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“They treat us like we are nobody!”

A phenomenological study of female sex workers’ experiences in accessing public health
care services in Central Malawi

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ABSTRACT

Female sex workers in Malawi are exposed to multiple occupational health and safety risks. Despite the fact that FSWs are impacting the general public's health status, health care access is limited due to different challenges. In order to identify the barriers and receive a deeper understanding of the experiences FSWs make when accessing health care and how these experiences impact the women's agency and well-being, a phenomenological study was employed. Even though health care experiences for key populations have been researched in other countries in Sub-Saharan Africa, no comparable study has yet been conducted in Malawi. In this study, seven FSWs were interviewed on an individual basis and 4 FSWs in pairs. In addition, 9 FSWs participated in two focus group discussions. Transcripts were analysed by identifying emerging and recurring themes that were specifically related to interactions with health services. Empirical findings include that generally, FSWs are facing hostility, stigmatization and discrimination from health care providers when accessing public health care in Malawi. These experiences constitute as barriers to health care access, besides various financial, structural and individual barriers. Furthermore, they aggravate FSWs' agency due to an inhibited ability to control decisions and actions affecting their health, which eventually also negatively impact their well-being.

Key words: phenomenology, sex work, prostitution, health care access, experiences, barriers, stigma, Malawi

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TABLE OF CONTENTS

<u>LIST OF ABBREVIATIONS</u>	7
<u>SECTION 1: INTRODUCTION</u>	9
PURPOSE AND AIM	9
<u>SECTION 2: BACKGROUND AND LITERATURE REVIEW</u>	11
HEALTH CARE IN MALAWI	12
PROSTITUTION, SEX WORK, TRANSACTIONAL SEX AND SURVIVAL SEX	13
SEX WORK IN MALAWI	14
HEALTH NEEDS OF FEMALE SEX WORKERS	16
SEXUAL AND REPRODUCTIVE HEALTH NEEDS	16
AMBULATORY HEALTH CARE NEEDS	17
MENTAL HEALTH NEEDS	17
STIGMA AS A BARRIER TO HEALTH CARE	18
<u>SECTION 3: THEORETICAL GROUNDING AND KEY CONCEPTS</u>	21
HEALTH CARE ACCESS BARRIERS	21
FINANCIAL BARRIERS	22
STRUCTURAL BARRIERS	23
INDIVIDUAL BARRIERS	23
STIGMA AND DISCRIMINATION	23
WELL-BEING	24
AGENCY AND EMPOWERMENT	26
OPERATIONALIZATION OF THE FRAMEWORK	28
<u>SECTION 4: METHODOLOGICAL DISCUSSION</u>	29
RESEARCH STRATEGY	29
RESEARCH DESIGN	30
ONTOLOGICAL AND EPISTEMOLOGICAL ASSUMPTIONS	31
ACCESS	31
DATA COLLECTION	32
SECONDARY DATA SOURCES	33
KEY INFORMANT INTERVIEWS	33
SEMI-STRUCTURED INTERVIEWS	34
FOCUS GROUP DISCUSSIONS	35
PROFILE OF RESPONDENTS	36
DATA TREATMENT	36
TRUSTWORTHINESS AND LIMITATIONS	37
ETHICAL CONSIDERATIONS	38

SECTION 5: ANALYSIS	41
EXPERIENCES ACCESSING HEALTH CARE	41
HEALTH CARE ACCESS BARRIERS	43
STRUCTURAL	43
INDIVIDUAL	45
IMPACTS ON AGENCY AND WELL-BEING	46
SECTION 6: IMPLICATIONS FOR POLICY AND PRACTICE	49
SECTION 7: CONCLUSION	51
IMPLICATIONS FOR FUTURE RESEARCH	52
REFERENCES	53
APPENDICES	62
APPENDIX A: CONSENT FORM	62
APPENDIX B: INTERVIEW GUIDE FOR FSWS	64
APPENDIX C: DEMOGRAPHIC CHARACTERISTICS OF INTERVIEWEES	66

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
CEDEP	Centre for the Development of People
FSW	Female Sex Worker
FSWA	Female Sex Worker Association
GIZ	Gesellschaft für Internationale Zusammenarbeit
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
SRH	Sexual and Reproductive Health
SRHR	Sexual and Reproductive Health and Rights
SSA	Sub-Saharan Africa
STI	Sexually Transmitted Infection
UN	United Nations
UNFPA	United Nations Population Fund
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation

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SECTION 1: INTRODUCTION

“Sex work [...] is the provision of sexual services for money or its equivalent” (Harcourt & Donovan, 2014: 201). In Malawi, approximately between 15,000 and 20,000 women are engaging in sex work, around 18% of them work in the capital Lilongwe and 12% in Salima (Chizimba & Malera, 2011; National Statistical Office of Malawi, 2014). Due to their profession, female sex workers (FSWs) are exposed to higher risks to contract diseases such as sexually transmitted infections (STIs) and HIV, but also other health issues such as intense stress, alcohol and drug use and urogenital problems. In addition, they frequently suffer sexual and physical violence. Often, family planning methods are inconsistently used, leading to unwanted pregnancies and termination thereof. Moreover, evidence shows that reducing the barriers FSWs face when seeking health care services reduce HIV incidence rates among their clients and thus the general public (Steen *et al.*, 2012). This view is also reinforced by Eric Dakamau, coordinating officer of the National Aids Commission in Malawi (Munthali, 2017). Therefore, health care services that address the needs of FSWs are crucial.

However, access to health care facilities for marginalised groups – such as FSWs – is generally limited in Africa due to stigma and discrimination against key populations (Dhana *et al.*, 2014) and thus contributes to their vulnerability. Since health care access is a fundamental human right, discrimination of sex workers in the delivery of health care services is considered to be a human rights violation since it limits their access to health care as well as their right to equality and non-discrimination.

PURPOSE AND AIM

While similar research studies have been conducted in other countries in Sub-Saharan Africa (Zimbabwe, Kenya, Uganda and South Africa), there is no study that focuses on FSWs’ experiences accessing health care in Malawi. Hence, this study contributes to fill in the research gap in this field. It is also devoted to attaining an analysis of the different barriers that impact the women’s lived experiences when visiting health care facilities and how these barriers impact their well-being, using Kabeer’s (1993; 2005) and Amartya Sen’s (1985; 1993) concept of agency and well-being.

This study's main addition is the elaboration of the barriers to access health care for FSWs in Malawi, as well as to present their experiences. These will eventually partially explain health disparities between FSWs and the general population in Malawi.

Consequently, the research questions for this thesis are as follows:

- *How do female sex workers experience health care services provided by public health facilities in Malawi?*
- *Which barriers, including stigma and discrimination, are female sex workers facing when seeking public health care services?*
- *How do these experiences and barriers affect female sex workers' agency as well as well-being?*

In order to answer these research questions, this study will firstly give an overview of the Malawian health care system, as well as sex work in general and specific to Malawi. Following this, the health needs of FSWs will be presented. Then follows a literature review on the stigmatization of sex work, partially regarding the access to health care. This study employs the health care access barrier (HCAB) model by Carrillo *et al.* (2011), as well as the key concepts of stigma and discrimination, well-being, as well as agency and empowerment.

Following the methodological section, results will be analysed and discussed, relating them to the HCAB model and key concepts. Additionally, implications for policy and practice will be given, followed by an empirical and theoretical conclusion.

SECTION 2: BACKGROUND AND LITERATURE REVIEW

Malawi is a land-locked country in South-Eastern Africa with a total population of around 18 million people of which almost 85% live in rural areas relying on subsistence agriculture (Food and Agriculture Organization of the United Nations, n.d.). The capital is Lilongwe, home to around 670,000 Malawians (National Statistical Office, 2008). The country is divided into 28 districts within three regions: Central, Southern and Northern region (see Figure 1 for a map of Malawi). Malawi is considered as one of the poorest countries in the world, with a GDP of \$5.4 billion and gross national income per capita of \$320 (The World Bank, 2016a and 2016b). The nation scored a Human Development Index of 0.467, ranking it 170th out of 180, due to its high poverty index: 70.9% of the population live under the income poverty line of \$1.90 a day (United Nations Development Programme, 2016).



Figure 1 Map of Malawi

Twelve major ethnic groups can be found in Malawi. In the urban central region, 42.6% of the population belong to the Chewa group, while 18.5% identify themselves as Ngoni. Furthermore, 13.5% are Yao, 9.8% belong to the Lomwe group, and 7% are Tumbuka. The rest of the population identify as either Nyanja, Sena, Tonga, Ngonde, Nyakyusa, Lambya, Senga or other (National Statistical Office, 2008).

The Malawian population is mostly Christian (82.7%), while 13% are of Muslim belief. Only 1.9% of the country believe in religions other than Christianity and Islam (ibid.).

The country's population has increased by 19% from 2010 to 2016, representing an annual growth rate of 2.9% (ibid.). The total fertility rate is estimated to be 4.9 births per woman in rural areas (National Statistical Office, 2017), despite the general knowledge and approval of family planning (FP) methods. Due to this high fertility rate, Malawi has a very youthful

population: 73% of the population comprises people aged below 29 years (National Statistical Office, 2008).

HEALTH CARE IN MALAWI

The Malawian health care system is based on three levels of health care: primary, secondary and tertiary health care. Primary or community care delivers primary health services, such as community initiatives, health posts, dispensaries, maternity units, health centres and community and rural hospitals. Referrals from primary health care level are services at district hospitals through in- and outpatient services. Secondary health care facilities have a wider range of specialized services including laboratory, diagnostic, blood bank, rehabilitation and physiotherapy services. Lastly, specialist hospitals constitute the third level of health care, providing care for specific disease conditions or specific groups of patients (African Health Observatory, n.d.)

All three levels of health care are provided by both public and private sectors. While public health care facilities are free of cost, private health care providers charge fees to cover their operational costs, which makes the fee a major barrier to accessing services for most poor people living in the rural areas (World Health Organization, n.d.).

Malawi suffers a lack of health care workers as the country's density of physicians only adds up to 0.018 physicians per 1000 people (World Health Organization, 2009). In 2013-14, a service provision assessment was carried out by the Ministry of Health with financial and technical support from the United States Agency for International Development (USAID). The analysis examined national and sub-national information on the availability and quality of services from all functioning health facilities in the country. In addition to the lack of trained staff, findings include that while almost all health facilities provide malaria diagnosis and/or treatment, STI diagnosis and/or treatment, and curative care for sick children, family planning services and HIV-related services are less commonly available (Ministry of Health and ICF International, 2014).

