

UNIVERSITY OF ZIMBABWE



**THE OPERATIONALISATION OF HIV STATUS DISCLOSURE:
THE USE OF DISCRETION TO DISCLOSE BY HEALTH SERVICE PROVIDERS
AND THE PLIGHT OF WOMEN:
THE CASE OF MALAWI'S HIV AND AIDS (PREVENTION AND MANAGEMENT)
ACT, NO. 12 OF 2017**

BY

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Abstract

The recent enactment of Malawi's HIV and AIDS (Prevention and Management) Act, 2017 allows, among other things, health service providers to exercise their discretion and inform sexual partners of their being at significant risk of being infected by their HIV positive sexual partner. This is in line with the intentions of policy and law makers who consider that status disclosure is considered a significant approach to eliminating the HIV and AIDS epidemic. The Act, however, omits some of the recognised disclosure criteria stipulated in the International Guidelines on HIV/AIDS and Human Rights.

Also, evidence revealed by this research shows that both health service providers at facility level and HIV infected persons prefer status disclosure initiated by the infected person. This is because it fosters positive outcomes within the wide, complex and sensitive relationships between the infected and affected persons and health service providers who perceive their first duty of care to maintain the confidence of their patients by respecting their privacy. The health service providers at a health facility have indicated an intention to at least partially implement Part V of the HIV and AIDS (Prevention and Management) Act according government directives. This poses problems for the effective implementation of the Act and gives rise to gender stereotyping caused by deeply engrained norms, attitudes, values and prejudices that heighten women's vulnerability upon HIV status disclosure. Sixteen women and six men

Support Group members from rural and urban settings in Zomba district were involved through focus group discussions. Their ages ranged from 20 to 60 years old. In-depth interviews on ideal and best practices on HIV status disclosure were conducted with health officials at district and ministerial level. Qualitative gender-sensitive methods in particular the women's law, grounded, structures and actors, and human rights based approaches were utilised in collecting and analysing secondary data and narratives of ideal and practice on HIV status disclosure. The findings revealed that the Act's failure to recognise the interplay between economic, social-cultural and health professional dynamics will eventually result in its failure to achieve the prevention and management of HIV and AIDS during its implementation, thereby worsening public service delivery and access for women, especially those infected with HIV.

Declaration

I declare that this paper, ‘Operationalisation of HIV Status Disclosure, A Discretion for Health Service Providers and Plight for Women: The Case of Malawi’s HIV and AIDS (Prevention and Management) Act No. 12 of 2017’ is my own and original work. Any reference to work done by any other person(s) or institutions or any material obtained from other sources have been duly cited and referenced. I further declare that this paper has not been submitted at any other institution of higher learning for the award of certificate or any other form of assessment.

Signature..... Date.....

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Signature..... Date.....

Professor Julie E. Stewart, Director

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Dedication

To Dorica Noniwa.

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List of abbreviations and acronyms

ACHPR	African Charter on Human and Peoples' Rights (Banjul Charter)
AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral drug/s
ART	Antiretroviral therapy
Banjul Charter	African Charter on Human and Peoples' Rights (ACHPR)
CEDAW	Convention on the Elimination of all forms of Discrimination Against Women
CESCR	Committee on Economic, Social and Cultural Rights
DC	District Commissioner
DHO	District Health Office
EC	Expert Client
HAD	HIV Diagnostic Assistant
HIV	Human Immunodeficiency Virus
HIV and AIDS Act	HIV and AIDS (Prevention and Management) Act, No. 12 of 2017
HSA	Health Surveillance Assistant
HTC	HIV testing and counselling
ICESCR	International Covenant on Economic, Social and Cultural Rights, 1966
Maputo Protocol	Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, 2003 (ACHPR or Banjul Charter)
MDHS	Malawi Demographic Health Survey
MLC	Malawi Law Commission
MoHP	Ministry of Health and Population
NAC	National Aids Commission
NHSRC	National Health, Science Research Committee
NAPHAM	National Association for People Living with HIV and AIDS
NSP	National Strategic Plan
PMTCT	Prevention of Mother to Child Transmission of HIV
SEARCWL	Southern and Eastern African Regional Centre for Women's Law
UN	United Nations
UNAIDS	United Nations Joint United Nations Programme on HIV/AIDS
WHO	World Health Organisation

List of international human right instruments

African Charter on Human and Peoples Rights, 1981 (ACHPR or Banjul Charter)

Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa, 2003 (Maputo Protocol)

African Commission's General Comment No.2 on Article 14 of the Maputo Charter

Convention on the Elimination of all forms of Discrimination Against Women, 1981 (CEDAW)

CEDAW Committee's General Recommendation No. 24 on Article 12 of CEDAW (Women and Health), 1990

International Covenant on Economic, Social and Cultural Rights, 1979 (ICESCR)

ICESCR's General Comment No. 14 on Article 12 of the ICESCR: The Right to the Highest Attainable Standard of Health, 11 August 2000

International Guidelines on HIV/AIDS & Human Rights 2006 Consolidated Version

List of national legislation

Constitution of the Republic of Malawi

Disability Act, No. 8 of 2012

Gender Equality Act, No. 49 of 2012

HIV and AIDS (Prevention and Management) Act, No. 12 of 2017

Pharmacy, Medicine and Poison Act, No. 15 of 1988

Public Health Act, 1968

List of national policies

National HIV/AIDS Policy (2003)

National HIV Prevention Strategy (2015-2020)

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CHAPTER ONE

1.0 INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 Introduction

The Human Immunodeficiency Virus (HIV) remains a dire threat to the global population. It is estimated that globally 35 million people are living with HIV of whom 24.7 million live in sub-Saharan Africa comprising 71% of the global total.¹ The UNAIDS Gap Report also indicates that women account for 58% of the total number of persons living with HIV in the region, and most of them face human rights violations due to legislation that specifically allows for the criminalisation and disclosure of a patient's HIV status, stigmatisation, discrimination, and lack of access to health services.² HIV and AIDS raise many human rights issues directly linked to the human right to health as provided in international human rights instruments. Eradicating the HIV and AIDS pandemic remains a top priority at international, regional, and national level. However, the control and prevention of HIV infection depends on the success of the strategies in place to combat it.

HIV testing and counselling is a critical strategy in the prevention and management of the HIV and AIDS pandemic. Currently, emphasis within HIV testing and counselling programmes is placed on the importance of HIV status disclosure among HIV-infected persons to their sexual partners, and it is considered to be one of the most significant approaches in achieving public health goals.³ Some countries in sub-Saharan Africa have enacted laws for the mandatory disclosure of HIV.⁴

According to Loubiere *et al.* (2009), Brou *et al.* (2007), Stirratt *et al.* (2006) and Simoni & Pantalone (2004) as cited by Conroy and Wong, HIV status disclosure promotes and facilitates partner HIV testing, adoption of safer sex behaviours, social support and engagement in HIV care and treatment programmes.⁵ On the other hand, HIV-status disclosure comes with diverse risks especially for women in contrast with men. Women often

¹ UNAIDS-GAP Report (2014).

² UNAIDS-GAP Report (2014).

³ WHO (2004); UNAIDS-GAP Report (2014).

⁴ Patterson *et al.* (2015); Bott & Obermeyer (2013).

⁵ Conroy and Wong (2015).

experience psychosocial, economic, and social-cultural risks upon disclosing their status to their sexual partners, family members, or friends.⁶

In Malawi, as with most sub-Saharan African countries, HIV was first reported in 1985 and it is still affecting men and women. The country accounts for 3% of people living with the virus in the region.⁷ The 2015-2016 Demographic Health Survey Report indicates that 8.8% of people age 15-49 are HIV positive, and HIV prevalence for women is at 10.8% higher than 6.4% for men.⁸ The HIV/AIDS pandemic in Malawi remains generalised and feminized because of women's biological vulnerability and men's sexual power and privilege.⁹ HIV disproportionately affects women in both rural and urban settings due to their physiological vulnerability, gender inequalities, and lack of economic means and it becomes worse upon disclosing their status to sexual partners, family members, and friends.¹⁰

So far, Malawi's HIV and AIDS (Prevention and Management) Act, No. 12 of 2017 is the only explicit law on prevention and management of HIV and AIDS in the country. The Act, among other things, promotes HIV status disclosure as a step toward eliminating the HIV epidemic and to this end it provides for and protects the rights and well-being of people living with HIV and their sexual partners. It also gives discretion to health service providers to disclose the status of HIV positive persons to their sexual partners. Considering that HIV status disclosure impacts more negatively on women than men, research into women's experience, expectations and dilemmas in urban and rural settings as regards the operationalisation of Part V of the HIV and AIDS (Prevention and Management) Act is of great relevance. These research findings will be useful in reviewing the Act, assisting different stakeholders in policy development, designing, and implementing HIV related programmes that promote and take into consideration women's experiences and expectations.

The following section presents Part V of the HIV and AIDS (Prevention and Management) Act, No. 12 of 2017 that was passed by parliament on 29 November 2017¹¹ and it come into force on 1 February 2018.

⁶ Obermeyer *et al.* (2011); UNDP (2012); WHO (2004).

⁷ UNAIDS (2014).

⁸ MDHS (2017).

⁹ UNAIDS (2016); Haggins (2010).

¹⁰ Maman *et al.* (2002); Bobrow (2008); Brown *et al.* (2011); Anglewicz & Chintsanya (2011); Kamanga *et al.* (2015).

¹¹ Nthenda (2017).

1.1.1 HIV and AIDS (Prevention and Management) Act, No. 12 of 2017

This section presents Part V of HIV and AIDS (Prevention and Management) Act, No. 12 of 2017 (HIV and AIDS Act) as a point of departure. Part V deals with HIV status disclosure and the relevant sections 9, 10 & 11 read as follows;

‘Part V– Disclosure

Right to Privacy and confidentiality

- 9(1) A person living with HIV has the right to privacy and confidentiality with regard to information concerning his status.
- (2) It shall be the duty of every health service provider to strictly observe confidentiality in handling all medical information concerning a person living with HIV.

Disclosure by Health Service Provider

- 10(1) A health service provider shall not disclose any information concerning a person’s HIV status to another person

Except –

- (a) With the written all consent of the first person, his guardian, partner or parent, as the case may be;
 - (b) To a health service provider directly involved in providing health care to that person, where knowledge of the patient’s diagnosis of HIV infection is necessary or relevant to making clinical decisions in the best interest of the person;
 - (c) For the purpose of an epidemiological study, where the release of information cannot be expected to identify the person to whom it relates; or
 - (d) Upon an order of a court, where the information contained in the medical file is directly relevant to the proceeding before the court.
- (2) A health service provider providing treatment, care or service to a person living with HIV may notify a sexual partner of the person living with HIV,
 - (a) where the following circumstances exist –

- (i) in the opinion of the health service provider, there is a significant risk of transmission of HIV by the person living with HIV to the sexual partner;
 - (ii) counselling of the person living with HIV has failed to achieve change in behaviour necessary to sufficiently reduce the risk of HIV transmission to the sexual partner;
 - (iii) the person living with HIV has refused to notify or consent to the notification of the sexual partner;
 - (iv) the health service provider gives the person living with HIV advance notice for a period that is reasonable in the circumstances;
 - (v) in the opinion of the health service provider, the person living with HIV is not at risk of serious harm as a consequence of any notification to the sexual partner;
 - (vi) the person living with HIV is dead, unconscious or otherwise unable to give consent to the notification; or
 - (vii) the person living with HIV is unlikely to regain consciousness or the ability to give consent; and
- (c) in the opinion of the health service provider, there is or was a significant risk of transmission of HIV by the person living with HIV to the sexual partner.

Unlawful Disclosure

- 11 A person who discloses the HIV status of another person otherwise than as provided for under this Act commits an offence and shall be liable, upon conviction, to –
- (a) in the case of an individual, a fine of K5,000,000 and imprisonment for five years; or
 - (b) in the case of a legal person, to a fine of K10,000, 000.’

Most of interviewed key informants in sampled health facilities indicated that they were not aware of this Act; some had heard about it in passing, whereas most officials in senior positions in the Ministry of Health and Population (MoHP) were aware of it but were not conversant with its exact wording. All but two of the twenty-two male focus group

participants indicated that they had heard about the Act; the rest heard about it for the first time during group discussions.

1.2 Statement of the problem

It is estimated that 19 million people in sub-Saharan are living with HIV.¹² Most of them are facing specific challenges in relation to the right to health as stipulated in several international and regional human right instruments that specifically provide for the enjoyment of the highest attainable standard of physical and mental health. The right to health is also echoed in the Constitution of Malawi though it does not expressly recognise other determinants of health, e.g., water, nutrition, shelter and food as substantive justiciable rights but as elements of other substantive rights such as the right to development.¹³ Several pieces of legislation, e.g., the Public Health Act, 1968 provide for the right to health but the main focus is on achieving public health goals in general as opposed to addressing pressing issues arising from HIV and AIDS. In addition, some legislation does not recognise human rights principles that play a key role in the prevention and management of HIV and AIDS as stipulated in the Constitution and international human rights instruments.

The country has enacted the HIV and AIDS Act which both specifically gives rights to persons living with HIV and places obligations on the state to promote and protect these rights to health in the effort to eliminate HIV and AIDS. In addition it specifically allows health service providers to exercise discretion concerning the disclosure of an HIV positive person's status. There are about 8.8% people ages 15-49 years who are HIV positive, and the prevalence rate for women is at 10.8% compared to 6.4% for men with that of women being higher in both rural and urban areas.¹⁴ HIV positive persons, especially women, are facing diverse challenges ranging from the lack of access to health services to their concerns over the failure of health service providers to uphold the confidentiality of patients especially concerning their status. This has caused the majority of HIV positive patients to opt for other methods of disclosure, e.g., self-disclosure, which is contrary to the government's plans for reducing and eventually eliminating HIV and AIDS which is given expression through its HIV and AIDS Act which grants health service providers with discretion concerning the status of an HIV positive person.

¹² UNAIDS (2016).

¹³ Section 30 of the Constitution of Republic of Malawi.

¹⁴ MDHS (2004).

1.3 Objective of the research

This section presents the main research objective and specific objectives which guided the whole research process.

1.3.1 Main research objective

The main research objective is to analyse the operationalisation of HIV status disclosure as provided by the HIV and AIDS (Prevention and Management) Act and to examine how it will affect women's right to health and privacy.

