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**Informed Consent requirements in HIV testing in Zambia:  
“a question of a borrowed bucket”?**

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A dissertation submitted for the Degree of  
Doctor of Philosophy (PhD) in Law  
Birkbeck School of Law  
University of London

**15 September 2017**

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## **Declaration**

I hereby confirm that the work presented in this document is the result of my own research, except where I have used material from other sources of which to the best of my knowledge and belief I have fully referenced.

Signed: .....

Date: .....

## **Abstract**

### ***Background***

Zambia has one of the highest rates of HIV prevalence in the world. As of the year 2016, HIV prevalence in Zambia stood at 13.3% among people who are between 15-49 years of age. It is very important to reduce this, and to ensure that PLWHA are able to access appropriate treatment and support. This results in a better quality of life, improves health and well-being, and can help combat the stigma associated with the disease. In order to achieve this, PLWHA need to know their status, and this means testing. This is why exploring informed consent to testing – and understanding whether the value of autonomy and its application in HIV informed consent practice is appropriate, is important to this research. This research focusses on reviewing the appropriateness of individual autonomy in HIV testing in the Zambian context.

### ***Methods***

I conducted both literature analysis and fieldwork for this study. I reviewed the notion of individual autonomy and informed consent by analysing the value from both Western liberal and sub-Saharan African (Zambian) traditional and moral theses. Having reviewed the value through literature analysis, I also decided to go to Zambia to learn about how the ordinary people there experience and view their autonomies, particularly in HIV testing. 103 participants from Lusaka and Chongwe, Zambia took part in this research's fieldwork. The participants came from various demographics: PLWHA, pregnant women (and women in general), men in general, churchgoers, health-providers, policymakers, and participants in rural areas.

### ***Results***

The results showed that the universalisation of the value of individual autonomy in HIV testing in the sub-Saharan Africa is inappropriate. It was found that individual decision-making is inextricably enmeshed in multiple influences – factors both internal and external to an individual – therefore, also making rational choice (internalist) theories to be inadequate accounts of autonomy. It was concluded that individual autonomy is an illusion. Moreover, it was also found that application of individual autonomy in HIV testing in the Zambian (and sub-Saharan Africa context) is morally indefensible. It was demonstrated that HIV does not only affect PLWHA, but also the common good.

### ***Conclusion***

The findings have confirmed that individual autonomy is an illusion; and indicated that sub-Saharan Africa has an indigenous value system of Ubuntu which can appropriately be transposed in HIV testing informed consent requirements in Zambia. The traditional African ontological thesis of the human condition offers a more plausible basis for HIV informed consent requirements than the Western liberal perspective.

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It was said by one sage, Lao Tsu, that “The Journey of a thousand miles begins with one step”, by another, Natalia Makarovo, that “people tell me I am dancing better than ever”, and yet another, Karl Jung, said “one looks back with appreciation to the brilliant teachers, but with gratitude to those who touched our feelings”. I started on this journey in 2014; my first step was to contact my supervisor, Professor Matthew Weait, to check if I could be his student. He accepted me! I was exceedingly delighted that he could give such a rare and invaluable opportunity to me! This led to the second part of my journey; I started my research to discover what people say I am.

Yet, unknown to me, this journey was to take me through both a wilderness of tears and a paradise of joy and enlightenment. I cried at several moments and danced in delight at several others. I despaired and my heart fainted at several times, but hope was infused into my breast by others at several others. As a result, sometimes I wondered whether I should discontinue this journey; I had walked several steps by then.

Then I heard my supervisor, family members, and friends tell me (directly and indirectly) that since I started my research they have seen me dance “better than ever”. In my heart I said to them “I am dancing better than ever” because of you who have compassionately and with endurance played the delightful music which has enabled me to learn how to dance. Now, I wish to take this opportunity to say my heartfelt thanks to them!

I wish to express my gratitude to a great man; my wonderful, preserving, patient, tolerant, and critical (but fair) supervisor, Professor Matthew Weait. It is him who has not only been a brilliant teacher to me, but touched my feelings and brought me down to earth. In other words, without him, his endurance, and support I wouldn’t have known how to dance. Indeed, I shall forever hold close to my heart the invaluable lessons he taught me when I was his student. I had a supervisor who did not only guide me on how I can access knowledge, but he also taught me through his own actions and deeds how I could use that knowledge for self-improvement and the common good.

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It is on the basis of the supportive, loving, nurturing and illuminating pedestal of these others that I now venture to submit the ideas presented in this thesis.

Kasoka

September 2017

## List of Acronyms

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral Therapy
AVERT	Anti-Virus Emergency Response Team
BSAC	British South Africa Company
CD4	Cluster of Differentiation 4
CIA	Central Intelligence Agency
DCT	Diagnostic Counselling and Testing
ECTHR	European Court of Human Rights
FG	Focus Group
GDP	Gross Domestic Product
GRZ	Government of the Republic of Zambia
HAART	Highly Active-Retroviral Therapy
HB	Haemoglobin
HTC	HIV Testing and Counselling
HIV	Human Immunodeficiency Virus
MTCT	Mother To Child Transmission
MP	Member of Parliament
NGOs	Non-Governmental Organisations
PEPFAR	President Emergency Plan for AIDS Relief
PITC	Provider-Initiated Testing and Counselling
PLHIV	People Living with HIV
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother to Child Transmission
STIs	Sexually Transmitted illnesses
TB	Tuberculosis
UK	United Kingdom
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGA	United Nations General Assembly
UNICEF	United Nations International Children's Education Fund
UNFPA	United Nations Fund for Population Activities
USAID	United Nations Agency for International Development
U.S.A	United States of America
UTH	University Teaching Hospital
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation
ZAMPHIA	Zambia Population-Based HIV Impact Assessment
ZDHS	Zambia Demographic and Health Survey

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# 1

## Introduction

Although globally AIDS is no longer among the top ten causes of death (Media Centre - WHO, 2017), HIV/AIDS is still the number one cause of death in Africa (Shaban, 2016; Mwaniki, 2017). Despite Africa accounting for 17% of the world population (United Nations Department of Economic and Social Affairs (UN-DESA), 2017), Africa accounts for 25.6 million of the 36.7 PLHIV worldwide (Media Centre - WHO, 2017). With respect to knowledge of HIV status, globally only 70% of PLWHA know their HIV status (Media Centre - WHO, 2017). In the Eastern and Southern Africa region where HIV prevalence is particularly high, standing at 19 million PLHIV, only 56% know their HIV status (UNAIDS, 2016). In Zambia, (for example, the Western Province of the country has a 16% HIV prevalence among people aged 15-49 years) only 67.3% of PLHIV countrywide know their status (ZAMPHIA, 2016).

HIV testing is critical as an entry point for HIV treatment and care. UNAIDS and WHO have confirmed that adherence to an effective ART regimen can result in reduction (by 96%) of the risk of transmitting the virus to an uninfected sexual partner, and can cause viral suppression that will lead to a PLHIV living a normal lifestyle and longer life expectancy. Without ART, PLHIV develop AIDS as a result of a compromised immune system, thereby exposing them to development of infections, certain cancers, and other severe clinical manifestations (United Nations Department of Economic and Social Affairs (UN-DESA), 2017; UNAIDS, 2016).

In fact, HIV testing, “early diagnosis, linkage and retention in care and earlier ART initiation have been identified as key components to achieve the” UNAIDS’s “proposed 90-90-90 Fast-Track treatment” to end HIV/AIDS epidemic (Gueler, et al., 2017, p. 1). Indeed, with the availability of ART, a positive HIV test result is no longer a death sentence, but a chronic manageable illness. Moreover, in relation to Zambia, people can now be encouraged to know their status because since 2002 Zambia in collaboration with its cooperating partners like USAID (through PEPFAR) has rolled out free ART throughout the country (WHO, 2005;

Schumaker & Bond, 2008; Geloo, 2011; United Nations, 2013). Therefore, besides the need to urgently address the prevailing realities of HIV stigma and discrimination in the country, there are no longer any more general excuses as to why people cannot voluntarily avail themselves to test for HIV. Indeed, stigma is prevalent in Zambia and impedes HIV uptake (Bond, et al., 2003; Geloo, 2011; International Center for Research on Women (ICRW), 2006; Kapungwe, et al., 2010; Network of Zambian People Living with HIV/AIDS, Zambia, 2012; Smith, 2014; AVERT, 2017). In the light of the reality of stigma and human rights, it is imperative that VCT is retained as a testing approach in Zambia.

However, according to UNAIDS/ WHO guidelines (which Zambia has adopted), the Zambian constitution, legal precedence in the country, and the country's current documented HIV testing, counselling and treatment guidelines, a person has got a right to accept or refuse HIV testing due to, among other things, her autonomy as a human being.

In this study I seek to critically analyse if the value of autonomy can be theoretically and empirically defended, and be appropriately applied in sub-Saharan Africa where HIV is an epidemic. Nonetheless, two weeks ago from today (August 30, 2017), the Government of Zambia through its current President, Mr Edgar Lungu, proclaimed a policy decision to the effect that HIV testing in the country is now mandatory. However, the government at the time of my amending this thesis's introductory chapter (in my effort to reflect the said declaration) had not yet publicly issued any guidelines or policy directions on how or if it will indeed proceed to implement the proclaimed policy.

That said, I wish to mention that the issues on which the President foregrounded the said policy decision of mandatory testing had already been raised and analysed in this study. Hence, the conclusion of the analysis also leads me to oppose the proclaimed mandatory HIV testing policy decision. Mandatory HIV testing can result in violations of human rights and increased stigma, and there is no available empirical evidence to suggest that a mandatory HIV testing regime can lead to stopping and reversing HIV/AIDS.

Moreover, I wish to say that President Lungu's recent policy declaration further legitimises the relevancy of this research project. Indeed, some of the pronouncements made so far in relation to the ongoing debate surrounding the proclaimed testing policy confirms what I

found during fieldwork in Lusaka and Chongwe, Zambia regarding how HIV testing is in practice carried out in medical facilities.

## **1.1 Problem statement**

This thesis is a product of research I undertook to investigate the appropriateness of the value of informed consent requirements in HIV testing. I wanted to find out about whether an individual who is surrounded by multiple realities is in fact capable of being an autonomous agent, and if capable, whether autonomy is still a value which should be promoted no matter the circumstances. The right to autonomy does not allow an individual to interfere with another person's choices. The individual is held to be a sovereign of her choices.

In fact, HIV law and policy in various countries around the world and literature from various disciplines suggest that the application of informed consent during health worker – service-user contact ought to be mandatory in order to secure autonomy. Informed consent requirements require that an individual is given information regarding an envisioned medical intervention, and is provided with an opportunity to reflect, form and act upon such information for her own good and purposes.

I use the concept 'autonomy' (being autonomous) in this thesis to mean (as a working definition) an ability to self-govern or to be sovereign over one's life and choices (Oshana, 1998; Gaylin & Jennings, 2003; Jackson, 2013). Further discussion and analysis of the concept is provided in chapter 3.

In other words, after a period of self-reflection and discussions with my PhD supervisor, I began to suspect that the bioethical and legal universalisation of HIV testing informed consent requirements in Zambia could be problematic. I thought it could be problematic, firstly because individual human beings didn't seem to be capable of acting autonomously, and secondly, because the culture of individual autonomy even though it correctly celebrates that there can be no free society without individual freedoms, does not seem to advance with equal force that "there can be no sustainable society that rests on autonomy alone" (Gaylin & Jennings, 2003, p. 167).



In this vein, I built my hypothesis on the premise that the universalisation of informed consent requirements in HIV testing in Zambian law and policy mismatches the observed reality of the practice of autonomy. This study hypothesises that individual decision-making is enmeshed in multiple influences and realities; hence, individual autonomy in practice could be illusory. When it comes to the application of the doctrine to HIV testing, my hypothesis posits that, whilst HIV and AIDS affects individual PLWHA, it also affects other people.<sup>1</sup> Given this, is individual autonomy in HIV testing justified, or should HIV testing informed consent requirements reflect the putative reality of being surrounded by others? Should socio-cultural and economic realities take precedence over individual human rights in HIV testing?

This study supports an HIV testing policy which respects human rights, and at the same time is not blind to the practical aspect of individual autonomy, and the socio-cultural and economic experiences and realities of a given people.

### **1.1.1 My voice in this research**

Before I continue to introduce the subject of my research, I wish to share my own story on how I came to this time in my life. I share this story for three reasons: to declare my personal interest in this study; to provide a background for why a qualitative research was chosen for this inquiry; and to indicate why I chose the topic of HIV testing. That said, the following narration speaks about the journey which led me to this research.

“What is your name?” “Where do you come from?” “What do you do for your living?” “Have you got family in England?” are questions people often ask me. “Where do I come from?”

---

<sup>1</sup> On an individual level, the HIV epidemic in Zambia has altered individual quality of life and lifestyles (Mweemba, Zeller, Ludwick, & Gosnell, 2009), and causes suffering and death. Moreover, HIV also affects other people, other than PLWHA. For example, with more than 1 in every 10 adult persons living with HIV in Zambia, the epidemic has taken a toll on the country’s health workforce. In a cross-sectional study (2001-2005) carried out in the country, it was reported that HIV is a leading cause of patient work load which is putting strain on the already under-staffed and over-burdened medical workforce (Vwalika, 2010). The HIV epidemic also affects the well-being of PLWHA’s immediate families, caregivers, communities, and the country as a whole. Other people suffer because a relative is suffering from AIDS, or dies. On a national level, the country has lost a lot of skilled workforce through AIDS, and also a lot of money has been spent in response to the epidemic – money which could have been allocated to address other pressing developmental concerns, for example, development of the educational and health infrastructure of the country.

“Who am I?” “Where am I?” “Why am I here?” “Who am I in relation to other human beings?” “Where am I going?” are the questions I have been asking myself since I became conscious of my being and mortality.

I was born in Zambezi, Zambia in 1981, a Lunda<sup>2</sup> by ethnicity and Zambian by nationality. I became a self-conscious living being through no peculiar means, but the natural provision set apart for mankind. Moreover, upon coming to the conscious me I was inevitably given to this inquiry common to human beings: to find out about where I came from, why I am here, and where I am going.

The Christian Bible, science, and philosophy all gave me different answers. The questions about where I come from and where I am going, that is, how I came to be a living creature who is capable of exercising charity and yet at the same time capable of hate; one who is able to aspire, achieve, and grow, and yet at the same time has his days marked by pain, sorrow, rejection, failure, and subsequently death, are questions which have intrigued and plagued me over the many years of my consciousness. They are questions which to my disappointment have been asked over and over by various philosophers, theologians and scientists, and yet the various answers which have been offered do not establish a common thesis to which every man can appeal to for comfort. This uncertainty has led to every man choosing what “ism” fits best her personal worldview and comfort.

The Christian Bible and my mother told me that it is God who created me, and that the days of my life are predestined by the very Divine. Various schools of science tell me that I am either a descendant of a primate, or that the life of my ancestors came to being by chance, such as with the crash of a meteor or comet that came from another galaxy. That is, notwithstanding the explanations by the Russian biochemist Aleksandr Oparin (Pirie, 1956) and the English geneticist John Haldane who suggest that original life on earth (of which I am alleged to be billions of years’ evolutionary product) is the product of a mixture of various organic chemical compounds in a primordial soup (Phillips, 2010).

With regards to my mortality, my mother and the Christian Bible tell me that I am a ‘pilgrim’ here on earth who will be required to give an account one day to God when my allotted days on earth have been exhausted. I am told that my pending judgment will be premised

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<sup>2</sup> The Lunda people are a Bantu-speaking people whose origin is traced to the Niger-Congo.

on how I have related with God, with myself and fellow man in this life. Put simply, the aforementioned premise on which my judgment is said to be based is understood to be hinged on how my life's account will fair in regards to the Biblical injunction:

Love the Lord your God with all your heart and with all your soul and with all your mind and with all your strength... [And] love your neighbour as yourself" (The Holy Bible, New International Version, 2001, p. 561).

On the other hand, commenting on the state of being and meaning of my life, celebrated luminaries, e.g., Leo Tolstoy, invite me to understand that my consciousness is primary, boundless and eternal. That it is:

Part of the boundless creating universal consciousness, and simultaneously this consciousness itself. [That] it makes, through human conscience and creative mind, that indestructible meaning of the person's life, which can be defined as working for the common good (Riakkenen, 2008).

And yet when I consider my father's Lunda traditional religion on the question of mortality, I am told that after my demise I am going to become either an ancestral spirit or a wandering evil spirit, depending on how I have related, not only to myself, but also to my neighbour.

Science, on the other hand, has indicated that when I die that will be it (total annihilation). That is, there is no life or consciousness of self beyond the grave. One of Britain's most eminent scientists, for example, on being asked about the afterlife puts it this way:

I regard the brain as a computer which will stop working when its components fail. There is no heaven or afterlife for broken down computers; that is a fairy tale for people afraid of the dark (Sample, 2011).

I must confess that my search to establish a common truth of 'where I come from and where I am going', is something that I have now come to appreciate I am in no position to provide a response to. This is because whatever answers I may come up with one or more readers may, by applying their own critical minds, accuse my position of being farcical, misinformed, ludicrous or dogmatic. Indeed, it would be right for anyone to pass such an indictment because the question of 'where I come from' and 'where I am going' is one which has stretched human thought and imagination over many centuries and yet has persistently resulted in a lack of a coherent common concept.

Tolstoy lamented:

I searched through human knowledge for an answer to this question [the question of “who am I?”], which is the same whatever it way it is expressed. I found that according to their relation to the question, all branches of human knowledge are divided, almost into two opposite hemispheres, at the opposite ends of which are two poles: one positive and one negative: yet at neither pole were there any answers to the question of life... One branch of knowledge does not even seem to acknowledge the question and yet gives clear and precise answers to its own independently posed questions: this is the realm of experimental knowledge... The other realm of knowledge recognises the question but does not answer it. This is the sphere of speculative philosophy... Thus, whatever way I twist these speculative answers of philosophy, I can find nothing resembling an answer. This is not because, as in the case of clear, experimental sciences, the answer does not relate to the question, but because despite all the intellectual effort directed at my question, there is no answer. And instead of an answer all one gets is the same question, only put in a more complicated form (Tolstoy, 1987, pp. 35-38).

However, there is at least one question amongst the questions asked above which human beings are in a position to find a response to by way of empirical research, and this is the question I have researched in this study. The question is “who am I in relation to me and others?”

As a new entrant into this world I was born but a mewling, helpless, fragile, and a defenceless creature wholly dependent for my being and daily sustenance on the benevolence, non-maleficence, and justice of other human beings. Prompted by natural appetites, as an infant, I would at several times expend my tears in protest on being denied (by my care-givers) the opportunity to play with a knife, to twist the tail of a cat, to drink anything which appeared consumable, to taste or eat anything which was in sight, etc. Actions by my caregivers to arrest my appetites which exposed me to self-harm seemed nothing to me at the time but systematic and contemptuous injustices and behaviours which violated my conceived sense of self and wellbeing.

Actually, during my childhood life I was brought-up through an extended social family system whose values and goals inspired the actions of my parents and other caregivers. Thus, being enmeshed into such a social system had consequences on how I later developed my sense of being, and perceived the world. At once I began to share consciously and unconsciously in the ways of a culture which established and obliged the very values of my

caregivers, and those with whom I shared the immediate geographical environment, tongue or common ancestry.

I have often thought that my personality was not only influenced by the instructions I consciously received from my elders, but also unconscious disciplines I may have experienced when my faculties as a baby were still developing. And, I also feared that the conscious and unconscious in-take of my ancestors' cultural norms made me not only blind to other peoples' cultural practices around the world, but also made me a destitute to those very alien values and ethos.

Culture shows the world and also makes man blind and deaf. We are vastly various and yet laughably alike (Endleman, 1967, p. 3).

Indeed, I became enmeshed (consciously and unconsciously) in a culture of shared pains, joys and a world of solidarity. In other words, I became voluntarily and at the same time involuntarily initiated into the traditional ethos of my deceased ancestors. Although a unique, separate individual with sometimes riotous appetites, I also helplessly saw in me a creature who desired social contact, satisfaction, approval, and warmth from others. However, unlike when I was a baby, now as an adult I was not only to cry for nourishment, affection, and happiness from others, but I was now also expected to reciprocate the same to others. I had helplessly become entombed in social networks. My natural appetite for love, approval and aid from others had also become others' desires for my love, approval and aid.

It is such realities which have made me question my autonomy as a human being. Can a human being who has been socialised since she was born, and who is interconnected and interdependent with other human beings, claim to be autonomous? Can she authentically and justifiably claim individual autonomy in HIV testing?

Retracing back to my boyhood years, I remember being told about HIV and AIDS. My primary school teacher indicated that "this" HIV and AIDS threatened the very fabric of the society in which I was born into. She did not say "HIV was a menace to me as an individual", now coming to think about it. Indeed, in subsequent years, as my awareness developed, I came to witness very close relatives and friends die of AIDS-related illnesses. Over the years

to date I have witnessed AIDS-related deaths and suffering not only amongst close relatives and friends, but also many families I know in Zambia.

Amongst some of my close friends and relatives whom I witnessed die of AIDS-related illnesses, most of them lived in denial of the possibility of living with HIV or AIDS. They were afraid to imagine that they could be living with HIV or AIDS, and so they refused to test for HIV. They chose to die of an 'unknown' illness, instead. Some later tested, but only when the disease had already reached an advanced stage; they eventually died because at this stage their CD4 counts were so low, that the administration of ART had become effectively useless. They did not test for HIV and no one could have forced them to do so because they all enjoyed the right to bodily integrity or autonomy. Had they tested, it is most likely that they could have been alive today.

I say this because HIV testing as an entry point to treatment has made an invaluable contribution in curbing the epidemic. Thus, encouraging HIV testing uptake is an effective tool in response to the epidemic:

Significant progress has been made in curbing HIV-AIDS prevalence, incidence and burden in the past two decades. However, over 36 million people still live with the disease worldwide especially in Sub-Saharan Africa. The advent of Highly Active-Retroviral Therapy, (HAART), has drastically changed the course of HIV infected persons. The disease has evolved from being a deadly infectious condition, to a chronic disease. Nowadays, most infected persons live a normal life due to the improved access, availability and effectiveness of Anti-Retroviral Therapy (Bain, et al., 2015, p. 2).

Put differently, it is these experiences and knowledge which motivated me to review the basis of informed consent requirements in HIV testing. This also allows me to learn from others about what they think I am as an individual human being. Do they regard and celebrate me as an autonomous individual who can do whatever I please for the sake of the good and purposes of my own life, or am I regarded by others – as I was by my elders at Chifwisha village in the Zambezi district of Zambia – as an inextricably social creature with social and/ or moral responsibilities towards others? Or am I both? How would my deceased Bantu ancestor and the contemporary Zambian adult walking the streets of Lusaka and Chongwe respond to me if I emphasised to her that I am never going to test for HIV because I can do whatever I want to do with myself as I am a sovereign of my own life?

I became critical of the value of individual autonomy in informed consent requirements in HIV testing after suspecting that such proclaimed autonomy appears to be in conflict with human nature and clinical interests. In relation to clinical interests, I wanted to find out about whether individual autonomy is a necessary and justified value that would need securing no matter the consequences to others. In other words, granted that a healthy individual is of benefit to the individual herself, her family, community, country, etc., I thought, “Could there be a need to promote individual health beyond the mere interests of individual citizens?”

A qualitative methodology which I employed in seeking to answer these questions gave research participants the opportunity to tell their own stories from their own perspectives in their own words. Hence, I was able to gain an understanding of what the majority of research subjects thought about autonomy and HIV testing.

Indeed, whether someone considers oneself to be a product of a natural accident that happened billions of years ago or as a creation of God, at least one thing of which we can be sure of is that we are living individual human beings born into a society of people, a people with whom we consciously interact on a daily basis. We can also celebrate that as human beings we are endowed with the ability to self-reflect. This is what I have done in this research, learned from other people’s products of self-reflection on the question of “who am I in relation to me and other people around me?” Indeed, this research is based on exploring what every conscious rational person cannot only subjectively but also objectively attest to because of things she has experienced, observed or perceived within and outside of herself.<sup>3</sup>

## **1.2 The global HIV epidemic and testing**

Three decades into the HIV epidemic, HIV still poses a real health challenge from which no country in the world is immune, more especially sub-Saharan African countries. According to UNAIDS’ factsheet, at the end of 2015 36.7 million people worldwide were living with HIV

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<sup>3</sup> This is what I have done in this section: I have reflected on my experiences regarding how, since I became conscious of me, I have related with this life and other human beings. However, this study is devoted to learning about what other people’s experiences and views say I am as an individual human being.

(UNAIDS, 2016). The same source indicates that 78 million people as of the end of 2015 became infected with HIV since the beginning of the epidemic. Of the 78 million infected, 35 million have since died from AIDS-related illnesses. This makes HIV one of the major causes of morbidity and mortality in the world.

Given the threat of the epidemic, it is not surprising that all the United Nations member states agreed to reach certain targets in response to the disease. These targets were earlier set to be achieved by 2015. Some of the targets included the reduction of sexual and parental transmission of HIV by 50%, elimination of vertical HIV transmission, reduction of TB deaths among people living with HIV by 50%, and delivery of ART to 15 million people (Suthar, et al., 2013, p. 2; Udjo & Lalthapersad-Pillay, 2015). However, it was noted that the achievement of such goals required that people test for HIV since it is only through knowledge of one's serostatus that one can be linked to prevention, treatment and care services (Suthar, et al., 2013).

On how countries have fared in regards to the meeting of the 2015 goals, a study shows that the majority of Southern African countries were unlikely to meet the goals by 2015, even though some countries like Botswana and Namibia showed trends of reductions in the spread of HIV (Udjo & Lalthapersad-Pillay, 2015). Overall, HIV infections are approximated to have been reduced by 40% between 2000 and 2013, with 13.6 million people globally reported to have been receiving ART as of June 2014 (United Nations, 2015).

It is encouraging to note that such degree of progress in response to AIDS was achieved. It is to this effect that new worldwide efforts are now being made to end the epidemic by 2030. On 8 June 2016 UNGA member states adopted a new declaration that seeks to end AIDS by 2030 (UN News Centre, 2016). The declaration includes a set of time-bound targets to fast-track response to reach three identified milestones by 2020. The 2020 milestones being: reduction of new HIV infections globally to less than 500 000; ensure that 90% of people newly infected with HIV know their HIV status, 90% of people who know their status are on ART, and 90% of those on ART have a suppressed viral load; and, there is zero discrimination of people living with HIV (UNAIDS, 2015; UNAIDS, 2016; UN News Centre, 2016).<sup>4</sup> According

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<sup>4</sup> One of the principles of the Fast-Track approach calls for change; that is, among other things, stopping what does not work when it comes to the HIV response "and scaling-up proven programmes" (UNAIDS, 2015, p. 6).



to UNAIDS, scale-up of ART has put the reach of the global commitment to end HIV by 2030 on track (UNAIDS, 2016). Moreover, Kharsany & Karim state that the substantial declines in HIV infections are the result of HIV testing scale-up and widespread coverage of ART (Kharsany & Karim, 2016, p. 35). Thus, it is apparent that the above UNGA targets can only be achieved if there is an increased uptake of HIV testing and counselling (HTC), and increased access to HIV prevention and care services (Suthar, et al., 2013, p. 23).

As of 2016, it was estimated that only 60% of PLWHA knew their HIV status worldwide (WHO, 2016) and by June 2016 there were 18.2 million PLWHA accessing ART. Furthermore, in relation to 2005 when AIDS-related deaths were at their peak, such deaths have now fallen by 45% (UNAIDS, 2016). According to the National Alliance of State & Territorial AIDS Directors (NASTAD), Zambia, there was a 38% decline in new HIV infections from 2001 – 2013 and a 35% decline of AIDS-related illnesses from 2005 – 2013, since 2009 PMTCT programmes have prevented 900 000 new HIV infections in children, and ART at the end of 2013 prevented 7.6 million deaths worldwide (NASTAD Zambia, 2015, p. 10).

### **1.2.1 HIV epidemic in sub-Saharan Africa**

Sub-Saharan Africa accounts for approximately 70% of the worldwide burden of HIV infection (Kharsany & Karim, 2016). Out of the estimated 6000 new HIV infections which happen daily worldwide, 2 out of 3 daily HIV infections happen in sub-Saharan Africa (Kharsany & Karim, 2016, p. 34). Of the 36.7 million PLWHA, 19 million of them are estimated to be living in the Eastern and Southern Africa region. In total the region of sub-Saharan Africa accounts for 25.6 million PLWHA (WHO, 2016).<sup>5</sup> In 2015 alone about 470 000 people living in the region are estimated to have died of AIDS-related illnesses. However, between 2010 and 2015 AIDS-related deaths in the sub-Saharan African region were reported to have fallen by 38% (UNAIDS, 2016).

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<sup>5</sup> Sub-Saharan Africa makes up 12% of the world's population (Kharsany & Karim, 2016). According to The World Bank, as of 2015 sub-Saharan Africa had a population of 1 billion people (World Bank Group, 2016).

## 1.2.2 HIV in Zambia

A quick glance through the history of the HIV epidemic in Zambia shows that the first case of HIV was diagnosed in 1984, and that HIV prevalence in the country peaked in the mid-1990s when 16% of people living in Zambia aged 15-49 were living with HIV and AIDS (National AIDS Council, 2015). Despite strong interventions from the government of Zambia over many years, HIV is still a debilitating major public health risk in the country. For example, it has been reported that despite the country making progress in scaling-up HIV prevention and treatment, still more than 1 in 10 adults (46,000 adults infected with HIV every year) are infected with HIV (Human Rights Watch, 2014). Put differently, despite various governmental interventions, the HIV prevalence in the Zambia has stabilised at rather high levels, which makes HIV and AIDS a major health threat to the nation (National HIV/ AIDS/ STI/ TB Council, 2015). The 2013-2014 ZDHS demonstrates that “a comparison of the 2001-02, 2007, and 2013-14 ZDHS surveys shows that HIV prevalence among adults age 15-49 in Zambia has decreased over time, from 16 percent in 2001-02 and 14 percent in 2007 to 13 percent in 2013-14... (Central Statistics Office (CSO) [Zambia], Ministry of Health (MOH) [Zambia], and ICF International, 2014, p. 25).

Moreover, the HIV prevalence amongst certain age groups in the country is still very high. For example, the recent ZDHS study shows that 24.2% of women living in Zambia aged 35-39 are living with HIV. Table 1 shows the HIV prevalence demographics in Zambia. From the table it will also be seen that HIV prevalence among women and men aged 15-49 is 15% and 11% respectively. UNAIDS estimates that between 1.2 – 1.3 million people living in Zambia are infected with HIV (UNAIDS, 2015).<sup>6</sup> According to the same report, between 20 000 – 24 000 died of AIDS-related illnesses in the country in the year 2015. With such high HIV morbidity and mortality, Zambia remains one of the countries with the highest HIV prevalence in sub-Saharan Africa and the world (National HIV/ AIDS/ STI/ TB Council, 2015).

It is also apparent that the epidemic is a public health concern more especially so because it is the productive age group in Zambia which make up the majority of PLWHA. The 2013-2014 ZDHS study indicate that HIV is more prevalent amongst people who have more than

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<sup>6</sup> As of 2015 Zambia had a population of 16 211 767 million people (World Bank Group, 2016).

secondary education, and is prevalent in urban areas where the country's economic activities mostly take place.<sup>7</sup>

The major causes or drivers of the HIV in Zambia include, among others, high rates of multiple and concurrent partnerships, low and inconsistent use of condoms, mother-to-child transmission, low levels of circumcision, gender inequalities, population mobility, alcohol and substance abuse, and high poverty levels (PEPFAR, 2014; National HIV/ AIDS/ STI/ TB Council, 2015). Heterosexual sex is the main cause of new HIV infections accounting for an estimated 71% of new infections (National HIV/ AIDS/ STI/ TB Council, 2015; PEPFAR Zambia, 2016).

Table 1 HIV prevalence by demographic characteristics

Percentage HIV positive among women and men age 15-49 who were tested, by socioeconomic characteristics, Zambia 2013-14

Background Characteristic	Women		Men		Total	
	Percentage HIV positive	Number	Percentage HIV positive	Number	Percentage HIV positive	Number
<b>Age</b>						
15-19	4.8	3,273	4.1	3,246	4.4	6,519
20-24	11.2	2,745	7.3	2,307	9.4	5,052
25-29	15.0	2,521	10.1	1,894	12.9	4,415
30-34	20.7	2,199	14.0	1,840	17.6	4,040
35-39	24.2	1,774	17.6	1,591	21.0	3,365
40-44	24.1	1,300	21.0	1,339	22.5	2,640
45-49	19.5	907	19.3	922	19.4	1,830
50-59	na	na	17.9	1,148	na	na

<sup>7</sup> About 40% of Zambia's population live in urban areas (National HIV/ AIDS/ STI/ TB Council, 2015).

Religion						
Catholic	15.9	2,682	12.4	2,557	14.2	5,239
Protestant	14.9	11,840	10.9	10,318	13.0	22,157
Muslim	17.1	84	13.0	93	15.0	177
Employment (last 12 months)						
Not employed	12.6	7,103	6.4	2,682	10.9	9,785
Employed	17.3	7,616	12.6	10,457	14.6	18,073
Residence						
Urban	21.0	6,805	15.0	6,128	18.2	12,932
Rural	9.9	7,915	8.1	7,012	9.1	14,927
Province						
Central	14.8	1,316	9.8	1,115	12.5	2,431
Copperbelt	20.0	2,544	16.2	2,330	18.2	4,874
Eastern	10.9	1,732	7.7	1,660	9.3	3,392
Luapula	12.1	1,025	9.7	830	11.0	1,855
Lusaka	19.4	2,931	13.0	2,752	16.3	5,683
Muchinga	6.9	779	5.8	659	6.4	1,438
Northern	10.4	1,077	10.6	904	10.5	1,981
North Western	7.9	640	6.4	539	7.2	1,178
Southern	14.7	1,801	11.0	1,713	12.8	3,513
Western	17.5	876	12.5	639	15.4	1,514
Education						
No education	13.4	1,199	11.4	461	12.8	1,661
Primary	14.3	6,952	9.9	5,180	12.4	12,132
Secondary	16.2	5,846	12.0	6,504	14.0	12,350

More than secondary	16.7	712	14.3	985	15.3	1,697
Wealth quintile						
Lowest	9.0	2,548	6.6	1,972	8.0	4,519
Second	9.6	2,573	8.8	2,385	9.2	4,958
Middle	14.4	2,788	9.7	2,475	12.2	5,263
Fourth	20.9	3,201	15.0	3,058	18.0	6,260
Highest	18.6	3,610	13.8	3,249	16.3	6,859
Total 15-49	15.1	14,719	11.3	13,140	13.3	27,859
Men 50-59	na	na	17.9	1,148	na	na
Total men 15-59	na	na	11.9	14,288	11.9	14,288

Note: Figures in parentheses are based on 25-49 unweighted cases. Total includes 99 women for whom information on type of union is missing, 16 women and 14 men for whom information on times slept away from home in past 12 months is missing, 15 women and 26 men for whom information on time away in past 12 months is missing, 46 women for whom information on ANC for last birth in the last 3 years is missing, and 14 men for whom information on circumcision is missing. na = Not applicable

Source: Central Statistics Office (CSO) [Zambia], Ministry of Health (MOH) [Zambia], and ICF International (2014).

