literacy is higher among men (83%) than women (72%) (National Statistics Office, 2016). The median number of schooling years completed has increased significantly over time; in 1992, it was estimated at 0.4 years for women and 4.3 years for men compared with 5.6 years for women and 6.6 years for men (National Statistics Office, 2019). This indicates that Malawi has made significant improvements

in narrowing gender disparities in education, although more still needs to be done. The free primary school education policy introduced in 1994 has contributed to the country's achievement in gender parity in primary and secondary enrolments, with girls slightly surpassing boys (84% for girls as compared to 82% for boys). The 2015–2016 Malawi Demographic and Health Survey has demonstrated increased female empowerment over time. For example, the percentage of women involved in decisions about their health increased from 55% in 2010 to 68% in 2015–2016. Women's involvement in decisions about major household purchases increased from 30% to 55% over the same period (National Statistics Office, 2017). It is estimated that nearly three quarters of the population live below the poverty line, with most people surviving on less than one US dollar per day (Government of the Republic of Malawi, 2012).

The key issue in the social sectors remains unequal access of various groups of the population to basic human rights such as education, employment, and healthcare. However, there have been some marginal improvements in the situation for FSWs, but these factors remain powerful drivers of significant levels of poverty that can influence the prevalence of sex work.

1.5.6 Healthcare system in Malawi

This section provides an overview of the structures for health delivery in the health sector in Malawi, to contextualise understanding of FSWs and their experiences of accessing services. Health services in Malawi are provided by public, private for profit (PFP), and NGO health institutions. Each of these institutions has an actual or potential role to play in the health sector response to FSWs' health needs. The primary health sector responses focus indirectly on FSWs by dealing with health consequences in HIV, STI, family planning and reproductive health services. Despite the chronic shortages of skilled HCPs and other resources, health services are provided free at the point of use in all public health institutions (Government of the Republic of Malawi, 2011).

The public sector includes all health facilities under the MoH: district, town and city councils, the Ministry of Defence, the Ministry of Internal Affairs and Public

Security (Police and Prisons) and the Ministry of Natural Resources, Energy and Mining (Government of the Republic of Malawi, 2015b). The PFP sector consists of private hospitals, clinics, laboratories, and pharmacies. Traditional healers are also prominent and classified as PFP. The NGO sector comprises religious healthcare facilities and institutions, static and outreach clinics acting as statutory corporations and agencies and companies (Government of the Republic of Malawi, 2011). The major religious healthcare provider is the Christian Health Association of Malawi (CHAM), which provides approximately 29% of all health services in Malawi (Government of the Republic of Malawi, 2015b). However, most private and CHAM healthcare facilities charge user fees for their services. Table 1.1 shows the numbers of current health facilities in Malawi by type and ownership.

Facility Type	CHAM	Government	NGO	Private	Total
Dispensary	4	49	4	30	87
Health Centre	107	413	4	8	532
Health Post	18	132	2	0	152
Hospital	38	28	2	18	86
Private hospitals/clinics with admission services				37	37
Outreach Clinics	968	4,008	43	71	5,090
Village Clinic		3,542			3,542
TOTAL services provided.	1,135	8,172	55	164	9,526

Table: 1.1 Number of Health facilities offering services in Malawi.

Source: UNICEF Health Facility Mapping Report (2016).

Malawi's health system is organised at four levels: community, primary, secondary, and tertiary. These different levels are linked with each other through an established referral system. Community, primary, and secondary-level care falls under District Councils. The District Health Officer (DHO) is the head of the district healthcare system and reports to the District Commissioner, who is the Controlling Officer of public institutions at the district level.

1.5.6.1 Community level

At the community level, health services are provided by health surveillance assistants (HSAs) at health posts, dispensaries, village clinics and maternity clinics. Each HSA is meant to be responsible for a catchment area of 1,000 and, currently, there are about 7,932 HSAs supported by approximately 1,282 senior HSAs in post (Government of the Republic of Malawi, 2016). HSAs mainly provide promotive and preventive healthcare services through door-to-door visitations as well as village, outreach and mobile clinics with the assistance of community-based distributing agents, village health committees and other volunteers, mostly from NGOs (Government of the Republic of Malawi, 2011). The services include HTC and provision of immunisation services. The work of each HSA is supported by the health centre within the catchment area where she/he is based.

1.5.6.2 Primary level

At the primary level, health services are provided by health centres and community hospitals. Health centres offer outpatient and maternity services and are meant to serve a population of 10,000. Community hospitals are larger than health centres. They offer outpatient and inpatient services and conduct minor procedures. Their bed capacities can reach up to 250 (Government of the Republic of Malawi, 2016). Further, the primary level includes community initiatives, health posts, dispensaries, maternity facilities, health centres and community and rural hospitals. Health centres are responsible for providing both curative and preventive Essential Health Package (EHP) services. At a higher level, there are community hospitals (also known as rural hospitals), which provide both primary and secondary care. Each has an admission capacity of 200 to 250 beds. Although this level has the potential for HIV

prevention and treatment, in practice, the main role at this level is upward referral for specific HIV treatment. These levels of healthcare facilities are managed by clinicians and nurses/midwives as frontline service providers.

1.5.6.3 Secondary level

The secondary level of care consists of district hospitals and CHAM hospitals of equivalent capacity. Secondary-level healthcare facilities account for 9.5% of all healthcare facilities. They provide services to referral patients from health centres and community hospitals as well as providing both outpatient and inpatient services to the surrounding population. There is HIV management and treatment at this level and post-rape care is provided, including post-exposure prophylaxis for HIV infection.

1.5.6.4 Tertiary level

The tertiary level consists of central hospitals that provide services of referral cases within their respective regions. Central hospitals offer specialised services. Currently, there are four central hospitals, namely: Queen Elizabeth in Blantyre with more than 1250 beds, Kamuzu Central hospital in Lilongwe with a bed capacity of more than 1200, Mzuzu Central hospital with more than 300 beds and Zomba Central and Zomba Mental hospital with a bed capacity of more than 450 beds. A comprehensive referral system within the health services links these various levels of the delivery system. In practice, however, around 70% of the services they provide are either primary or secondary services because of the lack of a gatekeeping system (Government of the Republic of Malawi, 2016). These healthcare structures, their origins and development provide an important context for understanding FSWs' experiences of services and the potential changes in the nature of services that this thesis aims to explore.

1.5.6.5 Health sector reforms

The Malawi health sector has undergone reforms over the last few decades. For example, the provision of health services has been decentralised in accordance with the 1997 Decentralisation Policy and Decentralisation Act. The policy involves merging offices at the district level to establish one

administration. Understanding reforms to the sector is important to the current study because understanding the experiences of FSWs and any study recommendations that have emerged in respect of FSWs' access to healthcare services have to consider the service framework for delivery. The MoH at the national level is no longer responsible for service delivery because this has become the responsibility of the Ministry of Local Government and Rural Development (MoLGRD). The district assemblies are responsible for implementing services (Tolhurst, 2004).

The Malawi health sector has undergone reforms. For example, the provision of health services has been decentralised in accordance with the 1997 Decentralisation Policy and Decentralisation Act. The policy involves merging offices at the district level to establish one administration. Understanding reforms to the sector is important to the current study because any potential recommendations in respect of FSWs' access to healthcare services have to come within this framework. The MoH, at the national level, is no longer responsible for service delivery because this has become the responsibility of the Ministry of Local Government and Rural Development (MoLGRD).

Furthermore, health sector funds are managed by the District Health Management Teams under the responsibility of the local authorities. The local authorities follow District Implementation Plans (DIPs) to implement activities. The DIPs are involved in preparing and implementing local strategic planning statements as part of their strategic planning framework. The aim of each DIP is to enhance collaboration across the government, local councils, and private sector, with each having clear roles and responsibilities. Although the DIP has its benefits for long-term planning, the MoH is concerned that DIPs are not the greatest option for meeting the immediate needs of health services (Government of the Republic of Malawi, 2011). Figure. 1.5 (below) shows the governance of the MoH at both national and district levels.

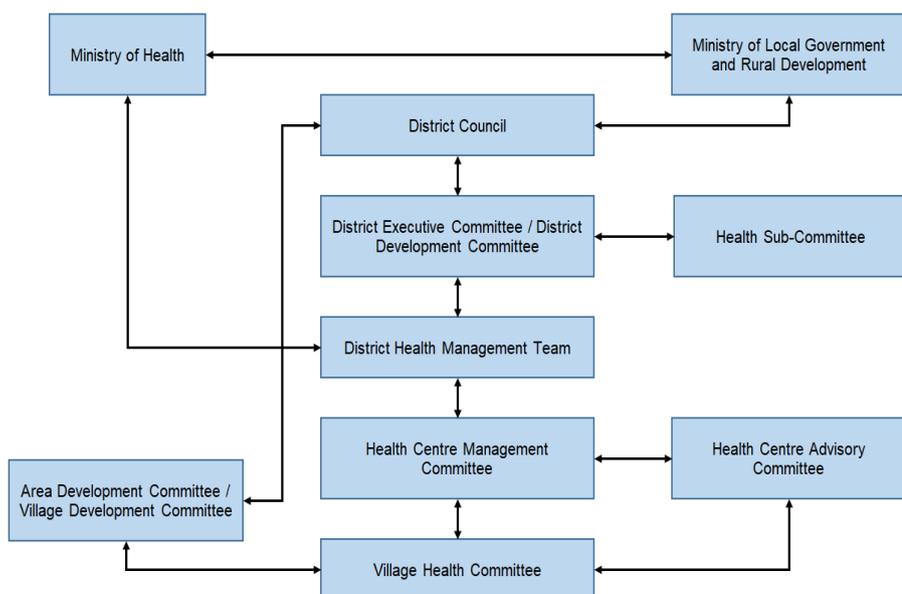


Figure 1.5: The health delivery system in Malawi adapted from Health Sector Strategic Plan (HSSP) 2011-2016 Moving towards equity and quality.

1.5.6.6 Health sector-wide approach, essential health package, and programme of work

In 2004, the MOH and development partners started implementing a health sector-wide approach (SWAp). SWAp integrates all vertical disease programmes and their finances into an EHP so that technical efficiencies can be achieved (Pearson, 2010). There is no ‘official’ definition of what the SWAp is, but it is a common framework for planning, budgeting, and performance. SWAp uses a basket funding approach where directorates plan their activities and draw funds from the pool (Pearson, 2010). It is guided by a six-year joint programme for work (POW) 2004–2010, the priorities of which revolved around the provision of EHP. EHP was a package of basic healthcare services meant to address health problems (including those faced by FSWs) that contribute to increased disease burden.

Eleven major conditions that predominantly affect the Malawian poor were targeted. Of relevance to FSWs is that these reforms were introduced as a way of ensuring equitable and accessible essential healthcare to the people of Malawi after acknowledging that investments made in the health sector had not produced significant gains in health status (Banda *et al.*, 2006). The

provision of EHP was seen as a way of enhancing achievement of health-related MDGs; it was a departure from the 'balkanisation' or 'segmentation' of the health sector by donors, which led to 'islands of excellence' operating within the public health structure (Pearson, 2010).

The introduction of EHP necessitated the implementation of a service agreement between the Government of Malawi and CHAM hospitals. This was done to promote the delivery of EHP and improve access to basic healthcare in rural areas. CHAM is quite critical of the delivery of EHP considering that most of their services are delivered in rural areas, where close to 85% of the Malawi population live (Banda *et al.*, 2006). In addition, the MoH implemented a comprehensive, country-wide and integrated routine Health Management Information System (HMIS) (Government of the Republic of Malawi, 2003).

The HMIS supports EHP and is an integral part of the national health system. The HMIS aims to provide relevant, reliable, updated, current, reasonable, and complete data for those managing health from community to central levels. The HMIS reports on EHP components in a way that allows it to act as an indicator of service delivery and utilisation throughout the public and formal health sectors in Malawi (Banda *et al.*, 2006). However, violence issues against FSWs and other women were not part of EHP, making monitoring of the problem in health services nearly impossible (Banda *et al.*, 2006).

This study's background information provides the researcher with insights on the experiences of FSWs both in Malawi and across the world; but also stimulated the researcher to conduct a more in-depth study into the experiences and perceptions of FSWs with access to healthcare and their experiences with healthcare systems in Malawi. Having provided the broader context to the study, the next section presents the study aims and objectives.

1.6 Aim and Objectives of the Study

The aim of this study was to explore FSWs' experiences with access to healthcare services provided by public and non-governmental organisation (NGOs) healthcare facilities in Malawi. The following were the research objectives that supported the study aim:

- (1) To explore the lived experiences of FSWs regarding using healthcare services.
- (2) To examine the lived experiences of FSWs living with HIV and those with unknown HIV status regarding access to healthcare services.
- (3) To explore female sex workers' perceptions of services provided by Family Planning Association of Malawi or Theatre for a Change and how their experiences affected their perception of the health services.

1.7 The Research Questions

- (1) What is the lived experience of female sex workers regarding using healthcare services?
- (2) What did female sex workers with unknown and known human immunodeficiency virus (HIV) status expect and what did they experience during their access to healthcare?
- (3) What is the lived experience of access to services provided by different organisations including Family Planning Association of Malawi and Theatre for a Change and how have these experiences affected their perceptions of the health services?

1.8 Rationale of the Study

FSWs worldwide have a very high HIV prevalence and face major challenges with regard to accessing healthcare services, with few services developed that address their needs based on studies that explored their experiences (Nnko *et al.*, 2019; Nyblade *et al.*, 2003; Stadler & Delany, 2006; Wagner *et al.*, 2010; Woodford *et al.*, 2014). The high burden of HIV among FSWs and the challenges they face accessing healthcare services is even more pronounced in regions with the highest prevalence, such as sub-Saharan Africa (Baral *et al.*, 2012). These challenges include the stigma associated with HIV and, in some cases, those due to infrastructure issues, such as the state of the roads, which makes it difficult to reach people in remote areas. Moreover, FSWs have high levels of morbidity related to their lifestyles and, therefore, need high-quality care (Day & Ward, 1997; Ward *et al.*, 1999). With the common

challenges to the legitimacy of FSWs receiving high quality services, the Global Network of Sex Work Projects (GNSWP) emphasised that FSWs living with HIV and those with unknown HIV status are all entitled to the same quality of sexual, reproductive, and HIV/STI services as everyone else (Global Networks for Sex Workers Project, 2018).

Unlike in developed countries, where people have easy access to healthcare through drop-in clinics, confidential clinics, and general practitioner surgeries (GPs), access to healthcare services in developing countries such as Malawi is still limited for those who are marginalised because of inadequate resources and scanty government support (Dhana *et al.*, 2014). However, several initiatives have been undertaken in Malawi to improve FSWs' access to SRH services. These include services offered by NGOs in outreach and mobile clinics dedicated to and targeted at FSWs and other vulnerable groups. Such initiatives aimed at improving access to SRH services are critical (Theatre for a Change, 2012; Vuylsteke *et al.*, 2001) because they offer FSWs choices about where, when, and how to seek care and present their needs. This study acknowledges the importance of NGOs, including Theatre for a Change, as sources of change in the way services are designed and delivered in Malawi.

This introduction has set out the national context of Malawi, the needs of FSWs and the limited development of health services to meet their needs. As the literature review demonstrates, in chapter 2, there is an important need to understand better FSWs' experiences and perceptions of healthcare as well as their needs and to utilise this knowledge in forming service recommendations.

1.9 Description of Proposed Study and Sample

This thesis consists of two main samples, the first focusing on FSWs' positive experiences, with data collection between January 2014-September 2017 (Study1) and the second focusing on a wider range of experiences of FSWs with access to healthcare, with data collection between October 2018-April 2021 (Study 2).

In Study 1, 45 FSWs from both Family Planning Association of Malawi and Theatre for A Change with different experiences were interviewed. 10 HCPs

from healthcare facilities named by FSWs as providing positive experiences were recruited, and six service providers from both Family Planning Association of Malawi and Theatre for a Change were interviewed. The project explored positive experiences of FSWs' experiences from the perspectives of both services users and service providers, in Malawi.

Following feedback from the thesis examiners of Study 1, the researcher realised that the project needed to be expanded to capture a more complete view of FSWs' experiences, including both positive and negative experiences and other factors that were important to understand FSWs' experiences and perceptions of what service delivery means to these women. This time of reflection and collection of additional data enabled the researcher to build a more comprehensive data set to underpin the discussion and recommendations.

In Study 2, a second period of data collection was undertaken, with face-to-face interviews with 25 FSWs, both living with HIV and those with unknown HIV status. These interviews explored FSWs' experiences and perceptions of access to healthcare services in Malawi through a broader experiential lens. FSWs were recruited through Theatre for a Change. FSWs aged 18 years and above, and those who had been engaged in sex work for more than six months, were asked to describe what it is like being a sex worker in their day-to-day lives. A full description of the recruitment and the interview processes including the data analysis are described in the methodology chapter (Chapter Four).

1.10 The Significance of the Study

Understanding the factors that contribute to FSWs' experiences and their perception of healthcare, can be useful in the efforts to improve service delivery and encourage FSWs accessing services, particularly in public health facilities. Evidence of the factors or issues may be helpful in planning and developing efficient health service policies that address FSWs' health needs. Developing the relevant training policies may increase knowledge of FSWs' health needs among HCPs and improve FSWs' experiences with accessing healthcare. FSWs experience violence throughout their life, increasing

awareness of the importance of the health needs of FSWs and its implications for public health can lead to the change of community attitudes towards sex workers and could help reduce violence as well as transmission of HVI and STIs. This study will further contribute to increasing the knowledge and understanding of FSWs' perceptions of the needed services and how they should be delivered in Malawi. The next section presents the structure of the thesis.

1.11 Organisation of Thesis

This section outlines the nine individual chapters of the thesis.

Chapter One provides an introduction to the study. It then provides a brief overview on what is currently known about FSWs including the laws affecting sex work and a brief description of Malawi's HIV Progress and public health implications for prevention and treatment of HIV. This is followed by a description of "Family Planning Association of Malawi" and "Theatre for a Change" (these are non-governmental organisations that were utilised to access participants for both studies). The country's profile including the healthcare systems is presented. A description of the organisations (Family Planning Association of Malawi and Theatre for a Change) is presented. Some background information Malawi's HIV Progress and public health implication for prevention and treatment of HIV, what is known about FSWs in Malawi, the background information on the Malawi country profile including the health systems. The chapter further presents a brief description of the process of recruiting participants (both FSWs and service providers), which is fully described in Chapter Four. Furthermore, this chapter outlines the study's aim, objectives, the research questions, the rationale, and the significance of the study. The restructured thesis sets the context for embedding my learning journey into the thesis. The chapter ends with a summary.

The general aim and objectives of the study are outlined, and research questions are formulated. The study's rationale is presented; the contribution of the study is highlighted, and the chapter concludes with the summary.

Chapter Two reviews the literature on factors affecting female sex workers' experiences and perceptions with access to healthcare. The literature review

methods for both Study 1 and Study 2 are presented, and definitions of the key terms used in the study are described. Findings of research studies about factors influencing FSWs experiences and service use are presented from many developing and developed countries including the context of Malawi.

Chapter Three presents theoretical perspectives that are relevant to utilisation and FSWs' experiences and perceptions of healthcare. Health promotion theories and models, such as the health belief model (HBM), the empowerment theory, the socio-economic model, the right to health framework, Dahlgren and Whitehead's social model of health and the socio-ecological models.

Chapter Four outlines the research methods and methodology for both Study 1 and Study 2. In this chapter, participants' recruitment, data collection technique, data sources, data collection procedure and methods of data analysis for both Study 1 and Study 2 are presented. Ethical considerations are highlighted, and methodological perspectives presented.

Chapter Five analyses and presents the findings from the Study 1 which explored positive experience of FSWs with access to healthcare from the perspectives of FSWs, HCPs and service providers from Theatre for a Change and Family Planning Association of Malawi.

Chapter Six analyses and presents the findings of the Study 2 which collected data from 25. Study 2 explored the experiences and perceptions of FSWs' with access to healthcare.

Chapter Seven provides more detailed discussion of Study 1 and Study 2 findings, and how they can be integrated and evaluates the research objectives.

Chapter Eight discusses the researcher's positionality and reflects on what the researcher has learned throughout her PhD journey.

Chapter Nine provides a general conclusion to the thesis, the strength and limitations of the study and recommendations for policy makers, education, practice, and further research.

1.12 Summary

This chapter introduces the major issues influencing FSWs' experiences with access to healthcare and Malawi's HIV Progress and public health implications for prevention and treatment of HIV. It provides background information on Malawi in terms of the political, economic, social, administrative and health service contexts, which are important to a better understanding of the wider context in which FSWs operate. The description of the proposed study and sample is presented in the next section before a final summary which signposts the thesis. The next chapter will present the methods and findings of literature review.

Chapter Two: Literature Review of the Factors Affecting Female Sex Workers' Experiences and Perceptions with Accessing Healthcare

2.0 Introduction

This chapter reviews the factors affecting FSWs' experiences accessing healthcare. The literature review methods presented, the first focusing on the systematic review method conducted in Study 1 and Study 2 focusing on a thematic literature review and definitions of the key terms used in the study are described. The chapter identifies the factors influencing experiences of healthcare services among FSWs in developing countries including Sub-Saharan Africa and, specifically, Malawi. This chapter describes the method used for the literature search, including search strategies to identify studies affecting FSWs' experiences with access to healthcare services. The next section presents the search strategies for the literature review.

2.1 Systematic Literature Review Strategies

The purpose of Study 1's project's systematic review was to explore FSWs' experiences with accessing sexual and reproductive health (SRH) services in the sub-Saharan African region and Asia. A comprehensive search for both published, peer-reviewed records and "grey literature" was conducted by searching key electronic databases, hand searching relevant journals websites, screening the reference lists of included papers and consulting experts in the field to check for completeness. There was no time limit on publications, the studies were from African and other developing countries. The search strategy addressed the following research questions that were outlined during Study 1:

- (1) What are the factors described by FSWs as determinants of sexual and reproductive health needs?
- (2) What are FSWs' perceived facilitators and barriers to accessing sexual and reproductive health services?
- (3) What are the factors that are seen by FSWs as influencing satisfaction with sexual and reproductive health services?

The next sections outline how the search strategy was conducted, how studies were selected, how quality was assessed and how data was extracted.

2.1.1 Data sources

A systematic search strategy was applied using a range of electronic databases for searching experiences of FSWs with access to healthcare. The databases included CINAHL (Cumulative Index to Nursing & Allied Health), MEDLINE (Medical Literature Analysis and Retrieval System), Science Direct, EMBASE (Excerpta Medica Database), WEB of Science. Study designs searched included qualitative, quantitative, and mixed methods studies relating to FSWs' experiences with access to SRH and HIV/STI utilisation among FSWs. The following MeSH terms were used for the literature search: sex workers or prostitutes or commercial FSWs and transactional sex workers; health service need and demand, accessibility to SRH or HIV/STI services; and experiences with SRH services, barriers/facilitators to access to SRH services, violence, empowerment, taboos, or culture norms. The terms were combined using the Boolean operators 'OR' and 'AND' * indicated truncation to capture variations in terminology.

In addition, search engines such as Google, Yahoo and Google Scholar were also used to locate grey literature to identify FSWs' experiences with SRH services related articles, news, and reports. This also included published and unpublished reports, policy, and government documents. Citation and hand searches were also made for related resources such as books, journals, newsletters, and editorials. World Health Organization (WHO), United Nations Fund for Population Activities (UNFPA), Ministry of Health of Malawi (MoH), and National Statistics Office (NSO) of Malawi websites were also searched to identify any relevant grey literature. Language restrictions on retrieved articles were applied limiting them to the English language.

2.1.2 Study selection

Inclusion and exclusion criteria were developed. The decision of whether to include a study was determined by reviewing the abstract and if abstract was not clear, the full paper was read. The studies were screened with support of the two supervisors of Study 1. The two supervisors also, each screened titles

and abstracts of 10% of random sample of the studies identified. The researcher screened the whole list of titles and abstracts. Studies were excluded that were not relevant based on the title and abstract. Studies that could not be confirmed as meeting the inclusion criteria (Table 2.1) were placed in the 'unsure' folder. A full text was obtained for studies included at abstract level and those that were in the unsure folder. Those that did not meet the inclusion criteria were excluded. A further screening was conducted on full text, and studies were excluded if they did not meet the inclusion criteria (see Figure 2.1). A colleague (AA) who was also a PhD student at the University of Warwick screened the same list of titles and the abstracts. There was a 99% agreement. Together with the first two Study 1 supervisors, we discussed the results of the screened papers and reviewed the eligibility criteria.

Empirical research both published and unpublished
AND
study participants were females aged 18 years and above
AND
the study explored FSWs perceived sexual and reproductive health needs
OR
the study investigated FSWs' perspectives of access to sexual and reproductive health services including HIV/STI
OR
the study identified factors described by FSWs as facilitators/barriers to access with healthcare services

Table 2.1 illustrates the Criteria for inclusion of studies.

The search criteria identified 1274 papers from databases and 26 records from other sources, there were 69 duplicates. Following removal of duplicates, 1231 records were screened with reference to the inclusion criteria (Table 2.1).

Results of the search were documented within the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram. (Figure 2.1).

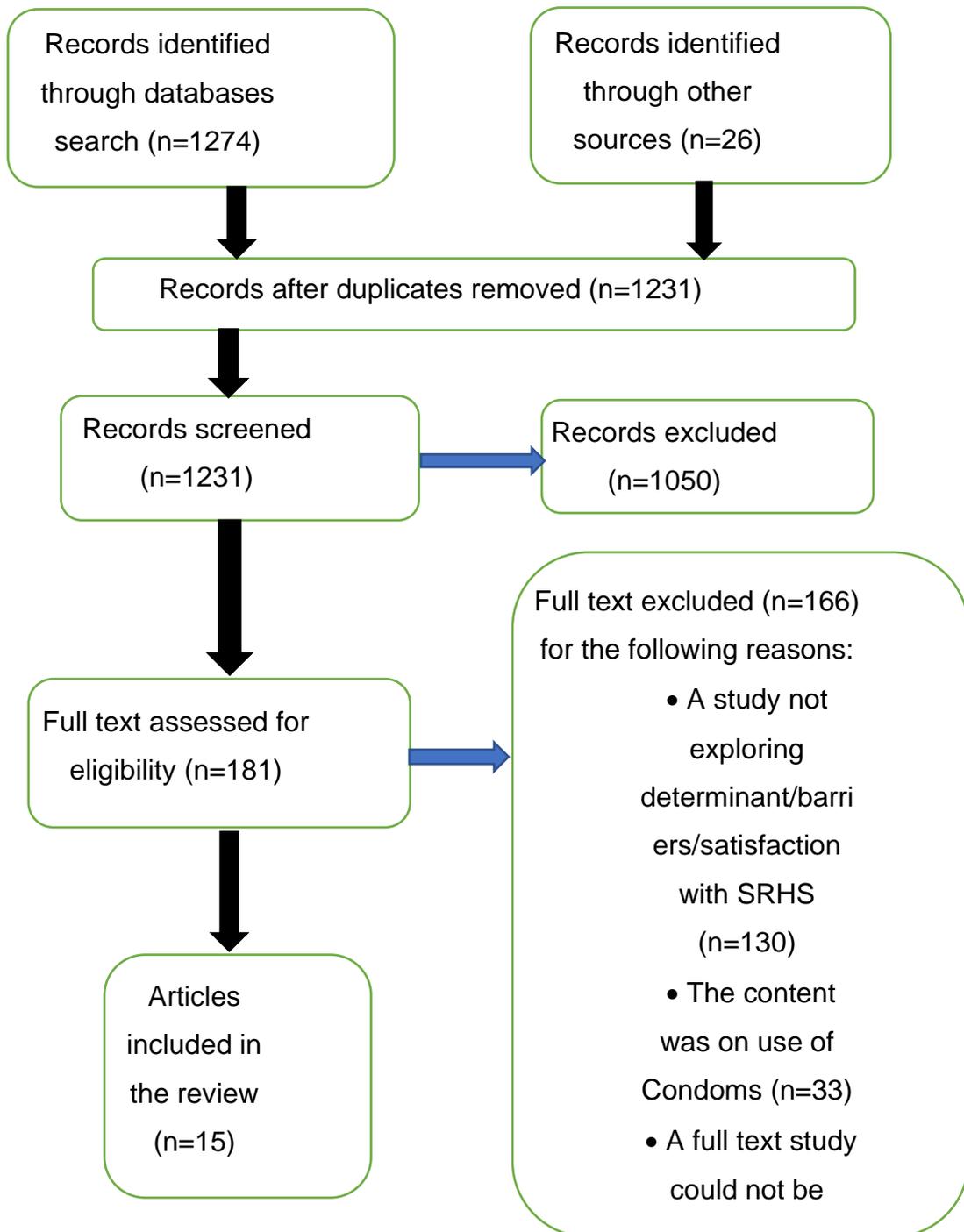


Figure 2.1 illustrates the process of screening the studies

2.1.3 Quality assessment

Quality assessment is a subjective process (Booth *et al.*, 2012). To minimise the subjectivity, the researcher assessed all included articles for their quality and 16% were checked by the two project supervisors. Four stages of assessing quality of the study namely: preliminary understanding –skimming or quickly reading to gain familiarity with the content and layout of the paper, comprehensive understanding, increasing understanding of concepts and research terms, analysis understanding, breaking the study into parts and seeking to understand each part the synthesis understanding – pulling the above steps together to make a (new) whole, making sense of it and explaining relationships (Greenhalgh, 2010).

The included qualitative studies were assessed for quality and appraised using a checklist for critical appraisal of qualitative study, Critical Appraisal Skills Programme: (CASP) as described by Centre for Evidence-Based Management (CEBM) (Greenhalgh & Brown, 2014). Quality assessment checklists are helpful in guiding the process of quality and relevance assessment. Included surveys and quantitative studies were appraised using the Crombie tools for a survey for Critical Appraisal of Surveys/quantitative (Booth *et al.*, 2012). Three core components of quality assessment were considered when reading the studies. These are: Are the results of a study true? (validity); what are the results? (reliability); and can I generalise the results? (generalisability).

2.1.4 Data extraction

Data extraction involved highlighting the relevant findings from included studies and recorded on a form designed by the researcher and agreed by the project supervisors. The form was designed specifically for this review and piloted on ten papers. Data extracted for analysis included verbatim quotations from participants. Only data that was relevant, or potentially relevant, to the review question was extracted and recorded into a standard grid. The next section describes how the thematic literature review was carried out during Study 2.

2.2 Thematic Literature Review for Study 2

The thematic analysis fits well in Study 2 which is informed by phenomenology in that the synthesis will focus on participants' subjective experiences, perceptions, and sense-making. This thematic literature synthesis was based on grouping of different literature sources by their topic and theoretical concept in order, by their relevance and importance to the study's topic (Warhurst *et al.*, 2017). Furthermore, thematic literature review was chosen for Study 2 because the method requires the researcher to analyse the topics, theories, and concepts central for this study (Alhojailan, 2012). The literature searched had no time limit of publications and literature from both developed and developing countries were included in the search. The aim of this study was to explore FSWs' experiences with access to healthcare services provided by public and non-governmental organisation (NGOs) healthcare facilities in Malawi. The following were the research objectives that supported the Study 2's aim:

- (1) To explore the lived experiences of FSWs regarding using healthcare services.
- (2) To examine the lived experiences of FSWs living with HIV and those with unknown HIV status regarding access to healthcare services.
- (3) To explore female sex workers' perceptions of services provided by Family Planning Association of Malawi or Theatre for a Change and how the experiences affected their perception of the health services.

2.2.1 Data sources

Similar strategies to the systematic literature review were used to search for studies relevant to Study 2. For example, a range of electronic databases were searched to identify studies that were relevant to FSWs' experiences with access to healthcare. The databases included CINAHL (Cumulative Index to Nursing & Allied Health), MEDLINE (Medical Literature Analysis and Retrieval System), Science Direct, EMBASE (Excerpta Medica Database) and WEB of Science. Study designs searched included qualitative, quantitative, and mixed methods studies relating to FSWs' experiences with access to healthcare

services including SRH and HIV/STI utilisation among FSWs. The following MeSH terms were used for the literature search: sex workers or prostitutes or commercial FSWs and transactional sex workers; health service need and demand; accessibility to SRH or HIV/STI services; experiences with healthcare services; barriers/facilitators to access to service/care; violence; empowerment; taboos; culture norms. The terms were combined using the Boolean operators 'OR' and 'AND' * indicated truncation to capture variations in terminology.

In addition, search engines such as Google, Yahoo and Google Scholar were also used to locate grey literature to identify FSWs' experiences related articles, news, and reports. This also included published and unpublished reports, policy, and government documents. Citations and hand searches were also considered for related resources such as books, journals, newsletters, and editorials. World Health Organization (WHO), United Nations Fund for Population Activities (UNFPA), Ministry of Health of Malawi (MoH), and National Statistics Office (NSO) of Malawi websites were also searched to identify any relevant grey literature. Language restrictions on retrieved articles were applied, limiting them to the English language. A total number of 2296 of studies were identified, of which 93 were retrieved from CINAHL, 87 from EMBASE, 1187 from MEDLINE, 182 WEB of Science and 747 from other sources.

2.2.2 Inclusion criteria

Articles were included if they met the following criteria: (1) qualitative and/or quantitative studies, or systematic reviews; (2) report on FSWs aged 18 years and above; (3) described at least one of the following: experiences with healthcare services, sexual and reproductive health services including HIV/STIs, healthcare providers attitudes toward sex work/workers, barriers/facilitators to access to service/care, violence, empowerment, taboos, or culture norms. Before presenting the literature review in detail, it was important to provide definitions for several concepts mentioned in the literature.

2.3 Definition of Terms Used

Female sex worker: There is lack of an agreed definition of 'sex worker. For instance, some studies have defined sex workers as people with as few as three sexual contacts per year, even where those involved do not identify those sexual transactions as commercial or even income generating (Overs, 2002). Overs defines a FSW as: a woman who receives money or goods in exchange for sexual services and who consciously defines those activities as income generating even if they do not consider sex work as their occupation (Overs, 2002). Other studies define a sex worker as a person who engage in sexual activity in exchange for payment (Weitzer, 2010). For the purpose of this thesis, a FSW is any woman aged 18 years and above who has self-declared herself as a sex worker and who has been in sex work for more than six months at the time of recruitment. The term "sex worker" recognises that sex work is work (Overs, 2002; Ward *et al.*, 1999) because it provides an income for the person performing sexual activities.

Commercial sex: The exchange of money or goods for sexual services. It always involves a sex worker and a client and it frequently also involves a third party (Overs, 2002).

Prostitution: Is generally considered to refer to a woman over the age of consent who willingly exchanges sexual services for money. However, the name prostitute encompasses much more. For instance, all forms of engagement in sex industry, be it pornographic actor or a call girl equal prostitution (Overs, 2002). The term prostitute/prostitution is only used in this thesis when referred to by a reference or by a participant's own words because prostitution has connotations of criminality and immorality.

Clients/customers or sexual partners: people (usually men) who pay cash or other resources for sexual services, either explicitly or within an agreed package that includes other services such as entertainment or domestic service.

Transactional sex: is defined as a relationship that involves the exchange of money or material goods for sex (Dunkle *et al.*, 2004). While this transaction has both an economic and sexual component, it is often differentiated from

formal sex work. This is because women engaging in transactional sex do not always view themselves as sex workers (Hunter, 2002).

Sexual and Reproductive Health Services: These services include provision of HIV/STI educational, counselling and testing services and treatment, contraceptives, as well as post-abortion and antenatal services. However, abortion services are not part of the services included in this study since abortion is illegal in Malawi unless performed for health purposes (JHPIEGO *et al.*, 2001).

Sexual and Reproductive Health behaviours: these include the use of modern contraceptives such as oral contraceptive pills, injectables, loops and implants, as well as both male and female condoms, prevention of unplanned pregnancies, prevention of HIV and knowledge of available SRH services (Bisika, 2009).

Healthcare facilities: hospitals and health centres/clinics that provide health-related services on a continuous basis and include mobile and outreach clinics because they were accessible to most of the participants of this study. A healthcare facility maybe owned by a government or non-profiting organisation or profiting business (Ahmadi-Javid *et al.*, 2017).

Healthcare professionals: these include nurses, midwives, doctors, clinicians and healthcare assistants and support workers.

Structural violence: a term for the social forces that exist which create conditions of harm that would otherwise be avoidable. In most cases, structural violence is perpetuated and manifested by unequal power and, ultimately, unequal life chances (Galtung, 1969).

2.4 Socio-cultural Factors Affecting Female Sex Workers' Experiences

The literature review identified a range of factors, including socio-cultural factors that affected FSWs' experiences of services. Previous sections have identified the context in which FSWs operate, as it is important to understand the concept of culture and norms and their implications on FSWs' perceptions and experiences. The term culture literally means lifestyle of people in a

community. Cultural values refer to shared understandings about what is important and about desirable ways of being, while social norms are the informal rules that shape understandings of acceptable behaviours and sanctioned pathways for achieving goals (Portes, 2006).

Literature in sub-Saharan Africa is full of evidence of the role of social and cultural norms that influence the experiences of FSWs in society (Bisika, 2008; Onelove, 2008; Theatre for a Change, 2012; Wanyenze *et al.*, 2017). The cultural norms include gender norms, gender relations and the gendering of social roles. In most countries in sub-Saharan Africa including Malawi, women who engage in sex work are perceived to be acting against gendered roles and expectations. These norms dictate that sex is an inappropriate topic for open discussion, especially outside marriage (Onelove, 2008). Both these gendered roles and expectations have an implication on FSWs' experiences. For instance, literature shows that cultural norms are more likely to influence stigma associated with sex work.

Other evidence also shows that some health workers become judgemental or hostile to unmarried people who come for SRH services (Chirwa & Kudzala, 2001). Therefore, the socio-cultural environment of many societies is the container of norms around what are acceptable and unacceptable sexual behaviours, especially for unmarried young women (Kurebwa, 2020). Those who do not observe these social norms may face social disapproval, stigma and discrimination which may effectively influence their experiences with healthcare services because these are matters of great cultural sensitivity (Munthali *et al.*, 2004).

2.5 Taboos Regarding Sex

Sex work is often seen as a social taboo, even though many millions of adults engaged in consensual sex work globally. When people think of sex work, in most cases they tend to associate a negative meaning to it (Seidman, 2003). In Africa, culture, religion and individual cultural norms dictate sexual practices (Gama, 2009). Many African societies frown on selling sex for money (Echezona-Johnson, Undated). However, in many African cities, sex work is rampant. Publicly, women will condemn the act but, secretly, they will engage

in sex work themselves as a source of money. As a result of these taboos and secrecies, HIV/AIDS continues to thrive uncontrollably in Africa (Echezona-Johnson, Undated).

Some social values also restrict parents' involvement in providing sex education and, instead, only allow traditional counsellors to provide sex and SRH information to young people (Kroger, 1998). Studies show that most parents believe that talking about sex with one's children is shameful and immoral (Limaye *et al.*, 2012). Most parents in Malawi believe that talking about sex with children encourages sexual activity among the youth (Limaye *et al.*, 2012). Moreover, even in situations where a parent may wish to give information about sex and sexuality to their children, culture dictates that parents are not the sex educators of their children (Limaye *et al.*, 2012). Instead, grandparents and traditional leaders are often given that responsibility (Stewarts *et al.*, 1998). In some societies young people are taught about sex when they are being initiated from the age of ten years and even younger (Gama, 2009).

Traditionally, premarital sex is not acceptable in Malawi and, in some cases, provision of SRH services to unmarried women is equated to promoting premarital sex which is a taboo (Chirwa & Kudzala, 2001). This, however, denies adolescents easy access to SRH information that could empower them for SRH promotion. While HCPs could be an alternative source of SRH information, several studies show that the cultural background of the HCPs also influences their role in providing SRH services to unmarried women including FSWs (Chirwa & Kudzala, 2001). Most HCPs promote the cultural norms at the expense of the unmarried women's SRH promotion especially if the health promotion activities are against their own cultural beliefs. Nevertheless, these norms are contradicted by others who believe that discussions about sexuality and sexual activity are inevitable (Wamoyi, 2008).

Overall, cultural taboos disempower unmarried women (FSWs) and promote stigma and discrimination among the women who engage in sex work. Therefore, the next sub-section presents an overview of how stigma and discrimination stemming from cultural beliefs influence FSWs' experiences and

remains a barrier to the utilisation of healthcare including SRH services among this group of women.

2.6 Stigma and Discrimination

Stigma and discrimination continue to inform legal, social, and cultural attitudes towards FSWs and remains a barrier to health, human rights, justice, and social support. Moreover, religion and culture being the major custodians of morality across the continent, its agents and institutions, tend to perpetuate the shaming and ridicule of women who dare to challenge the social norms (Boyle, 2018; Campbell *et al.*, 2005).

UNAIDS and the World Health Organization (WHO) cite fear of stigma and discrimination as the main reasons why people are reluctant to be tested, disclose their HIV status and take antiretroviral drugs (Avert, 2019). Stigma is a powerful tool to make people hide or stay quiet when they experience an injustice. Evidence shows a growing recognition across the globe about how stigma and discrimination towards sex workers play key roles in increasing the vulnerability of sex workers to HIV infection and the effort to combat HIV/AIDS (Hargreaves *et al.*, 2017; Nyblade *et al.*, 2017; Phelan *et al.*, 2008). Moreover, stigma and taboos towards FSWs discourages these women from disclosing their involvement in sex work to HCPs, which negatively affects their desire to seek healthcare services as well as their uptake of HIV prevention and treatment services (Hargreaves *et al.*, 2017; Pando *et al.*, 2013).

Stigmatisation is a complex process that contains cognitive, emotional and behavioural aspects (Bos *et al.*, 2008). According to Weiss *et al.* (2006), stigma involves the perception of being rejected, judged or blamed for something that is not a consequence of one's personal will. Moreover, stigma involves more general attributes about character and social identity. Individuals who experience stigma are more likely to have individual-based responses related to their identity (Dovidio *et al.*, 2000; Phelan *et al.*, 2008; Stafford & Scott, 1986). Evidence shows that there are two types of stigma that might be experienced by FSWs, namely, enacted and internalised stigmas (Hargreaves *et al.*, 2017). Enacted stigma involves negative attitudes that the general population might hold against certain groups of people or an individual that

may result in them experiencing negative attitudes and feeling discriminated against, whereas internalised stigmas refer to an individual's anticipated fear of societal attitudes and potential experiences of discrimination (Boyle, 2018; Hargreaves *et al.*, 2017).

Both enacted and perceived stigma have an influence on both the psychological and behavioural effects of an individual's health-seeking behaviour (Crocker & Quinn, 2000). Given that stigma is a social process that strengthens differences and supports inequalities (Raingruber *et al.*, 2010), FSWs attempt to hide their involvement in sex work as well as their HIV status for fear of litigation (Gilmore & Somerville, 1994). Studies have shown that sex work and HIV related stigma are major barriers for FSWs when accessing services (Wagner *et al.*, 2014). Available evidence also reveals that some HCPs' negative attitudes towards sex workers, especially those living with HIV, resulting from their socio-cultural and moral belief (Super & Harkness, 2002) deny FSWs' access to services (Hargreaves *et al.*, 2017; Zulliger *et al.*, 2015a; Zulliger *et al.*, 2015b). In addition, the common view of FSWs as 'vectors of disease' within public health systems has reinforced stigma among FSWs (Global Networks for Sex Workers Project, 2018).

Stigma creates an environment that condones human rights violations against FSWs (Karandikar & Prospero, 2010). Addressing stigma and discrimination is essential to ensuring the human rights of sex workers and people living with HIV. Stigma results in the creation of laws and policies that harm sex workers and people living with HIV while creating barriers to HIV prevention and treatment services (Global Networks for Sex Workers Project, 2020; Pando *et al.*, 2013). While an increasing number of countries are including people living with HIV in legal protections against discrimination, the fact is that even in places where people living with HIV are protected, such as Australia and Europe, stigma and discrimination persist and are a daily experience for people living with HIV (Global Networks for Sex Workers Project, 2020). FSWs frequently experience stigma and discrimination when accessing healthcare services. This stigma manifests in a form of denial or delay of healthcare service, breach of confidentiality, judgemental and stigmatising attitudes (Bos *et al.*, 2008; Global Networks for Sex Workers Project, 2020). Other studies have recommended that stigma reduction is a crucial component that should

be included in government plans for designing services for FSWs that can ease and improve accessibility and perception of the healthcare services (Grubb *et al.*, 2014).

This section has demonstrated that FSWs and those living with HIV experience multiple layers of stigma, resulting in severe discrimination and violations of their human rights. The negative impacts of stigma extend into all areas of their lives and occur at both individual and institutional levels. The next section outlines violence as a violation of human rights among FSWs and its implication on public health.

2.7 Violence Among Female Sex Workers and its Implication on Public Health

Violence against FSWs has been reported worldwide, both on a physical, sexual and psychological levels including, in extreme cases, murder both inside and outside the workplace (African Sex Workers Alliance, 2019; World Health Organization & UNAIDS, 2015). Physical and sexual intimate partner violence forms the largest proportion of abuse that FSWs are exposed to in their lifetime (Farley & Barkan, 1998). Other literature indicates that FSWs experience physical and sexual violence from both clients and police officers who patrol the streets and places of entertainment (Cooper *et al.*, 2004; Shannon *et al.*, 2008).

Violence can be in a form of structural or personal in nature. Structural violence is a term used to describe any constraint on human potential and the harm resulting from social exclusion, a limited social welfare state, institutional racism and lack of access to social goods and resources (Galtung, 1969). Structural violence occurs when it is born of policies within the system itself, such as those that affect life chances and describes the way socially constructed institutions stop individuals, groups, and societies from realising their full potential (Varga, 2012). Therefore, structural violence provides a useful framework to examine the way social, economic, and political factors affect a vulnerable population's use of healthcare. On the other hand, personal violence can amplify an environment of structural violence (Bent-Goodley, 2007). For instance, the violence experienced can potentially affect health-

seeking behaviours due to shame, guilt, stigma, fear, and distrust of a discriminatory health care system.

FSWs are recognised as the population group most vulnerable to HIV infection (World Health Organization & UNAIDS, 2015). Empirical evidence suggests that they are at a greater risk of experiencing violence and contracting HIV including STI (Beattie *et al.*, 2010). A nationwide survey conducted in Malawi among the general population, indicated that FSWs had the highest prevalence rate of HIV, estimated at 62 percent compared with 12 percent in the general adult female population (National Statistics Office, 2016).

Violence from clients and when being arrested are both strongly associated with HIV infection among FSWs (Beattie *et al.*, 2015). Clients may force FSWs into unsafe sex, for example, sex without condom, anal or oral sex while police arrests can increase vulnerability to HIV/STIs through multiple mechanisms (Decker *et al.*, 2014). For instance, the fear of a police raid or arrest can stop FSWs from carrying condoms and drive sex work underground, forcing FSWs to work in more perilous settings and to agree to unprotected sex (Beattie *et al.*, 2015). Also, because of the illegality of sex work in many parts of the world, FSWs often have to sell sex to clients in discreet and isolated spaces where they are less likely to be caught by the police. As a result of this isolation, FSWs are made more vulnerable to attacks by their clients. In countries such as Malawi, for example, sex work is 'illegal' and so, sex workers are not able to report violence carried out against them for fear of being arrested themselves (Mahapatra *et al.*, 2014; Sherwood *et al.*, 2015). Even in cases where violence against FSWs is reported, police are less likely to investigate attacks on sex workers because of the stigma that exists around sex work (Baral *et al.*, 2012; Wong *et al.*, 2011).

FSWs may also experience violence from HCPs when seeking healthcare services (Beckham *et al.*, 2015). Violence may include denial or delay of services or lack of confidentiality and, in some cases, abusive narratives from HCPs (Wagner *et al.*, 2014). Such types of violence may influence FSWs' negative perception of healthcare systems and, eventually, non-utilisation of the services. Other studies have shown that factors related to approachability, acceptability, availability, affordability and appropriateness of the services are

crucial in influencing experiences with access to services among FSWs in sub-Saharan Africa (Nnko *et al.*, 2019). However, violence perpetrated by HCPs, can act as barriers for FSWs to access services and perceive those services as not approachable or acceptable.

In many African countries, diverse conceptualisations of violence exist, as they do around the world (Kathewera-Banda *et al.*, 2005). Cultural explanations in many African countries including Malawi, define how violence is perceived and responded to among different groups of women (Heise, 1998; Kim & Motsei, 2002). Culture, traditional customs and norms that support male dominance have been blamed for the high prevalence of intimate partner violence in Africa (Bowman, 2003). For example, violence against women, including FSWs in Malawi and other African countries, is culturally perceived as individuals taking responsibility for their actions (Kanuha, 2002; Mkandawire-Valhmu *et al.*, 2009).