1.3.2 Specific research objectives

The following specific research objectives guided the research process:

- To investigate the advantages and disadvantages of giving health service providers the discretion to disclose a person's HIV status to her/his sexual partner/s.
- To investigate appropriate strategies through which health service providers can engage and disclose the status of an HIV-positive person to his/her sexual partner/s.
- To investigate the practicality of disclosing the HIV status of an index person to his/her sexual partner by health service providers.
- To investigate the extent to which women's rights to health and privacy are protected when HIV status disclosure is at the discretion of health service providers.
- To investigate, from a women's perspective, the factors that increase their vulnerability to HIV status disclosure or non-disclosure.

1.4 Research assumptions

This section presents the main research assumption and sub-assumptions which guided the research process in achieving the research objectives:

1.4.1 Main research assumption

In fulfilment of this research's main objective, the main research assumption is that giving health service providers the discretion to disclose the status of an HIV-positive person to their sexual partner/s will undermine the prevention and management of HIV and AIDS and subject women to various forms of oppression.

1.4.2 Research sub-assumptions

1. The Act's giving to health service providers the discretion to disclose the status of an HIV-positive person to their sexual partner/s will assist in reducing the risk of HIV transmission especially to women.
2. Empowering the broader category of health service providers in the HIV and AIDS Act could lead to ethical problems.
3. The Act's lack of stipulated procedures as to how health service providers are to exercise their discretion when disclosing the status of an HIV-positive person to her/his sexual partner/s could adversely affect the health service provider-patient relationship.
4. Health service providers will experience problems in locating the sexual partner/s of an HIV-positive person.
5. The Act's giving a health service provider authority to disclose the status of an HIV-positive person is likely to pose problems as to how they should exercise their discretion.
6. Women could be subjected to violence, discrimination, and neglect when health service providers exercise their discretion and disclose their HIV status to their sexual partner/s.

1.5 Research questions

This section presents main research question and specific research questions, which guides desk and field research process:

1.5.1 Main research question

Based on the main research assumption, the main research question is, Will giving health service providers the discretion to disclose the status of an HIV-positive person to their sexual partner(s) undermine the prevention and management of HIV and AIDS and subject women to varied forms of oppression?

1.5.2 Specific research questions

The following research questions formed the basis of conversations with women and a few men, allowing them to narrate their personal experiences as far as HIV status disclosure or non-disclosure is concerned.

1. Will the Act's giving to health service providers the discretion to disclose the status of an HIV-positive person to their sexual partner/s assist in reducing the risk of HIV transmission especially to women?
2. Could empowering the broader category of health service providers in the HIV and AIDS Act lead to ethical problems?
3. Could the Act's lack of stipulated procedures as to how health service providers are to exercise their discretion when disclosing the status of an HIV-positive person to her/his sexual partner/s adversely affect the health service provider-patient relationship?
4. Will health service providers experience problems in locating the sexual partner/s of an HIV-positive person?
5. Is it the case that the Act's giving a health service provider authority to disclose the status of an HIV-positive person is likely to pose problems as to how they should exercise their discretion?
6. Could women be subjected to violence, discrimination, and neglect when health service providers exercise their discretion and disclose their HIV status to their sexual partner/s?

1.6 Definition of key concepts

Disclosure

There is no precise definition of disclosure. Available literature provides a contextual understanding of disclosure. Sandelowski *et al.* (2004) and Chandra *et al.* (2003), as cited by Greeff *et al.*, have discussed disclosure in four contexts, namely, managed disclosure and concealment, disclosure without consent, and voluntary disclosure.¹⁵ In managed disclosure, persons living with HIV maintain control over the decision to disclose, selecting disclosure methodology ranging from full to selective. Concealment ranges from selective concealment to full concealment. Disclosure without consent refers to disclosing the status of an HIV-positive person without her/his approval. Voluntary disclosure is divided into voluntary disclosure as a positive desirable act and voluntary disclosure where there is no other choice.¹⁶ This research considers disclosure as discussed in the context as defined above.

Expert client

An Expert Client is an HIV positive person who has publicly disclosed her/his HIV status, and is employed to work as a member of support staff at a public health facility.¹⁷

1.7 Outline of chapters

This research paper commence with chapter one which introduces the topic and the reason the topic was chosen. The second chapter covers the literature review on the research topic. The third chapter deals with the theoretical, methodological, and methods used which provide detailed steps that were followed during the research process. The fourth chapter discusses the experiences and lessons learnt from health service providers themselves experienced or observed in their professional capacity. The fifth chapter discusses experiences and lessons learnt that women in Support Group themselves experienced in their personal life, family or observed in their respective communities. Lastly, chapter six is on the conclusion, recommendations and areas for consideration during implementation of the Act.

¹⁵ Greeff *et al.* (2008).

¹⁶ Greeff *et al.* (2008).

¹⁷ Catholic Relief Services (2014).

CHAPTER TWO

2.0 LITERATURE, HUMAN RIGHTS AND LEGAL FRAMEWORK

2.1 Introduction

This chapter discusses and reviews existing literature and laws on HIV status disclosure and then positions this research. It also compares the provisions of international and regional human rights instruments with those at the national level and determining the government's obligations and the practices.

2.2 Literature review

In an effort to eliminate the HIV and AIDS pandemic through HIV status disclosure, privacy and confidentiality as human rights issues and obligations take centre stage of the debate. Since there is no precise definition of disclosure, recourse must be had to the majority of available literature. It tends to contextualise disclosure (i.e., disclosure by an HIV-positive person to their sexual partner/s, by health service providers) by focusing on effective disclosure strategies and the factors that affect women upon disclosure. Sandelowski *et al.* (2004) and Chandra *et al.* (2003), as cited by Greeff *et al.*, provide contextual definitions of disclosure namely managed disclosure and concealment, disclosure without consent, and voluntary disclosure.¹⁸ Disclosure is still considered to be the best approach in preventing and managing, and ultimately eliminating the HIV pandemic, despite the absence of a precise definition.

Scholars such as Stemple,¹⁹ Garumma *et al.*²⁰ and Gallet and Dickson-Gomez²¹ have suggested for policy development, the modification, or enactment of laws providing rights for HIV positive persons, their sexual partners, and the obligations of health service providers. Several sub-Saharan Africa countries are considering and some have developed policies and enacted laws encouraging disclosure or mandate disclosure to sexual partners as a crucial step towards reducing and eventually eliminating HIV and AIDS.²²

¹⁸ Greeff *et al.* (2008).

¹⁹ Stemple (2008).

²⁰ Garumma *et al.* (2012).

²¹ Gallet and Dickson-Gomez (2009).

²² Bott and Obermeyer (2013); Obermeyer *et al.* (2011).

Disclosing a person's status becomes complex when considering the rights of persons living with HIV, their sexual partners, and medical confidentiality.²³ Oftentimes, health service providers are faced with legal and ethical dilemmas arising from disclosing patient's status. As a result, some health service providers prefer an indirect approach to disclosure (Watermeyer, 2013). In the same vein, Kamanga *et al.* (2015) who researched on maximizing HIV partner notification opportunities for index patients and their sexual partners in Malawi, noted that people preferred the passive method of notification to the provider assisted partner notification method considering the psychosocial, social-cultural and economic implications arising from notification by a third party.

Contrary to the above, the findings of Brown *et al.* and Rutstein *et al.* indicate that provider assisted partner notification is feasible, acceptable and effectively helps reduce the risk of infection.²⁴ Their research focused much on the effective means of disclosure strategies based on information from locatable sexual partners. Neither groups of authors however captured women's views, perceptions, expectations, and dilemmas particularly on the preferred method of notification considering that most women do not enjoy the same greater economic means as men. Their findings link up with my research considering that it aims at analysing the operationalisation of HIV status disclosure in Malawi and the fact that disclosure strategies will form part of my discussions surrounding the reasons for disclosure as considered from a woman's perspective.

Contrary to Kamanga's discoveries, the findings of the research of Rutstein *et al.* (2014) on the cost-effectiveness of HIV status disclosure by evaluating provider-based HIV partner notification strategies, builds upon the findings of Brown *et al.* (2011). However, Rutstein *et al.* noted that provider notification is more expensive and slightly more effective than contact notification.²⁵ Although this is the case, the research did not focus on the indirect costs incurred by individual patients, particularly women, most of whom do not enjoy the same greater economic means as men in both urban and rural settings. Furthermore, it did not capture women's expectations or desires as to how to deal with economic dilemmas that result from HIV disclosure. However, the research provides an insight into the economic aspect of disclosure strategies, which also links up with this research especially when looking

²³ Bott and Obermeyer (2013).

²⁴ Brown *et al.* (2011); Rutstein *et al.* (2014).

²⁵ Rutstein *et al.* (2014).

at the practicability of a third party, e.g., a health service provider, disclosing the HIV-positive status of a person to her/his sexual partner(s).

HIV status disclosure is affected by diverse factors as noted by numerous pieces of research that have been conducted focusing on identifying factors associated with disclosure or non-disclosure. The most common factors are stigma, abuse, and abandonment. Bobrow's research into women's participation in the Prevention of Mother to Child Transmission of HIV (PMTCT) programme and exploration into factors associated with HIV disclosure by pregnant women in Malawi, found that 90% of pregnant women in urban settings disclosed to their partners due to means of exposure to transmission.²⁶ The research further noted that good negotiations between partners enhanced disclosure among couples. However, the research did not go deeper and capture the factors that affect women in rural settings where health resources are limited. Anglewicz & Chintsanya's research on voluntary testing and counselling in rural settings found that HIV status disclosure is relatively common among rural Malawians, and those diagnosed positive are less likely to disclose due to stigma and discrimination.²⁷ Hardon *et al.* also noted that the rate of disclosure to partner varied due to stigma and the fear of negative reaction.²⁸ However, Anglewicz & Chintsanya's research treats women and men equally, and did not capture women's views, expectations, and underlying challenges which they face considering that women in a patriarchal society are expected to be submissive in areas of life, a phenomenon that heightens their vulnerability to HIV transmission.

2.3 International legal framework

This section discusses rights issues as provided for in relevant international and regional human rights instruments. Specifically, it discusses the right to health as provided under article 12 of the International Covenant on Economic, Social and Cultural Rights, 1979 (ICESCR) and the Committee on Economic, Social and Cultural Rights' (CESCR's) General Comment No. 14 on Article 12 of the ICESCR: The Right to the Highest Attainable Standard of Health (11 August 2000).

²⁶ Bobrow (2008).

²⁷ Anglewicz & Chintsanya (2011).

²⁸ Hardon *et al.* (2013).

2.3.1 The International Covenant on Economic, Social and Cultural Rights (ICESCR)

The International Covenant on Economic, Social and Cultural Rights (ICESCR) is widely considered as the most imperative and comprehensive provision on the right to health although the realisation of the right is progressive. Article 12 of the Covenant is the most authoritative provision on the right in international law. It lays down measures that state parties should take to guarantee the full realisation of the right to health. Article 2 obliges state parties to recognise the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and to act appropriately to eliminate all forms of discriminatory practices in health system. The ICESCR is not comprehensive in addressing discrimination affecting vulnerable members of society especially women and persons living with HIV and AIDS.

The Committee on Economic, Social and Cultural Rights' (CESCR's) General Comment No. 14 on Article 12 of the ICESCR: The Right to the Highest Attainable Standard of Health (11 August 2000) clarifies the essential elements of the right to health as guaranteed under article 12 of the Covenant. The Committee states that the right to health contains both freedoms and entitlements. The freedoms include among other things the right to be free from interference, and the right to certain entitlement which includes the right to a system of health protection that provides equality of opportunity for people to enjoy the highest level of health. It further clarifies the nature and scope of a state's obligation in the realisation of the right for all persons including persons living with HIV and AIDS. The Committee recommends that all health facilities and services must be respectful of among other things medical ethics and be culturally appropriate (namely, respectful of the culture of individuals, communities), sensitive to gender, designed to respect confidentiality, as well as being culturally acceptable. Contrary to the above, the HIV and AIDS Act does not take into consideration the social-culture factors intertwined in HIV and AIDS service delivery especially on the issue of HIV status disclosure.

2.3.2 The Convention on the Elimination of all forms of Discrimination Against Women (CEDAW)

The Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) was adopted in 1979 and it entered into force on 3 September 1981. This occurred

during the time when HIV and AIDS were commonly associated with homosexuality.²⁹ This explains the reason why article 12 of the CEDAW does not explicitly deal with HIV and AIDS specifically for women. Unlike the ICESCR that refers to the right to health in general, CEDAW applies more specifically to the rights of women and children. Article 12(1) of CEDAW obliges member states to eliminate all forms of discrimination and to ensure equal access to health care services. The CEDAW Committee's General Recommendation No. 24 on Article 12 of CEDAW (Women and Health), 1990, focuses on HIV/AIDS and confidentiality and obliges states to ensure that their health legislation, executive action and policies comply with the Covenant. These are crucial and have a directly influence on HIV status disclosure.

The CEDAW Committee notes that issues of HIV and AIDS are central to the rights of women in view. It recommends that the state ensure that HIV related services are performed by properly trained personnel, respects women's right to privacy and confidentiality. The CEDAW's Committee's view on confidentiality is that 'all health services should be consistent with human rights of women, including the rights to autonomy, privacy, confidentiality, informed consent, and choice.' The CEDAW Committee notes that the failure to respect a patient's confidentiality might deter women from seeking health services thereby adversely affecting their health and well-being. The issue of confidentiality is central in as far as disclosure is concerned. Most of my respondents raised concerns over the issue of confidentiality considering that the HIV and AIDS Act gives health service providers a discretion to disclose a patient's HIV status. In addition, the Act has not specifically singled out women as being the most infected and affected by HIV and AIDS and therefore being in the greatest need of help; instead, it treats both women and men equally.

2.3.3 International Guidelines on HIV/AIDS & Human Rights

HIV and AIDS raise so many human rights issues such as the right to life, privacy, equality, and not to be discriminated against and these are essential in the management and prevention of the further transmission of HIV and the reduction of the impact of AIDS on the lives of people.³⁰ In view of this, the International Guidelines on HIV/AIDS and Human Rights (setting out specific guidelines in ensuring the rights of persons living with HIV and AIDS) was developed. The Guidelines aim at providing the best approach to promoting, protecting,

²⁹ Centers for Disease Control (1981).

³⁰ UN Fact Sheet No. 31 on The Right to Health.

and achieving human rights in the context of the HIV epidemic. Of special interest is Guideline No. 3 paragraph (g) (vi) & (vii) which states:

- ‘(vi) The identity of the HIV positive person is concealed from [her/his] sexual partner(s), if this is possible in practice; and
- (vii) Follow-up is provided to ensure support to those involved, as necessary.’³¹

Guideline No. 3 paragraph (g) provides for the concealment of the identity of an HIV positive person and the provision of psychosocial support to the sexual partner of an HIV positive person after informing them of their risk of infection of HIV. Malawi’s HIV and AIDS Act does not provide for the above criteria but rather leaves the infected and affected persons themselves to deal with such outcomes, be they positive or negative.