### 1.2.2.1 HIV testing and treatment

As mentioned earlier, the Zambian government in collaboration with non-governmental stakeholders has made significant gains in response to the HIV epidemic (PEPFAR Zambia, 2016). Such gains were even pointed out as early as 2009 when Hon. Kapembwa (MP), then Minister of Health, observed that the HIV prevalence in Zambia had gone down (National AIDS Council, 2009). Due to HIV testing uptake the country has made major inroads in its rapid scale-up of ARV treatment which has seen many people living with HIV being put on treatment,<sup>8</sup> and also by virtue of the PMTCT policy the country has seen very significant

<sup>8</sup> Ester Lungu, the wife to the current President of Zambia at the time of writing this thesis, reported during a General Assembly of the Organisation of African First Ladies against HIV and AIDS (OAFLA)

reductions in vertical transmissions of HIV from mother to child.<sup>9</sup> To this effect, HIV testing and the availability of ART to those tested positive, especially pregnant mothers, will continue to play a major role in the Zambian government's response to the HIV epidemic.

### **1.2.2.2 The PITC and DCT regimes, and their importance in response to the HIV epidemic**

Talking about HIV prevention and treatment, PEPFAR states that in a country like Zambia increasing HIV treatment threshold “in accordance with national capacity offers a realistic, sustainable path towards helping achieve an AIDS-free generation” (PEPFAR, 2012, p. 9). I wish to emphasise that there cannot be treatment without people availing themselves to test so that they can know their status. According to Sitali & Nzala, 80% of the adult population living in Zambia doesn't know its HIV serostatus (Sitali & Nzala, 2014, p. 20).<sup>10</sup>

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Ordinary Session that over 400,000 women in Zambia were on ART as of 2016, as compared to only 26 in 2002 (Lusaka Times, 2017). Overall, as of 2016, a total number of 720,000 PLHIV in Zambia were on ART (PEPFAR Zambia, 2016). According to PEPFAR, “thousands of babies are born free from HIV each year because nearly 100% of women in high burden regions of Zambia have access to HIV prevention of mother-to-child transmission (PMTCT) services” (PEPFAR Zambia, 2016, p. 3).

<sup>9</sup> It appears that the effort made to eliminate mother-to-child transmission of HIV in Zambia has resulted in a significant decline of new HIV transmission between mothers and their children. This significant progress in HIV prevention can especially be seen from the huge difference in new HIV transmission between 2010 and 2016. Referencing 2010 HIV incidence among children, a 2013 study provided that “despite current efforts to prevent mother-to-child transmission of HIV in Zambia, vertical transmission has recently been estimated at 20%, with 16,000 children newly infected with HIV in 2010” (Scott, et al., 2013). Actually, vertical HIV transmission has gone down since 2010. In 2013 the government of Zambia launched the Option B+ policy for elimination of MTCT. According to PEPFAR, the Zambian government drove “the policy shift to Option B+ for HIV+ pregnant women as a step in the phased approach towards a “test and treat” policy” (PEPFAR, 2014, p. 6). Through Option B+, pregnant women who test positive for HIV are immediately offered life-long ART no matter their CD4 count (UNICEF, 2012). According to UNAIDS, only 4,700 children in 2015 became newly infected with HIV in Zambia (UNAIDS, 2016). Indeed, it appears that PMTCT HIV testing and treatment during antenatal can lead to prevention of mother-to-child transmission of HIV. For example, a study at two district health facilities in Lusaka found that the PMTCT approach is effective in reducing HIV transmission in babies and young children. It has been estimated that more than 90% of children living with HIV get infected during pregnancy, birth or through breastfeeding (Shichitamba, 2012, p. 38). Shichitamba's study found that the employment of HAART effectively reduced the risk of HIV transmission to the infant to only 6.6%.

<sup>10</sup> HIV testing uptake remains low in Zambia. As of 2013, it was reported that 60% of women and 78% of men had never tested for HIV before (Musheke, 2013). The author noted that the common reason why people tested for HIV was physical health deterioration, and/ or demise of a partner or a child. Stigma and discrimination, perceived low risk of infection, perceived psychological burden of

Owing to such low HIV testing uptake, it is encouraging to see that Zambia has adopted the PITC approach to HIV testing. The introduction of the PITC regime was held by the Ministry of Health, Zambia as a necessary approach to scale-up HIV testing.

This entails that people in Zambia can be tested for HIV not only through VCT but also through the “opt-in” and “opt-out” testing regimes. The integration of the approach is a welcome development since the PITC approach has been found to result in the scale-up of HIV testing uptake; the approach has also been welcomed by service-users (Stringer, Stringer, Cliver, Goldenberg, & Goepfert, 2001; Kennedy, et al., 2013; Banda, 2013).<sup>11</sup>

According to a study done in Macha, Zambia, PITC was supported by 80.3% of the respondents. The study reports:

...the majority (80.3%) of the respondents and all the key informants supported the policy [PITC]. Furthermore, most (89.5%) of the respondents indicated that they would accept to be tested if they were hospitalised. Support for the policy was on the premise that the community has realised the importance of HIV testing as an entry point to HIV care, treatment, and support (Sitali & Nzala, 2014, p. 19).

From 2008, the government of Zambia through the Ministry of Health introduced PITC for service-users who present at health facilities (Sitali & Nzala, 2014, p. 19). DCT is another approach which was adopted. Illustrating how PITC and DCT regimes operate in Zambian health facilities, a study explains:

Since the National Council AIDS Council was enacted in the early nineties, the country adopted a number of testing guidelines that have guided testing approaches in the country. The commonest approach in the nation has been voluntary counselling and testing... Provider-initiated-testing & counselling has been practiced in the nation. This is an approach where HIV testing is routinely offered to all patients attending sexually transmitted infections (STI) services, ante-natal clinics, and other reproductive health services, and all TB clinic services. Diagnostic counselling and testing is another approach which has been in place. Under this approach, counselling and testing is considered for diagnosing HIV and TB patients,

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living with HIV, and fear of losing social support networks are among other factors which inhibit uptake of HIV testing (Musheke, 2013).

<sup>11</sup> Evidence suggests that introduction of PITC in antenatal clinics is associated with an increase in HIV testing rates, in that, with increased HTC uptake and access to ART as a result of the introduction of PITC “mother to child HIV transmission has been virtually eliminated in some countries...” (Baggaley, et al., 2012, p. 655). WHO recommends that people who present for medical attention in countries where the HIV prevalence is more than 1% should be offered HTC (WHO, 2007).

in HIV management, and for patients who present with signs and symptoms that could be attributed to HIV (Sitali & Nzala, 2014, pp. 19-20).

A cross-sectional survey study done on a UTH ward in Lusaka to assess HIV prevalence among in-patients in 2003 and 2006, indicates that providing HIV testing services to inpatients leads to an increase in HIV testing uptake.<sup>12</sup> It concluded:

After ART programme expansion, inpatients in 2006 were far more likely than their 2003 counterparts to know their HIV status and to be taking ART. In both years, 63-73% of medical inpatients were HIV-infected and 98.5% of inpatients agreed to test. On-the-ward testing in 2006 avoided the 2003 problem of patient discharge before learning of their test results. Hospital testing is an essential clinical service in high prevalence settings and can serve further as a surveillance system to help track the community impact of outpatient AIDS services in Africa (Kancheya, Jordan, Zulu, Chanda, & Vermund, 2010, p. 71).

From the above, one can argue that exclusive VCT impedes testing. Therefore, PITC approaches are necessary in scaling-up of HIV testing. Groves et. al have noted:

Proponents of the opt-out HIV testing argue that the method of obtaining consent under previously endorsed testing approaches was “ethnocentric Western rhetoric” (Holbrooke, 2004), which “exceptionalised” HIV and was a barrier to uptake (Bayer & Fairchild, 2006; K.M. De Cock, Mbori-Ngacha, & Marum, 2002; K.M.D. De Cock & Johnson, 1998). Advocates in favour of “streamlined” consent point to consistent increases in testing uptake under opt-out policies as evidence that earlier consent processes impeded testing... (Groves, Maman, Msomi, Makhanya, & Moodley, 2010, p. 2).

### **1.3 HIV testing as an entry point to prevention, treatment, and care services**

As mentioned above, HTC is a critical entry point for HIV prevention, treatment and care (Jurgensen, et al., 2013, p. 210). WHO suggests that expanding ART to all PLHIV and extending prevention choices “can help avert 21 million AIDS-related deaths and 28 million new infections by 2030” (WHO, 2016, p. in press). UNAIDS provides that people who know their HIV status are able to protect themselves, prevent infecting others, and that testing is also a critical factor in decisions to seek treatment (UNAIDS, 2015).

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<sup>12</sup> The study provides that “ward-based counselling and testing is superior to sending patients for VCT off the ward...” (Kancheya, Jordan, Zulu, Chanda, & Vermund, 2010, p. 75).



Its importance has also been noted by the Zambian government:

HIV testing is critical that people have access to services and ensuring scale up of services. HIV testing and counselling is essential to the prevention of HIV as it is a critical gateway to services... HIV testing and counselling (HTC) empowers individuals and couples to adopt measures to prevent the transmission or acquisition of HIV infection. Furthermore, testing provides access to HIV prevention services, including prevention of mother to child transmission (PMTCT) and male circumcision, and it is a necessary component of emerging antiretroviral HIV interventions... (Ministry of Community Development Mother and Child Health (MCDMCH), 2015, p. 14).

Early HIV diagnosis and administration of ART can contribute to reduced HIV prevalence and reduced AIDS-related mortality, and can result in immune system reconstruction (Patel, Moyo, & Bositis, 2010, p. 118). According to these authors:

Increasing evidence, including a study partially conducted in Zambia, suggests treatment can result in decreased sexual transmission of HIV... A more recent study for Kenya showed a 92% reduction in HIV transmission when the infected individual is on ART with the greatest benefit seen in individuals with low CD4 counts or high viral loads... (Patel, Moyo, & Bositis, 2010, pp. 118-119).

In this vein, it is critical for people living in Zambia to test for HIV. I also wish to emphasize that in the light of the availability of free ART in Zambia, and the potency of the current regime of ART, scaling up testing is necessary in order for Zambia to recover from the impact which the HIV epidemic continues to weigh on the country (Geloo, 2011). An HIV positive test result is no longer 'a death sentence' since people in the country can now access free potent HIV treatment; HIV is now a chronic manageable illness. A study carried out in Zambia, which among other things indicated that the majority of its participants had the quality of their lives improved due to ART, noted that HIV is now a manageable illness:

Once a terminal illness, HIV/AIDS has become a chronic illness and those infected are living longer. Advances in drug therapy have led to highly potent antiretroviral therapy (ART) that has dramatically extended the life expectancy of persons living with HIV/AIDS (PLWHA)... (Mweemba, Zeller, Ludwick, & Gosnell, 2009, p. 143).

A year later, Mweemba and colleagues conducted a study to analyse the quality of life due to ART adherence, they concluded:

Antiretroviral therapy has led to a substantial reduction in HIV-associated morbidity and mortality. Efficacy of antiretroviral treatment in HIV/AIDS is showing inhibition of viral replication and reduction of viral load to a point where viral particles are undetectable in the blood of the infected individuals. This has led to the realisation that HIV/AIDS is a chronic illness and hence the quality of life of PLWHA needs to be enhanced (Mweemba, Makukula, Mukwato, & Makoleka, 2010, p. 31).

Another Zambian study has shown that commencing ART at least 13 weeks prior to giving birth has the benefit of prevention of MTCT of HIV (Leach-Lemens, 2011). Therefore, given that knowing one's HIV serostatus has many benefits inter alia, it acts an entry point to prevention, care and support (e.g., PMTCT, preventive therapy for other STIs and TB, early access to ARV treatment, enables psychosocial support, and it facilitates behaviour change that results into prevention of transmission and re-infections of HIV), it should indeed follow that scale-up of HIV testing is critical in response to the epidemic in Zambia. Indeed, unlike a decade ago when "AIDS was wiping out a generation of individuals" and nothing was done to save the dying because ART was prohibitively expensive or unavailable at the time (PEPFAR, 2012, p. 2), HIV treatment in Zambia is now free, accessible and the medication is now more potent (Mweemba, Zeller, Ludwick, & Gosnell, 2009).

#### **1.4 Informed consent and mandatory HIV testing – the current debate in Zambia**

On August 15, 2017 the President of Zambia announced that HIV testing is now mandatory for those who visit health facilities for medical attention. Local Zambian and some international media sources carried a story to the effect that the Zambian government has made HIV counselling, testing and treatment mandatory for anyone living in Zambia who visits any public health facility for medical attention (Nkhowani, 2017; Lusaka Times, 2017; Zande, 2017; Akwei, 2017; Xinhua, 2017). These sources quoted President Edgar Lungu as having announced the policy in Lusaka during the launch of the 2017 HIV Testing, Counselling and Treatment Day (HTCTD).

Mr Lungu, among things, foregrounded the new public policy on the premise that the HIV epidemic "has claimed hundreds of thousands of lives since the mid-80s" (Times of Zambia,

2017), hence his government was left with no choice but to intervene in this manner in order to stop the HIV epidemic in the country. He said:

Protecting the life of those affected overrides the human rights argument about voluntary... [HIV testing]. There is no need to wait for people to fall sick before they can start life-saving treatment (Siame, 2017).

He also stated:

I admit that there were some colleagues [Cabinet Ministers] who felt that this policy would infringe on human rights but the [sic] no one has the right [to] take away somebody's life. Just the same we don't consult you for consent when we are testing for malaria, we will go ahead and test you for HIV and we will counsel you and if you are positive, we will commence you on treatment (Lusaka Times, 2017).

Prior to this announcement HIV testing, even through the PITC approach where service-users had a right to "opt-out",<sup>13</sup> required informed consent. Mandatory HIV testing was not allowed in Zambia as per the current country's 1996 constitution, case law, and policy guidelines. Mandatory testing was only allowed in very limited circumstances: in screening of blood destined for blood transfusion or for manufacture of blood products, and screening of donors prior to them donating body organs or bodily fluids (Gallant, et al., 2008).

In relation to the new declaration, I have not specifically addressed the current issue of mandatory HIV testing in this project. This is because the declaration was made after I had already concluded my research. Moreover, the Zambian constitution has not yet been amended, neither has legal precedence been reversed to reflect the proclaimed policy. Thus, technically speaking it can also be argued that since the Zambian constitution which is the supreme law of Zambia has not been amended to reflect the proclaimed policy, informed consent is still the legal basis for HIV testing in the country (GRZ, 1996). There is actually ongoing debate regarding the policy, in that various political parties and civil society organisations have rejected the policy.<sup>14</sup>

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<sup>13</sup> In regards to "opt-out" it was provided in Zambian HIV testing guidelines that services-users must explicitly consent to HIV testing, and that when an HIV test is routinely recommended and provided to each service-user, the service-user must be informed about her right to refuse testing (Gallant, et al., 2008).

<sup>14</sup> Therefore, I have addressed the question of informed consent in this thesis on the basis of the current un-amended 1996 Zambian Constitution, legal precedence which has not been reversed, and the current un-revised official HIV testing guidelines.

Prominent amongst such opposing organisations are the Forum for Democracy and Development (FDD), the Treatment Advocacy and Literacy Campaign (TALC), the Human Rights Commission (HRC), the Non-Governmental Organisation Coordinating Council (NGOCC), the Patriots for Economic Progress (PeP), and the Green Party. Among the opposing reasons advanced by these organisations are, inter alia, that the policy violates the country's constitution, offends Zambian legal precedence, violates human rights, that it impinges upon international Conventions and Protocols to which Zambia is a signatory, and that the policy is not supported by sound empirical evidence regarding HIV testing uptake and behavioural change (Chabala, 2017; Lusaka Times, 2017; Ngosa, 2017; Chabala, 2017). They also argued that forcing people to test without their voluntary consent is amoral, that implementing it would promote stigma, and that it is antithetical to the promotion of good public health values. Furthermore, the PeP leader, Sean Tembo, has concluded that for the policy declaration to be legally binding, the present Constitution would need to be amended.

In other words, the declared policy has been rejected by various critical civil and political sections of the country. Compounding this is the fact that the government has not yet issued any policy directions or guidelines to the public on how it is going to implement the declaration in health facilities. No wonder the government has been accused of policy inconsistency and/ or lack of clarity on the proclaimed policy (Chabala, 2017; Funga, 2017; Nkhowani, 2017; Ncube, 2017). In other words, the topic of informed consent in HIV testing is still relevant. Moreover, even UNAIDS Zambia also appear to suggest (after the policy declaration by the President) that the policy of HIV testing in Zambia has not changed, HIV testing in the country still requires consent (UNAIDS, 2017).

However, even if the debates surrounding informed consent were no longer relevant, I only used Zambia as a case study. My research generally sought to investigate the appropriateness of informed consent and individual autonomy in HIV testing in the sub-Saharan African context.

The two concepts (since the Nuremberg trials) have been celebrated through various international treaties, national law, regulations and policies to be necessary to protect individuals' right of choice. Health workers in most countries are now required to seek informed consent from service-users for a medical intervention to be lawful. Talking about

its historicity in HIV testing, it has been established that “informed consent has historically been a cornerstone to ensuring autonomy during HIV testing” (Groves, Maman, Msomi, Makhanya, & Moodley, 2010, p. 1).

#### **1.4.1 HIV testing consent and human rights: the quintessential historical relationship**

This study, as alluded to in section 1.1, maintains that respect for individual human rights in HIV testing is critical, not only in sub-Saharan African countries but globally. It is, thus, opposed to any potential HIV testing law/policy in Zambia which has the potential to disregard and violate individuals’ right to exercise choice in HIV testing. Hence, it is contended in this thesis that the HIV epidemic in sub-Saharan Africa cannot be addressed outside a human rights-based approach.

The HIV epidemic does not only pose a threat to society (in general), but also to individual human beings within a given society. That is, since the HIV epidemic affects the enjoyment of both communal and individual rights, it is imperative to protect the human rights of both individuals and collective society. Indeed, the issue of HIV is a human rights concern which can only, at best, be legitimately addressed by embracing a comprehensive human rights approach (Gumedze, 2004).

In other words, it is understood in this study that informed consent requirements in HIV testing interventions are still core in response to the HIV epidemic in sub-Saharan Africa. The only concern which this study wishes to critically review regarding informed consent requirements is their premise on individual autonomy.

Put simply, this study supports a human rights-based approach where the need to protect and promote individual and societal human rights is used as a framework for HIV testing law/policy. However, despite this study celebrating and underscoring the critical need to make human rights standards an integral basis of the design, implementation, monitoring, and evaluation of HIV testing law/policy, it critically assesses the appropriateness of the grounding of HIV testing informed consent requirements on individual autonomy. It seeks to understand whether or not individual autonomy is a theoretically grounded and appropriate

human rights value which has support universally (in this case support within the sub-Saharan African setting, Zambia in particular).

#### **1.4.1.1 The critical importance of informed consent requirements in HIV testing**

Patterson & London (2002) advance that human rights are inherent and universal entitlements for all, which must be protected and proclaimed within society irrespective of a person's sex, religion, culture, nationality or other status. Indeed, according to the same authors, the protection of human rights must shape the way national jurisdictions around the world respond to the HIV epidemic. These thinkers appear to agree with Jonathan Mann, the first Director of World Health Organisation's Global Programme on HIV/AIDS, who advocated for a public health HIV approach which is rights-based (Mann, 1996). These thinkers, and many others not cited in this thesis, rightly point out that protection and promotion of human rights and fundamental freedoms for all is an essential or imperative element in the global response to the HIV epidemic.

According to Mann (1996, p. 924) since, as WHO recognises, health is "a state of complete physical, mental and social well-being" the promotion of individual health goes beyond medicine. This suggests that HIV testing should not only be seen from the medicinal perspective, or 'public health' point of view. Mann states that "medical care is a relatively minor, albeit important, contributor to health, far outweighed by societal factors..." (Mann, 1996, p. 924). He later added:

Paradoxically, the discipline of public health has generally ignored societal roots of health in favour of medical interventions, which operate further downstream. For example, public health efforts at preventing and controlling sexually transmitted diseases have focussed on diagnosis and treatment, along with educational programmes, rather than confronting societal inequality or societal issues as "essential conditions" underlying the spread of sexually transmitted diseases (Mann, 1996, p. 924).

Mann concluded that, health can only be effectively and legitimately promoted through the adoption and application of human rights (as established in the 1948 United Nations

Universal Declaration of Human Rights) in public health policy and practice. In other words, the author suggests that adoption and implementation of universal human rights is a necessary condition to ensure physical, mental and social well-being of individuals within a given society, thus, promotes public health.

Put differently, according to Mann, promotion and protection of individual human rights is an essential element in the promotion and protection of health in society, in particular a quintessential approach in the response to the HIV epidemic; especially in the light of rampant stigma and discrimination against PLWHA (Mann, 1998).

Discussing the relationship existing between the promotion and protection of human rights and HIV/AIDS discrimination, Maluwa, Aggleton & Parker (2002) argue that respect for human rights is critical in response to the HIV epidemic:

Discrimination against people living with HIV and AIDS, or those thought to be infected, is therefore a clear violation of their human rights. People living with or infected with HIV or affected by HIV and AIDS are entitled to the same rights as all other members of society and to equal protection under the law. They must be legally protected from discrimination in all spheres of life... (Maluwa, Aggleton & Parker, 2002, p. 8).

In this vein, informed consent requirements in HIV testing (as a human rights protection and promotion mechanism) indeed provide a legal framework within which state action is directed towards outlawing law, policy and conventions which violate people's rights to health. Actually, not only are such consent requirements intended to outlaw human rights violating precepts and conduct, but they are also intended to oblige governmental agencies to provide redress to people whose rights to health and other fundamental rights have been violated by virtue of their HIV status and/ or social status.

Indeed, a human rights-based approach which recognises the social impact of stigma and discrimination on public health, and seeks to respect the rights of every human being (including sex workers, injecting drug-users, MSMs, immigrants, etc.,) underscores the quintessential necessity of informed consent requirements in HIV testing. In other words, this thesis maintains that the promotion of informed consent requirements is paramount because HIV is currently an inextricably human rights-linked challenge (Mann & Tarantola, 1998).

Informed consent requirements play a crucial role in response to the HIV epidemic, inter alia, by protecting every individual in society against inhuman and degrading treatment, protects individual privacy, and protects and promotes everyone's (irrespective) right to health (Mann, et al., 1994; Mann, 1996; Mann & Tarantola, 1998; Maluwa, Aggleton & Parker, 2002). Through the adoption and implementation of informed consent requirements, it is recognised that sound public health policy essentially lie in the protection and promotion of the physical, mental and social well-being of all human beings in a given society.

Indeed, experience from three decades of HIV/AIDS has shown that failure to respect human rights and dignity has not only been identified as tragic, but also shown to be “a primary root cause of vulnerability to becoming infected with HIV, and to receiving inadequate care once infected” (Gruskin, et al., 1998, p. 1). Hence, the protection and promotion of human rights in response to the HIV epidemic shouldn't be seen as undermining public health; informed consent requirements in HIV testing are an essential public health tool (Fee & Parry, 2008).

#### **1.4.1.2 Informed consent requirements in HIV testing in sub-Saharan Africa (and the Zambia context, in particular)**

John Illife provides a very rich history of the HIV epidemic in Africa (Illife, 2006). He explains the origin, nature, and spread of HIV in African regions. In this book, he contextualises the epidemiological, economic, political and social histories on the spread of HIV epidemic in the regions in African regions. Illife's book “has become an invaluable contribution for those trying to understand the layers of the shifting sands caused by [HIV] the virus' epidemiological mutations and ripple effects on the fabrics of societies, economies and the polities of HIV's amorphous presence” (Sehovic, 2016).

And regarding social and political effects on the evolution of the HIV epidemic in sub-Saharan Africa, the author notes that African political leaders shunned away from the topic of HIV because they felt helpless and shame in the face of the epidemic. In this vein, people living with HIV, and those who were vulnerable to infections (e.g., women and sex workers)



had no political voice. This entails that lack of political will from African leaders that resulted into lack of political voice from PLWHA led to the rights of PLWHA, and those affected by it being non-existent. Indeed, I wish to suggest that political and social denialism, stigma and discrimination of HIV in African regions led to abridgement of human rights of PLWHA and contributed to the spread of the epidemic in sub-Saharan Africa (Illife, 2006, pp. 67-145; (Kalipeni & Djukpen, 2007).

Indeed, the reading of Illife's book would give a reader an enforced sense of why it is argued and maintained in this thesis that informed consent requirements in HIV testing are necessary. The book provides a rich background from which arguments for informed consent in HIV testing can be safely advanced.

However, when I speak about the quintessential nature of informed consent requirements in HIV testing, this is not to mean that I agree with all the rationales and approaches undergirding the requirements. I support informed consent requirements in HIV testing chiefly because they are suited to address the issues of stigma and discrimination; factors which impede HIV testing and offend human dignity. Put differently, even though, on the other hand, this study finds the current human rights-based testing regimes in sub-Saharan Africa not quite effective<sup>15</sup> and find HIV testing and treatment exceptionalism troubling

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<sup>15</sup> However, even though the current HIV law/policy in Zambia is not quite effective (in response to the HIV epidemic), it appears counterintuitive to hope to see future governments' policy making being shaped in a way which would compromise the degree of the importance of human rights currently attached to HIV testing and treatment. In his answer in an article to the question "...Why doesn't HIV/AIDS Policies Work?", Tim Allen suggests, among other things, that setting aside the concerns of human rights to a degree can be the answer: "It is certainly true that there are many things that are not known about HIV/AIDS, but it is in fact known how to control it, and not just in rich countries. Enforced testing, enforced use of condoms, segregation of those who are positive, and perhaps enforced compliance with antiretroviral regimes: these are strategies which would have an effect. They also involve what might be regarded as infringements of civil liberties, and it seems likely that they could only be implemented in parts of the world by military force. Such authoritarian measures have already been introduced in certain places. Enforcements was an important aspect of the programmes in Thailand, and in Cuba all HIV positive people were compelled to live in segregated sanatoriums from 1986 until a partial easing of restrictions in the mid 1990s. These strategies provoked considerable criticism, but it cannot be denied they did help contain HIV/AIDS epidemics. Everywhere, the human rights of those who are HIV positive are being privileged over those who are not. It is very understandable why this is the case, but in public health terms it is potentially counterproductive. Moreover, if the rates of infection occurring in southern Africa were occurring in a rich country, such as the UK or Canada, it would be surprising if extreme measures were not introduced... As rates of HIV infection and AIDS-related mortality continue to rise, it is inevitable that at least some of those governments with the

(Cock, et al., 2002), it, nonetheless, understands that the promotion and protection of informed consent requirements in HIV testing is still relevant in the light of the prevalence of stigma and discrimination against PLWHA in sub-Saharan Africa (Maluwa, Aggleton & Parker, 2002). In this regard, consent requirements are employed to protect and preserve human dignity and promote the health of all (regardless of one's sex, sexual-orientation, HIV status, social status, etc) (Heywood, 2005).

Indeed, with discrimination against PLWHA (especially against women) being among one of the factors contributing to the rate of HIV infection in Zambia, informed consent requirements ought to be seen as a necessary public health measure. Actually, stigma and discrimination against PLWHA is a problem in Zambia (Orlando, 2007; Jurgensen, et al., 2012; Jurgensen, et al., 2013).

Paula Orlando has made the following observation regarding HIV discrimination against PLWHA (especially against women):

Discrimination is the basis of the other problems related to women's lower status and vulnerability to violations of human rights... Within this context, discrimination not only exposes women and girls to the epidemic in higher scale, but also generates extreme forms of violence addressed to those infected or affected by the disease... Violence or fear of hostility may discourage women from looking for HIV testing, prevent disclosure of their status and consequently delay their access to AIDS treatment. Women who test positive for HIV are vulnerable to violence from their partners as well as discrimination within their families and communities (Orlando, 2007, p. 89).

However, even though this study celebrates the necessity of informed consent requirements in HIV testing in Zambia (due to the problem of HIV stigma and discrimination), it is, nonetheless, concerned about the argument in bioethics and law to the effect that informed consent requirements also promote individual autonomy. Put differently, although this study agrees with the above premises on which informed consent requirements in HIV testing are supported, it however (on the other hand) seeks to review the appropriateness of grounding informed consent requirements on individual autonomy.

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capacity to act aggressively will do so. More generally, increased use of mass testing procedures is inevitable" (Allen, 2004, p. 1127).

## 1.5 Research questions

The over-arching question which this study considered, in the light of the issues raised under section 1.1 (problem statement), is “what is the relevance (or appropriateness) of informed consent requirements in HIV testing in the Zambian context; specifically as such requirements relate to the promotion and protection of individual autonomy? In an effort to find responses to this question, I came to understand that providing responses to the secondary questions which follow from the over-arching question would be crucial and relevant to such an endeavour.

In other words, the following secondary questions were fashioned as such so as, firstly, to enable me to critically review the value of autonomy as understood in liberal Western thought and dominant sub-Saharan African ontology. Secondly, these questions were designed so as to enable me to learn (through empirical research) how people in Lusaka and Chongwe experience and view the value of autonomy. And finally, responses to the two main parts of this thesis (responses from literature and field research) enabled me to critically review and appreciate the appropriateness or relevance of the value of individual autonomy in HIV testing in the Zambian context. The following are the secondary questions considered in the 7 chapters of this study:

- a. Chapter 3: What does it mean to be autonomous, and what are the implications of such understanding on how we view individual autonomy?
  - i) What does autonomy mean, and what are the established origins of the doctrine (addressed under sections and subsection 1.1, 1.5.1, 3.1 and 3.2)?
  - ii) Do individual human beings have the ability or capability to act autonomously, and what are the implications (addressed under sections 3.3 – 3.5, and the relevant subsections)?
  - iii) If individuals have abilities/ capacities to act autonomously, is autonomy still a value which ought to be promoted no matter the consequences on other values, e.g., the common good (generally addressed under sections 3.2, 3.4 and 3.5)?
  - iv) What is the relationship between the value of individual autonomy and informed consent requirements, specifically in HIV testing consent requirements (addressed under section 3. 6, and subsection 3.6.1)?

- b. Chapter 4: What is the dominant sub-Saharan African ontological position on individual autonomy?<sup>16</sup>
- i) What is the representative (in relation to autonomy) sub-Saharan African ontological outlook, and the implications of such an understanding, according to sub-Saharan African post-colonial political leaders; and also, according to both African and non-African scholars (addressed under section 4.1 and subsection 4.1.1)?
  - ii) Can sub-Saharan African peoples claim to have an ontological outlook which is dominantly shared in that region (addressed under sections 4.2 and 4.3)?
  - iii) Is the value of individual sovereignty (or autonomy) promoted in sub-Saharan African thought (addressed in section 4.4 and sub-sections 4.4.1 and 4.4.2)?
  - iv) Who is a human being, according to dominant sub-Saharan African ontology (4.4.2)?
- c. Chapter 5: Does a Zambian ontological outlook on autonomy exist (and what are the implications of such a perspective on HIV testing consent requirements in that country)?
- i) What is the dominant ontological outlook of the peoples of Zambia, according to available literature (addressed under sections 5.1)?
  - ii) Who does the HIV epidemic affect in Zambia; and what does this mean to way we understand individual autonomy in HIV testing in the Zambian context (addressed under sections 5.2)?
  - iii) Is individual autonomy in HIV testing in the Zambian setting appropriate (reviewed under sections 5.3, 5.4 and 5.5, and subsection 5.3.1)?

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<sup>16</sup> I am going to be using in this thesis the words ‘dominant’ and ‘representative’ when referring to sub-Saharan African ontology. The words are simply used in an effort to avoid simplifying the way of life of sub-Saharan African peoples. In other words, they are used to denote the persisting and embraced ontological outlook on personhood shared amongst the majority of people across sub-Saharan Africa (Gyekye, 1995). I am aware that not every person living in sub-Saharan Africa necessarily holds a homologous ontological outlook (Oyugi & Gitonga, 1987).

- iv) In regards to law and policy making, have foreign influences potentially have had an impact on how Zambia enacts and implements its laws and policies (reviewed under sections 5.6 and 5.7)?
  - v) What is the relationship of this study to similar studies done on the topic, in Zambia (addressed under section 5.8)?
- d. Chapter 6: How did fieldwork participants understand, view and experience informed consent requirements in medical practice?
- i) What is the law (and/or policy) of HIV testing in Zambia (discussed under 6.1)?
  - ii) How have policymakers and health workers understood and viewed informed consent requirements (addressed under section 6.3)?
  - iii) What were the service-users', health workers', and policymakers' experiences in relation to the implementation of informed consent requirements in HIV testing in clinical settings (addressed in sections 6.2, 6.4 and 6.5, and subsection 6.5.1)?
- e. Chapter 7: How did the fieldwork participants regard the value of individual autonomy (that is, in relation to their personal experiences and perspectives)?
- i) What themes emerged from how participants view themselves, as individuals, and in relation to their societies (reviewed under sections 7.1 – 7.4)?
  - ii) Did the fieldwork participants' experiences and views confirm a presence of a sub-Saharan African ontological outlook as discussed in the thesis (discussed under sections 7.0 – 7.4)?

### **1.5.1 Arrangement of chapters**

This study has nine chapters. Two out of nine chapters report on my fieldwork findings, and three chapters are concerned with literature review.

For the literature review, I embarked on finding out what various Western, African, and Zambian theorists have said concerning autonomy and informed consent. Such literature comparisons enabled me to appreciate the nature of the subject matter not only from a local perspective, but also from a global perspective.

I primarily reviewed Western literature on the subject of study because it has been suggested that the doctrine has its roots from the Western hemisphere. Moreover, reviewing Western literature was imperative for the purposes of the present inquiry because this study to a larger degree seeks to gain an understanding of the relationship between human nature and the theory of autonomy. In this sense, it is not only Zambians who can share their informed thoughts from their experiences on the subject of research, but also people from the Western world. To have a bigger picture I ventured to learn what Western and African theorists say about autonomy.

That said, the literature review chapter (chapter 3), as indicated in section 1.5, is concerned with a textual analysis of autonomy in the context of Kantian (Kant, 1785) and Millan (Mill, 2015) conceptions, notions upon which contemporary rational choice theories of individual autonomy have been developed.<sup>17</sup> By appealing to Western literature my aim was to provide an independent theoretical background from which the premise of individual autonomy in HIV testing could be further assessed and compared in the light of African and

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<sup>17</sup> Immanuel Kant's theory of autonomy is a rational theory of autonomy which premises autonomy on human will. Similarly, John Stuart Mill's account of autonomy is based on a rational choice premise. According to Mill, autonomy results from an action itself; it is to do with pursuance of self-regarding or self-interested actions provided they do not harm others. Mark Komrad's exposition of the relationship between Kant and Mill's notions of autonomy is instructive: "Kant's notion of autonomy is focussed on the rational human will. In the *Groundwork of the Metaphysics of Morals* Kant explains that free will inherent in human thought is the true province of autonomy and as such, autonomy exists prior to an action. The autonomous will is both self-governing and self-legislating. It is 'not merely subject to law, but... must be considered as also making the law for itself'... For Mill, the principle of autonomy does not arise in the prior will to act but from subsequent action itself. Mill uses the word 'liberty' when discussing autonomy in order to connote freedoms and restraints of action in the context of society. 'The principle [of autonomy] requires liberty of tasks and pursuits, of forming the plan of our life to suit our own character; of doing as we like, subject to such consequences as may follow: without impediment from our fellow creatures, so long as what we do does not harm others... [Komrad concludes] In summary, Mill's principle of autonomy is connected with overt actions based on self-interest while Kant's centres on the prior will to act. The former describes the external ordering of autonomy while the latter examines the internal. These two views are clearly complimentary. Combining the two we may see autonomy as a self-determined organisation of will according to *a priori* universal laws and also liberty to pursue self-regarded actions in so far as they do not harm others" (Komrad, 1983, pp. 38-39).

Zambian moral traditions, and subsequently with my fieldwork findings. Consequently, chapter 3 begins by defining autonomy<sup>18</sup> and provides a background of the doctrine. Secondly, it discusses what various scholars (mostly feminists) have provided regarding the concept. Thirdly, it reviews the relationship between individual autonomy and paternalism. Finally, it ends with discussing the relationship between informed consent and autonomy in medical decision-making. In other words, the concerns considered in chapter 3 are whether the concept of individual autonomy as promoted through informed consent requirements neglects to recognise the existence of another objective reality.