PROSTITUTION, SEX WORK, TRANSACTIONAL SEX AND SURVIVAL SEX

Due the fact that different terms to describe paid sex occur in many research studies, especially regarding HIV/AIDS, the distinction between the terms prostitution, sex work, transactional sex and survival sex is essential when discussing this topic. This chapter thus serves to define the terminology and as an explanation why *sex work* will be the term of choice for this study.

Even though often referred to as ‘the oldest profession’, the word *prostitution* connotes immoral and criminal behaviour rather than an economic opportunity. While prostitution was the original term for years, the expression is often criticized as being stigmatizing and morally loaded. (McMillian *et al.*, 2017; Bindman & Doezema, 1997; Tomura, 2009).

Thus, the expression for “the practice or occupation of engaging in sexual activity with someone for payment” (Oxford Dictionary, n.d.-a: para. 1) has been substituted with the term *sex work* (or *commercial sex work*). Activists have promoted this change in order to avoid the negative connotations of sex work and degrade her based on that, but regard it as an income-generating employment for both men and women (Bindman & Doezema, 1997). Despite the wide adoption of the term, those engaged in sex work are still often referred to as *prostitutes*.

Sex work, contrary to *prostitution*, can include activities that do not require physical contact, such as stripping, erotic dancing, pornography, and other work in the sex industry, which are often not regarded as *prostitution* (McMillian *et al.*, 2017).

Having become a socially accepted term in most literature, the usage of the terminology *sex work* to refer to all practices of economically motivated paid sex is criticized. The term sex work positions paid sex as a choice. Especially in low and middle income settings, viewing engaging in paid sex as choice and the conceptualization of it as a form of labour are denounced for being Eurocentric. It is also criticised for being a euphemism for prostitution as it possibly disguises characteristic vulnerabilities and reduced opportunities that often contribute to, and may be perpetuated by, engagement in paid sex (McMillian *et al.*, 2017; Benoit *et al.*, 2017).

Therefore, Leclerc-Madlala (2003) distinguishes needs-driven from consumption-driven sex by using the terminology *transactional sex* to describe paid sex practices, especially in sub-Saharan Africa. However, the term is also often criticized for its broadness and unclear definition as it also describes practices that are not necessarily economically motivated. Furthermore, *transactional sex* also refers to “sex that occurs within serially monogamous as

well as concurrent relationships, committed as well as casual relationships” (McMillian *et al.*, 2017: 5). Especially in sub-Saharan Africa, the act of gift-giving in exchange for sex is common. However, this practice is often a basic element of a relationship and may be used to mark exclusivity. Hence, these *transactions* with a primary partner are an affective gesture and be symbolic of a relationship bond (McMillian *et al.*, 2017).

Survival sex is extreme-need-driven transactional sex that involves the most disempowered people without any other mean of income. This form may include the exchange of shelter, food and laundry for sex. “As survival sex describes the engagement of the most exploited, marginalized, and disenfranchised people in sex for payment as a necessity, a lack of available options is a core premise.” (McMillian *et al.*, 2017: 7). However, individuals engaging in this form of paid sex refuse the label of being a sex worker. The terminology *survival sex* has been used in the past to describe the exchange of sex for cash, drugs, food, and shelter by drug users, the homeless, and youth in the U.S. (McMillian *et al.*, 2017).

While many FSW in Malawi may engage in survival sex due to a lack of alternatives, this thesis will use the term *sex work* or *sex workers* since it regards paid sex as an income-generating activity without negative moral or cultural connotations. However, the criticism of the term is acknowledged throughout its usage.

SEX WORK IN MALAWI

It is estimated that between 15,000 and 20,000 women engage in sex work in Malawi, most of them found in cities, e.g. Lilongwe and Blantyre, tourist destination areas, border districts, commercial farming areas and transit districts (Chizimba & Malera, 2011; National Statistical Office of Malawi, 2014). Other influencing factors that increase the number of sex workers in a certain place are economic activities, *inter alia*, mining activities (Karonga), tobacco marketing (Mzuzu), and construction projects (Mwanza).

Sex work in Malawi can be generally divided into two types: Outdoor and indoor sex work. The most common type of outdoor sex work in Malawi is street or other public sex work where clients are serviced in side streets, vehicles, houses, short stay premises, near bushes or behind cars (Harcourt & Donovan, 2014; Chizimba & Malera, 2011). Instead of waiting for passing trade, some sex workers actively seek their clients in male dominated venues such as pubs, clubs, liquor shops, hostels or hotels. However, many sex workers regard street work as

undesirable because of the danger of violence and other forms of social hostility and thus seek indoor sex work. One form of indoor sex work is ‘escort prostitution’ where sex workers are contacted by phone and travel to the clients’ premises. Private sex work resembles escort prostitution, but is provided at the sex worker’s premises (Harcourt & Donovan, 2014).

While the national HIV prevalence is around 8.8% (National Statistical Office, 2017), HIV infections rates are drastically higher among FSWs, around 62.7% (National Statistical Office of Malawi, 2014). Hence, sex workers are considered a key population among men who have sex with men, transgender people, people who inject drugs and prisoners as they are particularly vulnerable to HIV and frequently lack adequate access to services (UNAIDS, n.d.). However, only 29.5% of the respondents of a study conducted in 2011 had gone for HIV testing and counselling and accepted their results (Chizimba & Malera, 2011), implying a very low HIV status awareness rate among FSWs. Even though generally condoms have been used by sex workers, their usage depends on the form of sex engaged in: condom use is only common for vaginal sex (96.5%), but not for any other types, such as oral, anal, masturbation, breast and thigh as their usage decreases to 3.3%-17.1%. Client pressure is the most reported reason for unprotected sex (Geubbels & Bowie, 2006). Condoms are mostly purchased by the sex workers themselves, or are received for free at public hospitals or NGO-affiliated health centres (Chizimba & Malera, 2011).

According to a study by Dr. Humphreys Shumba (a key informant for this study), 98% of the FSWs engage in sex work due to poverty. However, not all transactions are paid in cash since around 14% of the services are paid in kind, such as phones (37%), clothes (27%), groceries (13.8%), maize (12.4%), rental money (5.1%), and airtime (4.3%) (Chizimba & Malera, 2011).

Governments have taken different standpoints on the issue of sex work. While some countries support the abolitionist viewpoint and criminalize either sex workers or their clients, others advance the view to decriminalize sex work. However, the legal situation of sex work has an immediate effect on the social environment that sex workers are facing. Various scholars have researched the relationship between criminalization and stigmatization of sex work. According to Vanwesenbeeck, “criminalization fuels stigma, by framing commercial sex as immoral, illicit, and unlawful, by declining sex workers’ (human and worker) rights and by powering negative opinions” (Vanwesenbeeck, 2017: 1632). Consequently, criminalization is correlated with cases of human rights abuses. Hence, the Joint United Nations Programme on HIV/AIDS (UNAIDS), United Nations Populations Fund (UNFPA) and the WHO recommend

governments to work toward decriminalization in order to reduce stigma and its effects, including the removal of all laws prohibiting sex work and sex work-related civil regulations (World Health Organization, 2012b). Even though there is no law criminalizing sex work in Malawi, police officers often assume that sex work is illegal due to a misinterpretation of section 146 of the Penal Code which prohibits a woman from living on the earnings of prostitution, originating from the British Colonial Office Model Criminal Code. Living on the earnings of prostitution, however, refers to third parties benefitting from women engaging in sex work, not the sex workers themselves (Parliament. House of Lords, 1912). Nevertheless, in practice, police officers often arrest sex workers under section 184(c) of the Penal Code, which provides that a person found in a place in circumstances which lead to the conclusion that such person is there for an illegal purpose, is deemed a rogue and vagabond, leading to numerous arrests each week (Malenga, 2016). This indirect criminalization of sex work leads to FSW pursuing their work in secret, and thus avoid health care services. Thus, they become potential transmitters of HIV (UNFPA, 2016). Hence, efforts aiming at reducing the HIV prevalence among FSWs can also limit the spread of HIV to the general population.

HEALTH NEEDS OF FEMALE SEX WORKERS

FSWs are exposed to many occupational risks that translate into health needs that are, in their extent, specific to sex work. Since this study researches public health care experiences, it is important to understand why access to public health care facilities is essential for this marginalised group, which will be discussed in this section.

SEXUAL AND REPRODUCTIVE HEALTH NEEDS

As mentioned, FSWs carry a disproportionately high burden of HIV globally (Baral *et al.*, 2012). In Malawi, the HIV prevalence rate for FSWs is 62.7% (National Statistical Office of Malawi, 2014). However, most FSWs are afraid to get tested for HIV because of their fear of being found to be HIV positive (Chizimba & Malera, 2011: 56). For FSWs that are found positive, routine visits to health care facilities to receive antiretroviral drugs are necessary in order to delay the progression of the disease, but also to hamper the transmission of HIV (World Health Organization, n.d.-a). However, as the World Health Organization (WHO) reports, “[t]reatment access is [...] much too low in settings where the epidemic is concentrated among marginalized

populations such as sex workers, people who inject drugs, men who have sex with men, and transgender women” (World Health Organization, 2012a: 11)

In addition, FSWs also often contract other STIs, such as syphilis, gonorrhoea, and chachroid (Chizimba & Malera, 2011). Therefore, there is a need for proper STI diagnosis, treatment and follow-up (Scorgie *et al.*, 2013).

In a study conducted in Zambia, more than 50% of the FSWs interviewed reported a history of unplanned pregnancy, which may indicate a large unmet need for family planning. This is reinforced by a study from 2017 conducted in three countries in SSA, where 25% of FSWs reported an unmet need for contraception (Schwartz *et al.*, 2017). Links have been drawn between an increased use of condoms as a family planning method and decreased unplanned pregnancy and termination of pregnancy. (Chanda *et al.*, 2017). Therefore, the availability of condoms is positively correlated with the usage of condoms; however, due to national stock-outs, accessibility in some areas in Malawi is low (Kapatuka, 2017).

AMBULATORY HEALTH CARE NEEDS

In addition to SRHR needs, there is a high need for ambulatory care. FSWs are often victims of physical abuse, including being beaten, raped or robbed. In some cases, clients of sex workers deliberately break the condom (Pakachere, 2013). A Kenyan study found that 35% of the FSWs reported being raped (Elmore-Meegan *et al.*, 2004), while a Nigerian study documented that 72% of the FSWs have been abused by clients, intimate partners and the police (Hubbard & Zimba, 2003 in Scorgie, 2012).

Victims of physical abuse need medical treatment, as well as post-exposure prophylaxis following rape. Furthermore, in Malawi, after cases of physical abuse, the victim needs to go to a health care facility to document the injuries as evidence for the police report.