2.4 Regional framework

This section discusses the right to health in relation to regional human right instrument. Specifically, the African Charter on Human and Peoples’ Rights (Banjul Charter), and Article 14 and 18 the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa (Maputo Protocol).

2.4.1 The African Charter on Human and Peoples’ Rights (ACHPR or Banjul Charter)

The African Charter on Human and Peoples’ Rights (ACHPR or Banjul Charter) was adopted in 1981 and entered into force in 1989. Article 16 of the Charter provides the right to health and obliges member states to take necessary measures to protect the health of their citizens and ensure that they receive medical attention when they are sick.

The Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa, 2003 (Maputo Protocol) is considered to be the main legal instrument for the protection of the rights of women and girls in Africa. Article 14 of the Maputo Protocol guarantees women’s right to health. The African Commission has commented as follows on this right and explained that the right to sexual and reproductive health right includes:

³¹ UNAIDS (2006).

‘...the right to self-protection and to be protected against sexually transmitted infections, including HIV/AIDS; to be informed of one’s and sexual partner’s health status, particularly if affected with sexually transmitted infections, including HIV/AIDS, in accordance with internationally recognised standards and best practices. It further puts obligations on states to take appropriate measures to promote and protect the right to health care without any form of discrimination for women.’³²

2.5 National framework

This section reviews the available national legal framework on the right to health, looking at what is provided in the Constitution and the extent to which it conforms with international human rights instruments on the right to health. It also reviews legislation and health policies.

2.5.1 Constitution

The Malawi Constitution does not expressly provide and protect for the right to health. Section 13 sets out principles for a national policy and obliges the state to provide adequate health care, commensurate with the health needs of Malawian society and in line with international standards of health care to encourage and promote conditions conducive to the full development of healthy, productive and responsible members of society and to provide a healthy living and working environment for the people through responsible environmental management. The state is further under obligation to achieve adequate nutrition for all in order to promote good health and self-sufficiency.³³

The Constitution’s Bill of Rights contains several provisions, which are directly related to the promotion, protection, and enjoyment of the right to health by its citizens. Section 20(1) prohibits any form of discrimination including on the basis of status or condition (including HIV status). Section 21 provides for the right to privacy. Section 23(2)(c) provides for the rights of children to be protected from any treatment that might possibly inflict harm to their health, and section 24 provides for the rights of women. Section 30(2) recognises the right to health as an element of the right to development. In its context, the Constitution does not explicitly recognise a justiciable right to health, but it contains provisions and other justiciable rights that constitute elements of the right.³⁴ Nor does it explicitly mention HIV or AIDS.

³² African Commission, General Comment No. 2 on article 14 of the Maputo Protocol.

³³ Malawi Law Commission (2008).

³⁴ Chilemba (2016).

2.5.2 National legislation

This section discusses the Public Health Act, 1968 and Gender Equality Act, No. 49 of 2012 looking at their relevance in providing the right to health in relation to the prevention and management of HIV and AIDS.

2.5.2.1 Public Health Act, 1968

This Act was enacted under a constitutional regime that did not recognise principles of human rights and freedoms. It is considered the country's main health legislation that provides for matters relating to public health. The main aim of this Act is to preserve and promote public health in the country. The Act lists several notifiable infectious diseases and obliges the head of the family and institutions to notify medical officers of the disease;³⁵ provides steps on the prevention and suppression of infectious diseases;³⁶ considers some diseases more dangerous than others diseases, e.g., cholera;³⁷ sets out measures to prevent the introduction of infectious³⁸ and venereal diseases.³⁹ However, most of the diseases listed in the Act are diseases that are curable, e.g., cholera or may be treated with vaccines, e.g., smallpox, but such diseases do not share the characteristics of HIV and AIDS.⁴⁰ The Act is irrelevant to the prevention and management of HIV and AIDS through status disclosure as provided for in sections 9, 10 & 11 of the HIV and AIDS Act as discussed in chapter one. Parts IV, V and VI of the Public Health Act requires, among other things, the removal of persons, the removal and burial of infected bodies and quarantining or isolating of patients which arguably amounts to discrimination and is in conflict with the Constitution and international human rights instruments.

2.5.2.2 Gender Equality Act, No. 49 of 2012

The Gender Equality Act is another piece of legislation that strengthens the operationalisation of some international and regional human rights instruments that encourage eliminating all forms of discrimination, e.g., CESCRR and CEDAW. The Gender Equality Act provides protective mechanism towards the violation of the rights of women and it explicitly provides for sexual reproductive health rights and further prohibits any form of discrimination in accessing and providing sexual reproductive health services. The right to sexual reproductive

³⁵ Part III of the Public Health Act, 1968.

³⁶ Part IV of the Public Health Act, 1968.

³⁷ Part V of the Public Health Act, 1968.

³⁸ Part VI of the Public Health Act, 1968.

³⁹ Part VII of the Public Health Act, 1968.

⁴⁰ Malawi Law Commission (2008).

health is a component of the right to health. Section 19 of the Act provides among other things, the right to adequate sexual reproductive health, which includes protection from sexually transmitted infection and self-protection from sexually transmitted infection. In this context, the Act partly addresses the issue of eliminating HIV and AIDS by protecting and allowing self-protection from HIV transmission. However, it has not expressly stipulated how and what approach to be taken in case of HIV and AIDS. Thus, women have the right to protect themselves under this Act. Section 20 further imposes a duty on health officers to respect the sexual reproductive health rights of every person without discrimination, respecting dignity and integrity of any person accessing sexual reproductive health services.

The Disability Act, No. 8 of 2012 is another notable piece of legislation that protects and promotes the rights of persons with disabilities. Sections 6 and 7 of the Act provide for the right to health care and prohibit any form of discrimination in accessing health care services. However, the Act does not specifically address HIV and AIDS. People living with HIV face problems in relation to their enjoyment of the right to health, and matters are far worse for a disabled HIV positive woman because she faces multiple forms of discrimination because of her physiology.⁴¹ Both the Gender Equality Act and Disability Act relate to the HIV and AIDS Act in that they all provide for the right to health and equality. However, the difference between them is that the Gender Equality Act and Disability Act do not specifically address HIV and AIDS which is addressed in Part V of the HIV and AIDS Act.

2.5.3 National policies

The National HIV and AIDS Policy (2003) provides direction for the prevention and management of HIV and AIDS in the country. Its objective is to prevent and manage HIV and AIDS and to mitigate the economic and socio-cultural impacts of HIV and AIDS at all levels of society. The Policy further recognises the human rights principles promoted in the country's Constitution and in international human rights instruments. It is of interest that the Policy provides for HIV testing and disclosure and allows health service providers to disclose the status of an HIV positive person to her/his sexual partners.

The National HIV Prevention Strategy (2015-2020) aims at responding to the current gaps in HIV prevention interventions. Its primary objective is the achievement of the 90-90-90 target

⁴¹ UN Fact Sheet 31 on The Right to Health.

by 2020. In addition, the National Strategic Plan for HIV and AIDS (2015-2020) recognises that HIV testing and counselling (HTC) is the gateway to accessing HIV treatment and care and a successful public health response to HIV. It further points out that the shared perception among nurses and clinical officers that HIV testing is the responsibility of lower level cadres has contributed to the unsuccessful provider-initiated testing and counselling measures.

Both the National HIV and AIDS Policy (2003) and the HIV and AIDS Act aim at preventing and managing HIV and AIDS. Of special interest is that both instruments place emphasis on the strict adherence to confidentiality and allow a health service provider to disclose a patient's status to their sexual partners. However, the Policy strictly emphasises that such disclosure should be made in accordance with the guidelines outlined in the International Guidelines on HIV/AIDS and Human Rights discussed in section 2.3.3 above. The Guideline as outlined in section 10(2)(a)(i)-(vii) of the HIV and AIDS Act does not provide that the identity of an HIV positive persons be concealed and follow-up support to sexual partners of an HIV positive person once informed of their being at risk from their sexual partner.

2.6 Conclusion

This chapter has dealt with the relevant literature, international and regional human rights instruments on the right to health. The following chapter discusses the relevance of theories, methodologies, and methods used in the evidence on which the research is based.

CHAPTER THREE

3.0 THEORETICAL, METHODOLOGIES AND METHODS

3.1 Introduction

This chapter discusses the theoretical framework, methodological approaches, research design and data collection methods that were utilised during the research process.

3.2 Theoretical approaches

I used the relational feminist, Nego-feminist and Socialist/Marxist feminist theories to guide the research process and help me to understand, analyse (responses, reactions, etc.) and constantly review the interaction between theories and research data as my research proceeded.

3.2.1 *Relational feminist theory*

During group discussions with women in the rural and urban setting, it emerged clearly that some married men behave strangely towards their wives once she has tested HIV positive. Women and men in sexual relationships handle information of their partner's status differently. Most women readily accept their status and even that of their husbands; but the reverse is not true of men who often find it very difficult to accept their wives' status. In most situations, men quickly abandon their HIV positive partners/wives as well as their own children.⁴²

The evidence showed that women take time to think through the issue and consider the welfare of their immediate family members who are dependent on them and, as a result, they hardly ever abandon their husbands and children. I found relational feminist theory effective in helping me understand the attitude and approach of women in this regard in that they tend to see their lives as being related to, connected with and even responsible for other individuals, especially those of their immediate family; men, however, tend to be motivated by issues of reason, rights, independence, self-interest and self-sufficiency.⁴³

⁴² Interview with Support Group at Matawale Health Centre on 15/12/2017.

⁴³ Banu (2017).

I also found that relational feminist theory showed me how to take a woman as a starting point of investigation in understanding the answer to ‘the woman question’ or understanding the reasons why women and men behave differently in the same situation. Asking a woman-question allowed women to think of the underlying reasons that made them behave differently from men in the same situation. This allowed women to think about their own personal point of view and share their reasons for staying with their sexual partner after he had tested HIV positive. The common reason given by women was that it is in their nature to value the lives of their immediate family members more than their own interests and lives. A female respondent shared her experience about how her husband reacted after she informed him that she tested HIV positive. She had never thought that she might test positive because she was not having sex with any other men, only her husband. Her husband was bitter after she told him and he immediately abandoned her and all this happened when she was pregnant.⁴⁴ Another female participant in a discordant marriage indicated that she was pregnant when she tested positive; she informed her husband who did not reject her and when he went for a test, he tested negative. She explained that her case is rare and that the majority of men simply abandon their wives once they test positive.⁴⁵

3.2.2 Socialist/Marxist feminist theory

Women’s lack of economic means was a recurring issue during discussions. Some women in rural and urban settings do not have the economic means to sustain themselves and their children. Some men capitalise on this and subject their sexual partners to different forms of abuse arising from issues of HIV status disclosure or non-disclosure. Women participants indicated that some women have been infected and affected because of their financial dependence on their sexual partners who in most cases are the ones who transmits the virus. Participants were quick to point out that there are some women who have their own economic means and are able to sustain themselves and their children but still experience abuse of one kind or another connected with the disclosure or non-disclosure of their HIV status.

I found Socialist/Marxist Feminist theory relevant to understanding and examining the underlying reasons why women, despite being economically independent, do not behave like men and leave them and their children if they test HIV-positive. I asked the women to truly ask themselves about the underlying reasons for their problems. Men’s inputs during

⁴⁴ Interview with Support Group at Matawale Health Centre on 27/12/2017.

⁴⁵ Interview with Support Group at Makwapala Health Centre on 15/12/2017.

discussions helped the women understand men's commonly shared sentiments, expectations, and their behaviour once they become economically independent within a patriarchal regime. The women participants shared that it is not all about their becoming economically independent; they also admitted that they needed to fulfil their sexual desires. One of them admitted:

'We are human beings, we do have feeling for sex and because of that we compromise and continue staying with our husband; in addition, having money cannot compare with parenting, which is why 'we get concerned about raising our children without their father.'⁴⁶

3.2.3 *Nego-feminist theory*

Nego-feminism, as ideally developed by Obioma Nnmaemeka, is the feminism of negotiation, in other words, it is feminism of knowing when, where, and how to negotiate with or negotiate around patriarchy in different contexts.⁴⁷ I found this theory useful in theorising, understanding, and examining the steps a woman takes to decide to take when she chooses to disclose her status to her sexual partner. I achieved this by firstly allowing a few men to be part of the discussions, making sure that the discussions started with women's perspectives and how they disclosed to their sexual partners after they had tested positive. Using this approach, the participants narrated their actual experiences, what they had observed happening in their respective communities, and what they had been told about disclosing by the staff at their health facility.

During discussions, it emerged that disclosing one's status greatly depends on the approach used. Participants indicated that HIV and AIDS is a very sensitive and serious issue, a person needs to thoroughly think through the approach for disclosing to prevent receiving negative feedback from the recipient. A female participant explained how she utilised her capability to cool down her boyfriend who was angry after discovering that she was on ARVs.⁴⁸ This agrees with Greeff's findings that disclosure is not a one off thing, but rather a complex and stressful process.⁴⁹

⁴⁶ Interview with Support Group at Makwapala Health Centre on 15/12/2017.

⁴⁷ Nnaemeka (2004).

⁴⁸ Meeting with Support Group at Matawale Health Centre on 27/12/2017.

⁴⁹ Greeff *et al.* (2008).

Throughout the discussions, participants agreed that women have the inherent ability to negotiate and convince their sexual partners to accept their status and to convince their partner to go for testing as well. Male participants agreed that some men do not utilise their inherent ability in the same way and prefer to conceal their status. Such inherent ability and capabilities are acquired with experiences about relations, cultural norms, and practices. Participants indicated that most health service providers lack such capabilities and that it is difficult for them to know exactly when and how to inform their sexual partner/s of their HIV positive status.

3.3 Methodological framework

This section outlines, analyses and explains how I used different methodological frameworks during research process. I used the women law approach, grounded theory approach, human rights based approach, and the influences of actors and structures approach, explaining what these methodological approaches entail in theory and how I used them in practice during field research process.

