

UNIVERSITY OF NAIROBI

**LAWS, POLICIES AND THE RIGHT TO PRIVACY FOR PEOPLE LIVING WITH
HIV IN KENYA**

BY

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DECLARATION

I hereby declare that this Research Project is my original work and has not been presented for any other academic award at the University of Nairobi or any other institution.

Signature

Date

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This Research Project has been submitted with our approval as the University Supervisor(s).

Signature

Date.....

Prof. Peter Wasamba

DEDICATION

This Research Project is dedicated to my beloved mum and dad, Mr. Duncan Omondi and Mrs. Mary Omondi. I am grateful for all the sacrifices you have made to see me through this journey. To my siblings George and Angela, thank you so much for your understanding and morale.

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LIST OF ABBREVIATIONS/ ACRONMYS

AIDS	Acquired Immune Deficiency Syndrome
ARVs	Antiretroviral
HAPCA	HIV Prevention and Control Act
HCW	Health Care Worker
HIV	Human Immunodeficiency Virus
HTC	HIV Testing and Counselling
PLHIV	People Living with HIV and AIDS
PMTCT	Prevention of Mother to Child Transmission
TBA	Traditional Birth Attendant

TABLE OF CONTENTS

DECLARATION	ii
DEDICATION	iii
ACKNOWLEDGMENT	iv
LIST OF ABBREVIATIONS/ ACRONMYS	v
ABSTRACT	viii
CHAPTER ONE	1
GENERAL INTRODUCTION	1
1.1 Introduction and Background to the Study	1
1.2 Statement of the Problem.....	2
1.3 Research Objectives.....	2
1.4 Research Questions	2
1.5 Justification of the Research	3
1.6 Scope and limitation	3
1.7 Literature Review.....	3
1.8 Theoretical Framework.....	7
1.9 Methodology.....	10
1.10 Data Collection	11
1.11 Data Analysis	11
CHAPTER TWO	13
HIV, LAW AND HUMAN RIGHTS	13
2.1 INTRODUCTION	13
2.2 International Human Rights Law	13
2.3 Common Law Protections.....	15
2.4 National Laws and Policies.....	19
2.5 The Constitution of Kenya 2010.....	19
2.6 Health Act 2017	21
2.7 The HIV & AIDS Prevention and Control Act (HAPCA 2006)	23
2.8 Employment Act 2007	24
2.9 The Health Information System Policy (2010 – 2030).....	27
2.10 National Guidelines for HIV Testing and Counseling in Kenya 2010	27
2.11 Redress to violations of privacy and confidentiality.....	28
2.12 Courts.....	28
2.13 Constitutional Commissions	29

2.14 Equity Tribunal	29
2.15 Conclusion	29
CHAPTER THREE	31
VIOLATION OF THE RIGHT TO PRIVACY FOR PLHIV	31
3.1 Introduction.....	31
3.2 Informed consent	31
3.3 HIV/AIDS Testing	33
3.4 Voluntary Testing	34
3.5 Routine Testing.....	34
3.6 Mandatory testing	36
3.7 Compulsory testing	36
3.8 Breach of Confidentiality.....	37
3.9 Conclusion	40
CHAPTER FOUR	41
THE NEGATIVE IMPACT OF VIOLATING THE RIGHT TO PRIVACY FOR PLHIV	41
4.1 Introduction.....	41
4.2 Stigma	41
4.3 AIDS and Stigma	42
4.4 HIV Stigma and Discrimination in Kenya.....	44
4.5 Implications of discrimination	45
4.6 Making the epidemic invisible.....	45
4.7 Limiting access to treatment	46
4.8 Domestic violence and abandonment	47
4.9 Impact on identity and coping of the person with HIV	47
4.10 Disclosure, support and protection of those close to the infected person.....	48
4.11 Impact on behavior change	48
4.12 Conclusion	49
CHAPTER FIVE	50
CONCLUSION AND RECOMMENDATIONS	50
BIBLIOGRAPHY	53

ABSTRACT

Despite significant scientific advancement in curbing the scourge of HIV/AIDS, the epidemic continues to register incredible resilience across various fractions of the society. It emerges that human rights abuses partly explain the HIV pandemic and increase in its impact. To this end, Kenya has enacted laws and policies and encouraged practices that support rights for persons who are at risk of HIV or Living with HIV. However, given concerns of abuse, stigma, discrimination and violations of the right to privacy are still reported by PLHIV. This study had three objectives; first, to examine the right to privacy of HIV/AIDS as provided for by law; secondly, to discuss the types of breaches PLHIV face in relation to the right to privacy in Kenya; thirdly, to interrogate the effects of violating the right to privacy for PLHIV. The study poses the argument of self-determination/autonomy under the theoretical framework, which PLHIV reclaim their power to decide the way their personal information relating to their health status should be handled. The control they have on this information in terms of who can access or even use it. Methodologically, the study was a desk review utilizing secondary data to address its objectives which were analysed based on key themes. The study found out that despite existence of laws protecting the right to privacy in Kenya, inadequate implementation of these laws contribute to the continuous violation of this right. Additionally, lack of implementation of certain laws has also led to violation of the right to privacy. Further, violation on the ground of preserving public health that can be used by the government to violate the right to privacy for PLHIV. Yet another reason is existence of gaps in certain laws that do not forbid pre- employment testing which violates the right to privacy and discriminate against PLHIV. Finally, inconsistencies in National Guidelines which previously were anonymous but currently introduced name based referrals in identifying PLHIV. Based on these finding, the study recommends a comprehensive review of the legal frameworks in the country that protect the right to privacy and addressing obstacles that hinder their full implementation. In addition, healthcare workers need to be trained on how to protect and promote the right to privacy for PLHIV since they are often the first contact in provision of healthcare service provision.

CHAPTER ONE

GENERAL INTRODUCTION

The rights of patients have been discussed for a long time as part of human rights. This date back to the time human rights was declared universally in the world. The fundamental focus of patients' rights is strengthening the social terms of patients. Most of these rights especially the main ones center on dignity, prior consent, right to being informed, privacy and the quality of health services. However, as technology keeps on advancing, there is need to ensure that these rights are protected at all the times. This is because with advanced technology it is possible to intrude private life. This affects the manner in which health services are provided and the new practices introduced into the provision of those services. As these changes take place, new discussions around medical ethics together with health law emerge because of the need to ensure that patients are protected all the times.

1.1 Introduction and Background to the Study

A review of the literature and facts from the national HIV/AIDS tribunal shows that for a long time the number of complaints relating to violation of human rights for HIV/AIDS victims has been rising on a continuous basis. Most of those complaints are directed towards the People Living with HIV (PLHIV) and the concern has been related to disclosure of health information for these people without their consent. Even though effort has been made to take care of PLHIV at national level, it would be important to note that the disclosure of health information without consent violates their rights to privacy. This is in the midst of the fact that the right to privacy remains an important element in developing countries due to possible stigmatization against PLHIV. While this is the case, prevailing stigma against HIV/AIDS patients' in the country validate the need for protection of patients' right. It would be important to note that a group of people might be tempted not to seek treatment if they know that their information would be shared with third parties and used inappropriately against them. In addition, those who seek treatment might be tempted to withhold important information fearing that it would be shared inappropriately. This would end up affecting the number of people who would seek treatment fearing that their information would be shared with unauthorized people.

The disclosure of information relating to patients' health conditions whether HIV/AIDS or any other disease without patients' consent is part of human right violation. It would be important to note that when such information is shared inappropriately it might bar HIV/AIDS victims

from equal employment opportunities by some employers, access to educational facilities, and even provision of insurance service. As a result, it would be vital to protect that information by making sure that it is not shared inappropriately. In some instances, women have been subjected to sexual and physical abuses at family and society level. In this respect, protection of such information is very vital because it minimizes stigma and discrimination in service delivery. One unique thing is that when health related information is protected and treated appropriately, majority of the people are encouraged to be tested and even seek treatment for other illnesses. This has great impact in improving the quality of health in the country.

1.2 Statement of the Problem

Whereas we have laws and policies regulating the right to privacy in Kenya, much work remains to be done particularly in protecting the rights of People Living with HIV (PLHIV) in particular, on the right to privacy that is still being violated in practice in spite of protection of the law. The continuous rise in the number of cases reported at the HIV and AIDS Tribunal relating to violation of the right to privacy for PLHIV arising from breaches such as lack of informed consent before being subjected to a HIV test, mandatory, routine and compulsory testing one is subjected to whether they would like to be tested or not and finally breach of confidentiality when healthcare worker share personal information concerning HIV test results with 3rd parties without their consent. The question we then ask ourselves is: why so? It is imperative then to try and understand the widespread violation of the right to privacy. To this end therefore, there exists a need to discuss breaches arising from violating the right to privacy and also interrogate the effects of violating the right to privacy for PLHIV in Kenya. It is against this background therefore, that this study generally examines the right to privacy of HIV/AIDS as provided for by law.

1.3 Research Objectives

1. To examine the right to privacy of HIV/AIDS as provided for by law.
2. To discuss the types of breaches PLHIV face in relation to the right to privacy in Kenya.
3. To interrogate the effects of violating the right to privacy for PLHIV in Kenya.

1.4 Research Questions

1. Which legal and policy provisions are in place to protect and promote the right to privacy for PLHIV in Kenya?
2. What violations do PLHIV face in claiming their right to privacy?
3. What negative impact arises from violating the right to privacy for PLHIV in Kenya?

1.5 Justification of the Research

Several countries across the globe have developed laws that protect the rights of patients. Some of those laws include omnibus national HIV laws, similar laws contain in constitution and the general laws that relate to HIV. In spite of this, it would be important to acknowledge the fact that violation of rights to patients especially PLHIV is a driver of HIV in the country and elsewhere. It does not only discourage them from seeking treatment, but it also discourages the realization and protection of human rights. Some countries have had these laws for many years, but ongoing reports on the violation against PLHIV on the right to privacy in Kenya suggest the need to strengthen the manner in which such laws are executed and enforced within the country. Laws commit countries to promoting internationally agreed principles on human rights. Most of those rights relate to equality, health and liberty, but for various reasons political chaos, unawareness and inadequate resources inhibit the implementation of these laws.

In the light of the above, it is quite evident that all countries including Kenya should review their laws and policies relating to HIV and obstacles that hinder their full implementation. This justifies the basis upon which the current study is conducted because there are few similar studies in the country and their findings vary from each other.

1.6 Scope and limitation

Several limitations should be acknowledged in this study. First, this research does not examine fully the violation of human rights relating to people living HIV/AIDs in the country. Second, the study methodology used is limited. It does not gather primary data such as the use of interviews, questionnaires or focus group discussion from PLHIV to generate structured responses from them to acquire personal lived experiences.

1.7 Literature Review

The concepts of confidentiality and privacy normally occur together. When they do this, privacy appears on the frontline whereas confidentiality follows thereafter. From this, privacy is considered to be a protective element that guards people from bodily harms. Confidentiality, on the other hand, is regarded as an act of not sharing information.

The previous studies on this field range from denial that there is anything tangible in this field to reducing the subject matter to other related issues such as liberty and even attempts to

describe the issue descriptively. The history of privacy as a political issue forms the basis upon which the US Supreme Court sought to protect contraceptive rights (*Griswold V Connecticut 1965*), the case concerned a Connecticut law that criminalized the encouragement or use of birth control. The Supreme Court ruled that the state's ban on the use of contraceptives violated the right to marital privacy and could not be enforced against married people. (*Roe V Wade 1973*) the reproductive choice case that established that the Constitution of United States provides a fundamental right to privacy which protects a pregnant woman's liberty and legal right to an abortion without excessive government's intrusion. Because of the shift, the discussion around privacy has now turned to liberty that centers on choices in making decision in areas of life that relate to sexuality. In *Planned Parenthood V Casey 1992*, the Supreme Court of United States invalidated a Pennsylvanian law that required spousal awareness prior to obtaining an abortion as provided under the fourteenth amendment on the right to privacy because it created undue burden on married women seeking an abortion.

From the time the rights to privacy were published by Samul D. Warren and Louis D. Brandeis within the *Harvard Law Review (1890)*, discussions around privacy have increased in great number both in philosophy and law. The authors argued that individual rights were guaranteed by general law in relation to the extent that people could express their feelings. Self-determination within right to privacy provides people with moral authority of their personal characteristics.