MENTAL HEALTH NEEDS

Studies have shown comparatively higher positive associations between depression and sex work (Benoit *et al.*, 2015). Higher rates of mental disorders, however, are related to the subjectively perceived burden associated with that kind of work. Objectively, it is open violence

in and apart from the work setting, which also significantly impacts on these women's mental health. (Rössler *et al.*, 2010)

Furthermore, FSWs are susceptible to alcohol and drug abuse. Most respondents of the study conducted by Chizimba and Malera mentioned beer followed by Chamba-Indian hemp as a substance they abuse. In addition, 43.8% of the respondents reported they drank more than four to five bottles of beer daily (Chizimba & Malera, 2011:47). Similar drinking patterns were found among FSWs in other countries in SSA. In South Africa, FSWs reported that alcohol consumption increases their courage to approach clients, but also to cope with the challenges of their work (Graaf *et al.*, 1995). Other drugs that are being abused by FSWs, even though only in small percentages, are mandrax, cocaine and heroin (Chizimba & Malera, 2011:47). Substance abuse has been correlated to unsafe sex as women with heavy drinking patterns are more likely to use condoms inconsistently and incorrectly, and is also negatively linked to the women's condom-negotiation skills (Chersich *et al.*, 2009; Graaf *et al.*, 1995). In addition, studies have found that massive alcohol consumption is associated with lack of HIV infection awareness among HIV-infected FSWs in Lilongwe, Malawi (Lancaster *et al.*, 2016).

Due to their susceptibility to heavy drinking, FSW need counselling by health workers to discuss their drinking habit.

However, Malawi suffers a lack of professional counsellors. Existing counsellors usually work in institutions such as mental hospitals, generally not accessible for the public. Therefore, FSWs counsel each other, e.g. through peer counsellors, as explained by key informant Likongwe.

STIGMA AS A BARRIER TO HEALTH CARE

Sex workers are facing stigma due to different reasons. Stigma can on one side be associated with the high prevalence of HIV/AIDS among FSWs (Wodajo *et al.*, 2017); but also with the occupation itself (Logie *et al.*, 2011). Globally, sex workers are facing stigma perpetrated by health workers as well as the community. Studies in Canada show that stigma constitutes a primary barrier to health care for street-based sex workers (Lazarus *et al.*, 2011). However, sex workers also face stigma in other parts of the world, such as India and Thailand (Scambler & Paoli, 2008). Nevertheless, other countries, e.g. Great Britain, seem to be more open regarding sex work as an occupation, with sex workers experiencing less cases of stigma than – in some cases – in their home countries (Scambler & Paoli, 2008).

Numerous researchers (Hunt *et al.*, 2017; Kurtz *et al.*, 2005; Mtetwa *et al.*, 2013; Chizimba & Malera, 2011; Scorgie *et al.*, 2013) describe FSWs' experiences of facing stigma when accessing health care, sometimes even being denied services due to their sex work, globally, as well in in SSA. Hunt *et al.* (2017) conducted a study about health care barriers and experiences among LGBTI people and sex workers in Zimbabwe. According to the study, "key populations experience unnecessary suffering from untreated conditions, exclusion from health care and extreme psychological distress" (Hunt *et al.*, 2017: 1). Another study in Zimbabwe reached an equivalent outcome, adding public humiliation and health care worker hostility as an integral aspect of treatment for sex workers (Mtetwa *et al.*, 2013). Similar findings can be detected in the study by Scorgie *et al.* (2013) who researched sex workers experiences of accessing health care in Kenya, Zimbabwe, Uganda, and South Africa. Findings include that sex workers regularly face denial of treatment as well as violations of privacy. Thus, health facilities often violate FSWs' human right to access health care by denying services.

In Malawi, no comparable studies have yet been conducted. Nevertheless, community perceptions about sex work or sex workers include stigmatisation and discrimination, perpetrated by community members, clients as well as bar owners (Chizimba & Malera, 2011). Sex workers are often accused of abusing hospital resources since they regularly seek treatment for STIs (Ndoza-Mana, 2017).

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SECTION 3: THEORETICAL GROUNDING AND KEY CONCEPTS

This section introduces concepts and frameworks that are essential for this research. This includes the presentation of the health care access barrier model, which will be followed by a discussion of the concepts of stigma and discrimination, well-being as well as agency and empowerment. Lastly, it will be explained how these concepts and models are operationalized in this thesis.

HEALTH CARE ACCESS BARRIERS

One of the major aspects of experiencing public health care is often consists of experiencing its barriers. While some scholars argue that access to health care should be solely measured by the availability of health care facilities (Mooney in Gulliford *et al.*, 2002), other writers suggest that also other measures should be taken into account. Even though people may be in need of medical treatment, they face challenges in utilising services. According to Donabedian, “the proof of access is use of service, not simply the presence of a facility” (Donabedian, 1972 in Gulliford *et al.*, 2002: 187). Pechansky and Thomas describe access as the “degree of fit” between clients and the health system (Pechansky & Thomas, 1982 in Gulliford *et al.*, 2002: 187).

Similar to Pechansky and Thomas’ approach and with the motivation to identify modifiable health care access barriers that lead to health disparities, Carrillo *et al.* (2011) developed the health care access barriers (HCAB) model that distinguishes barriers to access health care in three different types: financial, structural and cognitive (individual) barriers. According to this model, these three factors lead to a late presentation of symptoms, decreased prevention and decreased care, e.g. lack of treatment or insufficient treatment.

However, while the authors of the HCAB model acknowledge that it serves as a rather pragmatic way to identify measurable and modifiable barriers, it lacks the inclusion of social and cultural determinants (such as cultural norms) causing other barriers, including stigmatization and discrimination. However, the model encourages researchers applying the model to note and consider these barriers, although it also emphasizes that these barriers may not be suitable in the pursuit of solutions. Hence, this model will be used to structure this study and use its components as nodes for analysing interviews and focus group discussions, while

recognizing and paying special attention to barriers that may be caused through cultural elements, not capture by the model.

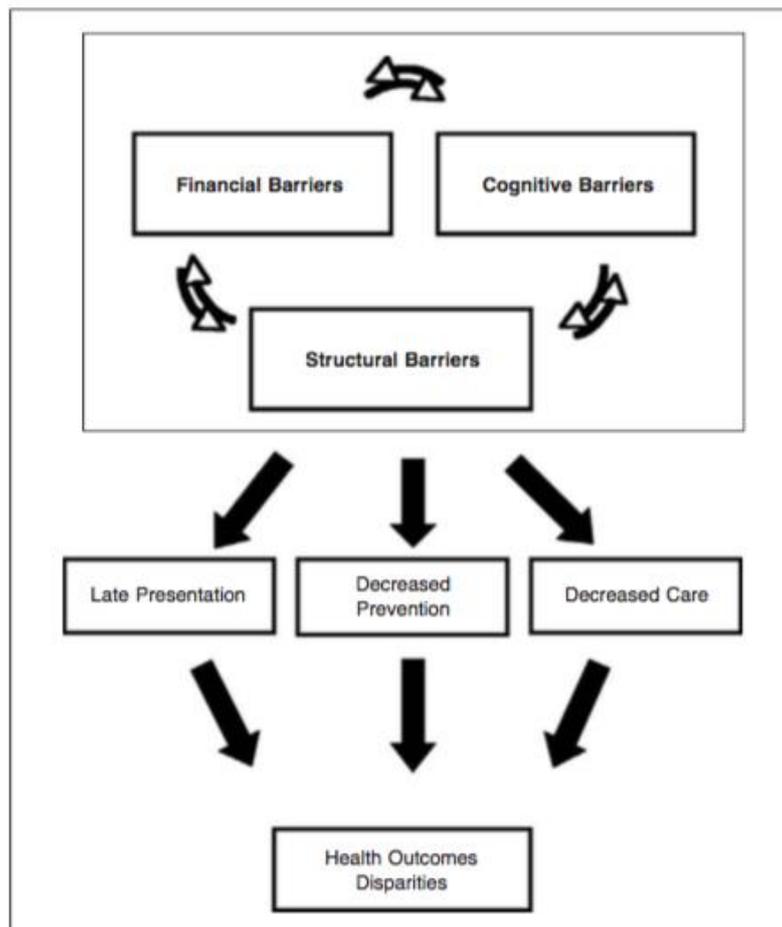


Figure 2 The HCAB Model (Carrillo *et al.*, 2011:565)

FINANCIAL BARRIERS

According to Carrillo *et al.* (2011), financial barriers include the cost of care. These costs, however, impact people differently since the magnitude of the costs, as well as the ability and willingness to pay does influence the utilization of health services (Gulliford *et al.*, 2002). In addition to the actual cost of treatment, the patients' health insurance status constitutes a barrier to access health care. Especially when individuals are uninsured or underinsured, they access health care facilities less often, go without a prescription for essential medication, or avoid recommended tests or treatments (Carrillo *et al.*, 2011).

STRUCTURAL BARRIERS

Institutional and organizational barriers constitute structural barriers when accessing health care services. The low availability of health care facilities and health care workers, especially of health care facilities directly targeted at FSWs (Dhana *et al.*, 2014), is only one factor that present a structural barrier. Connected to this is the waiting time to receive services since it is an opportunity cost for FSWs. Poor infrastructure and limited public transport, especially but not limited to rural areas, present another factor. Another barrier can be the operating hours of health care facilities that interfere with hours of operation (Carrillo *et al.*, 2011).

Lastly, social stigma constitutes an additional structural barrier, which will be further defined.

INDIVIDUAL BARRIERS

Individual or cognitive barriers are knowledge and communication barriers that – either alone or in combination with financial and structural barriers - adversely affect disease prevention and health care. These barriers include but are not limited to people’s awareness of service, drug seeking and use, street life distraction/sense of time, mental/emotional stability, fear of arrest generalized fear, client communication skills, client dress/appearance, negative attitude towards health care providers, and a low frustration tolerance (Kurtz *et al.*, 2005). According to Carrillo *et al.* (2011: 566), a “patient’s lack of awareness of accessible health services [...], limited health literacy, as well as linguistic and cultural barriers, may further prevent the patient from understanding and acquiring the necessary knowledge to carry out therapeutic directions”. Carmona (2006) highlighted the consequences of low health literacy including poor primary and secondary prevention efforts as well as increased vulnerability through miscommunication with health providers. Gulliford (2002) also includes beliefs, attitudes and past experiences in this category.

STIGMA AND DISCRIMINATION

Since stigma may constitute a major health access barrier (Kinsler *et al.*, 2007; Lieber *et al.*, 2006, Benoit *et al.*, 2017), the concept must be defined. Generally, stigma includes attitudes and beliefs that lead to social exclusion and discrimination of other people due to differences in sexual orientation, race, etc. (World Health Organization, n.d.-b). Nevertheless, variations in the definition of stigma exist.