As also can be seen under section 1.5, in chapter 4, the inquiry shifts to review what sub-Saharan African<sup>19</sup> moral theory says about individualism and society. The chapter reviews the nature of sub-Saharan African traditional and moral thought, its premise, and the impact such perspectives may have on the liberal conception of autonomy. According to Nussbaum, African values, if adopted, can add to world consciousness (Nussbaum, 2003).<sup>20</sup> It is these unwritten African values which I will seek to identify and discuss in this chapter. I wish to find out what the said African values say about individual autonomy, and what this would mean if applied to HIV testing.

Arguments are also made in this chapter about whether or not African ontology does capture the reality of a human condition or not. In chapter 8, this study discusses the implications of indigenous African ontology on the way we view informed consent requirements in HIV testing in Zambia. In other words, the African Ubuntu social philosophy is explored in this chapter in an effort to learn what autonomy means in African tradition and morality, and what this entails in relation to the current HIV testing policy in Zambia.

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<sup>18</sup> As alluded to earlier, I define autonomy for the purposes of study to mean, among other things, self-determination (Weait, 2005), or self-governance (Oshana, 1998).

<sup>19</sup> In discussing sub-Saharan African ontology, I have in certain places of this thesis called sub-Saharan African philosophical and moral thought 'African ontology' (or traditional African moral thought). I wish to state at this stage that the word 'African' or 'Africa' is in this study's discussions and analyses strictly meant to refer to sub-Saharan African ontology. In other words, the terms 'African' or 'Africa' when it comes to the claims, discussions, and analyses of the ontological outlook are strictly used as a short-hand for sub-Saharan African ontology. The African ontological outlook considered in this thesis is exclusively sub-Saharan African.

<sup>20</sup> She argues that African values have been misunderstood in the West due to the fact that such values cannot be found in books or journals, rather they have been communicated orally, and that, among others, "people in the West, for whatever reason, receive negative and limited information through the media – images of ethnic wars, dictatorships, famine and HIV AIDS predominate, so the potential contribution of African values is often lost in these images" (Nussbaum, 2003, p. 1).

The question answered at the end of this chapter is how does dominant sub-Saharan African traditional and moral thought view an individual person, a person whom HIV testing requirements hold to be autonomous?

Chapter 5 discusses individual autonomy in the context of Zambian socio-cultural and economic experience and reality. As indicated under section 5.1, this chapter also establishes the current human rights condition and HIV epidemiology in Zambia. Moreover, it reviews the relationship which exists between autonomy in Zambian law books and autonomy in practice, and the implication of such a relationship.

For example, a cross-sectional study of health workers in Zambia found that more than 80% of participants felt that patients' HIV status should be made known to medical staff and 50% felt that relatives should be informed about HIV status even without informed consent, and that relatives should nurse PLWHA (Vwalika, 2010). The study provided that staff want to know the HIV status of their patients at admission so that they could take necessary precautions to protect themselves when attending to a patient who is living with HIV (Vwalika, 2010, p. 20):

It was also observed that staff would want relatives to be the ones nursing these patients. This is also understandable that with the high HIV prevalence in Zambia and most HIV/AIDS patients contributing to high patient loads, the health workers are not coping. This is compounded by the severe staff shortages. Task shifting involving relatives to take care of some of the patient care seems the only realistic approach (Vwalika, 2010, p. 20).

A number of questions come up in response to such findings. For example, why should relatives be the ones to look after the patient since a given patient is a sovereign of her own life, and can choose or refuse to test for HIV if she sees fit? Could individual autonomy be said to be an ideal in HIV testing if HIV infections contribute to the already high patient loads in health facilities in Zambia? Since the majority of health workers in the study under consideration would like the status of their patients HIV status made known to them, does this mean that HIV does not only affect PLWHA but also health workers and others? If HIV testing and knowledge is not only beneficial for an individual, but the common good, then what does this say about the current informed consent requirements in Zambia?



Chapters 6 and 7 report my empirical findings. The data analysis chapters begin by establishing the legal and ethical status of informed consent requirements of HIV testing in Zambia. That is, the beginning of the analysis chapters endeavour to illustrate what the law courts and policymakers in Zambia have said about informed consent in HIV testing. Having provided this background the focus shifts to establish what was found regarding how participants view and have experienced individual autonomy in HIV testing. These chapters show whether or not fieldwork participants viewed individual autonomy in HIV testing as a value which Zambian HIV law and policy should necessarily sustain/ emphasise.

### **1.5.1. 1 PITC and clinical practice reported in results chapters**

It has been argued that the value of informed consent may be compromised by PITC approaches, with some even suggesting it can never be possible to secure informed consent through PITC (Csete, Schleifer, & Cohen, 2004; Bennett, 2007, cited in Groves, Maman, Msomi, Makhanya, & Moodley, 2010, p. 2). Questions have been raised as to whether it is even possible to decline HIV testing offered through PITC due to patient-provider power imbalances. A study by Groves, et al., for example, found that half of the women interviewed in their research reported that their sense of autonomy was compromised while receiving antenatal care – the said women are reported to have felt compelled or coerced either directly or indirectly to test for HIV when seeking antenatal services (Groves, Maman, Msomi, Makhanya, & Moodley, 2010, p. 5). Participants reported that they were told that testing them for HIV was critical because “it was the right thing to do for the health of the baby”, which the authors call indirect coercion. There were examples of perceived direct coercion; women in the study felt coerced into testing for HIV during antenatal care, describing nurses to be authoritative. They, nurses, were authoritative in that the women felt obliged to comply with their requests to test, and also feared that future health care was contingent on testing for HIV during antenatal care – fear that they would not be able to deliver their babies at a local health facility. The authors concluded:

This perception of direct coercion was the primary motivating factor for some women who tested. These findings are similar to a study 10 years ago, where 28% of women at a hospital in Durban felt that refusing to participate in the prevention of mother-to-child transmission of HIV (PMTCT) study would affect their ability to

refuse future care (Karim, Karim, Coovadia, & Susser, 1998). A woman who tests for HIV because she fears negative repercussions of not being able to receive future care has not freely consented for the procedure (Groves, Maman, Msomi, Makhanya, & Moodley, 2010, p. 6).

In another study carried out in Malawi, it was found that the majority of participants who had been tested during antenatal care said that they were not given an opportunity to refuse HIV testing (Angotti, Dionne, & Gaydosh, 2010, p. 10). The majority of women who participated in this study reported that they had no choice but to test for HIV believing that HIV testing during pregnancy is compulsory. Some participants are reported to have even said that pregnant women are required to test for HIV by law. These women reasoned that failure to test during pregnancy will mean that one will not access antenatal services and that on the day of delivery one will not be able to go to the hospital for delivery services. However, it is also apparent from this study that many women were happy with compulsory antenatal HIV testing.

In a study which examined PITC antenatal experiences among couples in Zambia, it was found that “health workers sometimes used coercive and subtle strategies to enlist women’s spouses for couple HIV testing resulting in some men feeling ‘trapped’ or forced to test as part of their paternal responsibility” (Musheke, Bond, & Merten, 2013, p. 1). It is not only health workers who used coercive means to have men tested in couple HIV testing. The authors also report that women also used coercive strategies by threatening their spouses that they (women) will not go for antenatal care if a spouse refused to accompany them. The women would threaten that if any pregnancy-related complications resulted from the refusal to go for antenatal services, it is the male spouse who has to accept responsibility.

In relation to HIV testing inside the clinic the study found:

During group counselling, observations revealed that the opt-out requirement was not explicitly articulated. Antenatal clinic staff often emphasised the bio-medical benefits of testing, including access to treatment and prevention of mother-to-child transmission (PMTCT) of HIV. Sometimes moral obligations were used to encourage uptake of HIV testing... By simply evoking maternal/paternal responsibility to encourage uptake of HIV testing, couples were deprived of the right to consent and time and opportunity to reflect on the implications of HIV testing... Some men reported feeling ‘trapped’ in the antenatal clinic and only acquiesced to test for fear

that partners could be denied antenatal care services... (Musheke, Bond, & Merten, 2013, p. 5).

Mutombo, in his research, found that even though various international instruments emphasise the value of voluntary HIV testing, most people in Zambia were tested for HIV either compulsorily or through provider-oriented testing (Mutombo, 2007, p. 1). He observed that “actually, provider-oriented testing, other than testing out of one’s own volition, is the major factor making people test for HIV in Zambia” (Mutombo, 2007, p. 15). Talking about PMTCT, he reported that in Zambia PITC mostly targets women and those who present for health services at health facilities, often leaving out men. He suggested that PMTCT compelled people to undergo compulsory HIV testing:

This paper has demonstrated that much of the HIV testing that has taken place in Zambia has not been voluntary in the strict sense and the majority (51%) of the ever tested persons were compelled to do so... Therefore, there is need to amend government policy on HIV testing so that more realistic approaches can be adopted in the identification of HIV-positive persons (Mutombo, 2007, p. 15).

On November 11, 2015, a news story was carried out to the effect that University of Zambia’s teaching hospital was carrying out HIV tests for inpatients (Post Zambia, 2015). The paper reported that UTH doctors confirmed that the hospital had been conducting compulsory HIV testing on all its inpatients. In that, even where patients refused to test medical staff still proceeded to secretly test them without consent. The reason the doctors gave for such conduct was that they need to know patients’ HIV status because having information about a patient’s HIV status would aid them to treat the patient, and that the earlier they detected HIV in patients when the CD4 count was still low, the better the prognosis for patients. They also argued that knowing patients’ HIV status was conducive for accessing HIV prevalence statistical data for the country.

What the foregoing discussion indicates is that the PITC regime may compromise individual autonomy in HIV testing, after all. In chapter 6, I report what I found in Lusaka and Chongwe regarding PITC HIV testing during antenatal care, and participants’ experiences with, and/ or knowledge of practices of DCT at public health facilities.

In chapter 7, I have reported, among other things, what participants said about living with HIV or AIDS, informed consent, autonomy, and socio-cultural reality. During fieldwork, I sought to find out what participants say about autonomy. In other words, I sought to find from participants if they view individuals as sovereigns and/ or interdependent, and what this means to informed consent requirements in HIV testing.

Imasiku's study which sought to find out how social support affects the well-being of PLHIV concluded:

When the level of social support is perceived to be high by an individual, then it's likely that physical illness behaviour will be low because those who had adequate social support from either their friends or families had less illness behaviour. The results therefore illustrate that less levels of social support and physical illness behaviour seem to co-exist. Therefore provision of adequate social support should be included in the management and treatment of HIV seropositive individuals in order to enhance their quality of life (Imasiku, 2009, p. 157).

The study found that PLHIV (67% of them) who did not receive adequate social support from family and friends "experienced somatic symptoms in the recent past as against 50% individuals from the normative population" (Imasiku, 2009, p. 157). Musheke in a study on factors inhibiting HIV testing uptake also found that availability of social network and support enables increased HIV uptake (Musheke, 2013).. His study reported that social network influence was connected to individual decision-making in sub-Saharan Africa. What these studies indicate is that individual well-being and decision-making has a social factor.

The question is, if it is true that autonomy is routinely violated, and also that people's HIV testing decision-making may be influenced by others, then is individual autonomy a value which we should continue to promote? Put differently, if individuals are so interdependent that HIV illness behaviour is influenced and/ or correlated with social support, then can we conscientiously and objectively say that individual autonomy is inalienable? Imasiku later in the paper argues that "social support from friends and family is one of the felt needs of HIV seropositive individuals", and he concludes that "the provision of appropriate social support to each person infected with HIV should be seen as a mandatory clear moral humanitarian obligation" (Imasiku, 2009, pp. 162-163). In chapter 7, participants, among other things, talk

about the appropriateness of the value of individual autonomy in HIV testing, treatment and care (in the light of their personal experiences and perspectives).

Chapters 8 and 9 are discussion and conclusion chapters, respectively. In these chapters I have critically reviewed the relevance or appropriateness of individual autonomy in informed consent requirements in HIV testing in the Zambian setting, in the light of my findings from literature review and fieldwork research.

## **1.6 Situating this research in relation to other studies**

Throughout my literature review I never came across any study which looks at HIV testing in Zambia from a socio-cultural perspective through analysis of individual autonomy by combining Western, African, and Zambian ontologies. No study so far conducted fieldwork in Zambia, in particular Lusaka and Chongwe, and sought to find out how the people living in that country view and treat individual autonomy and informed consent requirements in HIV testing. Hence, I wish to suggest that my study is necessary because it analyses the relevance of autonomy in HIV testing.

This research contributes to studies done by Silavwe (1995),<sup>21</sup> Gaylin & Jennings (2003),<sup>22</sup> Mutombo (2007),<sup>23</sup> Healy (2007),<sup>24</sup> and Musheke, Bond, & Merten (2013).<sup>25</sup> My research

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<sup>21</sup> Discusses international social work values from a Zambian traditional perspective and argues that some of these social work ethics are inappropriate in the African context, and Zambian cultural setting in particular.

<sup>22</sup> The authors propose a move from autonomy to an ethic of interdependence. The authors argue that “when people support public policies and social practices that maximize personal freedom of choice, no matter what the moral or financial cost to society and no matter how self-destructive the behaviour, they are responding to the seduction of autonomy... Rejection of commitments, relationships, discipline, and duty are openly celebrated” (Gaylin & Jennings, 2003, p. 252). What this book shows is that for individual human beings to flourish in society, ignoring the common good will be self-defeating. They argue that people “must not accept the culture of autonomy on its own terms”, rather “must confront that culture with an ethical discourse attuned to the human and moral significance of interdependence, mutuality, and reciprocity” (Gaylin & Jennings, 2003, p. 253).

<sup>23</sup> It indicates that the Zambian government policy on HIV testing should be amended to adopt more realistic approaches. In this study, the author found that compulsory HIV testing is done in Lusaka.

<sup>24</sup> Proposes that universal ethics should only be adopted having also considered the cultural ethos and philosophy of a given society. In this paper, she suggests that “social workers are attracted to respect for culture as both a moral position and as an element of practice effectiveness” in their work practice (Healy, 2007, p. 23). She supports a moderate universalism of ethics.

analyses Killmister (2013)'s paper and other feminist theories on autonomy, and concludes that Oshana (1998)'s socio-relational theory of autonomy offers a more plausible account of autonomy. Thus, this study has to a certain extent been influenced by Killmister and Oshana's analysis of autonomy, even though it ultimately finds some of the authors conclusions insufficient in explaining who an autonomous person ought to be.

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<sup>25</sup> Musheke, Bond, & Merten's study found that the practice of HIV testing in Lusaka at antenatal is not strictly speaking voluntary.

# 2

## **Methodology and Methods**

A qualitative research method was adopted for my fieldwork study. It was preferred because I came to appreciate that applying it to this particular study would enable me to gain original and reasoned insights from research participants' experiences and views. Thus, the responses shared in chapters 6 and 7 record participants own points of views, as opposed to an exclusive quantitative method which could have led research respondents to merely choose responses from a list of already designed responses.

### **2.1 Components of this study**

Before I go about explaining the fieldwork process, I wish to share at this stage that this research comprises two dimensions; analytical (textual) and fieldwork study (empirical). The textual analysis part of this study has three chapters. In these three chapters I analyse literature on autonomy from the Western, African, and Zambian philosophical and moral perspectives. The empirical results (chapters 6-7) report on what I found regarding participants' lived experiences and views of individual autonomy and HIV testing. The conflation of both analytical and empirical research in this research secures a ground where theory is checked against lived experience and personal views.

### **2.2 Fieldwork time frame**

The period of field study as agreed was initially six months, beginning at the start of January 2015 and ending at the end of June 2015. Various factors were considered in coming to this decision. Firstly, since I am an international student, we felt that staying longer than the stated period may lead to student status issues with the United Kingdom Border Agency (UKBA). Indeed, during the period I was in Zambia, as per UKBA regulations, I was on a number of occasions required by the International Student Office at Birkbeck College to confirm my continued studentship with the Institute.

Secondly having come up with a target number of study participants I wished to interview, I was confident 6 months of fieldwork would give me sufficient time to recruit and interview them. Since I had obtained a research ethics approval letter for my study in Zambia from the Ethics Committee at Birkbeck, I expected that once I arrived in Zambia I would be able to commence my research, and present the ethics approval letter to anyone or any institution which may wish to see it when I presented myself to recruit participants for interviews.

Unfortunately, I only managed to recruit participants and conduct interviews in Zambia for a period of 3 months, beginning at the end of March 2015 and finishing at the end of June 2015. Two unfortunate events took place: I was involved in a car accident during my time in Zambia, an accident in which a very close family member lost his life; and, later on the Zambia Ministry of Health Permanent Secretary refused me permission to carry out fieldwork in Lusaka and Chongwe. The Secretary required me to apply for research ethical approval from a Zambian authority.

After the car accident in mid-January 2015, I was traumatised, and I took some time off from my study to mourn and reflect on my life. In addition, culturally, it could have been understood to be a taboo and insensitive if I proceeded to conduct fieldwork within a short period of time after losing a very close relative in a violent car accident.

After my period of mourning and rediscovering my path, I went to the Ministry of Health Headquarters to seek permission to recruit and conduct interviews at some of the health facilities in Lusaka. I was referred to the said Ministry of Health by an official from one of the hospitals who informed me that I needed clearance from the Permanent Secretary at the Ministry of Health before I could be considered eligible to recruit and conduct interviews in Lusaka and Chongwe. It took more than seven weeks before clearance was granted for me to recruit and conduct interviews. Despite the time constraint, I had the privilege to recruit and interview 73 individual participants (in-depth interviews) and 6 focus groups.

### **2.3 Zambia: the choice for fieldwork**

I chose Lusaka and Chongwe in Zambia as sites for fieldwork. I chose Zambia for four reasons. The first reason was that Zambia is located in sub-Saharan Africa where HIV/AIDS



prevalence is very high in comparison to other parts of the world. Secondly, I selected Zambia because the country itself has high levels of people living with HIV/AIDS. The third reason was that Zambia's population is largely Bantu-speaking like majority of the population of Sub-Saharan Africa countries. Finally, I chose Zambia for personal reasons. I have witnessed many very close relatives in that country get ill and die of AIDS-related illnesses.

### **2.3.1 Zambia has one of the biggest HIV epidemics in the world**

UNAIDS reports that between 12.9% - 13.4% of people between the ages of 15 – 49 years in Zambia are living with HIV (UNAIDS, 2015).<sup>26</sup> The GARPR Zambia country report establishes that provincial HIV prevalence levels show that Lusaka, among other two provinces in Zambia, has HIV Prevalence higher than 16.3% among men and women between the ages of 15-49 (19.4% among women) (National AIDS Council, 2015). Lusaka is the largest city in Zambia, besides it being one of the provinces heavily affected by higher HIV prevalence (Stringer, et al., 2008). Chongwe is one of the biggest provinces and is largely rural. Owing to the foregoing, it became imperative that carrying out research in Lusaka was appropriate.

I also chose Lusaka for fieldwork research because as a capital city it contains a diversity of various peoples from around the country. The potential to interview different people who originated from around the country with likely different cultural upbringings motivated me to do interviews in Lusaka.

### **2.3.2 Zambia's bantu-speaking people**

In this research I have used some literature by African authors to investigate any cultural similarities that may exist between Zambia and the rest of sub-Saharan Africa countries. An understanding of sub-Saharan socio-cultural outlook, I would suggest, may be important in showing how the concerned countries could relate their HIV testing policies in response to

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<sup>26</sup> In a recent news report the UNPF Country Representative indicated that in the year 2016, Zambia recorded 46,000 new cases of HIV infections (Lusaka Times, 2017). The Country representative pointed out that Zambia is among the ten countries with the highest number of PLWHA.

the high prevalence of HIV/AIDS in sub-Saharan Africa to current HIV testing policies. Therefore, as much as this study is concerned with HIV testing in Zambia, this may also have implications on the HIV testing policies in other sub-Saharan countries if it is found that Zambia and the rest of sub-Saharan African countries share some common cultural worldview which may question adopted HIV testing policies in the region.

### **2.3.3 Personally affected by the HIV epidemic**

I have very close relations, friends, and colleagues living in Zambia who are living with HIV or have died of AIDS. The illnesses of those who are very close to me affected me personally, and worse the impact left by those who have died. The worst part of it is that most of the very close relatives, friends, and colleagues who died of AIDS did not know their HIV status until it was too late to seek treatment. That is, it was too late for them to go on ART that could have prolonged their lives. Witnessing close relatives and friends die or have their lives affected by HIV and AIDS made me decide to look behind the HIV testing policy and appreciate its appropriateness, hence the adopted methodology.

### **2.4 Data collection approach: qualitative methods**

A qualitative research method was adopted for this research because it had the qualities which enabled me to answer the questions I had regarding the subject of autonomy in HIV testing. It has been argued that people carrying out research in social sciences, interested in investigating social behaviour and the social world, would find it increasingly hard to try to explain human behaviour in quantifiable, measurable terms (Hancock, et al., 2009, p. 4) . It has been suggested, instead, that should a research inquiry involve exploring peoples' experiences, their individual views, or where the research is on sensitive topic, a researcher should consider using a qualitative methodology (Hancock, Ockleford , & Windridge, 2009). Mack et al., (2005, p. 1) suggest that the strength of a qualitative research approach is that it has the ability to provide complex textual descriptions of people's experiences to a given question: this is also what I found during my fieldwork.

I found the application of this methodology to my study highly rewarding because it enabled me to explore various dimensions of the social world, including the understandings, experiences and perceptions of the research participants, in that I was enabled to capture the texture and weave of daily life of the participants, the way that institutions work both formally and informally, the social processes at work, and the meanings underlying such processes (Mason, 2002). Indeed, the application of this methodology to this research eventually aided me to develop an outlook in chapter 8 which helps us appreciate a social phenomenon as generated from the meanings, experiences, and views of the participants (Pope & Mays, 1995).

Heyink & Tymstra (1993) suggest that quantitative methods are product oriented, whereas qualitative methods are concerned with what is the impact/ outcome of a given programme. Whereas quantitative methods explore “how much or how often something happens”, the application of qualitative methods enabled me to appreciate why things are the way they are in Lusaka and Chongwe (Hancock, Ockleford, & Windridge, 2009; Griffin, 2004). Indeed, Griffin notes that a critical strength of a qualitative research approach is that it focusses in greater depth on the operation of social processes (Griffin, 2004, p. 5).

I embarked on learning about the reasons behind certain meanings in life; that is, how individual participants made sense of the world. Thus, the thematic identification of the majority experiences and views regarding how participants saw themselves in the world around them has afforded a basis for this study, in chapter 8, to discuss the appropriateness of autonomy in HIV testing in Zambia.

In other words, the adopted qualitative research methods enabled me to identify participants’ views and experiences, and helped me trace what processes contributed to such views and experiences. Moriarty (2011) explains that by applying such methods we can understand why people in a given place behave as they do in particular situations: why they respond to particular interventions or stimuli in certain ways. Jones (1985a, cited in Heyink & Tymstra, 1993, p. 294) suggests that human beings “develop over their lives a personal framework of beliefs and values with which they selectively and subjectively build meaning and significance in events...” In chapters 6, 7 and 8, I have established what values I found were shared by the majority of participants. Values of which I have argued are founded on two particular ontological systems.

However, I concede that no particular research paradigm has a monopoly on the quality of data and findings (Peshkin, 1993, p. 28). Nevertheless, since my research is to a large degree a socio-cultural inquiry, it is argued that qualitative research methods were suited for this undertaking seeing that the methods are effective in obtaining information about the values, opinions, behaviours, and social contexts of particular populations which are culturally specific (Mack, Woodson, MacQueen, Guest, & Namey, 2005). Furthermore, qualitative research methods have been increasingly accepted and widely used in research since the 1970s, in that the relative importance of both qualitative and quantitative methods have been now argued to have levelled off over the years (Mays & Pope, 2000, p. 50; Alasuutara, 2007, p. 59; Allen-Meares, 1995). It has been noted that the combination of the depth of qualitative research and researchers' efforts to triangulate and cross-check one's data gives the qualitative methodology a stamp of validity (Ambert, Adler, Adler, & Detzner, 1995).

Moreover, a qualitative method was also suited for this study because my research hinges upon policy issues. It has been suggested that a qualitative method is appropriate for policy questions because it enables policymakers "to become more 'appreciative' of others' viewpoints" (Moriarty, 2011, p. 4). Powers argues that "an appreciation and understanding of cultural and contextual factors are imperative if we are to develop relevant responses" (Powers, 1998, p. 688).

Also, the approach was necessary because it is useful in research pertaining to HIV and AIDS – a sensitive topic (Powers, 1998). HIV and AIDS is a sensitive subject in Zambia. By adopting a qualitative method I had an opportunity to form, especially with PLHIV, confidential and ethical personal relationships before, during and after interviews. Such relationships created trust and gave participants an opportunity to openly share with me their experiences and views.

And finally, the methodology allowed me to follow-up emergence of unexpected data (Ambert, Adler, Adler, & Detzner, 1995, p. 883). The emergency of new data or questions generated during interviews made me explore further questions which I had never thought of before.

## 2.5 Sample

According to my understanding, although in social and behavioural sciences sampling procedures are divided into two groups - namely, probability and purposive sampling, actually there are four broad categories: probability, purposive, convenience, and mixed methods sampling (Teddlie & Yu, 2007, p. 78). Firstly, I did not adopt the probability sampling method for this research because the technique is suited for quantitative research which requires a selection of a large number of participants from a given population in a random manner (Teddlie & Yu, 2007). As established above, this study is a qualitative – it is purposive in its intent and purpose, with a small sample that enabled me to access in-depth understanding from interviews with every participant.<sup>27</sup>

Secondly, I did not adopt convenience sampling for the purposes of this study. I came to the understanding that convenience sampling is ideal in studies where potential participants are easily accessible and are readily willing to participate, two examples of samples under convenience sampling being volunteer and captive samples (Teddlie & Yu, 2007, p. 78). In fact, the employment of convenience sampling was unsuited for this study because HIV/AIDS is a sensitive topic where potential participants may not be easily accessible or indicate willingness to participate. I understood that it was going to be difficult to access volunteers who would bring themselves to take part in this study. In fact, through identifying, targeting and individually inviting research participants, I did manage to recruit and interview participants for this research.

Thirdly, I did not adopt a mixed sampling method due to the reasons I have provided under probability sampling, and partly due to immigration, time and financial constraints. Adopting a mixed methods sampling method which involves the adoption of both probability and purposive sampling in one study could have entailed doing fieldwork in Zambia for longer than six months and having a larger sample which could have required more financial input and time.

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<sup>27</sup> Commenting on small sample size in qualitative research approaches, Curtis, Gesler, Smith, & Washburn (2000) observe that samples in qualitative research are small, however these samples are studied intensively, and each of the samples usually generates a large amount of information. Indeed, my interviews in Lusaka and Chongwe generated a lot of data!

I instead adopted a purposive sampling technique. A purposive research approach is often applied to studies where small samples are investigated, using intense and focused approaches such as in-depth interviews which offer unique means of comprehending complex human behaviour (Gledhill, Abbey, & Schweitzer, 2008). I appreciated that a purposive approach is a technique widely used by researchers in qualitative studies (Palinkas, et al., 2013; Gledhill, Abbey, & Schweitzer, 2008). Teddlie & Yu (2007, p. 77) define purposive sampling methods as selection of “units (individuals, groups of individuals, institutions) based on specific purposes associated with answering a research study’s questions.

Individual participants were selected for this study with due regard to the important information which no other demographic of people could avail to this study (Teddlie & Yu, 2007). A purposive sampling approach “involves identifying and selecting individuals or groups of individuals that are especially knowledgeable about or experienced with a phenomenon of interest” (Palinkas, et al., 2013, p. 534). Moreover, as mentioned above, the sensitive nature of the subject of HIV and the cultural and social aspect of the sample made purposive sampling most suited for this research (Gledhill, Abbey, & Schweitzer, 2008).

## **2.6 Data Collection Methods**

### **2.6.1 In-depth interviews**

Observations, as a method of data collection, were not used. In-depth and FGs were applied in this research. It has been suggested that it is ideal to use an observation method when data collected through other techniques is of limited value or is difficult to validate, or where data cannot be collected through other means (Hancock, Ockleford , & Windridge, 2009, p. 18). The authors argue that where there is potential for participants to misrepresent one’s behaviour, then the application of the observation method would be appropriate.

In-depth interviews were chosen as a source of data collection: it has been observed that face-to-face interviews afford a researcher an opportunity to have participants express themselves in a way ordinary life rarely affords people to express their views. In comparison

to group interviews, in-depth interviews are well suited for acquiring data that would otherwise not be shared in a group setting because it is socially sensitive or highly personal, or both (Mack, Woodsong, MacQueen, Guest, & Namey, 2005).

In the design of face-to-face interviews, I used identical questions (in interview guides) for similar target groups. The questions used during interviews were open-ended, based on the issue of autonomy and informed consent in HIV testing. Participants were presented with a hypothetical scenario from which questions were partly derived. Prepared prompt questions were also used when a participant had difficulties answering a given question and/ or provided only a brief response (Hancock, Ockleford , & Windridge, 2009, p. 16).

The process consisted of presenting a hypothetical scenario; the participant was either given a copy containing the hypothetical case to read for themselves or I read it to him/ her depending on their preference. I then asked individual participants or as a group to give me a summary of what they understood from the hypothetical case. When some participants did not give a satisfactory summary of the issues in the hypothetical, I would then summarise the hypothetical to them, and again ask them to give me another summary from my summary. I only proceeded to ask interview questions when I was satisfied that a participant had understood the facts contained in a case. I also rephrased questions when I realised that an interviewee had not understood a given question.

## **2.6.2 Focus groups**

FGs as a source of data collection are ideal for research on the social norms of a community.

I used FGs for data collection:

Within a study, focus groups are typically one method among many that are used to create a complete picture of how a given issue affects a community of people. Focus groups contribute to this broad understanding by providing well-grounded data on social and cultural norms, the pervasiveness of these norms within the community, and people's opinions about their own values (Mack et al., 2005, p. 52).

Indeed, interviews done in FGs have informed my study on the variety of views within a demographic from which participants hailed (Mack, Woodsong, MacQueen, Guest, & Namey, 2005). It has also been provided that "sometimes it takes listening to the opinions

of others in a safe group setting before they [participants] form thoughts and opinions” (Elliot & Associates, 2005, p. 1). During FG interviews participants were given an opportunity to listen and argue amongst themselves as they formed their views.

It was encouraging to see FG participants labouring to be honest about their experiences and their views, because they felt more free to talk about their beliefs and practices in a group of people with whom they shared common realities of life – e.g., PLWHA felt more comfortable sharing their experiences with fellow PLWHA than they would with those who are not living with HIV. I have come to appreciate that this method gave an opportunity to participants, like school teachers, PLWHA, pregnant women and mothers, who share common life experiences to honestly share with this research their life experiences and views. I gained a lot of insights through this arrangement. Such an arrangement provided a sense of certainty as to what issues every participant in a given group discussion agreed upon, and which ones they disagreed upon. Moriarty (2011, p. 10) notes that “focus groups rely on the spontaneity and synergies created when different member of the group question and respond to each other so that data are generated by interactions within the group.”

I used interview guides during these meetings. Like in in-depth interviews, each group was given a hypothetical case from which questions were partly derived. The groups comprised of between 5 – 6 participants who shared certain demographics.

### **2.6.3 Hypothetical cases**

It has been stated that hypotheticals can be used to evaluate one’s ability to assess judgment and reasoning (Harvard Law School, 2017). That is, hypotheticals can be used as tools to assess one’s thought process in reaching particular decisions, and ability to defend those very decisions when challenged.

During interviews, hypothetical case scenarios were given to the research participants. The scenarios are derived from some stories or events I have heard, witnessed or read concerning the HIV epidemic in Zambia. For example, since mortality due to HIV and AIDS is rampant amongst young people, my hypotheticals had characters who were young. Not only were participants given the opportunity to share about how they would act in given



situations, they were also asked to give reasons for why they would act as they stated they would.

What was interesting about the hypothetical situations in this study was that a significant number of participants often said to me that the hypothetical facts are similar to a situation a participant had heard or experienced before.<sup>28</sup>

## **2.7 Target population**

It has been argued that in order to be enabled to answer one's research question the focus of one's research should determine one's choice of research participants (Saunders, 2012). The choice of my research participants was based on a judgment regarding people in given demographics who were positioned to satisfactorily inform this study on chosen research questions; that is, participants meeting certain demographic criteria necessary to assist in addressing the research subject. Thus, I am of the inclination that the different categories of research participants selected for this study represent participants whose experiences and views were critical in helping this study gain meaning and insight into socio-cultural ethos and views on autonomy in HIV testing, responses which could not have been gained from other sources (Saunders, 2012).

### **2.7.1 Participants I targeted**

Pregnant women, mothers, men, PLWHA, rural area-based individuals (both men and women), churchgoers, medical doctors, nurses, HIV counsellors, and HIV policymakers were chosen for this study (see table 2 for more information).

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<sup>28</sup> See subsection 1.7.1.1 for a discussion of how interview questions reflect research questions.

**Table 2: General characteristics of participants**

Entry	Age range (years)	Number of participants	Comment
Pregnant women/ mothers	18 – 25	6	Firstly, this number of pregnant women excludes the number of nurses/midwives and HIV counsellors who were also mothers. Also note that out of the total number of women interviewed for this study, only 11 were not mothers/ pregnant. The totals shown in this entry only include women who were pregnant and had recently (within 5 years to this interview) become mothers
	25 – 40	23	
	41 – 60	3	
	61 – 73	0	
Nurses/ midwives	18 – 25	0	The majority of nurses/midwives were also mothers. Out of 16, only 3 did not have children and/or pregnant
	26 – 40	8	
	41 – 60	8	
	61 – 73	0	
Medical doctors	18 – 25	0	Some of doctors (2) were also entered as policymakers in this column below, because even though they worked full-time as policymakers, they also practised part-time as
	26 – 40	3	
	41 – 60	3	
	61 - 73	0	

			physicians
HIV counsellors	18 – 25	3	The counsellors were recruited from both governmental and NGO institutions
	26 – 40	4	
	41 – 60	2	
	61 - 73	1	
Policymakers	18 – 25	0	The policymakers had senior policy positions relating to HIV. I recruited them from both governmental and NGOs.
	26 – 40	0	
	41 – 60	6	
	61 – 73	0	
PLWHA	18 – 25	1	Women who had children/ pregnant were also entered as pregnant women/ mothers in the column above
	26 – 40	5	
	41 – 60	2	
	61 – 73	0	
Chongwe rural group	18 – 25	3	With this rural group, I couldn't go on recruiting and interviewing more because after the comparing the many interviews already done in Lusaka and 14 people in Chongwe, I was getting similar responses to my research questions (saturation)
	26 – 40	8	
	41 – 60	2	
	61 – 73	1	
Teachers	18 – 25	2	The teachers totals included 1 university lecturer
	26 – 40	6	
	41 – 60	3	
	61 - 93	0	
Other groups interviewed but not individually	18 – 25	5	Other professional/ occupational groups
	26 – 40	14	

represented in the table:	41 – 60	12	interviewed were police officers, housekeepers, a taxi driver, cleaners, lawyers, Information Technology specialists, a computer scientist, workmen, subsistence farmers, a professional consultant, church pastors, a church elder, a priest, a nun, housewives, baby-sitters, a painter, Sales assistants, a pharmacy technologist, social workers, a secretary, and an ART adherence Officer
	61 – 73	4	
Total number: Women in general		69	
Total number: Men in general		34	
Total:	18 - 90	103	This total includes the 14 participants interviewed from Chongwe, and 89 participants from Lusaka

I targeted pregnant women and mothers partly because since 2001 the government of Zambia has been administering the PMTCT programme in clinics around Lusaka (Stringer, et al., 2008). Due to this policy pregnant women who go for antenatal services at various clinics and hospitals are required to test for HIV, unless they choose to opt-out. Indeed, pregnant women and mothers (who have had children after 2001) in Lusaka and Chongwe have had

to make HIV testing decisions when they became pregnant. This demographic is important to this study because pregnant women and mothers have had opportunities to test for HIV, therefore, were in the position to inform this study about their experiences, and reasons for testing or not testing. Indeed, since every pregnant woman who presents herself for antenatal services is offered the opportunity to test for HIV, I was interested to hear their stories, experiences and views. I was also interested to learn about their views on maternal autonomy.