The influence of the article that Warren and Brandeis published occasioned the history of privacy in law by Ken Gormley, *Wisconsin Law Review, One hundred years of privacy (1992)*. However, scholars continue to consider core meaning of privacy before they discuss it from moral or legal perspective. A symposium that focused on public affairs and philosophy immediately after the US Supreme Court pronounced itself in the *Roe v. Wade (1973)*, has formed the basis for other works that have been published in recent years. In the symposium, Judith Jarvis Thomson, *the right to privacy, philosophy and public affairs (1975)* advanced a reductionist view that held that privacy was not an independent right, but an aggregation of other rights. Thomson observed that people do not concern themselves with the things we own unless we expose them to the public. In this respect, there are rights that do not need to be safeguarded unless they are exposed to the members of the public.

Respondents to Thomson have attempted to capture explanatory issues of privacy that appear important. They have explained the reasoning behind the problem with intrusion to personal properties. Thomson's explain can be helpful in evaluating the criticisms of reductionist challenge. The example ranges from pornographic images not being locked into safe places to not torturing people so as to access their personal information. It would be difficult to consider these examples as having the same moral weight. This explains why Thomson presumes that privacy lacks explanatory value.

Diversity depicts the fact that privacy might not necessarily be a univocal idea. Various people who have responded to Thomson's argument have characterized the important aspects of privacy Thomson (1975). Scanlon contends that privacy would require all accounts to be considered in the analysis. Its norms would be structured in a way that would seek to protect the rights of other people. Jeffrey Reiman, (1976), describes Scanlon's argument as a tautology that forms the basis of "privatistic" interests. Writing in the same symposium, James Rachels (1975) posited an underlying value to the interests that fall under "privacy." The privacy's value as maintained by Rachels lies within the link between one's ability to control the person that accesses information and maintain different sorts of relationships with different people. Rachels contends that we maintain relationships with other people by choices that we make. Accordingly, if everything concerning us was known, then there would be no differences between friends and other people.

There are two main points from Rachels' viewpoint. The first one is that there lacks clear information relating to all forms of information because they all appear to be the same with respect to intimacy. It would be important to note that personal concerns such as age are normally sensitive to certain groups of people, but not all of them whereas cultural differences are more prevalent in certain places than in others are evident in the analysis. In this respect, it would be interesting to note the way certain types of information are of great importance in certain areas than in others. For instance, a postal code would be negligible in intimate relationship, but have great value in tracking thieves or even forecasting economic worth. Alternatively, the issue of temperature might not be so important in intimate relationships, but it might be important in medical practices.

In fact, when Ebola epidemic hit several countries in Africa, several airports around the world were fitted with infrared temperature sensors to spot feverish travelers including major airports

in Kenya. The second point from Rachels' argument places the issue of access to personal information without informed consent on the same account with confidentiality by considering the transfer of information. Rachels' view challenges us to consider the role of privacy as well as that of confidentiality in development of intimate relationships. In such instance, it would be necessary to consider the information that would be important, the context in which it would matter and the quantity of information that would be necessary as well as the purpose of that information. The most important aspect in this analysis would be the purpose for that information, but it would also be necessary to consider the control system that would bar the access to that information.

Jeffrey Reiman, (1976) while appreciating the connection between confidentiality and privacy like Rachel do asserts that intimacy is relatively unavailable. For Riemann, intimacy comprises the element of caring that highlights the need for sharing personal information. This context demands that people relate with each other willing fully so that they can develop relationships. This cannot occur unless people have senses of themselves and develop deep senses of their bodies or even their existence. Reiman contends that privacy is a social ritual through which individual moral titles are conferred. This explains why totalitarian regimes depend largely on deprivation of privacy to undermine the senses of the people they rule Erving Goffman, (1961).

Jonathan Burchell, (2009) argues that the African concept of ubuntu (we are human through others) highlights a spirit of interconnectedness or collectivity rather than individual privacy. A community-centered ubuntu needs to be complemented by the individualism implicit in the fundamental personality rights of dignity and privacy. But, the reasons for protecting privacy are wider than just protecting the dignity of the individual. He appreciates that a balance is needed between respect for our private spheres and the involvement of others in our lives. This echoes current situation in Kenya. Although Kenya does not have a strong general privacy protection law, privacy issues have been a dominant theme in Kenya close to a decade now. Furthermore, the promulgation of the Constitution of Kenya as a transformative instrument that not only reaffirms the inherent dignity, equality and freedom of all, but one that goes well beyond most other human rights instruments by providing protection for privacy rights. This is evidenced in constitutional petitions filed before the courts on the right to privacy such as *MWK & another V attorney general & 3 others (2017) ekr*, *KHRC V Communications Authority of Kenya & 4 others (2018) ekr*. We have reached a point at which it can be said

with confidence that the law recognizes and will appropriately protect the right of personal privacy.

Other authors link privacy to self and identity whereas others seek to clarify privacy by providing descriptive accounts of it as opposed to providing its normative accounts. For instance, Ruth Gavison, (1980) claims that many authors have evaluated privacy in terms of access it has over people in different forms. Gavison's view is as general in that as she responds to Thomson's reductionism theory claims that most of the articles that are cited in the analysis center on limitations of privacy. In this respect, perfect privacy would be inaccessible whereas total loss of privacy would be accessible. Forms of accessibility would include direct information, physical access and attention in terms of gaze. This view is rather descriptive and it defends privacy as a separate matter. It asserts that both types of privacy, total loss of it and perfect privacy, are undesirable. She claims that privacy serves many functions including mental health, intimacy, autonomy and democracy. Like other authors such as Anita Allen, Gavison conceptualizes privacy in terms of inaccessibility physically.

In the above respect, the current study focuses much of its attention on inaccessibility promoted by the concept of privacy. As a result, both physical and cognitive concepts will be utilized in the understanding of privacy argument. The focus shifts to breaches because we are worried about invasion. Ethical basis of privacy provides the basis for supporting the significance of confidentiality. The authors considered in the above analysis highlight the reason for preventing people from accessing information on the basis of the manner in which the information would be utilized once obtained. Breaches and invasion of the right to privacy present themselves as moral issues because sometimes people are barred from invading information because we do not want them to breach our privacy thereby protecting confidentiality.

1.8 Theoretical Framework

This study employs the theory of autonomy in understanding the right to privacy for PLHIV, which PLHIV reclaim their power to decide the way their personal information relating to their health status should be handled. The control they have on this information in terms of who can access or even use it.

1.9 Autonomy

From Kant's theory, autonomy is regarded as one's capacity to self-determine or self-govern which is an essential value of a person being a human being. Because privacy is so instrumental to autonomy implying that autonomy cannot be understood in the absence of privacy, then the loss of privacy would be dangerous to fundamental values of human beings. In this respect, the idea of freedom that emanates from autonomy thereby extends beyond the negative sense of freedom that originates outside of us. It thereby contains an element of law, which is laid out by oneself, and which has decisive authority over oneself. This study will thus primarily focus on autonomy at a personal level, but it will also extend to medical ethics and practice. In medicine practice, which is part of applied ethics, autonomy plays an important role. It is appealed by rights to free speech in hate speeches and right to freedom in similar types of speeches. In spite of this there lacks consensus in terms of the way autonomy needs to be utilized in different contexts. This relates to rationality required whether the issue should be centered on interference or moral reflection in self-regulation.

For a long time, autonomy has been a vital principle within medical ethics. In Belmont report, for instance, which was published in 1979, the rights of human subjects are articulated clearly in that report. The rights concern themselves with respect that every person in the study deserves. The report claims that research participants ought to be treated with high level of autonomy and those with diminished autonomy because of their physical capabilities need to be protected. This necessitates the need for informed consent meaning that they should understand every concept of the study before they take part in it.

According to the deontological theories, good things are known by their consistency with moral practices of doing things. Kant's theory, which is one of these theories, emphasizes the link between morality and reason. It defines reason as the attribute that separates human beings from other types of animals. This acknowledges the good aspect of moral law that considers people as moral agents because they are responsible for their actions Guyer, P. In *the Shorter Routledge Encyclopedia of Philosophy (2005)*. The ethics promoted by Kant object the aspect of consequentialism, but this does not mean that consequences should be ignored. Instead, it means that consequences are relevant if actions are morally acceptable. This implies that if actions are not acceptable morally, then their consequences do not need to be evaluated. Conversely, if actions are acceptable morally, then their consequences can be evaluated. This means that actions are wrong or right intrinsically irrespective of their consequences. For this

reason, when we want to know whether an action is morally right or wrong, then our focus should be on the guiding principles of that action as opposed to its consequences.

The *Principles of Biomedical Ethics* (2002) published by Tom L. Beauchamp and James F. Childress, which is a principle textbook in biomedical ethics, defends the aspect of autonomy in making decisions. This however does not mean that it should override other issues in moral considerations. This principle can either be positive or negative. From a negative perspective, the obligation of health workers in their profession should not be constrained by other people. From a positive perspective, the principle calls for respect of other people in the treatment process. Beauchamp and Childress appreciate the fact that patients have the right to autonomously decide to be guided by either traditional, religious or communal values and beliefs in deciding what should be done on them. While both of them acknowledge the difficulties involved in making decisions that relate to information sharing, they do not imply that patients should be denied the opportunity to respect patients' autonomy in making decision. They claim that respect for autonomy should not be an ideal practice in health care, but also a professional obligation. As a result, patients should have autonomous rights in decision making, but not a duty in it.

The above account of autonomy by Beauchamp and Childress is largely weak because while they appreciate the fact that selves develop within communal contexts, they claim that agents are presumed to have the ability to choose their courses of action. In contrast to the above, a strong concept of relational autonomy would involve dynamic balance between overlapping objects and people. As a result, autonomous people would be the ones who would be able to remake themselves within relationships that are rarely static.

In spite of the above, it would be important to appreciate the fact that criticisms have been raised against the issue of autonomy in medical ethics. However, in response to these criticisms practices published before did not pay attention to intimate relationships as well as social dimensions within patients' autonomy. Nevertheless, Beauchamp and Childress highlight the need for creating concepts that respect autonomy in decision making processes. They thereby develop autonomy, which is not individualistic in nature, to the extent that it would neglect social aspects and even not focus much on reason to the extent that it would neglect emotions and too much legalistic to downplay social practices.

Different authors highlight the significance of autonomy thereby appreciates the need for patients and research participants to provide informed consents in different scenarios. In this respect, confidentiality and informed consent have become important aspects in medical ethics and in other areas of study. Clouser, K.D.; Gert, B. (1990) claim that autonomy principle has dominated ethics in US health care. Nevertheless, public health is largely based on population-level utility, which makes it more attentive to epidemic issues, cost-effectiveness in decision making and social determinants of health. This utilitarian approach is interconnected to the issue of paternalism within public health. As a result, most of the ethical problems in public health have inbuilt tension between individual and social interests. The challenge thereby lies in relationships between population and individual health that many authors have addressed in bioethics.

Most of the contemporary philosophers and ethicists base their decisions on utilitarian theories. These theories are effective in maximizing benefits for majority of the people. However, there are various situations under which such practices do not maximize benefits for majority of the people and in so doing they might thereby undermine justice, honesty, fairness and other favorable values such as violating the right to privacy of PLHIV on the grounds of public health as provided under the Health Act in Kenya. In this respect, criticisms against utilitarianism highlight the intrinsic injustice of the theory because the theory focuses much of its attention on amount of good distributed among various groups of people. However, it might not be possible to measure benefits from a single standard. For instance, improvements made in health conditions cannot be measured in terms applied in extending life.

From the above discussion, it is evident that most of the scholars are in agreement that the right to privacy is the aptitude to control the person with access to information that concerns us. This right underpins the principles of self-determination which gives PLHIV autonomy in making decisions on their health information conversely protecting them against unwarranted intrusions.

1.9 Methodology

This section provides an outline of the research methodology used to answer the research questions, the research approach, description of secondary data collection process, data analysis techniques used.