Goffman (1963, in Parker & Aggleton, 2003: 14) defines stigma as “an attribute that is significantly discrediting”. The individual thus possesses “an undesirable difference” compared to norms that are culturally conceptualized by society. Although Goffman’s (1963) definition is widely accepted and used, it lacks the acknowledgement of regarding stigma as a changing social process rather than a static attribute due to its cultural feature. Criticism of the concept of stigma include its use for a wide range of circumstances – however, every case is different, leading researchers to conceptualize stigma differently depending on the case. Furthermore, research on the topic has been undertaken by researchers from different disciplines, such as psychologists, political scientists and anthropologists, leading to a different focus in each use of the concept (Link & Phelan, 2001).

Stigma can be either conceptualized as public or perceived stigma: Public stigma implies the stigmatizing attitudes that the general population holds, while perceived stigma refers to an individual’s anticipated fear of societal attitudes and potential discrimination they may experience (Kinsler *et al.*, 2007).

However, individuals may internalize these negative beliefs and attitudes that they experience from others, causing feelings of shame, anger, hopelessness and despair. Consequently, this leads to a loss of self-esteem and him/her fulfilling the negative public image. Eventually, self-stigma inhibits people from seeking social support or treatment for their health conditions, further aggravating their situation. However, not every individual is affected by self-stigmatization, but it is important to state that there is a link between public stigma and the development of the shame condition (Matthews *et al.*, 2017).

While stigma is an attitude or belief, discrimination can be considered to be a behaviour caused by those attitudes or beliefs. Discrimination occurs when individuals are treated unjust or receive prejudicial treatment due to stigma (Oxford Dictionary, n.d.-b). Discrimination may result in the exclusion or marginalization of people and deprive them of their human rights, such as access to health care.

WELL-BEING

FSWs’ experiences of public health care and barriers thereof, including stigma and discrimination, impact FSWs’ well-being, the concept of health and well-being should be discussed. Defined by the WHO in 1946, “health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health

Organization, 1946: 1). Naci and Ioannidis complement this statement including the features of “choice and activity aimed achieve physical vitality, mental alacrity, social satisfaction, a sense of accomplishment, and personal fulfilment” (Naci & Ioannidis, 2015: 121).

Well-being, on the other side, is often criticised for not having a clear definition and facing problems of researchers using a multiplicity of terms that are sometimes used interchangeably and at other times as if quite different. It is often accused of being ill-defined and broad when discussing health (Carlisle & Hanlon, 2008; Cameron *et al.*, 2006). Nevertheless, some scholars agree that well-being can be summarized as the presence of positive emotions, life satisfaction and live functioning as well as the absence of negative emotions. Health, or physical well-being, is a major component of well-being, among other aspects such as economic, social and emotional well-being, development and activity, and engaging activities and work (U.S. Centers for Disease Control and Prevention, 2016). This definition resembles the definition of well-being by Amartya Sen (1985: 197): “The primary feature of well-being can be seen in terms of how a person can “function” which are various doings and beings that come into this assessment as *functionings*. These could be activities [...], or states of existence or being”. He categorizes the collection of *functionings* as a *functioning vector*.

Sen further expands:

“A person’s capability set can be defined as the set of functioning vectors within his or her reach. [...] [I]mportance may well be attached to checking whether one person did have the opportunity of achieving the functioning vector that another actually achieved. This involves comparison of actual opportunities that different persons have. If one person could have achieved all the relevant functioning vectors that the other could, then in some important sense the first person had at least as much freedom to live well. The general idea of the freedom to achieve well-being can be called well-being freedom” (Sen, 1985: 201)

Therefore, choice plays an important role in effectuating well-being since its existence affects the character of the *functionings* (e.g. physical well-being) that can be achieved. Consequently, according to Sen, well-being is achieved through the realization of functioning achievements. “This view relates to the idea that the good life is, *inter alia*, also a life of freedom.” (Sen, 1985: 202).

AGENCY AND EMPOWERMENT

Since the definition of well-being includes the important component of choice, *empowerment* should also be defined in this study as it is considered a requirement to achieve well-being.

Naila Kabeer (1999) defines empowerment as the process of change between being denied choices and gaining the *ability to make choices*. This resembles the definition by Alsop *et al.* (2007, in The World Bank, 2007: 8), who interpret empowerment as the “actor’s ability to make meaningful choices, that is, to consider and purposively choose among options”. Relating the term empowerment to health, it is useful to involve the term *patient empowerment*, which the World Health Organization (1998: 6) defines as “a process through which people gain greater control over decisions and actions affecting their health”.

Kabeer (1999; 2005) made important contributions to the discussion by separating the process of empowerment into three dimensions: resources, agency and achievements (see Figure 3). According to Kabeer (1999; 2005), pre-conditions to agency are *resources* that include but are not limited to economic resources. Other important factors that determine a woman’s resource domain are human and social resources which enhance the woman’s position to use her agency to choose. Resources can thus be gained through society (family, market and community) and can take the form of actual allocations as well as future claims and expectations. Access to resources are determined by rules and norms of the society which gives certain actors a privileged position, e.g. heads of households, chiefs of tribes, directors of firms, managers of organisations, and elites. Therefore, if a woman is unable to participate in decision-making, it gives her limited capacity to make choices (Kabeer, 1999; Kabeer, 2005). Other resources that can predict an individual’s ability to make choices include informational, organizational, material, and psychological assets (Alsop *et al.* in The World Bank, 2007). *Agency* is the “ability to define one's goals and act upon them” (Kabeer, 1999: 438). It is often the internal process of decision-making; however, it can also take different forms, including negotiation, manipulation or resistance (Kabeer, 2005). Besides the action itself, agency also implies the “meaning, motivation and purpose which individuals bring to their activity” (Kabeer, 1999: 438). The term *achievements* refers to the extent to which this potential is realised. In relation to empowerment, achievements have been considered in terms of both the agency exercised and its consequences (Kabeer, 2005).



Figure 3 Three Dimensions of Empowerment (Kabeer, 1999:437)

Alsop *et al.* (2007 in The World Bank, 2007) complement this concept by including the opportunity structure which affects the individual's ability to translate his/her choices into effective action. These opportunity structures include the formal and informal laws, regulatory frameworks, values, and norms that govern people's behaviour, summarized as formal and informal institutions. These institutions firstly impact whether an individual can access assets and secondly whether the person can use these assets to exercise his/her choice. However, in cases where failure to achieve one's goal is caused by external constraints on the ability to choose, it is regarded as being a "manifestation of disempowerment" (Kabeer, 1999: 438).

According to Kabeer (2005: 16), "access to education can bring about changes in cognitive ability, which is essential to women's capacity to question, to reflect on, and to act on the conditions of their lives and to gain access to knowledge, information, and new ideas that will help them to do so". She argues that the years of education seem to have an immediate effect on a woman's health care seeking behaviour through increased knowledge of diseases and prevention. Furthermore, according to Kabeer, education appears to increase a woman's self-esteem, increasing her capacity to deal with unjust treatments, e.g. through health care providers. However, these positive effects are not uniform to all contexts. Education of girls often reinforces gender stereotypes, teaching girls to become good wives instead of equipping them with the necessary skills to question their environment. This learning environment further emphasizes the unequal status between men and women, eventually contributing to low self-esteem and low aspirations (Kabeer, 2005).

In addition to education, also paid employment may positively impact a woman's agency. Especially jobs in the non-agricultural sector appear to be a way to enjoy more independence and self-determination through generally high wages and stable employment as argued by Kabeer (2005). However, many of those jobs, especially in the informal sector, are characterized by poor working conditions and hence may not have any beneficial effects on a woman's agency (Kabeer, 2005).

OPERATIONALIZATION OF THE FRAMEWORK

Agency and empowerment play an important role when discussing well-being since a person's agency inevitably influences his or her well-being (Sen, 1985). This conforms with Kabeer's (1993; 2005) idea of achievements being the outcome of agency, which may constitute well-being. According to Sen (1993: 39), "[a]cting freely and being able to choose are, in this view, directly conducive to well-being". Therefore, any barriers that inhibit a person's freedom and thus their choice to achieve well-being, e.g. in the case of FSWs accessing health care, represents a limitation of their well-being freedom and thus an infringement on their agency.

In summary, the concept of agency describes the mechanism or process of change while well-being is regarded as the final product of the process of agency. Impairments in well-being are consequently due to limitations and restrictions in agency.

The concept of agency and well-being will be applied to FSWs' experiences when accessing health care. Hence, the health care access barrier model will constitute as a structure to describe the challenges FSWs are facing when accessing health care facilities. Furthermore, the descriptions of barriers for FSWs to access health care do not only constitute the pre-conditions to execute agency, but also describe the limitations to achieve well-being freedom. Well-being freedom will be regarded as the achievement of agency, thus the freedom to access health care services without barriers that inhibit the FSWs' agency.

SECTION 4: METHODOLOGICAL DISCUSSION

This chapter will present the study's research strategy, research design and methodological choices including data collection and analysis. Furthermore, ontological and epistemological assumptions as well as ethical considerations will be discussed.

RESEARCH STRATEGY

For this exploratory study, a qualitative research strategy was chosen. Qualitative research is especially applicable in cases where the researcher wants to gain a complex, detailed understanding of an issue through engaging with individuals and groups. According to Al-Busaidi (2008), qualitative research is widely used in health care to analyse doctor-patient interaction, but also to identify barriers to health care access. It is also highly suitable to empower individuals to share their stories, hear their voices and minimize the power relationship that often exists between the researcher and the participants (Creswell, 2007). This is further reinforced by the fact that qualitative research is associated with a feminist sensitivity that was engaged throughout this study. "In a feminist qualitative research, the researcher is generally avoiding a value-neutral approach and regards the people participating in the study as people and not simply as respondents to research instruments." (Bryman, 2012: 40).

Through interviews and focus group discussions the focus was on FSWs' voices to be heard and their perspective to be considered which are often excluded from knowledge production and policy making: "Sensitive research can help give the voiceless a voice" (Pratt & Loizos, 1992 in Scheyvens & Leslie, 2000: 127).

While qualitative research offers the possibility to deliver an understanding of a complex situation with a holistic focus, it also lacks a certain objectivity that is usually conveyed through a quantitative research design. Since this study does not make use of any quantitative data collection methods, statistical generalizations are not possible.

With the qualitative strategy of this study, an inductive reasoning approach was used, meaning that theory is the *outcome* of this research. In this study, the inductive nature of the relationship between theory and research can be seen in the way that theoretical ideas derive from the data rather than being formed before the data has been collected. Hence, it will be reflected on existing theories to add aspects that are not yet described in the concepts and model.