This literature review has revealed that FSWs' exposure to violence is multiple and pervasive, with important impacts on public health. Violence against FSWs can impede HIV prevention efforts and contravenes their human rights (Beattie *et al.*, 2010). Evidence has shown that physical and sexual violence against the sex worker community could potentially undermine the efforts of HIV prevention programming in multiple ways (Baral *et al.*, 2012; Beattie *et al.*, 2010; Mahapatra *et al.*, 2014). Moreover, FSWs who experience violence are more likely to report inconsistent condom use and inability to negotiate for condom use with sexual partners (Beattie *et al.*, 2010; Choi *et al.*, 2008; Pando *et al.*, 2013). HIV prevention interventions must explicitly address the links between the violence among FSWs and HIV risk behaviour to address the HIV pandemic. The following section presents an overview of Health-sector responses to FSWs' health needs and the public health importance of STI and HIV prevention in Malawi.

2.8 Health-Sector Responses to Female Sex Workers' Health Needs in Malawi

The Malawi government, through the MoH, has engaged other stakeholders and NGOs (e.g., Family Planning Association of Malawi, Theatre for a Change,

Linkage, Centre for the Development of People, Médecins Sans Frontières, Pakachere, Ukhondo) who are already doing extensive work with sex workers. However, because of limited resources, these stakeholders do not reach the wider population of sex workers; thus, many sex workers have no formal support (Theatre for a Change, 2012).

The MoH is responsible for raising the health status of all Malawians through the development of a health delivery system. This health delivery system should be capable of promoting health; preventing, reducing, and treating disease; and fostering the general well-being of all Malawians (Government of the Republic of Malawi, 2011). For the government to achieve its mandate, it collaborates with other relevant stakeholders, including CHAM and NGOs, all of which respond to FSWs' needs in various ways, to achieve its mandate (Government of the Republic of Malawi, 2011).

Evidence has shown that MoH has no specific, targeted interventions for FSWs but does provide condoms, STI and HIV diagnostic kits to NGOs that work with (Family Planning Association of Malawi, 2011). The MoH, through the National HIV and AIDS Unit, played the role of chair, in the development of the National Action Plan for Sex Workers, the task force that developed the plan (Government of the Republic of Malawi & National AIDS Commission, 2009). Despite these positive examples, the National Action Plan has not yet been implemented at the time of this study because of challenges relating to leadership in the area and the restrictions of the legal environment, which does not recognise sex work in Malawi (Family Planning Association of Malawi, 2011).

2.9 Summary of Literature Review

This chapter has described the literature review methods for both Study 1 and Study 2. The first section has presented the strategies employed in the systematic review which was initially decided upon by the researcher and the previous project supervisors as a stand-alone piece of study within the same Study 1. However, the examiners of this project recommended that it should have been part of the study and not a stand-alone piece of work. The second

part of this chapter presents the thematic literature review which was conducted in Study 2.

The review of the literature for both studies suggests that FSWs' experiences with access to healthcare is determined by several factors. These factors include socio-cultural norms and beliefs as well as the illegality of sex work in many countries around the world. The stigma and violence experienced by these women in both the healthcare system and the community are a result of societies' attitudes and beliefs about sex work. For several reasons, FSWs sometimes fail to seek support from the Police for fear of being arrested or even being raped by the police officers themselves (Onyango *et al.*, 2015). However, the review has also shown that there are some positive interventions designed by NGOs with the support from the government. The government of Malawi, through the MoH, has shown some interest in the welfare of FSWs but seems to lack full commitment, possibly due to the laws governing sex work and lack of political will. There is a gap in the literature not only regarding the importance of FSWs' experiences but also on how FSWs perceive the current healthcare services. There are some questions related to FSWs' perceptions and choices that have not been directly explored in past and current studies, hence, the need for this qualitative study.

Before describing the methods and methodology used in Study 1 and Study 2, the next chapter discusses theoretical perspectives of health service utilisation to understand better how theoretical frameworks are important for the understanding of the findings of Study 1 and Study 2 as well as developing theories.

Chapter Three: Theoretical Perspectives of Health Service Utilisation

3.0 Introduction

This chapter discusses the underpinning theories and models in the field of public health that contribute to understanding the variables and their interactions that affect health service utilisation, experiences, and perceptions. Theories and models are discussed and related to FSWs' experiences with healthcare services in Malawi. Theories and models can be applied to help understand FSWs' experiences and perceptions of access to healthcare.

As identified in the literature, FSWs' experiences and perceptions can be influenced by many factors including socio-cultural factors, for example, taboos, traditions, beliefs, and the economic, political, and physical environments. Using a theory or model may facilitate understanding of the social issues that affect FSWs' experiences and perceptions about access to healthcare. Theories and models may also contribute to policies promoting health service use through increased education, knowledge and awareness of individuals and communities including effecting changes in people's attitudes. The socio-ecological model of health service utilisation is the one mainly used to inform this study since this model addresses both individual and socio-ecological aspects influencing health service utilisation and experiences. However, using a single theory or model for this study may not be able to address all the issues associated with FSWs' experiences and perceptions of access to healthcare.

Selected theories and models are presented to provide an understanding of the social phenomena in FSWs' experiences and perceptions with access to healthcare. The health belief model (HBM), the empowerment theory, the socio-economic model, the access to healthcare framework, the Dahlgren and Whitehead's social model of health and the socio-ecological models are all described.

3.1 Theories and Models

According to Glanz *et al.*, (1996), a theory is a set of interrelated concepts, definitions and propositions that explain or predict events or situations by determining the relationships among variables (Glanz *et al.*, 1996). Kerlinger suggest that a theory is a set of interrelated constructs (variables), that present a systematic view of phenomena by specifying relationships among variables, with the purpose of explaining natural phenomena (Kerlinger, 1986).

Theories can be used to construct and develop principles and they become useful when applied to practical topics, goals and problems (Davies & Macdowall, 2006). In both Study 1 and Study 2, FSWs' experiences, and perceptions of access to healthcare in Malawi are explored. The theories and models described below could be useful in understanding study findings including factors affecting FSWs' experiences and perceptions with access to healthcare.

3.1.1 The health belief model

The health belief model is useful to understand people's health-seeking behaviour because this psychological model assumes that health service utilisation depends on individual beliefs and perceptions about health. The HBM, developed in the early 1950s, is one of the longest established theoretical models to explain health behaviour by understanding people's individual beliefs about health (Rosenstock, 1974). The HBM was developed in the United States (US) Public Health Service in an attempt to explain the lack of public participation in health screening and prevention programmes (Rosenstock, 1974). The model attempts to explain health behaviours in terms of individuals' decision-making about health-seeking and perception of a threat to their personal health and their belief that the recommended behaviour will reduce this threat (Janz *et al.*, 2002). Use of HBM in this study helps to understand FSWs' perceptions of access to healthcare decision making in health service (Rosenstock *et al.*, 1988) (see figure 3.1). These are outlined below.

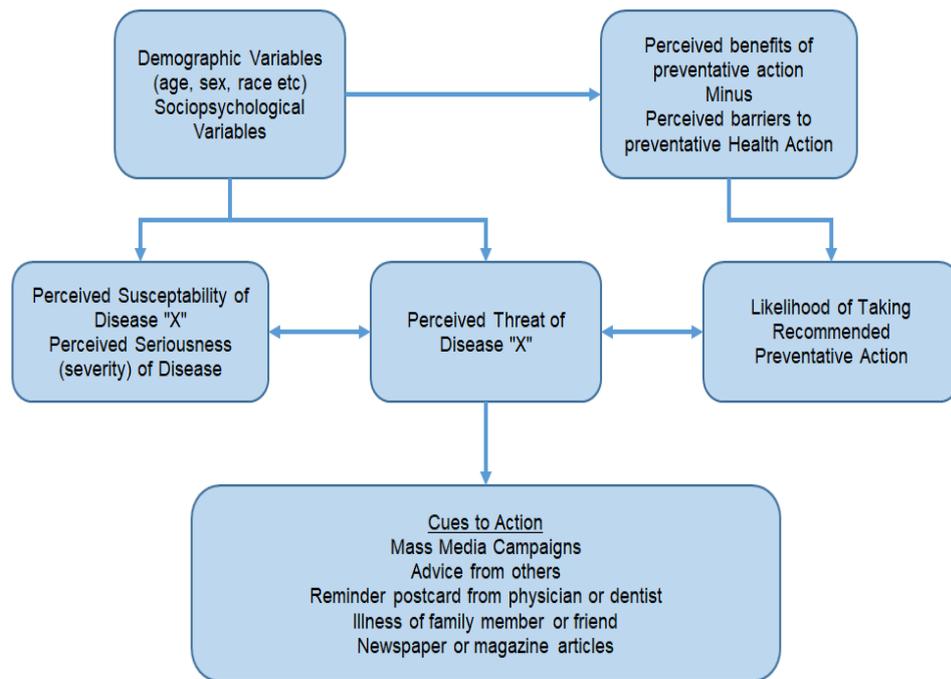


Figure. 3.1 Shows key variables of the Health Belief Model Source: (Janz & Becker, 1984).

3.1.1.1 Perceived threat

This consists of two parts: perceived susceptibility and perceived severity of a health condition. Perceived susceptibility: one's subjective perception of the risk of contracting a health condition. For example, FSWs' perceptions of the need to access service bases on their previous experiences with healthcare services. Perceptions and experiences may vary among FSWs.

Perceived severity: feelings regarding the seriousness of the health problem, which determines the level of motivation to act or not to prevent a negative health outcome (Rosenstock, 1966). If the outcomes of the health problem do not have a significant negative impact on an individual, they are less likely to act to avoid it (Carpenter, 2010). Only when they believe that they are susceptible to a particular negative health outcome are more likely to seek healthcare or adopt healthy behaviours (Norman & Bennett, 1996). FSWs may feel that their perception of healthcare does not matter if their condition is 'normal'. The outcome of the treatment also impacts on their experience with access to service.

3.1.1.2 Perceived benefits

Perceived benefits refers to the perception of the positive consequences that are caused by a specific action (Janz *et al.*, 2002). If the outcomes of the healthcare have a significant impact on individuals, they are more likely to act to avoid it getting worse. FSWs may feel that their perceptions and experiences of the health service does not matter if they perceive the outcome of accessing healthcare outweighs their experiences.

3.1.1.3 Perceived barriers

Barriers include the potential negative consequences that may result from taking particular health actions, including physical, psychological and financial matters (Nettleton, 1995). The poor financial situation of many families, lack of appropriate health services, distance from the health facility, distribution of health services and HCPs' attitudes all, significantly, affect use of services (Baral *et al.*, 2012; Scorgie *et al.*, 2011). FSWs may also be concerned about the potential negative impact of accessing healthcare from public health facilities, for example, fear of the negative attitudes of HCPs, lack of confidentiality and denial of treatment. Other factors like location of healthcare facilities and lack of resources also impact negatively on FSWs' experiences and perceptions of access to services.

3.1.1.4 Cues to action

Cues to action help trigger an individual's decision-making process and readiness to act towards the health behaviour (Rosenstock, 1974). Cues to action include external triggers such as mass media campaigns, reminder postcards from the physician and advice from others (Norman & Conner, 1993; Stacy & Loyd, 1990). For an individual to adopt a new health behaviour, they must perceive that the recommended health behaviour is potentially beneficial and will definitely prevent a negative health outcome (Conner & Norman, 1996).

3.1.1.5 Other variables

Other variables include demographic, socio-psychological and structural variables affecting an individual's perceptions and thus indirectly influencing health related behaviours (Rosenstock *et al.*, 1988). Infrastructure of health facilities, transportation, literacy status and community attitudes indirectly influence health service utilisation. The community's view of sex work may influence FSWs' experiences with access to healthcare.

The discussion of HBM suggests that individual perceptions influence FSWs' access to healthcare. Furthermore, this model helps to understand the psychological factors affecting healthcare access according to individual experiences and perception of that experience in relation to healthcare services.

3.1.2 The empowerment theory

Empowerment is both a value guidance for working in the community and a theoretical model for understanding the process and the seriousness of efforts to apply control and influence over decisions that affect one's life, organisational functioning and the quality of community life (Zimmerman, 2000). Empowerment theory seeks to challenge systems that prevent people having their needs met and focuses on helping marginalised people to improve their lives both at individual, interpersonal, organisational and political power levels (Kuokkanen & Leino-Kilpi, 2000). These levels are interconnected.

3.1.2.1 At individual level

Empowerment at the individual level usually happens as a result of participating in the work or activities within one's community or organisations. The individual level of empowerment is also called psychological empowerment, meaning an individual's perceived strength, efficacy, and understanding of their socio-political surroundings (Greene *et al.*, 2005; Zimmerman, 2000). Within psychological empowerment there are three dimensions including intrapersonal, interactional, and behavioural empowerment.

3.1.2.2 At intrapersonal level

The intrapersonal dimension deals with one's self-esteem, their motivations, and their perceived ability to affect the things in their lives. The interactional dimension covers one's ability to examine their socio-political setting and also to understand when a conflict is worth taking and how to reach certain goals. The behavioural dimension is used to discuss one's actions to represent their own or their community's interests (Zimmerman, 2000). According to Zimmerman (2000), an individual is always aware of his/her options between fighting and giving up, although the decisions may not be always right (Zimmerman, 2000).

3.1.2.3 At the organisational level

An organisational empowering process operates with shared responsibilities and leadership, with a supporting atmosphere and offers possibilities to take part in decision-making (Greene *et al.*, 2005). Empowered organisations are effective and can usually reach their goals and excellently mobilise resources. They are able to influence policy decision-making by successfully advocating for their chosen topics (Zimmerman, 2000).

When discussions of empowerment relate to FSWs' experiences, it is crucial to look at empowerment that goes beyond mitigating the negative aspects of a situation by searching for those that are positive (Zimmerman, 2000). Empowerment of FSWs should be seen as increasing the capacity of these women to take control of their circumstances, exercise power and achieve their own health goals, and the process by which, individually and collectively, they are able to help themselves and others in similar situations to maximise the quality of their lives (Adams, 2008). For instance, FSWs should be supported to organise themselves into small groups where they can share and discuss their experiences and come up with workable suggestion to improve their life experiences.

Empowerment in this study refers both to the capacity of individuals (FSWs) and to their decisions to make healthy choices regarding access to healthcare services. Moreover, empowerment-based health interventions have been implemented in gender empowerment and other participatory programmes by

empowering individuals with knowledge and skills to enhance their control over their sexual and emotional relationships (McWhirter, 1994). In fact, empowerment through participatory action with others is, in fact, one of the most effective ways to master one's fears, obsessions and disapproval of self or others (Wallerstein, 1993). It has many important individual benefits, including greater health, wellbeing, life satisfaction and happiness (Laverack & Wallerstein, 2001).

Such empowerment can enable FSWs to develop positive and adaptive behaviours that help them make decisions and manage the challenges they face in their day-to-day lives (Gage, 1998). For example, when FSWs are empowered with the knowledge of how to prevent HIV/STIs, they may be better able to negotiate condom use as a safety precaution in all their sexual relationships (Matovu & Ssebadduka, 2013).

3.1.3 The socio-economic model

Most public health problems involve the socio-economic, multifaceted nature of most social problems in the field of health (Suchman, 1968). Hence, social problems, in general, are interrelated (e.g., poverty, sex work and HIV/STIs). They are not separate problems; they need to be looked at in combination. For instance, sex work and HIV/STI are rarely an individual's problem; they almost always involve the important aspects of family and society. The sex work industry presents an obstacle to public health's aim to provide 'health for all', regardless of personal circumstance (Binns & Low, 2015). The low socio-economic status of women and gender inequalities are also driving the HIV epidemic in Malawi. Power relations between men and women are reinforced through sex, with men usually dominating and initiating sex (Gama, 2009).

The majority of people who engage in commercial sex work come from disadvantaged and poor backgrounds, minority groups and the ranks of the mentally ill (Binns & Low, 2015). In countries where HIV is endemic and access to treatment is limited, the risk of acquiring this infection represents the greatest risk associated with selling sex (Jeal & Salisbury, 2013). For example, despite being aware of the cause/risk of HIV/STIs, some FSWs tend to think of the economic benefits of having sex without a condom (i.e., men offer to pay

more for sex without a condom). It is such practices that predispose FSWs to high levels of HIV/STI transmission risk.

Further, FSWs often face other health conditions associated with lower socio-economic status (e.g. TB, contraceptive needs, unplanned pregnancies and unsafe abortions, drug use, alcohol dependence) and the ever-present risk of physical and sexual violence (World Health Organization & UNAIDS, 2015). Besides these, in most sub-Saharan African societies, the use of coercion by males is a normal practice in sexual relationships (Wood & Jewkes, 1997). Thus, to minimise risk to FSWs and to reduce transmission rates, it is important that public health services provide education and prevention and treatment services. This is made more difficult in situations where sex work is illegal, and workers are forced into locations that they regard as safe but that are difficult for HCPs to access.

The evidence indicates that the WHO and most public health organisations support the decriminalisation of sex workers to improve their access to public health services and to stop FSWs from living in fear of violence (Binns & Low, 2015). Moreover, many organisations have endorsed the so-called Swedish or Scandinavian model, which prohibits males from buying sex. However, the model has faced many challenges and has been criticised and viewed as a potential source of the increase of 'sex tourism' to other countries (Binns & Low, 2015). The next section presents the conceptual framework of access to healthcare which is important because it recognises access as the outcome of the healthcare of processes involving the interconnection between the characteristics of the health facility services delivery and FSWs' experiences and perceptions.

3.1.4 A conceptual framework of access healthcare

The right to access healthcare is central to the performance of healthcare systems around the world (Levesque *et al.*, 2013). Other authors view access as an attribute of health services, noting the fact that services can be accessed or utilised by those requiring care (Salkever, 1976). According to Levesque *et al.*, access is the opportunity to identify healthcare needs, to seek healthcare services, to reach, obtain and use health care services and to actually have

the need for accessing healthcare fulfilled (Levesque *et al.*, 2013). Levesque *et al.* (2013) identified relevant determinants that can impact on access from different levels including health systems, institutions, organisations and health service providers (Levesque *et al.*, 2013). The determinants include approachability, acceptability, availability and accommodation, affordability, and appropriateness. Five corollary dimensions of abilities include: ability to perceive; ability to seek; ability to reach; ability to pay and ability to engage (see Figure 3.2). These domains are described below.

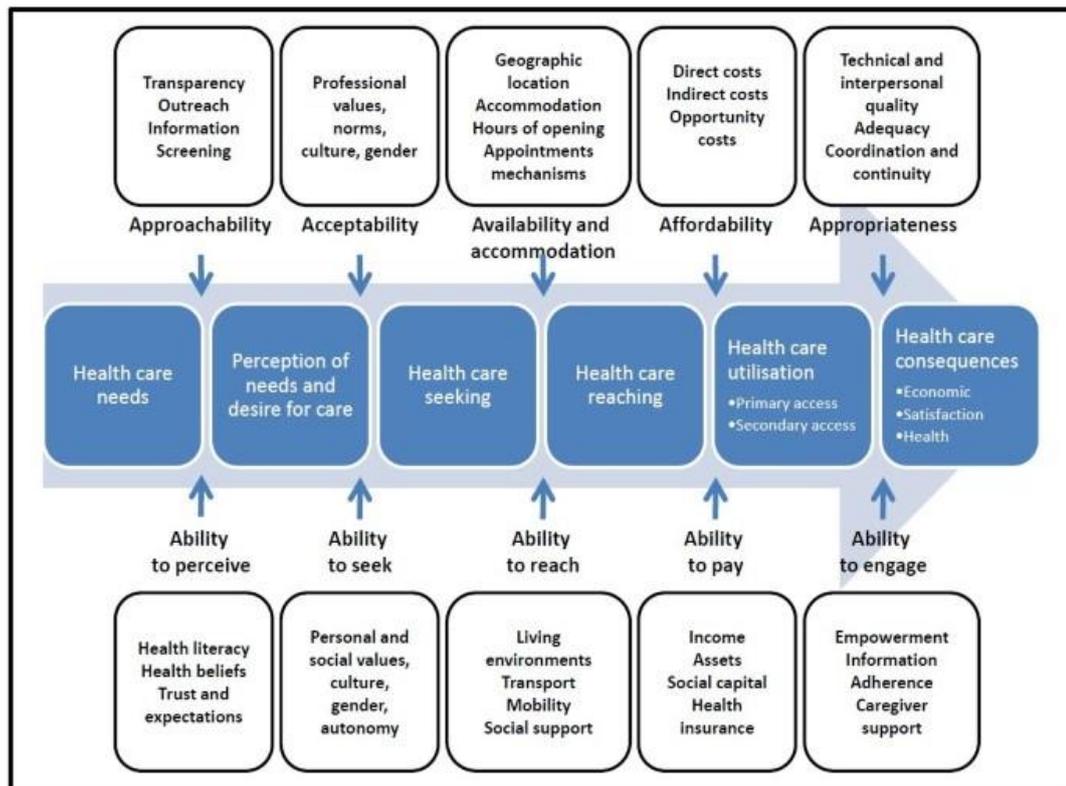


Figure 3.2 A conceptual framework of access to healthcare (Levesque *et al.*, 2013).

3.1.4.1 Approachability

Approachability relates to the fact that people facing health needs can actually identify that some form of service exists, can be reached, and have an impact on their health. Services can make themselves more or less known among various social or geographical population groups. Levesque *et al.*, (2013) however, stated that for someone to perceive the need for care is crucial and is determined by having information about health, knowledge about health and beliefs related to health and sickness.

3.1.4.2 Acceptability

Acceptability relates to those cultural and social factors determining the possibility for people to accept the aspects of the service (e.g., the sex or social group of providers, the beliefs associated with systems of medicine) and the judged appropriateness for the persons to seek care. For example, cultural norms that prescribe that women not to have sex outside marriages would reduce women's acceptability to seek HIV or STIs treatment if HCPs hold strong beliefs about cultural norms. In other cases, it might be that some services are inequitable in the way they are organised, making them unacceptable to some sections of the very communities that they are intended to serve (Whitehead, 1992). For example, when STIs or HIV services are provided within the public area, most unmarried women, including FSWs, may not feel comfortable to access such services. This relates to the challenge of ensuring that care meets the needs of different cultural, socioeconomically disadvantaged, and vulnerable populations. Because different groups may judge appropriateness and quality differently (Harris *et al.*, 2004), this is an important challenge for FSWs.

3.1.4.3 Availability and accommodation

Availability and accommodation refers to the fact that health services and HCPs can be reached both physically and in a timely manner (Frenk, 1992; Whitehead, 1992). It also relates to characteristics of HCPs providers and modes of services delivery, availability of transportation, occupational flexibility, and knowledge about health services that would enable individuals to physically reach HCPs and the services (Frenk, 1992). Services provided at certain times could be an example of these. In such cases FSWs maybe restricted to access services because of the nature of their work as most of them work during the night and sleep during the day.

3.1.4.4 Affordability

Affordability reflects the economic capacity for people to spend resources and time to use appropriate services. For example, travel time and the opportunity costs linked to it, patient's income, perceived quality of care and HCPs attitudes (Salkever, 1976). In cases where healthcare facilities are far from

where an individual lives or if one has to pay for a service, some people including FSWs may be restricted from accessing care because they may not have the capacity to pay for it.

3.1.4.5 Appropriateness

Appropriateness refers to how the services meet the clients' needs. This includes what health services are provided and the way in which they are provided (Frenk, 1992). Levesque *et al.* emphasise that one should not have access to healthcare based on geographical and organisational availability and affordability alone. One should be able to choose acceptable and effective services (Levesque *et al.*, 2013). In this case, FSWs may choose accessing healthcare where they perceive that the care, they are accessing is provided in the way that will address their needs. Access to optimal care, ultimately, requires FSWs to be fully engaged in care to improve their experience and perceptions of healthcare service delivery. The next section describes Dahlgren and Whitehead's social model of health.

3.1.5 Dahlgren and Whitehead's social model of health

The model, developed by Göran Dahlgren and Margaret Whitehead (1991), maps the relationship between the individual, their environment and health. The Dahlgren and Whitehead social determinants of health framework is a widely cited model of the main determinants of health and a recognised framework which identifies the range of social determinants (see Figure 3.3). The individual behaviours, social, cultural, environmental, and economic conditions are important factors which influence people in the use of health services. They are also important because they set the conditions for the health of individuals, communities, and populations. If the social determinants of health are not distributed fairly, they can lead to health inequities.

Figure 3.3 shows individuals are placed at the centre and surrounding them are the various layers of influences on health, such as individual lifestyle factors, community influences, living and working conditions, and more general, social conditions. These conditions can either promote one's health or damage it. Individuals are greatly affected by the people one associates with and the norms that one follows that represent their community.

The next layer to this is the influence created by the society and the community that helps in providing the mutual support for the community members within any unfavourable conditions. However, they can also provide no support or have a negative influence on health seeking behaviour. For example, FSWs may have difficulties accessing support from the community because of the negative attitudes of the community towards sex work.

The third and the last layer includes structural factors such as working conditions, housing, having access to provisions and services of those facilities that are essential and have an influence on service utilisation. These structural factors have the potential to influence inequalities in healthcare utilisation which are both unfair and avoidable. Such inequities are caused by unhealthy public policies and structural factors (Whitehead *et al.*, 2004).

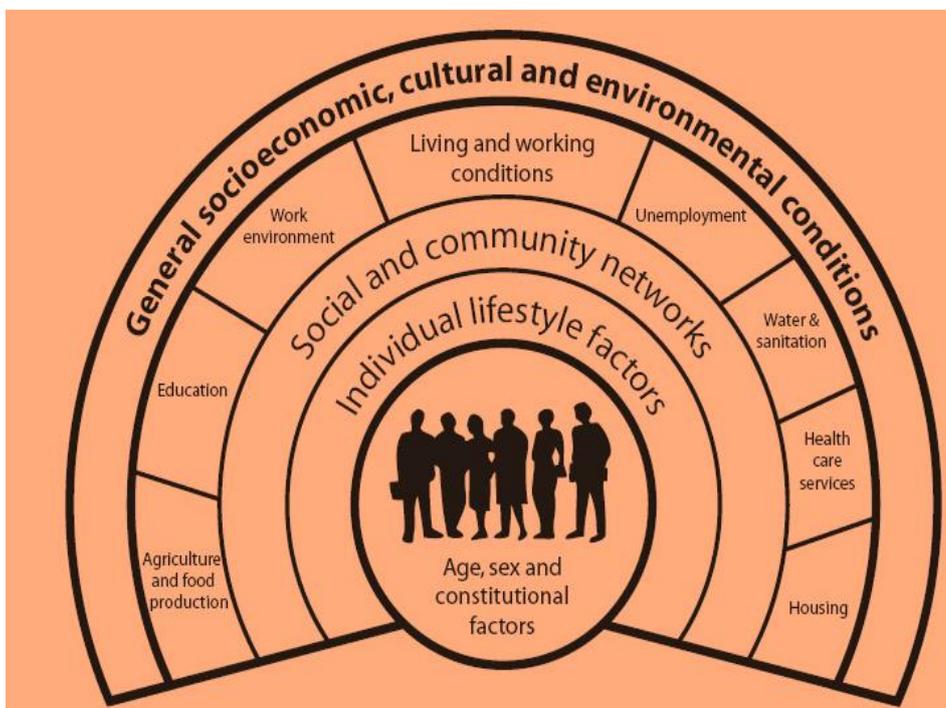


Figure 3.3 Illustrating *factors influencing healthcare access and outcome*, Source: (Dahlgren & Whitehead, 1991).

Some of the factors in Dahlgren and Whitehead’s social model overlap with the socio-ecological model of health service utilisation that is described in the next section.

3.1.6 The socio-ecological framework models

The conceptual framework provided by the socio-ecological model of health service utilisation interactions (McLeroy *et al.*, 1988) is also relevant to both Study 1 and Study 2 which explored FSWs' experiences with healthcare services. The model addresses both individual behaviour, the social environment, the influencing factors for healthcare utilisation and behaviour change at multiple levels (McLeroy *et al.*, 1988; Poundstone *et al.*, 2004). The socio-ecological model contextualises individuals' behaviours by using different dimensions. The dimensions include (1) intrapersonal factors; (2) interpersonal factors; (3) institutional factors; (4) community factors; and (5) public policies relevant to the service (McLeroy *et al.*, 1988) (see Figure 3.4).

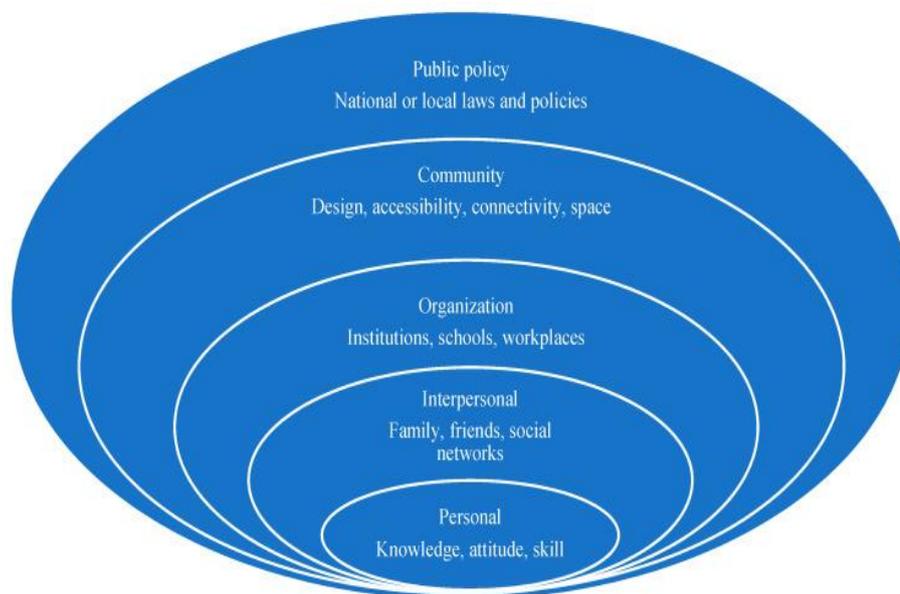


Figure 3.4: The social ecological model adapted from (McLeroy *et al.*, 1988).

In the socio-ecological model interpersonal behaviour, community perceptions and public health policy are all important factors influencing change in people's behaviour. This model further assumes that appropriate changes in the social environment may affect changes in individuals' behaviours (McLeroy *et al.*, 1988). All five dimensions in the socio-ecological model play important roles in FSWs' experiences and perceptions of healthcare. For example, FSWs' perceptions of service delivery and the community's (including HCPs) attitudes towards FSWs may influence health seeking behaviour. The dimensions in Figure 3.4, operating at different levels are now further discussed.

3.1.6.1 Intrapersonal factors

Individual characteristics such as age, educational level, knowledge and awareness and/or intention to comply with certain behavioural norms influence healthcare access (McLeroy *et al.*, 1988). Changing individual perceptions about health seeking behaviour can help increase healthcare use (Parker & Aggleton, 2003). For instance, the services provided by NGOs including Theatre for a Change and Family Planning Association of Malawi have led to an increase in positive perceptions of health services and improvements in health-seeking behaviour among FSWs (Kapindu, 2015).

3.1.6.2 Interpersonal factors

An individual can belong to one or more social groups and, through these different social networks, people acquire norms and such groups can have a significant effect on changing people's health related behaviour and their perceptions about access to health services (McLeroy *et al.*, 1988). For example, in Malawi, and other parts of the world, FSWs are organising themselves into social networks and such networks have a significant role in effecting change in health seeking behaviour and community's perceptions of FSWs (African Sex Workers Alliance, 2019; Global Networks for Sex Workers Project, 2018).

3.1.6.3 Organisational factors

Organisational characteristics within the socio-ecological framework are influential factors in behavioural change (Elder *et al.*, 2007). Different organisations like schools, workplaces, religious institutions, may have negative or positive influences on the health of their members because they might have social and cultural norms set up for the groups. In most cases the organisation may provide a platform for building social support for a desirable change in behaviour. However, the emphasis of the model is on long-term behaviour change support among individuals. For example, in Malawi, non-governmental organisations provide desirable support for FSWs but are not enough to cater for all sex workers and, in most cases, services are provided in town centres thus affecting support for the rural FSWs (Family Planning Association of Malawi, 2011; Theatre for a Change, 2012).

3.1.6.4 Community factors

Community organisations such as youth, women, prayer, or dance groups in the same community can have different perceptions towards healthcare delivery, thus affecting their access. Informal social networks and neighbourhood communities may be useful in providing social identity and resources (McLeroy *et al.*, 1988). Communities can also determine the relationships among organisations within a geographical area or political constituency, for example, village committees, political committees or religious-based committees (Elder *et al.*, 2007). In most cases, these groups play an important role in defining the community health problems, planning health promotion programmes and activities as well as in allocating resources because of the coordination and collaboration among the groups (McLeroy *et al.*, 1988).

3.1.6.5 Public policy

Delivery of public health services focuses on the health of the wider population (McLeroy *et al.*, 1988). In Malawi, despite the chronic shortages of skilled HCPs and other resources, health services are provided for free in all public health institutions (Government of the Republic of Malawi, 2011). The MoH, at the national level, is no longer responsible for service delivery because this has become the responsibility of the Ministry of Local Government and Rural Development (MoLGRD) (Tolhurst, 2004). This shift in responsibility was aimed at equal distribution of resources. In the same year (2004), the government of Malawi, through the Ministry of Health, integrated all vertical disease programmes (e.g., Malaria, Diarrhoeal diseases, Tuberculosis, Schistosomiasis and HIV) and their finances into an EHP so that technical efficiencies could be achieved (Pearson, 2010).

These policies have been mainly focused on control and reduction of morbidity and mortality from these diseases and many other infectious diseases. Success in disease control has led to the development of public awareness campaigns. Increasing public awareness of the control of disease and health lifestyle is important as part of the policy development process (McLeroy *et al.*, 1988). However, these policies fail to address those gender and cultural issues

which particularly affect FSWs' experiences. The next section presents a summary of the theories and frameworks described in this chapter.

3.2 Conclusion Remarks

A review of the theories and frameworks has shown that there is, currently, no single standard framework which can be used to explore FSWs' experiences and perceptions with accessing healthcare. Each of the theories and conceptual frameworks has valuable workable components as well as limitations. Although HBM attempts to explain health behaviour in terms of individual decision-making about health seeking and perceptions of threats to their personal health, the theory only uses certain components to describe the experiences and perceptions of FSWs. However, for one to be able to make a decision about their health and whether to seek help, they need to be empowered with knowledge. Thus, empowerment models also play an important part in FSWs' experiences and perceptions with accessing healthcare. On the other hand, the socio-ecological model addresses both individual and socio-ecological aspects to influence an individual's utilisation and experiences with healthcare. Hence, these theories are fundamental as they guide the exploration of FSWs' experiences and perceptions with accessing healthcare and each can be applied in their own unique context. The next chapter outlines the research methods and methodologies utilised in Study 1 and Study 2.

Chapter Four: Methods and Methodology

4.0 Introduction

This chapter outlines the research methodologies and methods used to address the research question and objectives of Study 1 and Study 2. The decision for the research methodology and the methods are explained. A qualitative approach was adopted to explore FSWs' experiences with accessing healthcare services in both studies. A qualitative study is an umbrella concept covering various forms of inquiry and investigations that help to explain the meanings of social phenomena with as little disruption of the natural setting as possible (Merriam, 1998). The focus of a qualitative study is on the interpretation and meaning of the experiences. Moreover, participants are the primary units of analysis, with their informed consent (Bailey, 1996).

Study 1 explored positive experience of FSWs accessing healthcare services during 2014-2017. The researcher initially thought that the study was an interpretative, phenomenological, analytical study but later realised that it was more an exploratory, qualitative descriptive study. Realising I had not undertaken an IPA, formed part of the learning process during this PhD study and was also identified by the examiners of the Study 1's thesis.

Study 2 explored perceptions and experiences of FSWs but including negative, positive, and more neutral experiences during 2018-2021. To explore both negative, positive, and more neutral experiences, a phenomenological approach was employed. The choice of the phenomenological approach is described in Section (4.11.2). The first section of this chapter will present the aims and the research questions and the rationale for the methodology and method utilised in Study 1. Furthermore, a description of how participants were accessed and recruited, sample selection, data collection tools and data management including how data was analysed will be described. The second section will describe the methodology and methods utilised in Study 2 including the rationale for the study's choice of methods, a description of the study site, how participants were recruited, data collection tools and how data was synthesised and analysed. A summary of the processes for the two studies

and how they inform the discussion of the studies' findings is summarised in Figure 4.2.

The third section will present the ethical approval and considerations as they relate to the two studies, and it will consider the trustworthiness of the data analysis. Before describing the study setting, ontological, epistemology and philosophical tenets are described to provide to inform the Study 1 and Study 2.

4.1 Ontology

Ontology is the claim researchers make regarding knowledge and the nature of reality, i.e. what constitutes reality and how we can understand its existence (Creswell, 2003). Hence, the investigator's ontological position describes the investigator's view of reality and how it exists. For this reason, Study 2 structure is designed with an ontological view that assumes the experiences of the FSWs being studied are complex and, inevitably, include unwanted occurrences (Guba & Lincoln, 1994). The manner in which humans' (in this case FSWs) respond to the social environment are based on their perceptions that significantly affect their experiences, including interactions with healthcare services (Crotty, 1998; Guba & Lincoln, 2005). These ontological assumptions helped to highlight the lived experiences, worldviews, and self-perceptions of FSWs.

4.2 Epistemology

Epistemology is the theory of knowledge, how it is obtained and what is considered as acceptable knowledge (Gergen, 2003; Maynard, 1994; McNabb, 2008; Saunders *et al.*, 2007). There are two major epistemological positions: objectivist and constructivist (Charmaz, 2000; Denzin & Lincoln, 2008). An objectivist, epistemological view embraces the idea that knowledge that exists can only be derived from scientific observation and measurement (Neuman, 2004). On the other hand, constructivist epistemologists argue that knowledge is a product of the social context in which meaning develops (Crotty, 1998). Constructivist epistemology, therefore, seeks to discover and describe the distinct nature of those being investigated (Broido & Manning, 2002). This epistemological position fitted well with this study and placed

FSWs' perceptions, constructions, and voices at the centre of the analysis. The rich description of FSWs' narratives guided the analysis of the data, with emphasis placed on the evolving stories told by FSWs (Creswell, 2014).

4.3 Philosophical Tenets

According to Broido and Manning (2002), the interactive relationship between the constructivist investigator and those being investigated is subjective, in that guiding is required as multiple realities emerge creating complex phenomena that are not easily measured. However, the constructivist epistemology enabled the researcher to plan and direct the study project with the open-minded approach of investigating both negative and positive experiences of FSWs. This was also based on the understanding that context-specific interpretation would be influenced by the values of both service providers and services users. Furthermore, to investigate these values better, the investigator needed to engage the study participants actively in the constructivist foundations of shared history, language and actions (Locke, 2001).

Moreover, the related philosophical persuasion of the current study assisted the investigator in constructing the framework around which the study was designed (Broido & Manning, 2002; Charmaz, 2006). To this end, the study was founded on practical suggestions, with the belief that meaning is created through interactions and actions and that knowledge is an accumulation of experiences (Corbin & Strauss, 2008). As such, the investigator assumes that truth is what the participants in this study acknowledge as a contemporary worldview and that new knowledge is useful in changing and further developing what has previously been accepted as reality (Hofer & Pintrich, 1997).

This qualitative study investigated in depth the experiences of FSWs' access to healthcare so as to provide the reader with a thorough understanding of how and why FSWs have such experiences (Creswell, 2014). Furthermore, the flexibility associated with the design enabled the investigator, as a primary data collection instrument, to probe for more profound meaning through continued dialogue with the study participants (Creswell, 2003). The following section

outlines the study setting, providing an understanding of the context for Study 1 and Study 2.

4.4 Study Setting for Study 1 and Study 2

The studies were conducted in Malawi, within the low-and-middle-income locations around the city of Lilongwe, in which FSWs were likely to reside. The most suitable sites for this study were areas to which the rural population migrate in search of jobs and to manage small-scale businesses and where the study population is likely to access healthcare services within the city. The decision to conduct the study in these areas was supported by previous studies by Underwood *et al.* (2011) and Family Planning Association of Malawi (2011), which suggest that poor and new immigrants from rural parts of Malawi, coming to the city in search of jobs, prefer to live in these areas because they offer a relatively affordable lifestyle (Family Planning Association of Malawi, 2011; Underwood *et al.*, 2011). These areas are characterised by high population density and have low, or a lack of, building standards (see Figure 4.1).



Figure 4.1 An example of a residential area where most FSWs live.

The next section presents the aim and research questions in Study 1.

4.5 The aim and the research questions of Study 1

The aim of the study was to explore FSWs' positive experiences with accessing healthcare services in Malawi and the following were the research question:

- (1) What reasons do FSWs give for their choice of where to access healthcare or advice regarding their health needs?
- (2) What are the self-reported positive experiences of FSWs who have access to healthcare?
- (3) What influences FSWs' self-reported experiences and where were they received?
- (4) How do HCPs deliver care which is reported by FSWs as a positive experience?
- (5) What other necessary non-healthcare support services as perceived by FSWs, HCPs and care providers including Family Planning Association of Malawi and Theatre for a Change, are not available to FSWs in Malawi?

The next section presents the research method for Study 1.

4.6 Research Method for Study 1

A qualitative approach was adopted to explore FSWs' experience of healthcare access because of its emphasis on people's lived experiences (Creswell, 2014). This approach would allow the researcher to get rich, in-depth information of FSWs' experiences when accessing healthcare services. The individual interview was considered best suited to topics that are sensitive in nature and was employed in this study (Bowling, 2002). The rationale for using a qualitative approach is presented in the next section.

4.6.1 Rationale for choosing a qualitative study in Study 1

Study 1 aimed to explore FSWs' positive experiences with access to healthcare in Malawi. Qualitative exploratory research seeks to provide a rich description of the experiences described by participants in their own words

(Lambert & Lambert, 2012). The choice of an exploratory approach was relevant in this study because it enabled exploration of sensitive topics in the way women wanted to report them (Bradshaw *et al.*, 2017; Polit & Tanto, 2008). Moreover, the aim of the first exploratory study was to develop an understanding and describe FSWs' positive experiences from the perspectives of FSWs and those providing services to add to knowledge and improve practice (Sullivan-Bolyai *et al.*, 2005). Another reason for choosing this approach for this study was that the researcher wanted to learn from the participants' (FSWs, HCPs and service providers) descriptions of the experiences and to use this knowledge to influence service delivery in ways that would be perceived as positive (Sullivan-Bolyai *et al.*, 2005). The next section presents the methodologies used to collect and analyse data in the research process of Study 1.

4.7 Research Method for Study 1

4.7.1 Accessing participants for Study 1

Access to the study participants took place after the study was granted ethical approval by the University of Warwick, Biomedical and Scientific Research Ethics Committee (BSREC) (on 29th September 2014 (BSREC: REGO-2014-1040) (Appendix 8) and by the Ministry of Health in Malawi, National Health Service Research Ethics Committee (NHSREC) (on 17th November 2014 (NHSREC: 1348) (Appendix 9). As FSWs are a hidden population, and to ensure easy entry and accessibility, participants were recruited through two NGOs based in Lilongwe and providing health-related services to FSWs and other vulnerable groups within and outside the city. To access FSWs, the researcher initially contacted Family Planning Association of Malawi and Theatre for a Change managers for information about who to contact and how best to reach them. During the subsequent meetings, the researcher informed the managers that the purpose of the study was to explore the positive experiences of FSWs with accessing healthcare services and that the study was being carried out as a requirement of her PhD.

The researcher further explained the objectives and the type of participants required for the study and provided the directors/managers of the specified

NGOs with participant information leaflets outlining the research aim and the objectives of the study and what would be expected from participants if they agreed to take part (Appendix 1A/B, 2 and Appendix 3 respectively). The directors/managers agreed that their institutions would participate in the study as gatekeepers. The researcher was then introduced to two Community Reproductive Health Promoters (CRHPs), who were working directly with FSWs in the community under Family Planning Association of Malawi during the time of the fieldwork.

The researcher and the CRHPs had a meeting, in which the researcher informed the CRHPs about the aim and objectives of study and explained the roles of the CRHPs during the fieldwork, i.e., as gatekeepers and as participants if they wished. As gatekeepers, the CRHPs were to act as the link between the researcher and the FSWs; they were not to force or persuade anyone to participate in the study but were to explain to FSWs what they knew about the study and let each FSW make her own decision about whether or not to participate.

The CRHPs contacted the 'Queen Mothers' within the townships where participants were to be recruited. These are well-respected women among FSWs, who Family Planning Association of Malawi and Theatre for a Change use as gatekeepers when recruiting FSWs to their programmes. The researcher was introduced to these 'Queen Mothers' by the CRHPs in a meeting that was organised at a time and place that was convenient for all concerned. The 'Queen Mothers' were informed of their roles, i.e., as gatekeepers and as participants if they wished. FSWs contacted by 'Queen Mothers' were assessed to see whether they met the inclusion criteria. Those deemed not to meet the criteria were thanked for their time and interest in the study. The researcher noticed that while 'Queen Mothers' did their best to identify potential participants, there were some biases in the way potential participants were selected. For example, some potential participants disclosed that they were not sex workers but had heard from their friends that 'if you say you are a sex worker you are given money'. This was the money used as a token of appreciation for participating in the study.

With the support of the CRHPs, the researcher opted to recruit participants residing within bars and those who lived outside bars/pubs and were actively doing other jobs (e.g., beer selling, hairdressing and any other small income-generating business) but also engaged in sex work. The CRHPs contacted an ex-sex worker within the area where some participants were residing (Chinsapo and Chigwirizano). This person, after a brief meeting in which the researcher and the CRHPs explained the purpose, aim and objectives of the study, agreed to act as a gatekeeper in identifying potential participants. Chinsapo and Chigwirizano have previously been reported to have high numbers of FSWs (Ghosh & Kalipeni, 2005). The researcher, accompanied by the ex-sex worker, identified a central point where the recruitment and interviews were to be conducted while protecting women participating in the study, from disclosure of their identity as sex workers. Recruitment was carried out in a clinic run by Family Planning Association of Malawi in Chigwirizano area.

During recruitment, the researcher explained the aim and objectives of the study and read through the participant information leaflet (Appendix 1A/B), and any questions regarding the research process were answered. Where an interviewee showed interest in the study, the researcher exchanged mobile phone numbers with a view to arranging a time and date for the interview. The researcher informed the potential participant that the mobile number provided by the researcher was only valid during the time of fieldwork and that the SIM card would be destroyed thereafter.

4.7.2 Sample for Study 1

To answer the research questions FSWs, HCPs from different healthcare facilities and service providers from both Family Planning Association of Malawi and Theatre for a Change were included. Potential participants were informed that, for one to participate in the study, they were required to sign a consent form (Appendix 4A/B) before the interview commenced and to allow the researcher to audio-record the interview. 45 FSWs aged 18 years and above, 10 HCPs with different experiences and six service providers from Family Planning Association of Malawi and Theatre for a Change were interviewed.

4.7.2.1 Sampling criteria of Study 1

There are different sampling techniques, such as snowball sampling or purposive sampling to include a range of perspectives in qualitative research (Holloway & Wheeler, 2013). Two types of sampling techniques were utilised, because of the nature of the study and the wish to collect data from both service users and non-service users of services provided by Family Planning of Malawi or Theatre for a Change. In this study, snowball and purposive sampling techniques were used to identify participants. Snowball sampling techniques (Finlay & Ballinger, 2006) were used to identify FSWs who may not have known about the study and those that were not using services provided by Family Planning Association of Malawi or Theatre for a Change. These women were then asked to identify other possible potential participants that were FSWs (Griffiths, 2009).

To sample HCPs and service providers, purposive sampling techniques were used (Bowling, 2002). FSWs were asked to name a HCP or facility where they perceived that their experiences were positive when they accessed services. FSWs in this study did not name any specific HCP but named a few healthcare facilities where their experiences were positive. The named facilities were contacted and when permission was given to interview HCPs who have had direct contact with FSWs, then, those HCPs were interviewed.

4.7.2.2 Inclusion and exclusion criteria in Study 1

Any adult female (18 years and above) who self-declared as a sex worker and who had been in sex work not less than six months and those willing to be interviewed at the health facility were eligible for inclusion in the study. FSWs who insisted that the interviews should be conducted at their residences or place of work were excluded because in such circumstances the researcher could not be sure of her own safety.

4.7.2.3 Sample size in Study 1

The sample is the number drawn from a population using the relevant sampling method, depending on whether a quantitative or qualitative data collection method is being used (Holloway, 2006). The researcher aimed to recruit

participants with a range of experiences. A total of 45 interviews with FSWs, 10 interviews with HCPs and six interviews with service providers from Family Planning Association of Malawi and Theatre for a Change were conducted. In this study a sample was chosen that could illuminate FSWs' experiences. Sampling continued until data saturation point was reached until no new or relevant data seemed to emerge regarding a category from the data (Creswell, 2009; Saunders *et al.*, 2007).

4.8 Methods of Data Collection

There are several methods and tools that can be used to collect data. For example, questionnaires and face-to-face interviews are the most commonly used methods of data collection (Berg, 2012; Maxwell, 2005).