The second group of participants I invited for interviews were men. Men in Zambia occupy an important place in this study for two reasons, their cultural status as heads of families and their status as husbands who are normally invited to test for HIV with their pregnant wives or girlfriends. Taylor (2006, p. 92) notes that there are differences in the power, positions, and status between men and women in the Zambian society. Men in Zambia (generally speaking) have more say or play a larger role on a lot of social issues. In this study I endeavoured to find out from male participants their self-conceptions about their identity, and that of their wives or lovers, their children, and the society in which they live. I was especially interested to learn about their views on the HIV epidemic and current testing policies.

PLWHA was the third group I targeted for interviews. It was obvious that every PLWHA who knew their HIV status had tested for HIV before. I was interested to find out from this demography what led them to test for HIV, why they tested for HIV, what their experiences had been since they found out their status, what their views on HIV testing policies were and why, and what advice they have for those who have not yet tested for HIV (and why the advice). The responses to these questions by the PLWHA provided this study with insights into motivations behind HIV testing.

The fourth group chosen comprised of medical professionals (doctors, nurses, and HIV counsellors). These medical professionals are the everyday people whom health service-users come into contact with whenever they visit health facilities. Furthermore, it is the health professionals who implement PITC policies in clinical facilities. I was interested to learn from these professionals about their experiences of the implementation of the informed consent HIV testing policy in medical facilities, and their views on the same.

The churchgoers are the fifth group I chose. Zambia is largely a Christian nation. As many people in Lusaka and Chongwe go to church, it became imperative to learn this demography's views on autonomy in HIV testing. I was especially attracted to this group of research participants when I came to learn through a close relative who was getting married that she and her potential husband were required by the church eldership to test for HIV as one of the conditions for the officiation of her marriage. Refusal to test for HIV could have resulted into her pastor refusing to officiate her marriage, she informed me.

The rural area-based group of people was another group targeted. Since I did most of my interviews in the city of Lusaka, I felt it important to also include people from the rural areas. My interviewing of persons from the rural areas enabled this study to cross-check if there are any differences or similarities in the conceptions of the "self" and "others" between people living in urban areas and those in rural villages.

School teachers as a group, were also targeted since it is teachers in schools who are expected to disseminate knowledge to communities. Therefore, I wished to find out from this group of people their knowledge of informed consent and their perspectives on autonomy. I am of the opinion that school teachers' understandings and conceptions of informed consent requirements and autonomy could have an impact on the nature of knowledge they disseminate to others in their communities.

The final group of interest was that of policymakers. From them I wanted to establish clarity on HIV testing policies, rationales, their experiences, and individual views.

### **2.7.1.1 The research questions of which the targeted participant demographics answered**

I wish to state at this juncture that all the questions (in the various interview guides) asked to targeted participants from various demographics were designed to answer the main research question established under section 1.5. In this vein, I would like to establish that interview guides were designed so as to contain hypotheticals and questions which border on an individual's ability to act autonomously. And, as to which interview guide was used for

which demographic, the interview guides appended at the end of this study indicate which demographic audience a given study guide was intended for.

In other words, the combinations of the questions in the relevant interview guides were all-together adapted to answer the secondary questions established in section 1.5. For example, if one looks on page 14 (in the appendices), it can be seen that the questions there were appropriated so as to seek responses from pregnant women/ mothers on their experiences and views regarding informed consent requirements and respect for their autonomies. For example, question 1 (on page 14 in the appendices) was devised so as to find out whether a participant has tested for HIV before (this question was relevant because it enabled me to find out further on a participant's experiences of testing for HIV in medical facilities). Secondly, on the pages 14 – 16, questions 2 – 7 and prompt questions were devised so as to find out about how the HIV test was offered to a participant when attending antenatal services, why a participant accepted or refused to test for HIV, what her views on the Zambian HIV testing policy were (and why), and how a participant conceived her personal identity (the responses given in this regards bordered on issues surrounding respect for informed consent requirements and autonomy).

Put differently, the questions in the various interview guides were put together to help me answer the specific questions under section 1.5 on participant experiences and perspectives regarding HIV testing and autonomy. The only conceived reason why I prepared many interview guides was so that I could have an opportunity to adapt hypotheticals and questions to specific demographics. Adaptive hypotheticals were used in order to give participants an opportunity to relate to what (potentially) goes on within their given demographics. If it wasn't for this, I could have been happy to only have employed one interview guide for all the groups concerned.

Put simply, all the questions (not appearing in the same order and language they appear under section 1.5) in interview guides were arranged to help me direct the conversations towards the questions raised under section 1.5 (Patton & Cochran, 2002; Kennedy, 2006; Turner-III, 2010; Harvard University, 2017). That is to say, the questions asked in interview guides were designed in alignment with the research questions (Castillo-Montoya, 2016). And, I am happy to report that having analysed the participants' responses from the interviews, the responses did indeed provide answers to the research questions.

## 2.7.2 FG demographics

Regarding FGs, I identified six groups: churchgoers, nurses, women, school teachers, PLWHA, and a rural area group (See table 3 below for further details).

The rationale behind each chosen group is the same as explained for individual face-to-face demographics. That is, the persons concerned represent a particular population that is either affected or infected with HIV; they are likely to have been given the opportunity to test for HIV at one or more points in their lives; they have come into contact with people at health facilities seeking medical attention; they may have a role to play in medical decision-making by reference to their status in society; they may belong to a particular community and may identify themselves with particular beliefs; and, they are policymakers.

**Table 3: Focus Groups**

<b>Focus group</b>	<b>Age range (Years)</b>	<b>Number of participants in the group</b>	<b>Comments</b>
Pregnant women/mothers	19 – 35	5	This group comprised of one nurse, one HIV counsellor, two pregnant women, and three of the participants were mothers
Men/teachers	35 – 50	6	All the participants in this group were men, and teachers by profession
Nurses/midwives	35 – 59	6	All the participants were midwives; with experiences in nursing and midwifery. It was composed of fives females and one male
Chongwe rural	20 – 65	6	I recruited and interviewed



			<p>this group of participants from a very remote of rural Chongwe. The group comprised of three women and three men. One of the participants was a village Headman. The participants lived in muddy and grass-thatched houses, had no access to electricity, tap water, and modern ablution facilities.</p>
Churchgoers	55 – 73	6	<p>This group of women was also actively involved in charity work (the participants were members of a church outreach group to PLWHA).</p>
PLWHA	21 – 45	6	<p>This group comprised of participants from different walks of life. It included a lorry (truck) driver, a bus conductor, a teacher, baby-sitter, merchandise seller, and housewives</p>
Total number of FG Participants		35	

## **2.8 Safety / Ethical Considerations**

### **2.8.1 Participants**

The Social Academy of Nigeria identifies six possible harms which a participant could incur in the process of field research (Erinosho, 2008). These possible harms are: violations of a participant's privacy through asking sensitive questions, violation of a participant's right to privacy by disregarding the participant's right to informed consent by having access to his/her records without permission, secretly observing the participant without his/her consent, disclosure of information gained from the participant during an interview to a third party, and failure to respect a participant's cultural values, taboos and traditions.

I made available to participants information prior to an interview. Only potential participants who consented to having an interview with me having read through the information sheet were interviewed. Secondly, I made sure that participant identifying information collected was protected against third party access. I informed potential participants that the information they shared with me would never be identified with their names or other identifying data, unless they expressly consented to append their names next to whatever data they shared during interviews.

Another concern raised by the Social Academy of Nigeria is that there could be failure by a researcher to respect a participant's cultural values, taboos and traditions. In this light, the said institution advises that a researcher must orient themselves with prevailing cultural values, taboos and traditions amongst his target participants. I am originally from Zambia where the interviews took place, so I had some knowledge of common cultural taboos, and also asked various friends and family of behaviour which is culturally inappropriate before I started my fieldwork in Zambia.

The final issue I addressed to participants was to inform them about the risks they will be taking if they decided to take part in the project. The risks involved are mentioned in the information sheet. Informing participants about the risks involved enabled them to make informed decisions on whether to take part in the research or not.

### **2.8.1.1 Recruitment**

To recruit participants, I did not publicise my fieldwork in Zambian media or social media. Potential participants were approached in person. The question of not publicising participants' recruitment through MSM, social media, or other media was deliberate, largely aimed at promoting and assuring participant privacy.

In fact, two approaches, when it came to recruiting participants, was adopted. Firstly, I personally approached individual participants to invite them for an interview. I recruited the majority of participants from health facilities, other vocational places of work, faith and other social institutions. Those who agreed to have an interview with me were interviewed on a later mutually agreed date, time, and place. I recruited most participants through this approach.

The second approach was I asked friends, potential participants, my family members to ask in confidence their acquaintances, friends or family members if they would be willing to have an interview with me. Once potential participants indicated willingness to take part, I would then contact them on phone, text, or reach them in person to confirm with them if they were still willing to be interviewed. Having met them in person I then availed more information to them regarding the nature of my research (see the information in the appendices), and why their participation and contribution was critical to this study. I then arranged a date, time and place of interview with those potential participants who agreed to be take part.

No participant was forced to or coerced into taking part in this research. All participants were told that taking part in this research was absolutely voluntary. Those participants who were approached and refused to take part were thanked for the opportunity to talk to them, and were never approached again to ask them to reconsider their refusal. Indeed, all the participants voluntarily consented to take part in this study, as respect for participant consent was exceedingly paramount to this research endeavour.

### **2.8.1.2 Referral and support services**

Ewoigbokhan (2008) establishes that reporting of adverse events involving research subjects is essential. He describes adverse events as any untoward occurrence in research participants. An adverse event, the author argues, “can be any unfavourable and unintended sign, symptom, event, or occurrence that affects a participant’s physical, mental, social, financial, legal, or psychological well-being” (Ewoigbokhan, 2008, p. 68).

To tackle any adverse event that could have resulted from fieldwork, when I arrived in Zambia I consulted the National Directory for contact details for service providers (health and legal support) to which participants could have been referred to (in consultation with participant), had there been any adverse event. For legal advice and concerns, I was prepared to refer clients to Buta Gondwe and Associates or Zambia Police Victim Support Unit or provide the participants with appropriate anonymous helplines. Where a participant could have been upset or his/ her participation could have resulted in him/her being highly likely to incur financial, social, or legal costs due to participating in this project, such participants could have been advised not to take part in this research.

### **2.8.1.3 Resolving of disputes within FG settings**

The Family Health International Guide (Mack, Woodson, MacQueen, Guest, & Namey, 2005) enumerates how to handle different personalities and emotional states of participants in a FG setting. It establishes that if a member of a FG presents an obstacle to achieving the goal set for a study group such as, inter alia, dominating the discussion, having emotional outbursts, and expressing a negative feeling - the moderator should know how to reduce such negative impact on the group in order to have a productive interview.

With talkative participants, the Guide suggests that the moderator may need to intervene by thanking the participant for his/her contribution and inviting other participants to comment on what the thanked participant has said/ provide a platform for alternative views. In regards to participants who are prone to interrupt when another participant is sharing his/her point of view, the moderator may need to remind the group that one of the ground rules of the group is to refrain from interrupting other participants when they are

speaking/ they can express their point of view once a speaker at a time has completed his /her contribution. For aggressive and/ or angry participants, it is provided that the moderator needs to remind the participants “of the ground rule that no one is permitted to insult or personally attack anyone else”, and for angry participants, if their cause of anger is related to the subject in discussion, the moderator should try “to soften the level of emotion by acknowledging that the issues at hand are indeed sensitive and controversial ... steer the conversation toward the idea that it is the issue that is upsetting rather than another participant” (Mack, Woodsong, MacQueen, Guest, & Namey, 2005, p. 62).

Alternatively, it has been identified that since anger and aggression are often a product of frustration and feelings of powerlessness, that listening and reacting accordingly is the most important tool in defusing anger. Whether the dispute has come about due to the content of what is being discussed or due to participant dislikes, misunderstandings, or prejudices towards others, the moderator will need to show respect to the aggressive participant with “appropriate listening skills and non-aggressive body language”, exhibit a genuine interest in resolving the issue and meeting the concerns of the aggressive participant, refrain from openly judging the participant’s conduct, communicate some empathy to the participant and not disagreeing with him/her, and finally, it notes that the objective of all this effort is not to cure the anger or aggression but to simply avoid escalation (Eastern Washington University Press, 2017).

I adopted the advice by FHI and that of Eastern Washington University and was ready to apply it to disputes that could have arisen in focus groups discussions. However, I am happy to report that all my interviews went smoothly. If anything, participants were fond of joking amongst themselves especially when speaking about private experiences. Also, recalling sad events made some participants express pain, regret, sorrow, hopelessness, helplessness and loss, but no aggression.

I must also mention that during almost all the focus group interviews, there were participants who were more dominant. Such interviewees were in more cases rhetorically assertive, more knowledgeable than others, more open, or had more experiences to share. As a moderator I ensured that I carefully thanked the more domineering participants and gave opportunities to those who spoke very little by asking them whether they agree/ disagree with what an earlier speaker had expressed or ask them if they have any

experiences which they could share with the group. I believed that every individual focus group participant had information to offer to this study no matter one's background, education or experiences.

### **2.8.2 Risks to me as a researcher**

Physical and emotional risks are the concerns identified in literature. Physical safety risks which were of concern to me included physical threat or abuse arising from, for example, the recruitment of one's spouse without the knowledge of the other; psychological trauma (due to actual or threatened violence or the nature of the content disclosed during interviews); and danger of being in a compromising situation - where I could have been falsely accused of improper conduct (especially during in-depth interviews) (The Research Ethics Guidebook, n.d).

Others have also reported that field researchers are liable to emotional harm (Bloor, Fincham, & Sampson, 2010). Emotional harm can come, among other things, in form of role conflict (this is where a researcher learns something in confidence from the participant, something which could harm the participant if the researcher does not share the problem with relevant persons or authority who could give needed help to a participant) (Johnson & Clarke, 2003). Dickson-Swift, James, Kippen, & Liamputtong (2006) note that an emotional situation could also trigger a range of physical and psychiatric symptoms which may include depression, exhaustion, headaches, insomnia and nightmares.

During fieldwork, I did not experience any physical or emotional harm. I wish to believe that such risks were averted through prior assessment of risks in the selection of fieldwork sites, taking precautionary measures before and during interviews, resort to coping strategies when I heard very sad life experiences, etc. Researchers are also advised that they can minimise physical harms by being honest in regards to being cautious about the expression of one's opinions, informing the participants about the research intentions (Loftsdottir, 2002).

### **2.8.3 Risks to Birkbeck, University of London/ ERES Converge IRB**

I did not find, after extensive research, documented risks which universities or schools sending students abroad for research face. However, knowing that a student is arguably a representative of his/her university of study, I am of the belief that my behaviour during fieldwork had a bearing on Birkbeck, School of Law. To the best of my knowledge, I adhered to Birkbeck, University of London and ERES Converge ethics during and after my time of fieldwork.

### **2.9 Confidentiality and informed consent**

All the interviews were carried in locations mutually agreed between the research participants and me as the researcher. Only locations which offered reasonable privacy and allowed participants to freely express themselves without fear were used as venues for interviews. Such neutral venues gave participants a sense of being in control of the interview environment, provided assurance to them that no one else knew that they were having an interview with me, and enabled them to appreciate that I took confidentiality requirements very seriously.

I did quite a lot of interviews at research participants' own homes. I also did a number of interviews in their offices during lunch breaks or other times when they told me they had some time to spare. Other venues where I carried out interviews included church premises and private club locations.

To ensure informed consent prior to and after conducting interviews every individual participant was given the information sheet, and were reminded after every interview that if they did not wish me to use whatever information they shared with me during the interview they had the right to withdraw their consent. That is, they were made aware of their right to decline to participate in this project, to withdraw their consent at any given time, and to refuse to answer any questions posed to them during interviews, and advise me not to use information they may have shared.

Unfortunately, regarding the availing of the information contained in the information sheet for them to read, I came across some participants who were illiterate and could not read for

themselves. In this case, I read all the relevant information contained in the information sheet to them, by concurrently translating the information into Nyanja, a language which all my participants spoke and understood. Also, for those participants who expressed disinterest to read the information in the information sheet, I read it to them by also mentioning all the relevant information they needed for consent. No interview was carried out without the provision of the information and the signing of a consent form.

## **2.10 Data Analysis**

I employed both deductive and inductive approaches in the analysis of data. That is, in the analysis process I coded data into themes by reading through the transcripts for emergent and recurring participant experiences and views, and I also used the interview guide questions to identify questions which needed answers. Burnard, Gill, Stewart, Treasure, & Chadwick (2008) explain that in the deductive approach one establishes one's own structure and theories from which data is analysed. In comparison, when a person adopts an inductive approach for data analysis she does not predetermine theory or structure, but "uses the actual data itself to derive the structure of analysis (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008, p. 429).

This study had 103 participants expressing their views and sharing their experiences. If I were to report on all the themes which subsequently emerged from the interviews, it could have taken more than 5 chapters to do so.<sup>29</sup> When determining what data was most critical to include in the two data analysis chapters 6 and 7, I decided to report on participants' experiences and views on informed consent requirements and autonomy since these are the questions which this study was concerned with. In other words, the information shared in the two analysis chapters contain findings on the knowledge of lived experiences, and expressed opinions of participants regarding the theory and practice of informed consent and autonomy in decision-making.

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<sup>29</sup> See as annexed on page 58. The table identifies 5 themes, of which each theme would have constituted a chapter.



Talking about inductive approach, I followed a certain process in sorting and analysing the data. I classified data from participants' expressed views and lived experiences into the themes and emergent concepts (Lacey & Luff, 2007). The generated concepts and themes are a product of participants' most commonly shared experiences, views, phrases and expressions. Noting phrases, words, and expressions of participants enabled this research to appreciate the social, interpersonal and behavioural differences of research subjects (Akpaka, 2006). Put simply, it is the addition of experiences and ideas commonly shared by the majority of the participants which characterises the information reported in chapters 6 and 7.

## **2.10.1 Analysis stages**

### **2.10.1.1 Handwritten field notes and voice-recordings transcriptions**

The information recorded in chapters 6 and 7 was derived from transcriptions from audio recorded interviews, and from field notes written and typed after some participants declined to have interviews voice-recorded. Handwritten field notes were taken during every in-depth interview, and were extremely useful in interviews where participants refused to be voice-recorded.<sup>30</sup>

In handwritten notes, a four process format was followed for each and every in-depth interview. 1) During each interview I listened very attentively to what participants shared. I concurrently took notes when a participant was talking. Where I missed out on what had been shared, I requested a participant to repeat what he/she said. I never proceeded to ask other questions until I had finished recording in pen and paper a concerned response. In this manner, most times participants, having finished sharing their perspectives and/ or experiences waited for me to finish writing what they had just shared before we moved on

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<sup>30</sup> According to Mack, Woodsong, MacQueen, Guest, & Namey (2005), interviews can be documented, among other things, in the form of field notes, and it is recommended to expand them within 24 hours. The authors state that if one cannot voice-record an interview, taking notes of the same suffices. During fieldwork, the majority of participants refused to be voice-recorded. Owing to this, I took notes using pen and paper during such interviews. I expanded all the field notes mostly after an interview and saved them into computer files. All the notes were expanded within 24 hours of an interview, and labelled. Interview responses which were not recorded because a given participant declined to be recorded during interview are reported in italics in the result sections.

to the next question. 2) Within 24 hours of every in-depth interview, I sat down to transcribe it and store it on a computer file. I decided to type these interviews when the ideas shared by participants and handwritten by me during the interview were still very fresh in my memory. This left no opportunity to misquote or misrepresent expressed experiences and views. Having finished expanding handwritten notes, I made sure I re-read the handwritten data and compared it to the typed transcripts to check for any inconsistencies. 3) Typed interviews were at once stored on files on my laptop, with every transcript appended to the original participant's code name. 4) Prior to and after transcriptions of voice-recordings, I randomly checked some handwritten field notes against voice-recorded interviews to verify consistency between what was voice-recorded and handwritten. I was satisfied to find that the consistency between the notes taken using both voice-recording and handwritten (later expanded) was striking. Having validated the consistency in the two methods used, I satisfied myself that the handwritten notes (which were later typed) were not inferior to voice-recorded transcriptions. The only difference, to my observation, between the two methods of recording the data was that one method was strictly verbatim.

When it came to voice recordings transcriptions, the transcriptions for each of the interviews took approximately between 4 to 9 hours. The length of the fieldwork interviews were approximately 30 to 110 minutes. I only managed to transcribe all the voice-recordings later on when I returned to the UK.

Every participant was allocated a code number and an audio recorder file number; a few participants were identified by their names. The code and audio file numbers on the recorder was linked to the correct participant who gave a particular interview.

### **2.10.1.2 Generation of themes**

Having completed fieldwork, I allocated ideas from expanded and voice-recorded transcriptions according to the common themes which emerged from the transcribed

interview discussions, and I also used the interview guides to check what questions needed answering and responses to such questions.

These are the strategies I employed in an effort to code the big and complex amounts of data generated from the interviews. The generated themes epitomise the participants' common responses to questions which this study sought to investigate. Put differently, it is the thematic data which comprises chapters 6 and 7 of this thesis. In other words, what makes up the sections in the two analysis chapters are the recurrent participants' ideas which I identified from the data.

I conducted all the interviews, read through handwritten field notes and expanded notes, listened to voice recordings, transcribed the voice recordings, and read the voice recordings transcripts. In other words, through the process of interviewing, reading, expansion, and transcribing I was able to gain a general feeling of what most people have experienced and thought regarding the questions of investigation (O'Connor & Gibson, 2003). Having finally availed myself to all the field notes and voice recording transcripts, I again re-read through them. When I was re-reading through the data I also embarked at the same time on grouping similar kinds of information into categories or themes (O'Connor & Gibson, 2003). These various categories contained common ideas which emerged from the data. Such manner of analysis constitutes the inductive approach (thematic content analysis) side of my data analysis. According to Burnard et al. (2008), the thematic content analysis process "involves analysing transcripts, identifying themes within those data and gathering together those themes from the text" (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008, p. 429).

On the other hand, in the generation of themes, I also used the questions in my interview guides as representing themes which I needed answers to. For example, if the question in the guide was "what are the official HIV testing policies in Zambia?" I would go through all the responses given by the participants in regards to such a question, and was able to identify the common responses, frequently used phraseology and expressions given in response to such a question. In this way themes or emergent concepts were also identified. It has been suggested that the use of an interview guide in the analysis of data has an advantage:

The amount of data generated by one interview (never mind 20 or 30) could answer an incredible number of questions. You could spend the rest of your life trying to analyse all of the information. That's why it is important to go back to the original questions that you are trying to answer. Analyse your data always keeping in mind what you are trying to find out and why you wanted to do the interviews in the first place (O'Connor & Gibson, 2003, p. 66).

Discussing deductive approaches in data analysis, it has been noted:

Deductive approaches involve using a structure or predetermined framework to analyse data. Essentially, the researcher imposes their own structure or theories on the data and then uses these to analyse the interview transcripts (Burnard, Gill, Stewart, Treasure, & Chadwick, 2008, p. 329).

Indeed, through such processes I was able to realise participants' pattern of beliefs, emergent concepts and themes which linked participants to their experiences and worldviews. It is these experiences and worldviews which this study sought to learn. And, it is these subjective experiences and views of various individuals and groups which shape the findings of this study.

As far as the identification of emergent themes and concepts was concerned, however, I did not ignore the minority participants' experiences and views which can be said to be contrary to what was shared by the majority. In this sense when I noticed in two or more transcripts that there was something that was shared that did not agree with the majority views, or was never shared by anyone before, I would then re-read through the transcripts to check if there were many others (whom I may have missed) who had a similar view, or had a corresponding experience. In this case, nothing that was material to answer my research questions was ignored.

### **2.10.1.3 Arrangement of sections in the analysis chapters**

The information presented in the chapters does not come from one single source (a single participant or single demography, or exclusively from in-depth interviews) but multiple sources (from both in-depth and FG sources) (Lacey & Luff, 2007; O'Connor & Gibson, 2003; Flick, 2013). To this effect, the sections in chapters 6 and 7 are arranged in such a way they

have subheadings sharing what policymakers, medical professionals (doctors, nurses and HIV counsellors), men and women said (O'Connor & Gibson, 2003).

## **2.11 Research limitations and potential bias**

I would suggest that the weaknesses for this study's adopted methodology and methods are also its strengths.<sup>31</sup>

In relation to limitations and bias it has been suggested that the quality of a research project may be compromised because the researcher may be influenced by personal biases and temperament (Anderson, 2010). At the beginning of this chapter I made no secret in declaring my own experiences. This study entails the investigation of the experiences and views of unique individuals in Lusaka and Chongwe, other than me. It is the search for the majority voice, not my voice, which I endeavoured to discover during the fieldwork process. In other words, this research was about finding out the experiences and worldviews of other people on the issue of autonomy in HIV testing, not my worldview. And since I was exclusively interested in learning about the views of others, I honestly endeavoured to the best of my knowledge, to be impartial and un-suggestive in the way I asked questions and analysed the data. Owing to such an approach, I even had participants on several occasions saying to me "have you been 'Westernised'?" This question was often asked, for example, when I challenged individual participants to explain the reasons underlying their given beliefs or views without me taking any side or indicating otherwise.

Put in a different way, I could not afford to be biased in the way I asked questions because the findings of this study were critical to me personally in my journey to discover "who I am in relation to others". That is, I embarked on this study journey to learn about what the majority of my countrymen from Lusaka and Chongwe and thinkers would say "I am" as a human being. Am I autonomous, according to them, or I am not? "What makes me or does

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<sup>31</sup> For this reason, I will only address one issue in this section (the problem of researcher biasness), since the issues of validity, reliability, sample size have been implicitly addressed in my explanation of my research methodology and methods. The findings referenced in this study are an accurate representation of the responses of the phenomena investigated. Various sources were consulted during fieldwork and participants' experiences and views have been represented in the data analysis chapters, unaltered.

not make me autonomous?” It was only by being unbiased in my approach throughout this study that I hoped I would find answers to these questions, otherwise my search for answers to “who am I in relation to others?” could have been a futile exercise, and a waste of my time.<sup>32</sup>

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<sup>32</sup> I have addressed the question of my research limitation in chapter 8.

# 3

## Literature review

Zahavi (2014, p. 11) argues that we cannot discount the me-ness, or the “I” pronoun, or self-consciousness of individuals. He rejects the premise which regards the self to be utterly socio-cultural in origin. He suggests that a minimalist experience-based notion of selfhood is more persuasive than the social construct thesis, arguing that, we as human beings “have a distinctly different acquaintance with our own experiential life than with the experiential life of others, and vice versa, and that this difference obtains, not only when we introspect or reflect, but already in the very having of the experience” (Zahavi, 2014, p. 28). He claims that we have unique experiences as individual human beings, and this partly makes the ‘self’ or the individuals in us.

I have based my literature review for this study on autonomy and its relationship with informed consent because as will be shown later the Zambian HIV testing policy and law is, inter alia, grounded on individual autonomy. It is established in Zambian national HIV testing guidelines and legal precedence that testing an individual for HIV without one’s knowledge and consent is unlawful. In this vein, HIV counsellors are required to seek consent from persons prior to carrying out an HIV test. Counsellors and medical staff are enjoined to recognise the fundamental human rights of individual dignity, privacy and worthy in that people are not to be forced or coerced to test for HIV or conform to certain acceptable or conventional standards of living without consent. The national HIV testing guidelines require counsellors and health personnel to challenge service users to assess own personal values and make decisions for one’s own future (Ministry of Health and National HIV/AIDS/STI/TB Council, 2006).

Owing to such HIV testing policy and law which is premised on individual autonomy, this chapter concerns itself with a critical analysis of individual autonomy by considering whether human beings are actually capable of being autonomous or not, and what this means if applied to the current regime of HIV informed consent requirements in Zambia. To

do this, I will seek to provide a brief genesis of autonomy, analyse its nature and association with paternalism and informed consent, and then conclude. Establishing an understanding of individual autonomy (as conceived by Western liberal thought) is critical if we are to appreciate its value and implications in the light of sub-Saharan African communitarian moral ontology, and fieldwork findings.

In this chapter, it will be argued that the normative and narrative accounts of the rational and moral “self” offers an unpersuasive account of autonomy. It will be shown that rational or self-reflective theories of individualism – where a person is seen to be an agent if she identifies with a given desire as her own – are erroneous because they fall short of taking into account the structure and reality of human bio-social life. I will argue that ‘atomistic’ accounts of human agency as promoted by Western liberal thought are mistaken, in that, such accounts cannot be sufficiently defended in light of the social reality man finds herself in from the moment of birth to her demise.

It is not possible in this world for an individual to achieve autonomy, if we are to understand an agent or the self to mean a “unified, happiness seeking, unbrokenly persisting, ontologically distinct conscious subject who is the owner of experiences, the thinker of thoughts, and the agent of actions” (Zahavi, 2014, p. 42). I will argue that a person cannot plausibly call herself a self-determining, self-governing, self-directing, or self-sufficient individual if she cannot demonstrate that she is the self-owner of her experiences, thoughts, and given actions. It will be suggested that mere identification with or endorsement of certain experiences, thoughts and actions as one’s own does not make one an autonomous agent. In other words, seeing experiences, thoughts, and actions as being one’s own because one conceives them to be such or identifies with them does not make them in reality the agent’s own.

This research, however, will not dismiss the understanding that individual human beings are distinct persons with unique physiologies, bodily boundaries, varying mental capacities, experiences, natural appetites, personalities, pains and destinies. It acknowledges that human beings are unique and distinct individuals, but are also interdependent beings born in a social context which impoverishes their capacity for individual sovereignty. I will suggest, later in the chapter, that if the self does indeed exist, it only exists in the reality that we can personally identify ourselves as individuals by reason of our distinct body mass,



physiology, mental capacity, etc. Thus, it will be concluded that it would be misleading to refer to a human being as an autonomous agent since one's experiences, thoughts, perspectives, and actions have the potential of having been shaped by one's language, social relationships, biology, and other life events.

### **3.1 Individual autonomy: definition, origin, and its relationship with consent**

Individuals are construed to be capable independent agents who can self-rule through critical reflection and authentication of own values for one's own good (Mill, 2015). In Zambia, individuals are now regarded to be autonomous agents who are sovereigns in HIV testing decision-making (Torul, 1984; Njeru, et al., 2011; Malila, 2012). Thus, the question to be addressed in this chapter is human capacity for autonomous decision-making, and its consequent implications on how we understand consent.

Over many years there have been appeals to autonomy in ethical and political discourse (O'Neill, 2003). Academic theories and international/ domestic instruments are now replete with various conceptions of personal autonomy, where individuals are now celebrated as self-authors of their own lives; hence the promotion of individual virtues (Taylor, 2005).

Due to the conception of individual autonomy being problematic, there are many conceptions of autonomy as can be seen in Dworkin's *'The Theory and Practice of Autonomy'* where he offers a wide array of definitions (Dworkin, 1988, p. 6). These definitions include: liberty – positive or negative, dignity, integrity, independence, individuality, independence, responsibility and self-knowledge; freedom from obligation; critical reflection; absence of external causation; and knowledge of one's own interests (O'Neill, 2003, p. 2). Faden and Beauchamp (1986, p.7, cited in O'Neil, 2003 ) note that autonomy has been equated with other concepts including privacy, self-mastery, voluntariness, choosing freely, "choosing one's own moral position and accepting responsibility for one's choices."

These conceptions of, inter alia, individual self-ownership, privacy, sovereignty, dignity, self-mastery, freedom from obligation and critical reflection are now increasingly being promoted in sub-Saharan African countries, particularly in relation to HIV testing (Angotti,

2010). In fact, personal choice or autonomy language in healthcare has continued to grow over the past fifty years, whereby, respect for individuality is now celebrated as being one of the sovereign ethical principles in healthcare (English et al., 2002, p. 117). This conception of an individual's freedom from obligation is protected through informed consent requirements:

Informed consent did not spring full-armoured like Athena from the head of Zeus... only in more recent years, the doctrine has been appropriated by a broad-based movement to reform medicine in ways felt to be congruent with the general practices and aspirations of a free society... (Wear, 1998, p. 29).

Coggon & Miola (2011) have noted that patient autonomy is a central tenet to much of ethical argument within medical practice. They also note that the concept has supreme status in healthcare law and medical ethics.

Personal autonomy in healthcare is seen to be necessary, inter alia, because its constitution requires clinicians to inform patients about medical deliberations (Wear, 1998). This means that before a procedure or any treatment is carried out, consent must be sought and given by a competent patient. Prior to consent, a medical practitioner is required to have given a patient sufficient information concerning the benefits, risks, and alternatives that a patient can weigh to make an informed decision.

Autonomy has not only been recognised as a core in medical ethics, but also validated by court judgments as necessary, thereby contributing to the view that it is a primary good. In the ECtHR case (*YF v. Turkey, 2004*) the court held that Article 8 of European Convention on Human Rights protects the physical and psychological integrity of the person, in that, compulsory medical interventions interfere with this right. In other words, according to this law, every 'rational' human being has a right to self-determination, a right which must be protected from violation by others.

It is not only judges who have held personal autonomy to be a virtue, but also the media. Western media (especially the media on the left) has been proclaiming personal autonomy to be a quintessential human virtue in a free society. One example case where the media hailed the inviolability of individual autonomy and a case of which equally engaged the general public is the *R(Burke) v. The General Medical Council and Others, 2004* case. In the

*Burke* case, a patient who was faced with a degenerative brain condition (known as spino-cerebellar ataxia) prayed to the court to oblige doctors to fulfil his wish in regards to the future course of his illness. The patient claimed that the guidance by the General Medical Council impinged upon his personal right to have the doctors follow the direction of his wishes. He argued that a direction by the General Medical Council to doctors was unlawful because it violated his right to decide his own course of treatment. The High Court agreed with the claimant supporting his right to artificial nutrition and hydration. His advance directive regarding the course of his treatment was held by the court to be determinative. Mr Justice Munby, in the High Court ruling, acknowledged the importance of patient autonomy in medical practice, thereby giving it an overriding status in doctor-patient relationships.

However, the General Medical Council appealed against the High Court ruling. But, even though the High Court's decision was subsequently overturned by the Court of Appeal, the media in the UK hailed the earlier decision of the High Court as a triumph for patient autonomy and rights. No wonder English et al. (2006, p. 117) have observed that "some legal judgments contribute to this perception of the primacy of autonomy, implying that society has obligations to meet the individual's requirements, almost regardless of the consequence for the general public good."

The authors argue that the use of rights language by the media in the coverage of the *Burke* case has the potential to disregard the fact that the needs of others also matter. The authors allege that the media too is responsible for fostering the perception of primacy of personal autonomy. They state that the media through television dramas and documentaries foster the perception that individual choices or wishes are/ ought to be primary in medical decision-making (English et al., 2006, p. 118).