RESEARCH DESIGN

According to Creswell, “a phenomenological study describes the meaning for several individuals of their lived experiences of a concept or a phenomenon” (Creswell, 2007: 57). Patton further explains that a phenomenon may be, *inter alia*, an emotion, a culture or a job. Al-Busaidi (2008) further argues that phenomenologists assume similarities between the experiences of participants. Since there are no studies devoted to understand the lived experiences of female sex workers in accessing health care in Malawi, a phenomenological research lends itself best to examine this question.

The procedures for a phenomenology are described by Moustakas (1994, in Creswell, 2007) and include the determination of using phenomenology as a research design. Data must be collected from individuals who have experiences of the phenomenon – in this case female sex worker who have tried to access health care facilities. According to Polkinghorne (1989, in Creswell, 2007:61), a total of 5-25 interviews should be conducted. In a phenomenology, the interview questions are generally limited to two open-ended questions, namely “What have you experienced when accessing health care?” and “What effect did this experience have on your life?”. However, probing and prompting questions were asked in order to receive a deep understanding of the narrative. Through subjective, direct responses, the researcher is able to gain first-hand knowledge about what participants experienced through broad and open-ended inquiry (Patton, 2002). Revisions can be made along the way as new experiences emerge giving the researcher the ability to construct themes and patterns that can be reviewed by participants (ibid.)

However, there are certain challenges that will come with this design. Before using phenomenology as a research design, the underlying philosophical assumptions need to be understood (Creswell, 2007:62). Furthermore, attention needs to be put on the selection of interviewees. In this case, all interviewees either must be experts regarding health care access for key populations, or have to be sex workers who have accessed a health care facility. Furthermore, I must “bracket” my own experiences/values, meaning to set aside personal experiences, biases and preconceived notions about the topic, in order to maintain objectivity (Creswell, 2007: 62). However, since this is not always completely possible, I include a section on this topic.

ONTOLOGICAL AND EPISTEMOLOGICAL ASSUMPTIONS

The term ontology refers to the nature of reality. While researching different individuals, e.g. when performing a phenomenology, it is acknowledged that several realities exist among those being studied. There is no universal explanation (Moses & Knutsen, 2012: 169); the focus is laid on finding patterns, regularities as well as differences among the experiences of female sex workers when accessing health care in Central Malawi. (Moses & Knutsen, 2012: 173). This may be shown through the inclusion of quotes of different individuals with different experiences as evidence of different perspectives. Since my research aims to identify how female sex workers are experiencing health care, the focus will be put on how these women construct reality through their experiences (Moses & Knutsen, 2012: 201), which makes the ontological position of this research constructivist.

Epistemological issues include the question of what can be regarded as acceptable knowledge in a discipline (Bryman, 2014:27). Opposing positivism, interpretivism claims that social science requires a different logic of research procedure, reflecting the distinctiveness of humans as against the natural order. Initially described by Max Weber (1947 in Bryman, 2012: 29) as the concept of *Verstehen* (meaning understanding), sociology attempts the “interpretive understanding of social action”. Alfred Schutz (1962, in Bryman, 2012) later applied Weber’s concept, pioneering in the field of phenomenology. According to him, it is the phenomenologist’s task “to interpret [the individuals’] actions and their social world from their point of view” (Schutz, 1962 in Bryman, 2012: 30).

These ontological and epistemological standpoints further reinforce the feminist approach engaged in this study due to their focus on the individuals’ experiences and their perspectives.

ACCESS

This study was made possible through my connection with the Female Sex Workers Association (FSWA) of Malawi. The organization was first established in August, 2016. The establishment was based on the fact that FSWs were not well coordinated and involved in the issues affecting their well-being as sex workers. Therefore, the association brings in ownership as it is composed of FSWs themselves. FSWA has an office in Lilongwe and employs three volunteers who represent as Regional Coordinators for the three regions. FSWA envisions a society in which all female sex workers are able to enjoy the fundamental rights and freedoms and are

free from violence and discrimination. Its mission is to contribute towards improving human rights status of female sex workers and advocate for the respect, protection and promotion of the rights of FSWs in Malawi by designing and implementing innovative, evidence-based and cost-effective advocacy campaigns capable of influencing public policy and practice in the field of human rights (FSWA, 2017).

During the period of data collection for this study, I volunteered for FSWA, supporting the members in developing activity budgets, writing funding proposals and revising their strategic planning document. This work relationship also served as a point of access to FSWs in Lilongwe and Salima due to the organization’s facilitation of trainings for FSWs in both cities (see p.11 for a map of Malawi).

DATA COLLECTION

The data came from a mix of methods, being semi-structured interviews, key informant interviews and focus group discussions (see Table 1 below) that all served the purpose of answering the first two research questions through narrative information regarding experiences and health care access barriers. Secondary data gathered from published literature and unpublished documents as well as key informant interviews provided contextual background information, which is essential to place the women’s experiences into a wider context.

<i>Method</i>	<i>Number</i>	<i>Total number of respondents</i>	<i>Dates</i>
Key Informant Interviews	3	4	January – February, 2018
Individual semi-structured interview	7	7	January – February, 2018
Pair semi-structured interview	2	4	February, 2018
Focus Group Discussion	2	9	February, 2018
Total		24	

Table 1 List of Interviews

Several reasons made participant observation impossible for this study. Time constraints, language barriers, but also privacy regulations within health care facilities inhibited the possibilities to conduct participant observation as a data collection method. Furthermore,

surveys/questionnaires seemed to be unsuitable since quantitative methods are incompatible with the chosen research questions.

SECONDARY DATA SOURCES

Secondary resources were especially useful for the context analysis, the literature review as well as the theoretical framework including different concepts necessary for the chosen research questions. Literature included mainly journals, but also newspaper articles and online databases as well as unpublished documents such as the FSWA strategic document which were accessible through my work with the association.

Secondary sources also helped at positioning this study in a wider context, analysing the research that has been done in this area and region. It therefore identified the research gap for Malawi, justifying this study's *raison d'être*.

KEY INFORMANT INTERVIEWS

For key informants, expert sampling, a type of purposive sampling technique, was chosen in order to answer the research questions. It is defined as selecting individuals that are linked to the research question (Bryman, 2012: 416). Key informants include other researchers on the topic as well as experts working for organizations that support FSWs through targeted interventions. Whilst being prone to researcher bias, expert sampling is useful to examine specific issues further and receive a general overview of the topic. In total, four key informants and experts were interviewed.

One of the key informants and experts is Dr. Humphreys Shumba, who is working as the HIV Specialist at the Country Office of the United Nations Population Fund in Malawi and recently wrote a PhD dissertation on FSW in Malawi. As an HIV Specialist, he supports interventions that centre on FSWs since they bear the burden of the HIV epidemic in Malawi.

In addition, Han Marcel Kok and Dominic Likongwe were interviewed, both working as technical advisors at the Gesellschaft für International Zusammenarbeit (GIZ), the German Development Cooperation. GIZ also advocates interventions targeted at key populations, including FSW. Furthermore, Likongwe was previously in charge of programming and coordination of HIV programmes, including FSWs. Consequently, it is presumed that because

of their experiences, both participants were knowledgeable in the field of health access of FSWs.

Lastly, Emma Kalea, Gender Projects Officer at the Centre for the Development of People (CEDEP) was interviewed as a key informant. CEDEP is an organization founded in 2005 to address the needs of sexual minorities in Malawi, including FSW. Kalea supports FSWA as a mentor as well as SRHR and human rights training facilitator. Hence, her experiences working closely with FSWs are valuable for this study.

Key informant interviews were generally administered at the offices of the experts. The interviews with Dr. Humphreys Shumba and Emma Kalea were performed on an individual basis, while the interview with Han Kok and Dominic Likongwe was conducted as a pair.

SEMI-STRUCTURED INTERVIEWS

Interviews with FSWs were chosen as the primary source of data collection. An interview guide was prepared in advance that ensured the focus on the research topic while the semi-structured nature of the interviews allowed probing and prompting (see Appendix B for the interview guide for FSW). While the interview guide included questions on FSWs' experiences and the meaning they give to them, it also included demographic questions in order to identify any differences in age, educational level, ethnicity or religion during the analysis.

Because FSWs are generally considered to be a hard-to-reach or hidden group, a combination of convenience and snowball sampling was chosen. Through my work relationship with FSWA, three out of four active members of the organization participated in the study. Furthermore, they were also asked to identify further FSWs that I could interview. The process continued until sufficient interviewees have been identified and data saturation was reached.

While convenience sampling inhibits the researcher's ability to make generalisations from the sample to the population, convenience sampling facilitated the access to the respondents (Bornstein *et al.*, 2013). In addition, snowball sampling proved to be suitable in this context since the recruitment of FSWs can be difficult due to the secretive nature of this stigmatized group. Snowball sampling helped to break down the (trust) barrier that may have inhibited some FSWs to take part in the study (Bryman, 2012).

Interviews with FSW were conducted by the researcher with the support of FSWs affiliated with FSWA, who are thus familiar with the working conditions through their own experiences. The interviews were therefore shaped by a mutually respectful, non-judgemental context. In cases where the FSWs did not speak English, questions and answers were directly translated by one of the Regional Coordinators of FSWA or a brother of another Regional Coordinator, allowing probing and prompting. Three FSWs did not feel comfortable to speak individually; hence, interviews were conducted in pairs in two cases. After the first three interviews, the interview questions were reviewed and adapted. In total, individual semi-structured interviews were conducted with seven FSWs to collect narrative information directly. Furthermore, four FSWs were interviewed in pairs, giving a total of 11 semi-structured interviews.

Semi-structured interviews are especially suitable for feminist research studies as it eliminates the 'one-way' process of the interview since interviewees were encouraged to also ask questions, which further decreases the hierarchical relationship between the participant and the researcher. Furthermore, I tried to establish a high level of rapport during the interviews by wearing a typical Malawian Chitenge cloth and taking a genuine interest through eye contact and listening, aiming to minimize the power imbalance.

FOCUS GROUP DISCUSSIONS

In addition to semi-structured interviews, focus group discussions complemented the interviews. While the focus group discussion developed as a spontaneous response trying to include nine FSWs offering to participate in the study on the spot, it proved itself useful in a qualitative research design since group-dynamics can generate new thoughts on certain topics, causing a more in-depth discussion. The 11 FSWs were divided into two groups as it seemed beneficial to keep the size of the group very small in order to reduce the effect of dominant of participants. This bias was tried to be reduced by encouraging quieter participants to engage in the discussion. For the group discussion, I impromptu adapted the interview guide for FSWs, trying to engage the women in a discussion. Since the participants were friends of one of the FSWA Coordinator who was also interviewed in the beginning, the focus group discussion made use of snowball sampling.