4.8.1 Data collection in Study 1

Face-to-face interviews were used to collect data for Study 1 using semi-structured interview questions. Both open-ended and closed questions were used to collect data with face-to-face interviews after explaining the objectives and aim of the study (Appendix 1A/B, 2 and 3 respectively) and consent was obtained from a participant (Appendix 4A/B). Data was collected from 45 FSWs (Appendix 5A/B), 10 HCPs (Appendix 6) and six service providers from Family Planning Association of Malawi and Theatre for a Change (Appendix 7) to explore FSWs' perceptions, HCPs', and service providers' views on the positive experiences of FSWs with accessing healthcare and individual behaviour in making choices in healthcare utilisation.

All FSWs and four service providers from Family Planning Association of Malawi and Theatre for a Change interviews were conducted in a local national language (Chichewa) while the other two service providers opted to be interviewed in English. Six HCPs' interviews were conducted in English and four were in the local language. The interview questions were field tested with five FSWs to ensure the clarity of the questions and the indicative probes. At the beginning of the interviews, use of certain words used to describe sex work in Malawi were agreed upon by both the participants and the researcher. FSWs stated that they were comfortable with words like 'hule' and 'mzimayi oyendayenda' to denote sex worker or commercial sex worker. During the

interview simple words were used regardless of the FSWs' tribe so that the questions were easily understood. The interviews lasted between 30 to 45 minutes long; this was due to the nature of the questions. The Study 1 examiners noted that the questions were structured in such a way that they did not always support exploration of experience and perhaps prompted shorter responses.

4.9 Data Storage and Management in Study 1

Participants' personal data, including name, telephone number and age, were directly recorded in the research diary, which was accessible only by the researcher; these were not audio recorded. Data that was recorded was collected using an encrypted audio-recorder. Transcripts were digitally stored on a password-protected, fully encrypted, personal laptop. Hard copies of participants' consent forms together with the laptop and audio-recorder were kept in a lockable cupboard provided by Malawi College of Health Science management which was only accessed by the researcher. When returning to the United Kingdom, the password-protected, fully encrypted, laptop and hard copies of the consent forms were carried as part of the researcher's cabin/hand luggage. For publication purposes, any direct quotations will be used anonymously to maintain confidentiality.

Some issues that were unclear were discussed with the study supervisors and resolved. For example, issues of FSWs reporting receiving Paracetamol for treatment of STIs and how did the researcher deal with this malpractice bearing in mind the assurance of FSWs' confidentiality. The issues were reported to the health facility in-charge about the malpractice without disclosing the participants' name. The facility in-charge (a Senior Clinician) promised to investigate the concerns raised and act accordingly.

4.9.1 Data analysis and interpretation

Qualitative data are mainly gathered in unstructured textual format, unlike quantitative data (Auerberch & Silverstein, 2003; Creswell, 2009). In most cases, the data analysis process in qualitative study, begins during the data collection stage (Barnett-Page & Thomas, 2009). However, there are no straightforward rules for analysing qualitative data (Bradley *et al.*, 2007).

Despite the lack of a single appropriate method for qualitative data analysis, there is general agreement that analysis begins in the early stages of data collection and continues throughout the study (Bradley *et al.*, 2007). The following stages were employed to transcribe the data.

4.9.2 Transcription and translation in Study 1

All recordings were transcribed *verbatim*. Transcription started immediately after a few interviews were conducted. Transcription was done by two professional transcribers in the original language (Chichewa) before translating it into English. 10 transcripts were 'back translated' into Chichewa for quality purposes and to ensure the accuracy of the translation.

4.9.3 Data analysis

Different approaches to qualitative data exist (Braun & Clarke, 2006; Silverman, 2005). In Study 1, thematic analysis processes were applied, although, the researcher initially thought the data was analysed using interpretative phenomenological analysis (IPA). The limitation in the use of IPA was also noticed by the Study 1 examiners. In thematic analysis, a number of themes are identified in the data (Alhojailan, 2012; Guest *et al.*, 2012). Thematic analysis is flexible and frequently used in health and social sciences research to analyse narratives from interview transcripts to identify themes (Silverman, 2005).

4.9.3.1 Data analysis in Study 1

Thematic analysis approaches were utilised in Study 1 to analyse data. The analysis of qualitative data involved discovering the patterns, themes and categories in the data and findings emerging out of the data through the analyst's interactions with the data (Gibson & Brown, 2009; Patton, 2002). The thematic analysis further provided an indication as to the recurring themes within the dataset (Alhojailan, 2012; Boyatzis, 1998). The researcher in this study reviewed the dataset from three categories of participants (FSWs, HCPS and service providers from Family Planning Association of Malawi and Theatre for a Change) and derived a set of themes that appeared throughout the dataset.

The thematic analysis followed six main stages including familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and the final phase of report writing (Ritchie *et al.*, 2003). The researcher presented the description of the data and made arguments in relation to the research aim and the research questions. Table 4.1 below presents the six stages followed in the thematic analysis undertaken in Study 1.

Phase		Description of the process
1	Familiarising with own data	Transcribing data, reading and re-reading the data, noting down initial ideas.
2	Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
3	Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme.
4	Reviewing themes	Checking if the themes work in relation to the coded extracts (level 1) and the entire data set (level 2), generating a thematic 'map' of the analysis.
5	Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6	The final report	The final opportunity for analysis. Selection of vivid, compelling, extract examples, final analysis of selected extracts, relating back to the analysis of the research question and literature, producing scholarly report of the analysis.

Table 4.1 shows the six stages that were followed in thematic analysis in Study 1.

The next section presents the objectives and the research question, methodology and methods utilised in Study 2 including the rationale for the study's choice of methods, how participants were recruited, data collection and how data was synthesised and analysed. A summary of how the process for the two studies and how they inform the discussion of the studies' findings is presented in Figure 4.2.

4.10 Aim of the Study, Objectives, and the Research Questions for Study 2

Building on Study 1, Study 2 aimed to explore FSWs' experiences and perceptions with accessing healthcare services provided by public and non-governmental organisation (NGOs) healthcare facilities in Malawi. The following section will present the research questions and objectives that supported the study aim.

4.10.1 Research questions for Study 2

- (1) What is the lived experience of female sex workers regarding using healthcare services?
- (2) What did female sex workers with unknown and known human immunodeficiency virus (HIV) status expect and what did they experience during access to healthcare?
- (3) What is the lived experience of access to services provided by different organisations including Family Planning Association of Malawi and Theatre for a Change and, how have these experiences affected their perception of the health services?

4.10.2 Research objectives for Study 2

- (1) To explore the lived experiences of FSWs regarding using healthcare services.
- (2) To examine the lived experiences of FSWs living with HIV and those with unknown HIV status regarding access to healthcare services.

(3) To explore female sex workers' perceptions and experiences of the services provided by Family Planning Association of Malawi or Theatre for a Change.

The next section describes the phenomenological approach utilised in Study 2.

4.11 Methodology for Study 2

4.11.1 Phenomenology

Phenomenology is the study of lived experiences from the viewpoint of the individual experiencing the phenomenon (Dowling, 2007; Sadala & Adorno, 2002). Furthermore, a phenomenological study attempts to deal with inner and deep experiences as they present in everyday life (Merriam, 2002). It also illuminates the experience which is concealed and typically taken for granted as normal (Dowling, 2005). Despite phenomenology frequently described and used as a qualitative research method, evidence suggest that it is rooted in philosophy (Dowling, 2005). However, none of the philosophers developed research methods, nevertheless, their work is often used as a framework to augment and underpin contemporary qualitative research (Cerbone, 2010).

Phenomenology emerged in the early 18th century and is considered as being founded by the German philosopher and mathematician Edmund Husserl (1859-1939) (Haralambos & Holbon, 2008). However, his one-time student, Martin Heidegger and other philosophers including Maurice Merleau-Ponty, Hans-Georg Gadamer and, more recently, Max van Manen subsequently expanded Husserl's phenomenology (Haralambos & Holbon, 2008). Husserl defined phenomenology as the science of consciousness and its structures or essences (Husserl, 1975; Parley, 1997). Because Husserl described the manner in which the world is constituted and experienced through conscious awareness of the phenomenon, his philosophy is often described as epistemological (Koch, 1999; McConnell-Henry *et al.*, 2009).

Heidegger (1889-1976) shared Husserl's view that phenomenology is concerned with human experience as it is lived (Dowling, 2005), but he expounded the importance of the nature of Being (ontology) (Inwood, 1999).

This is a philosophical theory which emphasises the existence of the individual person who determines their own development and gives meaning to life through acts of free will (existentialism) (Crotty, 1998). It is the interpretation of lived experience representation and understanding of human experiences and choices and the knowledge gained from these experiences and choices (Inwood, 1999).

Using Heideggerian phenomenology in research involves working to uncover what Being-in-the-world means by interpreting entities and events involving everyday experiences (Inwood, 1999; Racher & Robinson, 2003). Both the researcher's and the research participant's 'Being-in-the-world' are equally relevant in this situation and need to be taken into consideration since the participant's experience of Being-in-the-world can only be interpreted by another Being-in-the-world (Lowes & Prowse, 2001). Therefore, to describe the methods used in Study 2, the researcher has continually referred back to Heidegger's philosophy to ensure accurate interpretation of the study findings and she has reflected upon and considered her own positionality in the study (section 8.1) before returning to her study question: 'What is the lived experience of FSWs regarding using healthcare services?' to guide the methods that are utilised to answer this question. The next section describes the rationale for using phenomenological approaches in Study 2.

4.11.2 Rationale for using phenomenological approaches

Building on Study 1, Study 2 was informed by a qualitative, phenomenological inquiry into FSWs' experiences of access to healthcare services and what they believe to be its emerging trends, to enhance improved experiences with access to healthcare services (Carter & Little, 2007). This is an appropriate research method for an exploratory study (Robson, 2002; Russell & Stone, 2002) because a qualitative study investigates a phenomenon from the perspective of those experiencing it. Furthermore, qualitative studies aim to capture the complexity of everyday life and understand what an experience means from the perspectives of participants (Bryman, 2006).

Additionally, qualitative phenomenological studies focus on the first person 'meaning(s)' of the experiences that are of interest to the researcher, rather

than on mere objective interpretations of behaviours (Bless *et al.*, 2006). Furthermore, a phenomenological study attempts to deal with inner and deep experiences as they present in everyday life (Merriam, 2002). A phenomenological study describes the meaning of the lived experiences of participants about the phenomena being investigated (Creswell, 2007). Hence, the principle method of data collection, when the phenomenological approach is employed, is the interview (Wimpenny & Glass, 2002).

To achieve the purpose of the phenomenological study, participants are asked to describe their experiences and the researcher examines the experiences through the descriptions provided by individuals (Patton, 2002).

The reason for selecting a phenomenological methodology was to explore FSWs' experiences of access to healthcare services from their own perspectives and 'give voice' to their experiences. The phenomenological approach helped to identify the meaning behind the human experience as it related the experiences and perceptions of FSWs to a notable collection of factors associated with their day-to-day lives and access to healthcare (Creswell, 2009). Following a decision that a phenomenological approach was appropriate for the current study, the following propositions (outlined by Creswell (2014) and obtained from Moustakas (1994) were included in the study design and served as a procedural map for investigating FSWs' experiences with accessing to healthcare services in Malawi:

- A phenomenon of interest to the study was identified.
- the investigator recognised and specified the broad philosophical assumptions of phenomenology.
- data was collected from the individuals who had experienced the phenomenon.
- the participants were asked two broad, general questions (Moustakas, 1994): What have you experienced in terms of the phenomenon? What context or situations have typically influenced or affected your experiences of the phenomenon?
- data analysis occurred through organised collection of meanings and from these collections unfold both textural and structural descriptions of the

experience which leads to a composite description that presents the 'essence' of the phenomenon (Creswell, 2014). The next section describes the research method utilised in Study 2.

4.12 Research Method for Study 2

4.12.1 Access to participants during Study 2

Since the researcher had prior contact with Family Planning Association of Malawi and Theatre for a Change managers during Study 1, in this study, the researcher contacted the manager for Theatre for a Change to allow her to recruit through their mobile and static clinics. The researcher explained that this study was a follow-up to Study 1. Permission was granted for the researcher to visit the clinics and access potential participants. The researcher was introduced to providers of health-related services at the health facility by a member of staff from the Theatre for a Change offices. The researcher explained the study's aim and objectives and gave the participants' leaflet to the service providers at the clinic (Appendix 10 A/B). The researcher briefly explained the research questions that participants were likely to be asked during the interviews (Appendix 11 A/B).

The staff at the health facility introduced the study and the researcher to prospective participants. FSWs who showed interest in taking part in the study were then approached; the researcher explained the aim and objectives of the study and read through the participant information leaflet (Appendix 10 A/B), and where participants had questions regarding the study, the researcher gave an honest explanation. Potential participants were further informed that to participate in the study, they were required to sign a consent form (Appendix 4 A/B) before commencement of the interview and to allow the researcher to audio-record the interview.

This process occurred after new ethics approval was granted by the University of Warwick (Appendix 12) and an extension letter was obtained from the NHSREC (Appendix 13) to collect additional data to build up on data collected in Study 1. The NHSREC granted Study 2 an extension letter after the researcher presented the recommendations from the Study 1 examiners in which they required additional data for the study to be awarded a PhD.

4.12.2 Sample in Study 2

25 FSWs aged 18 years and above and who had been in sex work industry for more than six months were included in the face-to-face interviews. The reason for interviewing FSWs who have been in sex work industry was that it was assumed that within this period of time, potential participants would have had accessed healthcare services at some point. Based on the study's single encounter face-to-face interview design, the researcher planned to start with a sample of approximately 25 participants. Once the initial sample was determined, the researcher was prepared to broaden the sample up to 35 FSWs if necessary, to clarify the emerging data further until saturation had occurred (Strauss & Corbin, 1998).

4.12.3 Sampling criteria in Study 2

Purposive and snowball sampling were utilised to locate potential participants for the study (Griffiths, 2009; Holloway & Wheeler, 2013). Those who were interviewed were asked to share the information about the study with their colleagues and ask them to contact the researcher if they wished to participate on a project telephone number (given to potential participants who showed interest in taking part in the study). Recruitment took place at the Theatre for a Change static health facility. The site for recruitment was agreed by both potential participants and the researcher because it was felt that it was safer for both the participant and the researcher.

4.12.4 Inclusion and exclusion criteria in Study 2

Any adult females (18 years and above) who self-declared as sex workers and who had been in sex work not less than six months and who were willing to be interviewed at the health facility were eligible for inclusion in the study. FSWs who insisted that the interviews should be conducted at their residences or place of work were excluded because, in such circumstances, the researcher could not be sure of her own safety. Pregnant FSWs were not particularly the focus for this study because of the anticipated risks of pregnancy, these women were thanked for expressing interest in participating in the study. Where there was a language barrier between the researcher and a prospective participant, this potential participant was excluded from the study as no

resources were available to employ a translator. Any FSW who was less than 18 years old as verified *via* her national identification card (which is a legal form of identity in Malawi) was excluded from participating in the study.

4.13 Data Collection for Study 2

The careful framing of an opening question for a phenomenological interview is essential for generating data to answer a specific research question (Sorrell & Redman, 1995). Semi-structured interviews incorporating open questions and probes offer more assurance that the generated data were relevant to the research question (van Manen, 2007). In a Heideggerian phenomenological interview, the researcher shapes the discussion but is also shaped by the participants, acknowledging their own Being-in-the-world (Wimpenny & Glass, 2002). Therefore, phenomenological interviews are 'participated in' by both the interviewer and the interviewee (Draucker, 1999; Sorrell & Redman, 1995).

Face-to-face interviews were used to collect data using semi-structured interview questions to explore FSWs' perceptions and experiences with accessing healthcare in Malawi. Data was collected from twenty-five FSWs. All interviews were conducted in a local national language (Chichewa). The interview questions were field tested with five FSWs to ensure the clarity of the questions and the indicative probes. At the beginning of the interviews, the use of certain words used to describe sex work in Malawi were agreed upon by both the participants and the researcher. FSWs stated that they were comfortable with words like 'hule' and 'mzimayi oyendayenda' to denote sex worker or commercial sex worker. Asking participants to use words with which they were comfortable is also suggested by Britten (1995) who recommends that researchers should try to use the participant's own vocabulary (Britten, 1995).

Participants were told that all interviews will be completed in one sitting. During the interview, simple words were used regardless of the FSWs' tribe so that the questions were easily understood. Interviews lasted between 60-90 minutes.

4.14 Data Storage and Management in Study 2

Participants' personal data, including name, telephone number and age, were directly recorded in the research diary, which was accessible only by the researcher; these were not audio recorded. Data that was recorded was collected using an encrypted audio-recorder. Transcripts were digitally stored on a password-protected, fully encrypted, personal laptop. Hard copies of participants' consent forms were scanned immediately after interview and stored electronically on a password-protected, fully encrypted laptop in a separate file from the transcripts. The laptop and audio-recorder containing participants' information were stored in a locked cupboard kept in a secured room provided by one of the organisations participating in the study.

When returning to the United Kingdom, the password-protected, fully encrypted laptop on which transcripts and participants' consent forms were stored was carried as part of the researcher's cabin/hand luggage. For publication purposes, direct quotes will be used anonymously to maintain confidentiality.

4.14.1 Transcription and translation for Study 2

All recordings were transcribed *verbatim*. Transcription started immediately after a few interviews were conducted. The researcher transcribed the data in its original language (Chichewa) before translating it into English. Chichewa is a national language in Malawi and is my native language and my command of English language as an official communication language in Malawi made it relatively easy to translate the interviews. Five transcripts were 'back translated' into Chichewa by a colleague who is a secondary school Chichewa teacher for quality purposes and to ensure the accuracy of the translation.

Issues that were unclear were discussed with the study supervisors and resolved. For example, issues of FSWs reporting being denied HIV testing and treatment after a rape incident and how did the researcher deal with this malpractice bearing in mind the assurance of FSWs' confidentiality. The issues were reported to the health facility in-charge about the malpractice without disclosing the participants' name although, I would disclose names if there was a threat of harm to self/others as stated in the information leaflet. The facility

in-charge (a Senior Clinician) promised to investigate the raised concerns and act accordingly.

4.14.2 Data analysis in Study 2

The data was analysed using descriptive phenomenological analysis, which highlights conceptual patterns and describes the process (Colaizzi, 1978). The data analysis started as soon as the transcripts were done, and the text had become the 'empirical evidence' to be analysed. The following planned steps guided the researcher's data analysis, drawing on Colaizzi's data analysis model (1978).

First, the researcher was immersed in the data. For example, the researcher listened to the whole of each audio-recorded interview and re-read the transcripts several times to get a sense of the whole.

Second, the researcher gradually began to focus on small chunks of data, commonly called 'meaning units', i.e., phrases or passages of text, including non-verbal communications, each of which expresses a particular point or meaning that can be differentiated from the preceding text. This process was undertaken in an effort to extract a deeper understanding of the meaning of the experiences being expressed by the participants. Meanings were then crystallised and condensed, while efforts were made to stay as close as possible to the participants' actual words.

Third, the researcher gradually sifted and refined the meanings, resulting in a fine-grained analysis. This process allowed the data analysis to proceed through an organised collection of meanings and, from this collection, unfold both textural and structural descriptions of the experiences, leading to a composite description that presents the 'essence' of the phenomenon.

These steps overlapped and were non-linear. As participants' descriptions of their experiences were being examined and interpreted, the researcher was continuing to interview participants, identifying new themes, and returning to all the descriptions to look for patterns and differences, thus complementing the 'uncovering' that Heideggerian phenomenology aims to demonstrate.

The researcher analysed all the interviews with the supervision of the two study supervisors. NVivo 11 computer software for qualitative data was used to assist with data handling. In summary, Figure 4.2 shows an overview of the two studies' designs and methods undertaken and how the findings of the studies will be included in the discussion of the findings.

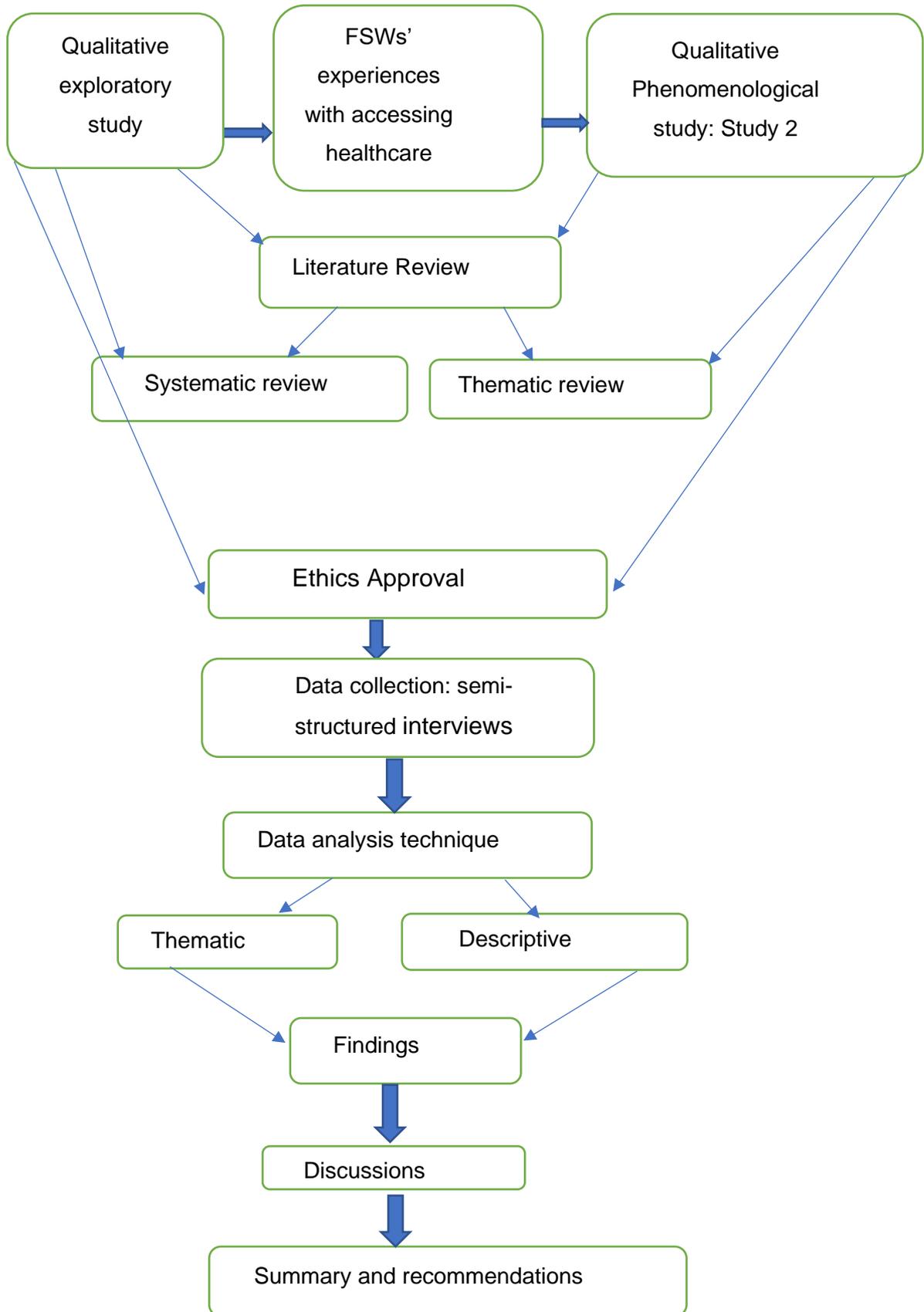


Figure 4.2 shows an overview of the two studies design and methods undertaken and how the findings of the studies will be included in the discussion.

The next section presents the ethical approval and considerations which were addressed for both Study 1 and Study 2.

4.15 Ethical Approval (Study 1 and Study 2)

Ethical approval is important in health and social research. Ethics and research governance are important components of any research and require careful consideration, particularly with respect to good ethical practice, obtaining fully informed consent and data protection (Holloway, 2006; Saks & Allsop, 2007). In both studies (Study 1 and Study 2), first ethical approvals were obtained from the University of Warwick Biomedical & Scientific Research Ethics Committee (Biomedical & Scientific Research Ethics Committee): REGO-2014-1040 and BSREC: 62/18-19 (Appendix 8 and Appendix 12) before applying for ethical approval in Malawi. Approval for both studies were obtained from the Ministry of Health in Malawi, National Health Service Research Ethics Committee (NHSREC: PROTOCOL #1348 and an approval letter for extension) (Appendix 9 and Appendix 13). To get access to interview HCPs in relevant departments of the hospitals as well as and service providers from Family Planning Association of Malawi and Theatre for a Change, the permission was sought directly from the directors of the health facilities and the organisations after they were shown proof of ethical approvals from the University of Warwick and the Ministry of Health, National Health Services Research Ethics Committee in Malawi.

4.15.1 Ethical consideration for Study 1 and Study 2

As a researcher with a healthcare background asking FSWs to disclose their experiences with healthcare services and their involvement in sex work was considered a sensitive issue. Sex work is a sensitive subject in many countries including Malawi because of its illegality (Dhana *et al.*, 2014; Overs, 2017). A sensitive topic in research is defined as a topic that causes a potential threat for those involved in the study causing data collection or dissemination to be problematic (Lee, 1993). The researcher was conscious that FSWs might not be willing to share their experiences to an unknown woman. It was, therefore, important to describe the purpose of the study before participants consented to take part in it. The presence of the CRHP, the ex-sex worker and the service

providers from Family Planning Association of Malawi and Theatre for a Change before interviews commenced helped to address those fears that FSWs might have about disclosing their experiences.

The ethical issues to be considered in this study included the type of participants to be recruited; the need for consent to record the interviews; the time scheduled for interview; the location of the interviews; and the language to be used before, during and after the interviews took place. These issues are particularly important when researching sensitive topics (Lee, 1993). Furthermore, sex work in Malawi is 'illegal' and FSWs may not particularly feel safe if they were identified as being interviewed in a place where safety was compromised. Appointments with participants were made before the interviews were scheduled and confidentiality was assured. Interviews were conducted in an environment in which the women could feel most comfortable. In both studies, the interviews were carried out within the healthcare facilities.

To show respect and appreciate participants' willingness to participate in the study, the researcher actively listened to participants' narratives, flexibility was applied during the interviews and enough time was given between agreeing to participate and the actual interview to prevent a feeling of obligation (Reed *et al.*, 2014). Furthermore, participants were also assured that they could withdraw from the study at any stage, if they wished and their withdrawal would not affect their access to services. Participants were informed that the information they provided would be kept secure (Reed *et al.*, 2014). Participants were encouraged to ask questions regarding the study before the interview started.

The participants were assured from the beginning of the recruitment that their identity would be protected, and their responses would remain anonymous. Participants were assured that the information they provided would not be used for any other purpose than this study. Moreover, they were told that personal information would not be disclosed to others. An encrypted, audio-recorder accessible only to the researcher was used to collect recorded data. Transcripts were digitally stored on a password-protected, personal laptop. Hard copies of participants' consent forms were scanned immediately after interview and stored electronically on a password-protected laptop in a

separate file from the transcripts. All hard copies of consent forms were destroyed immediately after they were scanned.

4.15.2 Reimbursement of Expenses for Study 1 and Study 2

Participants used their mobile phones and airtime ('calling minutes') for contacting the researcher to confirm interview times; the calling minutes were reimbursed through a system commonly used in Malawi called 'me to you', in which one mobile phone user shares their calling minutes with another. The cost of this was MK2,500 (£2.50) per participant. A reimbursement of MK2,500 (£2.50) was also given to each FSW participant to cover transport to and from the interview location. This was reasonable, as Malawi has standard transport (minibus) fares for most routes within the city of Lilongwe, which, in most cases, are not more than MK500 (£0.50) one way, though some participants may have used more than one minibus during a single trip.

4.15.3 Tokens of appreciation for participation for Study 1 and Study 2

Each FSW was given MK10,000 (£10) as a token of appreciation for their time and their interest in the study. This amount was decided upon because the researcher believed that participants would welcome it, due to their personal circumstances. Ideally, this token of appreciation should have been in the form of vouchers, but this was not feasible in the Malawian context as vouchers were not available during the period of fieldwork for use in the shops where most ordinary citizens do their daily shopping. In this study, tokens of appreciation were given as a way of overcoming some of the power imbalance between the researcher and the participants (Grant & Sugarman, 2004) and to build trust between the researcher and the FSWs. The next section outlines the steps taken for assessing and establishing the quality of data for the two studies (Study 1 and Study 2).

4.16 Trustworthiness of the Study

Issues of credibility, transferability, dependability and confirmability and the researcher's reflexivity are important in research especially in qualitative and mixed-methods studies for assessing and establishing the quality of the research (Bowling, 2002; Guba & Lincoln, 2005; Koch, 1999; Shenton, 2004).

It is important that issues of trustworthiness are discussed carefully throughout a study (Maxwell, 2005). Several elements such as: clearly written research questions, appropriate research design to address the research questions, purposeful sampling strategies, systematic collection and management of data and correct analysis of the data (Guba & Lincoln, 2005). These issues have been addressed throughout this study to ensure the trustworthiness of this study. Furthermore, reviews of existing studies and identification of any limitations in the methodology used also help to increase trustworthiness (Marshall & Rossman, 2006).

Therefore, to establish trustworthiness in the data, the research questions were clearly developed and stated, data collection from both FSWs, HCPs and service providers from Family Planning Association of Malawi and Theatre for a Change using semi-structured interviews, appropriate research designs and methods were employed. Information was obtained from different perspectives to enhance the trustworthiness of the study. In this case, the researcher formulated the interview questions of Study 2 after carefully reviewing participants' narratives of Study 1. Improving qualitative interviewing techniques was addressed by practising interviews with supervisors and attending a one-day course on 'Introduction to Qualitative Interviewing' at Oxford University, on 18 December 2018 (Appendix 14).

4.16.1 Credibility

Credibility in qualitative studies is essential to ensure participants' data are accurately identified and illustrated (Marshall & Rossman, 2006). To promote credibility and enable future verification, the researcher concurrently reviewed the methods and analysis throughout the study process. This provided the researcher with a balance as she undertook to interpret the data (Guba & Lincoln, 2005). Furthermore, discussions and the resulting comments from study supervisors, fellow PhD students and colleagues in higher education were noted and compiled for further reflection. Member checking occurred to allow participants to check the interviews, each was offered the opportunity to listen to their audio recording immediately after data collection, as a platform for further clarification. However, this poses a problem for Heideggerian research which is based on the co-construction of shared meanings between

the researcher and participant only. In practical terms, independent validation gives the researcher the opportunity to explain their decision-making process to others (openness) and may add to their reflexivity.

Finally, because the FSWs were the core of this study process, their unique voices were communicated through rich description to allow future researchers to determine the applicability and transferability of findings in other or similar settings (Creswell, 2009). The researcher in this study hoped to provide an accurate portrayal of how FSWs living with HIV and those with unknown HIV status, as well as user or non-users of service provided by Family Planning Association of Malawi and Theatre for a Change, understand their experiences and how those experiences determine future access to healthcare services.

4.16.2 Reflexivity

Reflexivity in research is described as a conscious and deliberate act undertaken by a researcher to help enhance rigour (Berger, 2015). Reflexivity in this study involves the self-examination of how research findings were produced and, in particular, the role of the researcher in their research design or construction (Heaton, 2004). Reflexivity or the researcher's reflection in qualitative research has been acknowledged as a variable part of the study as it examines and uncovers researchers' influences on the data (McCorkel & Myers, 2003; Seymour, 2007).

Furthermore, reflexivity brings honesty to the fore because of the multiple factors which shape the data produced. The researcher, as an instrument in qualitative research approaches, recognises that her knowledge, beliefs, values, and experiences may shape the data she produces and, subsequently, the interpretations. The literature indicates that reflexivity in research is an uncomfortable part of the writing-up process and that one has to be objective right from the initial plan of the study (Ryan-Flood & Gill, 2009). Hence, one's identity may present an opportunity to explore what initially was invisible and what motivated the researcher to do the study and this may include a desire to change some existing situation or curiosity about a particular phenomenon (Finlay, 2002).

Evidence suggests that qualitative researchers need to think about the best way of dealing with their own preconceived ideas or opinions about the participants they are researching (Maxwell, 2005). This is crucial because researchers' preconceived ideas or opinions may have a profound influence on the selection of the research topic and the selection of the method of enquiry. Additionally, there have been calls for researchers to engage in some careful reflective thinking, regarding their own personal values, insights and preconceptions as they may well feed into the research process at different points and inform the overall shape of the research (Goodley *et al.*, 2004; Sapsford, 2006). The researcher agrees with the views of other writers who argue that to write oneself out of a research project is to overlook a critical part of the research process and may lead to 'deceptively tidy' accounts of research (Ellingson, 2006; Seymour, 2001). Hence, the researcher in this study had to self-critique thoughtfully and develop self-awareness of how her own role influenced the study process. The researcher reflected on her own background, emotions and thoughts as described below.

After giving a brief description of reflexivity in research, I now describe the origin of my study. I have used the term 'researcher' throughout the chapter to refer to myself but, for the purposes of this section, I will revert to the first person since this is a critical awareness and acknowledgement of my own attitudes and beliefs about the study. The motivation to undertake this research was driven by my own experiences of FSWs' and health service providers' interactions and engagement whilst working in healthcare in Malawi. My experiences can be traced as back as far as 1999 when I was working in one of the government hospitals in Malawi as a senior nurse, coordinating in-service education programmes and training HCPs in a programme which is now known as Continuous Professional Development (CPD).

In my few encounters within a healthcare context in Malawi, I witnessed some hostile attitudes, disapproval, taunting and blame by HCPs towards FSWs. In one incident, while working in one of the government hospitals, I witnessed a nurse uttering discriminatory and disheartening words to one of the FSWs whilst she was accessing Anti Retro Viral (ARV) treatment. Quoting her words, she said: *"Why do you bother us, it is better for people like you to die, why waste government money treating people like you rather than giving the*

medication to important people.” I could not understand why the nurse could behave in this manner.

Having come from an extended family, as is always the case in the African context, some of my family members chose to engage in sex work and disclosed to me how some HCPs had treated them when they sought health care. At that point I did not know how to deal with the situation apart from listening and feeling sorry for the experiences they encountered. At times, I had tried, perhaps, unconsciously to justify why HCPs treated them in that way by explaining that HCPs are individuals with different beliefs and attitudes towards the work that FSWs were doing. I even tried to justify their behaviour by saying that, as HCPs were humans just like anyone else, they sometimes had bad days too. Thus, the experiences of my family members who are FSWs coupled with the experiences I encountered at the clinic heightened my interest about initiating research in this area.

In the course of time, I had many unanswered questions: *‘Why would anybody want to engage in sex work?’*; *‘What is the difference between women having sex in their workplace with their bosses for benefits of being promoted in their jobs and those that sell sex on the streets or in brothels?’*; *‘What makes it right that HCPs feel they can judge and deny treatment for a self-declared sex worker?’* While those questions remained unanswered, I came across an online document from *Malawi Nyasa Times* reporting that, in the year 2003, the president of the Republic of Malawi issued a decree to arrest all FSWs found loitering in streets, hotels and bars. Following the order of the president, arrests of FSWs increased in number. Thus, further questions emerged in my own mind: *‘If the head of state was giving such orders, what chances had an ordinary Malawian in situations where they decided to stand up and defend the rights of FSWs?’* I was soon to learn that the government had drafted provisions that mandated compulsory HIV testing of FSWs in Malawi.

Against these developments, I became more motivated than before to pursue a study of the population that most countrymen talked about but whom they seemed to know very little. Indeed, as I informed my work colleagues that I was applying for a PhD to research about the experiences of FSWs in their interface with healthcare services, I was startled by the reaction. One of my

colleagues asked why I had an interest in sex workers and wanted to know whether I was one of them? To this, I responded that '*everyone is a prostitute in their own way and that my interest in sex work had nothing to do with my social life.*' An opportunity came for me to pursue my goal at several universities but opted to take the offer from the University of Warwick for personal reasons. I tried to look for sponsorship but to no avail.

Because I was determined to achieve my goals and explore the experiences of FSWs while accessing healthcare, I decided to use all my savings and fund this study myself. My topic evolved as the research progressed, informed by the literature, and directed by my supervisors. I ended up with the intellectual goal of exploring the experiences of FSWs in Study 1. During Study 2 data collection, which started after getting a fresh ethics approval from University of Warwick (appendix 4) and an approval letter of an extension from NHSRC of Malawi, was the greatest opportunity for me to interact with a more vibrant group of FSWs who spoke of their experiences with a free mind.

My previous knowledge of researching sensitive issues (Dementia and Alzheimer's) was in degrees at Honors' and Master's levels, respectively. My experience of conducting qualitative research and my background as a Malawian and a nurse also provided me with the necessary knowledge and skills for collecting data within sensitive studies and contexts. As my field studies were based in my own home country, I am well versed in the appropriate modes of dressing, the setting of the room for interviews and how to address my participants to reduce the power imbalance that may arise between the researcher and participants. I was able to encourage the participants to express themselves freely and talk about their experiences. During the fieldwork, my role was to listen and learn from the experiences of my study participants. I received an immense level of support from the managers, clinicians, and nurses in the hospitals where I conducted the interviews. I received similarly full support from all the staff in the organisations who were gatekeepers to access FSWs.

Both 'insider' and 'outsider' views can be helpful when understanding data from multiple perspectives. I consider myself as an insider from the perspective that I am a nurse and a Malawian conducting a study in Malawi.

Geographically, I regard myself as an outsider, based on the fact that, at the time of writing up this study, I have lived in the UK for over 18 years. Moreover, because of my level of education, I have somehow become an outsider in many ways. My supervisors too would be considered as outsiders in that, in some ways, they have not had the same life experiences as in my context in Malawi. From my understanding as a researcher and having listened to the interview *verbatim* and read the transcripts, I found that the data collected was relevant to the questions.

I was mindful to ensure that I was accurate and that my participants were presented in a professional and respectful manner. As a senior nurse, and insider, there is the risk that I would want to present my profession in the best light possible. However, I believe I have presented an open and honest account of the participants' experiences. It was only as I immersed myself in the data and considered the participants' experiences more deeply, that I really appreciated their range and complexity. Therefore, my view of FSWs changed as they recounted their deep and complex experiences. I also believe that the use of a phenomenological approach to explore FSWs' experiences contributed to the way I view these women and gave a firm insight into FSWs' experiences particularly in relation to their access to healthcare services.

4.17 Summary

This chapter described the research design and methodology used in both Study 1 and Study 2. The studies were conducted in Malawi, within the low-and-middle-income locations around the city of Lilongwe in which FSWs were likely to reside. Study 1 employed an exploratory, qualitative, methodological approach to explore FSWs' positive experiences with access to healthcare. Data was synthesised and analysed utilising descriptive thematic analysis approach from the 45 FSWs, 10 HCPs and six service providers from NGOs providing health-related services who participated in this study.

Study 2 utilised a phenomenological approach in order to collect the data and generate ideas which would address the aim and objectives of the studies and the research questions. 45 face-to-face semi-structured interviews were conducted to explore FSWs' perceptions and experience with accessing

healthcare. Descriptive phenomenological data analysis was utilised to analyse and interpret the data in Study 2. Efforts were made to ensure academic/professional integrity, confidentiality, research ethics and participants' respect during the whole study periods of Study 1 and Study 2. An overview of the two studies' designs and methods was undertaken to consider how the findings of the studies will be included in the discussion. The trustworthiness of both studies (Study 1 and Study 2) has been described. The next chapter presents the findings that emerged from the analysis of the data in Study 1.

Chapter Five: Findings of Study 1

5.0 Introduction

This chapter presents the study findings that emerged from Study 1, the qualitative study conducted between 2014-2017. To understand FSWs' positive experiences with access to healthcare, 45 women who self-defined themselves as sex workers were interviewed. 10 HCPs and six service providers (two from Family Planning Association of Malawi and four from Theatre for a Change) were interviewed to understand the views of service providers regarding the services they provide to FSWs. The chapter presents the study results that address the research questions. In some cases, quotations are lengthy to incorporate contextual data whilst others have been edited to include only information relevant to the theme and omitted text is represented by an ellipsis (...). Thematic analysis of the data was undertaken based on reading and re-reading of the interview transcripts to understand the experiences of FSWs. Based on the data collected from participants in this study, to answer the research questions, three major themes emerged: (a) Approaches to improving access to healthcare, (b) Effects of the non-governmental organisations on provision of healthcare services to FSWs, and (c) Professionals' awareness of FSWs' needs.

5.1 Characteristics of Participants

The semi-structured interviews were conducted with 45 FSWs, aged between 18-45 years who had been in sex work for more than six months prior to the interview. 10 HCPs with different experiences were also interviewed to explore their perceptions regarding services provided to FSWs. HCPs included two clinicians, four nurses, two Clinic Receptionists and one HVI counsellor. One clinician and the HIV counsellor were from the Christian Hospital Association of Malawi hospital, one clinician, two clinic receptionists and two nurses were from the two HIV clinics and three nurses were from the STI clinic.

Two service providers from Family Planning Association of Malawi who were interviewed were CRHPs and four service providers were from Theatre for a Change. The theme, sub-themes and the codes are now presented.

5.2 Factors Contributing to Female Sex Workers' Positive Experiences

In this section, the findings about factors contributing to FSWs' positive experiences with access to healthcare are presented. These factors include approaches to improving access to healthcare, effects of non-governmental organisations on services to FSWs and professionals' awareness of FSWs' needs. These factors are described.

5.2.1 Approaches to improving access to care

Several approaches to healthcare were reported by both FSWs, HCPs and service providers as contributing to FSWs' positive experiences. The factors include the availability of outreach services, Home-Based care, a convenient location for a health facility near the FSWs and availability of resources (e.g., adequate HCPs, drugs, and condoms). Participants also described how these services influenced their perception of a good service.

5.2.1.1 Outreach services

FSWs face a lot of problems in accessing healthcare services. Distance and cost of transport to health facilities added further difficulties to using services. FSWs reported that bringing services closer to where they live, has helped them to access the services when they are needed most without having to worry about travel expenses. One FSW said this about outreach services:

The good thing is that the clinic is in the area where I live, and I do not have to travel far to get treatment. Because of this I do not have to spend money as well too much time going to the clinic after my night out. (MW/FSW13).

Some FSWs explained that outreach services provided them with basic treatment and acted as a gateway to mainstream health services because of their referral systems to hospitals when further treatment was required. One FSW who has benefitted from outreach services said:

At outreach clinics I was given free medication if found with the STD and if they found serious problems then we were given a referral letter to go to the district hospital. (MW/FSW32).

A HCP at the outreach clinic mentioned that FSWs were satisfied with the services because FSWs have informed him and fellow HCPs that they are happy with the services because, when they come to the clinic, they get the services that they require. Other HCPs also said that services are provided to everyone, even patients who come late for treatment at the clinic, because HCPs who provide services at these outreach clinics understand that most people have different challenges, especially with accessing service in a timely way. This statement was shared by a nurse working at an STI clinic:

Sex work is stressful due to the nature of their work. Most of them come from far places and some walk because they do not have money to get on a public transport. As a result, they arrive at the hospital late. We do not send them back without serving them because doing so would deny patients their right to receive treatment and may endanger their life. (HCP10).

Service providers from Theatre for a Change and Family Planning Association of Malawi explained that FSWs tell them (HCPs) that they are happy with the services they access through their Outreach/Mobile clinics or suggest ways in which services can be improved. The statement below is an example of the narratives from some of the service providers. This statement is from an ex-sex worker who is employed by Theatre for a Change:

They (FSWs) tell us that they are happy with our services and even give us feedback on how we should improve in implementing our programmes. To us, we take this as a great opportunity and invite a few to participate when planning for future service delivery. We also encourage our clients (we do not call them patients) to share the information with their colleagues who do not come to our clinics. (TfaC4).

5.2.1.2 Home-Based care services

FSWs who have accessed Home-Based care services provided by some nurses from public health facilities, mentioned that these services gave them some meaning of life. The services included counselling, provision of ARVs and nutritional supplements. They further said that they were able to express themselves while feeling safe and confident that their discussions with the nurse or support worker will be handled in a private environment and HCPs

will maintain confidentiality. For example, a FSW shared her experiences and perceptions of the services she received:

They (HCPs) are passionate towards patients, regardless of who one is, and they encouraged me to talk to them about anything that I felt needed help with. I was extremely ill when I started taking ARVs and there was a nurse from the HIV clinic who used to visit me twice a week and she used to bring me Chiponde (a high nutritious peanut butter therapeutic food) and encouraged me to keep eating other foods like fruits and vegetables among other foods. She also encouraged me to keep taking the medicine although I was ill.... in my life I never thought a nurse from the public hospital would visit a sex worker like me. (MW/FSW11).

HCPs, especially those providing HIV services said they provide Home-Based care services to those that are not well enough to come to the clinic and do not require a hospital bed. HCPs reported that patients receiving this service have benefited a lot and have expressed satisfaction with the services because it better met their needs broadly. HCPs encourage their patients to take medication as instructed and they also leave behind their work telephone numbers for patients to contact them if they need to talk about anything regarding their treatment. One of the HIV clinic Receptionists said this:

The Home-Based care service is provided to clients who are unable to come to the hospital because they are not well enough but did not need an ongoing hospital admission care. The services are provided to everyone whether a sex worker or any other person as long as they indicated that we could do so in their consent. We encourage them to live positively and continue living a normal life, take medications regularly and eat a well-balanced diet. (HCP1).

Service providers from the organisations that took part in the study said that they believe that taking services where FSWs are more likely to be found played an important role in enhancing access to healthcare for the those who may not have an opportunity to get to health facilities for other reasons, for example, not being well enough to travel to the clinic or taking the services to their workplace as seen in the following statement from a service provider from Family Planning Association of Malawi said:

We go right there where the sex workers stay. FPAM goes straight to their localities where we provide HIV testing and counselling (HTC), family planning methods, treatment of sexually transmitted infections and general treatment. When services are provided in bars and other entertainment centres, we introduce ourselves to the owners of the place, so they know who we are and what we are doing. (FPAM1).

5.2.1.3 Convenient location of a health facility

It was important for FSWs that health facilities were in convenient locations. Convenient, in this case, included a feeling that the health facility was perceived to be providing privacy and confidentiality. FSWs accessing services from HIV and STIs clinics felt encouraged to access care services at any time without fear of being spotted by others who may breach their confidentiality as seen below in a statement shared by many FSWs. One FSW shared her experience:

There was privacy in the consultation room and that atmosphere encouraged me to be open with the doctor. The clinic is also at a place where not many people can see you and the clinic is opened early in the morning and closes late, so I can come anytime of the day, so, one is sure that she will not expose herself as being infected with a sexually transmitted infection or HIV. (MW/FSW44).

Some HCPs at the HIV and STIs clinics mentioned that patients have told them that they feel comfortable accessing services at the facilities because they believed that everyone who seeks treatment at these facilities is either HIV positive or had an STI and felt that they were not going to be discriminated or stigmatised. One of the HIV clinic Receptionists said this:

They are happy because of the environment we provide; we are open, friendly and all our patients are either HIV positive or have an STI, so we treat everyone equally. The other thing is that our clinic is at an isolated place, and we encourage confidentiality whereas at other health centres there is no privacy. (HCP1).

Service providers stated that FSWs tell them that they were satisfied and grateful for the service because Family Planning Association of Malawi/Theatre for a Change provided the services in their location or at the place where FSWs are more likely to be found. A service provider from Theatre for a Change reported this:

We have schedules where we go and visit in different bars and provide our services like condoms and STIs treatment and our clients tell us that they are happy because it is convenient for them.... sometimes we arrange with our clients to have condoms delivered to their homes. (TfaC3).

5.2.1.4 Available of resources

Participants in this study reported that availability of resources determined the type of experiences with access to healthcare services. The resources they mentioned included adequate staff to provide service, enough drugs, and condoms. For instance, some FSWs compared their experiences between healthcare facilities where they felt that their care was better in one. Influencing factors such as the facility being well staffed and having a good infrastructure, as seen in the statement below. The statement below was shared by most FSWs:

I get better help at this hospital much faster as compared to the clinic near where I live because this is a big hospital and there are many doctors. Also, I had my blood tested for HIV and I was sent for an X-ray, the department is in the hospital compound, so everything was done on the same day. This is what I like about this hospital. (FSW12).

The HCPs at the STI clinic reported that they never run out of supplies including drugs for treating HIV and STIs as well as condoms as they felt these are essential commodities which is one reason their patients are happy with the services they provide. The nurses stated that they obtain some of the supplies from the University of the North Carolina (UNC) project with whom they said they have a working relationship. A nurse working at an STI clinic said:

Our clients trust us because they are thoroughly treated. We do not send clients back without medicine because UNC project is our partner and they supply us with condoms, STI medication and some of their staff work at this clinic so, clients get their treatment in time as we are never short of staff and medicine. (HCP8).