Personal autonomy has not only been promoted in medical ethics, by lawyers, and the media, but also by a larger section of scholars and legal practitioners across, especially from the Western liberal and libertarian world. Moral weight has been placed on an individual person's abilities to govern oneself, thus immunising her from her corresponding roles in political institutions and social structure (Christman, 2015). The words liberty, autonomy, choice, freedom, voluntarism, empowerment and personal rights have become the most celebrated words in the moral and civic vocabulary of our time (Gaylin, 1996). Behind

freedom, autonomy, choice, and personal rights now stands a particular vision of what it entails to be a human being and a self; social relationships and arrangements are only recognized as far as they are able to nurture that self (Gaylin, 1996). Behind such vocabulary of a sovereign human being is the belief that human behaviour is voluntarily chosen, and that other people's conduct can be modified through rational argument (Gaylin, 1996).

### **3.2 Autonomy background and its importance in relation to other ethics**

In tracing the roots of personal autonomy, Taylor (2005) provides that individual self-authorship has its roots in the Romantic liberalism of John Stuart Mill, where free development of individuality is promoted. Jackson (2013) explains that the word autonomy is from the Greek words *autos* (meaning self) and *nomos* (meaning rule), which originally was used to refer to independent self-rule of cities.<sup>33</sup> Feinberg (1986), among others, also notes that the word has a Greek origin which comes from the Greek for self and law, meaning the making of one's own laws. Feinberg (1986, cited in King 2004, p. 141) provides that individual autonomy has some interrelated meanings; that is, from one's capacity to govern oneself, to the sovereign authority to govern oneself.

However, O'Neil (2003) provides that the original view of autonomy in antiquity – meaning self-legislation – never referred to persons, but to property. That is, ancient autonomous city-states made their own laws, colonies being given laws by the colonizing parent cities (O'Neil, 2003, p. 3). So, unlike its original cities' self-rule application, autonomy has now been extended to mean the self-governance of rational individuals.

In the United States of America, this said individual capacity and right to self-rule was acknowledged and given a legal validation in the famous and most celebrated case of *Schloendorff v. Society of New York Hospital, 1914*, where it was decided that every human

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<sup>33</sup> Gaylin and Jennings also explain that "The word autonomy comes from the Greek *autos* (meaning "self") and *nomos* (meaning "rule, governance, or law")... [A]utonomy means "the state of being self-governed or self-sovereign"; living autonomously means living by a law that you impose on yourself. In other words, autonomy is the right to live your own life in your own way... One widely used by college ethics textbook teaches students that autonomy is the "personal rule of the self that is free from both controlling interference by others and from personal limitations that prevent meaningful choice... The autonomous individual freely acts in accordance with self-chosen plan" (Gaylin & Jennings, 2003, p. 28)

being of adult years and sound mind has a right to determine what shall be done with her own body. Respect for autonomy is held to give rights to an individual to be free to make decisions for one's intended course of life. As Gaylin indicates above, the right to autonomy imposes a duty on others to abstain from interfering with an individual's right. To "respect an autonomous agent is to recognise with due appreciation that person's capacities and perspectives, including his right to hold certain views, to make certain choices, and to take certain actions based on personal values and beliefs" (Faden & Beauchamp, 1986, p. 8).

To begin with, it is noteworthy to observe here that the thinking that supports respect for autonomy is historically incompatible with the Greek view of self-governance; now an individual person who is conceived to possess intrinsic value separated from circumstances that confer value. It is now celebrated that equally individual human beings are autonomous agents who are ends in themselves, who have the capacity and right to determine their own course of life, and must never be treated merely as means to the ends of others (Faden & Beauchamp, 1986). Due to this understanding, the autonomy of a person resident in Zambia who refuses to test for HIV is now hailed to be overriding and inviolable. But as human beings, are we really individually autonomous – as we are being told we are? Are the daily decisions I make really mine?

Moreover, the same clinician in sub-Saharan African countries who is required to respect patient autonomy is also bound by beneficence and non-maleficence imperatives. By beneficence it is meant the moral imperative to act for the benefit of other people, and non-maleficence being a duty above all 'not to do harm at all' to others. That value of promoting the welfare of others or benefiting others, as Faden & Beauchamp observe, has since time immemorial been treated as critical. Should the moral injunction to clinicians which states "do no harm" to patients, an imperative to the effect that one is to consider the welfare of others in what she does, be ignored because of individual autonomy?

### **3.3 The nature of autonomy**

Various conceptions of what autonomy is supposed to mean have been advanced by different schools of thought. O'Neill (2003, p. 2) points out such different definitions as follows: dignity, integrity, individuality, independence, responsibility and self-knowledge;

liberty; self-assertion; knowledge of one's interests; freedom from obligations; absence of external causation; choosing one's own moral position and accepting responsibility for one's own choices; self-mastery, voluntariness; privacy; and, choosing freely. I argue in this chapter that individual autonomy is an illusion. As individual human beings we are simply not capable of acting autonomously. What we conceive to be our autonomy is simply a delusion created by our environments over which we have never had control. Thus, it would be erroneous to hold that individuals who test or refuse to test for HIV do so autonomously. Instead, I suggest that autonomy as advanced by feminists is more plausible in comparison to Kantian conceptions.

Hence, in the following discourse, I will analyse autonomy as understood by various schools of feminist thought. Some of these feminist thinkers endorse the Kantian and Rawlsian conceptions of autonomy, the only difference being that they refute the thesis that individual human beings are capable of being self-sufficient. By analysing such rational conceptions of individual autonomy, I will therefore be at the same time be disproving Rawlsian conceptions of the same.

### **3.3.1 Relational autonomy**

Relational autonomy, conceived by feminists, notes that it is morally significant for human beings to have relationships of care and interdependence with each other. Feminists, in general, conceive autonomy to be relational. They deconstruct autonomy by rendering it compatible with social interdependency. Campbell (2002, p. 165) observes that feminists "make clear that the abilities required for appropriately self-reflective and self-directed lives are formed through relationships, can be thwarted or undermined by oppression, and even when developed, require the continuing support of others for their exercise."

This feminist account of autonomy rejects Kantian conceptions which pre-suppose an atomistic self. In this study it will be argued that Kantian rational conceptions of autonomy are not convincing because they fail to capture the significance of people's lived reality. It will be argued that rational choice theories fail to explain the nature of autonomy because they are premised on the idea of rationality as a quality for human autonomous conduct. Besides the failure to acknowledge that human beings are relational in nature, rational

choice theories fail to appreciate that people are not simply rational creatures, but also individuals whose choices are often influenced by emotional inducements: that human emotions are often far more reaching than logical argument in decision-making.

It is no wonder that feminists reject the Kantian autonomy notions of self-sufficiency. Mackenzie & Stoljar (2000) have argued that if it is morally significant and valuable to have relationships of care and interdependence, then it should follow that any theory of autonomy ought to be relational.<sup>34</sup> As much as this study will agree with the feminist assertion that autonomy is relational, I will depart from some feminist rational choice theories (just like Kantian conception) which offer self-reflective accounts of autonomy. At the end of this chapter, I will suggest that Oshana (1998)'s social-relational autonomy account offers a more convincing theory because it does not treat autonomy as a psychological feature of agents.

### **3.3.2 Autonomy does not lie in satisfying a psychological feature of the brain or mind**

Killmister (2013) surveys a range of autonomy accounts from procedural to substantive and submits that none of the theories offer sufficient explanation to resolve the problem of socialization. She states that socialization poses a challenge to how we conceive autonomy, noting that since autonomous individuals are self-governing, autonomous actions should originate from the self (Killmister, 2013, p. 95). The author argues that the self is a product of external influences, asserting that people are the products of the environment and that it is this very environment which compromises individual persons' abilities to act autonomously or independently.

In the following discussions I will be making a lot of references to and following Killmister's thoughts on feminist autonomy perspectives and other because the author identifies

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<sup>34</sup> In this study I will argue that it is not only morally significant and valuable for the concept of autonomy to be relational because human beings are interdependent, but also because human beings are inextricably social in nature and naturally born in social families and communities of people. The socialisations and indoctrinations from families and other environmental factors result in internalisations of ideals of which in turn compromises an individual's capacity to act autonomously (Locke, 2008). We cannot ignore the problem of socialisation if we are indeed to manage to explain away the non-autonomy condition of humans (Endleman, 1967; Killmister, 2013).

aspects of autonomy which have been overlooked in various theses by various celebrated luminaries. I have found her analysis of the subject matter to be instructive and enlightening.<sup>35</sup>

As mentioned earlier, even though feminists reject Kantian and Rawlsian notions of autonomy due to the former's argument that individuals are relational, there are still different theses within the feminist school of thought which are arguably similar to Kantian conceptions – the only major difference being that feminists advance a relational account of autonomy due to their rejection of self-sufficiency of human beings. In other words, I wish to mention that the analysis of feminist perspectives on autonomy for this study is critical because, besides Marina Oshana's constitutive theory (a feminist account) being arguably a more persuasive account of autonomy, some feminists' substantive and procedural accounts of autonomy still embrace Kantian and Rawlsian rational choice theories.

To analyse feminist accounts, I will begin by considering the reflective or historic endorsement accounts of autonomy of which Frankfurt (1988) and Christman (2009) are some of the protagonists. These thinkers hold that an individual's capacity for autonomy lies in her psychological dispositions. According to such theses, for a person to be autonomous she must be both reflectively competent and authentic – autonomy is also held to consist in wholehearted identification at a higher-order level with lower-order preferences, motives, or desires.

Christman's reflective endorsement theory has been credited to be an account which is placed to address the problem of socialization – it is argued that his theory overcomes the inadequacies identified in models such as those of Dworkin (1988) and Frankfurt (Killmister, 2013). Christman argues that Gerald Dworkin and Harry Frankfurt's second-order desire theory overlooks the autonomy-compromising nature of manipulation.

Being autonomous, according to these thinkers, is synonymous with a capacity to critically evaluate first-order values, desires and preferences by referencing them to one's second-order preferences, values, and desires – thus, one's capacity, "to accept or attempt to change these in light of higher-order preferences and values" makes one autonomous

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<sup>35</sup> Although at the end of this analysis I have disagreed with Killmister's conclusion.



(Dworkin, 1988, p. 20).<sup>36</sup> “By exercising such a capacity, persons define their nature, give meaning and coherence to their lives, and take responsibility for the kind of person they are” (Dworkin, 1988, p. 20). Second-order values take priority over first-order ones since the former are apparently considered to be an individual’s own.

I wish to argue that Dworkin and Frankfurt’s second-order accounts are philosophically, and in addition, morally inadequate. Philosophically, this rational thesis fails to account for the problem of socialization of values, desires and preferences, internalizations of which compromise second-order values. A person’s so-called second-order desires can be a product of socialisation. Dismissing this regime of rational choice theory, Killmister argues that effective manipulation can reach all the way to second-order desires. She observes that “to judge as autonomous individuals who are hypnotized, brain-washed, or otherwise manipulated into developing second-order desires, so the argument goes, is to misunderstand the very nature of autonomy” (Killmister, 2013, p. 98). Holton explains:

To see this [philosophical problem of first and second-order thesis], suppose that I implanted a second order desire in you by hypnosis. Then surely you wouldn’t have free will if you got your desires to conform to that; but Frankfurt’s account seems to have the consequence that you would (Holton, 2003, p. 2).

I would like to agree that such an account of autonomy is inadequate. This is because such an account possesses a great potential to declare someone who is acting on internalised values to be autonomous. Such an account is unauthentic because premising autonomy on acting upon second-order desires can lead to one acting on and identifying with internalised

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<sup>36</sup> “A first order desire is a desire for anything other than a desire; a second order desire is a desire for a desire. So, for instance, you might have a first order desire to smoke a cigarette; and a second order desire that you desire not to smoke a cigarette... Thus, I might wish that I wanted to give all money to charity, since I might think that having such a desire would show me to be an excellent person; but I might nonetheless not actually want that desire to be effective... But when a person does want the first order desire to be effective, when they want it to be their will, Frankfurt calls this a second order volition... Some creatures have no second order volitions” (Holton, 2003, p. 1). It can be inferred from this thesis that a person can act autonomously through identification with second-order desires. That is, a person is seen to have autonomy in so far as she has second order volitions and they can bring their first order desires into line with second order volitions or desires. Thus, according to this account, dogs and children don’t have autonomy because they lack second-order desires or volitions (Holton, 2003). They don’t have autonomous second-order desires which can be used to control first-order desires. I suggest that first order values can be values which compose the foundations of a given moral system. That is, common good morality can be situated in first-order values (Ockham's Beard, 2010).

norms as one's own, thus leading to one hailing oneself to be an autonomous actor. Moreover, such accounts seem to neglect the fact that external conditions (in the form of societal rewards and punishments, and human biological factors) have a tendency to make human beings conform to certain behaviours (Gaylin & Jennings, 2003). Indeed, internalised first-order desires can cause second-order desires due to the reality of natural sociality of humans, human interconnectedness and interdependence.

Internalisation of ideas, values of which we later on come to identify to be ours is a human fact (Lanier & Henry, 2010). A good example of internalised preference can be inferred from that of the 18-year-old student theorised by Benson (Benson, 1991). Benson theorises about an 18-year-old whom through internalisation of the Hollywood idea that appearance is a criterion of self-worth ends up regarding beauty and fashion as critical for her self-worth.

Thus, the question that follows is, does the 18-year-old come to regard such a perspective of self-worthiness through critical reflection, or does she come to this conclusion because the marketing industry through the contemporary media has potentially subconsciously deformed her vision on what amounts to self-worthiness? I suggest that the 18-year-old's deformed sense of self-worthiness is a product of the environment in which she lives. I would argue that her pursuit of self-worthiness through fashion and beauty is likely a product of prevailing social attitudes and stimuli (Winkielman & Berridge, 2003; Custers & Aarts, 2010). First and second-order autonomy accounts of Frankfurt and similar thinkers fail to explain away this social reality. Indeed, if it is media propaganda that has made her value and choose fashion and beauty as a means to self-worthiness, we cannot confidently call such a product autonomous. I suggest that it would be unsafe to argue mere identification of first-order desires with her first-order desires qualifies her actions to be autonomous. Her second-order desires in this case are arguably a product of Hollywood brainwashing or contamination.

Furthermore, even if it was possible to hold individuals to have acted autonomous by virtue of fulfilling Frankfurtian or Dworkinian first and second-order requirements,<sup>37</sup> I wish to argue that morally, this thesis of autonomy is also inadequate because by celebrating second-order values, individualism is made primary. The common good values which sustain

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<sup>37</sup> My analysis has concluded that first and second-order accounts of autonomy are inadequate.

and advance the wellbeing of the whole can be denigrated through such. The so-called first-order desires (which I have suggested above consist of common good values) are then trumped by the 'individualistic' second-order desires. Indeed, subscribing to such a thesis of autonomy would be worshipping a theory with unexamined awe:

One of the more astonishing features of current political debates on autonomy and coercion is the naïve underlying assumption about rationality and human motivation. Psychology – whether based on behaviorism or on its diametric opposite and antagonist, Freudianism (or any of the splinter of these two dominant branches) – views few pieces of human conduct as rational choices selected at the moment. Rather, modern motivational psychology tends to see most human behavior as being “conditioned” or “unconsciously determined,” a consequence or product of life experiences that tend to make responses to certain stimuli automatic and unchosen... (Gaylin & Jennings, 2003, pp. 16-17).

What about Christman's account of autonomy which Killmister claims is a more persuasive account of autonomy? “For Christman, the necessary endorsement must be directed at the process of desire-formation, rather than the desire itself” (Killmister, 2013, p. 98).

Christman's theory of autonomy is socio-relational (even though just like other rational choice theories it is an internalist theory). Stoljar has observed:

For Christman, preferences or desires will be nonautonomous only if they fail either a competence condition or a hypothetical reflection condition. Competency corresponds to the capacity of the agent to form effective intentions relative to a desire as well as to reflect critically about the desire. The hypothetical reflection condition employs the notion of non-alienation to characterize authenticity and hence autonomy... To be alienated is to feel negative affect, to feel repudiation and resistance (Stoljar, 2014, p. 235).

This means that for an action to be autonomous the individual must personally identify with the desire through the feeling of non-alienation. Killmister has differentiated Christman's account from other procedural accounts of autonomy as follows:

For instance, we can take an individual who desires to eat a slice of cheesecake. Rather than asking, as Dworkin and Frankfurt would, whether the individual desires to desire to eat a slice of cheesecake, Christman asks how she would feel about her desire, were she to be aware of how the desire were formed. If the desire were implanted by a hypnotist, and knowledge of this process caused the individual to feel alienated from the desire, then that desire would not be autonomous (Killmister, 2013, p. 98).

Like I have argued above concerning Frankfurt and Dworkin's vision of autonomy, likewise I am dissatisfied and therefore dismiss Christman's endorsement account. Endorsement accounts of autonomy equally fail to account for internalization of norms, values of which an individual may endorse or identify to be her own when making day-to-day life decisions. The problem with Christman's theory is not to do with the "inclusion of a historical version of reflective endorsement, as is commonly thought, but rather that this condition is insufficient to determine the autonomy of an individual" (Killmister, 2013, p. 100).

Christman's hypothetical reflection account is problematic because it fails to appreciate that due to deeply ingrained traditional values, imparted through oppressive (and non-oppressive) ideological socialization, individuals can identify with deformed desires and not feel alienated (Stoljar, 2014). Effects of ideological socialization can cause a socialized recipient to treat stereotypes as natural and thus formulate one's desires and plans based on the ingrained stereotype (Stoljar, 2014). Indeed, recipients of oppressive ideology "are unlikely to experience alienation from either the norms that they have internalized or the preferences formed on the basis of the norms" (Stoljar, 2014, p. 235). To this effect, I therefore dismiss Christman's psychological account of autonomy. Christman's account of autonomy merely ices the cake (Frankfurt and Dworkin's accounts) by identifying capability for autonomy with individual endorsement of a given desire.

The next theory of autonomy which we will now turn to is Alfred R. Mele's external historical account theory. Mele defines autonomy as self-rule or self-government (Mele, 1995, p. 3). His theory is a hypothetical counter-example to procedural accounts (Killmister, 2013, p. 101). He dismisses psychological (internalistic) accounts to be insufficient (Christman, 1999). He reasons that if all individual human beings were Athena (regarding ability for autonomy) his historical account of autonomy would serve no purpose, but because individual human beings are not Athenas his account is valid (Mele, 1995).

In fact, I find his account of autonomy to be more realistic and persuasive than Frankfurt, Dworkin and Christmans' accounts. He argues that for an agent to be autonomous her actions must not be compelled by another:

It is a historical property of agents required for responsibility for the possession of a pro-attitude. A necessary condition of an agent *S*'s authentically possessing a pro-attitude *P* (e.g., a value or preference) that he has over an interval *t* is that it be false

that S's having P over that interval is, as I will say, compelled – where compulsion is not arranged by S... (Mele, 1995, p. 166).

This theory implies that second-order desires must not be a product of compulsion. In another sense, it acknowledges that human beings are susceptible to acting on socialised values (compelled or instilled pro-attitudes).<sup>38</sup> Thus, compelled pro-attitudes, according to Mele, make individuals non-autonomous (Mele, 1995).<sup>39</sup> The following conditions as summarized by Killmister entail what, according to Mele, can make an individual's actions non-autonomous:

...an agent 'comes to have a pro-attitude because of an external force, rather than via exercise of her skills for critical reflection and evaluative judgment; (ii) the instilled pro-attitude is one she is unable (in the absence of radical counterfactuals) to eradicate or attenuate; (iii) she did not arrange the by-passing herself; and (iv) she does not, nor did she earlier, possess other pro-attitudes that would support her endorsing the instilled pro-attitude (Killmister, 2013, p. 101).

This thesis of autonomy suggests that human autonomous action cannot only be understood in terms of rational choice. It also ought to be viewed from a historical and motivational sense. The implication of this understanding is that human motivation is susceptible to socialized pro-attitudes. Mele dismisses rational choice theories of autonomy as inadequate because such perspectives explain that autonomy can be achieved as long as an agent is fully competent in turning her second-order desires into intentional action (Dworkin, 1988; Christman, 1999).

Mele's exposition of autonomy makes more sense. I am not convinced by rational choice theories because of their premising of capacity for autonomy on a person's mental state; such explanations offer an inadequate account of self-governance. Besides the satisfaction of mental states for autonomy, external conditions equally ought to be satisfied. A fully competent individual who is capable of acting rationally upon desires (values of which she has critically reflected upon) cannot necessarily by this token be safely considered to be

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<sup>38</sup> A pro-attitude is a person's mental attitude (a feeling or opinion about someone or something) directed toward an action under a certain description; pro-attitudes may include moral views, desires, urges, aesthetic principles and economic prejudices (Bunnin & Yu, 2004).

<sup>39</sup> Indeed, according to Mele, to be autonomous is to self-rule or self-govern.

autonomous because the values (of which she considers to be her own) could have been socialized (compelled<sup>40</sup>) earlier in life (Mele, 1995).

However, my contention with Mele's thesis of autonomy lies in his advancement of alternative theory of self-control as being a mechanism through which one can achieve autonomy. This perspective (of capacity for autonomy due to self-control) appears to water down the fact that inculcated cognitive biases can compose the very mechanics of self-control. Nonetheless, I reiterate that credit ought to be given to Mele's theory of autonomy because it is inclusive of external factors. Moreover, credit should be given especially because even though Mele suggests that an ideally self-controlled person can act autonomously, he, nevertheless, concedes that the ideally self-controlled person is not necessarily autonomous (Mele, 1995; Christman, 1999):

Despite being perfectly able to appraise critically and act upon her desires and values, the perfectly self-controlled person may nevertheless be acting on desires and values that have been implanted into her by artificial means, ones whose development has bypassed normal reflection and awareness. In those cases, the person is self-controlled but not autonomous (Christman, 1999, p. 96).

Indeed, Mele's self-control theory does at the same time convincingly explain away how the problem of socialization of pro-attitudes can be prevented since young children do not have competent mental capacities of which they can employ in preventing acquisition of pro-attitudes.

Indeed, Killmister argues that there is a problem in Mele's theory if it is to be used as a guide for identifying "autonomy-inhibiting socialization" (Killmister, 2013, p. 101). She argues that Mele's approach would rule out most early childhood education directed at developing the very necessary mental capacities. She reasons thus in light of Mele's submission to the effect that a pro-attitude is compelled when its acquisition bypasses capacities for self-control. The author observes that "if the relevant capacities are inoperative or not yet developed, as they will be in very young children, Mele takes them to have been bypassed" (Killmister, 2013, p. 70). Mele advances that bypassing is common in

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<sup>40</sup> "To be compelled is to be unable to shed the attitude in question and to have been conditioned to adopt it in ways that bypass the usual kinds of mental control normal agents enjoy – basic critical reflective capacities as well as skills in self-control" (Christman, 1999, p. 96).

infants, however, argues that such bypassing is not sufficient for compulsion unless the pro-attitude is also practically non-sheddable.

For Killmister, Mele's diagnosis as to what should count as autonomy-inhibiting socialisation is problematic. She notes that many people have pro-attitudes (traceable to early childhood socialisation) that practically they are unable to shed. She claims that even our attitudes towards evidence, reason, and reflection are both presumably inculcated and practically unsheddable:

The problem here is that one of the central roles of socialisation is to inculcate the very pro-attitudes that are required for the kind of self-control Mele sees as necessary for autonomy. To be self-controlled is to believe and desire on the basis of an assessment of evidence. This will rely upon having the appropriate pro-attitudes towards evidence and reasons, which must at some point have been instilled in the child (Killmister, 2013, p. 102).

Indeed, since as Killmister has argued self-control has to be cultivated through socialization, it will be hard in later life for a growing child to un-shed what was earlier inculcated as the nature of things when one was growing up. I therefore argue that the 'unsheddable' injunction by Mele is not a sufficient theory to qualify autonomy. This is because of the problem of early years infant socialisations which does bypass children's undeveloped mental abilities in that children at these early years in their lives lack skills of critical reflection to evaluate what is taught to them.<sup>41</sup>

In other words, I do not agree with Mele's conclusion, although I agree with his pro-attitudes analysis. I do not agree with him on the basis of his employment of self-control as a basis for autonomous action. I believe that an individual's campus of self-control can be a product of socialization which is highly unsheddable. Shedding what one has grown up

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<sup>41</sup> Can we not admit that "Human beings are born biologically premature, so that unlike most mammals, many of our neurological and physical functions and all of our behavioral capacities exist at birth in potential form only [?]. To come to fruition, these potentials must be molded by a social environment"? (Gaylin & Jennings, 2003, p. 34). The conditions which influence our everyday adult conduct are set by our parents and culture early in life through a conflation of coercion, parental encouragement, emotional intimidation, conditioning, and other mechanisms (Gaylin & Jennings, 2003, p. 125). Indeed, these tools which our parents and society consciously and/ or unconsciously employ inescapably shape, inter alia, our personalities, and sear into our consciences what we inevitably come to view as our own ideals or values.

thinking is one's natural personality or identity, even when the fact is that it was inculcated through childhood, is at best very futile task.

Thus, Kapitan (2000) also argues that Mele's account is not adequate as a response to the problem of manipulation. He dismisses Mele's argument by noting:

In our early development each of us is subjected to physical and social forces of which we are largely ignorant, over which we have no control, yet from which we acquire values, beliefs, motivations, and capacities for rational evaluation that subsequently guide our choices and actions. These forces 'destroyed' any capacity to become a different sort of person with self-control regarding any unsheddable pro-attitude that we happen to have. Consequently, every unsheddable pro-attitude is compelled, and anyone with firm unshakeable principles of action ends up being inauthentic and non-autonomous... (Kapitan, 2000, p. 89).

Kapitan concludes:

Historical factors have an undeniable bearing upon both moral character and moral accountability. Facts about how a person's mental states or character traits were formed and developed are relevant to his or her moral virtue and vice. Because these historical factors concern the change, formation, and integration of attitudes and character traits, they are internal to the agent's character development (Kapitan, 2000, p. 95)

Since the above theories, especially Dworkin's, Frankfurt's and Christman's accounts of autonomy, are unconvincing could the theory put forward by Natalie Stoljar provide a solution to the predicament of socialisation (Stoljar, 2000)? Killmister suggests that Stoljar's theory is initially promising as it acknowledges that "the question for all theories is what kinds of socialisation are incompatible with autonomy" (Killmister, 2013, p. 104).

Stoljar rejects procedural approaches to autonomy by replacing them with a substantive account. She argues that procedural conceptions fail to appreciate that people who have been subjected to false and oppressive internalized norms cannot be autonomous.

According to her thesis, oppressive socialisation can lead an individual to internalise false beliefs which the victim may later on come to endorse as her own. And, as that decisions made on the basis of internalized false beliefs are not autonomous. In this sense, Stoljar's thesis indicates that mere possession of false/ oppressive beliefs would make an individual non-autonomous.



I find Stoljar's account of autonomy to be less persuasive in comparison to Mele's self-control account. What makes her theory problematic is that it reduces autonomy to an individual who is free from false/ oppressive socialization (Killmister, 2013). Such a thesis of autonomy fails to consider that for an individual to be autonomous she does not only necessarily need to choose her own moral position, but also enjoys the absence of any form of external influences on her self-determination capacity. Autonomy is not about morality, but self-rule. What my argument entails is that even non-oppressive internalised norms can still be non-autonomous, provided they were instilled or regulated by another or something external to an individual. If to be autonomous is to be self-governing or self-directing or, in other words, to act on motives, values, and reasons that are one's own, then how can we restrict non-autonomous action to false/oppressive socialisation? Moreover, the fact that the person who is supposed to be a law unto self is at the mercy of false/oppressive socialization shows lack of sovereignty, hence autonomy (Kant, 1785).

The final feminist autonomy account I wish to consider is the dialogical approach advanced by Andrea Westlund (Westlund, 2009) and Paul Benson (Benson, 2011). Dialogical accounts of autonomy view the self to be a social self; thus a person's answerability to others becomes the key condition for autonomy. In other words, according to these accounts, autonomy is synonymous with a person's ability to have normative power or authority over one's decisions (Mackenzie, 2008). Autonomy is dispositional; ability to be answerable to others.

What is encouraging about dialogical approaches to autonomy is that they indicate that human beings are interconnected - in other words, social. However, this approach is equally unconvincing because capacity for autonomy, like all other rational choice theories, is premised on an individual's mental capacity.

Westlund argues that autonomy should not be understood in terms of an individual's psychology or history, rather it is constituted by a particular kind of disposition. Her theory suggests that an agent's answerability to others is a key condition for autonomy. She rejects psychological accounts which constitute an autonomous agent to be one who critically reflects in an appropriate way in evaluating one's preferences, desires and motives. In other words, she rejects the rational choice accounts because it is argued that autonomy is achieved when an individual engages in critical reflection or if an individual acts or chooses

to act in accordance with desires which she has self-reflectively endorsed (Friedman, 2003).<sup>42</sup>

According to Westlund, one's autonomy is instead undermined if one is unable to give reasons in defence for one's actions or choices (Westlund, 2009; Killmister, 2013). So an individual who readily answers for herself constitutes a self-governor or autonomous person. According to Benson, an autonomous act is achieved when self-regarding attitude is expressed in one's willingness to take responsibility for one's actions (Benson, 2011). In this case, if an agent claims authority over one's actions, then such an agent is autonomous. These accounts suggest that certain emotional states and attitudes to oneself are necessary conditions for autonomy. Such an approach appears to advance that reliance on critical reflection and judgment for autonomy is only possible if a person can sustain against criticism of one's own sense of basic competence and worth:

In acting autonomously, we strive to meet moral responsibilities to the self" and that acting autonomously involves having "justified self-trust" in that self-trust or distrust is not justified if agents overestimate or underestimate their competence. 'Claiming authority involves standing behind it, and speaking for, actions that we have performed... (Killmister, 2013, p. 108).

I wish to suggest that dialogical accounts of autonomy are philosophically and morally problematic. They are philosophically unconvincing because such approaches ground autonomy on a person's ability to offer reasons for one's choices and they are morally problematic because they are individualistic in outlook.<sup>43</sup>

Indeed, even though Westlund criticizes psychological accounts of autonomy, dialogical accounts of autonomy equally appear to be psychological in outlook to me. Thus, my criticisms of rational choice accounts of autonomy can to a larger degree equally be applied to dialogical ones; both approaches clearly ignore or brushes aside the reality of socialization or conditioning.

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<sup>42</sup> As earlier stated, such procedural (psychological) accounts of autonomy have been promoted by thinkers such as Dworkin and Christman (Christman, 2009).

<sup>43</sup> Such outlooks appear to promote autonomy on the basis of meeting moral obligations to self. The common good, a value which will be discussed from chapter 4, is arguably denigrated even though, ironically, the social condition of humans is acknowledged in such approaches. "To respect each person's interests in living her life in accordance with her own conception of good" (Mackenzie, 2008) propagates individualism.

In fact, for reasons that Westlund regards someone as non-autonomous if they defer to something or someone other than providing their own reasons in choice-making, she appears to ignore the fact that defending a choice is not necessarily synonymous with being its author, or with authentically identifying or individually valuing a given choice. An agent can defend, e.g., oppressive values, not because that is what the agent wants but because external circumstances condition the agent to embrace such oppressive values, and yet still be in a position to stand behind a given decision. In this sense, being answerable to one's choices or behaviour does not make one autonomous, but arguably makes one accountable to socialised values which one's external environment through interpersonal conditions have imposed upon or inculcated into an agent. A person can give a convincing and persuasive reasoned answer to something not because she necessarily has chosen the value, but because of environmental conditioning. Moreover, an agent is capable of defending inculcated or internalised oppressive values through adaptive preference formation (Elster, 2016).<sup>44</sup>

Put differently, the problem with Westlund and Benson's conception of autonomy is that individuals can stand behind decisions or actions which are paradigmatically non-autonomous. This is especially seeing that it is widely accepted that "we human are very good at inventing post-facto explanations of our actions, even to ourselves" (Moll, 2004, cited in, Killmister 2013, p. 108).

For Killmister, self-authorization alone is insufficient in constituting autonomy. She dismisses dialogical approaches to autonomy by arguing that "it is to be in control of one's interactions with the world, and it is to have those interactions correspond to one's self... realizing one's will in the world' that makes one autonomous (Killmister, 2013, p. 110). In other words, according to Killmister, for an action to be autonomous one must comprehend what something is about, need to reflect on whether the concerned act is in accordance with one's desires, commitments and values, and whether the subsequent action taken corresponds with one's intentional will. Indeed:

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<sup>44</sup> Adaptive preference formation stifles autonomy because individuals are through limited options available to them in society have their preferences unconsciously altered (Colburn, 2011; Elster, 2016). "Preferences formed through adaptation are characterised by covert influence (that is, explanations of which an agent herself is necessarily unaware), and covert influence undermines our autonomy because it undermines the extent to which an agent's preferences are ones that she has decided upon for herself" (Colburn, 2011, p. 52).

Self-governance must surely be taken to mean both governance by the self, and governance of the self. While concern with the former explains the focus on authenticity, concern with the latter should extend this focus to include the agent's navigation of the path through life. If the agent's authentic values and desires cannot be implemented in action, then it is hard to see how she is governing herself at all (Killmister, 2013, p. 111).

I agree with the above analysis of Killmister. However, I do not agree with her when she later concludes that individuals can be autonomous by merely being able to comprehend what something is about – having capacity to reflect on whether the concerned act is in accordance with one's desires, commitments and values, and whether the subsequent action taken corresponds with one's intentional will or not. I suggest that an individual can be mistaken to regard pre-inculcated values or beliefs to be hers and intentionally and innocently declare them to be hers, when the reality is that the values one has embraced potentially may have been inculcated or conditioned when one was still a child.

Also, when Killmister concludes that we do not have absolute autonomy, but 'degrees of autonomy', I hesitantly agree. However, I agree in the sense that 'degrees of autonomy' are restricted autonomies where individuals have been placed under laws where boundaries have been drawn on how far they can conduct themselves. One may as well call such 'permitted autonomy'. It is within the boundaries of laws (natural or positive), ethics, regulations and conventions where, I would argue, 'degrees of autonomy' can be found. In this regard, I agree that humans have no absolute 'autonomy'. Nevertheless, the illusion of founding autonomy on limited autonomy crumbles when the whole picture of human motivations is considered.

Gaylin (1996) establishes that human motivation and behavior is highly susceptible to environmental influences. Firstly, he asserts that human beings are products of the environment and its creators, in that a conception of a human being as independent of others is self-defeating. Secondly, he argues that "social controls are an essential aspect of any sustainable, viable society, including liberal and democratic ones" (Gaylin, 1996, p. 44). He notes that "the structure of organized society rests on defined limits of freedom" (Gaylin, 1996, p. 44). This suggests that that socio-relational morality motivates human conduct. Such morality is also enforced by law; law tells a person what acceptable behavior is and ensures compliance through legal enforcements.

Gaylin argues that protagonists of autonomy are mistaken in believing that human behaviour is voluntary. He argues that human behaviour is less voluntary by submitting that “present behaviour is significantly determined by past treatment” (Gaylin, 1996, p. 44). Moreover, he suggests that human behaviour is less rational than we are willing to admit. He advances that our conducts are influenced by our emotions which are usually more effective than logical argument, and adds that shame, fear, guilt, greed and pride influence human behavior. The implication of the above analysis is that a combination of societal morality (morality which can be internalized through effective socialization), the institution of law in society which define the boundaries of human behavior, and human natural susceptibility to emotions (as drivers of decisions) paints the argument for capacity for individual autonomy in bad light. Individual autonomy is an illusion.

Discussing the stifling nature of our biological make-up on human decision-making, Morison (1984) observes that besides historical influences our ‘agency’ is encumbered with genetic or environmental factors of which subtly motivate our day-to-day choices. For Morison, much of our human behavior is significantly influenced by events over which we as individual have little or no control. He quotes Melvin Konner’s *‘The Tangled Wing: Biological constraints on the human spirit (1982)’*<sup>45</sup> work as an extraordinary book which identifies, among others, the role which genes and the environment plays towards behaviours:

It requires only a little reflection to realise... that our choice is strictly limited to the possibilities displayed before our conscious in real time including those we can call up from memory or create by synthesizing bits and pieces of previous experience... Not nearly so clear is the degree to which the final choice is also so conditioned or ‘shaped’ by genetic patterning or by previous experience of which we are no longer conscious. My hunch is that such influences are much more numerous than we imagine and that autonomy in any strict sense is an illusion (Morison, 1984, p. 46).