However, in comparison with individual interviews, focus group discussions often do not reach the maximum depth of a certain topic. Participants sometimes don't reveal their honest opinion about the topic, especially when their thoughts oppose the views of another participant. Both

interviews and focus group discussions may suffer under the moderator/interviewer bias as well as the selection bias. However, the combination of both methods leads to a triangulation managing those biases and eventually ensuring the validity of the outputs (Bryman, 2012).

PROFILE OF RESPONDENTS

All respondents of the individual and pair semi-structured interviews as well as the focus group discussions were FSWs living in either Lilongwe (16 FSWs) or Salima (4 FSWs). Across sites, the age of interviewed sex workers ranged between 18 and 39 years with a mean age of 24.75 years (see Figure 4).

Most of the women finished primary school (12 FSWs), and dropped out of school during or before secondary level. Eight respondents reported to have finished secondary level. Two women have received some primary education or no education at all. None of the women had reached tertiary level.

The women were from different ethnic groups. While most respondents were Chewa (40%), others were Ngoni (25%), Lomwe (20%), Tumboka (10%) and Yao (5%).

One woman interviewed in Salima is of Muslim belief, all other respondents are Christian.

An overview of the demographic characteristics of the respondents can be found in Appendix C.

DATA TREATMENT

Generally, all semi-structured interviews were audio-taped and transcribed fully and accurately to verbatim as possible in cases where the interview took place in English. The overall method for data analysis is a thematic analysis where a matrix was constructed, using various themes and subthemes (Bryman, 2012: 578). Interview transcripts were analysed by going through the data and highlighting significant statements that summarize how the FSWs describe their health care experience as well as barriers to access health care (*horizontalization*).

Different coding methods were used during the first cycle coding process, such as evaluation coding, in vivo coding, emotion coding and descriptive coding. Since the main research questions aims to explore how FSWs experience public health care, their evaluation of services

is essential and thus coded, including recommendations given by them. In addition, this study also focuses on the emotions recalled through these experiences; therefore, emotion coding has also been applied by labelling any (nonverbal) cues about experienced emotions, either explicitly or implicitly (Saldaña, 2009). This was preceded by descriptive coding in order to discern which emotions occur with which specific experience. Descriptive coding also serves as a summary of the topic of a passage that leads to a categorized inventory of the data's context. In the second cycle, pattern coding was used in order to organize these statements into themes, which will further be used to describe what the participants have experienced (Saldaña, 2009). Ryan and Bernard (2003, cited in Bryman, 2012: 580) recommend to look for repetitions, indigenous typologies or categories, metaphors and analogies, transitions, similarities and differences, linguistic connectors, missing data as well as theory-related material. Based on this textural and structural description, an essence of the phenomenon will be described, often a common experience/structure, to give the reader an understanding of what it would be like to experience the phenomenon (Creswell, 2007:59).

TRUSTWORTHINESS AND LIMITATIONS

It is important to analyse a study's reliability and validity. However, some writers suggest that instead of using reliability and validity measures, different criteria should be used for qualitative studies. According to Lincoln and Guba (1985 in Bryman, 2012), trustworthiness is one criterion to assess the quality of a qualitative study, defined through four further components, namely credibility, transferability, dependability, and confirmability.

In order to overcome potential issues of credibility impairments, this research uses the technique of respondent validation. Key informants were sent interview transcripts to review if they have indicated this in the consent form. Furthermore, I fed back to FSWA some of my writings that are based on a study of that group to discuss the findings. In addition to that, in this study, different methods such as interviews and focus group discussions were conducted in order to triangulate the findings.

Since this research focuses on the lived experiences of sex work in Central Malawi, findings may not translate to rural settings or to the Northern/Southern region since there may be differences, compromising the study's transferability. Nevertheless, since this study provides thick description on the contexts of methods, results from this case can be transferable to similar contexts, to be judged in each case by the user (Lincoln and Guba, cited in Bryman, 2012). This

study may be prone to selection biases, however. Since a snowball sampling strategy was engaged, participants were often friends of FSWs working for FSWA. Hence, there is a high possibility that these women have received education through SRHR and human rights training by the organization. However, this does not impact the actual public health care experiences made by FSWs and hence the outcome of this study, but rather how FSWs are dealing with occurrences of discrimination which is not in the focus of this study.

While LeCompte and Goetz (1982 in Bryman, 2012) acknowledge that it is impossible to replicate a social setting and the circumstances of the original study, writers also agree that if a researcher would like to replicate this study, he/she must adopt a similar social role to that adopted by the original researcher (Bryman, 2012). In this case, the experiences by FSWs are dependent on cultural norms by society as they are at the time of the study. Therefore, culture (e.g. views on sex work) may change over time, consequently changing the experiences of FSWs accessing health care.

Lastly, confirmability must be discussed. As this social research is of a qualitative nature, complete objectivity is impossible (Bryman, 2012). However, I tried to not to let personal values impact the findings of this research, thus bracket personal experiences, biases and preconceived notions.

ETHICAL CONSIDERATIONS

When conducting research on sex work, two major ethical challenges arise. Firstly, due to the fact that sex workers belong to a marginalized group that is characterized by stigma, privacy and confidentiality are crucial. Consequently, respondents may often protect their privacy by providing unreliable answers. Secondly, in research, sex workers are often victimized, dichotomies are prevalent, and sex workers are represented as a homogeneous group. Even though scholars nowadays avoid the association between sex workers and victimization, dichotomies such as regarding the activity as either work or exploitation but not as a combination are common. Furthermore, sex work should be rather seen as a revenue-generating activity than an identity (Shaver, 2005)

Regarding the participant selection, it was ensured that participating interviewees are not under the influence of drugs or alcohol. Furthermore, no sex workers under the age of 18 were interviewed. Consent forms in line with the LUMID Ethical Guidelines for Fieldwork as well

as the framework of requirements and guidelines for research in the social sciences and humanities in Malawi were prepared, which not only included information about the purpose of the study, but also about issues of confidentiality such as the storage and access to these data (see Appendix A). The consent forms also included an indication whether the participant would like to be given a pseudonym in order to ensure anonymity and whether he/she would like to review the transcript before being quoted. Since financial compensation in exchange for information is illegal in Malawi, participants received a soda drink and a snack as an incentive.

Even though a feminist approach was engaged in the data collection process, it was evident that it is impossible to truly eliminate any power imbalances between the researcher and the participants. Notwithstanding that scholars such as Hartsock (1987) suggest that women are more suitable to conduct research on other women, this standpoint theory has been heavily criticized for ignoring other factors such as age, ethnicity, and class (Scheyvens & Leslie, 2000). Considering that the author of this cross-cultural study is also from a different background, being a 'White' and 'Western' woman, some commentators might consider the study inappropriate. However, research participants did not suggest they had negative feelings about this study, but rather welcomed the interest in their experiences and giving them the opportunity to portray the reality of their lives.

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SECTION 5: ANALYSIS

In this chapter, the empirical data is analysed and partially discussed through the theoretical concepts from the previous section. After describing the FSWs experiences when accessing public health care services, barriers to access public health facilities will be identified. Lastly, the impact of these barriers including experiences of stigmatization and discrimination on the FSWs' agency and well-being will be discussed. Hence, this section presents answers to all three research questions.

Even though expected demographic differences have been taken into account during the analysis of this study, no differences could be identified regarding age, education, ethnicity or religion. Hence, they will no further be discussed.

EXPERIENCES ACCESSING HEALTH CARE

This section aims to offer answers to the study's first research question: *How do female sex workers experience health care services provided by public health facilities in Malawi?* While only a few of the women's quotes are highlighted, their statements are representative.

Health care experiences were generally described negatively, portraying health care providers as hostile and abusive. One of the common findings was that nearly all interviewed FSWs reported that they have been denied health care services after queuing up to receive treatment.

“So, you know, [the hospital’s medical staff] know me that I am a sex worker, so they always say: ‘You are a sex worker, just go behind, we treat you some other time or you can go somewhere else. We want to treat important people!’”

Memory, 32 years, FSW from Lilongwe

However, not only are services denied by the health workers, they also refuse to hand out medicine which is technically free of charge. The case of the 25-year old FSW Dorothie is illustrative of the hostile treatment. One day, she was two days late to pick up her antiretroviral drugs at the hospital due to the lack of money for public transport. However, she was unrightfully withheld the correct amount of the necessary medicine, justified by the nurse because of the delay. This meant that she had to come back to the hospital earlier than

anticipated, having to spend more money on transport. Chiletso, a 39-year old FSW from Lilongwe working for FSWA, also experienced nurses telling her to buy the required medicine at the private hospital instead of receiving it for free.

If services have not been denied, FSWs reported inferior service quality compared to standard procedures. For example, incorrect drug treatment was reported by 18-year old Christina M. Upon asking she was told by a nurse: “Just go, don't waste our time”. Chiletso, a single mother of three children, reported to have been handed out antiretroviral drugs without leaflets. Even after asking specifically for it, the health worker did not hand out the bottle including its leaflet. This could be an indicator for stolen or expired medicine, since this information – expiry date and serial number – is printed on the box.

FSWs also reported cases of physical and sexual abuse. During an interview with Mariam, a 21-year mother of a new-born, explains that in exchange for medical treatment, she is forced to have sex with the clinician. In addition, Martha, one of the Coordinators working for FSWA responsible for the Northern region, experienced nurses deliberately causing pain through injections.

Health care workers, especially women, discriminate FSWs by accusing FSWs to sleep with their husbands. Furthermore, FSWs are often accused of abusing the resources due to their higher need of STI treatments. In addition, health care workers assume that FSWs engage in sex work out of choice as reported by Christina M., an 18-year old FSW from Lilongwe:

“The staff at the hospital also says a lot of things, like for those who are [HIV] positive, they tell them: ‘You were the ones going around with our husbands, so we cannot help you, we cannot treat you. You are just draining the resources from the government. You do this out of choice, so we cannot help you.’”

Christina M., 18 years, FSW from Lilongwe

Often, discrimination by health workers does not happen behind closed doors, but involves publicly humiliating FSWs by shouting at them, as reported by 20-year old Marcy and Ethel. Hence, this also raises issue of violating the FSWs’ right to privacy and confidentiality.

“When I was [at the clinic], I met [a doctor] who shouted at me. He shouted at me very, very loudly. Everybody could hear him; everybody could hear his voice.”

Ethel, 20 years, FSW from Lilongwe

Surprisingly, all participants disclosed that they usually reveal their profession to health professionals as they recognize the importance of disclosure since health workers can provide services that are better suited to them.