1.10 Data Collection

This study is a desk review utilizing secondary data to address its objectives. It involves collecting and reviewing existing literature by using desk research techniques to include internal desk research and external desk research. Internal desk research will be at the University of Nairobi Graduate Library, where books will be identified based on authors who have written on the right to privacy. Whereas in external desk research such as online desk research, will involve digging relevant data online. One, directly browse specific information and extract data from sites on life science and biomedical topics like PubMed. Secondly, using various search engines like google to search LexisNexis and Jstor to find relevant refined research data from journals, articles, reports, and other gray literature, and laws and policies that govern the right to privacy for PLHIV and that may affect it carried out by universities that is good and reliable.

1.11 Data Analysis

After reviewing available data, the next step is to analyze the data, what is known about the topic on right to privacy, what has been extracted from literature and what the secondary data analysis has revealed, while keeping in mind the research objectives, emerging themes and issues and any gaps for research. What does the desk review say about the right to privacy for PLHIV, has the review unearthed quantitative data that calls for qualitative information to interpret the disparities. What are the gaps and questions that remains to be discerned, confirmed and addressed during the research? The answers from this analysis will be summarized into a word document based on key themes.

1.12 Findings and recommendations

The findings helps to gain a broad understanding of the field of study. Findings emerge from the analysis while recommendations respond to the key findings by suggesting specific strategies and interventions to address the issues identified in the analysis. The findings will be evaluated on a priority basis, then narrowed down, once this is done recommendations will be developed that align with the findings.

This study is divided into five chapters. Chapter one details an introductory look of the study that covers the problem statement, research questions, objectives, literature review, theoretical framework, hypothesis, methodology, as well as limitations. The second chapter analyzes the

legal and policy provisions that protect the right to privacy and confidentiality for People Living with HIV (PLHIV) in Kenya from international, regional and national perspectives. The third chapter sets discusses the type of breaches that PLHIV face regarding their right to privacy and confidentiality. Chapter four on the other hand discusses the effects of the breaches in the previous chapter and how they violate the right to privacy for PLHIV. The fifth chapter contains conclusions and recommendations for further research.

CHAPTER TWO

HIV, LAW AND HUMAN RIGHTS

2.1 INTRODUCTION

Despite the considerable effort made to minimize the spread of HIV, the epidemic continues to spread at an alarming rate. This is largely aided by violation of human rights for the PLHIV at global and national levels. Majority of the people who suffer from the disease continue to be discriminated against despite the effort that has been made to minimize discrimination against them. Those who are deemed to be at high risks of contracting the disease and those already suffering it are in most cases stigmatized by the people who live with them or the members of the larger community. The discrimination held against them endangers equitable distribution of goods and services set to help them recover from the severity of the disease. This includes the ARV drugs, the counseling services as well as the routine testing services among others. To make the matter worse, as the number of PLHIV continues to rise, legal systems and social structures related to HIV do not become apparently obvious.

This chapter starts by evaluating the manner in which recognition of human rights led to applicability of international, regional and national laws that promote and protect the right to privacy for PLHIV. It concludes by discussing the available redress mechanisms for PLHIV in the protection of their right to privacy

2.2 International Human Rights Law

Human rights are enjoyed by all people regardless of their culture, religion, nationality and culture among other attributes. Most of these rights are contained in international laws that define the way countries in the globe should conducted themselves on various issues that are fundamental to various groups of people. Because of the critical roles that human rights play in our lives they affect almost every part of our lives including the manner in which we respond to PLHIV. This includes the way we identify deficiencies in the law *Twenty-five questions and answers on health and human rights. Geneva: World Health Organization; (2002).*

At the moment, there is a growing body of customary laws and treaties within international platforms that define the roles that countries have in protecting, respecting and fulfilling human rights *UNAIDS. (1997)*. The member states to the two sets of treaties do not only thereby minimize the abuses of political and civil rights of their citizens, but they also ensure that

private sectors do not discriminate against various groups of people that suffer from HIV. Accordingly, they should take apposite steps to ensure that no one is discriminated against in the processes of ensuring that cultural, social and economic rights of all people are achieved. This includes the health related rights, which are sometimes disregarded for no good reason International Covenant on Economic, Social and Cultural Rights, (1966)

The right to privacy is contained in almost all of the main international and regional human rights instruments, including: *United Nations Declaration of Human Rights (UDHR) (1948)*. The 12th article of this document clarifies that no one should be subjected to unfair treatment in areas related to privacy at whatever level because the rights of all people should be protected. The 17th article of (*ICCPR) (1966)*, goes ahead to state that everyone has a right to be protected from tacks and interferences of any nature so long as his/her rights are contravened. This ensures that no one is subjected to unlawful interferences on issues related to privacy. These aspects are enforced within the Kenya laws because the country is a member state of such treaties and practices. As a result, the PLHIV should not be discriminated against in service delivery because they are part of the people protected by the treaties.

The above position is supported by other instruments in human rights including the International Covenant on Economic, Social, and Cultural Rights (CESCR 1966) as well as the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW 1979) among other instruments. All of these instruments acknowledge that the right to privacy is a basic right within health care.

The role that human rights together with laws play in HIV related issues was recognized for the first time in 1989 under the International Consultation on AIDS and Human Rights convention that was organized jointly by the World Health Organization (WHO) and UN Centre for Human Rights. Later on, the international community identified the need to collaborate with both bodies in applying the existing human rights to PLHIV. They tasked governments with this responsibility because they were better placed in the public context. Jonathan Mann who was the WHO's first director on AIDs programs identified the international law on human rights as an all-inclusive framework that took care of PLHIV. He went ahead to recommend that all health practitioners should make use of those rights as they address themselves to HIV related issues. As a result of this, privacy was considered to be a fundamental right of PLHIV.

The *UNAIDS International guidelines on HIV/AIDS and human rights (2006)* were developed to guide governments in the processes of preventing, caring and managing the spread of HIV/AIDS. This issue was further emphasized in June 2011 when a high level meeting on AIDs was held in New York. This was a commemoration of 30 years from the time the epidemic was identified in the world. During the meeting, the member states reiterated their commitments to ensuring that the disease was prevented, treatment and care were provided to all people, support was provided to all people and discrimination against PLHIV was eliminated. During the *(2011) Political Declaration on HIV&AIDS*, governments including the Kenyan one omitted to ensuring that relevant laws that addressed themselves to HIV related issues were developed and adopted in different parts of the world.

The *Global Commission on HIV and the Law* was launched in June (2010) to ensure that evidence-based, human-based and actionable recommendations were taken into consideration within the processes of responding to HIV related issues. The findings from the commission '*Risks, Rights & Health*' (2012) established that law on its own could not stop the spread of AIDs. In addition, it established that law on its own could not be blamed for inadequacies within responses made towards HIV. In spite of this, legal environment was identified as one of the critical environments in promoting the wellbeing of PLHIV and those vulnerable to the disease. In the light of this, the commission observed that good laws could widen the process of preventing HIV, improving treatment, enhancing support offered to PLHIV, protecting the rights of all people and even play important roles in saving public money. As a result, the issue of addressing legal barriers was seen as effective in the processes of preventing, treating and managing HIV.

The UNAIDS global report that was published in 2013 recommended that nations needed to eliminate policies, laws and regulations that hindered the processes of preventing, caring and supporting vulnerable groups. It further observed that absence of relevant legal frameworks hindered the processes of dealing with HIV related discrimination.

2.3 Common Law Protections

Medical practitioners have the duty of maintaining confidentiality as they offer services to patients under the common law. This responsibility is established in tort law, equity and contract law. Under the contract law, they have the contractual duty that encourages patients to provide all relevant information to them so that they can be served best. This means that

there exists some level of trust that discourages medical practitioners from disclosing information they obtain from patients to anyone unless consent has been provided by the patient.

S Humber, in *Patient Confidentiality: Breach of Clinical Confidence*, (2001), stated that the responsibility expressed under the contract law was not only limited to ensuring that the information provided was not disclosed to other people, but also to ensure that it was utilized for intended purpose. This meant that in case extra information for other purposes was required, then permission had to be sought from relevant people using the right procedures.

Lord Denning in the *Parry-Jones* (1969) case observed that there was an element of contract within law that necessitated professionals to observe client's affairs in secret to the extent of not disclosing it to unauthorized people. As a result, under the contractual duty medical practitioners ought to conduct themselves in confidential manners. This means that PLHIV expect healthcare workers not to disclose personal information they provide to them to anyone unless they give them permission to do so.

The above duty also extends to equity, but it arises when patients rely on good faith that medical practitioners would not disclose their personal data to anyone. The rationale behind this concept is that no one should benefit unjustifiably from information obtained in confidence. In spite of this, this duty arises when information has an element of confidence in it. This means that it is provided in a situation where it is not intended to be used for any other purpose other than the one it was obtained for T.S. Kian, *Medical Confidentiality: Ethical Legal Issues* (1999).

Under the tort law, the duty of confidentiality falls under the law of negligence. Under this law, it is expected that medical practitioners would not cause predictable harms on other people that might result to damages. This element is illustrated by *Furniss v Fitchett* where negligence is utilized to remedy a breach of confidentiality. Under this case, a doctor was sued for breaching confidentiality because he had disclosed confidential information to plaintiff's husband. In concluding the matter, the judge claimed that the doctor needed to have foreseen that the content of certificate would have injured the health of patient thereby found the doctor guilty of the offense.

In this context, the actions of a person could be taken by PLHIV to seek for legal redress if breach of duty in relation to right to privacy would be identified. Depending on the nature of occurrence, the damages could be sought against an institution or doctor on the basis of duty pronounced under common law. It would be important to note that the contravention of this duty could result to huge fines imposed on the liable party either the doctors or institutions if statutory duty is breached.

The East African Community (EAC) HIV & AIDS Prevention and Management Act, 2012

This is regional act within the East African Community. The Act supersedes national HIV laws. It plays the crucial roles in HIV because it fills the gaps and addresses the inherent inconsistencies within existing national laws that regulate approaches utilized with HIV related issues. It consists of clear principles which are international in nature and which are applicable to each of the member countries of EAC. The act ensures that relevant services are provided to PLHIV.

Section 25(3) (a) provides for partner notification. This is a form of voluntary process that encourages trained providers to inquire about life partners of infected people with a view to encouraging them to go for HIV testing. Passive methods, which entail a lot of assistance, are utilized to entice life partners to go for testing and counseling, *consolidated guidelines on HIV Testing services, World Health Organization (2015)*. This aspect has become a common practice throughout the world as one of the way of preventing HIV from spreading any further. However, it has remained controversial for a very long time. For instance, a three-judge bench in Kenya, in the *AIDS Law Project V the Attorney General & 3 others (2015) eKlr*, decision argued that the 24th section of HIV and AIDS Prevention and Control Act, No. 14 of 2006 was unconstitutional because it was vague implying that it lacked clarity. Before its nullification section 24 of HAPCA legally required PLHIV to disclose their health status to “sexual contacts” in other words partner notification. The said section was found to be vague because it utilized the term “sexual contact” was considered unclear because prevention of HIV under partner notification is solely left in the hands of PLHIV whereas all parties in a relationship ought to take preventive measures to protect each other against venereal diseases. It was further argued that it violates the right to privacy for PLHIV as enshrined under Article 31 of the Constitution of Kenya.

In spite of this, health professionals justify partner notification because of the critical role it plays in preventing HIV and encouraging PLHIV to go for treatment and to disclose their health status to their spouses.

The general rule is that doctor must maintain patient confidentiality, namely any information received, disclosed to them by patients or acquired during official duty, which can only be disclosed with in presence of written consent from patients (Eisenhardt et al., 2006). The current study acknowledges the fact that medical practitioners should not harm patients in the processes of executing their duties. Accordingly, they should provide patients with relevant information to help them make informed decisions. This is largely because doctors should protect and safeguard societies from suffering from communicable disease, which can be prevented (Hiriscau, et al., 2014). Largely, the above is a conflict of duties because both privacy and confidentiality should be balanced. Mostly, dilemmas arise when doctors reveal patients' medical status without their knowledge and in the absence of informed consent. This amounts to professional misconduct; as such, no matter the outcomes, it should be punished. When doctors do this, they can be prosecuted in courts of law for breaching privileges placed upon their hands because they invade privacy and even act negligently (Hiriscau et al., 2014). In spite of this, when doctors fail to disclose important information to third parties, they might as well be sued by them for failure to warn or even inflicting emotional distress on them (Edwards, 2014). This might happen in certain countries meaning that it is not mandatory in all nations.