3.3.1 *The women's law approach*

In my endeavour to understand women's right to health and privacy in relation to HIV status disclosure or non-disclosure in urban and rural areas in Zomba District, I discussed with women in Support Groups at grassroots level, listening as they narrated their painful lived realities arising from disclosing one's HIV status or disclosed by a health service provider. I found the women's law approach significant because it allowed me to take women as a point of departure in analysing their position in law and society.⁵⁰ This approach was instrumental in engaging with women and a few men from different backgrounds but brought together by their health status. I listened and examined as women recounted their actual lived experiences, what they had observed in their communities, and at their local health facility as far as HIV status disclosure is concerned. I interacted with women and a few men, community gatekeepers and health service providers in both rural and urban settings, exploring the impact of HIV status disclosure and possible disclosure by a third party.

The women's law approach allowed me to use an interactive process whereby data, theory, and women's lived realities about perceptions and norms are constantly engaged with each

⁵⁰ Bentzon *et al.* (1998); Dahl (1987).

other.⁵¹ This approach helped my understanding of the current practices and challenges faced by women in HIV status disclosure specifically by examining the duty and the right to disclose HIV status from the point of view of women and health service providers. In addition, I employed the women's law approach because it provides a framework for analysing the implications for the health service provider-patient relationship in the light of third party HIV status disclosure and how public health goals are affected. For example, throughout the discussions, women indicated that giving a health service provider discretion over a patient's status would do more harm than good.

3.3.2 Grounded theory approach

I started researching when the HIV and AIDS (Prevention and Management) Act was a bill waiting to be tabled in parliament. My interest in the bill was to examine its disclosure clause considering that it gives rights to HIV positive persons, their sexual partners and obligations to health service providers. I went into the field with the assumption that the HIV and AIDS Prevention and Management Bill (which has since been passed into law) has provisions which, once it came into operation, would cause problems for health service beneficiaries especially women, and public health service providers.

I conducted in-depth interviews with key informants and several focus group discussions with women and a few men in Support Groups. I interviewed key informants at community level on my first day of fieldwork, and from the findings, issues started emerging concerning how impractical it is for health service providers to exercise their discretion in informing the sexual partner/s of HIV positive persons.

Based on the findings of the second day of fieldwork, I decided to re-plan the entire interview schedule by prioritising discussions with Support Group members in all the remaining sampled health facilities, adopting appropriate data collection methods thus giving women ample time to voice their real concerns, expectations and dilemmas as far as HIV status disclosure is concerned. This was achieved by allowing a few men to participate in the discussions. I further discussed the findings and issues that emerged during discussions at community level with policy makers, enforcers, and implementers. The idea was to find out if health policy formulators and enforcers are conversant with the current practices of HIV

⁵¹ Bentzon *et al.* (1998).

status disclosure at grassroots level; how social-cultural elements are interwoven with HIV status disclosure; and its implications for the public health service provision particularly in relation to women. Discussions revealed that health policy makers and enforcers are aware of the social-cultural dynamics at the grassroots level influencing one's decisions to disclose her/his HIV status. However, health policy makers and enforcers are more focused on treating and eliminating further transmission of HIV through their scientific logical reasoning and therefore they do not take into consideration the social-cultural dynamics involved in the process.

3.3.3 Human rights based approach

This research focuses on the right to health which is a human right recognised under different international and regional instruments such as ICESCR, CEDAW, the Banjul Charter and the Maputo Protocol as well as the Constitution and the HIV and AIDS Act at national level. The right to health as a human right has a specific meaning for different people including those living with HIV.

I employed the human right to health to show the current practices in HIV status disclosure and to expose the problems that will arise once the HIV and AIDS Act is operation. I framed my assumptions so that they would unearth rights issues relating to HIV positive persons particularly women, and obligations of health service providers in relation to the current practices in HIV status disclosure. My first and last assumptions focus on the impact of status disclosure by a third part on women and public health service delivery.

I adopted the human rights based approach on right health. This approach places the individual, in this case, the woman, as the holder of basic rights, at a centre of development.⁵² Using this approach, I analysed the right to health particularly by focusing on how the right is applied and enjoyed by persons who are infected or affected with HIV and AIDS. I did this by examining the ideal involving looking at government's obligations as stipulated in its laws and practices and comparing them with what is contained in international and regional human rights standards.⁵³ The findings show that the majority of available laws are irrelevant in addressing issues arising from HIV status disclosure, and that some clauses of the HIV and AIDS Act pose problems in its implementation.

⁵² Hellum (2000).

⁵³ Goonesekere (2000).

3.3.4 *Actors and structures perspective*

I identified several actors involved in public health service delivery at grassroots, district, and national level. In particular, I interviewed key officers from the Ministry of Health and Population (MoHP), the Ministry of Gender, the Ministry of Justice and Constitutional Affairs and the Malawi Law Commission, the District Health Office (DHO), the HIV Testing and Counselling (HTC) Coordinator, the Prevention of Mother to Child Transmission of HIV (PMTCT) / Antiretroviral therapy (ART) Coordinator, the STI Coordinator, the DAC from Zomba City Council, NGO Directors/Officers, Nurses/Midwife practitioners, Clinicians, HTC Counsellors, an HIV Diagnostic Assistant (HAD), and Expert Clients (EC). I also involved structures like the Ministry of Health and Population, hospitals, health centres, and Support Groups at community level. Talking to these actors and visiting these institutions helped in understanding and examining the roles they play in protecting and promoting the right to health and privacy on issues connected with HIV and AIDS.

The approach further helped in understanding the customs and practices shared by various actors in the position of making and implementing health related laws and policies.⁵⁴ Various approaches directly relate to my second assumption which asserts, ‘The broader category of health service providers could lead to ethical problems.’ My thinking behind this assumption was that granting discretion concerning a patient’s HIV status to a broader category of health service providers could lead to ethical problems because some service providers are not specialised in dealing with HIV issues and notifying sexual partners of an HIV positive person. I examined this assumption by talking to health service providers at a health facility, at district and ministerial level. For example, discussions with one of the senior officers in the Ministry of Health revealed that most of them share the understanding that HIV and AIDS is no special case and status disclosure should not be an issue of concern but rather focus should be concentrated on how to eliminate further HIV transmissions and how to manage the current HIV status of patients.

This revealed that health service providers at the highest level, especially those responsible in coming up with policies and laws guiding the implementation of health services delivery, do not take into consideration the social-cultural elements intertwined in HIV and AIDS issues. Contrary to the above, health service providers in sampled health facilities acknowledged that

⁵⁴ Bentzon *et al.* (1998).

HIV and AIDS is a serious issue that needs special approach especially when disclosing patient's HIV status. Health service implementers are accustomed to keeping patient's health information confidential and as such they would rather breach some sections of Part V of the HIV and AIDS Act on status disclosure rather than violate their patient's right to privacy.

3.4 Research design and methods

This section discusses the research design that was used during the entire research process.

3.4.1 Study location

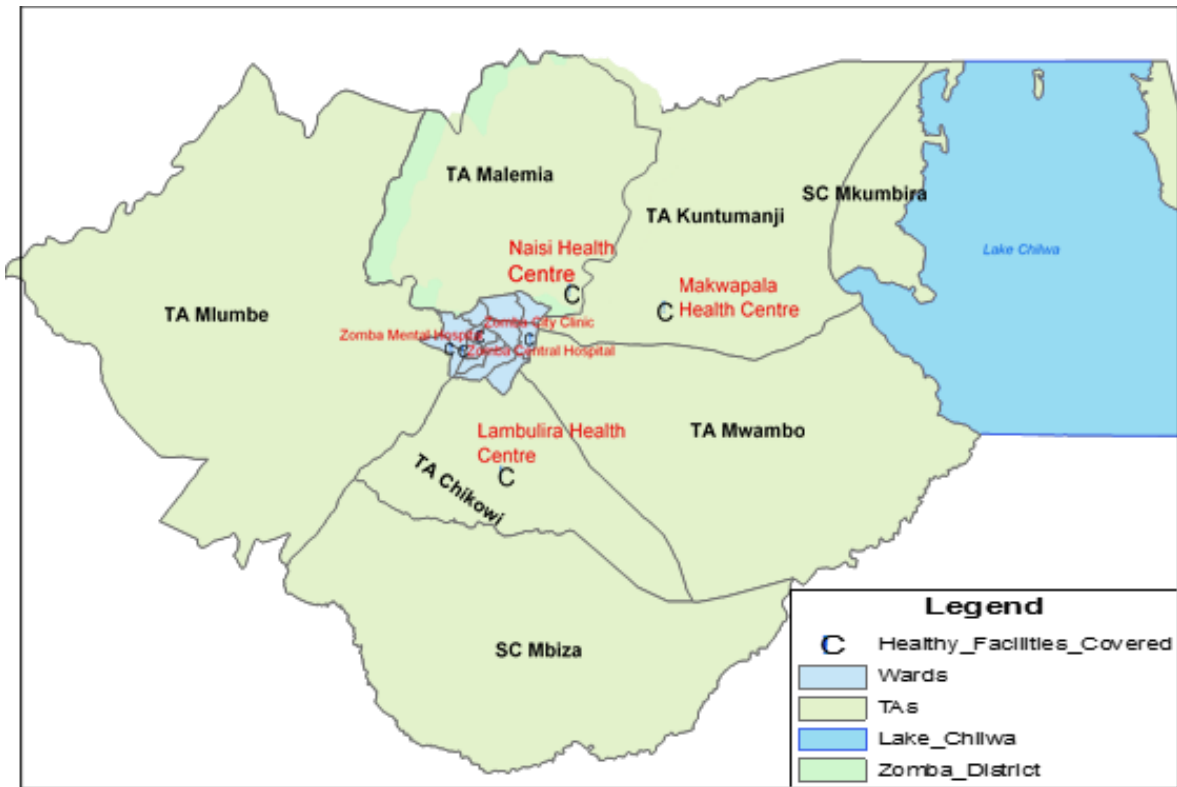
Initially, I sampled the Mulanje and Phalombe Districts as my research site considering that they have high HIV prevalence rates in the Southern Region. Nationally, statistics show that HIV prevalence is higher in the Southern Region at 12.8% which is at least twice as high as both the Central Region (5.6%) and the Northern Region (5.1%).⁵⁵ Mulanje District ranks the highest in the region with an HIV prevalence rate of 20.6% and Phalombe District ranks third with a prevalence rate of 15.5%. These districts would have been ideal for this research. However, due to swirling fears and the superstition of bloodsucking vampires in these areas which resulted in the mob-killings of several people, I decided against putting my life at risk and instead turned my attention to Zomba District which I sampled (Figure 1).

Zomba is the Fourth District in the Southern Region which has a high HIV prevalence rate of 13.2% of which 16.8% are women and 9.3% are men.⁵⁶ This clearly shows that HIV is affecting a large percentage of the district's population, especially its women, making the district an ideal site for this research. Working in Zomba was easier considering that I stay there. I have also participated in several other cases of research fieldwork and interacted with various people in the district. This made it easy for me to move around the area and secure interviews with some of the key informants as well as locate sampled health facilities in the district.

⁵⁵ MDHS (2017).

⁵⁶ MDHS (2017).

Figure 1: Map of Zomba district showing sampled health centres



3.4.2 Research target population

As discussed earlier, I started this research project when the HIV and AIDS Act was still a bill. I envisaged that it would take time for the bill to be tabled in parliament or to be assented to considering that different actors involved in HIV service delivery were demanding that various clauses in the bill such as disclosure, mandatory testing, and criminalisation of deliberate transmission of HIV to be changed or removed.

Then the HIV and AIDS Act came into effect. So I quickly contacted my country supervisor, explained the challenges, and justified my plan to come up with a new research topic. However, after a thorough discussion with my supervisor, she advised me to not to drop the topic but rather to carefully sample the right target population. According to her, targeting the general population would have turned the entire research into a speculative rather than a fact-based endeavour. She suggested that I target HIV positive persons who have already disclosed their status to their spouses or community. The rationale for this approach was that such persons are already infected and they would be in a position to narrate their actual lived experiences as far as HIV status disclosure is concerned. According to Ewich and Silbey

(1995), as cited in Stackpool-More, narratives are socially organised phenomena that provide social meanings and power relations expressed by and sustaining those meanings.⁵⁷ Capturing actual experiences as narrated by women living with HIV was the ideal approach to adopt for this research since experiences are facts that I could still use in the event of a minor or major change to the disclosure clause or if the bill passed into law.

I considered my supervisor's inputs and I decided to target women and a few men in Support Groups. Participants' ages ranged from 20 to 65 years old which would mean that I would capture the experiences of a wider age group. The rationale for this decision was that this group of people have already disclosed their status to their sexual partners and to their community. Also, they would not speculate but rather narrate their actual lived experiences as well as what they observed in their communities or at their local health facility. I decided to target women and a few men in Support Groups under the Community Based Organisations operating within the sampled health facility catchment areas in both urban and rural areas in Zomba District. Support Groups are generally composed of women and men who have disclosed their HIV status to their spouses, family members and above all to their community. Targeting such groups gave me an opportunity to capture their actual experiences by talking to women and a few men from all corners of the research-sampled areas.

3.4.2.1 Efficiency of expectations

During discussions with Support Group members, it emerged that the majority of them lack capacity. The findings revealed that the group's chairpersons, treasurers, and secretaries are the ones who have been trained. Only one out of four interviewed Support Groups indicated that they have never been trained; however, they are working based on personal experiences and by frequently seeking help from their fellow members. Because of this, group members have diverse expectations, for example, if called to a meeting. A female participant indicated that she has never been trained and because of that she did not know how to respond to questions. At this point, a few other participants expressed similar concerns. Some participants indicated that they accepted the invitation to be part of the discussion meeting because they thought that it was a meeting at which they would receive training and not be interviewed for this research. Besides such expectations, participants participated and contributed to the best of their knowledge. The issue of capacity was often mentioned as an

⁵⁷ Stackpool-Moore (2013).

area of concern for most of the group members because they have not been trained. According to National Association for People Living with HIV and AIDS (NAPHAM's) Support Group manual, these groups are self-forming which is why some of them have not yet been trained.⁵⁸ I later cross-checked this with the health service provider to find out who and whether the Support Groups would be trained. The health service provider confirmed that the Support Groups have not been trained and attributed this to a lack of resources, e.g., funds for the training.

3.5 Data collection methods and tools

This section discusses the data collection methods and tools that were used during the entire research process.

3.5.1 Interviews

I targeted officers in the Ministry on Health and Population, the Ministry of Gender, the Ministry of Justice, the Malawi Law Commission, NGOs, nurses, HIV testing counsellors, HIV Diagnostic Assistants, Expert Clients, community gatekeepers, women, and a few men in Support Groups found in sampled health facility's catchment areas.