HEALTH CARE ACCESS BARRIERS

This section discusses different health care access barriers that FSWs are experiencing, structured accordingly to the Health Care Access Barrier Model by Carrillo *et al.* (2011). Therefore, it also aims to deliver answers to the second research question: *Which barriers, including stigma and discrimination, are female sex workers facing when seeking public health care services?*

Participants reported challenges that are presumably faced by all patients, including, *inter alia*, the poor availability of health care facilities in the country. Even if there are health facilities close-by, they are often private as reported by participants of a FGD in Salima. In addition, long distances constitute as a barrier to access clinics. Other structural barriers that the participants cited are long waiting times due to the low density of physicians in the country.

Moreover, due to the poor economic situation of the majority of the Malawian population, limited financial resources also constitute a barrier to access health care. In addition to paying for transport to visit the hospital once, the three-tier health care system and its referral system make several appointments at different locations necessary when seeking specialized care, implying that patients need to spend more money on transport as well as invest more time to receive medical treatment.

However, sex workers experience additional challenges to receive decent care, being caused by structural and individual barriers which will be discussed in the following sections.

STRUCTURAL

In addition to the mentioned barriers to access health care services, the opening hours of the health care facilities represent a problem for some sex workers since their business hours are usually at night. Hence, they often sleep until late the next day and thus miss the opening hours.

However, this opinion is not shared by all respondents since some FSWs do not perceive the opening hours as difficult.

Furthermore, due to the positionalities of FSWs, some administrative processes at the clinics make it difficult for FSWs to receive treatment. Often, treatments – especially STI treatments – include the husband of the woman. Cathreen, a FSW who lives in a sex worker compound in Salima, also highlighted that married women are treated first. However, since many FSWs are unmarried and thus do not have a husband to bring to the hospital it is difficult for them to receive treatment as explained by the FSW Memory, who is engaging in sex work to support herself and her young son.

Lastly, FSWs face a lot of stigma by health care providers. Key informant Dr. Humphreys Shumba from UNFPA recognizes stigma as one of the major barriers to access health services in Malawi. He blames the unclear governmental position about the legality of sex work as it exacerbates stigma. Many women report that once their occupation is revealed, the behaviour of the health care providers changes and they are discriminated against.

“[The hospital’s medical staff] didn’t assist us very well. They treat us like we are nobody. Yeah. They treat us [FSWs] like we are evil because I am a sex worker.”

Ethel, 20 years, FSW from Lilongwe

Due to these past experiences, alternatives to seeking health advice in public health care facilities are common. With her baby on the back, held by a Chitenge cloth serving as a baby-sling, Mariam explained that she usually sends somebody close to the hospital or buys drugs from the pharmacy that she thinks will treat her disease in order to avoid the hospital. Other FSWs mentioned that they try to avoid public clinics by only visiting private clinics since their services are generally perceived to be better. For example, Mariam described the health care providers at private clinics as business people who do not care about the occupation of a patient. In addition, most FSWs stress the fact that they do not face any discrimination at private clinics. However, private clinics charge service fees; hence, FSWs can only use their services once they have enough funds to go pay for the fees as well as transport. Consequently, these experiences cause a delay in the presentation of symptoms. Emile, a FSW who also sells tomatoes to enhance her income, explains that despite being sick, she is working as a FSW to earn the necessary funds to visit a private clinic to avoid the discrimination by the public health care providers.

INDIVIDUAL

In addition to external factors, there are also individual factors that prevent FSWs from accessing health care. The ubiquitous stigmatisation from the outside provokes the internalisation of negative beliefs. This self-stigma aggravates FSWs' access to health care due to low self-esteem among FSWs. Emile, a 29-year old FSW from Salima, narrates that the lack of respect by community members makes her feel bad. People in her city gossip and point fingers at her at different occasions, for example when attending a funeral or church. During a focus group discussion, Hawa, a young FSW from a rural part of Lilongwe, mentions that also the children of these women suffer a lot due to discrimination within the community or at school.

After experiencing negative attitudes and beliefs from others, many women share feelings of despair and sorrow. Memory and Ethel, both FSWs from Lilongwe, shared how they feel after experiencing cases of discrimination:

“I cry inside my heart. Why? Why me? Am I... who am I? [...] It hurts me inside if somebody discriminates my rights.”

Memory, 32 years, FSW from Lilongwe

“I just feel sorry, because they don't know how much pain they cause us.”

Ethel, 20 years, FSW from Lilongwe

Many women highlighted during the interviews that they did not actively choose to engage in sex work and thus feel disappointed in health care workers assuming they have other choices. In addition, cases of discrimination against these women also make them feel socially excluded, making them feel as if they are “not in this world”, as mentioned during a focus group discussion.

In addition to despair, shame is another common feeling experienced by FSWs. For example, Martha, who is engaging in sex work already for seven years, reports that “she hates herself and her life sometimes”. Mariam, a mother of a new-born baby, reports that being discriminated makes her feel inferior compared to other people, especially through the hostile conduct of the medical personnel. This is also seconded by the key informant Dominic Likongwe, GIZ: “When [the FSWs] look at themselves, they look at rejected people of the community.” Similar

thoughts are shared by the expert Dr. Humphreys Shumba, UNFPA, who highlighted the importance of considering self-stigma when talking about health care access barriers.

However, since some women have received human rights training and know that they should be equally treated by health care professionals, also anger seems to be an emotion arising during these experiences. This anger turned into action, standing up for their rights and demanding treatment.

Without exception, all FSWs that were interviewed believe that they are treated worse by health workers than other patients. However, not only the discrimination itself, but also the fear of discrimination constitutes a barrier to access health care. Many FSWs reported that past experiences led to an avoidance of clinics.

Conversations with the facilitator of the sexual health and human rights training, Emma Kalea from the Centre for the Development of People (CEDEP), also highlighted that FSWs do not perceive health problems as such. Uncomfortable feelings, such as itching and burning in the genital area, are brushed aside as normal. Consequently, the women do not seek medical advice due to a lack of urgency.

Dr. Humphreys Shumba also included lack of information as a barrier to access health care. Since most of the women get their information from the health facility which are often resistant to support the women, they are facing challenges in accessing SRHR information.

IMPACTS ON AGENCY AND WELL-BEING

This section intends to identify the consequences of health care access barriers and stigmatization on the FSWs' agency as well as well-being, presenting answers to the third research questions: *How do health care experiences and barriers affect the female sex workers' agency as well as well-being?*

While the poor economic situation of FSWs in Malawi already aggravates access to health care facilities through the cost of transport, other pre-conditions add to the complication to exercise choice. In addition to financial resources, FSWs lack informational resources, including access to information on SRHR. Referring to Kabeer (2005), education is an important determinant for access to information and acting upon this information. However, regarding the participants of this study as an illustrative example, many FSWs lack secondary education, which further

impacts their knowledge of their (human) rights and hence the ability to demand them in case of violations. Training on SRHR and human rights may hence be essential and have an immediate effect on the women's agency.

Even though Kabeer (2005) acknowledges potential positive effects on agency through paid employment, she also recognizes that earnings generated through sex work have a low impact on a woman's inferior status. Negative experiences of discrimination and occupational stigma further worsen the FSWs' pre-conditions to exercise agency. Sexual, physical and verbal abuse from clients, police, the community as well as health care providers aggravate matters due to their effect on psychological resources in enhancing internalised self-stigma. In addition, close networks including other FSWs may contribute to self-stigma. Participants reported that among FSWs, hostility is prevalent due to perceived competition. They mentioned cases of other FSW taking prescribed drugs away from them, as well as threats when approaching bars. However, social resources may also positively impact the FSWs' decision-making process through friends and family that can serve as a source of encouragement to actively seek health care services.

In addition to resources, institutions impact the individuals' agency. While formal institutions including laws and regulatory frameworks that govern people's behaviour actively promote equal treatment, informal institutions reinforce stigma and discrimination which constitutes another barrier hindering FSWs to be fully able to make choices. While sex work may be theoretically legal, it contradicts cultural norms. Promiscuous behaviour is considered to be morally despicable, especially for women. To make matters worse, it is generally believed that sex work is illegal, reinforced by the state through false arrests by the police and insulting behaviour at health facilities.

Due to these institutions as well as barriers to resources, FSWs can barely exercise agency that would give them control over decisions and actions affecting their health. Referring to Sen (1985), the limited existence of choice affects FSWs' well-being since its non-existence influences the character of the *functionings*. There is no doubt that the barriers discussed in the previous chapter have an impact on the FSWs' physical well-being. As Carrillo *et al.* (2011) explain through the HCAB model, barriers to access health care have an immediate effect on the women's health due to late presentation of health problems, decreased prevention but also decreased care, eventually causing health outcome disparities. Moreover, experiences of stigmatization and discrimination also severely influence the FSWs' mental well-being, as

internalization of negative attitudes causes low self-esteem and self-stigma, potentially causing mental illnesses such as depression and drug addiction.

While agency and its influencing factors impact well-being, also other aspects affect the FSWs' well-being. Referring to the framework for measuring well-being and progress, income and wealth determine the women's well-being. Besides impacting their access to health as previously described, economic resources are important for FSWs to support themselves and their immediate family. Throughout the data collection process, FSWs highlighted that they are struggling to pay for their children's school fees and school uniforms. Since many FSWs lack education and are thus facing challenges to find work, many women engage in employment outside sex work, e.g. in the sale of vegetables. This double-burden leads FSWs to work during the day as well as night: These atypical working hours have implications on their well-being since they limit FSWs' ability to maintain family and social relationships. Furthermore, the situation adds to a poorer health status due to disturbances in eating and sleeping habits. Additionally, FSWs also face greater exposure to risky and harmful working conditions, which may have implications in terms of lower health outcomes as described previously.

Lastly, one of the factors impacting FSWs' well-being the most is the threat to personal security. Many of these women have faced situations of physical and sexual abuse, either by clients, police officers, or health care providers.

In summary, the health care access barriers that FSWs' are currently experiencing are a manifestation of disempowerment since the FSWs' ability to exercise choice is actively decreased through society's malevolence. This has severe effects on the women's well-being as they did not have the same opportunity of achieving the *functioning vector* – physical and mental well-being – that others could achieve due to stigmatization and discrimination.

SECTION 6: IMPLICATIONS FOR POLICY AND PRACTICE

Due to the severe effects of health care treatment and barriers on FSWs' agency and well-being, the need for change is indisputable. This section will discuss potential solutions at three different levels – national, network and individual level – that may positively impact the current situation for FSWs in Malawi in the medium and long term.

Without doubt, it is essential to clarify the legality of sex work in Malawi not only among government officials, but also among law enforcers such as police and judges and the public. Consequently, occupational stigmatization of FSWs in Malawi could decrease through the termination of the legal praxis of criminalizing sex work despite its legality, causing a facilitation in health care access for FSWs. However, a change in the policy is not likely to suffice to ensure human rights for FSWs. In addition, the inclusion of sex workers in policy development that refers to them as a marginalised group increases the policy's legitimacy.