The views posed by the above scholars represent two differing schools of thought on issues related to efficacy of human rights related to HIV. One of the schools downplays the role of human rights in preventing the spread of HIV because it diminishes the role that public health plays in this area. It is normally argued that public health provides practical ways of dealing with health related challenges. It would be important at this point to note that public health is concerned about ensuring that diseases are prevented under all cost for the sake of prolonging life as well as promoting good health among all people *Winslow Charles – Edward Amory: Modern medicine. "The united field of public health" (1920)*. Accordingly, the respect for human rights is regarded to be inconsistent with the objectives of public health because in protecting the rights the rights of other people are infringed. The other school presumes that protection of human rights and strategies utilized in public health reinforce each other.

Accordingly, it presupposes that the issue of safeguarding human rights responds to challenges faced within HIV.

It is worth noting that as a South African commission on HIV/AIDs notes the role played by law in preventing the spread of HIV is complex. The simple reason is that in the process of addressing itself to HIV it has to protect two opposing interests. On one hand, it should acknowledge the members of the public need to be protected from communicable diseases. We are aware on how HIV is transmitted and its categorization as a communicable disease which allows for the violation of the right to privacy of PLHIV through partner notification on the ground of public health is unfair and unjust.

On the other hand, it should recognize that the rights of individual people need to be protected as well. In this regard, the rights of patients need to be safeguarded. In this respect, the law should strike a balance between the two opposing and competing interests. This means that as societies strive to protect themselves they should also protect individual people.

2.4 National Laws and Policies

From the time HIV/AIDs epidemic was declared a national disaster in 1999, a number of Laws, Policies and Frameworks have been developed at National level to address the HIV challenge. These include the following:

2.5 The Constitution of Kenya 2010

The National Constitution provides the basis for handling human rights of all citizens because it sets out different provisions under the Bill of Rights that should govern PLHIV rights especially on their right to privacy. Some of the relevant articles within the Constitution that address themselves to HIV fall under chapter five the “Fundamental Rights and Freedoms of the Individual,” that safeguard the rights of PLHIV in relation to the right to privacy include:

The constitution under Article 2(6) acknowledges that the treaties that national government has signed on behalf of its people are part of its laws implying that they can be utilized in deciding matters of concern. It also outlaws the customary practices that contravene the bills of rights. In this respect, any HIV related treaty that the national government has signed can be utilized to safeguard the interests of PLHIV.

Article 19 (3) observes that the fundamental freedoms together with rights contained in the bills of rights are naturally intrinsic to citizens implying that they are not given by state. In this respect, the state cannot take them at one time or the other. This means that PLHIVs have rights that safeguard their interests and that the rights cannot be taken away by state government or anyone.

Article 21(1) declares that it is the duty of state and its various organs to promote, respect, observe and protect the rights of its people as contained in the constitution. This means that PLHIVs are at liberty to hold government to account if their rights are violated by it or even hold other people to account if they violate them.

Article 24 asserts that the rights contained in the Constitution cannot be limited in any way except by law when there is reasonable and justifiable ground to do so in a system that respects human dignity. This is intended to ensure that government does not act inappropriately to limit the rights under any circumstance that is not justifiable.

Article 28 asserts that people have inherent dignity that should be respected at all times. In this respect, the dignity of PLHIV should be respected.

Article 29 observes that citizens should not be deprived of their freedom anyhow without just causes. This empowers PLHIV in decision making processes concerning the medical decisions they make at any given time.

Article 31 observes that people have rights to privacy. This right extends to personal information that relate to family issues and private affairs that do not need to be disclosed to strangers. This ensures that the HIV status of PLHIV is not made available to strangers unless those people give permission to do so. This article is the basis of my research.

Article 43 observes that all people have rights of the highest attainable level in health. This includes their right to good health care.

The above articles are helpful in asserting the rights of PLHIVs including their rights to privacy. However, some of them are normally violated for no good reason.

2.6 Health Act 2017

The Health Act 2017 is a “mother legislation” that seeks to implement the health rights guaranteed by the Constitution. It is among the recent laws relating to HIV developed in the country. It seeks to promote good medical practices among all people including the PLHIV.

Section 11(1) of the Act, protects the “confidentiality of information relating to a patient and disclosure can only be done under a court order or informed consent for health research and policy planning purposes. Section 11(2) goes ahead to give exceptions to the right to confidentiality which only applies unless disclosure is in writing; court order or non-disclosure presents serious threat to Public Health. One thing to note is that the act does not define public health. Where disclosure is allowed when a threat to public health is not a very good law if there lacks a clear definition of what it entails. It can open doors for violating the right to privacy against public interest. As a result, it would be interesting to observe the way courts will interpret public health *viz a viz* public health directives from the Cabinet Secretary of Health in the future.

Previously, constraints on the right to privacy have always been justified on grounds of protecting public health. For this reason, public health has a tradition that is anchored on control of infectious diseases with a view to limit their spread for the good of many people. In this respect, public health combats diseases by erecting barriers between the infected people and those not infected. In HIV case, this is interesting because doing so infringes the rights of PLHIV. In addition, it creates a form of discrimination that stigmatizes against PLHIV in different ways. Because of the reaching effects of such a practice it would be interesting to see the way those in charge in the Ministry of Health would approach the issue when need arises. In spite of this, it would be worth noting approaching HIV from that perspective would be coercive and it would infringe on basic rights of PLHIV let alone discriminate against them.

To date, HIV/AIDS remains in the category of diseases that are transmitted casually just like venereal diseases. Yet in this act it is regarded as a notifiable disease. The unfortunate thing with this act is that the procedures utilized to define HIV as a notifiable disease are inadequate. This is because HIV is not an air-borne disease. At the same time, it is not transmitted when people mingle with each other without any blood transfer or unprotected sex. Therefore, breach of confidentiality by unlawful disclosure of HIV status of an individual based on public health fails to protect the right to privacy of PLHIV. It would be better for law to ensure that health

status are not disclosed anyhow because doing so would undermine the existing laws that address themselves to preventing the spread of HIV. The only thing that should be done would be to ensure that PLHIV should take precautionary measure to minimize the spread of the disease. If the law would insist on disclosure of HIV status of PLHIV, it would discourage people from going for testing. Inversely, this will encourage the members of public to go for testing if they are assured that their HIV positive status would not be shared with anyone (*UNAIDS, 2000*).

A South African court determined that the way societies react to people infected with HIV has largely deterred people from revealing their HIV status fearing that they would be discriminated against. This is in spite of compelling evidence that shows the way the disease is transmitted from one person to the other. Because most of the civil rights are not protected, civil society often finds it difficult to respond to HIV epidemic. Accordingly, clear reasons need to be developed to ensure that the objectives of public health and protection of human rights align with each other. In this respect, effort geared towards addressing health related issues should consider ethical issues as well as issues related to human rights. Ethics are normally based on moral principles and they seek to evaluate the rightness or wrongness of courses of actions (*Modeste 1996*). Most of ethical practices in professional bodies focus much of their attention on professionalism and moral trust that societies place on the health professionals (*Callahan.2000*). The purpose of ethics is to uncover whether conducts are good or bad on the basis of various issues.

In light of the above, there is need to ensure that there are systems in place that protect confidentiality in HIV related issues. As a way of ensuring this happens, the *International Guidelines on HIV/AIDS (UN)* observes that countries that are member to its practices need to reform their health laws to ensure that they address themselves adequately to HIV related issues. It goes ahead to state that the provisions that apply to other diseases that are transmitted casually should not be applied to HIV. The Ministry of Health should thus reconsider their position with regards to disclosure of HIV status on the ground of public health.

2.7 The HIV & AIDS Prevention and Control Act (HAPCA 2006)

This act provides the relevant measures that concern themselves with issues related to management, control and prevention of HIV and AIDs. It extends to issues related to counseling, supportive systems and the type of care that should be extended to people considered to be at high risks of HIV. Accordingly, the national assembly addressed itself to HIV related issues by enacting this law. In so doing, it hoped to empower PLHIV by ensuring that their rights were safeguarded. This act might thereby be regarded as a move in the right direction as far as HIV related issues are concerned.

Part five of the act talks about confidentiality. Section 20 under this part empowers the Minister for Health to develop rules applicable to privacy right which concern themselves about the manner in which data records are stored, the codes observed in data collection and forms utilized by PLHIV. It prohibits those handling the data and any other person from transmitting, storing or even handling data related to PLHIV in any other manner other than the prescribed one.

To begin with, no Privacy Guidelines have been developed under section 20 of HAPCA to date. This might be a contributing factor to violation of privacy rights for PLHIV yet section 20 provides for confidentiality. To a large extent, it would be important to note that the right to privacy has close connection with that of personal dignity. Accordingly, the sentiments contained in privacy right should provide patients with confidence that the information they provide to medical practitioners would not be shared with other people or institutions for whatever reason. Because patients would not be comfortable to provide such information in an environment especially the ones they consider are not private in nature. They might be tempted to hide some personal information unless the health worker guarantees them that they will not share it.

The right to privacy is normally evident when that for confidentiality is guaranteed. It would be worth noting that confidential information is vital within clinical practices. As a result, patients should be respected at all times as a way of encouraging them to share confidential information. In spite of this, the ability to hold such information with high level of confidentiality is an ethical issue. This is because of the data obtained related to body conditions/information of the patient. As a consequence, it would be an ethical liability for clinicians to respect decisions made by patients relating to such information Goelen G, Rigo

A, Bonduelle M, DeGreve J. *Moral concerns of different types of patients in clinical BRCA1/2 gene mutation testing (1999).*

In the case of *CNM V the Karen Hospital Ltd (2016) unreported*, in their judgement, the members of the Tribunal made one concluding remark, "...that the absence of Privacy Guidelines contemplated by section 20 of HAPCA is gravely injurious to the interests of medical doctors and medical institutions. This is because in the absence of such guidelines, it is extremely difficult to share records, documents, forms or any other material from which the HIV result or status of a patient can reasonably be inferred, with third parties, either within the hospital or with outsiders without violating sections 18, or 22 of HAPCA. This is in spite of the fact that medical practitioners as well as medical institutions must share such information in appropriate circumstances, if they are to continue in business. Before such privacy guidelines are developed, every hospital or institution that wishes to share whether within the hospital or with third party's information from which the HIV status of a person can be inferred, need to develop effective information management system that secures the privacy and confidentiality of the concerned person."

This case further reaffirms the need for the development of the privacy guidelines as mandated by HAPCA 2006.

2.8 Employment Act 2007

The Employment Act regulates the working conditions under which employers and employees conduct themselves in the country. The economic prosperity of every nation depends on the way employees are handled by employers. Additionally, employment relationships form the basis upon which PLHIVs are handled in their places of work just like other people. To ensure that PLHIV are protected against unfair practices, the UN identifies places of work as areas of special interest. Its 69th paragraph that address itself to social and economic impacts of employment commits the heads of governments to developing national legal frameworks and policies that protect the rights of PLHIV and those at risk of HIV from unfair treatment by their employers. This is in line with international practices of employment practices at places of work.

Clarification needs to be made at this stage. Although, Kenya has several legal statutes supporting HIV related interventions in the world of work. While not all are specific to the HIV pandemic, their interpretation and application create an enabling environment with provisions

that bear in mind the issue of non-disclosure of information that is gathered in the process of employment. These law however are limited by the fact that they protect only those employees who are covered by these statutes, they do not address themselves to the people who work within prisons, police services, armed forces and national youth service who are subjected to pre-employment testing which is my interest under the Employment Act.

My analysis, in this area as regards HIV/AIDS and employment, other than purely human rights concern include the issue of pre-employment mandatory testing of workers which directly undermine the fundamental rights of workers to privacy. Pre-employment testing is common in Kenya. Pre-employment testing is discriminatory and an abuse of human rights, because it does not only develop an element of stigma towards the people participating in the recruitment process, but it also discriminates against those found to be HIV positive. With the help of these laws, employers normally promote three reasons that justify their pre- employment testing practices. Firstly, they create an impression that testing is good for other employees because it protects them from possible infection. Secondly, it presumes that PLHIV are relatively less productive when compared to other people because their health status affects them in one way or the other. Thirdly, testing at workplaces works in favor of employment benefits such as training, medical aid and pension fund among other benefits.