### **3.3.2.1 Autonomy is a social phenomenon**

Owing to the foregoing discussions, I have become inclined to conclude that seeing that individual autonomy is a myth, it would be more convincing to regard autonomy as being possible in a social sense. In relation to the problem of self-sufficiency in autonomy,

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<sup>45</sup> Konner has demonstrated that man’s behaviour is influenced by nature and nurture (Konner, 1982).

Crittenden (1993) observes that critics of liberalism, and even some liberal theorists, have criticised the emphasis of autonomy by liberalists. The liberals' conception has been criticised because, as feminists have also argued, it is associated with self-sufficiency, thereby enforcing what Crittenden has referred to as 'the worst aspects of atomistic individualism, insulation, social isolation, and an indifference to society's values and interests'.

Crittenden, like Gaylin, acknowledges that human beings by nature are interdependent and interconnected. Hence, he argues that a conception of autonomy which is premised on self-sufficiency does not represent a fulfilment of autonomy but its abandonment. He submits that autonomy has a social nature, and explains that autonomy develops through sociality, and it also requires sociality for its exercise.

Crittenden quotes Anthony Arblaster who has noted that it is not normal or even desirable for a human being to be self-sufficient (Arblaster, 1984, p. 22). He also appeals to Jennifer Nedelsky who submits that "the perfectly autonomous man is thus the most perfectly isolated" (Nedelsky, 1989).

For Crittenden, autonomy does not entail isolation from the presence of the influence of others or a necessary rejection of societal values, but that the very concept of autonomy depends on these very factors. He argues that "the social nature of autonomy appears to undergird a communitarian notion of the self as socially situated" (Crittenden, 1993, p. 37). The author argues, among other reasons, why he believes autonomy is social that individual human beings are not born with autonomy, rather that autonomy requires psychosocial development. He also argues that "autonomy is social because we can only be autonomous when we know we are acting autonomously; and we can only know that when we give an account to others of how we arrived at a decision or action" (Crittenden, 1993, p. 38).

Indeed, according to Crittenden, an autonomous person is one who is able to remove herself from the social matrix, a matrix where she earlier identified. He argues that no person is born autonomous; can only be autonomous through socially distancing oneself from the social matrix. But also, that an autonomous individual needs a social context; a context from which to define oneself as separate from others. Also noting how even language is social, he states:

Any kind of introspection or reflection must be done in and through language, and the language we use is itself a cultural or social inheritance. We do not create it, and in this sense also autonomy has a social side... To make our actions and judgments intelligible to ourselves, we not only translate them into language, but also form them through language. The only language we have available by and through which to think rationally and self-reflectively, is one based on cultural tradition... There is implicit in every language, as part of that cultural tradition, a system of norms and standards that determine proper use (Crittenden, 1993, p. 44).

I agree with Crittenden's theory of social autonomy, even though there are some issues which arise from a further reading of his account which I do not necessarily agree with. I also credit Crittenden's acknowledgement that we do not create and shape ourselves, but our perspectives are formed through language, a language packed with cultural subtleties.

However, when Crittenden suggests that an autonomous person is one who is able to distance oneself from the social matrix - a matrix from which one earlier identified, I wish to argue that this suggests that an individual is capable of extricating oneself from the social context, and, I add, from one's genetic make-up. I wish to explain that if at all Crittenden means that an individual can extricate oneself from the environment (a reality which has made who she is), I would argue that doing so is not possible in reality due to common human frailty, vulnerability, interconnectedness and interdependence.

In other words, because we are 'social autonomous beings' who have inculcated or internalised pro-attitudes, it makes it even more difficult to disown or separate ourselves from what we personally are disillusioned to believe are our own personal values and aspirations, and worse our natural condition of interdependence prevents us from becoming recluses. Additionally, I wish to argue that giving an account for our envisaged or executed actions does not make us individually autonomous, but socially responsible as such action entails a desire for social validation. It is relegating for a 'sovereign' who has absolute rights to do things according to her good pleasure to account for or explain her actions to others.

### **3.4 Oshana's refutes rational choice theories: she advances a socio-relational account**

It is gratifying to find that Marina Oshana grounds autonomy on a socio-relational premise. She also submits that autonomy is equivalent to self-governance (she states that the synonyms for self-governing are; 'free-standing', to be independent (self-sufficient), to be separate, and to be self-ruling and sovereign) (Oshana, 1998).<sup>46</sup>

Like other authors reported above, Oshana rejects the psychological conceptions of autonomy; she, instead, advances an externalist account. She accounts for autonomy by invoking both the internalist (psychological) and externalist (socio-relational) perspectives.

Oshana reasons that the reality of self-government in an individual is social in nature. Dismissing psychological conceptions of autonomy, she argues that an individual does not become autonomous because of what goes on in her head, rather what also goes on around her in the world in which she is part of. She suggests that "autonomy is a condition of persons constituted, in large part, by external, social relations people find themselves in (or in the absence of certain social relations)" (Oshana, 1998, p. 81). In this sense Oshana's conception is similar to Crittenden's theory. However, unlike Crittenden, Oshana adds that manipulation, coercion, the subjection to the dominant will of others, and also "the internal phenomena native to the individual such as captivity to desires or physical impulses, psychological neuroses, or weakness of the will" compromise capacity for autonomy (Oshana, 1998, p. 83).

Like Killmister, Oshana similarly criticises, among others, Dworkin, Frankfurt and Christman's accounts as inadequate because such accounts are exclusively internalistic: procedural and dialogical accounts of autonomy premise capacity for autonomy as being dependent on "structural and/ or historical character of a person's psychological states and dispositions, and on an agent's judgments about them" (Oshana, 1998, p. 83). She argues that the hierarchical type of autonomy as advanced by Dworkin, which states that an agent is autonomous, granted that nothing has occurred, which compromises the structural integrity of that individual's rational well-being, is insufficient in satisfying the constituents of

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<sup>46</sup> Oshana's definition of autonomy is similar to the working definition I have adopted for this study. Such a definition is also in line with how the concept was originally conceived in ancient Greece.



autonomy. For Oshana, an individual does not become non-autonomous merely by being born in an environment where one has no control; but one becomes non-autonomous by virtue of the effects of the conditions of a given environment to one's decision-making.

She maintains that choice does not guarantee autonomy. This is because a person who may be exercising what appears to be genuine choice may be compelled to do so by others, and endorsing such choices from within does not guarantee autonomous agency (Oshana, 1998, p. 88). In regards to the assumption that critical reflection in a procedurally independent fashion makes one's choice an autonomous one, Oshana argues that "...being able to engage in critical reflection, to take stock of oneself and to shape oneself on the basis of this evaluation, does not guarantee that whatever state of affairs ensues from this activity will be one of autonomy" because autonomy does not exclusively depend on circumstances descriptive of an individual's psychology (Oshana, 1998, p. 89).

Owing to her refutation of internalist accounts, Oshana advances four conditions necessary for autonomy. The four conditions are the condition of critical reflection, of procedural independence, of access to a range of relevant options, and the condition of social-relational properties. She argues that an individual cannot be autonomous if one cannot engage in critical reflection or objective appraisal of one's motives or actions, and the environment in which one's putative values develop; that an individual cannot be autonomous if she is, in fact, influenced or restricted by others in ways that constrain autonomy (such influences can be by way of manipulation or coercion); that autonomy becomes questionable when one claims that their decision was autonomous in circumstances where one was lacking in access to an adequate range of options; and, that an individual who is in society (having relations with others) cannot be autonomous unless the relations she has with others enables her to pursue one's goals in a context of social and psychological security (Oshana, 1998, pp. 93-95). Oshana submits that the four conditions for autonomy which she has identified are not mutually exclusive; they must all be satisfied for one to claim autonomy.

For Oshana, her account of autonomy has three benefits: it recognises the human condition; it recognises the status of humans as moral agents; and, that a socio-relational account of autonomy "can easily explain how persons might be self-governing even when manifesting

external or communal virtues that might appear to reduce autonomy” (Oshana, 1998, p. 98).

To this extent of Oshana’s theory, I wish to argue that it makes sense to view autonomy as capable of being achieved in a social context. It is in this light that I have been compelled to conceive a concept of social autonomy, a conception I have derived from the social-self nature of humans. When I argue for a conception of social autonomy, I do not say so to mean that an individual should be ruled by the appetites of the majority (social others), but I mean to say that a socio-relational conception of autonomy is more convincing, philosophically and morally. I appreciate that human beings are unique, but I also recognise that they are only able to exercise such uniqueness or the ‘self’ in the social context by virtue of human natural sociality, interdependence and interconnectedness. Indeed, what my analysis suggests is that:

...the self is where our identity resides. It is the medium through which our actions are guided and our world is perceived... This is clear even from the dictionary definitions of self: “the total, essential, or particular being of a person,” or “the essential qualities distinguishing one person from another,” or “one’s consciousness of one’s own being or identity; the ego.”... [However] The self is not a truly autonomous ego, it is an interactive entity defined not just in terms of differences from others but in relationship to them. The answer to the question: “Who are you?” is not satisfied by you stating that you are a woman of forty-three. That much is self-evident; the questioner already knew that. It will usually be answered by such information such as: “I am a biologist at Columbia College, working on the problems of immune systems; married to my college sweetheart; I am a mother of two girls and a boy; I was born in Taiwan but am now a naturalized citizen of the U.S.A.,” and on and on and on...” (Gaylin & Jennings, pp. 145-146).

### **3.5 Paternalism and Autonomy**

One of the arguments for advancing personal autonomy in medical decision-making has been the claim that carrying-out a medical procedure without a patient’s consent is paternalistic (Buchanan, 1978; Komrad, 1983; Drolet & White, 2012). The interference consists in doing something for a patient without the patient being given an opportunity to consent or withhold consent for an intervention. Indeed, medical paternalism appears to have been practised over many centuries in general medical practice (Komrad, 1983;

Jackson, 2013). Similarly, Mason & Laurie (2013) acknowledge that a few decades ago the practice of medicine was paternalistic, whereby patients were treated without being given information of what was involved or the facts about the illness for which they were being treated. In this section I will show that contemporary public health and medical practice is still paternalistic. It will be concluded that lack of respect of individual autonomy through public health policy and clinical practice testify to the myth of autonomy.

The questions to be asked in our consideration of paternalism are: is it justifiable to treat a patient when the patient has objected to a treatment, and treating the patient will be in her best interests? Should we continue to celebrate the relegation of medical paternalism and view it as a historical perverse value (Drolet & White, 2012)? Put differently, should the ability to intervene in a patient's life only be always occasioned by a clinician's conviction that 'this is what the patient has chosen'? Should the cost of illness to one's family members, the community and the State always be ignored?

Mason & Laurie (2013) have suggested that paternalism is only acceptable in principle and necessary in practice when the person on whose behalf a decision has been made is incapable of making a decision on her own. These authors identify the unconscious, young children, and the psychiatrically ill as subjects to whom medical paternalism can be justifiably applied. However, my study will show that public policy, and often, clinical practice is still paternalistic.

The reality is that paternalism is still being applied to many public health decisions even though some people may choose to be in denial of such a reality. In Europe, a good example to start with would be the *Public Health (Tobacco) Act, 2002* implemented by the Irish government on March 29, 2004. The Act bans smoking in the workplace, pubs, restaurants, and other recreational places. One of the objections by a section of the Irish society before the implementation of the Bill was that introducing such a law would be yet "another instance of the nanny state", and it was held by many of those who were opposed to it that such an act would interfere with personal autonomy (King, 2004, p. 134). However, the Bill was eventually passed into law, as if in blatant disregard for the 'autonomous' claims of those who were opposed to it. The implication of such a deliberation by the legislative body in Ireland is that the legislature decided to regulate the lives of individual persons, where

the power to choose a place to smoke from as one chooses was now curtailed. England and Wales through the *Health Act 2006* have also made smoking in public places unlawful.

Owing to the foregoing observations, it becomes crucial at this stage that I briefly establish the definition of paternalism, in order to appreciate the implications of paternalistic laws. Arneson (1980, p. 471) describes paternalism as “restriction on a person’s liberty which are justified exclusively by consideration for that person’s own good or welfare, and which are carried out either against his present will, or against his prior commitment.” Feinberg, suggests that the term paternalism gives rise to opposition since it “suggests the view that the state stands to its citizens as a parent (or perhaps a male parent!) stands to his children...” (Feinberg, 1986, p. 4). The practice of paternalism, opponents argue, make it seem as though adult individuals lack competence to make own decisions.

Mill rejects paternalism where there is no harm to others (Mill, 2015) and, Dworkin (1983, p. 28) who supports Mill’s view has also contributed that paternalism is only justified in cases where the measure can “preserve a wider range of freedom for” a given individual. As shown, Dworkin’s argument does also not resonate with reality. Individuals’ freedoms are often curtailed to protect the common good. Moreover, and if we are to agree with the rationale for justifying paternalism which Dworkin gives, then would it be erroneous to suggest that since HIV testing and subsequent treatment could lead to an informed individual leading a quality life and continuing to enjoy more rights (e.g., the right to life, health and education), paternalistic HIV testing can “preserve a wider range of freedoms”, therefore, paternalism is justifiable?

Husak rejects paternalism declaring that paternalistic measures treat individuals as less than fully autonomous agents (Husak, 1981). However, unlike Mill and Husak, among others, who reject paternalism, Feinberg only rejects what he calls hard paternalism (Feinberg, 1986). He is in favour of what he calls ‘soft paternalism’. Pope (2005), in turn, rejects Feinberg’s conception of soft paternalism. (Soft paternalism accepts interference with a person’s conduct when an individual person’s decision to engage in a given conduct is not factually informed, coerced, not adequately understood, “or otherwise substantially cognitively or volitionally impaired” (Pope, 2005, p. 122). According to Pope, Feinberg’s “strategy seems to work only because the former ‘stretches’ soft paternalism to justify liberty limitation that is properly described as hard paternalism” (Pope, 2005, p. 122). Pope argues that the

normative appeal should not be masked if the public health restrictions rationale on liberty is grounded on hard paternalism. He accuses Feinberg's conception of soft paternalism as lying in the latter's biasness owing to his being a committed classical liberal philosopher:

Liberal philosophers like Joel Feinberg must explain or account for reasonable self-regarding liberty limitations either on the grounds that it is: (1) in fact, not self-regarding (and, therefore, not paternalistic; or (2) soft paternalistic (Pope, 2005, p. 126).

I agree with Pope to the extent that paternalism is still paternalism. There cannot be such a thing as soft paternalism because whether it be soft or not individual autonomy is still violated. Maybe we just need to admit that human beings are not autonomous after all, and instead come up with ideas on when paternalism can be justifiably applied in clinical practice and other spheres of life. In fact, instead of premising opposition of medical paternalism on individual autonomy, it would be more plausible to find an alternative premise against paternalism.

It is apparent that the legislators of the Irish Tobacco Act ostensibly chose the common good over individual autonomy because individual autonomy is not inherent. Indeed, such legislations and other laws, like road traffic legislations, suggest that the prevention of self-inflicted harm and harm to others can be legitimately employed to override personal autonomy. These legislations curb the autonomy of a person who wishes to smoke wherever he wishes, drive without a seatbelt, ride a motorcycle without a crash helmet, or drive under the influence of alcohol/ drugs. They are simply paternalistic.

In other words, since we claim to be self-governing, do we really need the legislature to act so protectively on our behalf, since as autonomous rational human beings we are supposed to be choosing what is best for ourselves as individuals? I suggest that the fact that governments all over the world make paternalistic laws which restrict individual freedoms indicate that we are not sovereigns of our own lives. Such governmental ethos around the world only goes to show that unlike the myth of autonomy paternalism is real.

We are faced with restrictions in our daily lives; 'you cannot do this', 'you cannot do that', and 'you cannot do the other' seems to be the character or recurring choruses we hear every day in our lives. In our studies, in our family lives, in our career lives, and in our social

lives, we are bombarded with expectations, goals set by others, conventions, policies, and rules, of which we are obligated or expected to honour. Is this not paternalism? And if it is paternalism, then what does this mean to our individual autonomies since we desire to conceive ourselves to be autonomous individuals? Why should society fail to respect our autonomy? I wish to suggest that paternalism may be necessary in certain circumstances in society because we are social creatures who are interdependent and interconnected with others.

For example, even though seeking consent from a patient would be imperative prior to intervening medically, sometimes there can be a problem with leaving the decision to a patient because medical decisions are emotion laden and often induce stress, confusion, and equally medical conditions can impair capacity to correctly understand and weigh provided medical information in order to reach an informed decision (Wear, 1998; Drolet & White, 2012). Hence, Drolet and White have concluded:

There are critical implications to the loss of physician-driven decision making in medicine... It is generally accepted that decisions are best made by experts. Within their respective fields, experts are charged with understanding the nuances required for best practice of the profession... Despite the common political opinion, medicine is not a simple consumer-producer market, and physicians cannot be forced into a fully patient-autonomous system. Furthermore, a default overemphasis on autonomy hinders the upholding of other central values in medical ethics: respect for autonomy must be balanced with nonmaleficence, beneficence, justice, and the paternalistic obligation to uphold standards of care (Drolet & White, 2012, p. 584).

I wish to end this section by suggesting that because the very premise of individual autonomy is questionable, it becomes extremely difficult to gratuitously dismiss certain forms of paternalism, and paternalism can be a 'necessary evil' in medical practice since in the majority of cases medical professionals know better than service-users. Human life is so intertwined that leaving all decisions to individuals cannot be supported unless a person chooses to live the life of the Koala. Moreover, because of the natural appetite which imbeds us with others' lives, the option we are left with is to accept that provided we

continue to live in a society of other people, we will never be able to free ourselves from paternalism.<sup>47</sup>

### 3.6 Consent in medical practice

Informed consent simply means duty of disclosure and consent.<sup>48</sup> As already alluded to, the concept has been regarded to be important, most notably, in research and clinical decision-making because it is held to promote autonomy. In fact, at least theoretically, informed consent is an important requirement in the patient-doctor relationship in many countries around the globe. In this vein, if a doctor touched a patient without the latter's consent (no matter how benevolently) such behaviour is held to unlawful (Jackson, 2013, pp. 166-167). It also follows that a patient who elects not to consent to a medical procedure has the right to do so, even though the patient's decision is conceived by the doctor or anyone else to be morally troubling, or irrational (*Hopp v Lepp [1979]*).

Thus, Faden & Beauchamp (1986) define informed consent, among other things, as a doctrine premised on the society's cherished value of autonomy that protects self-rule in medical decision-making. Mills, (2002, p. 60) also submits that the consent argument as an indispensable precursor to treatment is grounded on the concept of patient autonomy; "which in turn is based upon the rights of individual self-determination and of bodily integrity".

However, not everyone agrees with the pro-informed consent rationale (Taylor, 2009). Some sceptics view the doctrine as a value which is in an irremediable state of conflict with good medical practice, or simply, it is vague. For the purposes of this study, it be added in

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<sup>47</sup> Gaylin and Jennings argue: "... nothing more clearly contradicts the individualistic assumption of the culture of autonomy than the nature of birth and childhood. Social structures – community, family, state, and tribe – are not dispensable inventions of human history. The need for a social structure of some kind is part of our biology and a necessary part of our development and survival; we could not survive as a species or develop true to type did we not have a social structure to support us. Social order is not something from which we can be "autonomous." Rather it is the precondition of autonomy..." (Gaylin & Jennings, 2003, p. 105).

<sup>48</sup> Schuck establishes: "The most fundamental normative argument in favour of requiring health care providers to obtain patients' informed consent to medical treatments proceeds from the principle of autonomy – the notion that each mature individual has a right to make the basic choices that affect her life prospects..." (Schuck, 1994, p. 924).

the light of the foregoing discussions in chapter that the doctrine of informed consent is philosophically and morally problematic because of its premise on individual autonomy.

### **3.6.1 Origin, prominence, and rationale of informed consent in medical practice**

Informed consent's prominence in medical practice has its origin from the Nuremberg Trials. Manson & O'Neill (2007) trace its origins to the long history of liberal political thought, as well as economic theory. These values are traced back to the great European debates of enlightenment; informed consent requirements have not always been fundamental to medical ethics as it is in our day. Manson and O'Neill identify the Nuremberg Code of 1947 as a source of the doctrine's rise in biomedical practice. The 1947 Code embraced the '*volenti non fit injuria*' maxim which holds informed consent to be a means of providing assurance and evidence that there has not been 'force, fraud, deceit, duress', etc., but rather that a human being voluntarily and cognitively gave consent to a proposed medical intervention.

Jackson (2013) provides that in the past doctors did not have a duty to provide patients with information concerning an envisaged medical intervention. No information was made available to patients about the advantages or disadvantages of treatments. She notes that "on the contrary, the assumption was that a doctor would exercise his customary care and skill in deciding upon the best course of action for a patient" (Jackson, 2013, p. 166). She states that the practice where treatment decisions were left to the doctor alone has its roots in the Hippocratic Oath. Not only did the Hippocratic Oath assume that treatment decisions were for doctors alone, but it also enjoined doctors to hide most things (information) from their patients.

Thus, the enjoyment of not sharing medical information with patients as established in the Hippocratic principle lasted until the twentieth century. From the twentieth century onwards there was recognition to the effect that physicians have a duty to provide sufficient information to a patient in order to enable the latter to exercise control over one's own body.



Besides informed consent being seen as necessary to protect autonomy and also redress the doctor-patient imbalance (Jones, 1999), the concept also has a consequentialist justification; it is argued that giving patients control of the care they receive may result in better outcomes. It is suggested that giving control to patients may result in them complying with treatment, treatment which one has voluntarily chosen for oneself (Jackson, 2013). However, the focus for this study will not be on the other reasons given for informed consent, like the addressing of doctor-patient information imbalances or the fact that doctors are not omniscient or omnipotent, but will be on the notion's premise on individual autonomy.

I suggest that the claim that patients have a moral claim to bodily integrity when it comes to medical deliberations cannot be dismissed – as human beings we all want to be treated with respect, worthy and dignity. Indeed, it is necessary for patients to be informed about envisaged medical interventions, and to have control over one's course of treatment. To this extent disclosing information to a patient and seeking consent is necessary to protect human dignity and also encourage participation (Baumgarten, n.d.).

However, I wish to argue that basing informed consent requirements of individual autonomy is philosophically and morally problematic. Human nature and the common good would require that we acknowledge that we are social beings who ought to act socially in order for us to mutually survive and amicably co-exist; individualistic informed consent requirements do not appear to recognise this dimension of human reality. We are not existential sole actors, but interdependent beings whose thriving is equally dependent upon the promotion of the common good.

Moreover, Manson & O'Neil (2007) argue that the widely accepted accounts of informed consent requirements are characterised by exaggerated and impractical standards; standards which are unsurprisingly 'routinely flouted and ignored in biomedical practice'. Failures, the authors argue, arise because the advocated standards propose or presuppose 'inaccurate, excessive or even impossible views of informing and consenting'. So, besides informed consent requirements in medical ethics being problematic because they are individualistic in nature, they are also helplessly difficult to implement in practice.

It has been shown that patient incompetence and impaired competence are common in medical practice due to illnesses or injuries which compromise cognitive capacities. Most patients fail to grasp and appreciate medical information and purposes. Even persons at the apex of their mental faculties may not find it easy to understand medical information for informed consent purposes:

Very many patients are unconscious or too ill, cognitively impaired or mentally confused, too young or too frail to grasp the relevant information, so cannot give informed consent to their medical treatment. Few of them are likely to (re)gain competence in time for consent. Even those in the maturity of their faculties find it hard to grasp information about complex diagnoses or treatment, or severe outcomes. They may ignore or fail to grasp information they are given, mistakenly dismiss important information as routine or trivial, react to information with misplaced or disproportionate dread or fear. Mustering the cognitive grasp and emotional strength to give consent or refuse informed consent to complex or threatening proposals taxes even the most competent of us (Manson & O'Neill, 2007, pp. 5-6).

Wear provides:

The passive nature of the sick role has been recognized (Peabody, 1927), particularly in a way it often tends to produce a childlike state of regression... Paternalistic behaviour – Jay Katz's "silence" at the bedside – may well have been as much a cause of as a response to such regression... It at least seems accurate to say that patients have traditionally been given little opportunity, encouragement, or assistance to be other than passive... But such regression in patients is too common and significant to attribute it solely to clinician behaviour or the nature of health care delivery. The previously mentioned needs to be fixed and reassured are clearly not autonomy-enhancing factors, however common and "normal" such responses to the threat of illness are" (Wear, 1998, p. 58).

And she concludes:

Finally, even if patients are interested in and capable of understanding their situation and prospects, there is seldom time for them to internalize and deliberate about such matters, at least in a fashion that would make their consent other than knee-jerk and unreflective. Informed consent is thus a fiction masking a much simpler reality – that of the patient who chooses whether or not to trust in his physician's judgment" (Wear, 1998, p. 50).

I argue that a patient who is making a decision based on flawed understanding or miscomprehension of medical facts or has limited time to internalise medical information cannot claim that her subsequent decision is autonomous. So, such medical practices indicate that informed consent requirements are a paper tiger in practice. If the majority of patients do not understand information that is directed at them in order to make informed decisions that would desirably result in respect for individual autonomy, then it could be argued that informed consent requirements do not promote autonomy – and if they do not promote individual autonomy generally, then there would be no point in continuing to maintain their justifications on the individual autonomy premise.

## **Conclusion**

Indeed, “the general agreement that informed consent is required for the sake of autonomy, and that autonomy is a basic ethical value, is more apparent than real...” (Manson & O’Neill, 2007, p. 17). Hence, I would like to conclude that autonomy, as particularly and dominantly promoted by Western liberal and libertarian thought, is illusory, individualistic, immoral, and impractical. It is illusory because the social reality of human beings, and the limits placed upon them by genetics make autonomy resemble a fantastic ‘idea’ which cannot be appropriated or achieved in a human society. It is individualistic and immoral because it overlooks the fact that human beings are not asocial beings, but individuals are enmeshed in complex social realities of reciprocity, mutual obligations, responsibilities for amicable co-existence, survival, and well-being:

[1] ... The ghetto woman who is not free to leave her home unattended to do her nightly shopping in safety is not free... [2] Social control are an essential aspect of any sustainable, viable society, including liberal and democratic ones... [3] Human behaviour is less “voluntary” than libertarians and theorists of autonomy would have it. Present behaviour is significantly determined by past treatment... [4] Human behaviour is less rational than most of us would like to believe it is. When it comes to changing conduct, appeals to the emotions are usually more effective than logical argument. Fear, greed, shame, guilt, and pride fuel the machinery of behaviour (Gaylin & Jennings, 2003, pp. 7-8).

What this entails is that lawmakers ought to take notice of available philosophical, sociological, and psychological knowledge which is replete with knowledge to the effect that human motivation is not as rational as we would wish it to be.<sup>49</sup> Moreover, autonomy fails to define and explain what is most valuable in our lives as human beings; “how we come to be who we are, or how society must be arranged to promote both the individual and the common good” (Gaylin & Jennings, 2003, p. 11).

Hence, it is also not surprising that representative traditional sub-Saharan African communitarian moral thought equally sees individuals as naturally social, interdependent, interconnected, who necessarily have moral duties or obligations towards oneself and others for the sake of the common good. This view dismisses the atomistic individual as conceived in dominant Western liberal and libertarian thought (the Kantian, Millan, and Rawlsian conceptions). The dominant sub-Saharan African ontology does not view individual human beings to be autonomous, independent, and rational actors.

Put differently, the analyses under this chapter show that even though Kantian and Millan conceptions of autonomy still play an increasingly larger part in dominant Western political and ethical discourse, it is argued here that individual autonomy is an illusion. By appealing to Western theorists, this study has shown that even from within the Western hemisphere itself, the viewing of individuals as having ability or capacity to act autonomously is considered problematic.

Thus, when Western liberal autonomy is referenced and critiqued in the discussions in this study, it does not entail that this study holds every individual person, or thinker, or ethicist, or lawmaker hailing from the Western hemisphere to have subscribed to the view that human beings are autonomous agents. Nor does it entail that every person from the Western hemisphere is a liberal and/ or a Kantian.

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<sup>49</sup> Human motivation is conditioned or unconsciously determined biologically or socially by both internal and the external environment. This fetters our so-called individual rational choices. “Much of our behaviour... is a product of feelings and perceptions of which we are unaware. Most of the behaviour that we consider rational is actually motivated by unconscious needs and then, after the fact, supported by a logical rationalization... Given these facts of life, efforts at changing behaviour must be directed at the unconscious perception as well as the conscious biases of individuals. Appeals to reason alone will not suffice. The contribution of irrational elements to determining behaviour, long recognized by psychiatrists and psychologists but ignored or resisted by many theorists of autonomy and many policymakers, must now be acknowledged” (Gaylin & Jennings, 2003, pp. 122-123).

In fact, what has been analysed and dismissed in this thesis is the liberal Kantian, Millan and Rawlsian views of individual autonomy; views which have over the past half-century been largely adopted and promoted in Western political, civil and ethical discourse. In that, even in one of the most influential Western bioethics text books (Faden & Beauchamp, 1986), it has claimed that promoting and protecting informed consent requirements in medical practice is paramount because the doctrine is anchored on society's cherished value of autonomy.<sup>50</sup>

This chapter has shown that individual autonomy is an illusion; thus, it is arguably unsafe to premise informed consent requirements on an illusory edifice (individual autonomy). And, notwithstanding the analyses in this chapter, the next discussions in the chapters on sub-Saharan African (and Zambian) ontology suggest that dominant sub-Saharan African discourse and experience does not support the theory that individual human beings are sovereigns of their lives and choices.

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<sup>50</sup> For discussions of the understanding and evolution of the doctrine of individual autonomy, and how this conceptual understanding and evolution has its origin from Western liberalism, see the discussions in sections 3.1 - 3.6.

# 4

## Sub-Saharan African traditional and moral thought

In the previous chapter it was argued that individual autonomy as a concept is problematic when applied to the lives of human beings who are born into society, socialised by society, live in society, and live in biological human bodies which are susceptible to emotions (fear, pain, anger, etc.). Owing to this, it has been argued that the adoption of informed consent requirements to protect individual autonomy is unsupported. Hence, the implication of such conclusions so far is that since it is only the mythical Greek goddess, Athena, who is capable of autonomy, the employment of consent in HIV testing may need rethinking.

In this chapter, I will turn to sub-Saharan African traditional moral thought to find out how this system of thought and morality views human agency. That is, I will seek to find out how African traditional and moral thought view autonomy. Establishing an understanding of indigenous African philosophical and moral thought on autonomy is critical because it enables this study to appreciate if the African<sup>51</sup> philosophical perspective on autonomy, as dominantly understood and held in sub-Saharan Africa ontology, offers a more plausible explanation of who we are as human beings, and what would be the implication of such understanding on the current regime of HIV testing policy and human rights in Zambia.

In the following sections, I will discuss the views of a number of African writers and scholars on the subject in question. These writers have argued that individualism, as understood in the Western liberal world, is alien to dominant traditional African moral thought. As opposed to individual autonomy, this view suggests that human beings are social by nature, interdependent and interconnected. Thus, the difference between sub-Saharan African and Western liberal conceptions of autonomy can be put this way: as individual autonomy is to dominant Western (Soper & Schmidt-Nowara, 1996) liberal and libertarian conception of

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<sup>51</sup> As mentioned in the introductory chapter, the term 'African' or 'Africa' when used in the context of ontological outlook is in this thesis used to refer to sub-Saharan Africa. This study was exclusively concerned with sub-Saharan African ontology and experience. Moreover, most authors/ thinkers cited in this chapter referred to sub-Saharan African ontology as 'African' even when they were clearly writing (and they indicated so) about sub-Saharan African thought.

human beings, human natural sociality, interdependence and interconnectedness is to the dominant view in sub-Saharan African ontology.

#### **4.1 Sub-Saharan African ontology is communitarian**

Discussing how Africa was to plan for her future after colonisation, Senghor proposed that before drawing up any future plans, African leaders must first endeavour to understand African traditional civilisation, and then consider the impact of colonialism on such civilisation (Senghor, 1964, p. 48). He argues that having taken an inventory of traditional African civilisation and the impact of colonialism, the African leader's development plan must not be solely based on economic prosperity, but be social in the light of the African pre-colonial culture and reality. Senghor entreats African leaders and policy-makers to conform their laws and practices to African collectivism norms and values. He argues that it is only when Western concepts are confronted with African cultures and realities and found to be applicable to such realities that they could be integrated in African jurisdictions. The author claims that culture underpins all human activities, therefore, culture cannot be ignored without damage to the well-being of a given society. He laments that a nation that fails to respect the valuable lessons from its history or culture, that does not see itself as responsible for bearing a unique message to the present or future, is doomed (Senghor, 1964, p. 65).

Similarly, the first president of Tanzania, Julius Nyerere, when giving a speech in 1967 at Dar Es Salaam University argued that African traditional thought and realities must inform African methods of doing African business:

...We are Tanzanians and wish to remain Tanzanians as we develop. Certainly we shall wish to change very many things in our present society. But we have stated that these changes will be effected through the process of growth in certain directions. This growth must come out of our own roots, not through the grafting on those roots of something which is alien to our society... It means our change will be determined by our own needs as we see them, and in the direction that we feel to be appropriate for us at any particular time. We shall draw sustenance from universal human ideas and from the political experiences of other peoples; but we start from the full acceptance of our African-ness and a belief that in our own past there is very much which is useful for our future (Nyerere, 1968, pp. 93-94).

Writing on the nature of African faith and value and its place in contemporary African thought, David Kenneth Kaunda, the first president of Zambia, with equal force observed:

Leave out the religious dimension of African tradition, art, custom, language and law and there is precious little left of our past, and the bits and pieces which remain form an unpromising foundation for the future. This African-ness about which so many black people boast and that they proudly assert to counter the aggressiveness of Western culture is not just a political force – a drive towards freedom and racial equality. Nor is it solely a cultural one, as though one could be reborn into the past by revitalising tribal dancing and the music of the drums. The African-ness which has its roots in the soil of our continent rather than the lecture rooms of Western Universities is basically a religious phenomenon... (Kaunda, 1973, pp. 16-17).

But, why all this rhetoric: the rhetoric about understanding “African civilisation” (Senghor, 1964), about effecting development and growth through “our own roots” (Nyerere, 1968) and “African-ness” (Kaunda, 1973)? What is about? I would like to suggest this rhetoric is a product of sub-Saharan African post-colonial leaders’ view that representative indigenous African ontology was not acknowledged and reflected in the laws colonialists employed in the governing of the sub-Sahara African peoples. The arguments suggest that there is an African ontology which needed to be applied to sub-Saharan African problems, an ontology perceived by these former African leaders to be a conceptual response to problems which faced African peoples over different periods of time (Gyekye, 1995).

Indeed, my research confirms that representative indigenous sub-Saharan African philosophical and moral thought has a different ontological outlook to dominant Western liberal thinking regarding human condition and agency. Sub-Saharan African ontology is communal; an ontology which colonists did not acknowledge. Instead, they actively ignored it – they imposed their own way of thinking and governance on the African peoples. Hence, earlier in this chapter I have sought to establish what post-colonial African leaders who sought to affirm the importance of reclaiming African thought said. In other words, the general sub-Saharan African ontological outlook is that human beings are social in nature, interconnected, and interdependent, not individually autonomous (Senghor, 1964; Kenyatta, 1985; Tutu, 1999; Nussbaum, 2003).