3.5.1.1 Key informant interviews

Key informants were categorised into three categories namely those at national level (e.g., senior officers in the Ministry on Health and Population, the Ministry of Gender, the Ministry of Justice and the Malawi Law Commission.) The second category is that of those at district level (e.g., officers from government sectors, and non-governmental organisations.) the last category comprises policy implementers at health facilities and from the community (e.g., the health service providers and community gatekeepers.) I came up with this categorisation considering that those at national level formulate the policies and laws to be implemented by those at the district level. However, even at district level, some sectors do not do the actual implementation and instead give policy guidance to the actual implementers, e.g., NGOs and health service providers at health facilities in their communities. Details of my key informant interviews are found in Table 1.

⁵⁸ National Association for People Living with HIV and AIDS in Malawi (2012).

Table 1: Showing key informant interviews conducted at national and district level

Key Informants	Sex of Officer		Total
	M	F	
Ministerial level (National level)	3	1	4
District Central government officers	7	1	8
NGO Officers	5	4	9
HIV Testing & Counselling Counsellors	5	3	8
Nurses	3	1	4
Expert Clients	3	5	8
Community Gatekeepers	3	1	4
Total			45

When interviewing key informants at national level, I sought to ascertain the rationale for formulating the HIV and AIDS Act; whether there are guidelines in place for health service providers to follow when disclosing a patient's status; and whether the implementation of the Act poses risks to the public health service. When interviewing key informants at district level, I sought to establish whether they are aware of the Act, their understanding of whose duty it is to disclose a patient's HIV status, issues of confidentiality, and medical ethics versus patient's rights, and whether it is practical for health service providers to disclose a patient's status. When interviewing health service providers at health facilities, I wanted to find out the actual practice they follow and what they considered to be their ideal objective in the application of medical ethics, rights, confidentiality issues, and a provider's discretion concerning a patient's HIV status within the context of Part V of the HIV and AIDS Act. From community gatekeepers, I wanted to find out the role they play in the issues of HIV and AIDS service delivery, confidentiality, and subjects' status disclosure.

3.5.1.2 Collective individual interview

My initial plan was to conduct in-depth individual interviews with key community gatekeepers but this did not turn out as planned because some people whom I did not intend to interview, joined my interviews. This happened because my plans were overtaken by certain community members who were unaware that I was holding interviews, simply came along and joined in which is an accepted community convention or habit. I decided not to see

them as intruders but rather helpful contributors to the discussion. This method gave me the opportunity to capture and use all the available lived experiences that were narrated. For example, whilst interviewing a village Chief (a female) in Lambulira areas, three women joined in the interview. In most cases, the additional participants enlivened the discussions and they discussed issues just as they would in normal conversation. They even sometimes burst out laughing for example when discussing how some couples in the area hide their ARVs from each other, e.g., some women hide them in buckets of maize flour or in their mother's homes. Some husbands hide their ARVs in the toilet. This is all happening because of lack of disclosure.

3.5.2 Focus group discussion

Participants for the research were purposefully selected from different Support Groups within a sampled health facility's catchment area. The rationale was to have active and knowledgeable participants coming from all corners of the catchment areas. Focus group discussions were held at each sampled health facility (Table 2 and Figure 2). The rationale for conducting focus group discussions was to clearly understand and appreciate the community's shared views, expectations, challenges, and anticipated best practices in HIV status disclosure; to understand how issues of HIV status disclosure are handled considering that Zomba district has a heterogeneous population; and to obtain divergent views on the topic of research as participants engage in debate amongst themselves.

Table 2: Showing details of health facilities visited and the number of participants at each research site

Name of Health Centre: Rural (R)/Urban(U)	Support Group members	
	M	F
Lambulira Health Centre (R)	3	4
Naisi Health Centre (U)	1	4
Makwapala Health Centre (R)	1	4
Matawale Health Centre (U)	1	4
Total	6	16

Figure 2: Photograph of a focus group discussion with participants at Makwapala Health Centre



At all four focus group discussion I conducted, their participants did not readily come to any agreement especially on whether health service providers should exercise any discretion over a patient's status. Some women argued that it would assist in reducing the risk of HIV transmission especially for women because it is mostly men who sleep around and transmit the virus to their sexual partners, especially their wives. Some women did not agree but argued that not all women and men are unfaithful. The debate brought to light that even women themselves are aware that they are not a homogeneous group. The focus group discussions were lively and most questions were answered during their debates.

3.5.3 Observations

Apart from conducting interviews and group discussions, observation was utilised as a data collecting method and used to verify data on how women, men, and health service providers behave in their natural settings as far as access to and provision of HIV and AIDS services is concerned. This method worked well at health facilities especially in the morning because many people come to access their services. I observed what was going on in and around every health facility before I approached their member in charge to introduce myself and state my business. For example, I visited one of the sampled health centres on a Friday which I later discovered also happened to be the day on which HIV positive patients came to renew their ARV drugs. On that day, there were many people, approximately 80 (men, women, and

children), who had come to renew their ARVs. I observed that they were attentive, relaxed and sometimes laughed, and responded to and commented on whatever the health service providers were telling them. However, I made sure not to place too much emphasis on such observations and collected data was triangulated with follow-up questions to health service providers, policy makers, and enforcers at district and national level.

3.5.4 Secondary data sources

This approach requires collecting and using data which have already been collected and analysed by someone else. It was important for me to review articles (journals and newspapers), books, and court records. Reviewing articles and books was necessary in this research as I got to see what other authors had written about the topic in the wider field of research, any gaps it contained and then the position of my research within this broader context. Reading newspaper articles was of great assistance in keeping up-to-date with current affairs especially related to the topic of research and tracking progress concerning the HIV & AIDS (Prevention and Management) bill both before and after it was enacted and became an Act of parliament. I did not find any court judgements specifically dealing with HIV status disclosure. Judgments on the criminalisation of the deliberate transmission of HI/AIDS gave an insight into how women's rights to privacy, liberty, dignity and non-discrimination are violated in as far as HIV and AIDS is concerned.

3.5.5 Interview guides

I developed research interview guides for different participants. Most interview guides were in English and the two Chichewa versions were developed and used to interview Support Group members and community gatekeepers. Using the Chichewa interview guides allowed the respondents to express themselves in their own language. This approach contributed significantly to keeping discussions lively and more like conversations than interrogations.

Interview guides were developed to ensure the coverage of all areas of investigation and comparability of data across responses from different participants.⁵⁹ Being conversant with interview guides helped both me and my respondents to engage in lively conversations. This was a bit difficult during the first day of fieldwork because I had to frequently refer to my interview guide during the process. I noted that this made some of my respondents hold back

⁵⁹ Kumar (2012).

some information and others framed their responses to make them sound correct. This happened during discussions with Support Group members at Naisi health centre. Frequently referring to interview guides gives respondents the impression that there is an ideal way for them to respond to the questions and instead of narrating their actual experiences, they try to tailor their responses to suit the ideal they believe the researcher desires. This is avoided when using quantitative methods in which research questions are coded and respondents are more likely to provide ideal untainted responses.⁶⁰ Therefore, I explained to my respondents that they should recount their actual experiences and what they had observed in their community or at their local health facility. It was at this point that they relaxed and started recounting their actual experiences. This clearly shows that a researcher, especially in qualitative based research, needs to be conversant with interview guides to keep the discussions more like conversations to encourage respondents to express themselves freely and at the same time provide accurate data.

3.6 Data analysis

In qualitative based research, data analysis is an ongoing process throughout the research period until the final report has been written and approved. Basing on this, data analysis started on the very same day that I commenced my research. I constantly reviewed, compared, conceptualised and categorised emerging patterns from the data I collected whilst in the field.⁶¹ I found the constant comparative analysis technique useful since it helped me to review collected data and to categorise and verify the selected themes with my research supervisor. I used this technique whilst in the field by analysing each concluded interview. This allowed me to identify the next issues to follow up and to draw meaningful explanations from women's actual lived realities in relation to HIV status disclosure based on the collected data. Ultimately it also allowed me to point out possible problems in the implementation of Part V of the HIV and AIDS Act.

3.7 Ethical considerations

Researching on HIV and AIDS presents unique challenges considering issues of discrimination and stigmatisation which are often experienced by persons living with or those who are directly or indirectly affected by HIV and AIDS. Therefore ethical considerations when conducting research on HIV and AIDS is of paramount significance. According to the

⁶⁰ Kumar (2012).

⁶¹ Glaser (1967); Creswell (2014); Marshall & Rossman (1999).

Collins Dictionary, 'ethical' means 'in accordance with principles of conduct that are considered correct, especially those of a given profession or group.'⁶² Principles of respect, beneficence, non-malevolence, and justice are essential principles underlying the protection of human subjects in research.⁶³ I made sure that I adhered to the above-mentioned ethical principles throughout the research process to protect my participants at all levels. I also made sure that I strictly adhered to confidentiality which is a key component of SEARCWL research methodologies.

I also followed all the requirements set out by National Health Science Research Committee (NHSRC) in the Ministry of Health that gives clearance for all health research in the country. NHSRC approval processes take about three weeks. In this case, the approval letter came at a later stage. At district level, I also got an approval from the Zomba District Commissioner (DC) who is the overall in-charge of the district and the Zomba District Health Office (DHO) the overall in-charge of health services in the district. At community level, I made sure that I visited the health facility in-charge, showing them my research approval letters from the NHSRC and DHO. I also made sure that I obtained permission from the village chief before talking to members of Support Groups.

3.8 Significance of the research

To the best of my knowledge, no research from feminist perspective analysing the operationalisation of HIV status disclosure and its implication on women in Malawi has been conducted on the HIV and AIDS Act.

These research findings will provide a deeper insight into women's actual lived realities on HIV status disclosure, particularly disclosure by health service providers. The findings will be communicated to line ministries, e.g., the Ministry of Health and to the Malawi Law Commission to assist them in formulating and strengthening anti-discriminatory laws, reviewing and reforming, e.g., public health laws as most of such laws were enacted several decades ago under a Constitution that did not recognise human rights issues. Such laws do not adequately address the public health issues raised by HIV and AIDS.

⁶² Collins Dictionary (1979).

⁶³ Polit & Beck (2006); Thomas, (1992).

The findings will be useful in planning and implementing HIV and AIDS preventive and management programmes taking into consideration women's experiences, expectations, and dilemmas. The findings will also be useful to various stakeholders, e.g., Government sectors, national and international non-governmental organisations especially for developing HIV policies and programmes that will benefit both women and men. The findings will further be communicated to education and health institutions in the country, particularly to counsellors in HIV Voluntary Counselling and Testing Centres to assist them in formulating practical strategies, which will eventually help in promoting HIV status disclosure between women and men both in rural and urban settings whilst maintaining cordial relationships between health service providers and beneficiaries.

3.9 Assessment of methodology

The above discussed research methodologies were very effective especially during community and district level interviews. Most of my respondents at community level were calling each other by name showing that they knew each other. I was the only outsider in such gatherings with whom they were ready to engage in discussions concerning their personal experiences on HIV status disclosure or non-disclosure. During our discussions, some respondents expressed an interest in knowing whether I was there to train them since most of their members were new or practising based on their personal experiences or from responses obtained upon inquiring from their fellow members. Despite the above-mentioned challenge, the methodologies remained useful for data collection and triangulation. For example, I followed-up on the issue of capacity with policy implementers at health facility and district level and they confirmed that some Support Group members have not been trained due to a lack of funding.

3.10 Research limitations

Every piece of research has its own limitations. This study had its own set of limitations which were not fatal to the study.

Firstly, it was difficult to secure interviews especially with key informants at district and ministerial level. I overcame this challenge simply by involving sampled key informants in planning or scheduling interviews to eliminate refusals or delays. Despite this some key informants kept on rescheduling such pre-agreed meetings.

Secondly, I personally was at some point getting a bit uncomfortable listening to women and men narrate their experiences. Continually asking and listening to women and men as they narrate their actual painful lived experiences on HIV disclosure or non-disclosure was not an easy thing to bear. However, I managed to overcome this by showing empathy rather than being sympathetic to keep the conversation going on.

Thirdly, some sampled institutions especially non-governmental organisations proved difficult to interview. Most such sampled institutions instead of responding to the topic of research, they were spending substantial time talking about what they do as an organisation and trying to justify their project activities. At some point, they veered away from the topic of discussion. I tried to get them back on track by agreeing with what they were saying and then would go on to pose my questions again. This was not a big problem, but it still consumed time and less time was spent on discussing the research topic.

Fourthly, there was a concern as to how participants were sampled. I purposefully sampled active members in each Support Group to participate in the discussions. Although this was a preferred approach, it is likely that I left out some women whose personal experience explained more than the experiences of the active participants I sampled. For example, I only engaged one participant who is a discordant marriage.

Lastly, I commenced researching whilst the HIV and AIDS Act was still a bill ready to be tabled in parliament. The bill was passed with substantial changes and some clauses were completely removed. My first reaction after hearing about the changes was to drop the topic and come up with another one. I managed to discuss this with my supervisor, and cross-check the changes in the Hansard. I then found that the changes to the HIV disclosure clause were minor. This restored my confidence in continuing with the research topic despite the changes since the data was collected from HIV positive women and a few men who narrated their actual lived experiences.

CHAPTER FOUR

4.0 MAKING A CASE FOR PART V OF THE HIV AND AIDS (PREVENTION AND MANAGEMENT) ACT

4.1 Introduction

This chapter focuses on the experiences of health service providers in disclosing patients' HIV status to their sexual partner/s in rural and urban health facilities in Zomba district and the lessons learnt from their experiences.

4.2 Experiences

In this research, interviews were conducted with health service providers at facility, district, and ministerial level to understand and differentiate between what would be ideal and what is going on in practice in the task of HIV status disclosure. Health service providers shared their professional experiences and observations on HIV status disclosure. This painted a clear picture of the limitations of the laws regulating health service delivery as well as the interrelated economic and social-cultural factors which influence the highly sensitive process of HIV status disclosure.

4.2.1 *Experiences of health service providers*

Health service providers shared their professional experiences and personal points of view as far as disclosing a patient's health status is concerned. Issues that emerged during discussions centred on medical ethics, a patient's rights, disclosure and disclosure guidelines.

4.2.1.1 A patient's right to privacy and confidentiality

Promoting and protecting a patient's right to privacy and confidentiality was one of the issues that my research sought to establish. The national laws and guidelines, e.g., the Constitution,⁶⁴ the HIV and AIDS Act,⁶⁵ the Medical Council of Malawi Code of Ethics,⁶⁶ and the Charter on Patients' and Health Service Providers' Rights & Responsibilities⁶⁷ clearly provide for, protect and promote the right to privacy and confidentiality. During discussions, the majority of health service providers indicated that maintaining a patient's right to privacy

⁶⁴ Section 22 of the Constitution.