While the above argument appears good and reasonable, it is not supported by adequate evidence. Scientific in conjunction with medical evidence does not acknowledge the enormity of possibility of transmission of HIV at workplaces. They disregard this attribute; as such, this argument does not support best practices supported by science and medical practices. In the light of this, a South African supreme court established that there was no single case in South Africa that could be utilized to show that HIV had been transmitted at workplaces as a result of HIV victims who were hired. Likewise, the 1993 Medical and Dental Council's guidelines regarded pre-testing as unethical and misguided implying that it should not be conducted on potential employees.

Alongside the above, the argument that HIV victims are less productive than other people is not based on scientific evidence. In fact, with the development of ARVs and improved services within health practices, it would be wrong to presume that such people would be less productive given the improvements in their health status. In this respect, there is no doubt that PLHIV would be as effective as others. In spite of this, no scientific evidence is in existence that shows

that testing at workplaces has the ability to reduce economic impact and even rate of infection among workers.

Legally, the issue of pre-employment testing at places of work is complex because majority of employers base their employment decisions on common law in relation to hiring employees. As a result, PLHIV might be excluded from recruitment processes even without their knowledge based on HIV's outcomes. Even though it might appear as strange, the House of Lords' statement in *Allen v Flood* suggests that employers have the right to exclude employees from recruitment processes but that individual has no right of legal application against him. This is generally the situation in the country, during a job application one of the processes will involve undergoing a medical exam at a predetermined hospital by the employer, thereafter the medical results forwarded to the employer, heaven forbid that the prospective employee is HIV positive he/she will most likely not get selected for the job on account of the HIV status. However, when the employee decides to file a civil suit chances are the lawsuit will be lost due to lack of evidence and the defense of plausible culpability by the employer.

This absence of such a provision in the Employment Act is a serious lacuna which can result in a lot of uncertainty in the law leading to exploitation by employers. Clearly, there is need for statutory intervention for Employment Act to be amended so that it can create certainty and clarity while addressing issues of HIV/AIDS in the workplace. This would go a long way in discouraging pre-employment testing because of the negative effects it has on PLHIV. In the case of *WA V Guru Nanak Ramgharia Sikh Hospital & 3 others (2015) unreported*, the claimant The Claimant had been employed as a house caretaker by the 3rd Respondent before being reassigned the duties of a domestic servant by the 3rd and 4th Respondents. In 2011, he requested for lighter duties when his health began deteriorating. The 4th Respondent rejected his request for lighter duties, coerced him into writing a retirement letter and offered him Kshs. 6000/= as retirement benefits but the Claimant declined to take it. Later, the 4th Respondent accepted back the Claimant as his employee on condition that he went for a medical checkup at the 1st Respondent's facility. The medical checkup revealed that the Claimant was HIV positive and he was dismissed from employment on account of his status. The Tribunal found that the claimant's right to privacy was violated when he was forced to undergo HIV testing in order to get his job back.

It is important to note that although the National Code of Practice on HIV and AIDS in the Workplace (2009), disregard the need for pre-employment testing during recruitment processes at a policy level, it does not also expressly forbids it. This is because this policy does not have legal backing thereby can only be considered as a moral authority, but without legal authority of any form.

2.9 The Health Information System Policy (2010 – 2030)

The policy establishes the legal framework that relate to routine collection of health related data and its conveyance to relevant digital systems in health care. The policy acknowledges the right to privacy and protection of this right in the light of health information. In addition, it acknowledges the need for ensuring that soft data is secure at all times so that it is not accessed by unauthorized people inappropriately. In this respect, data security within health care is an important element that should be safeguarded at all the times.

Although this policy highlights the need for protecting health related electronic data, Kenya has no specific legal framework for data protection. With advances that occur within information science, electronic records face a number of challenges. This is in spite of the efficiency they provide in provision of health services especially in data retrieval and record keeping. This is especially true when electronic systems are not safeguarded in the right way making it possible for members of staff to share that data in the wrong way and even unauthorized people having access to it. Data breaches and hacking are on the rise thereby necessitates the need for data security within health care. Alarmingly, many organizations have their cloud repository servers based outside Kenya, which further increases data vulnerability. As a result of this, those in medical practices need to safeguard their systems. Otherwise, the confidentiality of their health data would be breached by hackers.

Once law, section five of the data protection bill will guarantee the confidentiality of health data obtained from PLHIV.

2.10 National Guidelines for HIV Testing and Counseling in Kenya 2010

These guidelines provide the national standards that all health institutions utilize in ensuring that right practices are implemented in all medical practices and HIV Testing and Counselling Services.

Previously, HTC services in Kenya were anonymous through the use of codes whereas the current guidelines permit name-based referral. This basically means the guidelines allows for the use of names in HTC services for PLHIV. The introduction of the use of names in identification of PLHIV takes back the efforts made in prevention, care and management of HIV. This is because in the cascade of HIV treatment and services many staff members have access to health data of PLHIV thereby controlling access to confidential information otherwise making it difficult to regulate staff from contravening patients' right and rules on confidentiality.

Since these guidelines are currently still in use, in order to protect the privacy and confidentiality of PLHIV, mechanisms should be put in place to prevent breach and violation of this right such as the use of unique identifiers to ensure that care is provided at all times while the chances of reducing inadvertent disclosure of that information is maintained. UNAIDS also encourages the use of unique identifiers to identify PLHIV in the process of health service delivery all the times. When this is implemented in the right way, the issue of exposing the identity of PLHIV is minimized. Additionally, the efficiency of providing services and continuity of care is improved greatly.

2.11 Redress to violations of privacy and confidentiality

Doctors or other supporting staff should not go unpunished for violating rules relating to confidentiality because they disclose personal information that should not be disclosed. As a result, disciplinary actions should be taken against medical practitioners who err while providing medical services.

2.12 Courts

The Kenyan Constitution provides the basis upon which violation for human rights should be heard and determined normally by High Courts, even Magistrate courts under certain circumstances are able to hear and determine such cases. In instances of violations of constitutional rights, the Constitution provides that there should be no filing fees for such cases, as well as minimal procedural requirements. PLHIV can therefore go to court for enforcement of their constitutional rights. In the case of *C.O.M v Standard Group Ltd & another (2013) eKLR*, the petitioner who was HIV victim filed a constitutional petition of infringement of right to privacy as enshrined and contemplated in Article 31 (c) (d) of the Constitution by the Respondents. In his judgement, Justice Lenaola established that Petitioner's right to privacy as

pleaded was violated by the respondents since written consent was never sought for the name and photograph to be included in the publication made by the respondents.

2.13 Constitutional Commissions

Most of violations on the rights of vulnerable groups such as women who are HIV positive in the country should be directed to the Kenya National Commission on Human Rights as well as the National Gender & Equality Commission (Article 59). Both of these Commissions promote the rights for vulnerable people by ensuring that they are safeguarded all times.

2.14 Equity Tribunal

The HIV Prevention and Control Act, which was established in 2006 establishes the basis upon which HIV and AIDS Tribunal in the country was developed to determine cases related to violation of basic rights at workplaces and other areas in life. Every one of us should appreciate the fact that the judiciary plays an important role in developing a legal framework that protects the rights of HIV victims.

To date, the tribunal has been able to hear and determine various cases relating to violation of rights especially for PLHIV. Some of those cases relate to breach of confidentiality, compulsory testing and unsafe practices and procedures among other things which are covered by HAPCA 2006. It would be necessary to appreciate the fact that the bills of rights contained in the constitution in conjunction with HAPCA 2006 have played major roles in protecting the rights of PLHIV.

Statutory regulatory bodies

At this point, it would be necessary to note that patients who feel that their rights are violated in one way or the other ought to lodge complaints with regulatory bodies. Some of these bodies include the Nursing council of Kenya and the Kenya Medical Practitioners and Dentist's Board among others. Patients may take this step on their own either against the doctor or the institutions for breach of statutory duty.

2.15 Conclusion

There are several laws and policies at the regional and national levels such as the EAC HIV and AIDS Prevention and Control Act 2012, the HIV and AIDS Prevention and Control Act 2006 and the Health Act 2012 among others. Despite the existence of all these laws, the right

to privacy for PLHIV in Kenya is still being violated in practice. The EAC HIV and AIDS Prevention and Control Act 2012, which supersedes national HIV laws in particular HAPCA 2006 still has a provision on partner notification by healthcare workers which violates the right to privacy for PLHIV while HAPCA 2006 had the same provision under section 24 which was nullified in 2016. Section 20 of HAPCA 2006 mandates the Minister of Health to develop privacy guidelines. Since the enactment of this act, no privacy guidelines have been developed to date. Lack of implementation of this provision might explain the continued violation of the right to privacy for PLHIV. The Health Act 2017 has exceptions on confidentiality on the ground of preserving public health which can be used by the government to violate the right to privacy for PLHIV. Pre- employment testing is a common practice in Kenya yet there is no provision in the Employment act forbidding it. The Health Information System Policy makes provision for collection of health service data and the conveyance of that data electronically yet Kenya has no specific legal framework for data protection which poses challenges in case of intrusion of these systems. The National Guidelines for HIV Testing and Counselling in Kenya 2010 introduced name based referrals for PLHIV which is a direct violation of their right to privacy.

In conclusion in as much as there are laws and policies for the protection of the right to privacy for PLHIV, this right is still being violated because of lack of implementation, gaps in some laws, consistency of laws and preservation of public health *vis a vis* the right of an individual.

CHAPTER THREE

VIOLATIONS OF THE RIGHT TO PRIVACY FOR PLHIV IN KENYA

3.1 Introduction

As seen in the previous chapter, Kenya has various supportive laws and numerous relevant policies and guidelines that specify legal, ethical and procedural ways of handling the right to privacy for PLHIV. Nonetheless, these laws and policies are not always implemented in the right way because there are always violations of human rights against PLHIV especially on the right to privacy. The inadequacy in their implementation, existence of gaps and disrespect for human rights heightens the rate of spread and impact of HIV, while undermining the rights for PLHIV. This chapter highlights the Common ethical issues namely informed consent, testing and breach of confidentiality that are continually violated in regards to the right to privacy for PLHIV.

3.2 Informed consent

This fundamental ethical principle was codified for the first time within the Nuremberg Code by Emanuel E, Wendler D, Grady. This was at the wake of Nazi experiments. From that time, the principle has been replicated in almost all major codes even in the International Covenant on Civil and Political Rights (ICCPR), the Council for International Organizations of Medical Sciences (CIOMS) guidelines and even the Declaration of Helsinki.

An informed consent basically means that relevant information is provided to patients before they engage in whatever medical exercise or any other activity that might harm their lives so that they can make informed decisions before they engage in those ventures. With regard to information share, it means that they understand the various people who might access that information and give permission to those people. This relates to their rights of privacy and human dignity as well as autonomy. In this respect, all medical practitioners have the duty to obtain this consent before they conduct medical examinations on patients. In the light of the above, the principle is a cornerstone within Kenyan laws and it requires patients to provide their consent before they receive major medical operations and treatments especially the therapeutic and diagnostic ones (Stoffberg v Elliot, 1912).

The national policies as well as international laws on human rights require patients to provide their consent before they engage in HIV testing. This is in line with human rights that provide

people with individual autonomy. It makes sure that patients freely give the go ahead in relation to medical processes that should be conducted on their bodies in line with respect for personal dignity. The need for this consent requires researchers together with health workers to obtain permissions from subjects and patients before they carry out various activities on them.

The United Nations Population Fund (UNFPA) and World Health Organization (WHO) together with other bodies especially those related to human rights acknowledge the importance of informed consent. In line with this, the International Guidelines on HIV/AIDS and Human Rights International Guidelines that were issued by UNAIDS together with the Office of the High Commissioner of Human Rights (OHCHR) provide the mechanism that should be utilized in the application of human rights' instruments. As regards HIV, they clarify that people should provide informed consents before they engage in HIV testing.

In the process of providing informed consents, patients should be provided with sufficient information to understand the way tests would be carried out, the procedures that would be involved, the manner in which findings would be utilized, the possible alternatives that would be available to them and the rights they have in accepting or refusing to engage in testing. In a South African case *C v Minister of Correctional Services*, Kirk-Cohen J lays out the constraints under which HIV testing is carried out. He held that informed consent is a prerequisite to every HIV testing. As a result, a person would be free to go for testing if he/she understands the purpose of test, the meaning of positive outcomes, is given time to understand the risks and benefits of engaging in testing.