Senghor (1964) notes that studies done by ethnologists, archaeologists, geographers, musicologists, historians and linguists show that African philosophy is existentialist and humanistic:

We could learn that Negro-African society is collectivist or, more exactly, communal, because it is rather a communion of souls than an aggregate of individuals... We would conclude that our duty is to renew it by helping it to regain its spiritual dimension (Senghor, 1964, p. 49).

#### **4.1.1 Sub-Saharan African philosophical and moral thought not reflected in sub-Saharan African countries' governing laws**

Senghor equally accused post-colonial African politicians of neglecting to recognise the importance of African culture when instituting laws and policies. He argues that it is a mistake for politicians and/ or policy-makers to ignore African culture, stating that since culture is the texture of a society, its values should be the basis and ultimate aim of politics. He defines culture as “the sum of objects, ideas, symbols, beliefs, feelings, values, and social forms that are transmitted from one generation to another” in any given society (Senghor, 1964, p. 49). Indeed, as can be seen from the arguments of post-colonial African leaders, many African thinkers have concluded that African jurisdictions must determine their own laws, policies, and priorities in the light of their own culture and realities. Senghor argues that it would be irresponsible for African politicians to ignore this imperative.

Senghor construes African traditional thought or philosophy to be a product of African problems which African sages endeavoured to solve over time immemorial. Owing to this, he argues that modern African philosophers have a duty to build on and further inform contemporary African philosophy by tackling contemporary philosophical issues which did not arise in time past. Gyekye (1995) argues that contemporary African philosophers should reflect the traditional African thinking in their philosophy on contemporary issues. He accuses them of having given less attention, if any, to the critical analysis and interpretation of traditional African concepts. He urges that “modern African philosophy must be linked to – take its rise from – African cultural and historical experience” (Gyekye, 1995, p. xii).

For Gyekye, contemporary African philosophy needs to integrate certain elements of traditional African thought because certain African values and norms have persistent influence, relevance, outstanding quality, and because such cultural ethos are inseparable from the life and well-being of a given African peoples. In reference to embracing foreign values, Gyekye argues that appropriated cultural values do not become values of another culture automatically. “For an appropriated cultural value or practice to take root in its new cultural environment, it must, as it were, become the property of a very large section of that environment” (Gyekye, 1995, p. xiii). This means that a cultural value or practice will never be adopted and integrated into an existing culture unless most members of a cultural group appreciate, enjoy and participate in it because they appreciate its value (Gyekye, 1995, pp. xiii-xiv).

He warns that where some contemporary thinkers and lawmakers fail to integrate indigenous African norms into modern African thinking or policy, indigenous African ontology and ethos, nonetheless, will still naturally find their place in modern African cultural practices (Gyekye, 1995, p. 33). The author identifies the social, non-individualistic character of African traditional moral thought, the traditional conceptions of the inherent value of human beings, mutual responsibility, relationships between people in a given society, and the sense of community and solidarity as values which can provide a basis for contemporary African social and moral philosophy (Gyekye, 1995, p. 41). What the author appears to suggest here is that because certain traditional African values or norms have persistent influence and outstanding relevance, ignoring them will not prevent the African who has been taught through her traditions and has since appreciated their utility from continuing to respect their value and applicability in her day-to-day affairs:

... If an African philosopher isolates his philosophical thought or analysis from its cultural context – his reflections bearing no immediate relation to the values, sentiments, experiences, and issues of that context – his philosophical works will most probably remain a lonely voice in the wilderness, as he will hardly have any impact on the intellectual and philosophical climate of his society (Gyekye, 1995, p. xiv).

Sentiments about Africans formulating their own philosophy in light of the African traditional philosophy and reality have also been expressed by the first president of Kenya,

Jomo Kenyatta (Kenyatta, 1985). Kenyatta argues that the African should not be taught without integrating into her vocational syllabus aspects of who she is. That is, the African's culture should be acknowledged and reflected in the education she is given. He suggests that any educator who comes to Africa must first sympathetically educate herself on what the African system of education is like before she can know how to educate an African. That is, by sympathetically inquiring after indigenous African ontology, the foreign educator will then "be able to find what are the significant things in the tribal culture, what it is the community regards as all-important and indispensable to its progress and self-maintenance..." (Kenyatta, 1985, p. 99).

In this thesis, it will be argued that the current regimes of HIV informed consent requirements in Zambia, and other sub-Saharan African countries do not reflect the general indigenous sub-Saharan African philosophical and moral ontology. It will be demonstrated that the above dissatisfaction by African post-colonial political leaders and other thinkers is founded. Indeed, at present, HIV testing informed consent requirements in Zambia and other sub-Saharan African countries do not reflect indigenous sub-Saharan African ontology and contemporary reality.

When these African thinkers argue that African cultural values and norms should be recognised and implemented as African solutions to African problems, this does not mean that dominant Western liberal ideas are, in principle, to be disregarded. Rather, the argument is that generalised foreign ideals are to be adopted in the light of indigenous sub-Saharan African ontology and prevailing reality. Indeed, having due regard to non-African philosophy is imperative. Human beings from other parts of the world may have solutions to common life perils (humans all over the world share some common experiences), solutions of which can be adopted and transposed into the Zambian medical policy in order to improve the lives of people living in that country. Gyekye (1995) adds that engaging other people's cultural values will also help deepen understanding of the African cultural thought and experience.

Indeed, Senghor presses that Western values should not be wholly adopted in African policy or law without due consideration to traditional African norms. He encourages African leaders to be open-minded in learning something from others around the world. However, he cautions them to only adopt foreign values which suit African experience and reality,

values which can ameliorate the life of the person living in Africa. He celebrated that the integration of African and European values is necessary in our global world:

This integration is necessary since our society today, in 1960 is neither Negro-Berber society of Middle Ages nor that of contemporary Europe. Our present society is in fact an original one, economically and culturally mixed, with African and European contributions (Senghor, 1964, p. 93).

Colson (2006) has commented that people around the world innovate through cultural borrowing, but they do not necessarily adopt foreign values at the expense of their own wellbeing:

People innovate as they borrow, and they distinguish themselves from as well, as they emulate their neighbours. If they use the same metaphors, they give them new meaning to adapt them to their own particular circumstances (Colson, 2006, p. 25).

Indeed, Senghor underlines that there is no doubt that African policy and law-makers can learn some valuable insights from Western methods and values:

It is a matter of selecting, among European methods, the most effective ones for an exact analysis of our situation. It is a question of borrowing those of its institutions, values, and techniques that are more likely to fecundate our traditional civilisation... We shall retain whatever should be retained of our institutions, techniques, our values, even our methods. From all this – African acquisitions and European contributions – we shall make a dynamic symbiosis to fit Africa and the twentieth century, but first of all to fit man (Senghor, 1964, p. 9).

What the foregoing conversation indicates is that sub-Saharan African countries have a humanistic (non-individualistic) indigenous philosophy and morality which is hardly recognised in those African countries' laws and policies. Hence, sub-Saharan African post-colonial thinkers have argued that African jurisdictions cannot afford to continue ignoring indigenous African ontology because such an ontology was developed from African experience and reality. In fact, African leaders are urged to rethink some of the imported Western liberal values because such values were developed in the context of Western experience and reality, a reality which the peoples of sub-Saharan African peoples may not necessary share.

I agree with this conclusion. In the following sections it will be demonstrated that the approach of adopting Western values in sub-Saharan African countries without consideration of its peoples' experiences and realities is a legacy of colonialism. However, it will be shown that colonialism and capitalism have failed to supplant communal ethos in sub-Saharan African countries. From the next section, I will show that sub-Saharan African ontology is dominantly communalistic.

It will be further established in later sections of this chapter that this humanistic indigenous sub-Saharan African ontology is real; it will be shown that this philosophical and moral outlook, which has been ignored since colonial times, does not regard individual human beings to be autonomous. Rather, it emphasises the commonality and interdependence of human beings.

Although it rejects individual autonomy, it recognises, celebrates, and respects a "person's status as a human being entitled to unconditional respect, dignity, value and acceptance from the other members of the community to which s/he belongs" (Mapaure, 2011, p. 160). "In contrast to the western vision of a society composed of atomistic "free contractarians," who are more often than not in conflict with each other and with the larger society", indigenous African communitarian ontology view human beings to be each other's brother or sister who are naturally situated to aid each other in achieving both personal and communal aspirations (Woods, 2002-2004, pp. 56-57). Put differently:

The ascendant nature of law inherent in the African worldview is illustrated in Akan society, wherein principles of morality are premised upon their consistency with human well-being rather than an abstract ethical construct... The Akan do not share the philosophical premise of the Lockean model; therefore, they view interdependence, not autonomy, as the essential characteristic of the human condition (Woods, 2002-2004, p. 56).

## **4.2 Sub-Saharan African traditional thought and Western influence**

The Sub-Saharan African was seen by the colonialist as a savage or brute who had no civilisation, so he was thought to be in need of civilisation through Western values. In this sense, the African's values were ignored. In an introductory chapter to Chinua Achebe's classic novel *Things Fall Apart*, Mpalive-Hangson Msiska explains that the colonialists

depicted sub-Saharan Africans as “grunting savages and cannibals with no language or cultural and historical links to their physical environment...” (Achebe, 2008, p. i).

However, a number of writers and scholars, as will be shown below, have argued that this approach by the colonialist which overlooked and was capable of supplanting pre-colonial African ontology failed to make the African abandon her vision of human nature. This goes to show that even when the prejudiced colonialist was not interested in investigating and transposing into law the values which comprised the life of an African, this did not discourage the African from continuing to hold on to her traditions passed on to her from one generation of her ancestors to another. It is these very ‘un-sheddable’ traditions which Olaudah Equiano relished.

Equiano (1789), among other things, gave an account of the customs and manners of the people from his country (the then kingdom of Benin). He reminisced that the customs and manners of his African origin were with great care implanted in him, so much that despite him now being removed through the chains of his slave masters, those very African customs and manners have made such an impression on his mind such that time could not erase them (Equiano, 1789, p. 21).

I wish to suggest that sub-Saharan African peoples have got values and institutions which can be said to be traceable to pre-colonial traditions. It will be shown in this chapter that the promotion of the common good is one of the pre-colonial values which motivated the actions of the traditional African society, and still does today.

Thompson’s 1990 observations, cited in Masina (2000) provide that Africans were not *tabula rasa* for capitalists to civilise. Masina adds that Southern Africans have over the many centuries been developing social orders and traditional cultures that capitalism, colonialism, and apartheid have modified but failed to supplant. Indeed, a person cannot understand how Africans have preserved their cultural traditions, in light of colonialism, capitalism, and apartheid, until that person comes to the knowledge of what African customary social values and networks mean to sub-Saharan African peoples (Masina, 2000). Despite the impact of colonialism, capitalism, apartheid and Christianity, African traditions have

continued to survive, Ubuntu being one of the African ethics which has survived the assaults of foreign influences.<sup>52</sup>

Exemplifying the impact of foreign influence on local culture, Manyena (2013) and Musonda (2013) give us an insight into the prejudices which the Tonga-people of the Gwembe Valley of Zambia and Zimbabwe experienced. Colonialist prejudice resulted in the early Europeans not being concerned to study the culture of the indigenous people in Zambia. Musonda observes that colonialists “did not expect to find any evidence of past civilisation anywhere south of the Sahara; rather they regarded indigenous cultures as a living museum of the human past” (Musonda, 2013, p. 7).

The colonialist proclamation has been proved wrong. In considering the religious life of the Tonga people Colson (2006) has observed that, the Tonga people of Zambia and Zimbabwe, like any other peoples in the world, have over time experienced a change of ideas, behaviours, and how they relate to one another. She states that the Tonga people since pre-colonial time have been rational beings who have an adaptive culture that has been received by descendants from ancestors before them and developed over many years.

Colson’s fifty years of longitudinal study of the Tonga people of Southern Zambia found that this people has a culture, and a philosophy which has sustained and directed their lives over centuries. She has demonstrated that the Tonga-speaking people of Zambia and Zimbabwe have since time immemorial thought about the nature of their world, the meaning of their lives, and the sources of good and evil in a society which is continuously being transformed through time. Indeed, the findings of such studies contradict the then prevailing prejudiced opinions of the brute African who needed to be civilised at any cost:

During the nineteenth-century period of European imperial expansion, due to the prevailing white opinion at that that time, early Europeans who came to Northern Rhodesia can be said to have had little or no interest in studying the African past.... Some Scholars had even argued that Africans had no historical role in the world, had

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<sup>52</sup> Ubuntu is an African term which represents the “cultural, social, political and economic dynamics of African societies” (Masina, 2000, p. 160; Asike, 2016). It is a term derived from the Bantu language which “connotes love, peace, humanistic, holistic building of a political community... and showing of remorse and repentance” (Asike, 2016, pp. 3&7). The word Ubuntu literally means collective personhood; a philosophy which promotes human co-existence and mutual development. In other words, Ubuntu is an African traditional ideology which encourages human compassion, caring, generosity, hospitality and friendliness (Tutu, 1999).

no development to exhibit, were not capable of development ... (Musonda, 2013, pp. 6-7).

Kenyatta laments that such approach by the colonialists was grievous. He suggests that what the colonialist should have done when he came to Africa could have been to establish a good understanding with the African people amongst whom he was to work, "and to learn how to appreciate what is good in the tribal law and custom of that particular community" before he could introduce his 'civilised' outlook to the African (Kenyatta, 1985, p. 124). For Kenyatta, they neglected to do so. Indeed, the coloniser who could be said to have purposed to lift the savage from her brutishness and misery did not realise that there was a great deal to learn and understand about the African before the coloniser could informally improve her colony's wellbeing:

We may mention here that the African who is being civilised looks upon this "civilisation" with suspicion with great fear mingled with suspicion. Above all, he [the colonised African] finds that socially and religiously he has been torn away from his family and tribal organisation. The new civilisation he is supposed to acquire neither prepares him for the proper functions of a European mode of life nor for African life; he is left floundering between the two social forces (Kenyatta, 1985, pp. 124-125).

Kenyatta continues:

...for without proper knowledge of the functions of African institutions, the more the European tries to influence his pupils in the direction of new habits, standards of life and general Europeanisation, the more he comes up against social background which he does not understand. In doing this the teacher follows the adopted educational policy of educating the Africans in the ways which the European think fit for the "poor savages"; a policy that has been carried out without due regard for the ideals and aspirations of the people concerned (Kenyatta, 1985, pp. 125-126).

Gyekye has added that even contemporary scholars squirm at the mention of African philosophy, even when they do not do so at the mention of African music, art, anthropology, religion or history (Gyekye, 1995, p. 3). Such misunderstanding, according to the same author, has led to some scholars stating that African philosophy is not yet established, therefore needs creating. He rejects this as fallacious since philosophical



activity is universal.<sup>53</sup> Gyekye observes that different cultures around the world ask similar philosophical questions, e.g. all human societies ask questions about human experience. Similarly, he differentiates African traditional thought from other philosophies arguing that the former's ideas are not to be found in written documents. He establishes that African ontology is embodied in aphorisms, proverbs, or fragments:

Socrates did not write anything, although he inherited a written culture; but we know, thanks to Plato, that he philosophised... Thus, traditional African philosophy is none the worse for the written absence of written philosophical literature does not in any way imply the absence of philosophical thinking of philosophical ideas (Gyekye, 1995, pp. 10-11).

The author notes that African traditions or philosophy has since time immemorial been relayed from one epoch to another through myths and folktales, proverbs, rituals, folk songs, dances, art symbols, socio-political practices, customs, etc. In fact, Mbiti (1970, cited in Gyekye, 1995, p. 14) has observed that "as with proverbs, the collection and study of religious songs is very scanty, and yet this is another rich area where one expects to find repositories of traditional beliefs, ideas, wisdom and feelings". And Busia (1962, cited in Gyekye, 1995, p. 14) also writes that the language of the Akan drum is full of riddles which conceal reflective thought and philosophy; also that their funeral dirges "philosophise on human life and death". The author adds that African traditional thought is also expressed in the social values of African societies.

### **4.3. The grounds for sub-Saharan African moral theory**

African proverbs have been described by some thinkers to be situational (Gyekye, 1995, p. 17). Bascom (1965, cited in Gyekye, 1995, p. 17) has observed that "proverbs, which are the most important type of aphorism in Africa, have a deeper meaning than is stated literary, a

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<sup>53</sup> Mapaure also rubbishes this perspective of a lack of an African philosophy: "[T]he people's philosophy constitutes their system of thought and has always served as the basis for their attitudes on life. In this light, to deny the existence of African law is to deny the premise of African life and the values that underpin it. Philosophy does not exist only in written form, but also in substance and orature. A system of thought does not have to be written in order for a philosophy for it to exist. Thus, it is ridiculous to suggest that, because there are no written records in Africa regarding jurisprudence, there is no African jurisprudence" (Mapaure, 2011, p. 152).

meaning which can be understood only through the analysis of the social situations to which they are appropriate.” It is argued that African proverbs cannot be properly understood without making reference to social situations from which the proverbs arose.

For example, the Akan proverb *woamma wo yonko antwa nkron a, wo nso wonntwa du* (translated: “if you do not let your neighbour have nine, you will not have ten) has a social message to the respective cultural group (Gyekye, 1995, p. 17). The proverb is employed to discourage individuals from pursuing own interests in total disregard of the interests of others. In other words, some of sub-Saharan African proverbs derive from their indigenous customs and beliefs and from certain events or experiences in their history as a people (Gyekye, 1995).

The situational nature of African proverbs can, for example, be found in the studied philosophy of the Akan. For example, the Akan proverb *asem mmae a abebu mma* (translated: “if the occasion has not arisen, the proverb does not come”), confirms the claim that African proverbs depict African peoples’ experiences and reality, and resulting ontological outlook (Gyekye, 1995, p. 18). Hence, Gyekye has concluded: “morality for the Akan originates from society and its experiences; it is the result of a social awareness and need; morality for them is essentially a social phenomenon” (Gyekye, 1995, p. 15).

#### **4. 4 Sub-Saharan African communal moral theory**

Generally, one of the representative values which sub-Saharan African societies still embrace to this day is the common good value (Gyekye, 1995; Nussbaum, 2003; Mapaure, 2011). Kenyatta and Masina claim that Western culture has failed to swallow up the principles of reciprocity and mutual aid. Kenyatta, even as early the 1980s when a number of African countries were still politically colonised, notes that “in spite of the foreign elements which work against many of the Gikuyu institutions and the desire to implant the system of wholesale Westernisation, this system of mutual help and the tribal solidarity in social services, political and economic activities are still maintained by the large majority of the Gikuyu people” (Kenyatta, 1985, p. 120). He concludes that individuality is the ideal of life to the European, but to the Africans right relations with other people is the ideal (Kenyatta, 1985, p. 122).

Kenyatta even claims that the Western luminaries have now come to recognise that education in Africa should conserve all the good and healthy elements of African social bonds. He notes that it is not only professional, economic and religious associations which bind the Africans together, but more: the ties of sex, age-groupings, family and kinship and many more. In other words, what makes an African is her connection to her fellow beings and mutual aid. Thus, he argues (in the light of what he considers to be the communal nature of African societies) that if education in Africa cannot recognise, promote and keep social:

bonds vital and strong, it [education] cannot be expected to mould the African in the way which will make him fit in his community on one hand and to establish good relations with the outside world on the other. If the African is to derive any benefit from Western education, his training should be directed to the strengthening of these basic relationships which are the foundation of moral sentiments and the means of building a character. As Dr. Oldham writes in the course of a review on Dr. Knak's book on African problems: "But whatever change may take place, men will still have fathers, mothers, brothers, sisters, children, blood relations, neighbours, companions of the same age and fellow workers, and whatever change may come, the vital thing is that the sense of mutual obligation and responsibility which is found in existing relations should be conserved and express itself in the new conditions (Kenyatta, 1985, pp. 122-123).

Indeed, Senghor's claim that Africa has got precolonial institutions and values which need promoting has support from literature. The implication of this acknowledgement is that we may now suggest that sub-Saharan Africa can retain or promote for posterity's sake values which it can claim to be primary to its own identity in the globalised world. An African or anyone seeking an alternative view to dominant Western liberal thinking may now view herself through the mirror of Ubuntu or "sub-Saharan African communitarianism" to appreciate the perspectives of the African sages who regarded human beings to be social beings, as opposed to atomistic agents. If she may find that Ubuntu is a concept that promotes our common humanity, then we cannot comfortably dismiss her resolve if she argues that social responsibility is one of the dominant indigenous African values that need retention and reintegration into the ethics that govern her relationships with others.

#### **4. 4. 1 “Communalism” a sub-Saharan African philosophy**

Discussing the African concept of Ubuntu or African communalism Masina provides that the fundamental characteristics of the ethic are compassion, caring, unity, consultation, respect, tolerance, generosity, compromise, hospitality, empathy, closeness, hospitality and genuineness (Masina, 2000, p. 170). Mbigi (1995 cited in Masina, 2000, p. 170) provides that “Ubuntu is an expression of our collective personhood, and invokes images of group support, acceptance, co-operation, care, sharing and solidarity.” Masina adds that Ubuntu is an indigenous social perspective/philosophy whose roots can be attributed to South Africa.

I wish to state here that it is the term ‘Ubuntu’ which is special to South Africa but when it comes to the concept, it is a sub-Saharan African ontological outlook. The claim that Ubuntu is an African philosophy (not unique to South Africa) can be seen in a subsequent statement by Masina where she notes that “in traditional African view, human existence is seen as unified, interconnected, and integrated (Masina, 2000, p. 169). Metz (2007) notes that the Ubuntu concept does not only capture Southern African moral thought, but is also represents sub-Saharan Africa outlook. In this this study I am going to use the phrases African “communalism”, “Ubuntu”, “commununocracy”, or “communitarianism” to mean one and the same thing: indigenous African communal ontology.

Gyekye notes that several Western scholars have for decades been saying that Africa has diverse cultures and therefore cannot be seen to hold a singular ontological outlook. Gyekye disagrees. He states that there are a lot of similarities among different African tribes from different African countries (Gyekye, 1995). He argues that the misconception that African culture is different across sub-Saharan Africa ignores the existence of similarities existing between various African cultures. The author identifies some Western anthropologists who have acknowledged the common features that are found amongst African cultures. He notes that most of the scholars who have found cultural affinities in Africa have carried out field investigations in Africa for many years, if not decades (Gyekye, 1995, xxv).

Kopytoff (1987, cited in Gyekye, 1995, p. xxvi) has written about ancestral pan-African culture patterns, the existence in African society of common pan-African cultural base, the existence of certain Pan-African principles, and pan-African cultural unity. He concluded that

pan-African cultural unity is on the same level of generality as is the case with certain Western cultural principles (Kopytoff, 1987, cited in Gyekye, 1995, p. xxvi).

Common African cultural attributes have been attributed to Africa's prehistory (the ancestral concentration of African populations in the Saharan-Saharan region of the northern part of Africa thousands of years ago). The Saharan-Saharan region is seen to be the base of African culture. Gyekye calls it "a region of persistent cultural interaction and exchange" (Gyekye, 1995, xxv). Kopytoff (1987, cited in Gyekye, p. xxvi) notes that most of sub-Saharan Africa has been inhabited and culturally dominated by populations who came from Neolithic Saharan-Saharan. Gyekye reports that "[t]he segmentation and fission in African social groups led to sub-groups disengaging themselves from existing groups and constituting themselves into another cultural group, bringing with them a basically similar kit of cultural and ideological resources" (Gyekye, 1995, p. xxvi). Kopytoff concludes that sub-Saharan Africa exhibits a striking degree of fundamental cultural similitude or unity.

The second author whom Gyekye identifies as establishing the existence of commonalities in the cultures of people from sub-Saharan Africa is Curtin et al. (1978, cited in Gyekye 1995). The authors assert that despite the cultural differences amongst African social groups, the cultures in Africa have all grown from very similar origins, and yet that underneath the diversities common cultural themes which go back to the "hallowed" roots or past can still be discerned in modern African cultures.

When Gyekye uses the term "culture" he sees culture as a conglomeration of values, beliefs, mentalities, habits, institutions, ways of life, etc. The basis for African philosophy, according to Gyekye is composed of customs, beliefs, traditions, values, socio-political institutions, and historical experiences of African societies (Gyekye, 1995, p. 191). He argues that affinities can be found in the customs, belief systems and other of various African people in sub-Saharan Africa. He observes that a "painstaking comparative study of African cultures leaves one in no doubt that despite the undoubted cultural diversity arising from Africa's ethnic plurality, threads of underlying affinity do run through the beliefs, customs, value systems, and socio-political institutions and practices of the various African societies" (Gyekye, 1995, p. 192).

Forde (1960, cited in Gyekye, 1995, p. 193) in his essays on social values and cosmological ideas of various African ethnic groups observed that “when ...studies are considered together one is impressed not only by the great diversity of ritual forms, but also by substantial underlying similarities in religious outlook and moral injunction.” Forde acknowledges the existence of religious ideas and social values as being widespread in Africa. Taylor (1963, cited in Gyekye, pp. 193-194) has observed that “there is in Africa, South of Sahara, a basic view which fundamentally is everywhere the same.” Common African values or norms are said to have been handed down from one generation to another.

Kenyatta notes that African traditional thought, which is unwritten, has been passed from one generation to another. Talking about the cultural and historical traditions of the Gikuyu people of Kenya, Kenyatta notes that Africans in every stage of life are exposed to competitions which are arranged to test their abilities “to recall and relate in song and dance the stories and events which have been told to them, at such functions parents and the general public form an audience to judge and correct the competitors” (Kenyatta, 1985, p. xiii). The stories, dances, proverbs and rituals, notes Gyekye, have been the mediums through which African traditions have been passed from one generation to another.

Nyerere observes:

The fact that pre-colonial Africa did not have ‘schools’ – except for the short periods of initiation in some tribes – did not mean that the children were not educated. They learned by living and doing. In the homes and on the farms they were taught the skills of the society, and the behaviour expected of its members. They learned the kind of grasses which were suitable for which purposes, the work which had to be done on the crops, or the care which had to be given to animals, by joining with their elders in this work. They learned the tribal history, and the tribe’s relationship with other tribes and with the spirits, by listening to the stories of the elders. Through these means, and by the custom of sharing to which young people were taught to conform, the values of the society were transmitted. Education was thus ‘informal’; every adult was a teacher to a greater or lesser degree. But this lack of formality did not mean that there was no education, nor did it affect its importance to society (Nyerere, 1968, p. 45).

Parents in traditional African societies play a critical educational role in passing ancient cultural ethos to their children. Kenyatta narrates that when children grow beyond

babyhood mothers take charge of their daughter's education, and fathers boys' education. The mother takes the responsibility in teaching her daughters all things concerning the domestic duties of a wife in managing and harmonising the affairs of a homestead. The mother is also in charge of the co-education of her children. In the evening she teaches both boy and girl the laws and customs, especially those governing the moral code and general rules of etiquette in the community. The teaching is carried on in the form of folklore and tribal legends. At the same time the children are given mental exercises through amusing riddles and puzzles which are told only in the evening after meals, or while food is being cooked (Kenyatta, 1985, pp. 102-104).

On the education in one's traditions through cultural dances Kenyatta writes:

There are children's dances held occasionally at which praise songs are sung. The children merge insensibly into the dances of later years, and it is amazing to see how a small child can capture with his or her feet and bodily movement the complicated, difficult rhythms which have been learned by merely watching their elders and imitating them. These dances are attended by almost every child in the district. Among the spectators parents are prominent, their chief interest being to observe the conduct of the children in public dances and to judge how much they absorbed the things taught by the parents. Very strong criticism is directed at the parents whose children do not behave according to approved tribal law of conduct. Such parents are considered to have neglected the important task of preparing their children to become worthy members of the community (Kenyatta, 1985, p. 104).

He concludes that Gikuyu education is not concerned with natural phenomena, but with personal relations. The Gikuyu people are taught from early age that the most important thing they should understand which sums everything they have been taught is their station in the community. For the Gikuyu people, according to Kenyatta, different families are unified and solidified through clans which are held to be an organic whole.

Indeed, literature on African culture and experiences shows that sub-Saharan African peoples share cultural similarities. Affinities in languages, similarities in familial and communal arrangements, and common ancestral origins point this out to be the case (Herskovits, 1955; Smythe, 1960; Nduka, 1980; Gyekye, 1995; Tutu, 1999; Mapaure, 2011; Behrens, 2013):

The African family structure itself differs considerably from the immediate, conjugal one common to the West. Although there are differing ecological, economic, social, and political conditions under which African people live, as well as underlying regional and areal differences, there are some broader unities. Significant among these is a generally common characteristic family type which is in reality an agglomerated grouping... The African philosophy of living is based principally on the group, rather than the individual (Smythe, 1960, pp. 194-195).

David Lutz reports:

One of the most striking features of the cultures of sub-Saharan Africa is their non-individualistic character. "Although African cultures display awesome diversity, they also show remarkable similarities. Community is the cornerstone in African thought and life"... "People are not individuals, living in a state of independence, but part of a community, living in relationships of interdependence" (Lutz, 2009, p. 314).

#### **4. 4. 2 Individualism is not encouraged in dominant sub-Saharan African ontology**

In his promotion of socialistic ideas, Senghor states that agriculture in sub-Saharan Africa was traditionally socialistic. He attributes this arrangement to what he terms the communal nature of black African society. According to Senghor, the African communal society did not comprise an aggregate of individuals, but was "made up of family cooperatives in the framework of the village mutual" (Senghor, 1964, p. 59). He claims that the basis of mutual family cooperatives had religious feelings in which the members in the society lived as a single soul. This depiction of a sub-Saharan Africa social arrangement is consistent with what other scholars have found (Gyekye, 1995, Nussbaum, 2003, Woods, 2002-2004; Metz, 2011, Mapaure, 2011).

Senghor quotes, among others, the French ethnologist, Delafosse (1925) who states that black African society is collectivist. He argues that the traditional collectivist African society is distinguishable from the collectivist society of the then European communistic countries like Russia:

To return to the distinction between Negro-African and collectivist European society, I would say that the latter is an assembly of individuals. The collectivist society inevitably places the emphasis on the individual, on his original activity and his



needs. In this respect, the debate between 'to each according to his labour' and 'to each according to his needs' is significant. Negro-African society puts more stress on the group than on the individual, more on solidarity than on the activity and needs of the individual, more on the communion of persons than on their autonomy. Ours is a community society (Senghor, 1964, pp. 93-94).

Senghor, in effect, states that the communal good in the African society took precedence over individual autonomy. In other words, even though people were recognised as a collection of individuals, working for and solidarity towards the communal good was seen as inseparable from the enjoyment of individuality. Indeed, the African communal society did not disregard or ignore the person as an individual (Senghor, 1964, p. 94). Rather, unlike the European who embraces his autonomy by distinguishing himself from the members of his society as the sovereign of her own life, the traditional African autonomous person sees herself as a member of the community society. The sub-Saharan Africa person "feels, he thinks that he can develop his potential, his originality, only in and by society, in union with other men..." (Senghor, 1964, p. 94). In this sense, the author regards the traditional Africanist as one who saw herself as part of the whole, as opposed to being the 'whole of the whole'.

In the remainder of this chapter, I am going to discuss what a number of African scholars (especially Gyekye (1995) and (1997)) have said regarding personhood and autonomy. These scholars and writers have argued that African traditional thought does not regard individuals to be divisible, but an aggregate of souls born in a community of people. In other words, individualism as properly understood in Western Kantian theory has no primacy in African traditional theory and practice; communal good is what is promoted.

African communitarian moral and political theory regards the community as a fundamental human good, vouching that a life lived as a member of a community promotes an altruistic ethos of mutual consideration when an individual is faced with a decision. In fact, sub-Saharan African traditions acknowledge the distinctiveness of a human being; however, they consider an individual person as one who is not born from self into a vacuum, but one born from another into a society of others. In this regard, human beings are viewed to be born as natural members of the human society who need society and all it offers in its social structure for an individual to grow, aspire and achieve a worthwhile life. In other words, as

much as an individual is regarded to be unique, she is however understood to be naturally and essentially dependent on relationships with others to realise her goals, desires, potentials, and for survival.

Put in another way, human beings in traditional African moral thought are viewed to be interlinked beings who are essentially relational, needing others to realise own potentials and whom the community also needs for its common continuous well-being and survival.

This African traditional communitarian ontology is reflected in the following:

We say a person is a person through other persons. We don't come fully into the world... We are made for togetherness, we are made for family, for fellowship, to exist in a tender network of interdependence (Battle, 1997, p. 65).

Gyekye (1997) explains the nature of relationships existing between an individual and the community in African societies. He employs the Akan people of Ghana as special case study on the conception of personhood in indigenous African ontology. The author suggests that African communitarian scholars and politicians have over time immemorial favoured social responsibility, and he submits that he is in support of an African moral and political theory that conflates respect of individual rights with community commitments and responsibilities.

Kaunda postulates:

We can neither applaud nor tolerate irresponsible and wholly selfish individual development. Freedom without moral commitment is aimless and self-destructive. Here is a tension of opposites which every educationist must appreciate and try to harmonise – to instil in his students both a vigorous sense of individuality and at the same time a sense of shared purpose with their fellows (Kaunda, 1973, p. 29).<sup>54</sup>

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<sup>54</sup> In an introduction, Omaswa states: "Several of the chapters in this book make use of the skills of communities and rely on strong family and local bonds. These ties and traditions must undoubtedly remain at the heart of the way we as Africans improve health in our countries... Individuals live their lives in private and in public. They make choices in lifestyles that have consequences for their personal, household, and community health; independently or in consort with others... This is why it becomes critical for children in families and during school days to grow up recognizing how important the life choices they make in everyday life and how these impact on themselves, their families and communities. Individuals should grow up with positive attitudes to health-seeking behaviour and personal responsibility for their own, their family and their community health..." (Omaswa, 2014, p. 28).

Scholars and non-scholars (African and non-African) have acknowledged that African communitarian characteristics define traditional 'Africanness' as possessing communal type of life (Kwesi, 1977). What these authors have demonstrated is that individualism has no primacy in African moral thought. In other words, literature by African theorists is replete with direct or indirect understandings to the effect that the individual is a member of the whole, as opposed to being seen as a 'sovereign' of one's own life.

Kaunda argues that concern for an individual is not enough without equally having concern for the common good. In this vein, he claims that a man who is truly free is one who does not only live for herself, but also for her society. By contrasting the *modus operandi* of the then South African apartheid regime, Kaunda argues that African humanism holds that men belong to one another, in that, no man is an island or self-entire (Kaunda, 1973). He indicates that this belongingness is necessary because men have certain weaknesses which require correcting through the strength of others. He notes that traditional African religion promotes selflessness. Commenting on individual freedoms, values exclusively promoted by Western rational choice theories, he adds:

...it is a delusion to believe that freedom means doing what you like without restraint, pursuing one's own ambitions without regard to others... A complex balance of conditions is necessary to make freedom a reality, and a number of misconceptions have to be cleared out of the way before it is possible to get people to realise what a hard, burdensome thing is this freedom they demand as a right (Kaunda, 1973, pp. 86-87).

On the question of human beings being self-governing, Kaunda argues that such a view is tantamount to self-idolatry. He asserts that there is no other being who (or which) is self-entire, self-directed and totally without claims, but only God. He advances that "the assumption that freedom means complete independence of any outside force, sanction or personality is both a blasphemy and a delusion" (Kaunda, 1973, p. 87).

He adds that where an individual's will is hailed to be sovereign, such would amount to the denial of the social good and there will be no way of bringing to harmony all the individual wills of a given society through the process of compromise and sacrifice. He concludes that where individual self-will is held to be sovereign, the freedom of each individual becomes

the destruction of the freedom of others. Kaunda renounces personal autonomy as an idol of the modern world and concludes that:

Man is spiritually conditioned. His path can never be free as that of an airborne bird. He must pick his way painfully through a veritable jungle of alternatives, few of which are satisfactory, none of which is perfect. Man can never be the unconditional master of himself because he neither has complete control of himself nor of his environment. He is at the mercy of dreams, hopes, fears and lusts. So self-will which he possess as freedom will only result in a man putting himself under the heel of some subtle tyranny more frightening than any of those from which he fondly imagines he has freed himself (Kaunda, 1973, p. 88).