Service providers, both from Family Planning Association of Malawi and Theatre for Change said that, because they are donor-funded projects and get support from Ministry of Health, this means that the clinic has enough supplies and so, does not run out, making it a reliable service. They also mentioned that this was the reason that most FSWs access services from both static and mobile clinics located within Lilongwe city and urban areas. One such service provider said:

Family Planning Association of Malawi gets most of its supplies from the Ministry of Health and donors as such we always have enough supply of condoms to give to all our clients (FSWs) and they are asked to come and collect them whenever they have run out and this makes them happy. (FPAM2).

5.2.2 Effects of non-governmental organisations on provision of services to female sex workers

FSWs who reported satisfaction with healthcare services, HCPs, and service providers both from Family Planning Association of Malawi and Theatre for a Change, mentioned that the existence of non-governmental organisations in Malawi has played a major role in addressing sex workers' healthcare needs by offering support to vulnerable communities including sex workers. Participants spoke of the advocacy, management of sexual and reproductive health services including HIV/STIs and empowerment of sex workers with different knowledge level and skills as contributing factors to FSWs' perceptions of positive experiences with the services.

5.2.2.1 Engaging all stakeholders on provision of services

FSWs mentioned that participatory behavioural change workshops had played significant roles in their experiences with access to care in public healthcare

facilities. When organising workshops for FSWs, Theatre for a Change include HCPs from public health facilities within the city of Lilongwe as participants. Both FSWs and service providers have commended the organisation for its effort to improve service delivery for this group of women by changing HCPs' attitudes towards FSWs. Participants shared the following statements:

They (Theatre for a Change) organise workshops which some nurses and doctors attend and when we are helped by these nurses at the hospital, they treat us very well because they now understand our problems after attending these workshops. (MW/FSW19).

Some HCPs stated the way they interact with their clients, makes patients free to express their needs and the fact that they are given an opportunity to give a feedback on the service they received, patients including FSWs felt honoured and satisfied with the services when their suggestions are reflected in the services delivered. One of the nurses working at the HIV clinic reported this:

I think it is because of our communication skills and how we deal with our clients. We are very confidential in telling them to be open with us as we are there for them. We also encourage clients to give us feedback anonymously which we include in our weekly unit meeting and improve in how we deliver our services. (HCP4).

There was a general feeling among service providers that inviting HCPs to attend workshops organised for FSWs, improved service delivery and enhanced FSWs' access to services in public health facilities. One of the service providers from Theatre for a Change said:

At first, the sex workers were harshly treated at the hospitals, we develop good relationships with HCPs by inviting them to attend our workshops and spoke with them on how sex workers should be treated at the hospital and reminded them that prostitution and being sick are not the same thing. Because of this sex workers tell us that they receive the care needed and are treated well in hospitals when treated by HCPs who have attended the workshops and, in most cases, HCPs recognise FSWs. (TfaC 3).

5.2.2.2 Sexual and reproductive health services including HIV/STI management

Some FSWs mentioned satisfaction with services when HCPs included information relating to HIV and other STIs when providing services. For example, a female sex worker said:

Apart from obtaining treatment for HIV and sexually transmitted disease, the doctors always educate me on how I should be living, I mean, I should protect myself from sexually transmitted diseases by always using condoms when I have sex. They always advised me to always eat good food. As for me, this is what all patients should have, to make them happy with the treatment one receives. (MW/FSW 40).

All HCPs who participated in this study reported that their services are organised to address the needs of women including FSWs' sexual and reproductive healthcare needs. They also mentioned that prevention and management of HIV and sexually transmitted infections is a priority when planning services. A healthcare professional from an STI clinic reported this:

Our services include education and counselling services especially regarding sex work and the challenges associated with sex work. Reproductive health services are a must for sex workers because this type of client is at high risk of most diseases associated with reproductive health, for example, cervical cancer, unplanned pregnancies, and many others you know. (HCP 7).

Service providers mentioned that their services are supported by government through the Ministry of Health. A service provider from Theatre for a Change said:

We work with District Health Hospital and the Ministry of Health and most of the things we distribute are provided by Ministry of Health and other partners who provide HIV testing and HIV treatment, contraceptives, and condoms for use in our mobile clinic and our static clinic. (TfaC1).

5.2.2.3 Empowerment

Some FSWs who were accessing services provided by Theatre for a Change or Family Planning Association of Malawi reported that being involved with these organisations had improved their knowledge about HIV prevention and they felt empowered with knowledge such that they are able to share this knowledge to colleagues and the community through drama performances. For example, a FSW reported this:

We have more knowledge about being a sex worker and how we can prevent ourselves from infections and we share this knowledge with others. Sometimes we move around with them (service providers) in the markets, perform dramas which are aimed at disseminating messages like how to prevent HIV and sexually transmitted infections, how to access HIV testing and importance of eating good food. We also distribute the condoms to people who attend these performances. (MW/FSW9).

Service providers stated that their services are participatory meaning that they involve FSWs in delivering of some services, for example, condom, contraceptive distribution and organising workshops and dramas which has enhanced behaviour change among FSWs and improved their decision making regarding STI and HIV prevention, condom use and safer sex. A service provider from Family Planning of Malawi said:

As a community worker, we took the project to them and told them to handle the project as their own. We have trained them in proper condom use, negotiate safer sex and they use condoms to prevent HIV and STI. This is evidenced by the low number of STI's among the sex workers that work with Family Planning Association of Malawi. (FPAM2).

5.2.3 Healthcare professionals' awareness of female sex workers' needs

Some FSWs described their relationship with HCPs was good because they felt that HCPs were friendly, listened to their concern and FSWs were able to access services when they needed it. One of the FSWs said:

They give us treatment on time even on weekends the clinic is open, and they do not send patients away when it is time for the nurse and doctors to go home. They also visited me at my house when I was extremely ill even though they knew I was a FSW. So as for me I am incredibly grateful to this clinic (MW/FSW18).

Those FSWs who had accessed healthcare services from Family Planning Association of Malawi health facilities described the services as being of good quality and that HCPs are caring as seen in the following statement from one FSW:

They (Service providers) are interested with our welfare, especially how we live in night clubs and how our clients treat us. So, we do tell them about our ordeals like not being paid, sometimes being beaten by clients and they advise us to report to police for any abuse. They give us condoms and encourage us to use them all the time. At the clinic, we are given medication for free because the clinic was specifically designated for female sex workers. (MW/FSW15).

HCPs working in HIV specialised facilities mentioned that, when they see FSWs requesting HIV testing, they regard that as the best decision one could make in life considering the high risk of exposure to HIV and other sexually transmitted infections these women are exposed to. For example, one of the nurses who had worked at an HIV clinic for over three years said this:

One way of managing HIV/AIDS-related issues among sex workers is to avoid stigma. The best way is to treat them well and regard them as any other person. Because of this, our clients request HIV testing and are free to ask questions regarding their treatment. (HCP 5).

5.2.3.1 Breaking down barriers and healthcare professionals' attitudes towards female sex workers

Participants mentioned that the relationship between service users and service providers influenced the experiences of patients with healthcare. A good relationship between HCPs and FSWs including service providers, were all mentioned as influencing FSWs' experiences and perceptions about the

services they received because HCPs treated them like any other patient. One FSW said:

Although the doctor knew that I was a sex worker, his attitudes towards me was exceptionally good, he asked me a lot of questions about how I survived and wanted to know more why I became a sex worker. To me, he looked very sympathetic, cheerful, friendly, and understanding and that is why I was open enough to tell him my problems to get the required assistance. He gave me a lot of drugs which cured my Gonorrhoea. (MW/FWS 33).

Likewise, another healthcare provider from a privately-run Christian hospital explained how she felt that positive attitudes of HCPs towards FSWs had an influence on health seeking behaviour among FSWs. A healthcare provider reported this:

We do not segregate or discriminate them, and we talk their language, we listen to what they say and understand what they are trying to say and through this, we have established a 'good' relationship with them. After this, there is openness amongst us, and they are treated well. (HCP 6).

Service providers said that FSWs had told them that behavioural change workshops had played a significant role in the experiences of accessing healthcare in public health facilities. They said HCPs' attitudes towards FSWs was positive after attending the workshops. For example, a service provider from Theatre for a Change who organises Behavioural Change Workshops shared what FSWs had told her regarding the inclusion of HCPs in the workshops. One service provider from Theatre for a Change said:

FSWs tell us that lately, there are positive changes regarding healthcare providers' attitudes toward our clients and they say they treat them with respect when they present the referral letter which has our official logo. They tell us that nurses give them enough condoms and counselling on how to avoid getting re-infected with HIV or STIs. (TfaC 2).

5.2.3.2 Leadership

Participants mentioned that good leadership matters in the designing and provision of a good service that addresses the healthcare needs of FSWs. One of the FSWs shared her experience and said:

They are all caring. I think the managers at this clinic supervise what is going on and sometimes when we go to receive ARVs, the doctors ask us to write down what we think the staff should do for us so that we are happy with help they have given us. I am sure they are told by their bosses so that everyone is treated the same as we all come to get ARVs whether one is married or not. (MW/FSW27).

Likewise, HCPs mentioned that the support they receive from their leadership by taking the opinions of the staff, patients, and other stakeholders into account when planning and implementing programmes, motivated them (HCPs) to improve service delivery. A clinician from one of the HIV clinics stated his gratitude for providing services of high quality to the patients that he cares for every day. This is what he said:

The willingness of management to encompass, staff opinions, clients' opinions, and other stakeholders' opinions. This helps us to improve our services other than incentives we get. Sex workers are a peculiar cohort, if you bring them together and help discuss their own issues and hear from them, I think you can have an overview of what they want to be done to them and how to go about it and this is exactly what is done at this clinic. (HCP 3).

5.3 Summary

The findings of the Study 1 show that a wide range of factors influenced FSWs' positive experiences. This included improving access to healthcare, effects of non-governmental organisations on services to FSWs and professionals' awareness of FSWs' needs. The importance of the direct and indirect expenses associated with access to services, for example, avoiding paying for public transport was another factor positively affecting experiences.

The findings of the study show that access and availability of outreach and home-based care services influenced the positive experiences of FSWs. In addition, the location of the facility, good leadership and availability of human and material resources had a significant influence on the positive experiences.

FSWs' involvement in planning and implementing some activities organised by Family Planning Association of Malawi and Theatre for a Change, such as drama performance as a way of disseminating information on HIV/STI prevention, HIV testing and behaviour change influenced their positive experiences because FSWs felt valued and were empowered with new knowledge that they were also able to share with others and this enhanced how knowledge spread among FSWs. Moreover, HCPs' and service providers' attitudes and knowledge about the needs of FSWs played a role in FSWs' positive experiences with access to care. The next chapter describes the findings of Study 2.

Chapter Six: Research Findings of Study 2

6.0 Introduction

This chapter presents the Study 2 findings that emerged from the phenomenological interviews conducted with FSWs in Malawi. This chapter will provide a brief overview of the findings, then describe the participants and present the detailed findings. To summarise, 25 FSWs were included in the face-to-face interviews. The face-to-face phenomenological interviews explored FSWs' perceptions and experiences of access to healthcare services. Semi-structured interview questions were utilised to collect data from FSWs. In some cases, quotations are lengthy to incorporate contextual data whilst others have been edited to include only information relevant to the theme and omitted text is represented by ellipses (...).

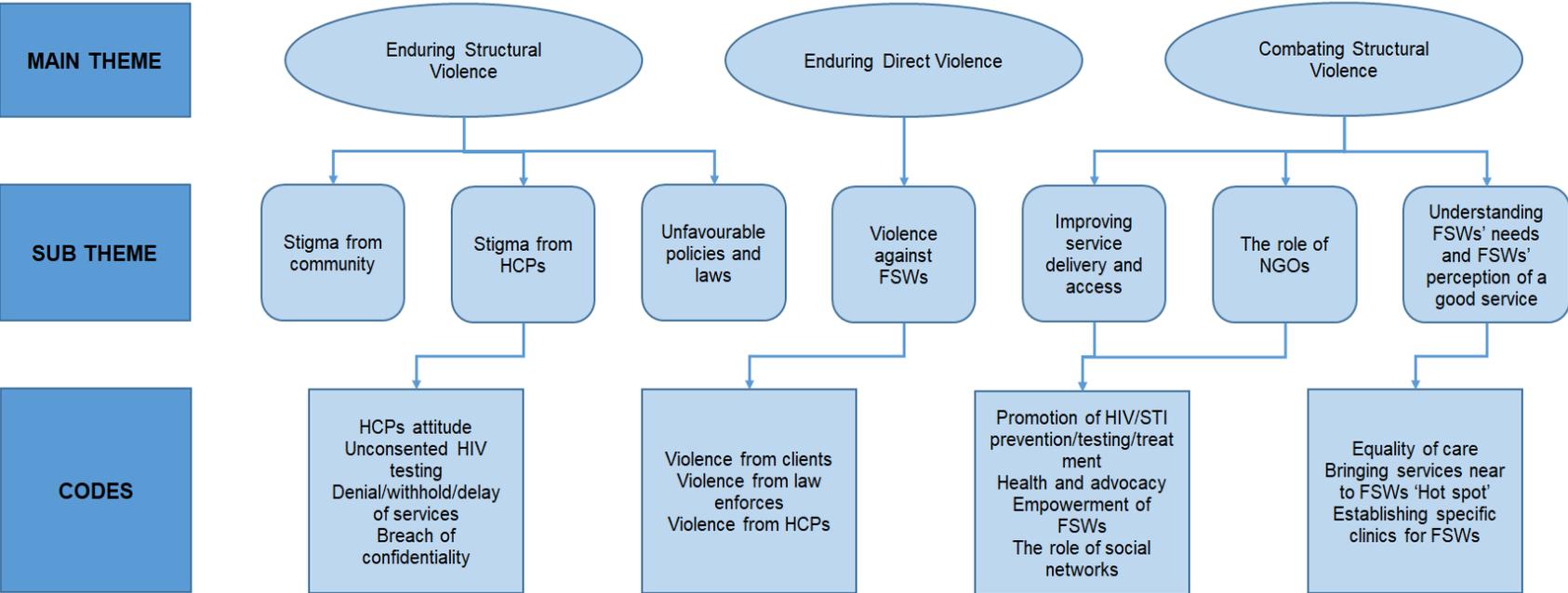
A descriptive phenomenological analysis was undertaken drawing on Colaizzi's data analysis model (1978). The audio-recorded interviews were listened, transcripts were read and re-read, and conceptual patterns were highlighted leading to a composite description of concepts that presents the 'essence' of FSWs' perceptions and experiences of access to healthcare. Three main themes emerged from the data based on the research questions:

(a) Enduring Structural Violence, (b) Enduring Direct Violence, and Combating Structural Violence.

Seven important sub-themes were also identified, and these are: (a) Stigma from community, (b) Stigma from healthcare professionals, (c) Unfavourable policy and laws, (d) Violence against female sex workers (e) Improving service delivery and access, (f) The role of non-governmental organisations, and (g) Understanding female sex workers' needs and female sex workers' perception of a good service.

Figure 6.1 below illustrates the main themes, sub-themes and codes identified during descriptive phenomenological data analysis.

Figure 6.1 illustrates the main themes, sub-themes and codes identified during descriptive phenomenological data analysis.



The following section presents FSWs' characteristics.

6.1 Participants Characteristics

25 semi-structured interviews with FSWs living with HIV and those with unknown HIV status were conducted. FSWs included those who have used services provided by Family Planning Association of Malawi or Theatre for a Change and those who had no access to these service. FSWs aged 18 years and above who declared themselves as sex workers participated in the study. The youngest FSW was 19 and the oldest was 42 years. The number of years in sex work ranged between one and 25 years.

15 FSWs mentioned accessing services provided by Theatre for a Change, five accessed services provided by Family Planning Association of Malawi and five were non-users of both of these services but had accessed services from other health facilities. However, all 25 FSWs had accessed services from public health facilities at some point while working as sex workers.

17 FSWs were living with HIV and reported knowing their HIV status while accessing healthcare services and they were all on treatment for HIV. Eight FSWs reported that they were HIV negative. All FSWs mentioned that their experiences with access to healthcare was influenced by the sex work rather than their HIV status or the number of years they have been in the sex work industry. The next section presents the emergent themes from the data analysis.

6.2 Enduring Structural Violence

Structural violence is a concept for a form of violence wherein some social structure or social institution may harm people by preventing them from meeting their basic needs. FSWs experienced specific forms of violence even outside their work setting because of their work, such as violence and harassment by neighbours, the general public and the police as well as discrimination and abuse in health settings. Violence denies sex workers their fundamental human rights to equal protection under the law, protection against torture degrading treatment and their right to the highest, attainable standard of health. This section presents factors that contribute to the persistent

violence that FSWs experience. The violence experienced by FSWs stems from social structures such as communities, clients, and HCPs with whom FSWs interact in Malawi, created inequality and suffering on multiple levels. The inequalities and suffering described by FSWs unfolded in terms of stigma and unfavourable policies which had a wider impact on FSWs' perceptions and experiences with access to services. The inequalities described in this section are based on the data collected from the semi-structured interviews.

6.2.1 Stigma from community

Communities have an influence on the well-being of their neighbours in general. Semi-structured interviews reveal that most FSWs were living in fear of discrimination and disapproval from families and friends once their involvement in sex work is known in the community. Some FSWs reported that, due to stigma surrounding sex work, their neighbours did not care for them when they were ill because some women in the communities believed that the illness was a result of one's bad behaviour. One FSW shared her experience of how stigma affects her whole life as she said this:

From my experience being a sex worker has a lot of effects on my access to healthcare services. One, when you are a sex worker, everyone thinks you deserve what you got.... the community including Religious Leaders thinks a sex worker is full of demonic spirits.... all sex workers have HIV and other sexually transmitted diseases.... when you are ill you need help to get to the hospital neighbours blame you for the illness even neighbours who work at the hospital do not want to help you. (FSW3).

A FSW who disclosed her HIV status to one of her neighbours reported this:

Its hard life. I get all sorts of abuses and for some reasons, my neighbours know that I am HIV positive, and they always talk bad things about me. Like, the other time I had Malaria and really very ill but none of them came to see me or take me to the hospital. I overheard two women saying, 'she is paying up for her immoral behaviour, I hope she repent her sins before she dies.... I was even afraid to go to the hospital because I thought I might meet someone who knows that I am a sex worker and tell the doctor not to treat me. (FSW2).

In some instances, FSWs felt that the stigma and discrimination from the community were even affecting their children's life. For instance, some FSWs shared experiences where they have had to move places of residence to try and protect their children's future.

My neighbours know what I do, and they tell their children that I am a prostitute, and they should not play with my children because they smell. I have move places twice, but things do not seem to get better. I know my children are emotionally affected when they hear these things and I worry about them. (FSW9).

The interviews also revealed that stigma from the community affects both their social and religious life. Others reported that they have chosen to accept the violence and just live with it. One FSW said:

I know people talk about me being immoral, and when they see me going to church, they tell me that I should not waste my time going to church and when I sit with them on the same bench in church, they leave the bench, but it does not bother me at all because it is my body that I am using so I just let them talk whatever they want to talk. (FSW18).

Other FSWs have reported that they live in fear because of death threats resulting from stigma associated with sex work. A FSW reported this:

My neighbours do not talk to me, and they always say bad things about me when they see me. They always say they will kill me if ever they have a chance and if I snatch one of the husbands of the women where I live I always live in fear. (FSW25).

6.2.2 Stigma from healthcare professionals

Structural violence, in this study, highlights the overlapping experiences that influenced FSWs' encounters with healthcare services. Furthermore, structural violence was defined by the negative power between the health facilities and the delivery of services to FSWs. Most FSWs mentioned being stigmatised and discriminated by HCPs, mainly in public healthcare facilities. The

interviews revealed that there is a generalised assumption among HCPs that all FSWs are infected with STI including HIV:

My own experiences prove that FSWs can be treated differently from other people who are not sex workers. Imagine, this nurse who said she would not be surprised if my blood test will come positive when I wanted to have my blood tested for HIV after I was raped. I do not think she would have said this to a 'normal' woman who reported being raped. She scolded me because I said I was a sex worker... I believe, in her own mind she does not think a sex worker can be HIV negative. (FSW13).

In some cases, FSWs mentioned that stigma from HCPs impacted their rights to access service and that the HCPs' demeaning and humiliating actions force them into not seeking services from public health facilities as seen in the statements from one of the FSWs who reported negative experiences and her perception of the services provided in one public health facility:

The nurse that I found at health centre had previous knowledge of my sex work because I live in the same locality with her. I was received with abusive words. She said this in front of everyone else: "This is a prostitute who sleeps with every man she even sleeps with mentally ill male patients as long as she can get money. Now the mad man has cut through her thigh, and she is coming here for what? She needs to be taught some lesson. Just stitch her without any local anaesthesia, so she can feel the pain and do not even give her antibiotics, she can afford to buy she has a lot of 'satanic money". She went on saying, "Be careful when stitching her she might infect you with HIV." I have never gone back to this clinic now for two years because of how I was treated. (FSW3).

Likewise, another FSW said:

A nurse came to start helping us and then she saw someone who she knew she was a sex worker, and she frowned her face and said, "all sex workers please make your own line, I will attend to these other people first because they have things to do at home and others need to go to work". This was so embarrassing, and it made me feel so bad that I decided not to go to this clinic anymore. (FSW 8).

Others mentioned that, because of the stigma around sex work and the assumptions that every FSW is HIV positive, HCPs refused to believe FSWs when they told the HCPs that they were HIV negative. One FSW shares her experience:

I went to the hospital because I had malaria-like symptoms and vomiting. I also had a smelly vaginal discharge for a few days and decided to get some treatment. The asked me if I was a prostitute and I had HIV. I told her that I had tested negative a month ago, but she did not believe me. I told her that I do get regular health check-up and screening for HIV/STIs. She then told me that if I wanted her to give me treatment, I have to get tested for HIV first. After all this is our policy here. Because I was in pain, I agreed and when the results came out negative, she said 'tell me what you did that a prostitute like you can be HIV negative'. I found her attitudes was not that of a caring nurse. She then gave me some tablets and she did not even explain whether they were for the vaginal discharges or the malaria. (FSW9).

6.2.2.1 Healthcare professionals' attitudes toward female sex workers

HCPs' attitudes played a significant role in FSWs' perceptions and experiences with healthcare in this study. Some FSWs mentioned that, in most cases, they failed to disclose their sex work status to HCPs in public healthcare facilities for fear of being shouted at. Most FSWs reported that majority of nurses were often judgmental once FSWs disclosed their involvement in sex work. The statements below were shared by the majority of FSWs in this study:

They (nurses), in public health facilities, have a bad attitude; they shout at us and question us - why we got HIV when condoms are readily available and why we were doing sex without a condom? And sometimes telling you that you smell of sperms. Such behaviour is the one that makes some of us not to go to these clinics. (FSW6).

The experience was very bad. The nurse I found at the health centre started asking me some unnecessary questions instead of helping me as I was in pain. She asked where was I assaulted and raped and at what time? I said I was raped at 10.00pm as I was doing my work. The nurse then asked me what type of work I do? I said I was a sex worker..... I was called names like 'hule'

[prostitute] and refused to treat me and told me to go and report to police about being raped and assaulted. She even said, “you be lucky if the police will even believe a prostitute like you has been raped”. (FSW5).

In some cases, FSWs reported that, because of the hostility and humiliating attitudes of the nursing staff, FSWs were blamed for being irresponsible and that, being infected with HIV and STIs or being raped, is because FSWs deserve what they get. One FSW who shared her experience during her previous pregnancy a couple years ago said:

The health surveillance assistant asked me where my husband was, and I told her that I was not married. She then said, ‘who gave you this pregnancy’? I said I am not sure. Then she said “Oooh, so you are Mayi Maria (Maria of the bible, the mother of Jesus) who got pregnant without sleeping with a man?” I said, “No I am a sex worker.” She then laughed loud..... and said, “a sex worker who does not use a condom, gets pregnant and HIV as payment for selling her dirty vagina you are a disgrace to all the women, especially your own mother.” I told her how I became a sex worker, but she did not believe me, and she even accused my parents of dying from AIDS. She said, “The baby I was carrying and myself were going to die with AIDS like my parents.” (FSW12).

Another FSW who went a public health facility after being raped by a client said:

I have been raped once by a client and when I reported to the hospital, the nurse refused to treat me, instead, she asked me very demeaning questions like “Mmmh how come that you as a prostitute can you even think of being raped? Is selling sex not your day to day bread and why complain? Where did they rape you, in your mouth because if the man did it in the right place, why would you say you are raped, did you not ask for it.... we do not treat prostitutes here.” (FSW7).

6.2.2.2 Unconsented HIV Testing

Most FSWs reported being unhappy with the way the HIV testing was conducted. The incidences were cited in public health facilities. In many

instances, FSWs were informed that HIV testing was a prerequisite to receiving any treatment. Most FSWs reported that they were not given an option to decline or postpone the HIV testing until such a time they felt ready to have the test. Semi-structured interviews reveal that lack of informed consent resulted in insufficient provision of pre- and post-test counselling which is essential for initiation, adherence to treatment and HIV care continuum. The statements below are some of the experiences shared by most FSWs who reported being forced by HCPs to have HIV testing:

I went to the hospital because I had excessive smelling vaginal discharge to get treatment.... when I arrived at the clinic, I explained my problems and she (nurse) examined me, and she confirmed that I had gonorrhoea and that I needed treatment. She said she was going to test me for HIV, but she did not explain the reason.... I agreed reluctantly because I was not ready for the test and I feared that if I refuse, she might not give me the treatment, but when the results came out, I was happy. (FSW17).

When I was pregnant with my second child the nurse at antenatal clinic asked me to have my blood tested for HIV and she said it was the government policy to have all pregnant women tested for HIV and that it was not a matter of 'yes or no'. So, she sent me to a female health surveillance assistant who tested my blood. (FSW12).

6.2.2.3 Denial/withhold/delay of services

FSWs mentioned that denial or withholding or delay of services was influenced by negative attitudes of the HCPs towards sex work. Semi-structured interviews indicate that denial or delay of services played a crucial role in FSWs' perceptions and experiences with access to healthcare. The majority of FSWs reported that HCPs allowed their own moral judgements to interfere with their professional mandate to provide service to all people without prejudice. FSWs reported a number of experiences as seen in the following statements:

The nurse asked me if I had children, I told her yes. She then said, "You are a sex worker and have children, how possible is that?" I did not answer because I did not understand what she was asking me.... "I have asked you a simple

question and you are failing to answer, no wonder you allow men to sleep with you without a condom and infect you with HIV.” She then continued insulting me as I kept quiet. After she finished shouting at me, I asked her whether she was going to give me the treatment or not? She said it was my choice and not hers and if I felt she was not going to give me treatment, I was free to go and ‘die’ with my chest infection which she said was related to HIV..... she threw the blood results at me, walked out of the room, and left me alone. I waited for her to come, and she did not come back, and I could hear her chatting to her friends, and I knew she was talking about me. After 15 minutes I left and went back home without treatment. (FSW15).

When I was raped, my experience was horrific at this public clinic. The nurse I found on duty asked me when and where was I raped? I told her that I was raped around midnight during my usual job. She then asked me what type of job that was. I told her I was a sex worker, she then looked at me and called the nursing assistant who was in the other room shouting her name and saying, “Come and see these shameless ‘hule’ (prostitute) as old as she is, she can afford to open her legs anyhow. Shame on you.” The assistant asked me another silly question, “Do you have children?” and I said yes and then she said, “I bet they are also prostituting like you.” They both said I was a disgrace to all women and that I was careless and irresponsible that is why I was raped. They told me to come in the morning and said health services in the night are not for prostitutes and they ordered me to leave immediately before they call the police to arrest me. (FSW 10).

In some instances, FSWs who tested HIV positive or those with other conditions at public health facilities, reported hostility and being humiliated by some HCPs resulting in delay, withholding of treatment, or not providing information regarding treatment:

The nurse asked about my marital status of which I said single. She then asked what job I do which I said I was a sex worker. Immediately her expression on the face changed and said my days to live in this world are numbered because I will die soon..... and when I entered the doctor’s room, he also asked me about my occupation, and I said I was a sex worker. He started insulting me saying, “You are the ones infecting people in this town and now you are

claiming that a man had sex with you without a condom. Who do you think you are lying to, you sex workers you like to have sex without condoms because you demand higher pay?” He then told me to wait until everyone else is seen. I was finally started on ARVs.... when I asked him how to take the ARVs, he was harsh and shouted to me, and said, “Go and read the instructions” so I left without asking any more questions. (FSW7).

Some FSWs reported that they felt that nurses in public healthcare facilities refused to give them medicine or to attend to them once their FSW status was known to HCPs. In some cases, FSWs were told to go and buy medicine. The experiences below were shared by the majority of FSWs who participated in this study:

The experience at this public clinic was bad, and it was at night, you know nurses do not like it to be disturbed at night, so I was shouted at and told to come in the morning with a police report or go and buy the medicine since sex workers make a lot of money from selling their body. I did not go back to the clinic because I knew they were going to send me back until I get a police report. I did not even go to the police because I was afraid, I might be arrested or even raped by police offices. (FSW17).

I told the nurse at this public healthcare facility that I am a sex worker and I had just been raped an hour ago. She refused to give me PrEp unless I have HIV test because she has never seen any sex worker who is HIV negative, and PrEp will not be of any use for someone who is already HIV positive. She said, “Come during the day and you will be tested in the morning because here we do not provide such services in the night and also, we do not attend to sex workers because you are evil people.” (FSW24).

6.2.2.4 Breach of confidentiality

Breach of confidentiality was one of the factors that influenced FSWs’ perceptions and experiences of healthcare services in public health facility. The majority of FSWs mentioned that their personal privacy was breached by HCPs when they were asked personal questions that had no connection to the care they needed. For instance, one of the FSWs said:

I said I was a sex worker.... this is what the nurse said to me in the presence of other patients and the nurse said, "This is a sex worker (hule) who has been out there snatching other women's husbands and sleeping with them without a condom. Now she has been infected with HIV and Gonorrhoea. I just do not know how many men she has infected. She is a disgrace to us women." She threw the blood and other results to me and said, "Go and see the Clinical Officer to treat that infection of yours." She did not even tell me which room I should go because the clinic has several consultation rooms. (FSW12).

In some cases, FSWs said they avoided going to the nearby clinic for fear of breach of privacy and confidentiality and travelled longer distances to access services where they felt no one would identify them. The following statements were shared by FSWs who mentioned that HCPs in public healthcare facilities were in breach of patients' confidentiality.

You know it is embarrassing to be seen as a FSW, especially if the HCPs know you personally. I feared that if I am attended by someone who knows me, I might be treated badly. What I am saying here is that some HCPs are good, but some are very rude, they tell others that you are a FSW and that they should discriminate us. Such things make you not want to go to hospital especially government hospitals where nurses are so rude, and you end up going to a clinic which is far from where you live. (FSW6).

After I was raped by the three men, I explained to my best friend that I was raped, and she advised me to seek medical help and get tested for HIV and Gonorrhoea. I told her that I was scared to go to the clinic near where I live because nurses at this clinic are known for their abusive attitudes towards patients regardless of whether someone is not a sex worker. She advised me to go to another clinic outside our community and tell them that I live in that community near the healthcare facility. She offered to escort me to the clinic. So, we went to the clinic and got some help. (FSW13).

6.2.3 Unfavourable policies and laws

Almost all FSWs in this study stated that they have been harassed by police in the course of their work and that this affects their seeking services provided by the police and this has negative consequences on their health and

wellbeing. Most FSWs mentioned that they have not reported assaults and sexual abuse from clients for fear of arrests and being physically or sexually abused by the police officers. FSWs said because they have not reported the assaults to police, some health facilities have refused to provide a service: For instance, one FSW said:

HCPs ask us to get police report when we are assaulted before they can give us treatment.... they say it is the hospital policy that anyone who come to the hospital for treatment following an assault should bring a police report.... they have bad policies at this clinic. (FSW25).

In some instances, FSWs said they were unhappy with some HCPs from public health institutions who request FSWs to bring their husbands or sexual partners while seeking treatment for sexually transmitted infections. They said that it is not feasible to trace their clients as they have sex with many clients. Moreover, clients of FSWs may not want to be identified with a sex worker. FSWs said, such police are some of the reasons they have negative attitudes towards services provided in public health facilities. One FSW said:

Staff at the hospital should stop asking us to bring our sexual partners when they know that we are sex workers, we sleep with so many men and most of them are married people. Such people will not want to be associated with sex workers. They should stop threatening us that they will not give us treatment for sexually transmitted infections if we do not bring our sexual partners and tell us to go and buy medicine when we say we cannot bring the clients to the hospital. This encourages people to infect others if they are refused treatment. (FSW24).

6.3 Enduring Direct Violence

Realising the human rights of FSWs requires an understanding of the intersecting factors that affect their safety and their protection from violence. Semi-structured Interviews reveal that FSWs experienced acts of violence from clients, law enforcers and HCPs. Furthermore, the interviews identified that prejudice or stigmatising attitudes towards FSWs as well as the use of misinterpretation of the laws by the law enforcers regarding sex work in Malawi was one reason FSWs perceived their experiences with access to services as

negative. The sections below present how FSWs described the violence perpetuated at different levels.

6.3.1 Violence from clients

FSWs reported experiencing physical, sexual (rape, and unconsented unprotected sex) and psychological violence (non-payment of sexual services and verbal abusive words) used with intent to exert control over them. The statements below describe how some FSWs experienced violence from their clients in the course of their work. The abuse ranges from financial to sexual or physical abuse.

Most of the times we have problems regarding payment after sex. A client will agree to give me what we have negotiated but after sex he pays me less than what we agreed claiming that I am not good enough and I did not satisfy him or that I refused to have sex from my backside or oral sex. There was one time I was beaten on my face as you can see the scar on my upper lip because a client was forcing his thing (penis) into my mouth and accidentally I bit his thing. He called me all sorts of names and threatened to kill me. I begged him not to kill me and he threw me out of his room, kicked me in the stomach and I did not go to police for fear of arrest. (FSW8).

I was once picked up by a man in a posh car and he told me he was taking me to one of the hotels in town where he was staying as he had travelled from another city in the south. Surprisingly, he drove at full speed out of town and stopped after a few miles where he picked two men and I thought to myself, well, this is it for me, I prayed and prayed as they tortured me in every way you can think of while the driver was still driving. I was scared and cried, they told me not to cry but enjoy the torture because that is what sex work is all about. After a while, the car stopped and I was raped by the three men, I was forced into oral and anal sex for over two hours each taking turns, I was in so much pain and I pleaded with them, but they did not listen to me all they did was laugh and make fun of me. After they had achieved their satisfaction, they dumped me on the roadside and they all disappeared, I was too weak to walk or ask for help. I lied there hopelessly until morning when a woman going to

the garden saw me lying helplessly and.... She took me to the nearby health centre where I was helped. (FSW13).

6.3.2 Violence from law enforcers/police

Sex work is generally perceived as illegal in Malawi. Semi-structured interviews reveal that police officers abuse the power entrusted to them and do not adhere to the legal recommendations for arrests. The majority of FSWs mentioned that police officers have contributed to the problems faced by FSWs both in the health service delivery systems and in the community in Malawi. Others said that police officers deny FSWs justice and or take advantage of their vulnerability (like demanding sex) to access a police report following an assault in the course of their work. Experiences presented here are shared by many participants in this study, who suffer at the hands of police officers:

One day I was arrested for no reason by a police officer, and he demanded money from me to avoid being taken to the police because I had broken the law.... I gave him all the money that I had earned that night because I did not want to get arrested. (FSW11).

I was arrested by a police officer during their normal raids. I was accused of loitering and the police officer said he was going to take me to cell. I pleaded with him to release me as I had small children at home and, if I am in a cell, they will have no one to look after them.... I continued pleading with him to release me. I gave him the money, my phone and he dragged me into the nearby bush and raped me and forced me to have oral sex. I was helpless and I did all this because I did not want to go to cell for the sake of my children. (FSW18).

For those who had reported their assault or rape to the police reported that, they felt let down by the police officers when they needed protection and support. FSWs mentioned said that in most cases, police officers behaved unprofessionally, as seen in the statements below:

I went to the police station to get a police report following a rape incident, instead of supporting me and trying to ask me if I knew the people who raped me, three police officers raped me again and they did not use any condoms.

In the morning I was given the report and they said abusive words regarding the rape and one police officer said he has given me HIV and that I should start taking ARVs. (FSW5).

I went to report to the police to report the assault, but instead of giving me a report to take to the hospital and investigate my case, they started harassing me and telling me that I was lying to them, maybe I was fighting with my fellow sex workers for a man, or someone's wife has beaten me because I was going out with her husband. They told me they have real problems to work on and not dealing with prostitutes' issues and asked me to get out quickly before they put me into a prison cell. So, I left without any help. (FSW8).

6.3.3 Violence from healthcare professionals

FSWs present unique health challenges and fear of stigma from HCPs which may be serious barriers to accessing healthcare. The interviews revealed that the majority of FSWs reported discrimination, rude remarks, or denial of services from HCPs. Most FSWs mentioned that, because of some HCPs' stigmatising beliefs and attitudes about them, FSWs could not openly engage with HCPs. They also said that, in most cases, the service they received was not up to their expectations. In such situations, FSWs perceived their experience with healthcare as negative. The interviews further revealed that the violence from HCPs was mainly experienced in public health facilities.

In government health institutions you are treated like an outcast and blamed for the of spread HIV/AIDS. If you are lucky, they will give you Aspirin or Panadol even if you say you have Gonorrhoea. (FSW2).

HCPs have bad attitudes, the worst of them are nurses, their attitudes for most of them is offensive. The discrimination, the way they address us (sex workers) and worst when they know you are HIV positive; others do not even talk to you. They say they do not want to associate themselves with dirty, evil creatures. Imagine someone being called an animal or a dog, would you even have the courage to go back to that clinic? (FSW10).

Some FSWs reported experiencing violence in the form of breaches of confidentiality among nurses as seen in the statements from some FSWs:

In some healthcare facilities, nurses make announcement in the midst of everyone else saying “Those with sexually infections and HIV go to room number 6” for example. This is not good because everyone will be talking about you, and this made me not go to that clinic anymore. (FSW9).

The nurse asked me whether I was married, and I told her that I was single, and I told her that I was a sex worker. The nurse then said rudely, “So you got this pregnancy from prostitution” and I said “Yes.” The nurse and her assistant they both laughed loudly that brought attention to other patients and all were looking at me strangely wondering what was going on. I felt so hurt about their reaction that I do not go to this clinic anymore. (FSW16).

6.4 Combating Structural Violence

Realising the importance of reducing structural violence requires an understanding of the intersecting factors that affect FSWs’ experiences and perception of health services and their protection from violence. Violence against FSWs has lifelong and life-threatening consequences for their physical, mental, and sexual health as well as significantly increasing their risk of HIV infection. This section presents FSWs’ perceptions and experiences that they mentioned as decreasing sex workers’ exposure to violence and HIV risk. Factors include improving service delivery and access, the role of NGOs and awareness/understanding of FSWs’ needs and their perception of a good service. The study identified that some HCPs (in public and NGO) health facilities delivered services that FSWs perceived were necessary to address their needs. In such situations, FSWs reported positive experiences and their own perceptions of a good service.

6.4.1 Improving service delivery and access

Some FSWs mentioned that being able to engage with HCPs was one of the reason their experiences and perceptions of healthcare was positive. Semi-structured interviews reveal that some HCPs from both public and non-governmental or private health facilities were providing service that FSWs perceive as good. FSWs described the nurses as having a positive attitude towards their patients regardless of the patient’s status. A FSW said:

I told a male nurse at the public clinic that I have been raped by a policeman and he has taken my phone and my money.... he examined me and gave me PrEp and he also gave me antibiotics and advised me to have my blood tested for HIV whenever I was ready.... he let me stay in a small spare room within the clinic until morning, he gave me some money for transport when it was time for to go home. He was very kind person and I thanked him so much for what he did to me. (FSW18).

Other FSWs said because they were able to engage with HCPs, they had no reason to hide their involvement in sex work. The statements below were shared by most of the FSWs who reported satisfaction with the service they received from their preferred healthcare facility:

The nurses' attitudes and the way they spoke to me made it easier for me to tell them that I was a sex worker.... they did not ask me anything regarding sex work or said anything bad about me. I was given the right treatment for my health problems because I got better after taking the medicine. Their attitudes showed that they are good people. (FSW4).

The nurse at the HIV clinic reassured me after I tested positive for HIV for me to live like anyone else.... she also told me not to have sex without using a condom and to continue eating well, to avoid excessive alcohol intake as this has a potential of exposing me to unprotected sex due to being drunk. I felt that the staff at the clinic were very helpful and supportive because they all seemed caring. (FSW19).

Some FSWs provided some advice on how the best services could be delivered to increase FSWs' accessibility to services especially in public health facilities if FSWs' experiences and perceptions of the services are to change. FSWs who said this were comparing their experiences and perceptions of services provided by NGOs and public health facilities which FSWs considered as good services. One FSW said this:

HCPs should be trained on how to handle sex workers like what Theatre for a Change train their staff and us because we, as FSWs, rely on nurses to treat our different problems... FSWs should be invited to give their testimonies on how they are treated by some HCPs, especially nurses. (FSW23).

In some instances, FSWs suggested that HCPs' attitudes and the way they work in public healthcare facilities of HCPs was indicative of the lack of governmental commitment to supervise the healthcare services. The statements below are examples of what some FSWs said:

Bad HCPs attitudes are the main problems, and the way clinic are run. They open at 0730 but sometimes they do not start helping people until after 09.30 and close the clinic at 12.00 noon until 1430hrs and then close around 1530 hrs. So, there is not enough time to see all the patients. They spend time chatting among themselves and not bothered about patients even when someone is very sick, they do not care to help her. This is all because of government lack of commitment to providing a good service and they need to copy what other institutions such as Theatre for a Change and Family Planning whose services are the best compared to public health facilities. (FSW14).

The problem is the government, they do not care about the health of the people and especially sex workers. For us to access good care, the government need to accept that sex workers are present in Malawi and ignoring their needs means putting the whole Malawi at risk because the people who come to us most of them are married people. So, the government should advice HCPs, especially nurses, to be friendly to patients and give us proper care. Also, when there is shortage of staff and medicine the government should employ more staff who are committed to provide care to everyone without segregation and buy medicine for the hospitals to give the patients. This is what I can call a good service because we will all be able to access treatment we need. (FSW21).

6.4.2 The role of non-governmental organisations

NGOs play a crucial role in clinical management and psychosocial support of sex workers in Malawi. This role extends from the provision of SRHs including HIV/STI management, health and advocacy, empowerment of sex workers to the role of social networks. In order to deliver on this, the NGOs, and the government, through its Ministry of Health, have to work cooperatively and complimentarily. Semi-structured interviews show that FSWs who accessed services provided by Theatre for a Change and Family Planning Association

of Malawi felt that accessing these services reported positive experiences and perceptions of the services. The following section presents how FSWs described their experiences with health-related services provided by the NGOs at different levels.

6.4.2.1 Promotion of HIV/STI prevention/testing/treatment

Most FSWs said Theatre for a Change provide more friendly services and they opt to access these services rather than seeking services from other public health facilities where they faced discrimination. Others said that every time they are seeking treatment, they are counselled before and after being tested for HIV and STI which most of the FSWs reported as being a better way of dealing with their health needs. A FSW reported this:

For example, there is this organisation (Theatre for a Change) which I am a member their services are specifically for sex workers. We work with them, and we are free to tell them our problems and they give us good treatment... if we have other problems which require treatment at the big hospital, they send us there... they encourage us to always use condoms to prevent further infections and they give us a lot of condoms. (FSW3).

Another FSW said:

They (Family Planning Association of Malawi and Theatre for a Change) do a lot of things for us sex workers. The nurses give us contraceptives and explain how to take them. Before they start the clinic, they tell us how to prevent contracting HIV and other infections by consistently using condoms. They encourage us to have HIV testing and explain to us the importance of HIV testing (FSW1).

6.4.2.2 Health and advocacy

Working together, the government and NGOs are mandated to ensure that they minimise violence among FSWs and provide the services that address FSWs' specific needs. Semi-structured interviews show that regular meetings through workshops with FSWs, police officers and HCPs from public health facilities reduced police harassment and ensure better access to justice. FSWs

mentioned that these workshops build relationships between FSWs, HCPs and police officers to minimise violence. A FSW accessing services provided by Theatre for a Change said:

Theatre for a Change organise workshops in consultation with sex workers on the topics to be discussed. They also invite police officers to attend these workshops. After listening to the concerns FSWs face at the hands of police officers, some police officers have changed the way they treat us. For example, I was once rescued by two police officers when a group of young men wanted to steal my phone.... these police officers had once attended the workshop which I also took part. (FSW10).

Other FSWs reported that, in most cases, the workshops are organised and led by FSWs themselves with the help of Theatre for a Change staff as seen in the statement from one FSW:

Staff from Theatre for a Change are well organised because we are the ones who decide on what health promotion messages to include in the drama or workshops that we conduct. Sometimes we are facilitators of workshops, and we can educate our peers which has positive effect because we talk from experiences. People from Theatre for a Change know that FSWs have first-hand experience with the issues experienced by FSWs, and we can therefore reach to other FSWs easily and more effectively. (FSW2).

Some FSWs mentioned that carrying referral letters from Theatre for a Change or Family Planning Association of Malawi helps to reduce violence and stigma from HCPs. This perception was shared by almost all FSWs who have accessed services from Theatre for a Change or Family Planning Association of Malawi:

I was referred to a public hospital with a letter. The experience was very good because the doctor who helped me had attended the workshop at Theatre for a Change offices and he recognised me and the logo on the referral letter. I think it is because they understand our problems after attending our behaviour change workshops. HCPs are told by the workshop organisers that we have the same rights as any other person in this country. (FSW3).

When we are referred to public hospitals and show the referral letter with Theatre for a Change logo we are treated well because they understand our problems. (FSW9).

Other FSWs mentioned that they are involved in distribution of contraceptives and condoms and said this was one reason they perceived services to be good because they felt that management at these organisations were committed to instil a sense of ownership of the programmes among FSWs. FSWs reported that their positive relationship with Theatre for a Change staff fostered their desire to engage in positive health-seeking behaviours which resulted in some becoming peer distributors of condoms and some other contraceptives as seen in the statements below shared by most FSWs:

There are a lot of activities that we as sex workers are involve. For example, I help with running of the clinic, giving my fellow FSWs condoms, contraceptive pills, counselling them on how to avoid places where they are more likely to face violence and to use female condoms because the client will not notice that they are using a condom and it is safe for them from those client who want to have sex without a condom. (FSW7).

Yes, look at what is happening here (Theatre for a Change static-mobile clinic) all these are sex workers, and we are all happy including the staff and as you know some of these women giving out condoms are fellow sex workers. You also saw two FSWs giving health talks at the beginning of the clinic. Here we work together; we are not segregated, and we speak the same language with the staff, they value our contributions. (FSW15).

In other instances, FSWs said that workshops organised for sex workers were also attended by chiefs and other community leaders. FSWs reported that attendance by chiefs and community leaders has helped to improve their relationships with the community and their neighbours. Semi-structured interviews show that FSWs were able to describe their experiences within the community to enhance understanding of the importance of supporting the FSWs. The statement below was shared by a FSW:

My block leader (chief) from where I live has changed my neighbour's views on sex workers after attending the workshops. He conducted regular meetings

with the community on health issues which he includes support for people with special needs and he specifically mentions FSWs as people needing support and not segregating them. He is a very good man and has influenced a positive relationship with community. (FSW 20).

6.4.2.3 Empowerment of FSWs

Semi-structured interviews reveal that empowerment strategies used by NGOs were advocated as a mechanism where FSWs achieved some power to overcome the violence from communities, HCPs, and the police. FSWs also, gained the agency to address their HIV vulnerability. FSWs described themselves as being empowered with a range of knowledge and skills gained through interactive workshops and participatory interactive theatres which they can easily share with the community to influence community views on sex workers. Some FSWs shared their experiences as seen in the statement below:

Theatre for a Change empowers us with knowledge that we can easily share with others. Sometimes we also perform some drama at public places like at the market or at the clinic where most people attend, and we encourage the public to ask us any questions.... we tell the audience real stories and how sex workers survive the abuse from clients (FSW12).

They felt that the knowledge gained from the workshops has helped them to acknowledge the importance of using condoms and regular HIV testing. Others said that the knowledge gained from workshops encourages them (FSWs) to actively identify and explore ways on how to avoid behaviour that would expose them and the community to risk and comply with HIV/STI prevention measures. The statements presented below are some of the experiences FSWs shared during interviews:

We encourage our audience to use condoms with their partners and to go for voluntary HIV testing, so they know their HIV status.... and we explain to them the importance of and how to use a condom to prevent HIV and STIs.... We also tell them that us as FSWs we always use condoms to avoid being infected with sexually transmitted infections and HIV. (FSW23).

6.4.2.4 The role of social networks

Semi-structured interviews show that Family Planning Association of Malawi and Theatre for a Change have brought noticeable benefits to lives by building a strong and powerful alliance or social network of FSWs. FSWs mentioned that belonging to social networks helped them to reclaim a sense of agency during their engagement with fellow FSWs and were made more aware of their rights. The statement below comes from a member of a sex workers group, supported by Theatre for a Change:

I have been empowered on my rights as a citizen of Malawi and on HIV/AIDS issues such as having regular HIV testing including the right to access good treatment and I have joined a group called sex workers network which empowers sex workers to advocate for their rights. (FSW2).