Even in the presence of ample provisions that relate informed consent, the issue of informed consent in healthcare provisions remains a problematic issue in the country. There is growing evidence from the cases filed at the Tribunal that certain elements of consent are never met. In case of *CNM V the Karen Hospital Ltd (2016) eklr*, the claimant visited the respondent's hospital complaining of severe diarrhea. She was subsequently subjected to a HIV test without her informed consent which the test results indicated she was HIV positive. The claimant filed a claim at the Tribunal for violation of her right to privacy when she was unknowingly subjected to a HIV test without her informed consent. In their decision, the members of the Tribunal found the respondent liable for compelling the claimant to undergo HIV testing without her informed consent. The Tribunal members went ahead to lay out the features of an informed consent in the judgment. They held that, Informed consent for HIV testing meant that

people undergoing tests needed to provide informed consent based on the information provided to them on account of understanding the reason and basis of testing.

At the moment, it is mandatory in the country that informed consent sought be sought from people undergoing HIV testing. Section 14(a) of HAPCA 2006, makes it clear that no testing can be done without the person being tested providing informed consent. Because testing is an important process in eradicating the spread of HIV then all the requirements should be met before it is conducted.

3.3 HIV/AIDS Testing

Testing is a crucial process because it provides the demographical spread of the epidemic as well as means that could be taken to prevent the spread of HIV and supportive measures that could be established to minimize its impact. HIV testing can be carried out for two main reasons. Firstly, it can be carried out for screening purposes as a way of evaluating the medical condition of the members of the public. Secondly, it can be carried out for case finding. As regards the first instance, testing is carried out to determine the extent to which HIV is spread within a country. Under this category, systematic data collection is the basic tool for evaluating the nature of health of a population. As a result, the identity of the people who take part in it should not be revealed to anyone. Because of this, epidemiological surveillance might be conducted without significant implications on violation of human rights because the identity of infected people is not disclosed to anyone. This process is necessary because it helps in preventing the spread of HIV by controlling it through preventive measures. Case finding, on the other hand, has significant implications on the rights of patients. It involves healthcare workers actively and systematically searching for people suspected to be at risk for a particular disease such as HIV and TB rather than waiting for them to present symptoms. As such, because of its human rights implications, it requires the right to privacy of people who are found to be HIV positive to be protected.

There are different types of HIV testing in Kenya. The first one is voluntary, which a person makes an informed decision of wanting to get a HIV test. The second one is routine testing which is carried on a regular basis for most at risks populations. The third one is mandatory, where consent is not sought before carrying out the test. The fourth one is compulsory testing, which is almost similar to the mandatory one. Under the National Guidelines for HIV testing and counselling 2010 , HIV testing should be preceded by counseling meaning that before one

is tested he/she should be provided with relevant information. Once the testing has been carried out, it should also be followed by another form of counseling, which is based on the outcomes of testing. Both sets of counselling enhance the testing process; it provides information relating to what it entails, the pros and cons of testing as well as the purposes for testing. Normally, the focus of counselling should be to help people understand the outcomes of testing. From a human right viewpoint, it helps people to exercise their rights in providing consent. Central to HTC services provided in the country are consent, counseling and confidentiality, which are referred to as 3Cs. Section 17 of HAPCA 2006 also provides for pre and post testing counseling.

3.4 Voluntary Testing

This type of testing allows people to exercise their rights in deciding whether they should be tested or not. Accordingly, there is no form of coercion in it. Under it, people might have reasons for testing thereby decides on their own to go for it. This type of testing has been practiced widely in the country from the time the country was struck by the HIV/AIDS epidemic. It is widely utilized for the people who wish to understand their health status. It is consistent with human right practices because it is based on free will thus promoting the right to privacy for PLHIV.

3.5 Routine Testing

This type of testing is offered to people who seek medical services in the country like any other test. It was adopted as an “Opt-Out Policy” mechanism where testing is carried out routinely within public health facilities. Because of this nature anyone who visits public health facilities is offered the opportunity to go for testing. Nevertheless, if anyone opts not to be tested then the testing cannot be forced on him/her. The opt-in mechanism was established to help people walk in public health facilities and go for testing. Nevertheless, after the need for preventing the spread of HIV was identified in the country, the mechanism was turned to routine testing. This was in line with UNAIDs and WHO practices that were introduced in 2007.

In some countries including Kenya, routine testing is normally carried out among the people who are considered to be at high risks of contracting HIV e.g. in Prevention of Mother to Child Transmission programmes (PMTCT) for pregnant women. These women are routinely tested during antenatal visits in hospitals. One thing to note is that these women only come to learn of their HIV positive status when they are immediately put on antiretroviral therapy (ARVs)

or told not to breastfeed their unborn babies once they give birth. *Center for Reproductive Rights and FIDA, At Risk: Rights violations of HIV positive women in Kenyan Health facilities (2008)*. It should be noted that coercing these women into testing amounts to violation of the right to privacy and it has great implications on their lives such as abandonment by their spouses, violence from their spouses and cultural stigma associated the disease resulting from not breastfeeding their newborns. The most important thing to note is that such practice has the ability to erode the confidence of pregnant women as such they might be discouraged to seek for medical services from public health institutions and resort to traditional birth attendants (TBA) who are not well equipped to care for HIV positive women . This would affect the government's effort that has been made in encouraging women to give birth in hospitals to reduce maternal and child mortality death rates.

It should be noted that when routine testing turns to being coercive, it denies women the opportunity to make informed decision on issues relating to their health. As such it violates their rights to make informed decisions, which is critical in health. Armstrong, *Mandatory HIV Testing in Pregnancy*.

Sexual, Reproductive Health & HIV/AIDS Guidelines notes that programs aimed at ensuring that women do not transmit HIV to children considers women as bearers of children thereby disregards their rights such as reproductive rights and right to privacy and human dignity. This might be dangerous to women because it stigmatizes and discriminates them.

Whichever form routine testing takes, it should be evaluated to ensure that it does not compromise the rights and dignity of various people. Because of the way it has been handled before it raises various questions relating to human rights because those engaging in it should do it freely without being compelled or coerced. As a result, there is need to strike a balance between the objectives that the government intends to achieve through this program and the rights of the people who engage in it. It should be noted that public education on issues related to HIV plays an important role in routine testing and even any other form of testing. It helps the members of the public to understand on the benefits of testing and that they can opt out of the process if they are not ready to undergo the test.

3.6 Mandatory testing

Under this type of testing, one is compelled by an organization or any other type of institution to undergo testing before he/she can be allowed into its processes. A good incidence might be before one that is carried at places of work or before a visa is issued to that person. This type of testing as demonstrated in the second chapter while discussing the Employment Act 2007 is normally carried out among people seeking employment in armed forces. Similarly, it is carried out in other places of work before further trainings are offered. It should be noted that PLHIV are able to carry out their jobs effectively even without going through mandatory testing that discriminates against them. In addition, it is required before donating blood.

Sections 9 and 10 of HAPCA 2006 allows for mandatory testing of donated blood and tissues. The sections seek to protect the rights of the people who receive the blood that is donated. They acknowledge that negligence might expose the people who receive blood; as such, they are not ignorant of this fact. They act in line with responsibilities placed on various health facilities to ensure that reasonable measures are taken to protect the recipients of blood. For instance, when one is involved in an accident and loses blood, the blood in blood bank should be tested to ensure that it does not have elements that can threaten the lives of that person. From my point of view, mandatory testing when conducted from the above perspective does not violate human rights because no one is forced into donating blood. The simple reason is that the need to ensure that blood banks in various parts of the country outweigh the issue of privacy because pre-testing has to be carried out before blood is donated. Additionally, blood stored in blood banks is stored as different blood types and not with the names of the donor therefore not violating the right to privacy.

The preconditions set for one to undergo mandatory testing before one is allowed to access services or certain facilities contravenes the right to privacy because it does not guarantee personal dignity. Also, it contravenes the right of non-discrimination because people are denied services on account of their HIV status. Normally, this type of testing fails to be a proportional test because other means could be utilized to achieve desired outcomes

3.7 Compulsory testing

This type of testing forces people into undergoing medical tests of any kind including the HIV one. The rationale for conducting this type of testing is based on restrictions placed under certain conditions especially when one is moving out of a country to another country. This type

of testing compromises human rights because it is based on prejudice. It basically blames certain groups of people of being responsible for spreading HIV or intending to spread it. It is also conducted in certain murder and rape cases that need to prove convicts as guilty of a criminal offence. As a result, these people do not have an alternative to give informed consents.

Equally important to the issue of compulsory testing is section 26 of the sexual offences act 2006. It would be important to note that a Lowdar based magistrate court convicted a victim under this section. This was in line with the criminal case number 99 of 2011 *Republic versus Peter Erukudi and Mary Itoot Ebenyo (unreported)*. The issue involved a person who was accused of engaging in gang rape. At the time of proceedings, it was noted that the co-accused knew that the first accused person was HIV positive. The medical results that were provided to the court proved it. To confirm the findings, the government carried out its own HIV testing. Based on the outcomes of the test, the accused person was convicted to life imprisonment. This gives an impression that compulsory testing is upheld by courts as the above case shows.

3.8 Breach of Confidentiality

John Godwin *et al.* (1993) define confidential information as information, which is made available to other people under circumstances that compel people possessing it not to share it with unauthorized people. It would be important to note that information would be shared with other people so long there is an agreement to do so. In spite of this, it would be possible for such information to be shared inappropriately as illustrated by the case of *Ansell Rubber Co. Pty Ltd. v Allied Rubber Industries Pty Ltd.* [1967]. The issue of protecting information, which is personal in nature, applies to personal information even if its disclosure to other people might not result to pecuniary loss. However, incomplete information might also violate the right to privacy for patients for instance forwarding medical invoice to insurance companies exposes personal information of the patient where one can deduce the condition e.g. HIV positive status of a person from the tests conducted or from the prescribed medication.

It should be noted that the extent to which health workers facilitate effective communication between them and the people they serve is critical during the counseling processes. These people should note that strict confidentiality in record keeping is important because it enhances the aspect of privacy in record keeping. It protects the interests of the people who are tested because the information is not shared with other people or kept in a manner that can enable them to access it. In this respect, confidentiality is very vital in privacy. Professional, health

workers have the mandate of protecting the information that patients give to them in line with section 21 of HAPCA 2006. This depends largely on the level of trust between those people and patients. Nevertheless, the trust that patients have towards medical processes might be eroded by unethical practices when promises of protecting confidential information are not fulfilled. Alongside with this, confidentiality within health sector might be eroded by constraints placed on the use of services.

The confidentiality duty in health facilities is vital because it persuades people to seek medical attention on a voluntary basis. The necessity of promoting the concept of confidentiality was noted in the English case *X v Y (1988) 2 All ER 648*. The case involved an application that was made to a court of law to bar a newspaper from publishing medical information that was considered confidential. It was noted that confidentiality was important in securing public health because patients would be unwilling to seek medical attention if confidentiality is not protected. R McClelland, R., (2001) asserts that in the absence of confidentiality patients would be unwilling to share information that they would consider sensitive to them. As a result, it would be important to note that while the law establishes mechanisms to protect public health, measures should be developed to encourage people to come forward to be tested by protecting individual right to privacy.

Even though health workers appreciate the fact that confidentiality is critical in provision of counseling services, they perceive the probable harms of strict enforcement of confidentiality. They claim that it places them in a dilemma whether they should maintain confidentiality when they know that if they do not share that information it would put other people at risk of infection. In Uganda, Nuwagaba- Biribonwoha et al. (2007) highlights the dilemma that health workers face when infected people feel uncomfortable to disclose their health conditions to their life partners. They claim that in such instances health workers face the dilemma of sticking to professional practices and that of breaching the confidentiality of patients.

Alongside the above, health workers also face the dilemma related to breaching the confidentiality promise or breaking it. The issue becomes even more complicated when those people are expected to ensure that HIV does not spread any further by ensuring that relevant information is made available to relevant people. Because of the challenge some of them disclose this information to spouses in the hope of protecting them. Such disclosures are based on belief that they would prevent HIV from spreading. While this is the case, the practice

exposes important details that PLHIV might want not to be shared with other people. This has the ability to expose PLHIV to stigma, social isolation, discrimination and violence.