⁶⁵ Part V of the HIV and AIDS (Prevention and Management) Act, 2017.

⁶⁶ Section 1(1)(4) of the Medical Council of Malawi: Code of Ethics.

⁶⁷ Medical Council of Malawi: Charter on Patients' and Health Service Providers' Rights and Responsibilities.

is vital, and compromising this would result in jeopardising public health service delivery and the rights of patients. One health service provider said:

‘We strictly observe confidentiality in handling all medical information including that of persons living with HIV and we follow what is stipulated in our training manuals to protect the rights of our patients.’⁶⁸

‘Our code of ethics and patients’ charter permits us to disclose [a] patient’s status when there is consent, without which we do not disclose.’⁶⁹

The above-mentioned code of ethics indicates that consent should be obtained before performing any medical procedure or disclosing a patient’s health information. Emphasis is on obtaining written consent for major medical procedures. However, it is not clear as to what constitutes a major medical procedure. The Patients’ Charter, however, does not emphasise the obtaining of written consent. Section 10(1)(a) of the HIV and AIDS Act, on the other hand, does require a health service provider to obtain written consent to assist their disclosing a patient’s HIV status. Thus, health service providers will not be in a position to assist with disclosure especially for most illiterate women.

While some participants indicated that they would partially implement Part V of HIV, others indicated that they would implement all of it simply because the government has asked them to do so. They were, however, quick to express their concerns that it was very likely that disclosing a patient’s status would cause enmity between themselves and the communities in which they work. They even expressed the fear that they could be assaulted by angry patients or their sexual partners and that some people especially women would be discouraged from continuing to access public health services.⁷⁰

On confidentiality, the participants expressed their concern that confidentiality is sometimes compromised especially by those who are not specially trained in handling HIV and AIDS issues or in disclosing a patient’s status. One participant reported how a workmate ended up disclosing a patient’s status to a village chief which led to almost the entire community coming to know of their status:

⁶⁸ Section 9(2) of the HIV and AIDS (Prevention and Management) Act, 2017.

⁶⁹ Section 9(2) of the HIV and AIDS (Prevention and Management) Act, 2017.

⁷⁰ Interview with ART Counsellor/ART Clerk at Makwapala Health Centre on 14/12/2017.

‘It happened in October last year. We asked one of our Health Surveillance Assistant (HSA) to make a follow up on an HIV positive young woman who defaulted because she had travelled to Blantyre. We normally approach the village chief to confirm if the person we are following is indeed from that village but we do not disclose the person’s status. Unfortunately, our HSA failed to strictly adhere to our rule and regulations and he ended up disclosing [her HIV-positive status] to the village chief. On her return, she was very angry, [she] came here, and shouted at us [saying] that we are all stupid for disclosing her status “*Nonse kuno ndi dzitsilu.*” She demanded to know [the] whereabouts of the HAS who disclosed her status. After shouting, she promised never to come again for [a] drug refill because we disclose people’s confidential information.’⁷¹

The above scenario gives a clear indication on the part of health service providers that people do not want their health status disclosed not even by health service providers. Health service beneficiaries will complain even if health service providers follow stipulated procedures because people are accustomed to the fact that their health status is a private matter and that health service providers have a history of assuring them of this.⁷²

4.2.1.2 Are people disclosing? To whom and why?

Health service providers indicated that people disclose their HIV status especially those who are married and possibly planning to wed.⁷³ In most cases, it is women who disclose the most because of their physiology. Respondents indicated that health laws⁷⁴ and their professional code of ethics⁷⁵ allow them to disclose once they have followed the procedures laid in the laws and regulations. The challenge comes when one starts talking about rights and economic and social-cultural factors interconnected with issues surrounding HIV and AIDS. The focus of health service providers is on eliminating the further transmission of any disease including HIV and AIDS.⁷⁶ Within this context, the issue of status disclosure is a controversial and fluid issue because people disclose to different people for different reasons. There are some people who disclose because they enjoy social support or to gain acceptance from their sexual partners, family members or community.⁷⁷ It is therefore a challenge for service providers to step in and disclose a patient’s status because service providers are more interested in eliminating further transmission; therefore, they tend to pay little or no attention to other

⁷¹ Interview with a HSP at Naisi Health Centre on 14/12/2017.

⁷² Interview with Expert Clients at Lambulira Health Centre on 12/12/2017.

⁷³ Interview with Health Centre Staff at Makwapala Health Centre on 14/12/2017.

⁷⁴ Section 10 of the HIV and AIDS (Prevention and Management) Act, 2017.

⁷⁵ Section 1(1)(4) of the Medical Council of Malawi: Code of Ethics.

⁷⁶ Interview with an Officer from the Ministry of Health on 2/2/2018.

⁷⁷ Interview with Health Centre Staff at Makwapala Health Centre on 14/12/2017.

social factors, and some of them are ignorant of the sensitive situations connected with economic and social-cultural factors in which the HIV positive persons and their sexual partners find themselves.⁷⁸

4.2.1.3 Health service provider initiated status disclosure

The issue of health service provider initiated status disclosure was investigated in this research. National health policies oblige health service providers to promote and encourage couple counselling and partner disclosure of HIV test results as a step towards reducing and eventually eliminating the HIV pandemic.⁷⁹ This approach is also reiterated in sections 9 and 10 of the HIV and AIDS Act placing such obligations on both the HIV positive person and their health service provider; it goes on also to allow the health service provider to exercise their discretion and to disclose a patient's HIV status.⁸⁰ I investigated this issue by interviewing actors responsible for formulating health-related laws and policies as well as those responsible for implementing them. The findings revealed that health service providers have the duty to provide HIV testing services as prescribed by the Act. They also encourage couples to go for couple counselling. This is common when a woman is pregnant. The current practice is that as health service providers, they only encourage people to be tested and to share the test result with their sexual partner. They also assist in disclosing especially when asked to do so by an HIV positive person. In most cases, such assisted disclosure is done at the health facility and not following or locating sexual partners to inform them about their sexual partner's status.

4.2.1.4 The duty to disclose a patient's health status

Generally, HIV and AIDS raise many human rights issues. Protecting and prompting disclosure is crucial for preventing the further transmission of HIV and reducing the impact of AIDS on the lives of people.⁸¹ Most available legislation on health broadly provides for the right to and protection of health, for example, the Gender Equality Act,⁸² and the Disability Act⁸³ as discussed in chapter two of this paper. However, the HIV and AIDS Act specifically aims at balancing the rights of citizens and the obligations of the state: the rights of healthy

⁷⁸ Interview with an Officer from the Ministry of Health on 2/2/2018.

⁷⁹ The National HIV/AIDS Policy (2003).

⁸⁰ Section 10(2) of the HIV and AIDS (Prevention and Management) Act, 2017.

⁸¹ UN. Fact Sheet No. 31 on The Right to Health.

⁸² Sections 19 & 20 of the Gender Equality Act, No. 49 of 2012.

⁸³ Sections 6 & 7 of the Disability Act, 2012.

citizens and the state's obligation to protect them from the continuing spread of HIV and the rights of those already affected and infected with HIV and AIDS.⁸⁴ A patient's right to privacy and confidentiality and a health service provider's duty to protect a patient's health information was investigated in this research and it was found that most health service providers strictly observe patient confidentiality whereas a few of them do not.

During discussions, most health service providers, particularly those implementing HIV and AIDS services, agreed that it is the absolute responsibility of an HIV positive person to disclose her/his HIV status to sexual partner(s).⁸⁵ It is not the responsibility of the health service providers as, in their words:

‘... we only encourage those who tested HIV positive to disclose to their sexual partners or a guardian whom we can contact in case the HIV positive people default for any other reasons.’⁸⁶

According to health service providers, they simply assist by using the ‘empty chair technique’ as a way of helping an HIV-positive person gather the courage necessary to disclose their status to their spouse.⁸⁷

Health service providers strongly emphasised that an HIV positive person is in a far better position (than themselves) to disclose their status to their sexual partner/s and if possible to their relatives or friends. Health professionals spend most of their time treating patients and are simply not familiar with the cultural diversities of those living in the health centre's catchment area. In addition, they have only a limited knowledge about how the HIV positive person relates with their sexual partner/s. Taken together, all these issues make it very difficult for health service providers to disclose a patient's status to their sexual partner/s.⁸⁸ The respondents all agreed that it is impractical, against medical ethics, and it infringes a patient's right to privacy and confidentiality for them to exercise discretion over a patient's status. They therefore explained that it would be a severe challenge for them to implement section 10(2) of the HIV and AIDS Act since it allows them to exercise their discretion to inform the sexual partner/s of an HIV positive person that they are at risk of contracting HIV.

⁸⁴ HIV and AIDS (Prevention and Management) Act, 2017.

⁸⁵ Interview with Coalition of Women Living with HIV and AIDS on 8/1/2018.

⁸⁶ Interview with PMTCT/ART Coordinator on 27/12/2017.

⁸⁷ Interview with HSP at Makwapala Health Centre on 15/12/2017.

⁸⁸ Interview with HTC Counsellor at Matawale Health Centre on 15/12/2017.

Some respondents indicated that they would not implement section 10(2)(a)(i) and (c) of the HIV and AIDS Act which allows a health service provider to inform a sexual partner. One respondent organisation explained:

‘This is in conflict with medical ethics and it infringes patient’s right to privacy.’⁸⁹

The Medical Council of Malawi’s Code of Ethics requires a health service provider to respect their patient’s confidentiality and to disclose their confidential information if it is directly relevant to court proceedings.⁹⁰ Implementing this section of the HIV and AIDS Act would sow enmity between health service providers and beneficiaries, especially women. This could initially undermine their confidence in health delivery services which could in turn eventually damage the provision of public health services. One respondent observed that one of their work colleagues had been beaten up by an HIV positive patient whom they had followed-up on after that patient had defaulted, leading the respondent to remark:

‘So what more if we start following sexual partners to notify them? Many of us will be beaten once we start notifying sexual partners of an HIV positive person.’⁹¹

The issue of capacity is also a challenge that exposed itself barely one day into the field research journey. Discussions with key informants revealed that most public health facilities are understaffed,⁹² a situation that would make it impractical if not well nigh impossible for a health service provider to leave their post and start seeking out and informing sexual partners of an index person. Eventually, this will result in poor service delivery especially for women who in most cases are the ones who access health services more often than men.⁹³

Contrary to the experiences expressed by health service providers at district level, health law and policy makers all share the understanding and agree that there is nothing special about HIV and AIDS and that it should not be treated as a special case and differently from any other disease, such as malaria or cholera. It does not matter who is HIV positive, when and to whom their status is disclosed; what matters most is containing their status. HIV status

⁸⁹ Interview with Coalition of Women Living with HIV and AIDS on 8/1/2018.

⁹⁰ Medical Council of Malawi. <http://www.medicalcouncilmw.org/mcm/ethics.php>.

⁹¹ Interview with an EC at Lambulira Health Centre on 12/12/2017.

⁹² Interview with Coalition of Women Living with HIV and AIDS on 8/1/2018.

⁹³ Interview with health staff at Naisi Health Centre on 14/12/2017.

disclosure by a health service provider is no different from disclosing to a person that they are suffering from malaria. One of the senior managers in the Ministry of Health added:

‘As a health professional, I do not care about the social-cultural issues because HIV is just like any other disease; it is just the same as cholera or malaria.’⁹⁴

This shows that there is knowledge gap between senior health officials especially at ministerial level and those implementing at the grass roots level health laws and policies formulated by senior officials.

4.2.1.5 Disclosure guidelines

The issue of disclosure guidelines was also investigated in this research. As discussed in chapter one, the HIV and AIDS Act provides guidelines under which a health service provider can disclose or exercise their discretion by informing the sexual partner/s of an HIV positive person that they are at risk of contracting HIV from their sexual partner who has tested HIV positive. According to section 10(1)(a) of the HIV and AIDS Act, this can be done upon obtaining the written consent of the first person, his guardian, partner or parents, as the case may be.

The findings from the discussions based on the actual experiences of health service providers revealed that patients are assured that their HIV status information will remain a confidential issue; it is the patient’s duty to disclose their status to their sexual partner/s. The other aspect is that currently health service providers only assist patients in disclosing where there is verbal consent. Participants indicated that it would be difficult to assist the majority of illiterate women who cannot write as is required by section 10(1)(a) of the HIV and AIDS Act which allows the health service provider to disclose a patient’s health information upon obtaining written consent. This raises the argument as to whether an illiterate woman can consent to a medical procedure by thumbprint. There are doubts about this:

‘Ssali *et al.* found that obtaining participant’s signature or thumbprint as consent does not necessarily mean that the participant is fully informed about the information relevant to their participating. Participants require sufficient time to understand the implications for participating.’⁹⁵ In addition, Cooper *et al.* found livestock-keepers preferred consenting verbally because they could

⁹⁴ Interview with an Officer from the Ministry of Health and Population on 2/2/2018.

⁹⁵ Ssali *et al.* (2016).

fully appreciate their involvement and implications as compared to consenting by signature or thumbprint.⁹⁶

In view of the above, the strict implementation of section 10(1)(a) of the HIV and AIDS Act which requires written consent will contribute to many women not knowing the status of their sexual partner just because the Act does not permit the health service provider to disclose based on verbal consent.⁹⁷

4.2.2 Lessons learnt from provider's experiences and the laws

The following lessons can be drawn from the research findings:

During discussions with key informants, it clearly emerged that a patient's right to privacy and confidentiality comes first. Respecting a patient's rights goes hand-in-hand with upholding professional ethics. According to the respondents, a patient's right to privacy involves allowing the patient to decide to whom and when they would want to disclose their health status. In as much as the Act provides and respects a patient's right to privacy,⁹⁸ it also permits a health service provider to infringe a patient's Constitutionally granted and protected rights⁹⁹ by acting in accordance with the Act's stipulated guidelines and the provider's opinion.

Issues that arise from HIV and AIDS cannot be completely separated from economic and social-cultural issues which are present and substantially influence an HIV positive person's decision to disclose her/his HIV status. This emerged during discussions with Support Group members and some key informants who agreed that these contextual factors are interwoven and cannot be possibly ignored in the consideration of any decision to disclose a patient's status. Recognition of this understanding and its application is completely missing from the Act, which in its current form, is focused solely on health professional's ambition of eliminating the further transmission of HIV.¹⁰⁰ The Act's stipulated guidelines do not take into consideration the important abovementioned factors that influence the lives of patients and those affected by them, in particular, the lives of their sexual partner/s who are left exposed to the likely negative outcomes unleashed by incautious disclosure. In addition, the

⁹⁶ Cooper et al. (2016).