Some FSWs said members in the network usually encourage each other to test for HIV and STI and consistently use condoms to prevent HIV/STI.

With the help of Theatre for a Change staff, we organise ourselves into groups.... we encourage each other to use condoms when having sex and those FSWs who are HIV negative are encouraged to have regular HIV testing. (FSW22).

Other FSWs mentioned that belonging to the networks helped them to connect with lawyers for support and how they support each other in many ways as seen in the following statements:

I am a better sex worker since joining Theatre for a Change such that I now know my rights. I have a lot of friends who are also sex workers. I have learnt a lot from these friends. We have organised ourselves into small groups where we share our experiences and advice from the lawyer whom Theatre for a Change introduced to us. If a member of the group is in hospital or is bereaved, we contribute some money and support her. (FSW1).

We even have our own lawyers who stands for us in case of court cases when one is arrested by police if they raid our place of work. (FSW15).

6.4.3 Understanding female sex workers' health needs and their perception of a good service

Understanding FSWs' health needs by HCPs played a big role in FSWs' experiences and perception of a good service. Some FSWs reported that HCPs from HIV and STI clinics including service providers from Theatre for a Change and Family Planning Association of Malawi had a better understanding of their needs. They were able to offer support at the time FSWs were receiving their initial HIV results as well as during their engagement with HIV treatment. The statements below were shared by the majority of FSWs who tested HIV positive at Theatre for a Change:

When I was first tested at Theatre for a Change clinic, the nurse and the ex-sex worker who run this clinic reassured me that being HIV positive is not the end of life..... they both disclosed to me that they too were HIV positive, but their life has not changed because they have accepted it and take medicine everyday The nurse advised me on how to take the ARVs, and to always use condoms even with my regular clients. The support that I had and that I am still having from the HIV and Theatre for a Change clinics has changed my perception of services provided in the public health facilities. (FSW10).

Semi-structured interviews also indicated that there were mixed experiences and perceptions among FSWs who had a negative experience at a public healthcare facility which resulted in not believing their HIV test results and opted to confirm the HIV result by having a second test at clinic run by Theatre for a Change. One FSW said:

After I had fully recovered from the abortion, I went to the clinic run by Theatre for a Change in our area to have my blood tested again for HIV not that I did not believe the previous results but just for confirmatory purposes because I had a very bad experience at this public health facility. They tested my blood and indeed it came positive. They told me to go to the HIV clinic and present the referral letter they gave me. (FSW16).

The semi-structured interviews also reveal that there was a general perception of what a good service is among FSWs. The statements below were mentioned by FSWs based on specific issues in relation to what individuals perceive a

good service entails. Others presented their perceptions in the form of advice to the healthcare systems as observed in the following statements:

There are a lot of things that I think that could make the service good. For example, if there are enough medicine and condoms at the hospital enough healthcare providers, positive attitudes of staff patients regardless of who they are or what health problems they are suffering from. With these things in place all sex workers will be able to get the treatment they need, and they will not be afraid to go to public healthcare facilities. (FSW1).

A good service should treat all patients with respect regardless of their health and social status. They should not tell us to go and buy medicine as some of us cannot afford and sometimes we may end up buying wrong medicine. The clinic should have staff who have a good attitude and who are well trained and are committed to their work and have patients to their heart. You know sex workers have a lot of problems such as psychological trauma because of what we go through as sex workers, so, we need a lot of support from healthcare providers who understand our problems. (FSW22).

Others described a good service in terms of individualised support and information regarding their situation and encouragement on safer living and how to prevent infections as seen in the following statements:

For me, a good service should include having enough trained staff who know their job and responsibilities. HCPs who understands what a patient need, and staff should have necessary knowledge regarding different diseases so that we are not moved around and referred to different departments. We need staff who are willing to support us and give us the right information about our problems and the medicine they give us and also on how and where we can get the support that we need. (FSW11).

In other instances, FSWs described a good service relating to HCPs being able to keep patients' information confidential and that staff should act professionally and dedicate their time to patients. The statements below were shared by the majority who accessed services from some public healthcare facilities and when their FSW status was disclosed to, or known by, HCPs.

As for me, a good health service should start with staff who keep your health problems confidentially and not telling everyone that you have this and that disease on top of giving you the treatment you need. (FSW6).

6.4.3.1 Equality of care

Need for equity of care (equal access for equal needs) was mentioned by every FSW interviewed. Some FSWs who were either living HIV or with unknown HIV status mentioned that they were always treated like any other patients. In some instances, some FSWs reported that HCPs' supportive attitudes had an influence on their experiences and perceptions of services they received. Statements of satisfaction with the services were reported by many FSWs as seen the following statements:

I have no words to express on how their (Nurses and clinicians) support made me feel even right now, nurses are like angels from God for me. They saved my life even though they knew I was a sex worker they treated me the same and they have always supported me up to now. Because of their support, I rely on medical assistance now such that I do not buy medicine without asking the HCPs. (FSW20).

The way they (HCPs) spoke to me. They were so friendly even after revealing my sex work status they never asked me any personal questions related to my work. They spoke to me like any other patient, and I believe that the treatment they gave was similar to those given to women who are not sex workers or those with unknown HIV status. I felt they behaved in a professional manner and their message was all about how to remain healthy and how to maintain safer sex by always using a condom and adherence to treatment. (FSW19).

Some FSWs who were asked to have their blood tested for HIV after presenting their problems including rape victims, said that HCPs supported them throughout the process of testing, receiving the HIV results and initiation of treatment as seen in the following statements:

Because, at the HIV clinic where I collect my ARVs, I see all sorts of people living with HIV, who are not sex workers and sex workers all treated the same. Nurses at this clinic do not segregate anyone and we are all respected as

patients. They told us that support and treatment for HIV is available for everyone who is living with HIV. **(FSW22)**.

*The nurse greeted me and spoke to me like any human being who can fall sick. They listened to me when I was telling her about my problems. She examined me, asked me if I was ready for HIV testing and I said yes, sent me to the laboratory for blood tests and told me to come back after blood tests.... She explained to me on how to take tablets. She also told me that I should use female condoms because they are easy. She did not discriminate me although she knew my work. **(FSW11)**.*

Those FSWs who reported previously accessed antenatal services from public healthcare facilities, stated that HCPs who provided care to pregnant FSWs were non-discriminative and compassionate towards FSWs who were pregnant. In some instances, FSWs mentioned that nurses at the antenatal clinics were sensitive to the needs of pregnant women who were living with HIV and the risk posed to their unborn babies as seen in the following statement:

*I told the nurse that I am not married, and I am a sex worker. The nurse nodded her head and then started telling me how important it is for me to keep coming to antenatal clinic and to make sure that I deliver at the hospital. She gave me ARVs to take for a month and then come back for check-up and get some more tablets. She also gave me some liquid medicine which she said will be given to the baby when it is born. She explained to me on how to take the tablets and that I should make sure that I do not miss a day without taking the tablets. **(FSW12)**.*

6.4.3.2 Bringing services near to female sex workers' 'Hot spots'

During interviews, FSWs described what other services they perceived as most needed to address their requirements. Semi-structured interviews show that FSWs perceived that distribution of condoms, HIV counselling and testing should be introduced within their workplace to help in HIV and STI prevention. The statements presented below were shared by almost all FSWs:

HCPs should set mobile clinics within the bars so that we can access condoms and HIV testing easily. At these clinics, HCPs should also reinforce health promotion messages especially advising sex workers on how they can protect themselves from sexually transmitted infections. (FSW3).

FSWs also need encouragement to go for HIV testing from HCPs who should frequently visit entertainment places where FSW s are likely to be found and give talks on importance of HIV testing and the benefits of knowing your status. When they come to these places (Hot spots) they should also bring condoms to give us because for us to avoid getting infected with HIV and other infections we need to use both female and male condoms. (FSW23).

6.4.3.3 Establishing specific clinics for female sex workers

FSWs mentioned facing a number of challenges while accessing services in public healthcare facilities. Most FSWs said establishing specific health facilities for sex workers can enhance access to care without experiencing any type of violation and humiliation perpetuated by HCPs. The following statements below illustrates how most FSWs perceived how the experience would be like if such services were put in place:

Sex workers will not be regarded as ‘dirty’ people by HCPs who think that sex workers deserve punishment as such they do not have time for us and in most cases, we are denied treatment, and told to go and buy medicine from private pharmacies. (FSW7).

We will be treated with respect because staff working at the clinic will be people (HCPs) who understand our problems. We will be able to explain our problems and HCPs will understand us; because these people (HCPs) already know that their job is to treat sex workers so no one will be treated differently. (FSW11).

Some FSWs explained that establishing specific clinics will enhance a truthful and open communication between FSWs and HCPs. FSWs felt that HCPs working in these facilities will have prior knowledge of the type of patients they are dealing with and there will be no issues of being discriminated. One FSW said this:

Yes. Because these clinics will offer more friendly services than public facilities. HCPs will have first-hand knowledge and experiences of problems and health needs of FSWs. FSWs will also feel comfortable discussing their problem because they will not segregate anyone because we will be all FSWs. (FSW5).

Some FSWs said that, while establishing specific clinics, the government should consider provision of SRH services and other services during the night as well as during the day so that services can be accessed when needed.

If we have clinics opening in the night, it would be easy to access help in cases of assault. The clinic should provide everything for example, family planning and counselling services and treatment for any disease as one does not know when she will have a headache or stomach pain or even diarrhoea. (FSW8).

Others felt that establishing specific clinics could be an opportunity for FSWs' needs to be communicated to the government as HCPs working at these clinics will act as a bridge between sex workers and government officials responsible for designing health services.

The HCPs from these clinics will be able to speak for us as we have no one to take our problems to those people in power. Because of interacting with so many of us, they will be able to convince them on our needs. (FSW25).

Semi-structured interviews also identified that FSWs had different opinions regarding establishing specific clinics for FSWs. They said that this would enhance stigma within the community and that the government may be viewed as encouraging sex work in the country. The following statement was from one FSW:

I think this will increase discrimination among us sex workers and it will be like segregating ourselves and it will increase the stigma among sex workers. I do not think the government would do that for fear of being seen as encouraging sex work in the country. (FSW20).

In some instances, FSWs felt that being seen going to these clinics would have an effect on their relationships with their children and their lives as they hide their sex worker and HIV status from the children.

I would not want my children seeing me to this clinic because I have never told my children that I am a sex worker and that I have HIV. I also think if I am seen going to this clinic, my children might be bullied at school or even where we live by other kids. My children might not respect me. (FSW1).

6.5 Summary

This study finds that violence against FSWs is pervasive and severe, with clear patterns of violence across all levels of FSWs' life. The study has also shown that violence was not related to age, duration of sex work or HIV status. The semi-structured interviews reveal that FSWs experienced specific forms of violence even outside their work setting because of their work, such as violence and harassment by neighbours and the general public as well as discrimination and abuse in health settings.

Some FSWs reported neglectful, abusive, and harmful practices by police officers. Even when participants had severe injuries from a violent incident from clients few sought support and protection from the police. The semi-structured interviews have shown that police violence fuelled violence and increased sex workers' vulnerability to client violence and HIV transmission. Semi-structured interviews reveal interconnections between police violence and FSWs' experiences and perceptions of services, in part due to the impunity created by fear of reporting to the police and reduced access to healthcare in the context of some HCPs demanding a police report before service is provided. However, some FSWs reported positive experiences from police officers who attended workshops organised by Theatre for a Change.

Several FSWs reported positive experiences with service accessed from HIV/STI and those provided by NGOs. However, a small number of FSWs reported positive experiences from public health facilities especially when served by HCPs who had attended workshops organised by Theatre for a Change. In addition, the study has shown that FSWs perceive that successful

HIV prevention requires reaching the majority of sex workers through the provision of services where they work.

While healthcare providers are trained and expected to provide the best service and ensure no harm comes to their patients, this study identified instances of lapses in service delivery. The interviews with FSWs living with HIV and those with unknown HIV status, has highlighted gaps and inconsistencies in the delivery and access of healthcare services meant to address FSWs' health needs. The interviews have revealed on-going vulnerability of these women to HIV and other sexually transmitted infections, abuse, and violence. A number of gaps can be identified in public health facilities as well as within the law enforcement environment that undermines efforts to address violence and stigma against FSWs in Malawi. The next chapter will present the discussion based on the findings of Study 1 and Study 2.

Chapter Seven: Discussion

7.0 Introduction

The purpose of this chapter is to discuss the findings of Study 1 and Study 2 regarding FSWs' experiences and perceptions of accessing healthcare in Malawi. The discussion considers FSWs' experiences in relation to the socio-cultural and political contexts of Malawi and their relationship to the models described in Chapter Three. FSWs' vulnerability to violence in healthcare facilities and factors related to the HCPs are highlighted. More specifically, the implications of social inequality as related to sex work and limited service delivery specifically designed for FSWs are discussed.

The discussion first presents themes identified as influencing FSWs' positive experiences which include approaches to improving access to healthcare; the effects of the non-governmental organisations on provision of healthcare services to FSWs and professionals' awareness of FSWs' needs. Finally, structural violence and combating structural violence are discussed.

7.1 Female Sex Workers' Positive Experiences with Accessing Healthcare

Issues of service delivery and access including outreach and home-based services and HCPs' awareness of FSWs' health needs are discussed in this section. Both studies reveal that experiences are influenced by factors ranging from improving service delivery to professionals' awareness of FSWs' health needs. This supports the findings of Ma & Loke (2019), who found some positive experiences and perceptions in terms of healthcare services delivery among FSWs (Ma & Loke, 2019). However, the findings of Study 1 and Study 2 in this thesis, indicated that positive experiences and positive perceptions of services were reported from HIV/STIs clinics and NGO's health facilities rather than from public health facilities. The latter makes up most of the provision of sexual health services.

Service delivery by NGOs (for example: Family Planning Association of Malawi and Theatre for a Change) were a major influence of FSWs' positive experiences and perceptions of accessing healthcare. Data from both studies

reveal that there is some evidence of changing perceptions and experiences of FSWs in public health facilities. Examples of the evidence include regular meeting, through workshops, between FSWs, police officers and HCPs from public health facilities, with NGOs and government of Malawi working together in addressing sex workers health needs (see Section 6.4.2.2). Additionally, the use of suggestion and feedback boxes in HIV clinics also have an influence on FSWs' positive experiences.

Despite indications of FSWs' positive experiences and perceptions and in the views of HCPs and service providers from NGOs towards use of healthcare services, data from these studies, particularly in Study 2, indicates that negative experiences and perceptions of services are still strong in public health facilities in Malawi. Data from both studies suggest that FSWs' negative experiences resulted from stigma and discrimination from HCPs whose beliefs of social norms and personal perceptions regarding sex work affect their service delivery (see Section 6.2.2.3). While we understand that sex work is a matter of great cultural sensitivity in Malawi and other African countries (Munthali *et al.*, 2004), HCPs should be respectful of one's social status and demonstrate a better understanding of clients' needs and provide better quality care (Evens *et al.*, 2019).

Lack of privacy, HCPs' disrespect and poor confidentiality are important issues influencing FSWs' experiences and perceptions of healthcare (Ma & Loke, 2019). Data from both studies suggest that FSWs experienced a lack of respect and confidentiality, mainly from public health facilities, which resulted from stigma and discrimination associated with sex work. These issues were reported as mainly coming from the nursing staff rather than the medical teams. These factors impede the delivery of services as women who had negative experiences often vowed not to return to that particular service. The next section discusses themes related to positive experiences.

7.2 Issues Related to Service Delivery and Access

The issues related to delivery of and access to services included delivery of outreach and home-based services and location of HIV/STI services. The data in the Study 1 and Study 2 is supported by other studies that have explored

choices of where FSWs accessed healthcare (Dhana *et al.*, 2014; Scorgie *et al.*, 2013; Vuylsteke *et al.*, 2001).

7.2.1 Outreach and Home-Based Services

Data from Study 1 and Study 2 showed that FSWs were in favour of the Outreach and Home-Based Services provided by NGOs and HIV facilities. Outreach services included services provided within the community where participants live or within their workplace. This is partly about the services being delivered within areas where FSWs could easily access them without the worry of using public transport which they considered costly and where HCPs had respect for basic human rights as well as FSWs' dignity. Some participants in these studies who accessed these services reported changing their previous perceptions of healthcare services (see Section 5.2.1.2). Data suggest that a friendly manner in communication between HCPs and FSWs built trust and fostered more positive relationships. Furthermore, data from the two studies show that positive attitudes of staff at the clinics encourage FSWs to engage with HCPs openly and truthfully without fear of being judged.

Similar views were also expressed by providers of services (HCPs and service providers from NGOs), suggesting that the creation of a positive environment for service delivery can improve FSWs' experiences and perceptions with accessing healthcare. This could indicate that the experiences and perceptions of FSWs with access to healthcare were influenced by the institution factors. For example, the healthcare facilities may provide a platform for building social support for a desirable change in FSWs' perceptions and experiences of accessing healthcare (Elder *et al.*, 2007). This data is supported by other studies that revealed that sex workers felt that services accessed within their work locations were more friendly (Zachariah *et al.*, 2003) than those in public health facilities.

Data from both studies suggest that, where resources were adequate enough, FSWs reported positive experiences with accessing healthcare. Resources included HCPs, drugs, and condoms. While FSWs reported receiving adequate treatment including condoms from HIV/STI facilities, there were resource supply issues in public health facilities as well as in some outreach

clinics run by Theatre for a Change. For instance, participants reported of shortage of drugs and HCPs in public health facilities which resulted in FSWs being told to buy drugs from privately owned pharmacies.

While FSWs were happy with the services provided by Theatre for a Change and the Family Planning Association of Malawi, some FSWs and some NGO service providers report that FSWs testing HIV positive at the clinics were not able to access ARVs and have to be referred to public healthcare facilities. This data suggests that HIV treatment still remains fragmented in Malawi.

7.2.2 Location of HIV/STI facilities

While there are likely to be differences in FSWs' views regarding locations of service delivery points, most participants in both studies reported a feeling of security when accessing services at HIV/STIs facilities. Participants reported that they perceived that everyone who reported at the HIV/STIs clinic was also seeking treatment similar to that needed by FSWs. Moreover, other FSWs stated that meeting people with similar conditions at designated facilities encouraged them to access healthcare because all patients were treated with the same respect. Furthermore, these informal social networks played an important role in defining FSWs' experiences and perceptions with accessing to healthcare (McLeroy *et al.*, 1988).

7.3 Healthcare Professionals' Awareness of Female Sex Workers' Healthcare Needs

Data from Study 2 extended my knowledge that understanding FSWs' health needs could significantly influence positive experiences and perceptions of healthcare by FSWs. Some FSWs spoke very favourably of the HCPs of HIV/STI clinics and service providers from Theatre for a Change and Family Planning Association of Malawi. Most of the participants interviewed in both studies said their relationship with HCPs was positive. They reported that, because HCPs listened to their concerns, this influenced FSWs' positive experiences and perceptions of healthcare. Data also reveal that the flexibility of service delivery in HIV/STI facilities was acknowledged by both FSWs and HCPs. This finding provides highlights into HCPs' awareness of the challenging lifestyle of FSWs which could lead to stress and subsequent

physical health problems. It was encouraging to notice that almost all HCPs and service providers interviewed in this study, had a good understanding of FSWs' health needs and their willingness to serve FSWs. Their focus on the requirements of these women caused HCPs to feel a pressing need to respond to FSWs' health needs. HCPs commended FSWs for coming forward to access services, for example: HIV testing services (see Section 5.2.3).

Data reveal that HCPs, especially those from the public health facilities, hold negative and discriminatory attitudes towards FSWs. FSWs reported that they were often met with blame, judged as sinful and diseased, nurses were rude and did not maintain confidentiality (see Section 6.2.2). This finding suggests that HCPs' stigmatising attitudes played an important role in FSWs' negative experiences and perceptions of healthcare. This data is supported by other qualitative studies that have explored FSWs' experiences with healthcare elsewhere (Mellor & Lovell, 2011; Mosedale *et al.*, 2009; Nyblade *et al.*, 2009).

In some instances, the majority of FSWs worried that, if they disclosed their sex work, they would be inviting moral judgments from HCPs who would gossip about their identity, leading to shame and embarrassment as well as possibly impacting the service that they would receive. Thus, the majority attempt to protect their privacy when seeking health care services in public health facilities. In situations where FSWs perceived that being a sex worker was a 'taboo' among HCPs in public health facilities, they opted to seek service from clinics run by Theatre for a Change or Family Planning Association of Malawi, where they would not have to worry about disclosure of their sex work.

Also, data suggest that FSWs were confident about the maintenance of confidentiality in the HIV/STI facilities and clinics run by NGOs and, therefore, did not see the need to conceal their identity from these health care providers. FSWs perceived these services to be more supportive and empowered them to be open. Data from both studies suggest that understanding FSWs' health needs could significantly influence positive perceptions and experiences with accessing healthcare in public health facilities if considered in service delivery. These findings have implications for FSWs' access to healthcare services, to reach, to obtain or use health care services and to actually have their need for accessing healthcare fulfilled (Levesque *et al.*, 2013). The next section

discusses factors affecting negative experiences. This data is mainly from Study 2 where a fuller range of experiences were reported by FSWs. This discussion will be around the main themes that emerged from Study 2.

7.4 Structural Violence

According to Farmer (2005), the poor are the main victims of violence and they are less likely to have their suffering noticed (Farmer, 2005). Structural violence occurs whenever people are disadvantaged by political, legal, economic or cultural traditions (Christie *et al.*, 2001). These elements of structural violence prevent people (FSWs) from obtaining basic necessities, for example, medication and information on HIV prevention and treatment. Structural violence is almost invisible and normalised by stable institutions because they are longstanding structural inequalities (Corrigan & Lam, 2007). Recognising structural violence in healthcare services helps staff to care about the people they serve (Christie *et al.*, 2001). However, as HCPs we need to ask ourselves how and why we tolerate it. Data from Study 2 suggest that FSWs experienced gender-based violence (which is a product of structural violence) at all levels, including from the community, clients, the police, and HCPs which creates multiple implications for FSWs' experiences and perceptions of accessing healthcare. Gender-based violence is any violence directed at an individual based on their gender identity or behaviours that are inconsistent with social norms (Evens *et al.*, 2019).

7.4.1 Direct violence from community

It has been previously stated that, social norms dictate what a woman should do, how she should behave and when should she do what society perceives as 'normal'. FSWs, in this study, reported experiences of direct violence from the communities where they live. Data reveal that FSWs felt humiliated or threatened by physical assaults from their neighbours (see Section 6.2.1). FSWs reported that some parts of their communities, especially married women, were prejudiced against sex workers and, in most cases, FSWs lived in fear and shame.

The findings from the two studies also show that most FSWs were made to feel ashamed of their occupation, resulting in acknowledging that their work

was socially unacceptable. Additionally, FSWs perceived that the lack of public acceptance of their work, led to fear and shame when accessing healthcare in the nearby health facilities. However, using performance drama in public places by FSWs had the potential to reduce stigmatisation and violence towards FSWs. Other studies have different opinions regarding drama performance in public places. For example, Chima (1999) suggests that discussing sensitive issues in some instances, may potentially create barriers and more stigma where sex work is viewed as culturally unacceptable (Chima, 1999). These findings are supported by previous studies that explored FSWs' experiences of access to healthcare (Scorgie *et al.*, 2011).

Using the empowerment model described in Section 3.1.2 that seeks to challenge systems that prevent people having their needs met, such empowerment could enable HCPs develop positive and adaptive behaviours that could help FSWs to take part in decision-making (Greene *et al.*, 2005) and improve their experiences and perceptions with accessing healthcare. As said elsewhere, Theatre for a Change empowered FSWs with knowledge about their rights to access healthcare and any other support that they may need, including the importance of using condoms when having sex even with regular clients. Narratives from FSWs reveal that they were empowered with knowledge which they were able to share with the general population during their performances at open markets (see Section 6.4.2.3).

As previously said in the sections above, most FSWs preferred to access services provided by NGOs where they could access both medical treatment and emotional support without being identified by their neighbours for fear of stigma. Gender and social norms, therefore, continue to be major factors influencing the choices that women make in all areas of their lives in accessing healthcare and all these play a role in their experiences and perceptions of the services they access.

7.4.2 Direct structural violence from clients

Data from both studies suggest that FSWs experienced a range of violent acts from their clients based on socio-economic status as well as cultural norms. FSWs in these studies came from disadvantaged and poor backgrounds

(Binns & Low, 2015) and their low-socio-economic status predisposes them to structural violence. The multiple components of direct structural violence experienced by FSWs include physical, sexual, and economic violence suggesting experiences were related to violations of fundamental human rights. FSWs reported being forced to have unprotected sex and, in cases where a FSW requested to use a condom, she was either beaten, or verbally abused with the client claiming they had paid for sex. These acts of violence place sex workers at high risk of acquisition of HIV/STIs.

In most cases, FSWs did not seek support after the violence partly because sex work is culturally perceived as immoral and for fear of arrests by the police. The perception of sex work as immoral and 'illegal' plays a crucial role on FSWs' healthcare seeking behaviour as well as their perceptions of the current service delivery. The findings of both studies regarding direct violence from clients are supported by previous studies who have explored FSWs' experiences, reporting that FSWs experience violence as a result of their work (African Sex Workers Alliance, 2019; Beattie *et al.*, 2012; Bharat *et al.*, 2014; Ekstrand *et al.*, 2013; Kim & Motsei, 2002). These findings suggest that violence from clients, in the lives of FSWs, is a matter of concern in terms of public health and the welfare of these women.

7.4.3 Direct violence from healthcare professionals

Data from both studies suggest that FSWs experienced violence and stigma from HCPs in public health facilities. HCPs would judge them as sinful, irresponsible, diseased, and responsible for spreading HIV/STIs. FSWs perceived that stereotypes held by HCPs, especially in public health facilities, were that all FSWs were HIV positive. Despite the available, accessible and affordable public healthcare services in Malawi (Government of the Republic of Malawi, 2011), being a FSW is not socially acceptable and there were significant concerns for FSWs when accessing healthcare in public health facilities. The findings of Study 2 are supported by existing literature suggesting that, for FSWs, stigma is an important element when accessing HIV/STIs healthcare services (Beattie *et al.*, 2012; Mtetwa *et al.*, 2013; Scorgie *et al.*, 2013). These findings provide insights into the FSWs' internal dilemma, about deciding whether or not to disclose their identity when seeking care

especially in public health facilities. However, holding back disclosure would lead to accessing inadequate care. The burden of HCPs' stigmatising attitudes, holding back disclosure and inadequate care could lead to stress and subsequent physical health problems.

Meanwhile, the findings of Study 2 indicate that stigma facilitated FSWs' negative perceptions and experiences of accessing healthcare in public health facilities. However, a small number of FSWs reported that, even though they feared being stigmatised, they still disclosed their involvement in sex work, but the disclosure facilitated support from HCPs (see Section 6.4.1). These findings suggest that direct violence from HCPs could have implications for assessing FSWs' health needs, hence, affecting FSWs' experiences and perceptions of healthcare. The right to healthcare framework suggests that the healthcare that patients are accessing should be provided in ways that will address their needs and that they are fully engaged in the decision making regarding their care (Levesque *et al.*, 2013). Violence from HCPs towards FSWs affects access to optimal care because FSWs may not be able to fully engage in decision making regarding their care, resulting in negative experiences and perceptions of healthcare service delivery.

Similar findings are reported in other studies (Benoit *et al.*, 2018). These findings suggest that it is crucial to raise the awareness of HCPs that their support could end the vicious cycle of stigma and illness among FSWs. The links between HCPs' stigmatising attitudes towards FSWs and barriers to accessing services are well documented but effective strategies to tackle the problems are still absent, in part due to the lack of attention given to how unique FSWs are in a population, with their high chances of transmitting HIV/STIs (Ma & Loke, 2019; Nyblade, 2006; Pulerwitz *et al.*, 2015). In addition, data from these studies reveal that FSWs faced human rights violence from HCPs built on the fundamentals of power inequalities. Human rights violations included unconsented HIV testing, denial or withholding of treatment, breach of confidentiality and unfavourable policies and laws.

7.4.3.1 Unconsented HIV testing

HIV testing is a road map to end the HIV epidemic and link patients to HIV management and should be a priority when planning healthcare services for every government including Malawi's. As discussed in Section 1.2.2 that Malawi has the highest HIV prevalence in the world, with 9.2% of the adult population (aged 15-49) (Avert, 2019), the WHO recommends that HCPs and planners of healthcare services review their commitment to achieving universal access to HIV prevention, care and treatment (World Health Organization, 2012). Similarly, in 2014, UNAIDS set a goal of controlling the HIV epidemic by 2020 and ending the AIDS epidemic by 2030 through a targeted 90-90-90 programme involving comprehensive HIV testing and treatment programmes (United Nations Programme on HIV/AIDS, 2016). Despite Malawi making significant progress towards 90-90-90 (Marukutira *et al.*, 2018), unconsented HIV testing is a human rights violation. Most FSWs were forced to test for HIV during access to non-HIV healthcare, there was lack of confidentiality as well as discrimination from HCPs in public health facilities.

Moreover, these findings highlight the importance of tackling overlapping stigma and discrimination among FSWs in order to enhance HIV testing. Although, some FSWs were happy with their HIV testing results, the majority were not happy with the way the testing was conducted (see Section 6.2.2.2), resulting in negative experiences and perceptions of service delivery. This also indicate that FSWs were not well informed about the HIV testing. Other studies have shown that counselling prior to and after HIV testing can have a strong effect on HIV testing outcomes, initiation of treatment and treatment adherence. For instance, in their systematic review and meta-analysis, Mountain *et al.* (2014) suggest that counselling, including monthly support, may contribute to the high adherence to HIV treatment among people living with HIV. Similarly, as part of intensifying efforts to reduce HIV prevalence among FSWs, the WHO recommends that everyone attending a health facility in regions where there is a generalised HIV epidemic should be offered HIV testing and counselling (HTC) (Suthar *et al.*, 2013). Patients should be informed if HIV testing will be performed as part of the care provided to them. It is also expected that patients should be given the option to decline or defer testing without being denied access to services.

7.4.3.2 Denial or withhold of treatment

Denial or withholding treatment by HCPs forms a barrier in the HIV treatment cascade (Schwartz *et al.*, 2014) as well as undermining the human right to health (Lancaster *et al.*, 2016). FSWs were denied some essential services such as Post-Exposure Prophylaxis (PEP) treatment following a rape incident. PEP is primarily intended for the prevention of possibility of infection where there has been a known high-risk work-related exposure to HIV. Moreover, provision of PEP presents an opportunity to link FSWs of sexual violence to HIV prevention and treatment (Kim *et al.*, 2003). These findings have important public health implications, posing threats to prevention and treatment in HIV programmes. The findings of this study suggest that the marginalisation and inequality faced by FSWs are located within the broad diversity of human rights violations which requires an urgent multi-sectoral approach, for example, the government of Malawi working in partnership with organisations already working with sex workers to reinforce a culture of tolerance and human rights respect for every citizen regardless of their social circumstances.

7.4.3.3 Breach of confidentiality

Lack of confidentiality in public healthcare facilities was identified as a major concern for participants in both Study1 and Study 2. Data show that HCPs disclosed and shared patients' HIV status with other members of staff without their (FSWs) consent and in an undignified manner. FSWs reported that there were times where HCPs made announcements within reception areas asking FSWs and those with HIV to queue separately from other patients in order to access treatment. These findings suggests that lack of confidentiality compromised service delivery of optimal quality of care in public health facilities, as well as influencing negative experiences and perceptions of those services.

Furthermore, this data indicate that HCPs in public health facilities lacked awareness of the importance of confidentiality and how it could negatively affect FSWs' uptake of services. However, the studies identified that, where FSWs were assured, that confidentiality was guaranteed, it was easier to have

discussions with HCPs on sensitive issues related to their needs, including sexual and reproductive health needs. Confidentiality for FSWs is also an important element in term of their privacy and security. The findings suggest that the lack of a concerted effort by health planners and policy makers to develop interventions that can substantially reduce violation of confidentiality is a major barrier to FSWs' access to and uptake of HIV services as well as their negative perceptions of service delivery in public healthcare facilities.

7.4.3.4 Unfavourable policies and laws

Data from both studies suggest that HCPs in some public health facilities utilise laws, policies, and practices as an excuse to withhold treatment or force FSWs to HIV testing. It can only be speculated that it was an excuse because some patients who accessed services in similar facilities were not subjected to forced HIV testing or having to provide a police report in cases of assaults. However, some FSWs reported HIV testing was mandatory and a prerequisite for treatment in some public health facilities. Examples of these are mandatory HIV for every pregnant woman seeking antenatal services (see Section 6.2.2.2) where a pregnant woman was told it was not a matter of 'yes or no' to have HIV testing. Although the intention is clear, patients should be given counselling and an option on when to have the HIV testing. This idea is supported by previous suggestions that HCPs are expected to ask for consent before any HIV testing is conducted (Hardon *et al.*, 2012). However, conflicting laws and public health policies create confusion among HCPs providing services especially where HCPs themselves have little understanding of the consequences of their actions.

In other instances, FSWs were requested to provide a police report before treatment for an assault. Failure to produce such a report resulted in denial of service. Notably, data reveal that FSWs reported that police abuse restricted their ability to report abuse. This vicious cycle of abuse suggests an urgent need to prevent and address violence inflicted on FSWs, in order to improve their experiences and perceptions of the services. Moreover, criminalisation of sex work, punitive laws and unwelcoming healthcare environments inhibit FSWs from accessing help from both the police and HCPs (Bekker *et al.*, 2015).

One striking claim made by one FSW after being raped by a police officer is that the police officer told her that he had infected her with HIV after having sex without a condom. Ultimately, this is a public health concern, and an urgent response by policy makers is required to stop such acts. However, it raises an ethical dilemma because participants who reported this type of abuse declined to mention the officers' names or the police stations where the abuse occurred. Structural violence in the lives of FSWs is a matter of concern in terms of public health and of the welfare of these women and require urgent solutions. Moreover, the criminalisation of sex work not only hinders access to services but also affected the way services are delivered to FSWs. These findings are supported by other studies that have explored FSWs' experiences (African Sex Workers Alliance, 2019; Bharat *et al.*, 2014; Decker *et al.*, 2015). The next section discusses issues related to factors that are relevant to combating violence.

7.5 Combating Structural Violence

While the factors that contribute to structural violence against FSWs are complex and systemic, skilled, and knowledgeable HCPs can improve FSWs' experiences and perceptions of healthcare services. Data from both studies suggest that improving service delivery, not only in a healthcare setting but even outside the health sector, can have an influence on FSWs' perceptions and experiences of access to services. Findings revealed that services provided by Theatre for a Change or Family planning change perceptions and experiences of FSWs of those services provided in public health facilities as well as police attitudes toward FSWs.

The findings from both studies suggest that training and workshops organised by Theatre for a Change helped to empower FSWs with knowledge on human rights such that they are able to share this knowledge with the wider population through drama performances. FSWs reported having positive experiences with the police officers who had attended workshops lead by FSWs. This finding shows that NGOs have the capacity to bridge the gap between HCPs, the police and FSWs; as well as changing the views of the police officers and HCPs towards FSWs. Eventually the change in views of these two

stakeholders will influence FSWs' perceptions both of healthcare and the services provided by the police.

FSWs also said NGOs created some form of lobbying with different stakeholders, specifically where NGOs organised workshops in which participants included HCPs, police officers and community leaders. Lobbying in advocacy within public health has been acknowledged in previous studies (Carlisle, 2000) as supporting disadvantaged individuals to gain control over and improve their own health and achieve their full potential. Some of the strategies perceived as important elements in combating violence among FSWs included the building of FSWs' social networks which are mostly supported by NGOs and establishing special health facilities or 'Hotspots' clinics.

7.5.1 The role of social networks

FSWs also mentioned the importance social networks have had on their experiences with healthcare and safety in general. Data revealed that FSWs were sharing information about their experiences and how to deal with or avoid violent situations. They also encouraged each other to undertake regular HIV/STI screening and promoted adherence to treatment (see Section 6.4.2.4). Also, data indicated that FSWs said that belonging to social networks has helped them to link with lawyers who provide free legal advice when needed. The findings of both studies suggest that FSWs' social networks can establish health behaviour norms and create positive relationships between FSWs and HCPs. Other studies also suggested that social networks have facilitated social cohesion and mutual support between FSWs within the broader context of their sex work (Behets *et al.*, 2005).

Thus, the use of social networks can be utilised as part of a strategy for overcoming violence experienced by FSWs in their day-to-day life including access to healthcare. However, other agencies, especially faith-based organisations, believe that supporting FSWs is not socially or culturally acceptable. For instance, the WHO (2012) observed that NGOs who have made strong public commitments on sex work, are perceived as acting against socially and culturally acceptable norms (World Health Organization, 2012).

7.5.2 Establishment of special health facility or ‘Hotspot’

Also, FSWs’ expressed a need for the establishment of special service delivery points or ‘Hotspots’ in order to reduce violence experienced in public health facilities. FSWs reported that they are more likely to access service Hotspots without experiencing any type of violence or stigma because HCPs will have prior knowledge of who they are providing service to (see Sections 6.4.3.2 and 6.4.3.3). FSWs also said that such services will be ideal considering that FSWs mostly work during the night and may not be able to access services during the day. Some FSWs expressed the need to have the facilities operating 24 hours a day. Some FSWs were of the opinion that HCPs working in these facilities will act as a link between FSWs and the government, making their concerns and needs known. These findings suggest that services offered in hotspots are preferable to traditional hospital/clinics. These findings are supported by previous studies who have suggested that services provided in ‘Hotspots’ increases access to positive perceptions of access to healthcare including HIV testing facilities (Chersich *et al.*, 2013; Katz *et al.*, 2015; Steen *et al.*, 2015). The findings of this study offer new insights into what effective services look like in the context of the FSWs in Malawi.

By contrast, others were of a different opinion. They felt that establishing specific health facilities could potentially enhance stigma and discrimination. Others felt that being seen going to these clinics, would have an effect on their relationships with their children because they have never disclosed their sex work and their HIV status to their children. These findings are consistent with those from studies exploring preferences of FSWs’ access to healthcare. For example, Malele *et al.* (1999) found that, once an STI clinic in Democratic Republic of Congo was established specifically for FSWs, attendance dropped due to the fear of discrimination from the public (Malele *et al.*, 1999). The next section presents what this thesis contributes to new knowledge.

7.6 Contribution to New Knowledge

The major findings of Study 1 and Study 2 is that FSWs’ experiences with healthcare services were marred by negative experiences in public healthcare facilities and most FSWs were not happy to seek care from public health

facilities. However, new knowledge was generated that HIV/STI facilities and clinics run by NGOs have a service delivery feedback system. This enables the health facility to improve service delivery for their clients. If this took place in all the healthcare facilities with facility managers' support, it could mean that FSWs and patients, in general, will be able to access service that is appropriate.

In addition, new knowledge about the lack of capacity and unwillingness of some HCPs in public healthcare facilities to work with FSWs was identified to be a significant challenge to scaling up to a more far-reaching response to violence experienced by FSWs within the healthcare systems. The studies' findings show that the majority of FSWs would have received better quality care if healthcare planners and policy makers significantly invest in capacity building for HCPs at all levels through pre-and post-training services. These findings could also be used by policy makers to enhance capacity building in other developing countries.

The results of this study support previous research about FSWs' experiences with healthcare as outlined above but go further, indicating that more meaningful information is gained when FSWs are asked to report on specific aspects of their experience of healthcare. For example, the majority of FSWs clearly expressed their wish to access care from public healthcare facilities because they felt that holistic services can be accessed free and at the same time.

Another contribution to new knowledge is that FSWs had extensive knowledge of what a good service should look like, and, above all, they wanted to be listened to and not be judged on the basis of their work. This study contributes to increasing awareness of, and respect for, the healthcare needs and human rights of FSWs by HCPs in the healthcare systems in Malawi which could be applied to similar situations elsewhere.

The findings of this study provide new knowledge on the extreme nature of the structural violence that these women experienced both in the community and healthcare systems. This clearly demonstrates the need to strengthen a human rights approach to supporting FSWs.

7.7 Summary

This study has tried to capture the essence of FSWs' experiences and perceptions with access to healthcare in Malawi. Previous studies have suggested a wide range of factors influencing experiences and perceptions of FSWs of accessing healthcare and these were significantly confirmed by the analysis of the data from the Study 1 and Study 2. Factors that influence FSWs' experiences and perceptions of accessing healthcare included cultural factors and structural violence affecting delivery of healthcare. Socio-cultural norms, traditions, cultural attitudes, and gender-related factors pose challenges when considering how structural violence could be changed and improve the current service delivery to meet FSWs' expectations and perceptions of healthcare in Malawi. The findings from this study support the suggestions as illustrated in the socio-ecological model of health service utilisation (McLeroy *et al.*, 1988). The theories helped to understand the data from both Study 1 and Study 2. The experiences and perceptions of FSWs with accessing healthcare is affected by individual, interpersonal, community, organisational, and public policy factors.

However, data from Study 1 and Study 2 about FSWs' actual experiences and perceptions of accessing healthcare with regard to positive experiences have yielded new knowledge which has implications for improvement of existing service delivery and development of new services based on FSWs' preferences. FSWs who accessed services providing HIV/STIs help, outreach and home-based services including those provided by Theatre for a Change and Family Planning Association of Malawi, described these as a positive experience, due to the positive attitudes of staff. In addition, many of the FSWs said they were happy with the location and sites of the health facilities. Others said they would prefer if specific health facilities were established in 'Hotspots' areas.

There has been some improvement in experiences and perception with accessing services among FSWs in Malawi with the support from NGOs but, there are still significant challenges to improving health services, including expansion of what NGOs are already providing. There is a specific need for services provided by NGOs to be fully supported by the Malawi government

through its Ministry of Health. Data reveal that FSWs would be happy if Theatre for a Change could provide them with ARVs after testing positive for HIV. The support of the Malawi government could improve accessibility of services for FSWs and enhance their positive experiences and perceptions with accessing healthcare.

Despite the positive experiences reported in the Study 1 and Study 2, data revealed that FSWs who accessed services in public health facilities describe their experiences and perceptions as negative, due to the rude behaviour, lack of confidentiality and denial of services by some HCPs especially nursing staff, with direct implications for the training and management of staff. However, the government has attempted to take some initiatives which would improve the experiences of FSWs in public health facilities. The measures taken, for example, working together with NGOs (some HCPs attending workshops organised by Theatre for a Change and Family Planning Association of Malawi), cannot overcome the overwhelming stigma and discrimination expressed by participants in these studies.

Stigma and violence experienced by FSWs were perpetuated by their clients, communities, and police officers as well as HCPs themselves. All these have implications for a need to change the cultural attitudes towards sex workers. Generally, FSWs experienced structural violence at each of these levels and, given that FSWs' play an important role in the effort to eradicate the HIV/AIDS pandemic in Malawi, the government, and HCPs efforts in combating violence among FSWs should be directed at all these levels. The next Chapter presents the researcher's positionality and what has been learnt in the process of the PhD study.

Chapter Eight: Researcher's Positionality and Lessons Learnt

8.0 Introduction

This chapter presents an overview of the researcher's position in both Study 1 and Study 2 and what has been learnt throughout the process of doing the PhD. Doing a PhD is a process of reflecting and learning. This process of reflecting and learning has taught me a lot and has made me a stronger person as well as a better researcher. The experience of doing a PhD for me is a great teacher and I trust that sharing my experiences will help others deal with challenges and struggles faced as a PhD student as well a researcher. Before discussing the learning journey, I will discuss my positionality in the two studies (Study 1 and Study 2) because my positionality is as important as the research process when someone engaged in a study of FSWs.

8.1 Researcher's Positionality

In Heideggerian phenomenological studies, it has been suggested that the researcher's own Being-in-the-world and fore-structures can affect the findings. Therefore, it is crucial that researchers using this method be open and truthful about their philosophical standpoint and pre-understandings before and during the process (Mackey, 2005). The researcher looks to understand the participants' lived experiences by first examining the researcher's own fore-structures of the phenomenon of interest (Koch, 1999; Mackey, 2005).

Positionality is a term used to describe how people are defined by their locations within existing networks of relationships, which can be analysed and changed during the research process (Russell & Stone, 2002). Positionality may include aspects of identity (e.g., gender, class, and sexuality), as well as personal experience of research and previous projects worked on, which may influence the interactions between the researcher and the research participants. Thus, understanding positionality is crucial to effective data collection and analysis: the various identities of the researcher(s) may influence and shape the encounters, processes and outcomes of a study

(Street, 1998). I had previously worked as a Senior Nurse and a CPD coordinator and thereby I could interact with the healthcare providers and the communities in the study setting. I have multiple identities which include health worker, manager, researcher, and a mother, all of which could influence the research process.

While the methodological approach to the study required the researcher to be an 'outsider', her familiarity with the communities in the study setting made her an 'insider' in some ways, as previously mentioned. This is so because, in some situations, participants in the study considered me an insider because of commonalities between them and me, for example, nationality, colour, familiarity with the study settings, being a nurse and having the ability to converse in local languages.

On the other hand, others considered me as an outsider because of my education, research role and my lack of shared views with the participants (especially FSWs). This blended insider-outsider position had benefits, challenges, and implications for the research process. For instance, my familiarity with the community facilitated instant access to, and rapport with, research participants. The institutions with which I interacted before data collection (e.g., the Family Planning Association of Malawi, Theatre for a Change, the Ministry of Health, and CHAM healthcare facilities) also showed a willingness to cooperate with me in the research process. Some were eager to learn about the research and others believed that the findings would allow the relevant stakeholders and healthcare planners to implement appropriate healthcare interventions that would influence access to health services. Furthermore, because of the participants' familiarity with me, my position of the researcher as perceived by participants in the study setting was nothing new.

In addition, my 'insiderness' provided an insight into the linguistic, cognitive, emotional and psychological principles of the study participants as well as the practical day-to-day events in the study setting (Wimpenny & Glass, 2002). Familiarity and closeness to the people in the study setting also helped me to collect data through informal interactions. On the other hand, my 'outsider' positionality helped me to be a 'learner' in respect of the social issues

surrounding sex work and its workers rather than a 'knower/informant' during the research process.

However, my insider positionality also posed challenges to the research process and may have negatively affected the data collection process. Being in this position I may have biases in interviewing and may not seek an in-depth understanding of the issues as I have considered myself a 'knower' of the issues being studied (Fraenkel & Wallen, 2003). In this way, the awareness of insiderness challenges the investigator to be fully and continually cognisant of her researcher role. My position as both insider and outsider in this study meant that the way I viewed myself changed from the beginning of the study. I now consider myself a learner in respect of FSWs' day-to-day life experiences. The next section presents the steps that have been undertaken through my learning journey and what has been learnt as the two studies were being conducted.

8.2 What Has Been Learnt?

I write this section in an effort to present the issues that I encountered during the completion of Study 1 and Study 2 and the knowledge gained. The topic of the research had, as its focus, the experiences of FSWs with their access to healthcare services in Malawi. Between conducting Study 1 and Study 2, the study topic has been refined at least three times while still focusing on the experiences of FSWs. Throughout my preparations to conduct this study, from the formulation of the initial topic, drafting the questions to the drafting of the interview questions, my position as a nurse exploring FSWs' experiences with access to healthcare remained at the forefront of my mind. Throughout the rest of this section, I discuss these issues, the assumptions I made throughout the process and the lessons that I continue to learn and apply regarding my learning process of doing Study 1 and Study 2.

8.2.1 What and how I have learnt

There are a number of things that I have learnt while doing this PhD. Some are personal and others are related to academic achievements. After Study 1, I took a break for six months before deciding to conduct the Study 2. Some of the attributes that I have learned during my PhD studies are reflected through

this thesis. However, below are some specific thoughts regarding my learning journey.

While conducting Study 1 and Study 2, I have learnt that conducting a research sometimes includes exploring what others claim is true and extending that understanding into new knowledge and something we want to know more about. In this case, for instance, I would not claim that my studies to explore FSWs' experiences are the only studies exploring such experiences, but my studies want to add new knowledge to the knowledge that is already in existence. When I reflect on my interviews with the participants in Study 1, I know that some could have gone better but with time, my techniques and abilities improved greatly. This is evidenced by the wealth of data that was borne out of phenomenological interviews with the participants in the Study 2. It was apparent that these participants had no shortage of experiences to draw upon and enhanced my understanding of their experiences.

I have also learnt that there are many things I thought I already knew about my study topic and my study participants, but which were incomplete or wrong after I learned more drawing on the literature findings from the Study 1 and Study 2 and the valuable comments from my two study supervisors as well as the thesis examiners of both Study 1 and Study 2. I have also learnt that I should have done more reading around IPA and/or discussed with those who have expertise in IPA to fully understand this. I wish I had invested more time in developing my interview techniques for Study 1 as I thought a research interview was more like a clinical interview but, on reflection, found they were very different things.