Normally, the success of the existing laws depend on the mutual respect that each of them has on confidential information that relates to patients. Because of this, the confidentiality duty is vital since it discourages discrimination against PLHIV. As John Godwin et al notes, the issue of HIV carries with it discrimination and stigma, which are not common in other types of diseases. The simple reason is that exposure of such information might also expose the sexual habits of the PLHIV. Because of this PLHIV might lose certain benefits they enjoy in their places of work or even within their communities. For instance, members of community might voluntarily reject such people. Besides, it is possible that such people would encounter various problems within their communities or even within their families E. Farmer (1996). The problems might range from loss of friends and family to rejection including loss of jobs.

Like Harms AJA observed in relation to the issue of confidentiality within a South African case: *Jansen van Vuuren v Kruger*: the learned judge held that the reason behind confidentiality is twofold. On one hand, it focuses on protecting the privacy of patients whereas, on the other hand, it is aimed at promoting public interest. This is in line with *X v Y and Others (1988) 2 All ER 648 (QB)* where it is observed that the preservation of confidentiality is the way that secures public health in the long run. Otherwise, doctors would be discredited for violating this right, which they should protect. In this respect, confidentiality is crucial because it secures the future of health in general whether public or private.

The US Supreme Court also provides the rationale behind confidentiality in *Doe v The City of New York Commission on Human Rights*. It asserts that PLHIV have rights to privacy; thereby their health status should be treated as such. In *Whalen v Roe (1977)* it recognizes the existence of such rights within the constitution thereby advises that individual interests should be protected in HIV tests. This extends to other medical practices within the country. It acknowledges that information related to health is personal and as such they should be treated with utmost respect. Because of this patients have rights over that information implying that they can decide what should be done or not done with it. In this respect every person has the right to inform others about his/her medical condition freely without being coerced to do so. Even though this fact applies to other medical conditions, it applies largely to HIV, which for a long time is considered to be a terminal disease. This relates to the unfortunate feeling that

develops within majority of PLHIV especially when they expose their health conditions to other people unaware of possible discrimination. It is in view of these challenges that HCWs ought to maintain confidentiality of communication divulged by the patient during the course of treatment. This would help to reduce the unconstructive repercussions of being sued for breaching the right to privacy.

3.9 Conclusion

The main violations faced by PLHIV regarding the right to privacy are on informed consent, testing and breach of confidentiality. Under informed consent, healthcare workers do not seek consent before subjecting PLHIV to a HIV test. Several types of testing exist such as routine testing done in PMTCT programmes for pregnant women without seeking their consent and subjecting them to testing. Mandatory testing also denies PLHIV autonomy whether to be tested or not and also discriminates against them by denying them opportunities in employment where they are refused employment on the basis of their HIV status. These forms of testing violates the right to privacy for an individual. It is only voluntary testing which gives PLHIV the autonomy to decide whether to be tested or not. Breach of confidentiality arises when a healthcare worker share personal information concerning HIV test results with 3rd parties without consent. These unethical practices might erode the trust that patients have towards medical institutions and the use of services when promises of protecting the right to privacy are not fulfilled.

CHAPTER FOUR

THE NEGATIVE IMPACT OF VIOLATING THE RIGHT TO PRIVACY FOR PLHIV

4.1 Introduction

When rights to privacy are not safeguarded in the right way through informed consent, testing and breach of confidentiality results to devastating effects on the spread of HIV epidemic. Its effects can extend to family break ups, loss of jobs, violence, school expulsion, and property loss, denial of medical and even insurance services in certain organizations, self-rejection and even abandonment and in certain instances, discourage people from using strategies such as condoms because of fear of being stigmatized and discriminated. In so doing, the spread of the disease increases the more. The World Health Organization (WHO) claims that stigma coupled with discrimination is a major hindrance to testing and even disclosure of HIV status as well as uptake of antiretroviral drugs. Because of this majority of the people are discouraged from seeking medical attention even when they suspect they suffer from the disease. Despite the pervasiveness of stigma and discrimination together with their negative effects on national health system, the abuse of human rights for PLHIV remains widespread. This chapter will start by looking at stigma so as to understand it, its relation to HIV/AIDS and the impact of discrimination for PLHIV and the general community.

4.2 Stigma

Stigma refers to marks of infamy or disgrace that people develop out of bad experiences *Dictionary.com Unabridged. Random House, Inc. 11 July. 2011*. Goffman defines it as an attribute that discredits people and even reduce them to nothing. From whatever definition one adopts, stigma might result from attributes perceived as undesirable and it might develop undesirable bad experiences both physically and emotionally for PLHIV. Emotionally, it might impact attitudes that people develop towards others.

Under Goffman's definition, Lisanne Brown, Lea Trujillo, Kate Macintyre, regard stigma as a societal label that people develop towards others. In this respect, studies on HIV have evaluated the correlation between misunderstanding and misinformation on such labels in relation to the spread of HIV. Jones E, Farina A, Hastorf A, et al. (1984) contemplate stigma as an aspect that link people to unwelcome characteristics. In the light of this, Crocker et al claim that stigmatized people tend to possess characteristics that convey social identities devalued in

certain social contexts. Link B, Phelan J (2001) perceive stigma as societal processes that link to structures of power within societies. Because of the negative effects stigmatization raises, the society is able to develop prejudiced actions, behaviors and thoughts within various places including places of work, community or within governments Cameron E. (1993).

In his book, *living with AIDS- an unforgiveable crime? Growing Up. (1999)* Ogunyombo defines discrimination as an attribute of stigma. Discrimination in this case refers to forms of exclusion, prevention from accessing services, marginalization and restriction from expression. Discrimination might be expressed forcefully, through deaths and even from actions taken to avoid things that threaten life. It normally occurs when people are treated unfairly because of their identities in groups. It might be regarded as the manner in which stigma manifests itself. Both of the two attributes are cruel processes that prompt the need for protection from the powerful people. They burden the victimized people. Because of this stigma might also be viewed as a tool that powerful people use to protect their interests. However, it is viewed from the impacts it has on victims through discrimination (Douglas, 1995).

4.3 AIDS and Stigma

The Global Context of HIV claims that stigma and discrimination among the PLHIV remains a widespread issue for almost thirty years into the HIV epidemic. In this respect, stigma among PLHIV remains a powerful tool that undermines the efforts made within health ministry to combat HIV. Logie CH, James L, Tharao W, Loutfy MR (2011). Stigma and Discrimination within HIV/AIDS context are unique when they are compared to communicable and infectious diseases. Most of the time, they tend to develop hidden epidemics in form of social injustices. One notable thing is that the fear that surrounds the spread of HIV from 1980s persists even today. In spite of this, very little is known about HIV transmission, which scares people from interacting effectively with the infected ones.

During a UN convention held in 2001 under the UN Declaration of Commitment on HIV/AIDS, governments committed to reducing discrimination and stigma on PLHIV and other groups susceptible to HIV infections. Furthermore, a political declaration that was made in 2006, governments affirmed their commitments to protecting people from HIV infection by scaling up their HIV related programs. Accordingly, one of the 3 elements of the UNAIDS vision towards zero in 2015 is zero discrimination. According to the UNAIDS Global Commission on HIV and Law Report (2012) that evaluates the impact of stigma and

discrimination in various parts of the world, stigma on PLHIV is said to result to discrimination, which has devastating effects on HIV. In some instances, it might break up families, result to job loss, school expulsion, property loss and even denial of medical and even insurance services in certain organizations. At other times, it might result to violence and denial of support from relevant institutions. This might result to fear that might discourage people from going for medical tests related to HIV and even taking precautionary measures to protect themselves.

Because of the above, stigma related to HIV has attracted the attention of various researchers. Most of the studies that are conducted in HIV field and other related fields draw from Goffman's (1963) seminal work. They describe the issue on the basis of people who are perceived as possessing attributes considered as discrediting. From this perspective, Goffman's idea has been applied to studies conducted on the psychological elements of stigma. This is in spite of the fact that the original idea by Goffman centered on social and psychological elements of stigma processes Klienman A, Hall-Clifford R (2009).

In the light of this, Brown L, Macintyre K, Trujillo L, (2003) claim that stigma hinders the effort made towards preventing HIV from spreading. Similarly, it is widely agreed among various people that stigma hinders the effectiveness of programs developed to prevent HIV from spreading Fanta W, Worku (2012). Vanable PA, Carey MP, Blair DC, Littlewood RA (2006) notes that stigma results to depressive symptoms, hindering people from going for testing and even adhering to medication. In other instances, it discourages people from seeking maternity services and going for testing Turan JM, Hatcher AH, Medema-Wijnveen J, Onono M, Miller S, et al. (2012). A systematic review that assessed the impact that stigma had on efforts made to prevent HIV established that stigma among PLHIV was linked to rising instances of unsafe practices among those people, decreased use of biomedical related practices, use of prevention of mother-to-child transmission (PMTCT) practices, and use of antiretroviral treatment (ART) Mahajan AP, Sayles JN, Patel VA, Remien RH, Sawires SR, et al. (2008). It was also established that majority of the people who had not gone for HIV testing feared stigma emanating from HIV related diseases. As such, such people were likely to engage in unsafe sexual practices Pitpitan EV, Kalichman SC, Eaton LA, Cain D, Sikkema KJ, et al. (2012).

Even though the above conceptualization has been prevalent in the field of study, a new body of work has begun to imply that stigma related to HIV is a multi-level process that need to be

handled at community, familial and individual level Smolak A, El-Bassel N (2013). This necessitates the need to understand factors linked to HIV-related stigma as well as threat posed to different sub-groups. As a multi-level as well as multidimensional process, stigma emanating from HIV is linked to different factors. As a result, various studies have been able to demonstrate the link between higher levels of growth in economy and low levels of stigma that emanate from HIV. For instance, in a study that was conducted in three African nations namely Zambia, Ghana and Burkina Faso, Stephenson (2009) established that people who lived in communities that had high number of educated males or higher levels of employment had positive attitude towards PLHIV. To some extent, this could be as a result of knowledge on HIV among those people. Other factors that link to stigma that emanates from HIV include the exposure brought by mass media, experiences that people have with HIV, knowledge on PLHV, demographic attributes such as gender and age, people living either in urban or rural areas and HIV knowledge. Even though the spread of HIV manifests itself from different perspectives, heterosexual sex practices remain the main route through which HIV is spread in Africa. As such, most of HIV-related stigma focuses mainly on infidelity. This is more prevalent in Kenya where a number of factors including weak health systems together with weak legal frameworks hamper the effective implementation of programs aimed at minimizing the spread of HIV.

Even though studies highlight variability in HIV related stigma in sub-Saharan Africa, the problem of stigma that emanates from the epidemic remains an issue of concern in Africa and elsewhere (UNAIDS 2012). As a result, it has been recognized that stigma and discrimination remain to be the main obstacle towards effective implementation of HIV/AIDS prevention programs.

4.4 HIV Stigma and Discrimination in Kenya

Since independence, no disease has affected the country in the magnitude that HIV and AIDS has. In spite of this, for the last three decades from the first instance of HIV/AIDS incidence was reported in the country, tremendous effort has been geared towards treatment and prevention of the disease. Regardless of this, the number of victims remains relatively high with about 101,560 new cases of infection being reported every year. This makes the country number three with high incidences of the epidemic in the continent. This translates to about 1.6 million people who live with HIV. With a prevalence of over 5% according to the Kenya AIDS Indicator Survey 2012, a large number of the population is infected with HIV. The implication

of this on the health sector is that more needs to be done to ensure prevention of further infection in unaffected populations. Evidence has also shown that stigma is the main hindrance towards HIV testing and treatment. This is stimulated by discrimination that results from stigma. The unfortunate thing is that stigma still persists within programs geared towards preventing HIV despite the significant progress that have been made in eradicating the epidemic. Accordingly, as the country contend with the issue of reducing the number of new cases reported every year, stigma coupled with discrimination continue to hamper education on HIV an support offered to PLHIV (Kenya Stigma index 2014). The Stigma Index shows that stigma and discrimination emanating from HIV has risen to a high of 45% even though the perception varies from one region to the other. The issue also varies within different groups in our societies; as such, people in different age groups experience it differently. In this respect, some groups of people experience higher levels of stigma than others. This discourages people from those age groups from seeking medical interventions (Kenya AIDS response progress 2014).