Considering that deeply-rooted cultural norms are not easily changed, it is important to bring the culture of impunity to a termination. Abusive behaviour by state actors, including police and health care providers, and the state's failure to respond to reports of violence “foster impunity that perpetuates violence, and conveys an acceptability of violence towards sex workers” (Decker *et al.*, 2015: 195). Countries such as Poland and India have successfully introduced partnerships between FSWs and the police by training officers in sex worker rights (Decker *et al.*, 2015). Thus, governmental partnerships, including police, health care providers and judges, may hence contribute to a social climate that recognizes and tolerates this marginalized group.

While some experts and organizations advocate targeted interventions, others favour strengthened general population services to support FSWs (DIFFER Consortium, 2013). Most sex workers interviewed for this study supported the idea of having ‘*sex worker-only clinics*’ in Malawi since they expect less discrimination and more understanding for their situation, hence better treatment. On the other side, other respondents raised the issue of privacy. Many FSWs will not attend these clinics as they are ‘*hidden sex workers*’, thus not publicly engaging in sex work. During a key informant interview, Likongwe furthermore pointed out that services specific for certain people will cause discrimination. In addition, others may unrightfully use these services to take advantage of these services. Whether targeted inventions or strengthened public services or even a combination thereof will be the most beneficial must be decided from

case to case, with different experiences made in Kenya, Mozambique and South Africa (DIFFER Consortium, 2013).

Hence, a potential solution would be to create linkages between health care providers and FSWs. This includes identifying specific health providers within a facility that are interested in serving sex workers. These providers would then receive training to build their capacity. Eventually, sex workers will share these contacts, which may facilitate health care access. These linkages could be constructed by NGO targeting sex workers partnering with sex workers to distribute these contacts. Even though these linkages are already being put in place, there is a much higher need for sensitized health care providers in public health care facilities.

In addition to linkages between sex workers and health care facilities, associations will need to work on their mobilization of sex workers to create a fully functioning network. This network may then be used for the organization of activities, but will also serve as safe space for FSWs to share experiences and prioritize their own needs. Moreover, functioning organisations can then be used efficiently to arrange SRHR and human rights trainings that will target sex workers nationally, and support their process in achieving agency through education. Furthermore, identifying peer educators among sex workers, who will receive training on teaching fellow sex workers SRHR and human rights related topics, may also improve the individuals' agency and thus reduce the impact of self-stigma as a barrier to access health care services. Their long-term aim would be to engage in political lobbying on public policy, projects of legal reform of sex work, and help provide individualized assistance to sex workers inside and outside their worksites on health issues, criminal offences and business matters.

Therefore, most changes must focus on the network level. However, these forms of collectivism face challenges, including the criminalization of sex workers and lack of resources as explained by Gira Grant (in Gall, 2016: 157). Due to these difficulties, capacity building of FSWs engaging in these organizations is crucial, equipping them with the necessary skills to become increasingly empowered to be able to succeed in these tasks and hence bring change to the thousands of FSWs living in Malawi. Thus, it is in the hands of (international) non-profit organizations to not only support grass-root organizations financially, but also by acting as a mentor for these organizations.

SECTION 7: CONCLUSION

Sex workers face extraordinary occupational risks, including sexual and physical abuse, mental health issues but also STIs. Considering the impact of FSW's health on the general public's health due to transmission, efforts to improve FSWs may directly benefit the overall health status of the Malawian population due to reductions in the transmission of diseases. However, FSW generally face hostility and humiliation in public health care facilities. Discrimination is faced in terms of health care providers withholding services and medicine. Furthermore, cases of public humiliation and accusations add to the negative experiences, additionally to FSWs being victims of physical and sexual abuse.

Additionally, FSWs face various barriers to access health care in the first place. While these barriers include challenges that are applicable to all patients, such as limited financial resources as well as long distances to public health care facilities, they also encounter barriers that are specific to FSW. Due to the fact that FSWs generally work at night, opening hours of public health care facilities were partially presented as being difficult. In addition, since FSWs are often unmarried, administrative procedures that require a partner make adequate health services impossible for these women. Lastly, stigmatization and discrimination cause FSWs to either avoid public health care facilities, delaying visits or seeking care elsewhere. In addition to these structural barriers, FSWs also face individual challenges that make accessing health care even more difficult. Due to health illiteracy, many FSWs do not perceive health problems as such. This adds to the problem of many FSWs suffering under a lack of information, including where to go. Moreover, negative past experiences cause the internalization of stigma, further leading to low-esteem as well as feelings of shame, anger, despair and hopelessness, which inhibit FSWs to access public health care services. In conclusion, these empirical findings resemble the experiences and barriers in other countries in SSA.

This research also added to the understanding of the major concepts and theories applied in this study. Health care access barriers as well as negative experiences have a serious impact on FSWs' agency and empowerment. Poor pre-conditions aggravated by limited access give FSWs less control over own health choices, but foster disempowerment. While certain resources may on one side have a positive impact on the FSWs' agency, resources have to be closely examined. For example, social capital does not necessarily increase a person's agency since networks may also discourage a person to seek health care as experienced through discrimination among FSWs.

Although stigma is not included in the HCAB model, it nevertheless has a severe impact as a structural and individual barrier on FSWs' access to health care which should not be ignored. If a system is loaded with stigma, discrimination is in essence the biggest barrier of all to access health care for FSWs. Therefore, the model itself in its current form is only of limited suitability for measuring health care barriers for key populations in these contexts and is thus more fitting in well-meaning health care systems.

Since health is a major contributor to well-being, access to health care is a key determinant. This supports Amartya Sen's (1985) understanding of well-being as regarding it as the opportunity to act. However, as shown by this research, well-being is severely impacted by individual, structural and financial barriers to health care. These barriers do not only negatively impact an individual's physical health through delayed presentation of symptoms, decreased prevention and care as described in the HCAB model, but also influences a person's mental health through (perceived) stigmatization and self-stigma, that, in turn, also constitutes as an individual barrier to seek health care in the first place. Therefore, health care access also contributes to subjective well-being which is often regarded as another aspect of well-being. While this thesis happens to look at health care access and its impact on well-being, the findings also demonstrate that health care access is only one of many aspects to well-being for FSWs, besides, *inter alia*, education or security.

In order to tackle these barriers, overcome health disparities and eventually improve the health status of the population, various actions should be taken, in the long- and medium-term as well as on different levels - the national and network level.

IMPLICATIONS FOR FUTURE RESEARCH

Considering that health is only one aspect of well-being, further studies on other aspects of well-being would be of interest to receive a comprehensive understanding of the determinants that impact FSWs' lives in Malawi.

In addition, quantitative research can be used to implement interventions. Knowing about the distribution of certain attributes in a sample can be used to establish the most suitable course of action for social change (Bryman, 2012: 412). It is also suitable to measure change after certain intervention, e.g. regarding changes in the health care providers' attitude towards FSWs after receiving human rights training.

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APPENDICES

APPENDIX A: CONSENT FORM

Consent for participation in research interview

“Female sex workers’ experiences in accessing health care services”

I, _____ (full name) agree to participate in a research project conducted by Sarah Roos which is part of her Master’s degree from Lund University, Sweden. The research involves a qualitative study to portray female sex workers’ experiences in accessing health care services in Lilongwe, Malawi.

1. I have been given sufficient information about this research project and I understand my role. The purpose of my participation as an interviewee in this project and the future management of my data has been explained to me and is clear.
2. My participation as an interviewee in this project is voluntary. There is no explicit or implicit coercion whatsoever to participate.
3. Participation involves being interviewed by the interviewer. The interview will last approximately 45 minutes. I allow the researcher to take notes during the interview. I also may allow the recording of the interview and subsequent dialogue by audio tape. It is clear to me that in case I do not want the interview and dialogue to be taped I am fully entitled to withdraw from participation.
4. I don’t expect to receive any benefit or payment for my participation.
5. I have the right not to answer questions and if I feel uncomfortable in any way during the interview session, I have the right to withdraw from the interview without penalty.
6. I understand that all information I provide for this study will be treated confidentially.
7. I understand that I am free to contact the researcher to seek further clarification and information.
8. I have been given a copy of this consent form co-signed by the interviewer.
9. I have read and understood the points and statements of this form. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

I also understand that my words may be quoted directly. With regards to being quoted, please initial next to any of the statements that you agree with:

- I wish to review the notes, transcripts, or other data collected during the research pertaining to my participation.
- I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.

Signature of research participant

Signature of participant

Date

Signature of researcher

I believe the participant is giving informed consent to participate in this study.

Signature of researcher

Date

Contact details of the researcher:

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APPENDIX B: INTERVIEW GUIDE FOR FSWS

Demographic Questions:

1. What is your name?
2. How old are you?
3. Which ethnic group do you belong to?
4. Which religion do you follow?
5. Which educational level did you achieve?

General:

6. For which reasons do you go to health care facilities?
7. Do you go routinely for STI screening tests? (Why not?)
8. Do you usually go to public or private hospitals? Why?

Barriers:

9. What makes it difficult for you to access health care facilities?
 - a. Financial
 - i. Is money a problem, for example for transport?
 - ii. Do you think you are missing out on business while going to the hospital?
 - b. Structural
 - i. Are there health care facilities around the area where you live?
 - ii. Are the operating hours a problem?
 - iii. Have you been discriminated by a health care provider before?
 - c. Individual
 - i. Was the quality of service good?
 - ii. Do you think that health care providers treat you worse in comparison to other people?
 - iii. Are you afraid of getting stigmatized by a clinician?
 - iv. How do you feel about being sex worker?

Experiences:

10. Please describe your experiences when accessing a health care facility
 - a. How have you been treated by the staff?
 - b. Did you tell the staff that you are a sex worker? (If not, why?)
 - c. How did this experience make you feel?

11. What effect did this experience have on your life?
 - a. Will/did you return to this facility?
 - b. Did your experiences change your health care seeking behaviour?
 - c. What is it like to be discriminated because of your occupation? What is the hardest part? How does it make you feel?

Recommendations:

12. What would you like to see happen regarding your situation as a FSW in terms of health care?
13. What should be done to make it easier for you to access health care?
14. Would you prefer sex worker only health care facilities or improved public services? What should they offer?

APPENDIX C: DEMOGRAPHIC CHARACTERISTICS OF INTERVIEWEES

	N
<i>Age</i>	
18-20	3
20-24	6
25-29	7
30-34	3
35-39	1
> 40	0
<i>Ethnic Group</i>	
Chewa	8
Ngoni	5
Yao	1
Lomwe	4
Tumboka	2
<i>Religion</i>	
Christian	19
Muslim	1
<i>Education</i>	
None	2
Primary	12
Secondary	6
<i>Place of Residence</i>	
Lilongwe	16
Salima	4