As I have stated above, the study topic has undergone some refining. The topic has been reorganised and refined from: 'FSWs' experiences with access to healthcare services'; 'FSWs' positive experiences with access to healthcare; and now to 'FSWs' experiences and perceptions with access to healthcare'. This has all been part of the learning process for me and justifies two of my initial thoughts i.e., maybe my knowledge about the study topic was incomplete or wrong; and that not everyone will agree with me and understand my topic, methodologies, or the research gap. I have learnt to appreciate and value both positive and negative recommendations and criticisms and this has influenced

Study 2. However, this required utmost patience, passion for my study, being humble enough to realise that I can learn from both the negative and positive recommendations and criticism from anyone, including my study supervisors or my thesis examiners.

Exploring FSWs' experiences enabled me to learn that there are several ways to reach groups that are harder to reach - like FSWs but I have learnt that FSWs can be reached through other FSWs who are highly respected within their circle called 'Queen Mothers'. The use of the 'Queen Mothers' as gatekeepers to identify potential participants in Study 1, played an important role as it was my first time to associate closely with this hard to reach group of people.

As I mentioned, I took a break from my PhD studies after Study 1 for six months before resuming my studies. The best aspect of my PhD transition was meeting and working with two amazing new supervisors for Study 2. They each played a role in shaping the person I am today, and they continue to encourage me to reach my goals and made me believe that I have what it takes to become a researcher. This made me realise that no two PhD journeys are the same, even though academic aspirations could be similar, but what you go through and what you experience, is unique in each journey. My reflections on both Study 1 and Study 2 have led me to consider the interaction between myself and the participants (especially FSWs) who were kind enough to share their time and thoughts and, in some cases, very sensitive and personal experiences with me. Through these developmental experiences, I learnt the joy derived from interacting with this group of women. Reflecting back on my initial motivation to undertake this study enables me to appreciate the experiences and perceptions of how healthcare services are delivered for this group of women and how their perceptions of the services influence the uptake of healthcare services within the public health sector.

Through interactions with FSWs, HCPs and service providers, I discovered that working collaboratively on issues that affect FSWs was a recipe for success in the provision of services that can address FSWs' broader needs by encouraging FSWs' development through involvement opportunities.

I could go on and on describing what I have learned but, to summarise, here are the four points I would like to share with the readers of my thesis:

- (1) As I have reflected back on the research experiences throughout my two studies, my mind has become flooded with valuable information. While I hope that the unique experiences that emerge from the data collected in Study 1 and Study 2 contributes to my field, the greater lessons that have emerged thus far pertain to the research experience itself. For example, focusing only on positive experiences in Study 1 meant I missed out on rich data about their overall experiences and only had partial understanding of their experiences. I did not consider the importance of letting the participant talk more about their experiences as I did not follow up on issues that were not on my interview questions in Study 1 which could have been very important to the participant. I have learnt from both Study 1 and Study 2 that it is important to have a broad perspective on what is important to the person being interviewed.
- (2) Choosing phenomenology as the philosophy behind the qualitative part of the Study 2 seemed quite straightforward as I knew the participants' individual experiences were going to be important to answer my research question and build on the Study 1 experiences. However, the complexities of what phenomenology actually is and the different approaches to it were both an experience and a learning curve. Fortunately, my Study 2 supervisors were very supportive and connected me with one of the PhD students who had just published a paper on Heideggerian phenomenology. This gave me an opportunity and the knowledge to conduct a Heideggerian phenomenological study myself, including interview techniques.
- (3) I chose to embrace my path and make the best out of it because it has helped building my character and confidence. My professional journey as a nurse and a researcher continues to speak to my interest in serving vulnerable groups of people and further demonstrates my disposition relating to this research.
- (4) This research project has provided me with deep insight into how FSWs, HCPs and service providers from NGOs perceive delivery of existing health services influence FSWs' experiences.

8.3 Summary

This section has presented my own positionality in both Study 1 and Study 2. I have described my positionality as both an insider and an outsider. As someone concerned with FSWs' experiences and perceptions of access to healthcare I became an insider with FSWs as my research interest is their lived experience. Furthermore, as someone engaged in qualitative research with FSWs in Malawi, my positionality is an important element of the research process.

I have also presented issues that I encountered during the completion of Study 1 and Study 2 and how the experiences have helped me to acquire knowledge during Study 1 and Study 2. I have specifically reflected on the learning process that took place both in Study 1 and Study 2 through interaction with participants of both studies and the data they provided as a valued contribution to my field of study. The final chapter presents overall conclusions to this thesis, contribution to new knowledge, strength and limitations and the implications of the findings of both Study 1 and Study 2.

Chapter Nine: Conclusions and Recommendations

9.0 Introduction

This chapter presents the key conclusions of this thesis and considers some implications of the findings for improving FSWs' experiences and perceptions of accessing healthcare in Malawi. The thesis utilised a qualitative approach to collect data (for Study 1 and Study 2) from a variety of sources including FSWs, HCPs and service providers from Theatre for a Change and Family Planning Association of Malawi. Three findings from each study particularly reveal FSWs' experiences and perceptions of accessing healthcare and indicated that most FSWs had positive experiences and positive perceptions of accessing healthcare in facilities providing HIV and STIs services and those services provided by Theatre for a Change and Family Planning Association of Malawi. These conclusions have significant implications for policy and planning interventions in Malawi's healthcare systems, with particular reference to services to address FSWs' needs.

The findings of these studies confirmed those from previous studies in suggesting that inter-related factors influence FSWs' experiences and perceptions of accessing healthcare. These include issues related to service delivery, affecting both positive and negative experience and perceptions of accessing healthcare; as well as issues related to violence experienced by FSWs at all levels as a result of social and cultural norms. Since the experiences are significantly affected by the social and cultural norms of the general population, development of services and policies and programmes (e.g., mass media campaigns) aimed at changing attitudes, the overall attitude of the community and HCPs could also play an important role in reducing the violence and stigma that affect FSWs accessing essential and high quality care. The studies also identified a number of strengths and limitations which are presented before considering key conclusions and their recommendations.

9.1 Strength and Limitations of both Studies

Both Study 1 and Study 2 used qualitative approaches to explore FSWs' experiences and perceptions of accessing healthcare in both public and NGOs' health facilities in Lilongwe, Malawi. In Study 1, 45 FSWs, 10 HCPs

and six service providers from NGOs (Theatre for a Change and Family Planning Association of Malawi) were interviewed to explore positive experiences of FSWs with access to healthcare. HCPs interviewed in this study were named by FSWs as providing positive experiences. The service providers from NGOs interviewed were those working in programmes that directly supports sex workers. HCPs and service providers were interviewed to obtain their views on why they thought FSWs named them as providing positive experiences. In Study 2, 25 FSWs were interviewed to explore both positive, negative, and neutral experiences and perceptions of accessing healthcare. Study 2 revealed a more diverse range of experiences which contributed to the strength of this thesis' findings.

9.1.1 Strengths of the Study

Based on the available literature at the time of conducting Study 1, no previous studies had been conducted focusing on FSWs' positive experiences with access to healthcare in the Malawi context. Because FSWs are a hidden population and harder to reach, the researcher contacted NGOs that were already supporting sex workers in order to access participants. As for HCPs and service providers, access was through contacting the organisations to seek permission to access the potential participants. All participants were given a chance to choose whether to take part and when interviews could be conducted.

As a native Malawian with a background in nursing I understood the local dialect making it easier to explore the topic and understand the cultural norms as well as being mindful that my nursing background should not be seen as a barrier. The researcher is fluent in English and the local language (Chichewa) which had positive implications for translation of both the information leaflet, the consent form, and the interview questions.

The number of participants in both studies provided rich data which, in turn, produced the original findings. The data from HCPs and service providers supported the data from FSWs. The data from both FSWs, HCPs and the service providers presented a diverse range of perspectives on issues of service delivery. They indicated some of the differences (e.g., planning

services based on clients' feedback) between the public and the HIV and NGOs' health facilities and giving reasons why FSWs preferred accessing services in these facilities. However, looking at both studies in combination, I was able to uncover positive and negative perspectives of FSWs, NGOs and HCPs. The findings, therefore, could be important in contributing to the development of services which are better adapted to the needs and wishes of FSWs in Malawi.

This study provides an important new insight into the experiences of FSWs in Malawi with access to healthcare and adds to our understanding of factors associated with service delivery within this vulnerable group of women. The researcher tried to ensure a diverse sample by interviewing FSWs who had accessed services from public, HIV/STI and NGO healthcare facilities as well as HCPs and service providers within the selected study area. The researcher believed that the study findings may, in part, represent the perceptions of most Malawian FSWs and HCPs working in similar facilities when it comes to serving or readiness to serve FSWs.

9.1.2 Limitations of the study

The limitation is that HCPs who had provided service to FSWs which were regarded as negative experiences in Study 1 were not interviewed, meaning that their perceptions of FSWs were not explored. Sampling of FSWs, service providers and HCPs was only done in the city and urban areas of Lilongwe, leaving out those in rural areas and the other 27 districts in Malawi, who may have different perceptions of their experiences with healthcare services. The transferability of findings in this study to the larger Malawian FSWs' populations should be regarded with care.

Another limitation is that both Study 1 and Study 2 were conducted in Lilongwe which has a very unique Malawi population, in that most of the population migrate from other districts in search of work because Lilongwe is the capital city of Malawi, and these people may have different social and cultural norms and beliefs which could influence their experiences and perceptions of access to healthcare.

Additionally, as a result of the sampling strategy, FSWs who were currently pregnant were excluded in both studies, so their perspectives were not captured. However, the experiences and perceptions of accessing antenatal care were provided by those FSWs who had previously accessed services during pregnancy.

Similarly, the researcher missed FSWs who attended the clinics on days when the in-depth interviews took place, however, through snowball sampling the study was able to capture those that might have attended the clinic when the researcher was interviewing and even those that did not use services provided by the NGOs.

Furthermore, FSWs in this study could have participated in other studies conducted within Theatre for a Change. Therefore, the study's sample of FSWs may be more likely to be aware about responding to interview questions. However, the researcher was very flexible in her questions and used a variety of questions and probes and the transcripts revealed that rich data was obtained from interviews.

This study did not reach women who did not disclose their sex work status to anyone and were not enrolled in care or connected to other FSWs, indicating that this population should be a priority for future efforts.

Due to the highly sensitive nature of the topic and the researcher's background (nurse), the possibility exists that FSWs gave socially desirable responses when describing their experiences with healthcare services and their HIV status. However, the researcher worked hard to establish a rapport with participants and, being mindful of her positionality in the study, leading to participants describing a wide range of experiences, so the researcher thinks this is less of a limitation.

The study might have missed some literature and policy documents that were not published in English, however, for most of the literature reviewed in this thesis, the abstracts were both in English and other native languages.

This study provides an important new insight into the experiences of FSWs in Malawi with access to healthcare and adds to our understanding of factors

associated with service delivery within this vulnerable group of women. The next section presents the key conclusions and some relevant implications.

9.2 Key Conclusions and Recommendations of Study 1 and Study 2

There are three main key conclusions from the range of findings from both Study 1 and Study 2. The first is that FSWs who participated in these two studies and had accessed services provided by either HIV or STIs facilities or NGOs had a more positive experience as compared with accessing a service in a public health facility. However, Study 2 extended the data on positive experiences. FSWs said they had positive experiences accessing healthcare in public health facilities when services were delivered by HCPs who attended workshops organised by NGOs. The other finding is that there is a need and preference for FSWs to have their own services and have these services delivered in their workplaces. These findings have important implications for HCPs and policy makers who need to be aware of FSWs' health needs, which have overall public health implications of prevention of transmission and treatment of HIV and STIs. However, in linking the findings to the Malawi social and cultural context, other conclusions can be drawn which have wider implications. The three key conclusions will be presented before the recommendations based on the findings of the Study 1 and Study 2.

9.2.1 Improving health service delivery in public health facilities

Understanding service users' perspectives, experiences and choices can play a crucial role in informing policy makers and service providers about the services needed and how they can be delivered. However, it seems that FSWs' views on accessing services have not been taken into account in developing plans and interventions for FSWs. For example, the National AIDS Commission (NAC) in their National HIV and AIDS policy: 2011-2016, Priority Area 8 (Pg.20) talks about capacity development, and it reads: 'Capacity development efforts should involve the strengthening of systems and services through training, retention and motivation of personnel at all levels; infrastructure development and availability of adequate resources at all levels. The key issue is to achieve sustainable capacities for the implementation of the rational response at all levels' (National AIDS Commission, 2011) (pg. 20).

The Malawi National HIV/AIDS policy in 2003, policy 5.7 (People engaged in transactional sex) describes the responsibility of the government as follows: 'Government shall ensure that people engaged in transactional sex have access to confidential and respectful health care, particularly sexual and reproductive health, life skills, female and male condoms and treatment and care in the case of sex workers who are living with HIV/AIDS' (National AIDS Commission of Malawi, 2003 Pg. 22). One could argue that, if the policies that are in place were addressed by the Malawi government through its Ministry of Health, FSWs would not have the experiences presented in this thesis.

Data has revealed that FSWs' negative experiences with accessing healthcare, were a result of the negative attitudes and stigmatising behaviour of HCPs. Both of these negative aspects could be addressed through training. The healthcare planners, policy makers and professional controlling bodies (Nurses and Midwives Council and Medical Council of Malawi) need to systematically integrate violence issues against vulnerable population in the pre- and in-service curricula for health service training and other related programmes. In the short term, the leadership in public health facilities could improve the quality of services addressing issues related to ethical and professional behaviour and accountability.

That nurses were mostly identified for negative attitudes towards FSWs in both Study 1 and Study 2 could be related to cultural and gender norms affecting FSWs' experiences and this requires HCPs suspending their cultural or social beliefs about FSWs. The nurses' professional regulatory body (Nurses and Midwives Council of Malawi) should regularly update nurses on the importance of adhering to the code of ethics that govern their professional practice.

Findings from both Study 1 and Study 2 indicate that FSWs preferred accessing services from HIV, STIs and NGOs facilities who respected them and treated them with compassion. Specifically, they were happy with the services because they said they took part in planning and implementation of the services (e.g., planning and facilitating workshops and distribution of condoms and contraceptives). Public health facilities could learn from these ideas in an effort to improve service delivery and the experiences of FSWs accessing services.

Strengthening the already existing partnership working between the public and the NGOs, public health facilities could learn from this and play a part in knowledge development on FSWs needs and how services are organised and implemented.

9.2.2 Developing services specifically for female sex workers

Both Study 1 and Study 2 have shown that many FSWs would like to have services delivered in facilities specifically designed for sex workers and these could also be allocated within the bars and entertainment places where they frequently visit, citing that they will not be stigmatised by HCPs because HCPs will have knowledge of their clients. While literature indicates that some NGOs are implementing such services (e.g., Family Planning Association of Malawi, Pakachele and Médecins Sans Frontières: MSF/Doctors Without Borders), the services are not nationally available. While this could be due to limited resources, as these are donor-funded programmes, it is also related to policy and political issues, political leaders not wanting to be seen as supporting sex work. NGOs providing such services have played an important role in training FSWs as community health workers who have carried out outdoor-to-door visits sharing information about HIV testing, care, and treatment and discreetly linked with other sex workers. If these services were adopted by the government, they could increase FSWs' access to their preferred services and also contribute to the locally based services. The next sections describes the cultural norms and beliefs and the implications for services delivery and enhancing FSWs' experiences.

9.2.3 Cultural norms and beliefs as determinants of FSWs' experiences

Study 1 and Study 2 have confirmed the theoretical view that FSWs' experiences and perceptions are influenced at various levels from the individual, community, and organisational factors, as well as public health policies. Findings from these studies also show that societal norms and cultural factors, particularly related to gender role and norms, have a considerable influence on FSWs' experiences with accessing healthcare. FSWs had negative experiences accessing healthcare when services were delivered by female nurses. The findings have also indicated that FSWs' experiences of

accessing healthcare were affected by the community when their sex work status was known and most of them avoided accessing services in health facilities that were within their community and travelled further away to access care, leading to extra costs, thus affecting their socio-economic status.

Addressing issues of stigma in the healthcare systems as well as in the wider society must be a goal for the government policy as well as it being community leaders' responsibility since they are more influential in imposing government policies and decisions at a local level in Malawi. Use of the media, information and communication technologies can play an important role in public awareness campaigns. There is scope for more targeted educational programmes within rural communities to address issues of stigma and awareness of FSWs. FSWs play an important role in the health of the society and have implications for public health and health promotion. Accessing healthcare in health facilities which are appropriate to current cultural beliefs and traditions and recognising the role FSWs play in the wider society, could have longer term positive benefits in the control of HIV and STI transmission and the health of the wider society. Where society is generally healthy, their socio-economic status is also better (McLeroy *et al.*, 1988). Therefore, improving the health of all Malawians through HIV and STI control programmes and society awareness, could lead to improved socio-economic status of the Malawi population which is currently one of the worst in the world as described in Chapter One. The next section provides recommendations for specific organisations and institutions based on the themes emerging from Study 1 and Study 2 data.

9.3 Recommendations

The study findings suggested a number of key opportunities for improving the experiences and perceptions of FSWs' accessing healthcare in Malawi that maybe considered in this specific context and considering their potential sustainability.

9.3.1 Implications for service delivery

The findings of these studies suggest that there is lack of guidelines, policies and frameworks guiding HCPs' responses to FSWs' broader needs and violence against FSWs. The following recommendations are made for:

9.3.1.1 Implications for healthcare policy and planners

- (1) Significant investment in capacity building for HCPs at all levels, starting at Village Health Committees. This could be achieved by:
 - Developing short, medium, and long-term plans aimed at improving health services delivery in public health facilities by increasing awareness of the importance of understanding FSWs' health needs and through resource allocation.
 - Systematically integrate violence issues against vulnerable populations in the pre- and in-service curricula for health service training and other related programmes.
 - Involve organisations already working with FSWs as there is evidence that they already act as a point of contact. Involve FSWs' networks and other groups of vulnerable women in developing, implementing, and up-dating the curricula.
- (2) Working together with different partners, including professionals, academics, and NGOs, the government could bring positive changes to FSWs' experiences and perceptions of healthcare in Malawi. However, the voice of FSWs and other service user also needs to be heard in improving the services and choices available to them regarding access to quality services.
- (3) These findings have important public health implications, posing threats to prevention and treatment of HIV programmes. The findings of this study suggest that the marginalisation and inequality faced by FSWs are located within the broad diversity of human rights violations which requires an urgent multi-sectoral approach, for example, the government of Malawi working in partnership with organisations already working with sex workers to reinforce

a culture of tolerance and human rights respect for every citizen regardless of their social circumstances.

9.3.2 Implication for practice

- (1) Managers at different levels of service delivery should increase awareness about the importance of stigma affecting delivery and accessing services among FSWs, through in-service training by adopting the in-service curricula already put in place by health planners and policy makers and adjusted to the knowledge need of the HCPs. Also, HCPs in public health facilities who have attended training events provided by Theatre for a Change or Family Planning Association of Malawi, could use the experiences and knowledge gained from these specialised facilities to act as a nurturing environment for the formation of training packages at local level to stimulate HCPs in public facilities.
- (2) HCPs in public health facilities could take advantage of FSWs' attendance at the facility to listen and act on their voices and this could increase FSWs' confidence and trust in the health services. For example, adopting a service delivery feedback system implemented by HIV/STI and NGOs facilities and adapt them to the changing needs and, where possible, improve them. They should use this knowledge and shared decision making to enable them to plan and deliver services that FSWs will perceive as positive thus increasing access and adherence to care.
- (3) HCPs working in both public and NGOs health facilities should explore both 'what FSWs expect and what they consider a good service' to ensure they have an increasingly accurate assessment on the health needs of FSWs. This should enable HCPs to improve service delivery and positively influence experiences and perceptions of accessing healthcare.
- (4) Ensure there are clear policies and guidelines for management of violence to support FSWs who experience violence within the health facility. However, the findings of both studies acknowledges that addressing violence among FSWs is not a straightforward process and requires precise action at multiple levels and by diverse range of stakeholders, hence suggesting a multi-sectoral efforts including professionals, educators, police officers NGOs, social networks and FSWs themselves.

9.3.3 Implications for future research

The areas arising from this thesis that have implications for research are:

- (1) While findings of the qualitative studies has shown that there is increasing support for FSWs from HIV/STI and NGOs' health facilities, the use of a longitudinal survey design could be used to improve understanding of FSWs' experiences and perceptions and can be used to answer future health research questions for a larger population of FSWs.
- (2) The studies in this thesis could be replicated in other rural FSWs' populations to enhance the research data dependability and feed the health planners and policy makers, helping in designing appropriate services for this group of women nationwide.
- (3) More research into what HCPs can do to add to service delivery to improve FSWs' experiences and perceptions of accessing to healthcare is required.
- (4) Ensure HCPs, the public and FSWs are involved effectively to help shape the future of this field of research in a meaningful way. The final section of this thesis presents a summary of the thesis.

9.4 Summary

This thesis provides a unique insight into FSWs' experiences and perceptions of accessing healthcare in Malawi. While some FSWs reported positive experiences while accessing healthcare in some healthcare facilities, more remains to be done considering that most Malawians are poor and exclusively access healthcare from public health facilities. The findings from the Study 1 and Study 2 could provide vital evidence for making improvements in the current service delivery and informing future plans and developments with particular attention to capacity building to enhance changes in HCPs' attitudes. In addition, the findings of the two studies call for a leadership which looks into how services for FSWs are delivered in public health facilities. This calls for developing strategies that aim to address the stigmatising attitudes of HCPs in public health facilities which was mentioned by almost all FSWs, even those who reported positive experiences in other health facilities.

References

Adams, R. (2008) *Empowerment, participation and social work*. New York: Palgrave Macmillan.

African Sex Workers Alliance (2019) *Every sex worker has got a story to tell about sex work: Violence against sex workers in Africa*. [online] Available from: https://www.nswp.org/sites/nswp.org/files/aswa_report_final_low_res-2.pdf (Accessed 20 January 2015).

Ahmadi-Javid, A., Seyedi, P. & Syam, S. (2017) A survey of healthcare facility location. *Computers and Operations Research*, 79 223-263.

Alhojailan, M. (2012) Thematic Analysis: A critical review of its process and evaluation. *West East Journal of Social Sciences*, 1 (1): 1-9.

Auerberch, C. & Silverstein, B. (2003) *Qualitative data: An introduction to coding and analysis*. New York: New York University Press.

Avert (2012) *HIV and AIDs in Malawi*. [online] Available from: <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/malawi> (Accessed 23 June 2015).

Avert (2019) *Global information on HIV and AIDS: HIV and AIDS in Malawi*. [online] Available from: https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/malawi#footnote8_p63n5ox (Accessed 08 February 2021).

Bailey, C. (1996) *A guide to field research*. Thousand Oaks, CA: Pine Forge.

Baird, S., Garfein, R., McIntosh, C. & Ozzler, B. (2012) Effects of a cash transfer programme for schooling on prevalence of HIV and Herpes simplex type2 in Malawi: a cluster Randomised trial. *Lancet*, (379): 1320-1329.

Banda, H. T., Bongololo, G. T., Ng'ombe, J. & Makwiza, I. (2006) Regional network for Equity in Health in east and southern Africa (EQUINET) Malawi. *REACH Trust Malawi, Malawi Health Equity Network*,

Baral, S., Beyrer, C., Muessig, K., Poteat, T., Wirtz, A., Decker, M., Sherman, S. & Kerrigan, D. (2012) Burden of HIV among female sex workers in low-income and middle-income countries: a systematic review and meta-analysis. *The Lancet Infectious Diseases*, 12 (7): 538-549.

Baral, S., Ketende, S., Green, J. L., Chen, P. A., Grosso, A., Sithole, B., Ntshangase, C., Yam, E., Kerrigan, D., Kennedy, C. E. & Adams, D. (2014) Reconceptualizing the HIV Epidemiology and Prevention Needs of Female Sex Workers (FSW) in Swaziland. *PloS One*, 9 (12): e115465.

Barnett-Page, E. & Thomas, J. (2009) Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology*, 9 (59): 1-11.

Beattie, T., Bhattacharjee, P., Isac, S., Mohan, H., Simic-Lawson, M., Ramesh, B., Blanchard, J., Moses, S., Watts, C. & Heise, L. (2015) Declines in violence and police arrests among female sex workers in Karnataka state, south India, following a comprehensive HIV prevention programme. *Journal of the International AIDS Society*, 18 (1): 1-16.

Beattie, T. S., Bhattacharjee, P., Ramesh, B. M., Gurnani, V., Anthony, J., Isac, S., Mohan, H. L., Ramakrishnan, A., Wheeler, T., Bradley, J., Blanchard, J. F. & Moses, S. (2010) Violence against female sex workers in Karnataka state, south India: impact on health, and reductions in violence following an intervention program. *BMC Public Health*, 10 476.

Beattie, T. S., Bhattacharjee, P., Suresh, M., Isac, S., Ramesh, B. M. & Moses, S. (2012) Personal, interpersonal and structural challenges to accessing HIV testing, treatment and care services among female sex workers, men who have sex with men and transgenders in Karnataka state, South India. *Journal of Epidemiology & Community Health*, 66 Suppl 2 ii42-48.

Beckham, S. W., Shembilu, C. R., Brahmbhatt, H., Winch, P. J., Beyrer, C. & Kerrigan, D. L. (2015) Female sex workers' experiences with intended pregnancy and antenatal care services in southern Tanzania. *Studies in Family Planning*, 46 (1): 55-71.

Behets, F., Rasolofomanana, J., Van Damme, K., Andriamiadana, J., Rasimindrakotroka, A., Hobbs, M., McClamroch, K., Raharimalala, L. & Dallabetta, G. (2005) Socio-demographic and behavioural factors associated with high incidence of sexually transmitted infections in female sex workers in Madagascar following presumptive therapy. *Sexual Health*, 2 (2): 77-84.

Bekker, L.-G., Johnson, L., Cowan, F., Overs, C., Besada, D., Hillier, S. & Cates, W. J. (2015) Combination HIV prevention for female sex workers: what is the evidence? *The Lancet*, 385 (9962), 72-87.

Benoit, C., Smith, M., Jasson, M., Magnus, S., Maurice, R., Flogg, J. & Reist, D. (2018) Canadian sex work workers weigh the cost and benefits of disclosing their occupational status to health providers. *Sexuality Research and Social Policy*, 16 (3): 329-341.

Bent-Goodley, T. (2007) Health Disparities and Violence Against Women: Why and How Cultural and Societal Influences Matter. *Trauma, Violence and Abuse*, 8 (2): 90-104.

Berg, B. (2012) *Qualitative Research Methods for the Social Sciences*. 8th edn. Long Beach: Allyn and Bacon.

Berger, R. (2015) Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, 15 (2): 219-234.

Bharat, S., Ramakrishna, J., Heylen, E. & Ekstrand, M. L. (2014) Gender-based attitudes, HIV misconceptions and feelings towards marginalized groups are associated with stigmatization in Mumbai, India. *Journal of Biosocial Science*, 46 (6): 717-732.

Binns, C. & Low, w.-Y. (2015) Sex Workers Need Public Health Too. *Journal of Public Health*, 27 (8): 804-805.

Bisika, T. (2008) *Cultural factors that affect sexual and reproductive health in Malawi*. [online] Available from: <http://srh.bmj.com> (Accessed 29 June 2015).

Bisika, T. (2009) Sexual and reproductive health and HIV/AIDS risk perception in the Malawi tourism industry. *Malawi Medical Journal*, 21 (2): 75-80.

Bless, C., Higson-Smith, C. & Kagee, A. (2006) *Fundamentals of social search methods: An African perspective*. 4th edn. Cape Town, South Africa: Juta.

Booth, A., Sutton, A. & Papaioannou, D. (2012) *Systematic Approaches to a Successful Literature Review*. Second Edition edn. London: SAGE Publications LTD.

Bos, E., Schaalma, H. & Pryor, J. (2008) Reducing AIDS-related stigma in developing countries: The importance of theory-and evidence-based interventions. *Psychology, Health & Medicine*, 13 (4): 450-460.

Bowling, A. (2002) *Research Methods in Health: Investigating Health and Health Services*. 2nd edn. Maidenhead: Open University.

Bowman, c. (2003) Theories of domestic violence in the African Context. *Journal of Gender, Social Policy and The Law.*, 11 (2): 847-863.

Boyatzis, R. (1998) *Transforming qualitative information: thematic analysis and code development*. Sage.

Boyle, M. (2018) Enacted stigma and felt stigma experienced by adults who stutter. *Journal of Communication Disorders*, (73): 50-61.

Bradley, E., Curry, L. & Devers, K. (2007) Qualitative Data Analysis for Health Services Research: Developing Taxonomy, Themes, and Theory. *Health Research and Educational Trust*, 758-1771.

Bradshaw, C., Atkinson, S. & Doody, O. (2017) Employing Descriptive Approach in Health Care Research. *Global Qualitative Nursing Research*, 4 1-8.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2): 77-101.

- Britten, N. (1995) Qualitative interviews in medical research. *BMJ*, (311): 251-253.
- Broido, E. & Manning, K. (2002) Philosophical foundations and current theoretical perspectives in qualitative research. *Journal of College Student Development*, 43 (4): 434-445.
- Bryman, A. (2006) *Social Research Methods*. 2nd edn. New York: Oxford University Press Inc.
- Campbell, C., Foulis, C. A., Maimane, S. & Sibiya, Z. (2005) I have an evil child at my house: Stigma and HIV/AIDS management in a South African community. *American Journal of Public Health*, (95): 808-815.
- Carlisle, S. (2000) Health promotion, advocacy and health inequalities: a conceptual framework. *Health Promotion International*, 15 (4): 364-376.
- Carpenter, C. (2010) A Meta-Analysis of the Effectiveness of Health Belief Model Variables in Predicting Behavior. *Health Communication*, 25 (8): 661-669.
- Carter, S. & Little, M. (2007) Justifying knowledge, justifying method, taking action: Epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, 17 (10): 1316-1328.
- Cerbone, D. (2010) *Heidegger: A Guide for the Perplexed*. London and New York: Continuum International Publishing Group.
- Chakrapani, V., Newman, P. A., Shunmugam, M., Kurian, A. K. & Dubrow, R. (2009) Barriers to free antiretroviral treatment access for female sex workers in Chennai, India. *AIDS Patient Care & Sexual Transmitted Diseases*, 23 (11): 973-980.
- Charmaz, K. (2000) Grounded theory: Objectivist and constructivist methods. In: Denzin, N. K. & Lincoln, Y. S., eds. *Handbook of qualitative research*. 2nd edn. Thousand Oaks: Sage: 509-535.

- Charmaz, K. (2006) *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks: Sage.
- Chersich, M. F., Luchters, S., Ntaganira, I., Gerbase, A., Lo, Y. R., Scorgie, F. & Steen, R. (2013) Priority interventions to reduce HIV transmission in sex work settings in sub-Saharan Africa and delivery of these services. *Journal of the International AIDS Society*, 16 17980.
- Chikaphupha, K., Nkhonjera, P., Namakhoma, I. & Loewenson, R. (2009) *Access to HIV treatment and care amongst commercial sex workers in Malawi*. [online] Available from: [https://assets.publishing.service.gov.uk/media/57a08b84ed915d622c000d21/PRARReport-Access to HIV treatment.pdf](https://assets.publishing.service.gov.uk/media/57a08b84ed915d622c000d21/PRARReport-Access_to_HIV_treatment.pdf) (Accessed 17 April 2014).
- Chima, P. (1999) Employee assistance roles in managing workplace diversity. *Employee Assistance Quarterly*, 15 (1): 61-76.
- Chirwa, A. & Kudzala, A. (2001) *Report on Assessment of Youth Friendly Health Services in Malawi*. Lilongwe: National Youth Council of Malawi.
- Choi, S. Y., Chen, K. L. & Jiang, Z. Q. (2008) Client-perpetuated violence and condom failure among female sex workers in southwestern China. *Sexually Transmitted Diseases*, 35 (2): 141-146.
- Christie, D. J., ., Wagner, R. V. & Winter, D. A. (2001) *Peace, Conflict, and Violence: Peace Psychology for the 21st Century*. Englewood Cliffs, New Jersey: Prentice Hall.
- Colaizzi, P. (1978) Psychological research as a phenomenologist views it. In: Valle, R. & King, M., eds. *Existential-phenomenological alternatives for psychology*. New York: Oxford University Press: 48-71.
- Conner, M. & Norman, P. (1996) *Predicting Health Behaviours: research and practice with social cognition models*. Buckingham: Open Press.
- Cooper, H., Moore, L., Gruskin, S. & Krieger, N. (2004) Characterizing perceived police violence: implication for public health. *American Journal of Public Health*, 94 (7): 1109-1118.

Corbin, J. & Strauss, A. (2008) *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Thousand Oaks, CA: Sage.

Corrigan, P. & Lam, C. (2007) Challenging the Structural Discrimination of Psychiatric Disabilities: Lessons Learned from the American Disability Community. *Rehabilitation Education*, 21 (1): 53-58.

Creswell, J. (2003) *Research design: Qualitative, quantitative, and mixed method approaches*. 2nd ed. edn. Thousand Oaks, CA: Sage.

Creswell, J. (2007) *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 2nd edn. Thousand Oaks: Sage Publications.

Creswell, J. (2009) *Research design: Qualitative, quantitative, and mixed methods approaches*. 3rd Edition edn. Los Angeles, CA: Sage Publications.

Creswell, J. (2014) *Qualitative Inquiry and Research Design: Choosing among Five Approaches*. 4th edn. Thousand Oaks: CA: SAGE.

Crocker, J. & Quinn, D. (2000) Social stigma and the self: Meanings, situations and self-esteem. In: Heatherton, T., Kleck, R., Hebl, M. & Hull, J., eds. *The social psychology of stigma*. New York: Guilford Press: 153-183.

Crotty, M. (1998) *The foundations of social research: Meaning and perspective in the research process*. London: Sage Publications.

Dahlgren, G. & Whitehead, M. (1991) *Policies and strategies to promote social equity in health*. Stockholm: Stockholm Institute of Future Studies.

Davies, M. & Macdowall, W. (2006) *Health promotion theory*. Berkshire, England: Open University Press.

Day, S. & Ward, H. (1997) Sex workers and the control of sexually transmitted disease. *Genitourinary Medicine*, 73 (3): 161-168.

Decker, M., Crago, A.-L., Chu, S., Sherman, S., Seshu, M., Buthelezi, K., Dhaliwal, M. & Beyrer, C. (2014) The Lancet Series on HIV in Sex Workers;

Paper 4 Burden and HIV Impact of Human Rights Violations Against Sex Workers.

Decker, M., Crago, A.-L., Chu, S., Sherman, S., Seshu, M., Buthelezi, K., Dhaliwal, M. & Beyrer, C. (2015) The Lancet Series on HIV in Sex Workers; Paper 4 Burden and HIV Impact of Human Rights Violations Against Sex Workers.

Denzin, N. & Lincoln, Y. (2008) *The landscape of qualitative research: Theories and issues*. Thousand Oaks, CA: Sage.

Dhana, A., Luchters, S., Moore, L., Lafort, Y., Roy, A., Scorgie, F. & Chersich, M. (2014) Systematic review of facility-based sexual and reproductive health services for female sex workers in Africa. *Global Health*, (10): 1-46.

Dovidio, J., Major, B. & Crocker, J. (2000) Stigma: Introduction and overview. In: Heatherton, T., Kleck, R., Hebl, M. & Hull, G., eds. *The social psychology of stigma*. New York: Guilford Press.

Dowling, M. (2005) From Husserl to van Manen: A review of different phenomenological approaches. *International Journal of Nursing*, 44 (2007): 131-142.

Dowling, M. (2007) From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44 (1): 132-142.

Draucker, C. (1999) The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing*, 30 (2): 360-373.

Dunkle, K., Jewkes, R., Brown, H., Gray, G., McIntyre, J. & Harlow, S. (2004) Gender-based violence, relationship power, and risk of HIV infection in women attending antenatal clinics in South Africa. *Lancet*, (363): 1415-1421.

Echezona-Johnson, C. (Undated) *Sexual Taboos and HIV/AIDS in Africa*. [online] Available from:

www.academia.edu/9986653/SEXUAL_TABOOS_HIV (Accessed 12 February 2021).

Ekstrand, M. L., Ramakrishna, J., Bharat, S. & Heylen, E. (2013) Prevalence and drivers of HIV stigma among health providers in urban India: implications for interventions. *Journal of the International AIDS Society*, 16 (3 Suppl 2): 18717.

Elder, J. P., Lytle, L., J., Sallis, F., Young, J. F., Steckler, A., Morton, D. S., Stone, E., Jobe, J. B., Stevens, J., Lohman, T., Webbere, L., Pate, R., Saksvig, B. J. & Ribisl, K. (2007) A description of the social-ecological framework used in the trial of activity for adolescent girls (TAAG). *Health Education Research*, 22 (22): 155-165.

Ellingson, L. (2006) 'Embodied Knowledge: Writing Researcher's Bodies Into. Qualitative Health Research'. *Qualitative Health Research*, 16 (2): 298-310.

Erausquin, J., Reed, E. & Blankenship, K. (2011) Police-related experiences and HIV risk among female sex workers in Andhra, India. *Journal of Infectious Disease*, 204 1223-1228.

Evens, E. L., M., Santi, K., Cooke, J., Ridgeway, K., Morales, G., Parker, C., Brennan, C., Bruin, d. M., Desrosiers, P., Diaz, X., Drago, M., Mclean, R., Mendizabal, M., Dais, D., Hershaw, R. & Dayton, R. (2019) Experiences of gender-based violence among female sex workers, men who have sex with men, and transgender women in Latin America and the Caribbean: a qualitative study to inform HIV programming. *BMC International Health and Human Rights*, 19 (9): 1-14.

Family Planning Association of Malawi (2011) *Counting the uncatchables! Report of the situation analysis of the magnitude, behavioral patterns, contributing factors, current interventions and impact of sex work in HIV prevention in Malawi, Lilongwe*. Malawi: UNFPA.

Farley, M. & Barkan, H. (1998) Prostitution, Violence and Post-traumatic Stress Disorder. *Women and Health*, 27 (3): 37-49.

- Farmer, P. (2005) *Pathologies of Power*. Berkeley: University of California Press.
- Finlay, L. (2002) 'Outlining the Researcher: The Provenance, Process, and Practice of Reflexivity'. *Qualitative Health Research*, 12 (3): 531-545.
- Finlay, L. & Ballinger, C. (2006) *Qualitative Research for Allied Health Professionals: Challenging Choices*. West Sussex. England: Whurr Publishers Limited.
- Fonner, V. A., Kerrigan, D., Mnisi, Z., Ketende, S., Kennedy, C. E. & Baral, S. (2014) Social cohesion, social participation, and HIV related risk among female sex workers in Swaziland. *PLoS ONE [Electronic Resource]*, 9 (1): e87527.
- FPAM (1999) *Family Planning Association of Malawi: Our Mission, Our Vision, Our Core Values*. [online] Available from: <https://www.fpamalawi.org/index.php/about-us> (Accessed 12 February 2015).
- Fraenkel, J. & Wallen, N. (2003) *How to design and evaluate research in education*. 5th ed edn. New York, NY: McGraw-Hill.
- Frenk, J. (1992) The concept and measurement of accessibility. In: White, K., Frenk, J., Ordonez, C., Paganini, J. & Starfield, B., eds. *Health Services Research: An Anthology*. Washington: Pan American Health Organization: 858-864.
- Gage, A. (1998) Sexual activity and contraceptive use: the components of the decision-making. *Studies in Family Planning*, 29 (2): 154-156.
- Galtung, J. (1969) "Violence, Peace, and Peace Research.". *Peace Research*, 6 (3): 167-191.
- Gama, J. D. B. (2009). *An assessment of the capacity of faculty-based youth friendly reproductive health services to promote sexual and reproductive health among unmarried adolescents: evidence from rural Malawi*. PhD. <http://etheses.qmu.ac.uk/132/>: Queen Margaret.

Gergen, K. (2003) *Knowledge as socially constructed*. [online] Available from: https://www.researchgate.net/publication/285849876_Knowledge_as_socially_constructed (Accessed 4 February 2015).

Ghosh, J. & Kalipeni, E. (2005) Women in Chinsapo, Malawi: vulnerability and risk to HIV/AIDS. *SAHARA J: Journal of Social Aspects of HIV/AIDS Research Alliance*, 2 (3): 320-332.

Gibson, W. J. & Brown, A. (2009) *Working With Qualitative Data*. London: Sage.

Gilmore, N. & Somerville, M. (1994) Stigmatization, scapegoating and discrimination in sexually transmitted diseases: Overcoming 'them' and 'us'. *Social Science and Medicine*, 39 (9): 1339-1358.

Glanz, K., Lewis, F. M. & Rimer, B. K. (1996) *Health Behavior and Health Education: Theory, Research, and Practice*. 2nd edn. San Francisco Jossey-Bass.

Global Networks for Sex Workers Project (2018) *Sex Workers' Access to Comprehensive Sexual and Reproductive Health Services: Promoting Health and Human Rights*. [online] Available from: www.nswp.org (Accessed 12 September 2018).

Global Networks for Sex Workers Project (2020) *Stigma and Discrimination Experienced by Sex Workers Living with HIV*. [online] Available from: www.nswp.org (Accessed 15 February 2021).

Goodley, D., Lawthom, R., Clough, P. & Moore, M. (2004) *Researching Life Stories: Method, Theory and Analyses in a Biographical Age*. Falmer: Routledge.

Government of Malawi. (2012) *Global AIDS Response Progress Report: Malawi Country Report for 2010 and 2011*. UNAIDS Secretariat: United Nations General Assembly.

Government of the Republic of Malawi (2016) *Health Sector Strategic Plan 11: 2017-2022 Towards Universal Coverage*. [online] Available from: <https://www.health.gov.mw/index.php/policies-strategies?download=4...> (Accessed 5 July 2018).

Government of the Republic of Malawi (1999) Panel Code Chapter (7:01).

Government of the Republic of Malawi (2003) *Malawi Health Information System: National Policy and Strategy*. [online] Available from: https://www.who.int/goe/policies/malawi_ehealth_strategy2011_2016.pdf (Accessed 22 September 2017).

Government of the Republic of Malawi (2011) *Malawi Health Sector Strategic Plan: Moving towards equity and quality*. [online] Available from: <https://www.mindbank.info/item/2307> (Accessed 12 January 2014).

Government of the Republic of Malawi (2012) *Population Reference Bureau: Malawi Population Data Sheet*. [online] Available from: <https://www.prb.org/datasheets> (Accessed 24 June 2014).

Government of the Republic of Malawi (2015a) *Malawi National HIV and AIDS Strategic Plan 2015-2020*. [online] Available from: <https://www.bing.com/search?q=Malawi+National+HIV+and+AIDS+Strategic+Plan+2015-2020-&FORM=EDGENA&PC=HCTS&refig=d491ec8c953f43c189cb97eebd781498> (Accessed 20 July 2017).

Government of the Republic of Malawi (2015b) *Malawi AIDs Response Progress Report*. [online] Available from: <https://hivstar.lshtm.ac.uk/files/2016/05/Malawi-AIDS-Response-Progress-Report-April-2015.pdf> (Accessed 17 March 2016).

Government of the Republic of Malawi & National AIDS Commission (2009) *National HIV Prevention Strategy 2009-2013*. [online] Available from: https://hivhealthclearinghouse.unesco.org/sites/default/files/resources/iiep_hiv_prevention_strategy_june_2009_malawi.pdf (Accessed 18 October 2016).

Grant, R. & Sugarman, J. (2004) Ethic in Human Subjects research : Do Incentives Matter? *Journal of Medicine and Philosophy*, 29 (6): 717-738.

Greene, G. J., Lee, M., Y., & Hoffpauir, S. (2005) The Languages of Empowerment and Strength in Clinical Social Work: A Constructivist Perspective. *Family Society: The Journal of Contemporary Social Sciences*, 86 (2): 267-277.

Greenhalgh, J. & Brown, T. (2014) Quality assessment: where do I begin. In: Boland, A., Cherry, M. & Dickson, R., eds. *Doing a Systematic Review*. London: Sage: 61-83.

Greenhalgh, T. (2010) *How to Read a Paper: The Basics of Evidence-based Medicine*. 4th edn. London: BMJ Books.

Griffiths, F. (2009) *Research Methods for Health Care Practice*. London: SAGE Publications Ltd.

Grubb, I., Beckham, S., Kazatchkine, M., Thomas, R., Albers, E., Cabral, M. & Group, I. T. f. K. A. P. W. (2014) Maximizing the benefits of antiretroviral therapy for the key affected populations. *Journal of the International AIDS Society*, (17): 1-8.

Guba, E. & Lincoln, Y. (1994) Competing pradigms in qualitative research. In: Denzin, N. K. & Lincoln, Y. S., eds. *Handbook of qualitative research*. London: Sage: 105-117.

Guba, E. & Lincoln, Y. (2005) Paradigmatic controversies, contradictions, and emerging confluences. In: Denzin, N. & Lincoln, Y., eds. *The SAGE handbook of qualitative research*. 3rd edn. Thousand Oaks, CA: Sage: 191-215.

Guest, G., MacQueen, K. & Namey, E. (2012) *Applied Thematic Analysis*. London: SAGE.

Haralambos, M. & Holbon, M. (2008) *Sociology: Themes and Perspectives*. Seventh edn. London: HarperCollins Publishers Limited.

Hardon, A., Vernooij, E., Bongololo-Mbera, G., Cherutich, P., Desclaux, A., Kyaddondo, D., Ky-Zerbo, O., Neuman, M., Wanyenze, R. & Obermeyer, C. (2012) Women's views on consent, counselling and confidentiality in PMTCT: a mixed-methods study in four African countries. *BMC Public Health*, 12 (26): 1-15.

Hargreaves, J., Bussa, J., Mushati, P., Fearon, E. & Cowan, F. (2017) Overlapping HIV and sex work stigma among female sex workers recruited to 14 respondent-driven sampling survey across Zimbabwe. *AIDS Care*, 29 (6): 675-685.

Harris, M., Harris, E. & Roland, M. (2004) Access to primary health care: Three challenges to equity. *Australian Journal of Primary Health*, 10 (3): 21-29.

Heaton, J. (2004) *Reworking Qualitative Data*. London: Sage.

Heise, L. (1998) Violence against women: an integrated, ecological framework. *Violence Against Women*, (4): 262-290.

Hofer, B. & Pintrich, P. (1997) The development of epistemological theories: Beliefs about knowledge and their relation to learning. *Review of Educational Research*, 67 (1): 88-140.

Holloway, I. (2006) *Qualitative Research in Health Care*. Berkshire, England: Open University Press.

Holloway, I. & Wheeler, S. (2013) *Qualitative Research in Nursing and Healthcare*. Chichester: John Wiley & Sons.

Hunter, M. (2002) The materiality of everyday sex: Thinking beyond 'prostitution'. *African Studies*, (61): 99-120.

Husserl, E. (1975) *Experience and Judgement*. Illinois, USA: Northwestern University Press.

Inwood, M. A. (1999) *A Heidegger Dictionary*. Oxford, UK: Blackwell Publishers LTD.

Janz, N. & Becker, M. (1984) The health belief model: a decade later. *Health Education Quarterly*, (11): 1-47.

Janz, N., Champion, V. & Stretcher, V. J. (2002) "The Health Belief Model .". In: Glanz, K., Rimer, B. & Lewis, F., eds. *Health Behavior and Health Education*. New York: John Wiley: 25-66.

Jeal, N. & Salisbury, C. (2013) Protecting the health of sex workers: will the real agenda please stand up. *Postgraduate Medical Journal*, 89 (1053): 369-370.

JHPIEGO, Government, M. & USAID. (2001) *Malawi National Reproductive Health Service Delivery Guidelines*. Lilongwe: Malawi Government.

Kanuha, V. (2002) *Colonization and Violence against Women*. IN: API Institute's National Summit. San Francisco,

Kapindu, H. (2015) *Family Planning Association of Malawi: Promoting Sexual and Reproductive Health for Quality Life*. [online] Available from: www.fpamalawi.org (Accessed 12 November 2017).

Karandikar & Prospero, M. (2010) From client to pimp: Male violence against female sex workers. *Journal of Interpersonal Violence*, 25 (2): 257-273.

Kathewera-Banda, M., Gomile_Chidyaonga, F., Hendriks, S., Kachika, T., Mitole, Z. & White, S. (2005) Sexual violence and women's vulnerability to HIV transmission Malawi: a right issue. *International Social Science Journal*, 57 (186): 649-660.

Katz, K. R., McDowell, M., Green, M., Jahan, S., Johnson, L. & Chen, M. (2015) Understanding the Broader Sexual and Reproductive Health Needs of Female Sex Workers In Dhaka, Bangladesh. *International Perspectives on Sexual & Reproductive Health*, 41 (4): 182-190.

Kayambazinthu, E. (1998) The language planning situation of Malawi. *Journal of Multilingual and Multicultural Development*, (5): 369-439.