To this end, Kenya has been committed to addressing the issue of stigma and discrimination within HIV. As a result, it has provided the relevant legal, social and policy environments at different levels to ensure that PLHIV are not barred from seeking supportive services offered in the country. As a demonstration of what the country has done, the HIV&AIDS Prevention and Control Act 2006, which developed the first HIV tribunal in the world, was developed to enhance access to justice for HIV related issues (Kenya AIDS Response Progress 2016).

4.5 Implications of discrimination

To date, the nature of stigma in Kenya against PLHIV is well established. It has been established that this does not only have significant implications on PLHIV, but it has also notable implication on the spread of epidemic as well as broader societies. Because of this, the notable impacts of stigma related to HIV should be acknowledged if effort to eradicate the vice has to succeed.

4.6 Making the epidemic invisible

One of the major impacts of stigma and discrimination is that it forces HIV to appear as a lesser issue as opposed to eradicating it. Because of this it forces people to hide the disease rather than eradicate it. In so doing, it has become almost impossible to eradicate the epidemic because the infected people are unwilling to come out and seek treatment. To make the matter

worse, when a family member is infected by HIV, this can be first step towards exclusion from society. Because of this, the disease can remain undisclosed as people try to protect themselves from discrimination. This practice and belief that people hold against HIV can thereby discourage people from seeking treatment (Skinner, 2001).

The practice of developing barriers between PLHIV and the rest of population takes away some of the energy geared towards eradicating the epidemic. This affects the effort that could be made towards eradicating stigma that emanate from HIV. Because of this, most of attention in the public eyes is directed towards discriminating the PLHIV. This can be dangerous because blame is directed towards a small group of people as the rest of the people in the country develop mistaken beliefs towards HIV (Douglas, 1995; van der Vliet, 1996). The major problem develops when those in power use discrimination to implement the programs that they develop. This can be dangerous when PLHIV are blamed instead of addressing the real challenges and human rights abuses they face. The fact remains that when intervention programs are developed from this basis, they discriminate against the PLHIV as opposed to helping them out of the problem.

4.7 Limiting access to treatment

Because stigma and discrimination have significant implication on things done towards diagnosis and treatment of HIV it is possible to hinder PLHIV from seeking supportive services offered in the country. This can delay the process of diagnosing the disease as well as its treatment including adopting healthy lifestyle practices. Normally, when there is stigma and discrimination, there is limited motivation towards testing because people do not see the need to be checked (Abdool Karim, Tarantola, Sy & Moodie, 1992). In certain instances, PLHIV have been depicted to fear stigma than HIV itself. As a result, stigma might be a great hindrance towards effort that people put in seeking treatment (Lie & Biswalo, 1994). This is a major challenge within PMTCT where women fear being tested because of discrimination that would come as a result of HIV (Grange, Story & Zumla, 2001) or where PLHIV fear accessing treatment due to exclusion of HTC services in hospitals. To make the matter worse, even the people who know their HIV status might be discouraged from seeking supportive services offered in different parts of the country (Grange, Story & Zumla, 2001; Rehm & Franck, 2000). The reason is that they might be shy to express their status even to family members (Wiener, Battles, Heilman, Sigelman & Pizzo, 1996; Yoshika & Schustack, 2001). In spite of this, there is need to acknowledge that testing is beneficial to us as a whole. If we would do this, we would

be able to promote better practices that would improve the health conditions in the country (Aranda-Naranjo & Davis, 2000).

4.8 Domestic violence and abandonment

The tendency that most of married women tend to be discriminated against by their in-laws when they are found to be infected with HIV discourage most of them to go for HIV testing, disclose their health status and even seek treatment. This is largely because most of these women depend heavily on men for economic stability and independence. As a result, they are vulnerable to abuses of all forms. In Kenya, majority of married women are at risks of domestic violence when found HIV positive by their partners. This forms part of the notable stigma against women living with HIV in the country. Such experiences discourage women from seeking supportive medical attention from hospitals which might worsen their health conditions.

4.9 Impact on identity and coping of the person with HIV

There is no doubt that stigma has notable effects on PLHIV. It affects their senses of identity as well as self-perception. This affects the way they relate with other people and perceive things. Studies have established that most of them normally feel guilty, shameful, dirty and even isolated. This affects their identities (Kalichman, 2004). In so doing, they are unable to take part in various activities of life (Sowell, Seals, Moneyham, Demi, Cohen & Brake, 1997). Self-inflicted stigma affects their abilities to live lives positively; it discourages them from adhering to treatment processes. Furthermore, it makes them feel lonely, demotivates them, and even affects their self-esteem because they lack interest in many things. In terms of practicing safe sex, some of them are discouraged to go for testing and even using preventive methods. The self-inflicted stigma as well as negative reaction from society is able to hamper efforts geared towards preventing the spread of HIV by allowing silence to prevail among the infected people. Similarly, the negative concept that emanates from worthlessness, blame and shame is also harmful to PLHIV, but it is normally disregarded most of the time. When stigma is internalized in the minds and hearts of PLHIV, it affects the way they perceive themselves, the way they interact with others and even the way they interact with those who offer health services to them (Lee, Kochman & Sikkema, 2002). Once again, this affects the way they accept themselves and even handle themselves in the processes of addressing challenges emanating from the epidemic.

4.10 Disclosure, support and protection of those close to the infected person

Discrimination has great negative effect on trust in any relationship. For the PLHIV, it leaves them with feelings of loneliness because they are normally left alone even by their family members, colleagues and members of community. As a result, discrimination has been demonstrated to discourage these people from disclosing their health status to other people because of possible rejection and isolation (Maman, Mbwanbo, Hogan, Kilonza, Sweat & Weiss, 2001). While it is understandable that people do this to protect their identities, it is rather obvious it increases the rate of transmission among people living together. This has the ability to break social commitment that people have of caring for one another.

4.11 Impact on behavior change

The stigma that results from HIV as well as discrimination that follows has great impact on measures put in place to prevent the spread of HIV (Grundlingh, 1999). The use of condoms have so far become an indicator of the epidemic; thus, there is a possibility of rejection for the people using those (Link & Phelan, 2002). For communities that encourage people to marry many partners, the people with single partners might be marginalized. This might encourage some of the people to engage in prostitution, gayism and lesbianism as they try to counter the challenges of stigma. Nonetheless, these groups of people are also vulnerable to HIV. As a result, people who result to such behaviors might increase stigma against them (Parker, Aggleton, Attawell, et al., 2002). Other forms of stigma such as those based on social classes, race and gender are also likely to increase the rates of infection as people attempt to cope up with stigma (Ziegler & Krieger, 1997). Because of this some people are forced to deny that they belong to such groups; as such, they practice unsafe sexual practices (Leclerc-Madlala, 1997). While this is the case, people who do not belong to such groups might be tempted to practice safe sex as they justify themselves and their courses of action (Crewe, 1992; Ross & Levine, 2002).

From the above analysis, it is evident that stigma has played a significant role in discouraging majority of the people to seek medical services and testing services from health institutions as well as using ART. According to Niehaus (2007), stigma that emanates from the epidemic emanates from the fact that majority of the people link it to death. As a result, when one is declared as positive, he/she views it as death sentence. This feeling is not new because it shifts the causes of the epidemic to unprotected sex and other sexual behaviors. According to Burn and Grove (2001), the perception developed towards HIV depicts the many aspects concerning

the way people respond to HIV including the manner in which they do not make use of health services available to them. It also depicts the manner in which most of these people make use of the services in private as well as hide their health status to other people. Most of these viewpoints are widespread in the country.

4.12 Conclusion

Stigma and discrimination impacts negatively on the right to privacy for PLHIV and can result to break up in families, result to job loss, school expulsion, property loss and even denial of medical and even insurance services in certain organizations. At other times, it might result to violence and denial of support from relevant institutions. This might result to fear that might discourage people from going for medical tests related to HIV and even taking precautionary measures to protect themselves. The fear of such consequences may discourage people from adopting safe health seeking behaviors thereby leading to increased HIV infections and negating prevention and control efforts.

CHAPTER FIVE

CONCLUSION AND RECOMMENDATIONS

The study set out to investigate why the right to privacy for PLHIV is still being violated yet Kenya has omnibus National HIV law, the Constitution and rights under general laws that are already there for the protection of this right. This research project has five chapters. The first one introduces the study by providing background information as well as identifying the main problem in the area of study, the objectives of the study, research questions, literature review, theoretical framework, methodology, as well as limitations. The second chapter analyzes the legal and policy provisos that protect the right to privacy for PLHIV in the country from international, regional and national perspectives. The third chapter sets out the type of violations that PLHIV face in regards to their right to privacy. Chapter four discusses the effects of the violations in the previous chapter and how they violate the right to privacy for PLHIV. The fifth contains conclusions and recommendations.

This research poses the argument of self-determination/autonomy, which PLHIV reclaim their power to decide the way their personal information relating to their health status should be handled. The control they have on this information in terms of who can access or even use it. As a result, PLHIV should have autonomous rights in making decisions affecting them and not a duty. This can be guided by either traditional, religious or communal values or beliefs.

This section provides an outline of the research methodology used to answer the research questions, the research approach, description of secondary data collection process, data analysis techniques used. This study relies on secondary data to address its objectives. It involves reviewing existing literature that relate to violation of human rights of PLHIV, the frameworks that protect them, laws and policies impacting on this right and related journals, publications and media documenting violations against PLHIV. The analysis is organized through thematic areas based on logic and systematic way. First by organization of keys themes, summarizing the information and finally discussion of the findings to build on the study objectives hence draw conclusions.

The findings establish there are several laws and policies at the regional and national levels such as the EAC HIV and AIDS Prevention and Control Act 2012, the HIV and AIDS Prevention and Control Act 2006 and the Health Act 2012 among others. Despite the existence of all these laws, the right to privacy for PLHIV in Kenya is still being violated in practice. The first, inadequacy of certain laws might explain the continued violation of the right to privacy for PLHIV. The EAC HIV and AIDS Prevention and Control Act 2012, which supersedes national HIV laws in particular HAPCA 2006, still has a provision on partner notification by healthcare workers which violates the right to privacy for PLHIV. While HAPCA 2006 had the same provision under section 24 which was nullified in 2016. Another reason why the right to privacy is still violated is lack of implementation of laws such as the HIV and AIDS Prevention and Control Act 2006. Section 20 of HAPCA 2006 mandates the Minister of Health to develop privacy guidelines. Since the enactment of this act, no privacy guidelines have been developed to date. Next is on public health.

The Health Act 2017 has exceptions on confidentiality on the ground of preserving public health which can be used by the government to violate the right to privacy for PLHIV. The health of many is esteemed against an individual's right. Yet another reason for continued violation of the right to privacy is existence of gaps in certain laws. Pre-employment testing is a common practice in Kenya yet there is no provision in the Employment act forbidding it. Additionally, the Health Information System Policy makes provision for collection of health service data and the conveyance of that data electronically yet Kenya has no specific legal framework for data protection which poses challenges in case of intrusion of these systems. In the final analysis is inconsistencies in policies. The current National Guidelines for HIV Testing and Counselling in Kenya 2010 introduced name based referrals whereas the previous guidelines were anonymous. To wrap it all up, this research establishes several reasons that may explain the continuous violation of the right to Privacy for PLHIV in spite of the existence of laws and policies. Based on these finding there is need to ensure that the processes of implementing and enforcing protective laws are strengthened. This would involve undertaking a comprehensive review of the legal frameworks in the country and addressing obstacles that hinder their full implementation.

While the focus of the study is on PLHIV in general, studies that would be carried out in the future should attempt to research on other areas that affect PLHIV. For instance, a gender approach focusing on women or marginalized groups such as LGBTQI, disabled among others

in violation of their right to privacy so as to comprehend the complex challenges that these groups face since vulnerability affects differently across the spectrum. Another recommendation would be to use a different methodology such as qualitative research to gather primary data from PLHIV on their lived experiences through the use of interviews, structured questionnaires and focus group discussions.

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