⁹⁷ Interview with Expert Client Coordinator at Zomba City Clinic on 23/10/2018.

⁹⁸ Section 9 of the HIV and AIDS (Prevention and Management) Act, 2017.

⁹⁹ Section 24 of the Constitution of the Republic of Malawi.

¹⁰⁰ Sections 9(2) & 10(1)(2) of the HIV and AIDS (Prevention and Management) Act, 2017.

Act's approach to eliminating HIV, as stipulated in section 12(2), lacks evidential justification based on the voices and lived realities of health beneficiaries; it is more of a top-down solution to a problem that has been arrived at as the result of logical but untested scientific thinking.

HIV status disclosure is a less complicated process and produces positive outcomes to both the HIV positive person and the public health service when disclosure is made by the infected person to her/his sexual partner(s). Disclosure by a third party, e.g., a health service provider, is likely to bring about unfavourable outcomes. The decision to disclose one's status is a soul-searching matter which takes time and is a very subjective process. This issue will arise during the implementation of section 10(2)(a)(iv) of the HIV and AIDS Act, which requires the health service provider to give the person living with HIV a reasonable time to disclose to her/his sexual partner/s. Yet the Act has not defined what constitutes 'a reasonable period'.¹⁰¹ A reasonable period is subjective and differs in every case.

Health service providers are accustomed to following their professional ethics; it is difficult for them to change and implement procedures that contradict what is stipulated in their training manuals. During discussions, some health service providers openly indicated that they will not implement some sections of Part V of the Act because it forces them to invade a patient's private space in order to reduce and eventually eliminate HIV and AIDS.

Capacity was mentioned as one of the pressing issues in sampled health facilities. At the moment under qualified personnel are working in positions such as HIV Testing and Counselling which require well-qualified personnel. During discussions, some Support Group members indicated that it would be better for them to be treated by well-qualified personnel or by a person who is also infected because they would be far more understanding of their situation.

There are contradictions between health professionals especially about how they view HIV and AIDS. During discussions, some health law and policy makers showed little to no concern about the economic and social-cultural issues which are inextricably tied up with HIV and AIDS issues. Some health professionals at the Ministry of Health and some top

¹⁰¹ Section 10(2)(a)(iv) of the HIV and AIDS (Prevention and Management) Act, 2017.

officials at district level consider these issues immaterial to efforts to reduce or eliminate HIV and AIDS through status disclosure. This intention is reflected through the wording of the Act and contradicts the sentiments of other health service providers at health facility level and HIV positive persons, particularly members of Support Groups.

4.3 Conclusion

This chapter has dealt with health service providers' experiences, the law, and the implications arising from the implementation of HIV and AIDS Act. The next chapter discusses experiences and lessons learnt from women in relation to status disclosure or non-disclosure.

CHAPTER FIVE

5.0 EXPERIENCES AND LESSONS LEARNT ABOUT HIV STATUS DISCLOSURE OR NON-DISCLOSURE

5.1 Introduction

This chapter focuses on the experiences of women in the rural and urban settings in Zomba district on HIV status disclosure and the lessons learnt from their experiences.

5.2 Experiences

During discussions, women narrated their experiences of what they went through after disclosing their HIV status to their spouses, family members, and friends. Women also discussed what is happening in their respective communities and local health facilities as regards HIV status disclosure. I captured men's voices during the discussions as well. Including men in the discussions proved to be the right decision for the research because they debated with women and at times confirmed their concerns, acknowledged their own treatment of women and shared their personal experiences about HIV status disclosure.

Listening to the women and the few men relate their personal experiences was no easy task, nevertheless, I tried to show them as much empathy as possible so that we could continue our discussions. I realised that capturing actual experiences was the ideal approach to understanding what was happening in the research study location, involving an examination of what is the ideal and actual approach to HIV status disclosure. Capturing experiences from those who are directly affected by the process added immeasurable value to the research because narrated experiences are facts and not speculation.

5.2.1 Women's experiences

Discussions with women in Support Groups started by finding out if they have ever disclosed their status, to whom did they disclose it and their reasons for doing so; whether other people in their respective communities are disclosing, whether men are disclosing, and whether the health service providers at their local health facility are disclosing the health status of their patients? Since the majority of my female respondents were aged between 20 and 65 years old this gave a good representation of other women in their communities.

5.2.1.1 Are people disclosing and to whom?

Of the twenty-two Support Group members I interviewed in sampled health centres, the majority of them indicated that they knew a number of people who had disclosed their HIV status. During discussions, participants generally agreed that both women and men are disclosing their HIV status. The issues that emerged during discussions were that HIV status disclosure is more common among married couples than among those planning to get married, and occurs far less among those in casual relationships. Women disclose their status more than men. Not all women and men disclose their HIV status to their sexual partner(s), and that people, in both rural and urban settings, disclose in order to obtain social support.

Husbands disclose to their wives because they know that they will need support especially when they fall sick and wives disclose to protect their husbands and, if pregnant, they also disclose to protect their unborn child.¹⁰² The reactions to disclosure are different for women and men. Participants gave many examples of HIV positive women being abandoned whilst pregnant or after delivering. A 45-year-old female participant narrated her experience:

‘I was pregnant when I tested HIV positive, I told my husband about my status. I expected him to understand my situation because I do not sleep with other men. Instead, he made it clear that he would wait until I deliver, then he will abandon me. He left the same day I delivered, and never come back. People laughed at me for being unmarried again. It was a painful experience.’¹⁰³

The current practice in HIV prevention and management is that once a person tests HIV positive, she/he is immediately counselled, is put on treatment, and asked to identify a guardian to disclose their status.¹⁰⁴ A guardian can be a relation, a friend, or a health service provider. In most cases, an HIV positive person discloses to a friend rather than a relation just because she/she is not on good terms with her spouse. All my sampled rural settings are predominately matrilineal in culture, and the findings indicated that before disclosing to their spouses, most women tend to disclose to their close relatives, especially their mothers.¹⁰⁵ This happens because men have the tendency to abandon their wives once they test HIV positive.

¹⁰² Interview with Support Group at Matawale Health Centre on 27/12/2017.

¹⁰³ Interview with Support Group at Makwapala Health Centre on 27/12/2017.

¹⁰⁴ Malawi HIV Testing Guidelines, 2016.

¹⁰⁵ Interview with Support Group at Lambulira Health Centre on 15/12/2017.

Contrary to experiences in rural settings, women in urban settings tend to disclose to a friend or neighbour since most of them are physically far removed from their immediate family relations. This is also common among widows in urban settings in that they usually disclose to a trusted friend. During discussions, it emerged that people do not only disclose their status to someone they trust. What matters the most is that an HIV positive person should identify a person with whom she/he feels comfortable to disclose to and the identified person should be willing to take up the responsibility that might arise concerning the HIV positive person.

Women were quick to point out that some married people especially men and a few women hide their status. In most cases, married couples especially women get to know their HIV status when they fall pregnant because that is when most of them get tested under the Prevention from Mother-to-Child Transmission of HIV program.¹⁰⁶ Most men do not want to be tested; some of them even refuse to accompany their wives to the antenatal clinic for fear of being tested. This is more common in urban than in rural settings, as most men are busy with office work or their businesses.¹⁰⁷ Respondents added that women are different and that in some cases even pregnant women do not disclose their status for fear that their husbands will beat or abandon them. Some though not many have the courage to disclose their status to their husbands or to persuade their husbands to get tested and go to collect their test results together.¹⁰⁸

The findings also revealed that people in both urban and rural settings disclose their HIV status in order to obtain social support. This emerged during discussions with community gatekeepers in all four sampled research areas. In rural settings, some women disclosed to their village chief besides disclosing to their sexual partner. Interviews with community gatekeepers in rural areas revealed that Village Chiefs have a register of HIV positive persons in their villages.¹⁰⁹ However, Chiefs quickly pointed out that they do not force people to disclose their status but this kind of disclosure is motivated by their need. People disclose so that they can benefit from handouts in the form of money or food supplements. This is somewhat similar to what is happening in urban settings. Most people in urban settings

¹⁰⁶ Malawi Guidelines for Clinical Management of HIV, 2016.

¹⁰⁷ Interview with PMTCT/ART Coordinator at Matawale Health Centre on 27/12/2017.

¹⁰⁸ Interview with Support Group at Naisi Health Centre on 14/12/2017.

¹⁰⁹ Interview at Makwapala Health Centre on 12/12/2017.

disclose at their workplace for support whereas those who are unemployed or run their own businesses are left without assistance.¹¹⁰

5.2.1.2 Whose duty is it to disclose a patient's health status and why?

The duty to disclose was one of the issues that was investigated. Participants indicated that it is an absolute duty of an HIV positive person to disclose to her/his sexual partners and if possible to family members and the community as well. The following issues emerged during discussions. The first is that the participants shared a common understanding that health service providers are not allowed by law to disclose the health status of their patients based on the exercise of their own discretion but only when asked to assist. Participants were unable to quote the exact law on which they relied for this understanding; all they could say was that it was the law. The second issue was that HIV and AIDS is closely bound up with the economic and social-cultural dynamics of the relationship between the HIV positive person and their sexual partner/s. The final issue was that status disclosure by and at the discretion of a health service provider will assist in reducing the risk of HIV transmission especially for some women. Part V of the HIV and AIDS Act fails to recognise the interplay between the economic, social-cultural, and health professional dynamics involved in the process of disclosure by a third party and this will create a problem in its implementation.

The findings revealed that participants strongly emphasised that it is the sole duty of an HIV positive person to disclose to his/her sexual partner/s and not their health service providers. Participants expressed their concerns over the fact that health service providers are not familiar with the nature of the relationship between an HIV positive person and their sexual partner/s, family members or their community.¹¹¹ It is easier when for disclosure to be done by an HIV positive person to his her/his sexual partners rather than by a health service provider or any other third party. At this point, a 53-year-old male participant narrated his experience in support of the above position:

‘I am a builder by profession, and it happened that in 2001 I travelled to Blantyre to construct a house there. I had sexual intercourse with another woman whom I just met. Time passed and I started noticing that my healthy started deteriorating. I decided to be tested and I tested HIV positive. On my way home, I made a decision not to have sex with my wife until she too gets

¹¹⁰ Interview with former District Aids Coordinator on 4/1/2018.

¹¹¹ Interview with Support Group at Lambulira Health Centre on 12/12/2017.

tested. My wife was furious with me considering that I was away for many months and she wanted us to have sex. I explained to her about my health status, she insisted but I refused considering that, I did not want to transmit to her. The following day we went to the hospital and she tested negative. We discussed the way forward and she told me that she would stay with me. My wife is still negative and we are living happily ever since.’¹¹²

In another interview, a 38-years-old female participant revealed how her friend was infected because a prospective husband failed to take up his responsibility to disclose.

‘We have a builder, the one standing over there...[at this point, I recognised the one being referred to as the builder. He was the person whom I sat next to whilst waiting for Support Group members to arrive. He explained to me that he and his wife had come for their monthly drug (ARVs) refill] ... he had unprotected sexual intercourse with his wife who was at that time a girlfriend. He did not disclose to her that he is HIV positive and on treatment. After they had finished having sex, the man took his ARV bottle and placed it on the table and said to her, “I am on ARV treatment so you too have to get tested.” The woman was angry and frustrated but eventually she just accepted it. The woman really loves the man but the man did not show love in the first place.’¹¹³

The people above emphasised that their marriages could have ended, and that there was a strong likelihood that the wives could have left their husbands. The bottom line is that an index person knows how best to approach her/his sexual partner(s) and are therefore the most ideal person to take sole responsibility for the duty to disclose their status to their sexual partner/s. A 49-year-old woman narrated her personal experience on how she managed to calm down her boyfriend after he discovered that she was on ARV treatment:

‘Some three years ago I happen to have a boyfriend to whom I did not disclose my status. I was HIV positive and on treatment when I was got into a sexual relationship. As a patient, I used to take drugs in the morning and in the evening. Unfortunately, some people informed my boyfriend that I was on ARV. I have no idea how those knew my status and that I often put my dosage in my boxer-short’s side pockets. It then happened that I was at my boyfriend’s house busy cooking, he quickly got hold of my boxer-short side pockets, and with anger, he asked me, what are these? I tried to cool him down and told him to hold his temper, so that I finish prepare food, eat and then will explain to him. I did that and he understood why I did not disclose in the first place.’¹¹⁴

¹¹² Interview with Support Group at Matawale Health Centre on 27/12/2017.

¹¹³ Interview with Support Group at Lambulira Health Centre on 15/12/2017.

¹¹⁴ Interview with Support Group at Matawale Health Centre on 27/12/2017.

According to the participants, most people will stop accessing health services especially reproductive health services in public health facilities if they know that their status is no longer a confidential issue since the health service providers will eventually disclose their status to their sexual partners. Participants emphasised that it is not proper for health service providers to have a discretion to disclose a person's health status; instead the disclosing of a person's health status should remain the duty of the HIV positive person themselves. The government should put more resources into already existing strategies for the continued sensitisation of people about the sensitive process of disclosure; but actual disclosure must ultimately remain the sole responsibility of an HIV positive person.¹¹⁵

5.2.1.3 Men and HIV status disclosure

During discussions, women and men engaged in debate on the subject of the research. One respondent narrated how a fellow woman discovered that her husband was HIV positive and on treatment:

‘It happened in our community; a man knew that he was HIV positive but did not disclose to his pregnant wife. The woman noted that she was often getting sick; she told her husband that she would go for screening on that day in the afternoon. Her husband quickly rushed to the hospital to ask the HTC counsellors to test him and his wife as if he had never been tested before. The man returned home to pick up his wife. Unfortunately, whilst in the HTC room, the man reminded the doctor that he should not open another file since he already has one there. At that very moment the woman started beating her husband.’¹¹⁶

During the discussions, the male respondents agreed that status disclosure definitely affects women more than men and that men are less likely to disclose than women in both rural and urban settings. The issues that emerged were that since men are culturally the heads of their households, they tend to control the rest of their family members; and that some husbands choose to abandon their wives and children if their wives test HIV positive.

The research findings further revealed that most men's motive for disclosing focuses on securing the support of their wives, especially when they fall sick, but they often do not bother disclosing when they still appear healthy.¹¹⁷ However, if their wives test positive, most

¹¹⁵ Interview with (male) Chief at Matawale Health Centre on 15/12/2017.