- Kerlinger, F. (1986) *Foundations of Behavioural Research*. 3rd edn. New York: Holt, Rinehart & Winston.
- Kim, J. & Motsei, M. (2002) "Women enjoy punishment": attitudes and experiences of gender-based violence among PHC nurses in rural South Africa. *Social Science & Medicine*. , 54 (8): 1243-1254.
- Kim, J. C., Martin, L. J. & Denny, L. (2003) Rape and HIV Post-Exposure Prophylaxis: Addressing Epidemics in South Africa. *Reproduct Health Matters*, 11 (22): 101-112.
- Koch, T. (1999) An interpretative research process: revising phenomenological and hermeneutic approaches. *Nurse Researcher*, 6 (3): 20-34.
- Kroger, J. (1998) Adolescence as a second separation-individual process: critical review of an object relations approach. In: Skoe, E. & Von der Lippe, A., eds. *Personality development in adolescence: a cross national and life span perspective*. London: Routledge.
- Kuokkanen, L. & Leino-Kilpi, H. (2000) Power and empowerment in nursing: three theoretical approaches. *Journal of Advanced Nursing*, 31 (1): 234-241.
- Kurebwa, J. (2020) The Capacity of Adolescent-Friendly Reproductive Health Services to Promote Sexual Reproductive Health Among Adolescents in Bindura Urban of Zimbabwe. *Higher Education of Social Sciences*, 18 (1): 61-72.
- Lambert, V. & Lambert, C. (2012) Qualitative descriptive research: An acceptable design. *Pacific Rim International Journal of Nursing Research*, (16): 255-256.
- Lancaster, K., Powers, K., Lungu, T., Mmodzi, P., Hosseinipour, M., Chadwick, K., Go, V., Pence, B., Hoffman, I. & Miller, W. (2016) The HIV Care Continuum among Female Sex Workers: A Key Population in Lilongwe, Malawi. *PLoS One*, 11 (1): 1-15.

Laverack, G. & Wallerstein, N. (2001) Measuring community empowerment: a fresh look at organizational domains. *Health Promotion International*, 16 (2): 179–185.

Lee, R. M. (1993) *Researching sensitive topics*. London: SAGE Publications Ltd.

Levesque, J.-F., Harris, M. & Russel, G. (2013) Patient-centred access to health care: Conceptualising access at the interface of health care systems and population. *International Journal for Equity in Health*, 12 (18): 1-9.

Limaye, R., Rimal, R., Mkandawire, G., Robert, P., Dothi, W. & Brown, J. (2012) Talking About Sex in Malawi: Toward a Better Understanding of Interpersonal Communication For HIV Prevention. *Journal of Public Health Research*, 1 (2): 117-125.

Locke, K. (2001) *Grounded theory in management research*. Thousand Oaks, CA: Sage.

Lowe, M., Glenwright, D. & Makaya, M. (2010) *SADC Gender Protocol Barometer 2010 Malawi*. [online] Available from: <https://genderlinks.org.za/shop/sadc-gender-protocol-barometer-2010-malawi/> (Accessed 12 August 2015).

Lowes, L. & Prowse, M. A. (2001) Standing outside the interview process? The illusion of objectivity in phenomenological data generation. *International Journal of Nursing Studies*, 38 (4): 471-480.

Lutnick, A. & Cohan, D. (2009) Criminalization, legalization or decriminalization of sex work: what female sex workers say in San Francisco, USA. *Reproductive Health Matters*, 17 (34): 38-46.

Ma, H. & Loke, A. (2019) A qualitative study into female sex workers' experience of stigma in the health care in Hong Kong. *International Journal for Equity in Health*, 18 (175): 1-14.

Mackey, S. (2005) Phenomenological nursing research: methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing*, 42 (2): 179-186.

MacPherson, E. E., Sadalaki, J., Njoloma, M., Nyongopa, V., Nkhwazi, L., Mwapasa, V., Lalloo, D. G., Desmond, N., Seeley, J. & Theobald, S. (2012) Transactional sex and HIV: understanding the gendered structural drivers of HIV in fishing communities in Southern Malawi. *Journal of the International AIDS Society*, 15 Suppl 1 1-9.

Mahapatra, B., Battala, M., Porwal, A. & Saggurti, N. (2014) Non-Disclosure of Violence among Female Sex Workers: Evidence from a Large Scale Cross-Section Survey in India. *PLOS ONE*, 9 (5): e98321.

Malele, F., Séguy, N., Tuliza, C. & Vuylsteke, B. (1999) *Do female sex workers need special health care services?* IN: XI International Conference on AIDS and STD in Africa. Africa; Lusaka,

Malikwa, M. (2015) Malawi sex workers win forced HIV test case. *The Nation* Available from: <https://www.nyasatimes.com/malawi-court-declares-mandatory-hiv-testing-illegal-sex-workers-win-case/> (Accessed 25 October 2015).

Marshall, C. & Rossman, G. (2006) *Designing qualitative research*. 4th ed edn. Thousand Oaks, CA: Sage.

Marukutira, T., Stooove, M., Lockman, S., Mills, L., Gaolathe, T., R, Jarvis, J., Kelly, S., Wilson, D., Lutchters, S., Crowe, S. & Hellard, M. (2018) A tale of two countries: progress towards UNAIDS 90-90-90 targets in Botswana and Australia. *Journal of the International AIDS Society*, 21 (3): 1-6.

Matovu, J. K. & Ssebadduka, B. N. (2012) Sexual risk behaviours, condom use and sexually transmitted infection treatment-seeking behaviours among female sex workers and truck drivers in Uganda. *International Journal of STD & AIDS*, 23 (4): 267-273.

Matovu, J. K. & Ssebadduka, N. B. (2013) Knowledge, attitudes & barriers to condom use among female sex workers and truck drivers in Uganda: a mixed-methods study. *African Health Sciences*, 13 (4): 1027-1033.

Maxwell, J. (2005) *Qualitative research design: An interactive approach*. 2nd edn. Thousand Oaks, CA: Sage.

Maynard, M. (1994) Methods, practice and epistemology: The debate about feminism and research. In: Maynard, M. & Purvis, J., eds. *Researching Women's Lives from a Feminist Perspective*. London: Taylor and Francis.

McConnell-Henry, T., Chapman, Y. & Francis, K. (2009) Husserl and Heidegger: exploring the disparity. *International Journal of Nursing Practice*, 15 (1): 7-15.

McCorkel, J. & Myers, K. (2003) What Different Does Different Make? Position and Privilege in the Field. *Qualitative Sociology*, (26): 199-231.

McLeroy, K. R., Bibeau, D., Steckler, A. & Glanz, K. (1988) An ecological perspective on health promotion programs. *Health Education Quarterly*, 15 (4): 315-377.

McNabb, D. (2008) *Research Methods in Public Administration and Non-profit Management: Quantitative and Qualitative Approaches*. Measham: ME Sharpe.

McWhirter, E. (1994) *Counseling for Empowerment*. Alexandria VA: American Counseling Association Press.

Mellor, R. & Lovell, A. (2011) The lived experience of UK street-based sex workers and the health consequences: an exploratory study. *Health Promotion International*, 27 (3): 311-322.

Merriam, S. (1998) *Qualitative research and case study application in education*. San Francisco: Jossey-Bass.

Merriam, S. (2002) Introduction to qualitative research. In: *Qualitative Research in Practice: Examples for discussion and analysis*. San Francisco: Jossey-Bass: 1-17.

Mkandawire-Valhmu, L., Rodriguez, R., Ammar, N. & Nemoto, K. (2009) Surviving Life as a Woman: A Critical Ethnography of Violence in the Lives of Female Domestic Workers in Malawi. *Health Care for Women International*, 30 (9): 783-801.

Mosedale, B., Kouimtsidis, C. & Reynolds, M. (2009) Sex work, substance misuse and service provision: The experiences of female sex workers in south London. *Education, Prevention and Policy*, 16 (4): 355-363.

Mountain, E., Mishra, S., Vickerman, P., Pickles, M., Gilks, C. & Boily, M. C. (2014) Antiretroviral therapy uptake, attrition, adherence and outcomes among HIV-infected female sex workers: a systematic review and meta-analysis. *PLoS ONE [Electronic Resource]*, 9 (9): e105645.

Moustakas, C. (1994) *Phenomenological research methods*. Thousand Oaks: Sage.

Mtsetwa, S., Busza, J., Chidiya, S., Mungofa, S. & Cowan, F. (2013) "You are wasting our drugs": health service barriers to HIV treatment for sex workers in Zimbabwe. *BMC Public Health*, 13 698.

Munkhbaatar, S., Aumakhan, B., Jantsansengee, B., Azyei, I., Sanjaajamts, Z., Badrakh, J., Sovd, T., Stromdahl, S., Baral, S. & Amindavaa, O. (2014) HIV and sexually transmitted infection-related risks among female sex workers in Mongolia: second-generation surveillance survey, 2011-2012. *Sexually Transmitted Infections*, 90 (6): 463-468.

Munthali, A., Chimhiri, A. & Zulu, E. (2004) *Adolescent Sexual and Reproductive Health in Malawi: A Synthesis of Research Evidence*. IN: New York, The Alan Guttmacher Institute.

Mywage (2004) *Sex work for survival in Malawi*. [online] Available from: <https://mywage.org/malawi/career/women-and-work/sex-work-for-survival> (Accessed 20th January 2014).

National AIDS Commission. (2011) *Malawi National HIV and AIDS Policy: 2011-2016*. Ministry of Health.

National AIDS Commission and Ministry of Health. (2003) *National Behaviour Change Interventions Strategy for HIV/AIDS and Sexual Reproductive Health Lilongwe*. Lilongwe: NAC/MoH.

National AIDS Commission of Malawi. (2003) *Malawi National HIV/AIDS Policy*. Ministry of Health.

National Statistics Office. (2016) *Demographic and Health Survey 2015-2016: Key indicators*.

National Statistics Office. (2017) *Integrated Household Survey 2016-2017: Household Socio-economic Characteristics*. Zomba, Malawi: NSO.

National Statistics Office (2019) *18 Malawi Population and Housing: Census Main Report*. [online] Available from: <http://www.populationmalawi.org/wp1/wp-content/uploads/2019/10/2018-Malawi-Population-and-Housing-Census-Main-Report-1.pdf> (Accessed 23 February 2021).

Nettleton, S. (1995) *The sociology of health and illness*. Cambridge: Polity Press.

Neuman, W. (2004) *Social Research Methods: Qualitative and Quantitative Approaches*. 3rd edn. Boston: Allyn and Bacon.

Nnko, S., Kuringe, E., Nyato, D., Drake, M., Casalini, C., Shao, A., Komba, A., Baral, S., Wambura, M. & Changalucha, J. (2019) Determinants of access to HIV testing and counselling services among female sex workers in sub-Saharan Africa: a systematic review. *BMC Public Health*, 1-12.

Norman, P. & Bennett, P. (1996) Health locus of control. In: Conner, M. & Norman, P., eds. *Predicting health behaviour*. Buckingham, UK: Open University Press.: 62-94.

Norman, P. & Conner, M. (1993) The role of social cognition models in predicting attendance at health checks. *Psychology and Health*, 8 (6): 447-462.

Nyblade, L. (2006) Measuring HIV stigma: Existing knowledge and gaps. *Psychology, Health and Medicine*, (11): 335-345.

Nyblade, L., Pande, R., Mathur, S., MacQuarrie, K., Kidd, R., Banteyerga, H., Kidanu, A., Kilonzo, G., Mbwambo, J., Bond, V(2003) *Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia*. IN: International Centre for Research on Women. Washington, DC,

Nyblade, L., Reddy, A., Mbote, D., Kraemer, J., Stockton, M., Kemunto, C., Krotki, K., Morla, J., Njuguna, S., Dutta, A. & Barker, C. (2017) The relationship between health worker stigma and uptake of HIV counselling and testing and utilization of non-health services: the experience of male and female sex workers in Kenya. *AIDS Care*, 29 (11): 1364-1372.

Nyblade, L., Stangl, A., Weiss, E. & Ashburn, K. (2009) Combating HIV stigma in health care settings: What works? *Journal of the International AIDS Society*, 12 (1): 15-21.

O'Brien, D., Mills, C., Hamel, C., Ford, N. & Pottie, K. (2009) Universal access: the benefits and challenges in bringing HIV care to isolated and conflict affected population in the Republic of Congo. *Conflict and Health*, 3 (1): 1-7.

Onelove (2008) *Multiple and Concurrent Sexual Partnership in Southern Africa: A Ten Country Research Report*. [online] Available from: <https://www.hivsharespace.net/resource/one-love-multiple-and-concurrent-sexual-partnerships-southern-africa-ten-country-research> (Accessed 17 February 2018).

Onyango, M. A., Adu-Sarkodie, Y., Agyarko-Poku, T., Asafo, M. K., Sylvester, J., Wondergem, P., Green, K., Wambugu, S., Brennan, A. T. & Beard, J. (2015) "It's all about making a life": poverty, HIV, violence, and other vulnerabilities faced by young female sex workers in Kumasi, Ghana.

Journal of Acquired Immune Deficiency Syndromes: JAIDS, 68 Suppl 2 S131-137.

Overs, C. (2002) *An analysis of HIV prevention programming to prevent HIV transmission during commercial sex in developing countries*. [online] Available from: www.who.int/hiv/topics/vct/ws_toolkit/115solution.pdf (Accessed 20 November 2017).

Overs, C. (2017) *Sex work and the law-it's complicated*. [online] Available from: <https://theconversation.com/sex-work-and-the-law-its-complicated-81316> (Accessed 29 August 2018).

Pando, M., Coloccini, R., Reynaga, E., Rodriguez Fermepin, M., Gallo Vaulet, L., Kochel, T. & Avila, M. (2013) Violence as a barrier for HIV prevention among female sex workers in Argentina. *PLoS One*, 8 (1): 1-10.

Parker, R. & Aggleton, P. (2003) HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine*, 57 (1): 13-24.

Parley, J. (1997) Husserl, phenomenology and nursing. *Journal of Advanced Nursing*, 26 (1): 187-183.

Patton, M. (2002) *Qualitative Research and Evaluation Methods*. Thousand Oaks, CA.: Sage.

Pearson, M. (2010) *Impact evaluation of the Sector Wide Approach, Malawi (SWAp)*. [online] Available from: <https://www.heart-resources.org/assignment/impact-evaluation-of-the-sector-wide-approach-swapmalawi/> (Accessed 12 May 2014).

Phelan, J., Link, B. & Dovidio, J. (2008) Stigma and prejudice: one animal or two? *Social Science & Medicine*, 67 (3): 358–367.

Polit, D. & Tanto, B. (2008) *Nursing Research: Generating and assessing evidence for nursing practice*. Philadelphia: Lippincott Williams & Wilkins.

- Portes, A. (2006) Institutions and Development: A Conceptual Re-Analysis'. *Population and Development Review*, 32 (2): 233-262.
- Poundstone, K., Strathdee, S. & Celentano, D. (2004) The social epidemiology of human immunodeficiency virus/acquired immunodeficiency syndrome. *Epidemiologic Reviews*, (26): 22-35.
- Pulerwitz, J., Oanh, K., Akinwolemiwa, D., Ashburn, K. & Nyblade, L. (2015) Improving Hospital-Based Quality of Care by Reducing HIV-related Stigma: Evaluation Results from Vietnam. *Acquired Immune Deficiency Syndrome Behaviour*, 19 (2): 246-256.
- Racher, F. & Robinson, S. (2003) Are phenomenology and postpositivism strange bedfellows? *Western Journal of Nursing Research*, 25 (5): 464-481.
- Raingruber, B., Uwazie, E. & Bowie, S. (2010) Women's voices: attitudes and behaviors of female Ghanaian sex workers regarding HIV prevention and AIDS-related stigma. *Issues in Mental Health Nursing*, 31 (8): 514-519.
- Reed, E., Khoshnood, K., Blankenship, K. M. & Fisher, C. B. (2014) Confidentiality, privacy, and respect: experiences of female sex workers participating in HIV research in Andhra Pradesh, India. *Journal of Empirical Research on Human Research Ethics*, 9 (1): 19-28.
- Ritchie, J., Spencer, L. & O'Connor, W. (2003) Carrying out Qualitative Analysis'. In: Ritchie, J. & Lewis, J., eds. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage.
- Robson, C. (2002) *Real World Research*. 2nd edn. Oxford: Blackwell.
- Rosenheck, R., Ngilangwa, D., Manongi, R. & Kapiga, S. (2010) Treatment-seeking behavior for sexually transmitted infections in a high-risk population. *AIDS Care*, 22 (11): 1350-1358.
- Rosenstock, I. (1966) Why people use health services. *Milbank Memorial Fund Quarterly*, (44): 94-127.

- Rosenstock, I. (1974) Historical origins of the health belief model. *Health Education Monographs*, 2 (4): 328-335.
- Rosenstock, J. M., Strecher, V. J. & Becker, M. H. (1988) Social learning theory and the health belief model. *Health Education Quarterly*, 15 (2): 175-183.
- Rushing, R., Watts, C. & Rushing, S. (2005) Living the reality of forced sex work: perspectives from young migrant women sex workers in northern Vietnam. *Journal of Midwifery & Women's Health*, 50 (4): e41-44.
- Russell, R. & Stone, A. (2002) A review of servant leadership attributes: Developing a practical Leadership model. *Leadership and Organization Development Journal*, 23 (3): 145-157.
- Ryan-Flood, R. & Gill, R. (2009) *Secrecy and Silence in the Research Process*. London: Routledge.
- Sadala, M. & Adorno, R. (2002) Phenomenology as a method to investigate the lived experience: a perspective from Husserl and Merleau Ponty's thought. *Journal of Advanced Nursing*, 37 (3): 282-293.
- Saks, M. & Allsop, J. (2007) *Researching Health: Qualitative and Mixed Methods*. London: Sage Publications Ltd.
- Salkever, D. (1976) Accessibility and demand for preventive care. *Social Science and Medicine*, 10 (9-10): 469-475.
- Sapsford, R. (2006) Methodology. In: Jupp, V., ed. *The Sage Dictionary of Social Research Methods* London: Sage: Chapter 1, 1-26.
- Saunders, M., Lewis, P. & Thornhill, A. (2007) *Research Methods for Business Students*. London.: Prentice Hall.
- Schwartz, S., Papworth, E., Ky-Zerbo, O., Ouedraogo, G., Samadoulougou, C. & Wirtz, A. (2014) *Engagement in the HIV care continuum among female sex workers in two concentrated epidemics in West Africa*. IN: 20th International AIDS Conference. Melbourne, Australia,

Scorgie, F., Nakato, D., Harper, E., Richter, M., Maseko, S., Nare, P., Smit, J. & Chersich, M. (2013) We are despised in the hospitals': sex workers' experiences of accessing health care in four African countries. *Culture, Health & Sexuality*, 15 (4): 450-465.

Scorgie, F., Nakato, D., Ogutu, D., Netshivhambe, M., Chakuvinga, P., Nkomo, P., Abdalla, P., Sibanda, S. & Richter, M. (2011) *I expect to be abused and I have fear": Sex workers' experiences of human rights violations and barriers to accessing healthcare in four African countries*. Available from: [www.https://samumsf.org/sites/default/files/2018-02/ASWA Report HR...](https://samumsf.org/sites/default/files/2018-02/ASWA_Report_HR...) (Accessed 11 May 2017). Johannesburg, Gauteng, South Africa.

Seidman, S. (2003) *The Social Construction of Sexuality*. New York: Norton.

Seymour, W. (2001) 'Putting myself in the picture: researching disability and technology'. In: Daly, J., Guillemin, M. & Hill, S., eds. *Technologies and Health: Critical Compromises*. Oxford: Oxford University Press.

Seymour, W. (2007) 'Exhuming the Body: Revisiting the Role of the Visible Body in Ethnographic Research'. *Qualitative Health Research*, (17): 1188-1197.

Shannon, K., Kerr, T., Chettiar, J., Shovelles, J. & Tyndall, M. (2008) Social and structural violence and power relations in mitigating HIV risk of drug-using women in survival sex work. *Social Science and Medicine*, 66 (4): 911-921.

Shenton, A. (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, (22): 63-75.

Sherwood, J. A., Grosso, A., Decker, M. R., Peitzmeier, S., Papworth, E., Diouf, D., Drame, F. M., Ceesay, N. & Baral, S. (2015) Sexual violence against female sex workers in The Gambia: a cross-sectional examination of the associations between victimization and reproductive, sexual and mental health. *BMC Public Health*, 15 270.

Silverman, D. (2005) *Doing qualitative research*. 2nd edn. London: Sage.

Sorrell, J. & Redman, G. (1995) Interviews in qualitative nursing research: differing approaches for ethnographic and phenomenological studies. *Journal of Advanced Nursing*, 21 1117-1122.

Stacy, R. & Loyd, B. (1990) An investigation of beliefs about smoking among diabetes patients: information for improving cessation efforts. *Patient Education and Counselling*, 15 (2): 181-189.

Stadler, J. & Delany, S. (2006) The 'healthy brothel': the context of clinical services for sex workers in Hillbrow, South Africa. *Culture, Health & Sexuality*, 8 (5): 451-464.

Stafford, M. & Scott, R. (1986) Stigma deviance and social control: some conceptual issues. In: Ainlay, S., Becker, G. & Coleman, L., eds. *The Dilemma of Difference*. New York: Plenum.

Steen, R., Wheeler, T., Gorgens, M., Mziray, E. & Dallabetta, G. (2015) Feasible, efficient and necessary, without exception - Working with sex workers interrupts HIV/STI transmission and brings treatment to many in need. *PLoS ONE*, 10 (10): 1-11.

Stewarts, L., Kachingwe, S., Murgueytio, P., Namasasu, J., Nerquaye-Tetteh, J. & Kanyama-Phiri, W. (1998) Assessment of Youth Reproductive Health Needs in Malawi.

Strauss, A. & Corbin, J. (1998) *Basics of qualitative research*. Thousand Oaks, CA: Sage.

Street, A. (1998) In/forming inside nursing: Ethical dilemmas in critical research. In: Shacklock, G. & Smyth, J., eds. *Being reflective in critical educational and social research*. London, UK: Farmer.

Suchman, E. (1968) *Sociology and the Field of Public Health*. United States of America: Russell Sage Foundation.

Sullivan-Bolyai, S., Bova, C. & Harper, D. (2005) Developing and refining interventions in persons with health disparities: The use of qualitative description. *Nursing Outlook*, (53): 127-133.

Super, C. & Harkness, S. (2002) Culture structures the environment for development. *Human Development*, 45 (4): 270-274.

Suthar, A. B., Ford, N., Buchanas, P. J., Wong, V. J., Rajan, J. S., Saltzman, A. K., Ajose, O., Fakoyo, A. O., Granich, R. M., Negussie, E. K. & Baggaley, R. C. (2013) Towards Universal Voluntary HIV Testing and Counselling: A Systematic Review and Meta-Analysis of Community-Based Approaches. *PLOS Medicine*, 10 (8): 1-23.

The World AIDS Campaign (Undated) *Sex Work and the Law: The Case for Decriminalization*. [online] Available from: <https://www.nswp.org/sites/nswp.org/files/Sex%20Work%20&%20the%20Law.pdf> (Accessed 9 February 2021).

The World Bank (2021) *The World Bank in Malawi: Overview*. [online] Available from: <https://www.worldbank.org/en/country/malawi/overview#2> (Accessed 24 February 2021).

Theatre for a Change (2012) *Building Advocacy Capacities for Sex Workers in Malawi*. [online] Available from: <https://www.tfacafrica.com/wp-content/uploads/2014/07/Building-the-Advocacy-Capacity-of-Sex-Workers-in-Malawi-2012.pdf> (Accessed 7 January 2014).

Tolhurst, R. (2004) *Involving district level fieldworkers in participatory research: possibilities and constraints as an approach to gender mainstreaming in health*. Liverpool: University of Liverpool.

UK Legislation (2003) UK Public General Act: Sexual Offences Act 2003.

UNAIDS (2019) *People living with HIV receiving ART*. [online] Available from: www.AIDSinfo.unaids.org (Accessed 8 March 2021).

Underwood, C., Skinner, J., Osman, N. & Schwandt, H. (2011) Structural determinants of adolescent girls' vulnerability to HIV: views from community members in Botswana, Malawi and Mozambique. *Social Sciences and Medicine*, (73): 343-350.

United Nations Programme on HIV/AIDS (2007) *Practical Guidelines for Intensifying HIV Prevention - towards universal access*. [online] Available from: http://data.unaids.org/pub/Manual/2007/jc1274-towardsuniversalaccess_en.pdf. (Accessed 13 December 2017).

United Nations Programme on HIV/AIDS (2014) *90-90-90 An ambitious treatment target to help end the AIDS epidemic*. [online] Available from: http://www.unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf (Accessed 10th July 2018).

United Nations Programme on HIV/AIDS (2016) *Fast-track commitments to end AIDS by 2030*. [online] Available from: http://www.unaids.org/site/default/files/media_asset/fast-track-commitments_en.pdf. (Accessed 12th January 2018).

United Nations Programme on HIV/AIDS (2018) *HIV and AIDs in Malawi*. [online] Available from: www.avert.org (Accessed 29 March 2020).

Van de Borne, F. (2003). *"I am not a prostitute": Discords in targeted HIV/AIDS prevention interventions in urban and trading centres in Malawi*. PhD. University of Amsterdam, NL.

van Manen, M. (2007) Phenomenology of Practice. *Phenomenology & Practice*. *Phenomenology & Practice*, 1 (1): 12-28.

Varga, L. M. (2012). *Structural violence and vulnerable population: Health and Health Care Utilization among Black, Female Sex Workers in Miami, Florida*. Doctor of Philosophy. Coral Gables, Florida: University of Miami, Florida.

Vuylsteke, B., Ghys, P. D., Mah-bi, G., Konan, Y., Traore, M., Wiktor, S. Z. & Laga, M. (2001) Where do sex workers go for health care? A community based study in Abidjan, Cote d'Ivoire. *Sexually Transmitted Infections*, 77 (5): 351-352.

Wagner, A., Hart, T., McShane, K., Margolese, S. & Girard, T. (2014) Health care provider attitudes and beliefs about people living with HIV: Initial

validation of the Health Care Provider HIV/AIDS Stigma Scale (HPASS). *AIDS and Behavior*, 18 (12): 2397-2408.

Wagner, J., Cummings, G., Smith, D., Olson, J., Anderson, L. & Warren, S. (2010) The relationship between structural empowerment and psychological empowerment for nurses: a systematic review. *Journal of Nursing Management*, 18 (4): 448-462.

Wallerstein, N. (1993) Empowerment and Health: The theory and practice of community change. *Community Development Journal*, 28 (3): 218-227.

Wamoyi, J. (2008). *Family context and the complexity of parenting: A focus on the influence on young people's sexual behaviour in rural Tanzania*. Doctoral. University of Southampton.

Wanyenze, R., Musinguzi, G., Kiguli, J., Nuwaha, F., Mujisha, G., Musinguzi, J., Arinaitwe, J. & Matovu, J. (2017) "When they know that you are a sex worker, you will be the last person to be treated": Perceptions and experiences of female sex workers in accessing HIV services in Uganda. *BMC International Health and Human Rights*, 17 (11): 1-11.

Ward, H., Day, S. & Weber, J. (1999) Risky business: health and safety in the sex industry over a 9 year period. *Sexually Transmitted Infections*, 75 (5): 340-343.

Warhurst, C., Wright, S. & Lyonette, C. (2017) *Thematic Literature Review: Understanding and measuring job quality*. Chartered Institute of Personnel Development: Warwick Institute for Employment Research.

Weiss, M., Ramakrishna, J. & Somma, D. (2006) Health-related stigma: rethinking concepts and interventions. *Psychology, Health and Medicine*, 11 (3): 277-287.

Weitzer, R. (2010) Sex work: paradigms and policies. In: Weitzer, R., ed. *Sex for Sale: Prostitution, Pornography, and the Sex Industry*. 2nd edn. New York: Routledge.

Whitehead, M. (1992) The concepts and principles of equity and health. *International Journal of Health Services* (22): 429-445.

Whitehead, M., Petticrem, M., Graham, H., Macintyre, S. J., Bambra, C. & Egan, M. (2004) Evidence for public health policy on inequalities: 2: Assembling the evidence jigsaw. *Journal of Epidemiol Community Health*, (58): 817-821.

Wimpenny, P. & Glass, J. (2002) Interviewing in phenomenology and grounded theory: Is there a difference? *Journal of Advanced Nursing*, 31 (6): 1485-1492.

Wong, W. C., Holroyd, E. & Bingham, A. (2011) Stigma and sex work from the perspective of female sex workers in Hong Kong. *Sociology of Health & Illness*, 33 (1): 50-65.

Wood, K. & Jewkes, R. (1997) Violence, rape, and sexual coercion: everyday love in a South African township. *Gender and Development*, 5 (2): 41-46.

Woodford, M., Chakrapani, V., Newman, P. & Shunmugam, M. (2014) "Barriers and facilitators to voluntary HIV testing uptake among communities at high risk of HIV exposure in Chennai, India. *Global Public Health*, 11 (3): 363-379.

World Health Organization (2012) *Prevention and treatment of HIV and other sexually transmitted infections for female sex workers in low-and middle-income countries: recommendation for a public health approach*. [online] Available from: http://www.who.int/hiv/pub/guidelines/sex_worker/en (Accessed 12th May 2017).

World Health Organization & UNAIDS (2015) *Violence against sex workers and HIV prevention*. World Health Organization, Department of Gender, Women and Health (GWH), Family and Community Health (FCH). [online] Available from: <http://www.who.int/gender/documents/sexworkers.pdf> (Accessed 17th November 2017).

Zachariah, R., Spielmann, M., Harries, A., Nkhoma, W., Chantulo, A. & Arendt, V. (2003) Sexually transmitted infections and sexual behaviour among commercial sex workers in rural district of Malawi. *International Journal of STD & AIDS*, 14 (3): 185-188.

Zimmerman, M. (2000) Empowerment Theory: Psychological, Organizational and Community Levels of Analysis. In: Seidman, J., ed. *Handbook of Community Psychology*. New York: Kluwer Academic/Plenum: 43-63.

Zulliger, R., Barrington, C., Donastorg, C., Perez, M. & Kerrigan, D. (2015a) High Drop-off Along the HIV Care Continuum and ART Interruption Among Female Sex Worker in the Dominican Republic. *Journal of Acquired Immune Deficiency Syndromes*, 69 (2): 216-222.

Zulliger, R., Maulsby, C., Barrington, C., Holtgrave, D., Donastorg, Y. & Perez (2015b) Retention in HIV Care Among Female Sex Workers in the Dominican Republic: Implications for Research, Policy and Programming. *Acquired Immune Deficiency Syndromes Behaviour*, 19 (4): 715-722.

Appendices

Appendix 1A (Study 1), information sheet for FSWs: The positive experiences of female sex workers in accessing health care in Malawi: an exploratory study.

The positive experiences of female sex workers in accessing health care in Malawi: an exploratory study

Investigator: Hilda Lexa Kabambe

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

The purpose of the study is to understand what factors influence some health care providers' deliver positive experiences to female sex workers. Beyond this the aim is to explore your positive experiences of health care provision.

Do you have to take part?

It is entirely up to you to decide. I will describe the study and briefly go through this information sheet, which I will give you to keep. If you choose to participate in the study, I will ask you to sign a consent form to protect you from being identified and ensure your safety in cases of police legally requesting data from the study consent will bear dated note made with the participant personalised ID number. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

What will happen to you if you take part?

If you agree to take part in the study, I will ask for verbal consent. The verbal consent will be taken by me, and a dated note made with participant personalised ID number. This will be done as a means of protecting your identity in cases of police legally requesting data from the study. You will be interviewed by myself (Hilda Kabambe), and this will be a face-to-face and the interview will take place at a place where there is safety for both you and me. This might be at the organization's (FPAM/TfaC) offices where a special room may be provided or at the outreach centres where safety is guaranteed. Time for the interview can be arranged for when it is convenient for you. The interview should last about half to an hour. The interviews will be recorded with your permission for transcription purposes. After the initial interviews, I might wish to meet with you for a further interview if further positive experiences from health care providers.

Possible disadvantages, side effects, risks, and/or discomforts of taking part in this study

There are no obvious disadvantages or discomfort for taking part in this study. However, if for some reasons the interviews bring about some of the unpleasant experiences that you might have encounter while accessing health related care, please feel free to tell me and we will discontinue the interviews and some support will be arranged. However, members of staff from the hosting organizations (FPAM/TfaC) will be around during the interview to assist in case you need to talk about how you are feeling after the interview.

Possible benefits of taking part in this study?

The benefits of taking part in this study is that you are given a chance to express your feelings regarding how you were treated when you accessed care related to health issues. Also, the information that you will provide might be used to motivate and change the attitudes of health care providers towards female sex workers.

Expenses and payments

In cases where participants will have to use their airtime for contacting me, the airtime will be reimbursed through a system called "me to you". This will be about MK1000 to each participant who has made contacts. MK1000 reimbursement of transport to and from the interview place will be given to each FSW participant and the money will be given in cash immediately after the interviews.

Tokens for participating in the study

I will give each participant MK2500 as an appreciation for their time and taking part in the study. The money will be given in cash immediately after the interviews.

What will happen when the study ends?

All your details and information collected during the study will be kept confidential and in a locked cupboard. After the study is completed all the information will be destroyed.

Will your taking part be kept confidential?

Yes. I will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

Who to contact if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study

The research is being organised by the University of Warwick in the United Kingdom and conducted by me (Hilda Lexa Kabambe) as part of my PhD thesis. It is not funded by anyone.

What will happen if you do not want to carry on being part of the study?

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study to protect you from being identified and ensure your safety from police in case, they legally request to see the data from the study I will ask for verbal consent. The verbal consent will be taken by me, and a dated note made with the personalised participant ID number.

If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact by me or anyone else as regard to this study after you withdraw.

Withdrawal from the study will not affect the usual care or any benefits (for female sex worker) to which would otherwise be entitled.

Who to contact if there is a problem

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact Jo Horsburgh (details below).

Who should you contact if you wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a Senior University of Warwick official entirely independent of this study:

Jo Horsburgh

Deputy Registrar

Deputy Registrar's Office

University of Warwick

Coventry, UK, CV4 8UW.

T: +00 44 (0) 2476 522 713 E: J.Horsburgh@warwick.ac.uk

Will your taking part be kept confidential?

Confidentiality and anonymity will be upheld throughout the study implementation. The interview transcripts will be analysed by looking for themes about what you and other participants say. This will be done using codes to represent these themes. During transcription of interviews the data will be anonymised by removing person and place names. Transcripts will carry a personalised identifying number. Storage of digital transcripts will be password protected. No names will be recorded and data on age, district of origin, educational level, reasons for coming to Lilongwe will be collected directly into a tally so that the interviews as recorded and transcribed do not include any data about the interviewee. I will ask the participants not to mention during the recorded interview that they are sex workers. If the participant does talk about being a sex worker this will be omitted at transcription and the audio recording immediately destroyed. Your details you provide will only be accessible to the people you have consented for example the research assistants who will assist

in the transcription of the interviews. To maintain anonymity on tape-recorded information, I will have a register with a personalised ID number along with pseudonym of each participant which will only be known by me (Hilda Lexa Kabambe) and kept in a lockable cupboard. The information I obtain from you will only be used for the stated aims in the information sheet that I will give to you. The information I collect will be treated in the strictest confidence and no one from your area or the area you access health related care will see the information that you have provided. The results of the study that will be published will remain anonymous as pseudonyms will be used throughout the study period. All names and addresses relating to this study will be destroyed. All data concerned with the study will be kept for 10 years after the study as per the University of Warwick's data management policy.

What will happen to the results of the study?

The results of this study will be presented at key meetings and conferences organised within the Warwick University and publications example journals likely to be accessed by the targeted audiences, in this case the health care providers and future researchers who may use the data as references. However, no names or any information that may identify your participation will be included in the presentations and publications.

Who has reviewed the study

This study has been reviewed and given favourable opinion by National Health Research Services Committee (NHRSC) in Malawi (Reference number to be inserted after approval from the committee) and the University of Warwick's Biomedical and Scientific Research Ethics Committee (BSREC): REGO-2014-1040.

What if you want more information about the study

If you have any questions about any aspect of the study or your participation in it not answered by this participant information leaflet, please contact: National Health Services Research Committee (NHSRC) on 0888344443 or

Hilda Kabambe, H.L.kabambe@warwick.ac.uk, Tel: 0884903767) or

Prof. Frances Griffith, f.e.griffiths@warwick.ac.uk Tel: +442476572950 (Reception number for Warwick Medical School).

Thank you for taking the time to read this participant information leaflet.

Appendix 1B (Study 1), information Sheet for FSWs (Chichewa Version): The positive experiences of female sex workers in accessing health care in Malawi: an exploratory study.

Kufufuza zomwe ofuna chithandizo cha chipatala amapezana nazo: *uthenga kwa azimayi oyenda yenda omwe awonetsa chidwi chotenga nawo mbali mukafukuyu.*

Wofufuza: Hilda Lexa Kabambe

Mau otsogolera: Mukupemphedwa kulowa nao mu kafukufukuyi, koma musanapange chisankho, mpofunika mumvetsetse kuti nchifukwa chiyani kafukufukuyi akuchitika ndipo kuti mutengapo mbali yanji. Welengani zotsatilazi mofatsa ndiposo mukauzeke anzanu.

Mbali yoyamba ikukamba za cholinga cha kafukufukuyi ndipo kuti chidzakuchikuchitikireni ndi chiyani. Mbali ya chiwiri ikufotokoza zambiri za kafukufukuyi.

Mbali yoyamba

Kafukufukuyi ndi wa chiyani

Kufotokoza muchilankhulo cha dela limenelo.

Cholinga cha kafukufukuyi ndikufuna kudziwa zomwe zimapangitsa a chipatala kuthandiza bwino amai oyendayenda. Kupitilila apo apangitsa kuti kuthandiza bwinoku kuonjezereke.

Ndilowe nao mu kafukufukuyi?

Kusankha ndikwanu, Ndifotokoza mwachidule za kafukufukuyi ndi kuwerengaso za m'kalatayi ndipo ameme abvomeleze kulowa mu kafukufukuyi ndiwafunsa kuti apelike umboni wapakamwa kusonyeza kuti mwabvomela kulowa nao mu kafukufukuyi. Izi ndapanga pofuna kuteteza ufulu wanu komanso ngati a polisi atafuna kuti aone zotsatila zakafukufukuyu sangathe kukulondolani. Mukhoza kutulukamo mu kafukufukuyi nthawi ina ili yose popanda kupereka zifukwa ndipo palibe chilichose chomwe chidzakuchitikileni.

Chidzandichitikila ndi chiyani?

Mukalowa mukafukufukuyi, Ine Hilda Kabambe ndidzacheza nanu pofusana nanu mafuso pawiliwili komaso pamalo otetezeka cha inu ndi ine, muliso ndi mwai osankha malo a mene inu mungawakonde ndi kumasuka. Nthawi yokumana idzakhala yogwilizana komaso yoyenelela kwa inuyo. Kuchezaku kudzakhala kwa pafupifupi ola limodzi. Ndipo ndi kubvomeleza

kwanu ndidzatepa zokambilana kuti tikazinthauzile bwinobwino. Patapita miyezi ingapo ndidzakupemphaniso kuti munditumizimileko zomwe mukukumana nazo mukapita kukapeza thandizo ku chipatala. Mwina padzafunika kuti tidzakumaneso kupitiliza kufusana mafuso.

Zobvuta ndi zosautsa zina mukalowa nao mu kafukufukuyi ndizotani?

Palibe zobvuta ndi zosautsa zilizose chifukwa choti mwalowa nao mu kafukufukuyi, komabe ngati zokambilana zathu zidzakukumbutsani zina zosayenera zomwe mudakumana nazo pokalandila thandizo ku chipatala, mudzakahale omasuka kundiuza ndipo sitidzapitiliza zokambilinazo. Ndidzayesetsa kuperekapo chilimbikitso kuti mukhaleso bwinobwino.

Ubwino olowa nao mu kafukufukuyi ndiotani?

Ndikukupatsani mwai kuti mufokoze momwe adakulandililani ku chipatala kukalandila chithandizo. Komaso zomwe mudzatiuza zidzathandizila kuti achipatala asinthe maganizo achabe kwa amai oyendayenda.

Ndalama zakafukufukuyi wapeleka ndani?

Ndalama zoyendera popita kumalo koka funsilana mafuso zidzabwezedwa, zokwanila MK1000 ndipo mukadzagwiritsa nchito lamya maunitsi okwanila MK1000 adzapelekedwa kwaliyense panjira yomwe a makampani amafoni amitichula kuti “me to you” yomwe anthu ambili timaidziwa. Komanso kwamunthu aliyense amene watenga nawo mbali pa kafukufuku uyu adzapatsidwa ndalama yokwana MK2500 pokuthokozani potenga nawo mbali mu kafukufuku uyu.

Pomaliza pakafukufuku

Zokambilana zose zidzasungidwa mwa chisisi mumalo okiyidwa. Pamapeto peni mu kafukufukuyi zose zidzaokedwa.

Kodi padzakhala chisisi kwa ine

Ine ndidzatsatila za umunthu ndi malamulo ndipo zose zokambilana zidzakhala za chisisi monga ndikufotozela mu mbali ya chiwili.

Nanga patapezeka bvuto

Dandaulo lili lose pa momwe tidzayendetsele kafukufukuyi, tidzayesetsa kulithetsa moyenelera. Onaniso mbali yachiwili.

Kumaliza kwa mbali yoyamba

Ngati mbali yoyambayi mwakondwela nayo ndipo kuti mukuganizila zolowa nao mu kafukufukuyi, muwelengeso mbali yachiwiliyi musanapange chiganizo.

Mbali yachiwili

Wakoza ndani kafukufukuyi?

Kafukufuyi akoza ndi a sukulu ya ukachenjedwe ya Warwick yaku mangalande, ndipo otsogolera wake ndine Hilda Lexa Kabambe, ngati mbali imodzi ya maphuzilo anga a pamwamba. Palibe amene akuperekapo ndalama zochitila kafukufukuyi.

Chidzachitika ndi chiyani ngati sindifuna kuchita nao kafukufukuyi?

Chisankho cholowa nao mu kafukufukuyi ndi chodzipereka yekha aliyese. Amene safuna kulowanao, palibe chili chose chomwe chidzamuchitikile. Ameme abvomeleze kulowa mu kafukufukuyi ndiwafunsa kuti apeline umboni wapakamwa kusonyeza kuti mwabvomela kulowa nao mu kafukufukuyi. Izi ndapanga pofuna kuteteza ufulu wanu komanso ngati a polisi atafuna kuti aone zotsatila zakafukufukuyu sangathe kukulondolani. Mukhoza kutulukamo mu kafukufukuyi nthawi ina ili yose popanda kupereka zifukwa ndipo palibe chilichose chomwe chidzakuchitikileni.

Nanga patapezeka bvuto lililose?

Kafukufukuyi ali ndi insulasi ya sukulu ya ukachenjede ya Warwick yothandiza pa bvuto. Ngati muli ndi zina zoti mubvetsetse fusani a Jo Horsburgh (Onani zambiri m'musimu).

Nditadzakhala ndi dandaulo ndidzaonane ndi ndani?

Mudzathandizidwa pa dandaulo lililose lomwe mudzakhala nalo nthawi ya kafukufukuyi komaso bvuto lililose lidzathetsedwa bwino lomwe. Mudzatumize dandaulo lanu kwa yemwe ndi m'modzi wa akulu a sukulu ya ukachenjede ya Warwick amene sakukhudzidwa ndi kafukufukuyi pa adelesi ili pasiyi.

Jo Horsburgh

Wachiwiri kwa olandira anthu

Ofesi ya wachiwiri

Sukulu ya Warwick

Conventry, UK, CV4 8UW

Tel: + 00 44 (0) 2476 522 713 E: J.Horsburgh@warwick.ac.uk

Chinsisi changa chidzusungidwa bwanji pochita nao kafukufukuyi?

Chisisi chose ndiku saulula zidasungidwa nthawi yose ya kafukufukuyi pakuti ndidzagwilitsa ntchito ya kabisibisi. Dzina lanu silidzaoneka pena pali pose pa nthawi imene kafukufukuyi adzasindizikidzidwa. Amene adzadziwa za inu ndi okha oyendetsa nao kafukufukuyi. Polimbikitsa kabisibisi wa zose zomwe tidzaika mu tepi, ndidzakhala ndi buku lomwe ndidzaikamo dzina lanu komaso dzina lina lopeka amene ndidzawasunga ndine Hilda Kabambe mumalo okiyidwa. Zodzachita nazo za inuyo ndi zomwe zalembedwa mu chikalata chomwe ndidzakupatsani. Palibe yese wa mudela lanu adzadziwa zomwe mudzandiuze chifukwa ndidzazisunga mwa chisisi. Podzasindikiza za kafukufukuyi chisisi chidzasungidwa poti maina omwe tidzagwilitsa ntchito pochita kafukufukuyi adzakhala opeka. Maina ose ndi ma adelesi zidzaonongedwa mukati mwa miyezi itatu atatha kafukufukuyi ku sukulu ya Warwick.

Chidzachitika ndi chiyani ndi zotsatila za kafukufukuyi?

Zotsatila za kafukufukuyi zidzaperekedwa ndikulengezedwa mumisonkhano pa sukulu ya Warwick ndi ndikusikizidwa m'mapepala komaso kuperekedwa kwa amene adzakhudzidwa naye kafukufukuyi. A chipatala ndi ena odzachita kafukufuku mtsogolo muno adzagwilitsaso ntchito zotsatilazi ngati zoyelekezela. Pa zosezi sipadzakhala maina osonyeza kuti inu munachita nao kafukufukuyi.

Anaunika kafukufukuyi ndi ndani?

Nthambi ya kafukufuku ya sukulu ya Warwick ndiyo idaunika ndikuikapo maganizo oyenela pa kafukufukuyi (BSREC) Komanso boma laMalawi kudzera muunduna wazumoyo.

Nditani kuti ndimve zambiri za kafukufukuyi?

Ngati zomwe zalembedwazi sizokwanila kuti mulowe nao mu kafukufukuyi, mutha kulumikizana ndi Hilda Kabambe pa adelesi iyi: H.L.kabambe@warwick.ac.uk komaso pa telefoni iyi 0884903767, kapena Prof. Frances Griffiths, f.e.griffiths@warwick.ac.uk Tel: + 44 2476572950.

Zikomo kwambiri potenga nthawi kuwelenga zofunikila pakulowa nao mu kafukufukuyi zomwe zili mu pepalali.

Appendix 2 (Study 1), information sheet for HCPs: The positive experiences of female sex workers in accessing health care in Malawi: an exploratory study.

Investigator: Hilda Lexa Kabambe

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

The purpose of the study is to understand what factors influence some health care providers' deliver positive experiences to female sex workers. Beyond this, the information collected will be used to motivate or enhance positive attitudes of health care providers towards female sex workers.

Do you have to take part?

I have identified you as someone who gives helpful health advice or health care to female sex workers either because you work for an organisation that provides this care or because a female sex worker has mentioned your health facility as one of the areas where they had positive experiences with the care they obtained. It is entirely up to you to decide whether or not to take part. I will describe the study and go through this information sheet, which I will give you to keep. If you choose to participate, I will ask you to sign a consent form to confirm that you have agreed to take part in the study. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

What will happen to you if you take part?

If you agree to take part in the study, you will be interviewed by myself (Hilda Lexa Kabambe). This will be done face-to-face, and the interview

will take place at a place where there is safety for both you and myself. This might be at the organisation's offices or at the outreach centres in rooms that are secure and where safety is guaranteed. Time for the interview can be arranged for when it is convenient for you. The interview should last about half to an hour. The interviews will be recorded with your permission for transcription purposes. I will ask you to sign a consent form as proof that you are willing to participate in the study. If you are not willing to sign a consent form but willing to take part in the study your rights will be respected however, the information contained in the consent will be read and a verbal consent will be accepted.

Disadvantages, side effects, risks, and/or discomforts of taking part in this study

There is no obvious disadvantage or discomfort for taking part in this study.

Will your taking part be kept confidential?

Yes. I will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

The research is being organised by the University of Warwick in the United Kingdom and conducted by me (Hilda Lexa Kabambe) as part of my PHD thesis. It is not funded by anyone.

What will happen if you do not want to carry on being part of the study.

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate. If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact with me or anyone else as regard to this study after you withdraw.

Withdrawal from the study will not affect you in any way.

If there is a problem with this study.

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact Jo Horsburgh (details below).

Who to contact if you wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a Senior University of Warwick official entirely independent of this study:

Jo Horsburgh

Deputy Registrar

Deputy Registrar's Office

University of Warwick

Coventry, UK, CV4 8UW.