¹¹⁶ Interview with Support Group at Naisi Health Centre on 14/12/2017.

¹¹⁷ Interview with Health Service Providers at Naisi Health Centre on 14/12/2017.

men choose to abandon them and their children; but women on the other hand do not make such decisions.¹¹⁸ The above finding cannot be generalised because the research sample is small.

5.2.1.4 Negative outcomes of HIV status disclosure

During the discussions, the respondents agreed that HIV status disclosure gives rise to more difficult outcomes for women than it does for men. Women are often abandoned once they test HIV positive and it becomes worse for a woman with many children as she continues to bear the responsibility of taking care of them. The tendency of men to abandon women is more common in rural than it is in urban settings where married couple migrate because of jobs or business opportunities.¹¹⁹ The respondents raised concerns that some husbands abandon their sexual partners once they have tested HIV positive. In most cases, wives and children are the victims. Also such men do not keep the HIV status of the woman they have abandoned confidential; but they rather use it to justify their own position when proposing a new marriage.¹²⁰ It was agreed among male respondents that disclosing a woman's status decreases her chances of remarrying. It sometimes takes many more years for a woman than a man in the same situation to remarry. Besides being abandoned, some women are physically beaten up by their sexual partners especially their husbands who often claim that it is their wives who have infected them. In most cases, such men refuse to admit even if they know that it is they who infected their wives.¹²¹

5.2.1.5 Are health service providers disclosing their patients' health status?

The HIV and AIDS Act contains stipulated procedures a health service provider can follow in order to disclose the status of an HIV positive person to her/his sexual partner(s). This issue was investigated to establish whether health service providers disclose the HIV status of their patients; whether there are procedures for disclosing, and whether health laws and policy makers and implementers share a common position regarding disclosing the status of an HIV positive person.

The majority of my respondents agreed that health service providers disclose the status of an HIV positive person to her/his sexual partners when asked to do so by an HIV positive

¹¹⁸ Interview with Support Group at Naisi Health Centre on 14/12/2017.

¹¹⁹ Interview with Support Group at Makwapala Health Centre on 12/12/2017.

¹²⁰ Interview with Support Group at Naisi Health Centre on 14/12/2017.

¹²¹ Interview with HTC Counsellor and Matawale Health Centre on 16/12/2017.

person. Such disclosure is done at the health facility. Issues that emerged during the discussions were that health service providers conduct HIV tests twice on a person upon request; that provider initiated status disclosure will do little and come too late to assist women especially those who happen to test positive when pregnant; and that health service provider initiated disclosure is practical on less influential persons in the community.

During the discussions, the respondents agreed that in an ideal situation, health service providers do not disclose a patient's health information at their own discretion. Nevertheless, in practice, some health service providers do not strictly adhere to their professional ethics and eventually they do disclose. One of the respondents narrated how his fellow health service provider failed to strictly adhere to the ethical standards and ended up disclosing the status of an HIV positive woman who was on treatment and how it personally affected her and the relationship between the patient and health service provider.¹²²

It was also revealed that in some circumstances, health service providers disclose the status of an HIV positive person. Such disclosure is done when there is consent; when a patient is chronically ill and unable to consent; when status information is required in the proceedings before a court; and to a fellow health service provider directly involved in providing health care services to the HIV positive person. Although this is now the law, the respondents emphasised that health service providers do not readily disclose without consent which is required by the Malawi Medical Counsel's Code of Ethics and is also the accepted and common understanding shared by the community.

The findings further revealed that the participants shared concerns that the Act will effectively be implemented on less influential persons in the community especially women who in most cases are already in a disadvantageous position because of their physiology, economic and social-cultural factors. This emerged clearly during discussions with an official from the Ministry of Health and a village chief, that it would be a challenging undertaking for health service providers to approach and inform influential person or her/his sexual partner/s that she/he is at risk of getting infected with HIV.¹²³ Eventually, this will result in the partial application of the law and defeat its very purpose in as far as disclosure is concerned.

¹²² Interview with health staff at Naisi Health Centre on 14/12/2017.

¹²³ Interview with an Officer from the Ministry of Health and Population on 2/2/2018.

5.2.2 *The reasons why women fail to disclose their HIV status*

One of the issues that clearly emerged during the discussions with Support Group members is that women are not a homogeneous group. Every woman's experience after the disclosure of their HIV status is different even if they look similar. Poverty is one of their main problems. They have to learn to cope on their own since society denies them the opportunity to initiate a sexual relationship. It is difficult for an HIV positive woman to remarry once abandoned and her status is publicly known. Once abandoned, some women also fear being scorned especially by fellow women. Women value and put first the lives and welfare of their immediate family members than their own health and development. These sentiments were shared by some key informants as the core problems women face upon the disclosure of their status.¹²⁴

Respondents expressed concerns that it is difficult for an HIV positive woman whose status is publicly known to remarry. A 54-years-old man narrated how his friend turned down a proposal after being told that his prospective wife was HIV positive:

‘I had friend who asked me to find a wife for him, it was after his wife had passed away after long illness. I managed to get a wife whom I did not know that she was HIV positive. The woman on several occasions disclosed her status to my friend that she is HIV positive and on treatment. My friend then left the woman and he complained to me that I found a snake for him.’¹²⁵

It is because of such comments, thinking, and behaviour that force some women and even men not to disclose their status. In other separate discussions, a respondent added that being divorced brings shame on women more so than men. In most cases, women are the first to scorn a fellow woman who has been divorced because they start suspecting that she could be sleeping with their own husbands. It is out of fear of having to face such abuse that some women endure and continue living with unfaithful husbands who may have possibly infected them with HIV.¹²⁶

5.2.3 *Lessons learnt and problems in the implementation of the Act*

The following lessons are drawn from the research findings:

¹²⁴ Interview with Nutrition, HIV/AIDS Officer at the Ministry of Gender on 8/1/2018.

¹²⁵ Interview with Support Group at Naisi Health Centre on 14/12/2017.

¹²⁶ Interview with Support Group at Makwapala Health Centre on 15/12/2017.

I started my research with a limited knowledge of the actors involved especially those implementing health laws and policies on the ground. The picture that I had was that all health service providers in public health facilities are government employees. However, during the field research, I interviewed Expert Clients employed by a non-governmental organisation¹²⁷ who are playing a crucial role in counselling and encouraging HIV status disclosure among sexual partners and the following of antiretroviral therapy (ART). Some such service providers have not been properly trained and are relying for their knowledge on their personal experiences. It is highly problematic to give unqualified personnel the authority to implement Part V of the HIV and AIDS Act,¹²⁸ i.e., the power to exercise their discretion and disclose the HIV positive status of a patient to their sexual partner/s.

HIV status disclosure by an HIV positive person to her/his sexual partner(s) facilitates a more positive outcome than disclosure by a third party; and failure to disclose a patient's status produces outcomes that are just as negative as those caused by disclosure by a health service provider. While the Act intends to provide for disclosure that aims at protecting the infected or affected persons, it is likely to achieve the opposite effect in its present form as its drafters have failed to base its construction on evidence based research as this study shows.¹²⁹ The research findings revealed that HIV positive persons and some health service providers strongly believe that status disclosure is the sole duty of an infected person and it is ultimately the most effective way of reducing and eventually eliminating HIV and AIDS. Infected respondents interviewed in this study did not see disclosure of their status by health service providers as a means of protecting them or others affected by their status and this poses problems for the implementation of the Act.

The knowledge of an HIV positive person's culture, the nature of their relationship with her/his sexual partner/s, family members, and the community at large is crucial for effective disclosure by a third party. Since some health service providers lack such knowledge and skills at handling this process they cannot be reasonably expected to exercise their discretion in a responsible, lawful manner in terms of the Act.¹³⁰ Their opinions might be entirely different from those which motivate an HIV positive person to decide whether or not to disclose their status to their sexual partner(s). The other challenge is that opinions are subject

¹²⁷ Interview with Expert Client Coordinator on 23/1/2018.

¹²⁸ Section 10(2)(a)-(c) of the HIV and AIDS (Prevention and Management) Act, 2017.

¹²⁹ Sections 9(2) & 10(2)(a)-(c) of the HIV and AIDS (Prevention and Management) Act, 2017.

¹³⁰ Section 10(2)(a)(i), (ii), (iii), (v) of the HIV and AIDS (Prevention and Management), 2017.

to interpretation by the service provider, infected and affected person as granted in the Constitution.¹³¹

Disclosing a woman's status that results in her status becoming publicly known decreases her chances of remarrying. The current HIV and AIDS Act¹³² aims at reducing HIV by giving health service providers the discretion to inform the sexual partner/s of an HIV positive person of their being at risk of becoming infected with HIV. The Act does not provide any clear procedures to be followed in this process. The lack of such procedures poses problems in the implementation of the Act and this is a challenge and will result in a person's health status becoming publicly known, and this is detrimental especially for women.

Health service providers in health facilities assist with disclosure once verbal consent has been given and this process is preferred by HIV positive persons especially women who fear negative feedback from their sexual partners. This practice is effective considering that almost half of Zomba's women population is illiterate.¹³³ Under the HIV and AIDS Act,¹³⁴ a health service provider is allowed to assist the disclosure process upon obtaining written consent.¹³⁵ This poses a challenge to the majority of illiterate women in the district and it will result in many women failing to know their partner's HIV status simply because they are illiterate, thereby exposing them to greater risks that could have been reduced.

The implementation of the HIV and AIDS Act¹³⁶ poses problems for health service providers who exercise their discretion informing the partner/s of the HIV positive status of their sexual partner. During discussions, officials from the Ministry of Health and Population revealed that health service providers are more likely to implement some sections of the Act in a biased manner especially if disclosure involves an influential person in the community. In addition, the issue of a reasonable period is subjective and open to interpretation on the part of a health service provider, infected and affected persons.¹³⁷ It will be a challenge for health service providers to detect and monitor behavioural change of the infected persons as

¹³¹ Section 34 of the Constitution.

¹³² Section 10(2) of the HIV and AIDS (Prevention and Management) Act, 2017.

¹³³ Malawi MDG Endline Survey, 2014.

¹³⁴ Section 10(1)(a) of the HIV and AIDS (Prevention and Management) Act, 2017.

¹³⁵ Section 10(1)(a) of the HIV and AIDS (Prevention and Management) Act, 2017.

¹³⁶ Section 10(2)(a)-(c) of the HIV and AIDS (Prevention and Management) Act, 2017.

¹³⁷ Section 10(2)(a)(ii), (iii), (iv) and (v) of the HIV and AIDS (Prevention and Management) Act, 2017.

stipulated in the Act.¹³⁸ Mostly marginalised individuals or groups especially women will fall victim to this Act.

5.3 Conclusion

This chapter points out potential difficulties in the implementation of the HIV and AIDS (Prevention and Management) Act by discussing women's actual experiences, expectations, and dilemmas in relation to HIV status disclosure by health service providers. The next chapter deals with recommendations that are made in view of the above chapters.

¹³⁸ Section 10(2)(a)(ii), (iii) and (v) of the HIV and AIDS (Prevention and Management) Act, 2017.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This research sought to analyse the operationalisation of HIV status disclosure as provided for under Part V of the HIV and AIDS (Prevention and Management) Act, 2017 and how it will affect women's right to health and privacy during its implementation. Field research was conducted in rural and urban settings in Zomba district. The lessons learnt during discussions reveal that HIV and AIDS Act is a stepping stone towards reducing and eventually eliminating HIV and AIDS in the country through HIV status disclosure. However, the Act's failure to recognise the interplay between rights, social-culture, and health professional dynamics in its content and implementation will eventually result in its failure to achieve its intended objectives thereby worsening public health service delivery, especially for women.

6.2 Recommendations

- The government should conduct thorough refresher courses, in-service training or employ sufficient, well-qualified health personnel to fill key positions in HIV and AIDS service delivery, e.g., in HIV Testing Counsellors rather than using support staff who often do not undergo thorough training in medical ethics and patient confidentiality.
- The government should conduct thorough community sensitisation programmes on mind-set change aiming at eliminating gender stereotyping caused by deeply engrained norms, attitudes, values, and prejudices that heighten women's vulnerability upon HIV status disclosure.
- Government should promote and encourage already existing HIV and AIDS prevention and management strategies. However, emphasis should be placed on involving men both during the pregnancy of their partners and after they have given birth. Currently, men are focused on during pregnancy but are left out after delivery.

- The duty to inform sexual partners of an HIV positive person should only be performed by a well-qualified person who is very conversant with the social-cultural dynamics of the particular health facility's catchment area.
- There is a need to narrow down the definition of health service providers who are authorised to exercise their discretion and inform sexual partners of HIV positive persons because in terms of the current definition not all service providers undergo the necessary training on issues of confidentiality and medical ethics to qualify them for the responsibility of health status disclosure.
- There is a need to develop a procedure which health service provider need to follow when informing the sexual partner/s of an HIV positive person. The developed procedures should clearly stipulate the proper approach to adopt and the means of communication to be followed when notifying sexual partners of an HIV positive person. Communications procedures should also take into consideration the right to privacy and confidentiality of both the infected and affected persons, especially in the cases of women and children.
- There is a need to include in the HIV and AIDS (Prevention and Management) Act verbal consent as a condition under which a health service provider can be allowed to assist in disclosing the status of an HIV positive person to her/his sexual partners. In its current form, the Act provides for written consent. Verbal consent will make it easier for the majority of illiterate women to be assisted and allow them to understand what they are consenting to rather than just signing a consent form.
- There is a need to provide a clear definition of what constitutes a reasonable period that a health service provider can give an HIV positive person to disclose their status to her/his sexual partners. The HIV and AIDS (Prevention and Management) Act is not clear as to what constitutes a reasonable period. The proper definition of 'a reasonable period' will help remove any misinterpretation by a health service provider, an infected and affected person.

- There is a need to include psychosocial interventions to assist persons who may very well encounter problems consequent upon disclosure of HIV status. Section 10(2) of the HIV and AIDS Act places duties on the HIV positive person towards their sexual partner/s. It also sets out obligations and conditions for the guidance of a health service provider in the exercise of their discretion concerning the disclosure of a patient's HIV status. However, the Act is silent about the protection needed for persons living with HIV especially women who often only discover their status when they are pregnant. The Act is silent on protection for sexual partners who are most often informed when they least expect to hear that they are at risk of contracting HIV. In other words, the Act does not go beyond informing sexual partners of an HIV positive person, and leaves them to deal with its multiple outcomes, be they positive or negative.

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