T: +00 44 (0) 2476 522 713 E: J.Horsburgh@warwick.ac.uk

Confidential

Confidentiality and anonymity will be upheld throughout the study implementation as I will use a coding system. Your name will not appear in any of the data that will be published. Your details will only be accessible to the people you have consented for example the research assistants who will assist in the transcription of the interviews. The interview transcripts will be analysed by looking for themes about what you and other participants say. This will be done using codes to represent these themes. To maintain anonymity on tape-recorded information, I will have a register with an actual name along with pseudonym of each participant which will only be known by me (Hilda Kabambe) and kept in a lockable. The information I obtain from you will only be used for the stated aims in the information sheet that I will give to you. The information I collect will be treated in the strictest confidence and, no one will see the information that you have provided. The results of the study that will be published will remain anonymous as pseudonyms will be used throughout the study period. All data concerned with the study will be kept for 10

years after the study as per the University of Warwick's data management policy.

What will happen to the results of the study?

The results of this study will be presented at key meetings and conferences organised by the Warwick University and publications example journals likely to be accessed by the targeted audiences, in this case, the health care providers and future researchers who may use the data as references. However, no names or any information that may identify your participation will be included in the presentations and publications.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by the University of Warwick's Biomedical and Scientific Research Ethics Committee (BSREC): (number and date will be inserted after approval from the ethics committee).

Who to contact if you want more information about the study?

If you have any questions about any aspect of the study or your participation in it not answered by this participant information leaflet, please contact:

Hilda Kabambe, H.L.kabambe@warwick.ac.uk, Tel: 0884903767 or

Prof. Frances Griffith, f.e.griffiths@warwick.ac.uk Tel: +442476572950 (Reception number for Warwick Medical School).

Thank you for taking the time to read this participant information leaflet.

Appendix 3 (Study 1), information sheet for FPAM/TfaC: The positive experiences of female sex workers in accessing health care in Malawi: an exploratory study

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the study about?

The purpose of the study is to understand what factors influence some health care providers' deliver positive experiences to female sex workers. Beyond this the information collected will be used to motivate or enhance positive attitudes of health care providers towards female sex workers.

Do you have to take part?

I have identified you as someone who gives helpful health advice or health care to female sex workers either because you work for an organisation that provides this care or because a female sex worker has mentioned you to me. It is entirely up to you to decide whether or not to take part. I will describe the study and go through this information sheet, which I will give you to keep. If you choose to participate, I will ask you to sign a consent form to confirm that you have agreed to take part in the study. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

What will happen to you if you take part?

If you agree to take part in the study, you will be interviewed by myself (Hilda Lexa Kabambe). This will be done face-to-face, and the interview will take place at a place where there is safety for both you and myself. This might be at the organization's offices or at the outreach centres in rooms that are secure and where safety is guaranteed. Time for the interview can be arranged for when it is convenient for you. The interview

should last about half to an hour. The interviews will be recorded with your permission for transcription purposes. I will ask you to sign a consent form as proof that you are willing to participate in the study. If you are not willing to sign a consent form but willing to take part in the study your rights will be respected however, the information contained in the consent will be read and a verbal consent will be accepted.

Disadvantages, side effects, risks, and/or discomforts of taking part in this study

There are no obvious disadvantages or discomfort for taking part in this study.

Possible benefits of taking part in this study

The benefits of taking part in this study is that you are given a chance to express your feelings regarding how you feel FSWs perceive about the services you provide and the experiences they get when accessing care related to health issues. Also, the information that you will provide might be used to motivate and change the attitudes of health care providers towards FSWs.

What will happen when the study ends?

All your details and information collected during the study will be kept confidential and in a locked cupboard. After the study is completed all the information will be destroyed.

Will your taking part be kept confidential?

Yes. I will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

The research is being organised by the University of Warwick in the United Kingdom and conducted by me (Hilda Lexa Kabambe) as part of my PhD thesis. It is not funded by anyone.

What will happen if you do not want to carry on being part of the study

Participation in this study is entirely voluntary. Refusal to participate will not affect you in any way. If you decide to take part in the study, you will need to sign a consent form, which states that you have given your consent to participate. If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way.

You have the right to withdraw from the study completely and decline any further contact by me or anyone else as regard to this study after you withdraw.

Withdrawal from the study will not affect you in any way.

If there is a problem with this study

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact Jo Horsburgh (details below).

Who to contact if you wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a Senior University of Warwick official entirely independent of this study:

Jo Horsburgh

Deputy Registrar

Deputy Registrar's Office

University of Warwick

Coventry, UK, CV4 8UW.

T: +00 44 (0) 2476 522 713 E: J.Horsburgh@warwick.ac.uk

Confidential

Confidentiality and anonymity will be upheld throughout the study implementation as I will use a coding system. Your name will not appear in any of the data that will be published. Your details will only be accessible to the people you have consented for example the research assistants who will assist in the transcription of the interviews. The interview transcripts will be analysed by looking for themes about what you and other participants say. This will be done using codes to represent these themes. To maintain anonymity on tape-recorded information, I will have a register with actual name along with pseudonym of each participant which will only be known by me (Hilda Kabambe) and kept in a lockable. The information I obtain from you will only be used for the stated aims in the information sheet that I will give to you. The information I collect will be treated in the strictest confidence and no one will see the information that you have provided. The results of the study that will be published will remain anonymous as pseudonyms will be used throughout the study period. All data concerned with the study will be kept for 10 years after the study as per the University of Warwick's data management policy.

What will happen to the results of the study?

The results of this study will be presented at key meetings and conferences organised within the Warwick University and publications example journals likely to be accessed by the targeted audiences, in this case the health care providers and future researchers who may use the data as references. However, no names or any information that may identify your participation will be included in the presentations and publications.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Biomedical and Scientific Research Ethics Committee (BSREC): (number and date will be inserted after approval from ethic committee).

Who to contact if you want more information about the study?

If you have any questions about any aspect of the study or your participation in it not answered by this participant information leaflet, please contact:

Hilda Kabambe, H.L.kabambe@warwick.ac.uk, Tel: 0884903767 or

Prof. Frances Griffith, f.e.griffiths@warwick.ac.uk Tel: +442476572950 (Reception number for Warwick Medical School).

Thank you for taking the time to read this participant information leaflet.

Appendix 4A: Consent for Participation (English version) Study 1 and Study 2)

The experiences of female sex workers in accessing health care in Malawi

I have read and understood the information sheet about the project that will explore my experiences of healthcare provision.

I have asked all the questions I want to know about the project that will explore my experiences of healthcare provision.

I have had my questions answered in a way I understand about the project that will explore my experiences of healthcare provision.

I understand that I can stop taking part at any time in the project that will explore my positive experiences of healthcare provision.

I understand that my participant data will be identified by an ID number or pseudonym in a project that will explore experiences of healthcare provision.

I understand I will take part in a one to one interview that will explore my experiences of healthcare provision.

_____ Date: _____
_____ Date: _____

Appendix 4B: Consent for participation (Chichewa version) (Study 1 and Study 2)

Umboni wobvomereza kuchita nawo kafukufuku.

Kafukufuku wa zabwino zomwe amai oyendayenda ndi kumagulitsa thupi lao amakapeza akafuna kukalandila thandizo kuchipatala.

Ndawerenga ndipo ndamvetsetsa nkhani ya mu kalatayi kuti ndiyakafukufuku wa zomwe ndinakumana nazo pamene ndimalandira chinthandizo chokhudzana ndi zaumoyo wanga.

Ndamvetsetsa zokhudza kafukufuku ameneyu kuti ndi zomwe ndinakumana nazo pamene ndimalandira chinthandizo chokhudzana ndi zaumoyo wanga.

Ndafusa mafuso onse amene ndinali nao pakafukufukuyu amene akufufuza zomwe ndinakumana pamene ndimalandira chinthandizo chokhudzana ndi zaumoyo wanga.

Ndadziwa kuti ndikhoza kutulukamo nthawi ili yonse mukafukufuku wazomwe ndina kumana nazo pamene ndimalandira chinthandizo chokhudzana ndi zaumoyo wanga.

Ndamva kuti nkhani yokhudzana ndi ineyo idzadziwika ndi chizindikilo changa cha nambala kapena dzina lopeka mukafukufuku wazomwe ndinakumana nazo pamene ndimalandira chinthandizo chokhudzana ndi zaumoyo wanga.

Ndavomeleza kuti ndidza funsidwa mafunso pandekha ndiomwe akuyendetsa kafukufukuyu wazomwe ndinakumana nazo pamene ndimalandira chinthandizo chokhudzana ndi zaumoyo wanga.

_____ Tsiku: _____
_____ Tsiku: _____

Appendix 5A (Study 1), female sex workers' interview guide: The positive experiences of female sex workers in accessing health care in Malawi: an exploratory study (English)

Question A and B are general questions to set up the interview and create rapport with the participants.

Opening questions

Tell me about yourself (name, language/tribe, home district, education, work)

How long have you lived here in this township?

Probe: What motivated you to come to this township?

Question C addresses the last part of objective number 1 to identify where FSWs chose to access health care and their experiences with health care providers

Access to health care related services

Since you have been in this township have you accessed any health care related services?

Probe: Was it from a hospital (private or government hospital?) or a chemistry/pharmacy or traditional healer/herbalist or friend or family member?

Which one?

What reasons do you give for your choice of where to access the care or advice?

Could you please tell me about the experiences you had?

What was it like?

Why do you think this was so?

How did that make you feel?

Why did you feel that way?

Tell me about any positive experiences?

How did that make you feel?

Question D addresses part of objective 1 with regards to what influenced their experiences as they interacted with the health care provider.

Was there anything about your contact with the person who provided the care or advice that made it easier or less hard to talk about your health related needs?

Probe: Could you please share what these were?

What was their reaction like?

How did that make you feel?

Question E addresses objectives number 3 and 4 with regards to how and whether health care providers provide the services which meet FSWs health needs.

What do you think are the areas that health care providers do well in addressing the health needs of female sex workers?

Probe: What makes them do well?

What is it that they are not doing well?

What makes them not function well?

How could they do it better?

Which are the health care services that you think are needed more for female sex workers?

Are there any particular health care that you would like health care facilities provide to you?

Closing the interview

I would like to thank you very much for accepting to be part of this study. As I promised at the beginning of this interview, I want to assure you again that the information I have collected will not be passed on to anyone else and will remain confidential.

Do you have any question that you would like to ask me related to the interviews that we have had?

Thank you very much.

Appendix 5B (Study 1), female sex workers' interview guide: The positive experiences of female sex workers with access to healthcare (Chichewa version)

Tandiuzani za inuyo

Dzina lanu

Chilankhulo/Mtunduwanu

Mudzi wanu

Boma

Sukulu munafika nayo pati?

Mumagwira ntchito yanji?

Mwakhalako nthawi yotalika bwanji kumalo ano?

Kupeza chithandizo cha chipatala

Chibweleleni kuno munapitapiko ku chipatala kukalandila thandizo?

Munapita chipatala chiti?

Chaboma, Cha mission, Cha pulayiveti, Kwa sing'anga Kwa anzanu?

Chifukwa chiyani munasankha kukapeza thandizo kumeneko
Munalandilidwa bwanji?

Zabwino zomwe munganene ndi zotani za m'mene anakulandilirani?

Inuyo munamva bwanji?

D, Padali chiyani chomwe chidapangitsa kuti mumasuke kapena kuuma
thupi pofotokoza mabvuto anu, fotokozani momasuka

Nanga okuthandizani anakuthandizani motani?

Inu munamva bwanji?

Ndiziti zomwe a chipatala amachita bwino pothandiza amai oyendayenda?

Chimawapangitsa kutelo ndichiyani?

Ndimbali iti yomwe sachita bwino?

Chimawapangitsa zimenezi ndichiyani?

Angatani kuti achite bwino?

Ndithandizo lotani lomwe likusoweka lokhudzana ndi amai oyendayenda?

Nanga ndithandizo lina lapadela lotani lomwe mukufuna litamapezekako kuchipatala?

Kumaliza: Ndikukuthokozani kwambiri pobvomeleza kulowa nao mukafukufukuyi. Monga ndinalonjezela poyamba paja, ndikukutsimikizilani kuti zonse mwandiuzazi zikhala za chisisi Ngati pali mafuso mutha kundifunsa pa zomwe takambilanazi?

Appendix 6 (Study 1), healthcare professionals' interview guide: The positive experiences of female sex workers in accessing health care in Malawi: an exploratory study

Opening questions

Question A and B are general questions to set up the interview and create rapport with the participants.

Tell me about yourself (name, profession/position, language/tribe, home district, education)

How long have you worked at this health facility?

Probe: What motivated you to work for this health facility?)

Do you encounter sex workers in your role?

Would you tell me more about your role?

Question C, D and E addresses objective No. 2 which explores the positive experiences of female sex workers from the perspectives of health care providers and how they provide this care and what influences such provision of care.

In your own opinion what do you think is the perception of sex workers about services you provide?

Probe: Why do you think sex workers feel that way?

What do you think is the perception of your staff towards sex workers?

Why do you think they perceive them that way?

What do you think is the perception of sex workers towards your staff?

Why do you think makes sex workers think that way for your staff?

What do you think are the services that your health facility do well?

Probe: What makes you think that way?

What is it that they are not doing well?

What makes them not do well?

How could they do it better than what it is now?

What are the challenges you that your staff encounter as they provide health care to female sex workers?

Probe: Why do you think staff encounter such challenges?

How do you think these challenges would be addressed?

Question F looks at an overview of services that are preserved as of importance to FSWs needs that may not be available at the health care facility and may assist in future planning for better services that will address FSWs health needs

Finally, what is your own perception are the most needed health related care services for female sex workers in Malawi?

Closing the interview

Is there anything that you think you could share with me in regard to sex workers accessing services that we have not discussed?

I would like to thank you very much for accepting to be part of this study. As I promised at the beginning of this interview, I want to assure you again that the information I have collected will not be passed on to anyone else and will remain confidential.

Do you have any question that you would like to ask me related to the interviews that we have had?

Thank you very much.

Appendix 7 (Study 1), interview guide for FPAM/TfaC participants: The positive experiences of female sex workers in accessing health care in Malawi: an exploratory study

The positive experiences of Malawi female sex workers in accessing health care: an exploratory study Investigator: Hilda Lexa Kabambe

Question A and B are general questions which set up the interview and create rapport with participants.

Opening questions:

Tell me about yourself (name, language/tribe, home district, education

Probe: How long have you worked at this organisation?

Could you explain to me what your role is in this organisation?

What motivated you to come and work for this organisation?

How easy is it to identifying female sex workers?

Probe: What do you do first?

Why do you do that first?

What do you think is the magnitude of sex work in Malawi?

Question C, D and F address the first part of objective number 2 especially with regard to the provision of health care services, which services and how are the services provided and what other services are not delivered and why is that so?

What services/resources and programmes are available for female sex workers in your organisation?

Probe: Are there any special reasons why your organisation embarked on services supporting sex workers?

Could you explain how these services are organised and delivered to sex workers?

What do you sex workers tell you about the services that you provide?

Why do you think they say that?

What health care related services do you feel are necessary but not available in our organisation?

What reasons do you give for your thinking that way?

In your own opinion which services do you feel that your organisation is doing well?

Probe: What makes you think that way?

What is it that your organisation is not doing well?

What makes it not do well?

How could your organisation do better than how it is now?

Have you at some point referred any sex worker to any health service delivery facility?

Probe: Which one? (Hospital (private or government), chemists/pharmacy or any health related counselling services).

What positive experiences did they say they had?

What reason did they give for experiencing the positive experiences?

3. Question F addresses the last part of objective number 2 with regard to what influences the way services are delivered to FSWs and what mechanisms would be put in place or what plans are there to address the challenges that the organisations face.

(f) What challenges do you think your organisation encounter while providing support services to female sex workers?

Probe: Why do you think the organisation encounter such challenges?

How do you think these challenges would be addressed?

4. Question G looks at an overview of services that are preserved as of importance to FSWs needs that may not be available at the health care facility and may assist in future planning for better services that will address FSWs health needs

(g) Finally, in your own opinion what do you think are the most needed health-related care support services for female sex workers in Malawi?

Closing the interview

Is there anything that you think you could share with me in regard to sex workers accessing services that we have not discussed?

I would like to thank you very much for accepting to be part of this study. As I promised at the beginning of this interview, I want to assure you again that the information I have collected will not be passed on to anyone else and will remain confidential. Do you have any question that you would like to ask me related to the interviews that we have had?

Appendix 8 (Study 1) Ethics Approval: BSREC Reference REGP-2014-1040

29th September 2014

Warwick
Medical School

PRIVATE
Hilda Kabambe
Health Sciences
Warwick Medical School
Coventry
CV4 7AL

Dear Hilda,

Study Title and BSREC Reference: *The positive experiences of female sex workers,*
REGO-2014-1040

Thank you for submitting your revisions to the above-named project to the University of Warwick's Biomedical and Scientific Research Ethics Sub-Committee for approval.

I am pleased to confirm that approval is granted and your study may commence.

Please keep a copy of the signed version of this letter with your study documentation.

Yours sincerely



David Davies
Chair
Biomedical and Scientific
Research Ethics Sub-Committee

**Biomedical and Scientific
Research Ethics Sub-Committee**
A010 Medical School Building
Warwick Medical School,
Coventry, CV4 7AL.
Tel: 02476-151875
Email: BSREC@Warwick.ac.uk

Medical School Building
The University of Warwick
Coventry CV4 7AL United Kingdom
Tel: +44 (0)24 7657 4880
Fax: +44 (0)24 7662 8375

THE UNIVERSITY OF
WARWICK

Appendix 9 (Study 1) Ethics Approval: Protocol #1348 NHSRC

Telephone: +265 789 400
Facsimile: +265 789 431

All Communications should be addressed to:
The Secretary for Health and Population



In reply please quote No. MED/4/36c
MINISTRY OF HEALTH AND POPULATION
P.O. BOX 30377
LILONGWE 3
MALAWI

01 November, 2017

Hilda Lexa Kabambe (Mrs)

Warwick University.

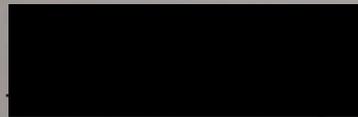
Dear Sir/Madam,

RE: Protocol # 1348: THE POSITIVE EXPERIENCE OF MALAWI FEMALE SEX WORKERS IN ACCESSING HEALTH CARE: AN EXPLORATORY STUDY.

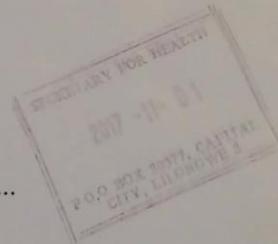
Thank you for the above titled proposal for amendment that you submitted to the National Health Sciences Research Committee (NHSRC) for review.

The Committee reviewed and approved the proposed amendments to the protocol.

Kind regards from the Secretariat.



FOR: CHAIRMAN, NATIONAL HEALTH SCIENCES
RESEARCH COMMITTEE



Executive Committee: Dr B. Chilima (Chairperson), Dr B. Nwira (Vice-Chairperson)
Registered with the USA Office for Human Research Protections (OHRP) as an International IRB
IRB Number IRB00000005 FWA00005976

Appendix 10A (Study 2), information sheet for female sex workers (English version): Female sex workers' experiences and perceptions with accessing healthcare in Malawi: a qualitative study

Investigator: Hilda Lexa Kabambe

Introduction

You are invited to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Talk to others about the study if you wish.

(Part 1 tells you the purpose of the study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study)

Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

PART 1

What is the study about?

The purpose of the study is to explore your experiences with access to healthcare services that are currently provided in Malawi.

Do you have to take part?

It is entirely up to you to decide. I will describe the study and briefly go through this information sheet, which I will give you to keep. If you choose to participate in the study. I will ask you to sign a consent form to protect you from being identified and ensure your safety in cases of police legally requesting data from the study consent will bear dated note made with the participant personalised ID number. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

What will happen to you if you take part?

If you agree to take part in the study, I will ask for verbal consent. The verbal consent will be taken by me, and a dated note made with participant personalised ID number. This will be done as a means of protecting your identity in cases of police legally requesting data from the study. You will be interviewed by myself (Hilda Kabambe), and this will be a face-to-face and the interview will take place at a place where there is safety for both you and myself. This might be at the organisation's (FPAM/TfaC) offices where a

special room may be provided or at the outreach centres where safety is guaranteed. Time for the interview can be arranged for when it is convenient for you. The interview should last about half to an hour. The interviews will be recorded with your permission for transcription purposes.

Possible disadvantages, side effects, risks, and/or discomforts of taking part in this study

There is no obvious disadvantage or discomfort for taking part in this study. However, if for some reasons the interviews bring about some of the unpleasant experiences that you might have encountered while accessing health-related care please feel free to tell me and we will discontinue the interviews and some support will be arranged, However, members of staff from the hosting organisations (FPAM/TfaC) will be around during the interview to assist in case you need to talk about how you are feeling after the interview.

Possible benefits of taking part in this study?

The benefits of taking part in this study are that you are given a chance to express your feelings regarding how you were treated when you accessed care related to health issues. Also, the information that you will provide might be used to motivate and change the attitudes of health care providers towards female sex workers.

Expenses and payments

In cases where participants will have to use their airtime for contacting me, the airtime will be reimbursed through a system called "me to you". This will be about MK2 500 to each participant who has made contacts. MK2 500 reimbursement of transport to and from the interview place will be given to each FSW participant and the money will be given in cash immediately after the interviews.

Tokens for participating in the study

I will give each participant MK10000 as an appreciation for their time and take part in the study. The money will be given in cash immediately after the interviews.

What will happen when the study ends?

All your details and information collected during the study will be kept confidential and in a locked cupboard. After the study is completed all the information will be destroyed.

Will your taking part be kept confidential?

Yes. I will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

Who to contact if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Will your taking part be kept confidential?

Yes. I will follow strict ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

Who to contact if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm that you might suffer will be addressed. Detailed information is given in Part 2.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

If you agree to participate, you may nevertheless withdraw from the study at any time without affecting you in any way. You have the right to withdraw from the study completely and decline any further contact with me or anyone else as regard to this study after you withdraw. Withdrawal from the study will not affect the usual care or any benefits (for female sex worker) to which would otherwise be entitled.

Who to contact if there is a problem?

This study is covered by the University of Warwick's insurance and indemnity cover. If you have an issue, please contact Jo Horsburgh (details below).

Who should you contact if you wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please

address your complaint to the person below, who is a Senior University of Warwick official entirely independent of this study:

Jo Horsburgh

Deputy Registrar

Deputy Registrar's Office

University of Warwick

Coventry, UK, CV4 8UW.

+00 44 (0) 2476 522 713

Email: J.Horsburgh@warwick.ac.uk

Will your taking part be kept confidential?

Confidentiality and anonymity will be upheld throughout the study implementation. The interview transcripts will be analysed by looking for themes about what you and other participants say. This will be done using codes to represent these themes. During transcription of interviews, the data will be anonymised by removing person and place names. Transcripts will carry a personalised identifying number. Storage of digital transcripts will be password protected. No names will be recorded and data on age, district of origin, educational level, reasons for coming to Lilongwe will be collected directly into a tally so that the interviews as recorded and transcribed do not include any data about the interviewee. I will ask the participants not to mention during the recorded interview that they are sex workers. If the participant does talk about being a sex worker this will be omitted at transcription and the audio recording immediately destroyed your details, you provide will only be accessible to the people you have consented for example the research assistants who will assist in the transcription of the interviews. To maintain anonymity on tape-recorded information, I will have a register with a personalised ID number along with pseudonym of each participant which will only be known by me (Hilda Lexa Kabambe) and kept in a lockable cupboard. The information I obtain from you will only be used for the stated aims in the information sheet that I will give to you. The information I collect will be treated in the strictest confidence and no one from your area or the area you access health-related care will see the information that you have provided. The results of the study that will be published will remain anonymous as pseudonyms will be used throughout the study period. All names and addresses relating to this study will be destroyed. All data concerned with the study will be kept for 10 years after the study as per the University of Warwick's data management policy.

What will happen to the results of the study?

The results of this study will be presented at key meetings and conferences organised by the Warwick University and publications example journals likely to be accessed by the targeted audiences, in this case, the healthcare professionals and future researchers who may use the data as references. However, no names or any information that may identify your participation will be included in the presentations and publications.

Who has reviewed the study?

This study has been reviewed and given a favourable opinion by National Health Research Services Ethics Committee (NHSREC) in Malawi: 1348 and the University of Warwick's Biomedical and Scientific Research Ethics Committee (BSREC): REGO-2014-1040 and BSREC: 62/18-19, respectively.

What if you want more information about the study?

If you have any questions about any aspect of the study or your participation in it not answered by this participant information leaflet, please contact Hilda Kabambe, H.L.kabambe@warwick.ac.uk, Tel: to be provided)

or

Prof. Sophie Staniszewska: Sophie.staniszewska@warwick.ac.uk

Tel: +442476572950 (Reception number for Warwick Medical School)

Thank you for taking the time to read this participant information leaflet.

Appendix 10B (Study 2), information sheet for female sex workers (Chichewa version): Female sex workers' experiences and perceptions with accessing healthcare in Malawi: a qualitative study

Kafukufuku wa zomwe amakumana nazo pamene akulandila thandizo la moyo wawo mzipatala zaku Malawi.

Wofufuza: Hilda Lexa Kabambe.

Mau otsogolera

Mukupemphedwa kulowa nao mu kafukufukuyi, koma musanapange chisankho, mpofunika mumvetsetse kuti nchifukwa chiyani kafukufukuyi akuchitika ndipo kuti mutengapo mbali yanji. Welengani zotsatilazi mofatsa ndiposo mukauzeke anzanu ngati mungakonde kutero.

Mbali yoyamba ikukamba za cholinga cha kafukufukuyi ndipo kuti chidzakuchikuchitikireni ndi chiyani. Mbali ya chiwiri ikufotokoza zambiri za kafukufukuyi.

Chonde ndifunsi ngati pali chichilichonse chomwe simunamvetse zaka kafukufukuyu. Mukupemphedwa kuti muganizire mozama musanapange chiganizo chotenga nawo mbali mukafukufukuyu.

Mbali yoyamba

Kafukufukuyi ndi wa chiyani?

Cholinga cha kafukufukuyi ndikufuna kudziwa zomwe mumakumana nazo pamene mukulandila chithandizo chokhudzana ndi moyo wanu.

Ndilowe nao mu kafukufukuyi?

Kusankha ndikwanu, Ndifotokoza mwachidule za kafukufukuyi ndi kuwerengaso za m'kalatayi ndipo ameme abvomeleze kulowa mu kafukufukuyi ndiwafunsa kuti apelike umboni wapakamwa kusonyeza kuti mwabvomela kulowa nao mu kafukufukuyi. Izi ndapanga pofuna kuteteza ufulu wanu komanso ngati a polisi atafuna kuti aone zotsatila zakafukufukuyu sangathe kukulondolani. Mukhoza kutulukamo mu kafukufukuyi nthawi ina ili yose popanda kupereka zifukwa ndipo palibe chilichose chomwe chidzakuchitikileni.

Chidzandichitikila ndi chiyani?

Mukalowa mukafukufukuyi, Ine, ndidzakufunsa chilolezi chanu ngati mwatsimikiza kutenga mbali, komanso nthawi nditsiku loti ndidzacheza nanu tidzagwiliza. Tsiku lakafukufuku lidzalembedwa komanso

mudzapatsidwa nambala yachinsinsi kutetezani ngatit kuona zotsatila zakafukufuyu. Mafunso omwe mudzafunsidwe adzafunsidwa ndiineyo (Hilda Kabambe) pawiliwili komaso pamalo otetezeka cha inu ndi ine, muliso. Malo omwe ndidzakufunsileni mafunsowa adzakhala komwe a FPAM/TfaC komwe tidzapatsidwe kachipinda komwe ndikotetezeka. Zokambilana zathu zidzajambulidwa ngati mungalole kutero kuti zikalembedwe bwino. Zokambilanazi zitha kudzatenga theka kapena ola limodzi.

Zobvuta ndi zosautsa zina mukalowa nao mu kafukufukuyi ndiziti?

Palibe zobvuta ndi zosautsa zilizose chifukwa choti mwalowa nao mu kafukufukuyi, komabe ngati zokambilana zathu zidzakukumbutsani zina zosayenera zomwe mudakumana nazo pokalandila thandizo ku chipatala, mudzakahale omasuka kundiuza ndipo sitidzapitiliza zokambilinazo. Ndidzayesetsa kuperekapo chilimbikitso kuti mukhaleso bwinobwino. Komanso anzathu ogwila ntchito ku FPAM/TfaC adzakha pafupi kuti zotelezi zitachitika atha kuti thandiza.

Ubwino olowa nao mu kafukufukuyi ndiotani?

Ndikukupatsani mwai kuti mufokoze momwe adakulandililani ku chipatala momwe mumakukalandila chithandizo. Komaso zomwe mudzatiuza zidzathandizila kuti achipatala asinthe maganizo achabe kwa amai oyendayenda ndikuwapatsa chithandizo choyenelera.

Ndalama zakafukufukuyi wapeleka ndani?

Ndalama zoyendera popita kumalo koka funsilana mafuso zidzabwezedwa, zokwanila MK2,500 ndipo mukadzagwiritsa nchito lamya maunitsi okwanila MK2,500 adzapelekedwa kwaliyense panjira yomwe a makampani amafoni amitichula kuti “me to you” yomwe anthu ambili timaidziwa. Komanso kwamunthu aliyense amene watenga nawo mbali mu kafukufuku uyu adzapatsidwa ndalama yokwana MK10,000 pokuthokozani potenga nawo mbali mu kafukufuku uyu.

Pomaliza pakafukufuku

Zokambilana zose zidzasungidwa mwa chinsisi mumalo okiyidwa. Pamapeto penipeni pa kafukufukuyi zonse zidzaonedwa.

Kodi padzakhala nchisisi kwa ine?

Ine ndidzatsatila za umunthu ndi malamulo ndipo zonse zokambilana zidzakhala za nchisisi monga ndikufotozela mu mbali ya chiwili.

Nanga patapezeka bvuto?

Dandaulo lili lose pa momwe tidzayendetsele kafukufukuyi, tidzayesetsa kulithetsa moyenelera. Onaninso mbali yachiwili.

Kumaliza kwa mbali yoyamba

Ngati mbali yoyambayi mwakondwela nayo ndipo kuti mukuganizila zolowa nao mu kafukufukuyi, muwelengeso mbali yachiwiliyi musanapange chiganizo. Ngati mwabvomeleza kutenga nawo mbali pa kafukufukuyu ndinu oloedwa kusiya nthawi iliyonse popanda kupeleka chifukwa chilichonse. Kusiya kutenga mbali sikuzasoneza chilichonse chokhudzana ndi kapezedwe kathandizo kuchipatala.

Mbali yachiwili

Wakoza ndani kafukufukuyi?

Kafukufuyi akoza ndi a sukulu ya ukachenjedwe ya Warwick yaku mangalande, ndipo otsogolera wake ndine Hilda Lexa Kabambe, ngati mbali imodzi ya maphuzilo anga a pamwamba. Palibe amene akuperekapo ndalama zochitila kafukufukuyi.

Chidzachitika ndi chiyani ngati sindifuna kuchita nao kafukufukuyi?

Chisankho cholowa nao mu kafukufukuyi ndi chodzipereka yekha aliyese. Amene safuna kulowanao, palibe chili chose chomwe chidzamuchitikile. Ameme abvomeleze kulowa mu kafukufukuyi ndiwafunsa kuti apelike umboni wapakamwa kusonyeza kuti mwabvomela kulowa nao mu kafukufukuyi. Izi ndapanga pofuna kuteteza ufulu wanu komanso ngati a polisi atafuna kuti aone zotsatila zakafukufukuyu sangathe kukulondolani. Mukhoza kutulukamo mu kafukufukuyi nthawi ina ili yose popanda kupereka zifukwa ndipo palibe chilichose chomwe chidzakuchitikileni.

Nanga patapezeka bvuto lililose?

Kafukufukuyi ali ndi insulasi ya sukulu ya ukachenjede ya Warwick yothandiza pa bvuto. Ngati muli ndi zina zoti mubvetsetse fusani a Jo Horsburgh (Onani zambiri m'musimu).

Nditadzakhala ndi dandaulo ndidzaonane ndi ndani?

Mudzathandizidwa pa dandaulo lililose lomwe mudzakhala nalo nthawi ya kafukufukuyi komaso bvuto lililose lidzathetsedwa bwino lomwe. Mudzatumize dandaulo lanu kwa yemwe ndi m'modzi wa akuluakulu a sukulu ya ukachenjede ya Warwick amene sakukhudzidwa ndi kafukufukuyi pa adelesi ili pasiyi.

Jo Horsburgh

Deputy Registrar

Deputy Registrar's Office

University of Warwick

Coventry, UK, CV4 8UW.

+00 44 (0) 2476 522 713

Email: J.Horsburgh@warwick.ac.uk

Chinsisi changa chidzusungidwa bwanji pochita nao kafukufukuyi?

Chisisi chose ndiku saulula zidzasungidwa nthawi yonse ya kafukufukuyi pakuti ndidzagwilitsa ntchito ya kabisibisi. Dzina lanu silidzaoneka pena pali ponse pa nthawi imene kafukufukuyi adzasindizikidzidwa. Amene adzadziwa za inu ndi okhaokha oyendetsa nao kafukufukuyi. Polimbikitsa kabisibisi wa zonse zomwe tidzaika mu tepi, ndidzakhala ndi buku lomwe ndidzaikamo dzina lanu komaso dzina lina lopeka amene ndidzawasunga ndine Hilda Kabambe mumalo okiyidwa. Zodzachita nazo za inuyo ndi zomwe zalembedwa mu chikalata chomwe ndidzakupatsani. Palibe aliyense wa mudela lanu adzadziwa zomwe mudzandiuze chifukwa ndidzazisunga mwa chisisi. Podzasindikiza za kafukufukuyi chisisi chidzasungidwa poti maina omwe tidzagwilitsa ntchito pochita kafukufukuyi adzkhala opeka komanso mudzapatsidwa nambala ya chinsinsi. Maina onse ndi ma adelesi zidzaonongedwa pamene zonse takambilana zitalembedwa.

Chidzachitika ndi chiyani ndi zotsatila za kafukufukuyi?

Zotsatila za kafukufukuyi zidzaperekedwa ndikulengezedwa mumisonkhano pa sukulu ya Warwick ndi ndikusikizidwa m'mapepala komaso kuperekedwa kwa amene adzakhudzidwa naye kafukufukuyi. A chipatala ndi ena odzachita kafukufuku mtsogolo muno adzagwilitsaso ntchito zotsatilazi ngati zoyelekezela. Pa zonsezi sipadzakhala maina osonyeza kuti inu munachita nao kafukufukuyi.

Anaunika kafukufukuyi ndi ndani?

Nthambi ya kafukufuku ya sukulu ya Warwick ndiyo idaunika ndikuikapo maganizo oyenela mu kafukufukuyi (BSREC) Komanso boma la Malawi kudzera muunduna wazumoyo.

Nditani kuti ndimve zambiri za kafukufukuyi?

Ngati zomwe zalembedwazi sizokwanila kuti mulowe nao mu kafukufukuyi, mutha kulumikizana ndi Hilda Kabambe pa adelesi iyi: H.L.kabambe@warwick.ac.uk (Number ya foni mupatsidwa)

Prof. Sophie Staniszewska: Sophie.staniszewska@warwick.ac.uk

Tel: +442476572950 (iyi ndi nambala yafoni ya munthu othandiza anthu pa Warwick Medical School).

Zikomo kwambiri potenga nthawi kuwelenga zofunikila pakulowa nao mu kafukufukuyi zomwe zili mu pepalali.

Appendix 11A (Study 2), female sex workers' interview guide (English version): Female sex workers' experiences and perceptions with accessing healthcare in Malawi: a qualitative study

Can you tell me about yourself?

Probe: You have said you are a female sex worker; can you please tell me what lead up to you becoming a sex worker?

How long have you been a sex worker?

Can you describe to me what is it like being a sex worker in your day to day life?

Have you accessed any healthcare since you have been a sex worker in this city?

Probe: If so, what were the reason that prompted you to seek the care?

What did you expect from the healthcare provider?

What was that experience like?

You have mentioned that you are a sex worker and that you are also HIV positive, can you tell me about what happened when you first came to learn about your HIV status? (This question will only be appropriate for FSWs living with HIV).

Probe: What happened then?

Did you get any support after your diagnosis of HIV?

From who and what type of support was it?

How did that support made you feel?

Tell me more about your experience as a female sex worker living with HIV mean to you?

How did your contact or engagement with HIV treatment start?

Can you tell me if there was anything that made it easier or harder for you to engage with health services?

Probe: Why do you think was the reason for that?

Can you tell me what effect you think being a sex worker/ living with HIV has on your experience with access to healthcare services?

Probe: How does it affect/how has it affected your health-seeking behaviour?

Tell me more on how that has affected your health seeking?

What about you keeping to HIV treatment?

Does this affect your work?

If so, how do you manage your treatment demands against your work demands?

Do you think FSWs living with HIV are treated differently as compared to those with unknown HIV status?

Probe: How do you know about this?

Tell me more about this?

Have you seen this?

If so, can you share an example?

If you were to decide how services were to be provided for FSWs living with HIV and those with unknown HIV status, what message would you give to healthcare planners and implementers?

Probe: What do consider a good health service?

Why do think that way?

What do you think stands in the way of a good health service?

Why do you think that is?

Other women have told me that they would like to have health clinics specifically designated for sex workers. What do you think about this?

Probe: Do you agree? Why?

What would be your advice to HCPs on services mostly need for FSWs?

Closing the interview

Is there anything else you would like to say, for example, anything that I have not asked you think is important?

I would like to thank you very much for accepting to be part of this study. As I promised at the beginning of this interview, I want to assure you again that the information I have collected will be treated confidentially. Finally, would you like to listen to the recorded interview?

Thank you very much.

Appendix 11B (Study 2) female sex workers' interview guide (Chichewa version): Female sex workers' experiences and perceptions with accessing healthcare in Malawi: a qualitative study

Mungandiuzeke za mbili yanu?

Mafunso otsatila: Mwati ndinu mzimayi oyendayenda, mungandiuzeke zifukwa zomwe zinakupangitsani kuti muyambe ntchito imeneyi?

Mwakhala nthawi yayitali bwanji mukugwila ntchito imeneyi?

Mungandifotokozereko mmene moyo wanu watsiku ndi tsiku mmene umakhalira monga inu ngati mzimayi oyendayenda?

Chiyambileni kukhala mzimayi oyenda-yenda mdera lino munalandilako chithandizo chilichonse kuchokera ku chipatala?

Mafunso otsatila: Ngati ndichoncho, ndichifukwa chiyani munaganiza zopita kuchipatala?

Chiyembekezo chanu chinali chotani kuchokela kwa azaumoyo?

Ndiye chiyembekezo chanu chinali chotani pamene munakumana ndi azaumoyo omwe anakuthandizani panthawiyi?

Mwanena kuti ndinu mzimayi oyendayenda komanso muli ndi matenda a HIV, mungandifotokozeleko zomwe munakumana nazo pomwe munauzidwa kuti mu ndi HIV? (Funso ili lidzafunsidwa kwa okha amene aulula kuti ali ndi matenda a HIV).

Mafunso otsatila: Ndiye mutauzidwa zinakhala bwanji?

Munalandila uphungu uliwonse mutauzidwa kuti mwapezeka ndi matenda a HIV?

Uphunguwu munalandila kuchokera kwandani ndipo unali otani?

Mutalandila uphungu umenewu inu munamva bwanji mtima mwanu?

Mungathe kunditambasulira za moyo wanu ngat mzimayi oyendayenda komanso kuti muli ndi matenda a HIV?

Pamene mumayamba kulandila mankhwala a matenda HIV zinali zotani kwa inu?

Tandifotokozerani ngati panali chomwe chinakupatsani chilimbikitso kapena choknhumudwitsa pamene mumalandila chithandizocho?

Mafunso otsatila: Nchifukwa chiyani mukuganiza choncho?

Kodi inu mukuganiza kuti kukhala mzimayi oyendayenda komanso kuti muli ndi matenda a HIV zili ndi zobvuta kapena zabwino kukhudzana ndi mmene mumanthandizidwila kuchipatala?

Mafunso otsatila: Zimenezi zimakhudza bwanji ganizo lanu lofuna chithandizo kuchipatala?

Tambasulani momwe zimenezi zimakhudzila umoyo wanu wa tsiku ndi tsiku?

Nanga mbali ya kamwede ka makhwala a matenda a HIV?

Zimenezi zili ndi mabvuto pa ntchito yanu yoyendayenda?

Ngati ndichoncho, ndiye mumakwanitsa bwanjii?

Mumaganiza kuti azimayi oyendayenda omwe ali ndi matenda a HIV amathandizidwa mosiyana kuyelekeza ndi azimayi oyenda yenda omwe alibe matenda a HIV mukapita kuchipatala?

Mafunso otsatila: Mukudziwa bwanji zazimenezi?

Mutha kutambasula pankhani yomwe mwangofotokozayi?

Inu munakumanazo kapena munaonapo zimenezi zikuchitika?

Ngati ndichoncho, fotokozani mmene zinalilii?

Mutapatsidwa mpata oti mupeleke maganizo anu pakapelekedwe kachithandizo zomwe azaumoyo amapeleka kwa azimayi oyendayenda omwe anapezeka ndi matenda a HIV komanso omwe alibe matenda a HIV, inuyo uthenga wanu utha kukhala otani kwa akuluakulu a unduna wa zaumoyo komanso opanga Malamulo?

Mafunso otsatila: Mmaganizo anu, chithandizo chabwino chiyenera kukhala chotani?

Nchifukwa chiyani mumaganiza choncho?

Mukuganiza kuti chimalepheretsa chithandizo chabwino ndichiyani?

Ndichifukwa chiyani mumaganiza choncho?

Azimayi anzanu omwe nawo amagwila ntchito yeyendayenda anena kuti amafuna kutakhala chipatala chongopeleka chithandizo kwa azimayi ngati inuyo. Inu mukuganiza bwanji pankhani imeneyi?

Mukugwilizana nayo? Chifukwa chiyani?

Mutati mwapatsidwa mwayi olangiza azaumoyo pa thandizo Lomwe ndilofunika kwambili kwa azimayi oyendayenda, inu munga walangize bwanji?

Mau omaliza

Palichilichonse chomwe mungafune kunenapo zokhudzana ndinkhani yomwe takambilanyi, mwachitsanzo, ngati pali zomwe sitinakambilane zomwe mukuganiza kuti ndizofunika kwambili tikanakambilana?

Ndikufuna ndikuthokozeni chifukwa cholola kutenga nawo mbali pa kafukufuku ameneyu. Komanso ndikutsimikizileninso kuti monga ndinalongosolera pachiyambi paja kuti zones zomwe tikambilane zidasungidwa mwachinsinsi. Pomaliza, mungakonde kuti mumvetsele zomwe zajambulidwazi nkucheza kwathu?

Zikomo kwambili.

Appendix 12 (Study 2), Female sex workers' experiences and perceptions with accessing healthcare in Malawi: a qualitative study: Ethics Application Reference BSREC 62/18/19



WARWICK
THE UNIVERSITY OF WARWICK

Biomedical and Scientific Research Ethics Committee
Kirby Corner Road
Coventry
CV4 8UW

Wednesday, 18 September 2019

Mrs Hilda Kabambe
Warwick Medical School
University of Warwick
Coventry
CV4 7AL

Dear Mrs Kabambe,

Ethical Application Reference: BSREC 62/18-19

Title: Female sex workers experience with access to healthcare in Malawi

Thank you for submitting your revisions to the Biomedical and Scientific Research Ethics Committee (BSREC) for consideration. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, full approval for your project is hereby granted.

Before conducting your research it is strongly recommended that you complete the on-line Research Integrity training:

www.warwick.ac.uk/ritraining. Support is available from the BSREC Secretary.

In undertaking your study, you are required to comply with the University of Warwick's Research Code of Practice:

https://warwick.ac.uk/services/ris/research_integrity/code_of_practice_and_policies/research_code_of_practice/

You are also required to familiarise yourself with the University of Warwick's Code of Practice for the Investigation of Research Misconduct:

https://warwick.ac.uk/services/ris/research_integrity/research_misconduct/codeofpractice_research_misconduct/

You must ensure that you are compliant with all necessary data protection regulations:

<https://warwick.ac.uk/services/idc>

Please ensure that evidence of all necessary local permissions is provided to BSREC prior to commencing your study.

Please also be aware that BSREC grants ethical approval for studies. The seeking and obtaining of all other necessary approvals is the responsibility of the investigator.

www.warwick.ac.uk



Any substantial changes to any aspect of the project will require further review by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes. The BSREC Secretary should be notified of any minor amendments to the study.

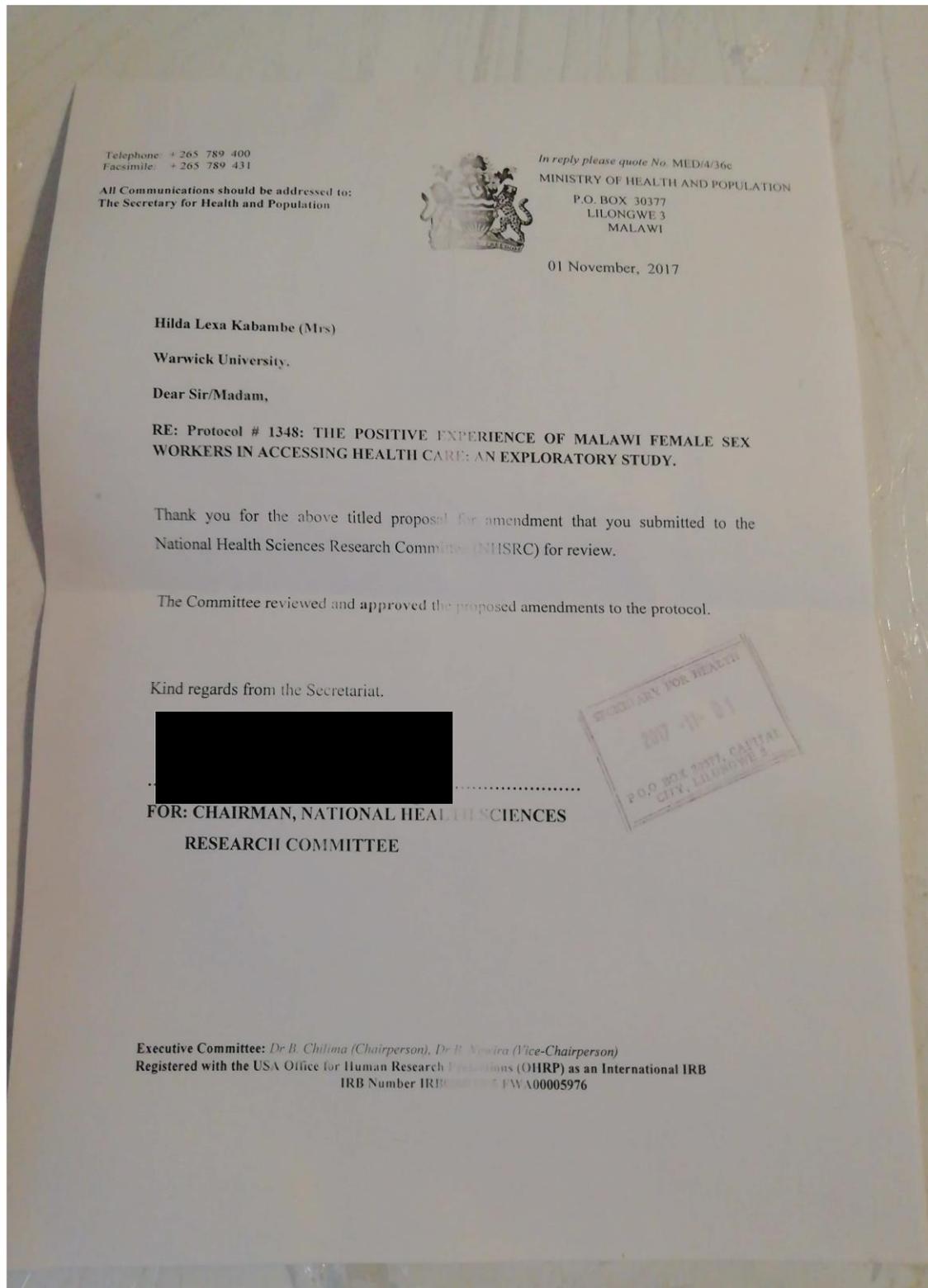
May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

pp. 

Professor James Covington
Deputy Chair, Biomedical and Scientific Research Ethics Committee

**Appendix 13 (Study 2) Protocol #1348 Approval for Re-data collection:
Female sex workers' experiences and perceptions with accessing
healthcare in Malawi: a qualitative study**





NUFFIELD DEPARTMENT OF
PRIMARY CARE
HEALTH SCIENCES

Introduction to Qualitative Interviewing



Health Experiences
Research Group

CERTIFICATE OF ATTENDANCE

Hilda Kabambe

Attended the one day course
Introduction to Qualitative Interviewing on the
11 December 2018

Organised by the Health Experiences Research Group, at the Nuffield
Department of Primary Care Health Sciences, University of Oxford.



Caroline Jordan: Course Administrator **Dated:** 11 December 2018