Indeed, Harding (1963) argues that human beings are not solitary beings rather, they are social animals. In discriminating Zambian culture from Western culture, Kaunda identifies that unlike the West which places great emphasis on individual performance, among others, the Zambian traditional society puts more stress on social cohesion.

Writing on Ubuntu, Nussbaum (2004) establishes that, as opposed to individualism, the African Ubuntu social philosophy is characterised by reciprocity, compassion, dignity, harmony and humanity in the interests of the building and maintenance of the community. It calls members of the community to believe and feel that one member of the community's pain is another's pain. It recognises human interconnectedness, common humanity, and mutual responsibilities resulting from human interconnectedness. Slogans such as "*I am because we are, and since we, therefore I am*"; "*I feel the other, I dance the other, and therefore I am*"; "*umuntu ngumuntu ngabantu* (translated 'a person through other persons) are everyday sayings in African communities. The individual in African moral thought is not seen to be self-entire or sovereign, rather she is held to be a part of the organic whole. Africans by and large, are communal inclusivists (Masina, 2000). Kenyatta (cited in Gyekye, 1997, p. 36) provides that "according to Gikuyu ways of thinking, nobody is an isolated island... or rather his uniqueness is a secondary fact about him; first and foremost he is several people's relative and several people's contemporary" also that "the personal pronoun 'I' was rarely used in public assemblies... the spirit of collectivism was much ingrained in the mind of the people".

For Gyekye, the community is an arrangement where individuals who are not necessarily linked biologically but by interpersonal links live together sharing common goals, values and

interests. He distinguishes a community from a mere association of individuals by saying that the difference lies in the sharing of an overall way of life where each member in the former recognises the existence of common values, prevailing obligations, understandings and are disposed through felt commitment to advance the common interests of the community. In this vein, members of the community are not expected to be indifferent to the well-being of the whole due to personal interests or comforts; rather, they are expected to show concern by doing what they can do to advance the welfare of the common good. This is in stark contrast to Western rational choice individualism where one's choice is held to be sovereign.

Gyekye advances that, "community life is not optional" because being part of a community life "follows from the natural sociality of the person and from the fact that she [a human being] is embedded in a set of necessary social relationships, some of which are certainly essential to the development of her individual personality and potential" (Gyekye, 1997, p. 42).

An individual (or a human being) and a person in African traditional thought are not one and the same thing. Personhood is earned; that is, personhood is not innate, it is a moral achievement which a human being can earn:

The various societies found in traditional Africa routinely accept the fact that personhood is a sort of thing which has to be attained, and is attained in direct proportion as one participates in communal life through the discharge of the various obligations defined by one's station. It is the carrying out of these obligations that transforms one from the it-status of early childhood, marked by an absence of moral function, into the person-status of later years, marked by a widened maturity of ethical sense – an ethical maturity without which personhood is conceived as eluding one (Menkitt, 1984, p. 176).

For Gyekye, the moral conception of personhood is relevant, interesting and of importance for the communitarian framework. He explains that the word used in Akan for "person" is "*onipa*", a word which also means "a human being" and in its plural meaning "people". The phrase "*onnye onipa*" which means "he is not a person" is used to refer to an individual whose behaviour consistently appears to be wicked, cruel, selfish, ungenerous, etc., (Gyekye, 1997, p. 49). The author points out that although a person who possesses the above conduct is not seen to be a person in the Akan people, he is still regarded as a human

being, not a tree or a beast (only that the individual is regarded as not morally worthy). He explains that “a clear distinction between the concept of a person is thus deeply embedded in that statement: an individual can be a human being without being a person” (Gyekye, 1997, p. 49).

The second inference that Gyekye draws from the Akan concept about being a person is that for a human being to be regarded as a person, one needs to conform one’s behaviour to certain basic social norms and ideals. The moral norms and virtues of personhood include generosity, kindness, compassion, respect and concern for others, and benevolence: “in short, any action or behaviour conducive to the promotion of the well-being of others” (Gyekye, 1997, p. 50). Also an individual is regarded not to be a person if he lives an isolated life, detached from the community. A life lived in isolation, according to Gyekye, is regarded by the Akan people to be egoistic, in that the person who lives in isolation is considered to be a morally irresponsible agent.

But why is there a moral conception of personhood in Akan, and generally, in African thought? The answer to this question lies in Gyekye’s explanation of Akan’s beliefs. The Akan people believe that God has created every individual to be good. The implication is that if God has created every individual human being to be good, then moral expectation from individual behaviour is justified. However, the statement by the Akan thought that each individual is created by God to be good does not imply that every individual is good, rather, it denotes, as Gyekye explains, that a human being is endowed with a moral sense, and as a consequence, he has the capacity for both moral judgment and virtue:

Personhood conceived in terms of moral achievement will be most relevant to the communitarian framework that holds the ethic of responsibility in high esteem: the ethic that stresses sensitivity to the interests and well-being of other members of the community, though not necessarily to the detriment of individual rights (Gyekye, 1997, p. 52).

Metz (2011) is another scholar who has written on the nature of African communalism. He notes that the interpretation of the Ubuntu maxim (in Nguni languages) is premised on “*Umuntu ngumuntu ngabantu*” (person is a person through other person). He argues that the claim (that we causally depend on one another for survival) above is not merely empirical, rather, it also means that the Nguni seek to establish what we ought to normatively value

most in life. The author argues that the call that a person is a person through other persons is an invitation to develop one's moral personhood. This means that having Ubuntu is having a moral personhood. Moral personality is acquired by way of communal relationships with others, concludes Metz.

Metz explains what a communal relationship means in African moral thought; it means 'identity' and 'solidarity'. To identify with each other, he argues, is to have people regard themselves as members of the same group. This means that such a people will see themselves to be a "we" as opposed to the "I", and this causes them to work jointly to realise the ends of the group. Where people cannot identify with each other, the result is that they suffer from alienation and incur divisions between each other, he asserts. Where there is no identity, the author concludes that people do not only live divided, but they also aim to undermine each other since they now see each other as 'I' and 'you'.

Metz explains that identity and solidarity are important concepts in African ontology. However, he says that identity and solidarity are different concepts. African moral theory (Ubuntu) views identity and solidarity as moral imperatives, that is, to be realised together (Metz, 2011). As a consequence, Ubuntu is held to be a combination of identity and solidarity; a person who acts in the Ubuntu manner is one who seeks a communal relationship that is characterised with the African moral themes of identity and solidarity.

By reason of African moral communal relationships which comprise of identity and solidarity, individuals through indigenous sub-Saharan African ontology consider themselves as integral parts of the whole community in which they are part, not as autonomous individuals (Metz, 2011). Writing about the traditional African family, Nyerere notes that its members lived and worked together and reinforced each other when they were faced with problems. They worked together for the common good, where each member of the society played a dynamic constructive role for the common good (Nyerere, 1968). He points out that the education which the colonialists introduced in Tanzania emphasised and encouraged individualistic behaviour, as a result it failed to capture the values of the Tanzanian society.

Julius Nyerere condemns this individualistic system of education arguing that it impeded the transmission of indigenous African values. He accuses colonialists of deliberately attempting to change African traditional values and knowledge by replacing it with individualism.

According to Nyerere, the traditional African family:

lived together and worked together because that was how they understood life, and how they reinforced each other against the difficulties they had to contend with – the uncertainties of weather and sickness, the depredations of wild animals (and sometimes human enemies), and the cycle of life and death... The family members thought of themselves as one, and all their language and behaviour emphasised their unity... (Nyerere, 1968, p. 106).

And, Gyekye notes:

In African social thought human beings are regarded not as individuals but as groups of created beings inevitably and naturally interrelated and interdependent. This does not necessarily lead to the submerging of the initiative or personality of the individual, for after all the well-being and success of the group depend on the unique qualities of its individual members – but individuals whose consciousness of their responsibility to the group is ever present because they identify themselves with the group (Gyekye, 1995, p. 210).

Indeed, what can be seen from the foregoing discussion is that indigenous sub-Saharan African ontology is not individualistic. It is communal; it regards individual humans to be part of the whole, not autonomous. This ontology does not subscribe to rational choice theories of autonomy. It does not agree that individual humans are metaphysically and morally free to be autonomous decision-makers. But, it views humans to be caught up and inextricably bound up with each other in a social human society:

The emphasis on community, identifying with others and solidarity and caring makes Ubuntu a relational ethic that prizes harmonious relationships. This challenges Western bioethics, which focusses on individual autonomy and the rational application of abstract theories and moral principles to ethical issues (Behrens, 2013).



## **Conclusion**

Sub-Saharan Africa as a region has a dominant communocratic indigenous traditional philosophy which the powers of colonialism, apartheid, and capitalism have failed to supplant. This indigenous ontology celebrates human sociality, interconnectedness and interdependence; it does not regard individual human beings to be autonomous or sovereign rulers of their own lives. Human beings are regarded to be a product of each other, and the environment (Woods, 2002-2004). Thus, many African thinkers have called for transposition of indigenous African traditional communitarian values into contemporary law and policy in sub-Saharan Africa jurisdictions.

The call to adapt African traditional moral thought, in particular Ubuntu, in current sub-Saharan African laws and policies has implications on the current HIV testing policies and law in Zambia which is premised on individual autonomy, among other things. The current HIV testing regime in Zambia may need rethinking.

# 5

## **Zambia: socio-cultural context**

In the previous chapters it was argued that individual autonomy as propagated by Western liberal protagonists is problematic. It is problematic because the notion of autonomy is both philosophically and morally unsuitable in the light of human condition and reality. When we observe the reality and nuances of our everyday lives, it becomes apparent that human beings who are social creatures, born into a social reality, and enmeshed in social relationships from birth cannot be individually self-governing and self-sufficient. Equally, their natural condition and shared humanity morally calls them to act responsibly towards each other for the common good.

Therefore, since human beings are incapable of being individually autonomous and consequently ought to be viewed as moral agents, human autonomy can be best understood in socio-relational terms. This conclusion has consequences on how we understand informed consent in HIV testing in Zambia. The premising of informed consent requirements on autonomy can no longer be sustained.

In this vein, I have been inclined to conclude that representative indigenous African ontology offers a more convincing account of human agency. It offers a relational account of autonomy; it considers human beings to be necessarily social, interconnected and interdependent – “a person is a person through other persons” (Battle, 1997, p. 65). In other words, I have come to reject the notion of individual autonomy because “to the European [general Western liberal and libertarian] individualism is the ideal life, to the Africans the ideal [the dominant view] is the right relations with, and behaviour to, other people” (Kenyatta, 1985, p. 122). Indeed, a thesis of human agency premised on social relationships offers a more persuasive account of autonomy, than rationality accounts.

Thus, a thesis to the effect that individual autonomy is only achievable in a social context (and, that the concept is morally indefensible) would have implications on how we view the HIV testing informed consent requirements in Zambia. Put differently, if autonomy, as

argued in chapter 3 is illusory, then sustaining the concept in HIV testing in a country where HIV prevalence is high can be difficult to conceive.

This chapter provides an insight into the nature of the general Zambian society, and how this relates to the present inquiry of individual autonomy in decision-making. It is hoped that this approach will give the reader an understanding of the Zambian reality, more so to familiarise oneself with that country's socio-cultural reality and experience in the current effort to assess the appropriateness of universal HIV testing policy. The identification of the Zambian socio-cultural reality and experience will inform the study's subsequent analysis of the appropriateness of individual autonomy in HIV testing in that country's context, a country which is surrounded by multiple realities different from those the Western liberal theorist may have experienced before. The analysis of the Zambian reality and experience provides a relevant context in which to understand my findings from fieldwork. Fieldwork findings will be reported and discussed in the following chapters.

Kenyatta argues that it is imperative for any person or government or a power interested in securing the welfare of a people, for whom one is in charge, to firstly grasp the concerned peoples' history, economy, politics, way of life, and aspirations before endeavouring to aid them. He asserts that when a governor ignores the social reality or background of the governed by imposing her own views, whether those views fits with the governed people's mode of life or not, such an approach will in the long run be counterproductive to the happiness and well-being of the governed:

With a better understanding of the African social structure, an educationalist would be able to adopt a practical theory and method to suit the situation, and satisfy the African aspiration, so that education... might help to create progress, and at the same time to preserve all that is best in the traditions of the African people and assist them to create a culture which, though its roots are still in the soil, is yet modified to meet the pressures of modern conditions (Kenyatta, 1985, pp. 127-128).

Thus, it is hoped that by chronicling the Zambian reality and experience we will have the background from which to appreciate the issues that may affect our celebration of individual autonomy in HIV testing in Zambia.

## 5. 1 The composition of the Zambian population, colonial disinterest, and its

**legacy** In the year 1100 the Bantu speaking people's<sup>55</sup> migration displaced the San peoples who were the indigenous people of the now modern Zambia (Taylor, 2006). It has been reported that the Bantu speaking people, who now occupy Zambia, displaced the San between AD 300 and 1500 (CultureGrams World Edition, 2008). Having settled in that country, the Bantu installed their own culture and languages. To date the country is composed (almost entirely) of Bantu-speaking people. It must be mentioned here that the Bantu languages spoken by the majority of Zambians have their origin from Niger-Congo language family (Meredith, 2014; Hobson, et al., 2016). This means that most Zambians trace their indigenous ontology to their Niger-Congo ancestors. 98.7% of the country's population is composed of native black Africans (Mwansa, 2008). As of the year 2015 the country had a population of 16,212,000 (WHO, 2016).

And, regarding colonial attitude towards the 'native' Zambian, it would be safe to suggest at this juncture that the colonialist's oppression, denigration and derision of an African culture that he did not understand made him unfit to rule Zambians. His mission or self-coronation, unfortunately, was to civilise the 'savage'. Thankfully, the colonialist's prejudice did not manage to override the fact that African societies, including Zambia, possess a cultural heritage (Musonda, 2013).

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<sup>55</sup> The Bantu speaking people are a group of people from the Niger-Congo language family. Olson (2004, p.3) reports that the Niger-Congo language family comprising of about 1,400 languages is the largest language family in Africa. It is found in sub-Saharan Africa, where it has also intermixed with the Khoisan and some Indo-European languages (Olson, 2004). The Niger-Congo family group comprises of several major sub-groups, namely, the Bantu, the Kru, the Gur, the Kwa, the Benue-Congo, and the Atlantic (Lafleur, 1999; Olson, 2004). However, it is the Bantu group which is the largest group of the Niger-Congo family. The other African language families, besides the Niger Congo family, found in Africa are the Afro-Asiatic, the Khoisan, and the Nilo-Saharan groups. Gyekye recognises and demonstrates that the peoples of sub-Saharan African countries have common cultural features or ethics (Gyekye, 1995). The Akan people whom Gyekye writes about are the *Kwa* speaking people, a subgroup of the Niger-Congo family. He argues that "a painstaking study of African cultures leaves one in no doubt that despite the undoubted cultural diversity arising from Africa's ethnic pluralism, threads of underlying affinity do run through the beliefs, customs, value systems, and socio-political institutions and practices of the various African societies" (Gyekye, 1995, p. 192). Idowu attributes the striking similarities in African cultures, or what he calls "common Africanness" to "the fact of diffusion or to the fact that most Africans share common origins..." (Idowu, 1973, cited in, Gyekye, 1995, p. 194).

In fact, it took Fielden's study, in 1905, for the colonialist to learn that he was wrong in remarking that the African does not have a culture or development that is worth of research (Fielden, 1905, cited in Musonda, 2013, p. 8):

During the nineteenth-century period of European imperial expansion, due to the prevailing white opinion at that time, early Europeans who came to Northern Rhodesia can be said to have had little or no interest in studying the African past. Africans were deemed incapable of making any technological, cultural or political achievements (Musonda, 2013, pp. 6-7).

Actually, the colonial government did not leave a good legacy among Zambians due, among other things, to its policy of segregation, externalisation of Zambian wealthy, and its apparent lack of interest in the development of Zambian infrastructure, education and health. For example, Mwanakatwe (1994) reports that when Zambia obtained her independence, she had very little to show. The colonial government had left many areas of the socio-economic sphere under-developed. At independence Zambia only had 100 university graduates and 1,500 graduates with school certificates (Mwanakatwe, 1994, p. 44).

It is no wonder that Zambia after independence was in need of technical aid from the Bretton institutions and other financial and technical houses. Mwanakatwe explains that the colonial power had no interest in the development of Zambia. For example, writing about the colonialist's disinterest in improving the life of the Zambian, he reports that the colonial administration at one time "appropriated £14,547 to support 20,146 pupils enrolled in African schools in contrast to the handsome figure of 27,001 in support of 774 pupils enrolled in European schools" (Mwanakatwe, 1994, p. 45). This shows that Zambia's colonialists, besides their gratuitous disinterest in studying and knowing about the Zambian's view of the world, were hardly interested in developing the Zambian materially.

## **5. 2 HIV and AIDS: macro and micro impact**

The HIV epidemic has been reported to be a major factor contributing to economic productivity decline in Zambia. For example, in the 1990s when Zambia experienced very high levels of HIV and AIDS infections and deaths, Kelly (1999) reports that its impact was

even felt in the education sector. He states that HIV has an impact on teacher mortality, productivity, stress and retraining costs (Kelly, 1999, p. 2). He narrates that “application at district level of adult prevalence estimates suggests that, out of approximately 31,600 primary teachers in 1996/97, some 6,300 (20 per cent) were HIV-positive” (Kelly, 1999, p. 2). These infections resulted in deaths of many teachers, in that there were 1,300 recorded deaths during the first 8 months of 1998 (Kelly, 1999). The author notes that “for the education system, the 1998 deaths were equivalent to the loss of about two-thirds of the annual output of newly trained teachers from all training institutions combined” (Kelly, 1999, p. 2).

By the year 2001, Zambia as a whole was estimated to have 15.6% of its adult population living with HIV. This has only dropped to 13.3% as of 2015. Ellyne (2002) notes that the majority of people living with HIV/AIDS are from the productive age groups, that is, people aged between 15-49 years. A decrease in productivity among people in the economically active age group, loss of labour input, lower output per worker, lower GDP output growth, and reduced standard of living, are some of the impacts the HIV epidemic has had on the Zambian economy – that is, besides the impact it has had on government spending on health and recruitment of new labour (Ellyne, 2002, pp. 5-15). UNAIDS (2015) reports that between 1,200,000 -1,300,000 adults aged between 15-49 years are living with HIV/ AIDS in Zambia today (UNAIDS, 2016).

The economic effects of AIDS are firstly felt by individuals and families, before firms and businesses, and subsequently the economy of the country (Bollinger & Stover, 1999). The loss of income by the patient (who in most cases is the breadwinner), poor school attendance of children or a spouse providing care for the sick person, medical expenses, the costs of permanent loss of income due to funeral costs, and, “removal of children from school in order to save on educational expenses and increase household labour”, are some of the economic impacts of AIDS on individuals and households (Bollinger & Stover, 1999, p. 4). The authors cite various studies undertaken in Zambia which have found this to be the case. For example, one of the studies undertaken in Kafue, Zambia found that:

Caregivers in the less affluent community reported lost earnings of 10,000 kwachas (K) per month, where half of the sample earned less than K100, 000 annually. Those in the more affluent area had lost earnings of K24, 583 per month, where 85% of the

sample had an annual income of over K1, 000,000. The average funeral cost between K112, 000 and K240, 000. The average cost for a visit to a clinic ranged from K8, 542 to K16, 500... The affected households also reported selling off assets such as bicycles and radios in order to pay costs such as health and funeral (Mutangadura & Webb, 1998/99, cited in Bollinger & Stover, p. 5).

The United Nations Economic Commission for Africa, Commission on HIV/AIDS and Governance in Africa (2005) reports that since it is people between the ages of 25 and 50 who are mostly living with HIV/AIDS in sub-Saharan African countries, this has consequences on households. The paper states that demise of men and women from this age group, due to AIDS, leads to surviving spouses and children having fewer economic opportunities, increased malnutrition, and diminished care for children. The paper also notes that HIV/AIDS impacts families, and overall communities through time spent on caring for patients. For example, a study carried out in South Africa found that 40% of caregivers (who are mostly women and girls) took time off from income generating activities in order to care for ill relatives, and that children also took leave from school to provide care for ill family members (United Nations Economic Commission for Africa; Commission on HIV/AIDS and Governance in Africa, 2005, p. 8).

Besides the HIV/AIDS epidemic impacting household economics and its effects upon the lives of the carers, it has also been shown that the mortality of parents causes an influx of orphaned children:

In addition to the daily care of people ill with HIV/AIDS or related illnesses. The care of children while a parent is dying and after the death is a major burden for immediate and extended families. Increasingly, one hears that the extended family system is overwhelmed by the magnitude of the burden of caring for so many orphaned children. The changes in living arrangements, well-being and opportunities for a secure future for children is one of the most significant long-term outcomes of the HIV/AIDS Pandemic (United Nations Economic Commission for Africa; Commission on HIV/AIDS and Governance in Africa, 2005, p. 9).

A study also found that orphaned children in Zambia work for many more hours than their counterparts who are not orphaned. That is, once a household member of the child's family became ill, the children's domestic and farm work participation also increased (United Nations Economic Commission for Africa; Commission on HIV/AIDS and Governance in

Africa, 2005, p. 10). As of 2015, it has been estimated that there are between 290,000 – 680,000 children orphaned by AIDS in Zambia (The Stephen Lewis Foundation, 2015).

Also, noting the impact of HIV on individuals, families and the nation in Zambia, is Taylor:

The HIV/AIDS epidemic has had devastating impact on marriage and families in Zambia. Estimated between 16 percent and 19 percent, the HIV-infection rate among the sexually active population has stabilised in recent years. Nonetheless, this still places the number of infected in the millions, a staggering number of infections in any country, let alone a poor country with an underdeveloped health care system and a population ill equipped to cope with the problem. Moreover, it has produced more than 600, 000 orphans, by some estimates, and this has overwhelmed the capacity of families – let alone the state... Many of the orphans have been absorbed into families of uncles, aunts, and other relatives who already confront the disease and, typically, poverty within their own immediate families (Taylor, 2006, p. 105).

The impact of HIV on the socio-economic well-being of Zambia has also recently been underscored (Tirivayi & Koethe, 2016). In this study, it is noted that besides the HIV epidemic having severe economic consequences on individuals living with HIV, it also affects families of PLWHA and national economics (Tirivayi & Koethe, 2016, p. 1). The authors report that “progressive debilitation from untreated HIV disease and the associated burden of caring for chronically ill family members reduce the capacity for labour force participation and economic productivity among working age adults, which negatively impacts the household through reduced income” (Tirivayi & Koethe, 2016, p. 1).

In a study carried out in two districts of Zambia by Dieleman, et al., it was also found that HIV/AIDS has an impact on health workers:

...HIV/AIDS has increased the workload and considerably changed or added tasks to already overburdened health workers in both study districts... Despite the fact that health workers are still relatively motivated, there are signs of emotional exhaustion, especially among counsellors and nurses. HIV/AIDS complicates the already difficult work environment (Dieleman, et al., 2007, p. 146).

The foregoing discussions show that the HIV epidemic has a socio-economic impact upon the Zambian peoples as a unit. It is no wonder that the first president of Zambia, David Kenneth Kaunda, in 1987 saw fit to announce to the world that his deceased son, Masuzyo, had died of AIDS-related illness (Thomas, 2015). It is apparent that, in doing so, Kaunda as a



leader of Zambia sought to sensitise and demystify HIV/AIDS to people. He also publicly tested for HIV in order to encourage HIV testing uptake among the Zambian population.

To conclude this section, if HIV/AIDS as has been shown does not only impact individual PLWHA, but also the family of patients, the community, and the national economy, should it then follow that HIV testing be prioritised by equally considering the common good? Should testing for HIV still be based upon individual autonomy? In the pages that follow, I will discuss the thinking of traditional Zambian moral thought on the nature of a person.

Thus far, as established in the preceding chapters, it has been argued that individual human beings are incapable of being self-governing (therefore the idea of individual autonomy is illusory), that individual autonomy is morally tenuous, and that African traditional ontology views human beings to be social not atomistic.

As a number of authors have reasoned, as established in chapter 4, I suggest that the search for a Zambian voice on the nature of human agency will afford this study a premise upon which to gain an informed view of the current HIV testing policy in that country.

### **5. 3 A way of life in a globalised world: the debate**

The people of Zambia since colonial time have had their cultural ways of life exposed to Western influences. However, even amidst such influences, Zambians, generally, still treasure communal ideals over individualism (Kaunda, 1973; Venter & Olivier, 1993; Silavwe, 1995; Taylor, 2006). It is reported that changes in the country's modern outlook have had little impact upon Zambia's dominant cultural outlook which recognises and encourages human interdependence (Hobson, et al., 2016). Commenting on Zambian socialistic humanism ideology which Kaunda has advanced, Mwanakatwe observes that the ideology is grounded on traditional Zambian ethics which promote the common good (Mwanakatwe, 1994). Venter and Olivier have reported:

Kaunda summarises the content of humanism as follows: "This high value of man and respect for human dignity, which is a legacy of our [Zambian] tradition, should not be lost in the new Africa. However 'modern' and 'advanced' this young nation of Zambia may become, we are fiercely determined that this humanism will not be

obscured. Africa society has always been 'man-centred' (Venter & Olivier, 1993, p. 26).

The same authors have noted:

The dignity of humans is a key concept in Kaunda's thought on justice and the adjudication of human rights... Kaunda identifies rights such as individual freedom and security. All persons should be able to exercise these rights freely within the limits of the law. The purpose of the law [according to Kaunda] is to protect the inhabitants of a state against selfish individuals that act in contravention of the common good (Venter & Olivier, 1993, p. 26).

It is obvious from the foregoing discussion that communalism is a critical value (a way of life) to Zambia's inhabitants, unlike the universalised value of individualism. However, despite having its own socio-cultural identity and experiences, HIV testing law and policy in Zambia requires informed consent, a concept premised on individual autonomy- an alien concept to indigenous Zambian ontology. Arguably, it is a regime of human rights which does not reflect Zambian experience and reality.

Hence, it is my understanding that certain Western liberal individualistic human rights (like informed consent requirements in HIV testing) are problematic when equally applied to the Zambian reality because such values (developed in the context of Western experience) are apparently inappropriate when applied to that country's context. In fact, Khinduka (1971) has argued that many of the issues or problems facing developing countries are not the same as those facing Western countries. He questioned the appropriateness of applying models or values developed in the Western sphere to developing countries since such values have evolved not from developing countries' realities and experiences, but from Western experiences and cultures.

According to Khinduka, developing countries still suffer from low per capita income and limited social services (e.g., high illiteracy levels), and similarly, he has confirmed that peoples from these countries are still attached to their traditional value systems and ethos despite their own governments' imposition of alien doctrines (Khinduka, 1971, pp. 62-63). Actually, the United Nations (1968, cited in, Khinduka, 1971, p. 64) found that the experiences of numerous international organisations in the field of social work showed that mere application of "foreign experience and ready-made solutions" failed to take root in the

target developing countries because of prevailing native attitudes and values. This indicates that a given peoples' way of life (if it is found that it respects human rights) ought to be respected. The implication of such an understanding is that a universal plural approach to human rights would be appropriate given Zambia's own experience and reality.

It must be noticed that the imposition of 'universal' doctrines upon the peoples of the developing world has been seen, among other things, as necessary because it depicts modernity and human progress. However, as Khinduka notes, despite the target peoples' admiration of the products of modern technology, these people who are expected to embrace modernity and human progress still revere and hold on to their own cultural traditions:

In general, one may say the third world is impressed by the affluence of the industrialised world (demonstration effect). It wants to catch up with it in the shortest possible time (compression effect). In doing so, however, it would like to retain the richness of its own heritage and yet acquire the productive technology of the industrial societies (Khinduka, 1971, p. 63).

The author explains that traditional societies from developing countries instead choose to adapt some Western values in a way that such ethics are commensurate with specifics of ones' cultural and historical background. Talking about social work, he adds that even social welfare experts from Western jurisdictions have cautioned developing countries against "blindly accepting the received pieties and priorities of Western social work" (Khinduka, 1971, p. 64). In the context of social work ethics, the author declares that it is inappropriate to make Western social work a universal applicable model for social workers in developing countries.

The implication of the foregoing discussion, I suggest, is that a project intended to supplant a respected indigenous ontology and in its stead implant alien doctrine is liable to fail. The implanting of 'universal' values into a local society (like Zambia) without due regard for the ways of life of its people is not only insensitive and disrespectful to the needs and reality of the subjects, but also such imposed values are liable to be ignored in practice. It will be, therefore, of interest to this study to learn in chapters 6 and 7 about how much Zambians relate to the value of individual autonomy in their day-to-day lives. The question answered

in the said chapters is “how does the health worker, the service-user, and the relative of a patient regard individual autonomy in every-day decision-making”?

### **5. 3. 1 Self-determination**

Healy has argued that the application of universal values or ethics to a local society is problematic if viewed from a multicultural perspective (Healy, 2007). For Healy, the universalism of Western values and ethics is incompatible since its application into non-Western countries may impinge upon the ways of life of a recipient people. However, by saying this, Healy does not mean that all the Western values and ethics which industrialised countries promote are not universally applicable. There are values and ethics that are arguably universal, for example, what one may call humanity’s belief in the worth and dignity of each person (Healy, 2007).

Healy turns to the discussion of the value of self-determination in the light of multiculturalism. Indeed, a discussion of self-determination from a cultural perspective is appropriate. In chapter 3, we discussed the concept from a general theoretical point of view; for the purposes of this section, it will be discussed from a socio-cultural point of view. In other words, this discussion is essential because self-determination is synonymised with individual autonomy. Thus, it will be fitting to find out whether the doctrine of individual self-determination has support in traditional Zambian cultural thought and practice, or not.

According to Healy, the doctrine of self-determination is intended to uphold the value of each person’s worth and dignity. However, she explains that the ethic of self-determination is also steeped in individualistic societies’ promotion of human agency. She defines self-determination as “respecting and facilitating the ability of the client to make his or her own life choices and decisions” (Healy, 2007, p. 18). It is noteworthy at this juncture to observe that the definition given by Healy is not different from the working definition discussed above. From this definition, it is evident that the individual is seen to be a “sovereign” whose choices and decisions for the steering of the course of her own life should not only be encouraged, but also respected and protected.

However, like Khinduka, Healy (2007) references the 1968 United Nations' findings in her exposition of the difficulties of applying Western values and ethics to countries which may have different socio-cultural realities and experiences. She establishes that social workers from different cultural jurisdictions around the world have tended to modify or even to dismiss certain aspects of self-determination. That is, the reported social workers engage in directive form of counselling (as opposed to advisory counselling) when they come into contact with their clients because they see themselves as responsible for ensuring the well-being of their clients. To this end, they also avoid offering options for individual choice (Healy, 2007, p. 18). It must be immediately pointed out that the ethos of the discussed social workers violates the tenets of individual autonomy. This is because clients' eventual choices and decisions are arguably induced or determined by a social worker who does not give autonomy promoting options to her clients.

A Jamaican social worker is reported to have shared that although it could be conceded that self-determination is an ideal value, a majority of social workers "engage in considerable amounts of advice-giving in practice and" their advice is prescriptive (Healy, 2007, pp. 18-19). This practice of withholding information was found among Indian social workers, and it is argued that the social workers behaved in this manner because clients hold them to be experts. This has also been demonstrated to be the case in Zambia (Silavwe, 1995). Indeed, Healy submits that culture has a role to play in such practices. Hence, she argues that there is need to rethink our view of the universalism of values.

Healy suggests that adoption of moderate universalism in the application of values and ethics would be conducive. She argues that doing so would not only lead to the recognition of fundamental human rights, but that existing social work codes of ethics will not be heavily biased towards individualistic cultural perspectives. She argues that biased respect for individualism at the cost of the common good diminishes the necessity of reciprocity, caring, and community-building, among other things. She recommends that "prioritizing the universal values in a more culturally relevant hierarchy" would be the right approach:

Given social work's strong affiliation with human rights, a stance in the mid-range of universalist-relativist continuum is recommended for the profession's ethics, with a reference towards moderate universalism. Such a stance would recognise that all humans have rights to equality and to the full protections, entitlements and responsibilities embodied in the UN human rights treaties. The importance of

diverse cultures and of ties to cultural groups would be recognised as among the human rights. Thus, specific practice decisions would promote universal rights while supporting the preservation of culture whenever possible (Healy, 2007, p. 24).

Earlier, she invokes a 1994 IFSW's Statement of Principles which instituted that individuals do not only have a right to self-fulfilment, but also an obligation to respect the rights of others, and an "obligation to contribute to the well-being of society" (Healy, 2007, p. 19). She adds that besides the value of self-determination, "It is widely agreed that professionals should take no action that causes harm to the client and should strive to reduce harm to as many parties to a situation as possible" (Healy, 2007, p. 21).

In fact, addressing the Zambian situation, Silavwe (1995) has argued that the principle of self-determination is inappropriate in the Zambian context. It is inappropriate, according to the same author, because it is grounded on the concept of individualism. He argues that employment of the value of individual self-determination in social work in Zambia is problematic. He argues that the value is an inappropriate tool to solve problems unique to Zambia, due to the peoples of that country's unique experiences and ontological reality.

Writing in the context of social work, Silavwe argues that Zambia should not be required to embrace Western social work values which grew up from and correspond with Western cultures and realities. He submits that since in African cultures, Zambia in particular, individuals are defined as part of a group, it ought to follow that the "self" in Zambia can only be defined in the context of a group, as opposed to being celebrated as an autonomous person. For Silavwe, the adoption of foreign values ought to be shaped in ways that help the Zambian peoples make sense of who they are as a people, in the light of the nature of their metaphysics and every-day life experiences. He concludes that Zambia being a communitarian society, the value of self-determination is, in fact, unsuited for that country's ethics and practice.

Silavwe notes that sub-Saharan Africa societies (Zambia being one of them) are communal. He explains that sub-Saharan African "society is closely knit, and much more of an organic entity than" Western societies (Silavwe, 1995, p. 75). Referencing the dominant ontological indigenous African outlook of human condition, he relates that a human being is viewed to be an inextricably communal being because, besides individuals being born into society,

“the whole of existence from birth to death is organically embodied in a series of associations, and life appears to have its full value only in these close ties” (Silavwe, 1995, p. 73).

In his work on church social teaching and HIV/AIDS, Professor Michael Kelly, a Zambian academician and Catholic Jesuit priest, also emphasises the social condition of human existence. He underlines that human beings are social beings, who at their various stages of life depend on one another “for existence and for the fulfilment of spiritual, intellectual, emotional, physical, and social needs” (Kelly, 2011, p. 4). He stresses that this social church teaching also finds support in indigenous African ontology which states that an isolated person is evidently a contradiction in terms.

Indeed, Silavwe argues that because of the social condition of man, individualism is held to be unsuitable in African traditional moral thought. Self-determination which assumes individual humans to be sovereigns of their own lives and thus promotes individual choice specifically for one’s own life, without equal regard for the common good, cannot be applied to the Zambian situation because the value has a disjunction with that country’s experiences, Silavwe indicates. He provides that individual self-determination is discouraged, if not treated with contempt, in the sub-Saharan African context because the peoples of sub-Saharan Africa find the notion ontologically disjunctive in the light of their unique experiences and their understanding of human condition.

There is little room for individual self-determination in sub-Saharan African morality; shared responsibility is, instead, encouraged.<sup>56</sup> In this vein, Silavwe concludes that self-determination can appropriately “be used in a Western cultural environment where conditions are markedly different from those currently obtaining in Zambia and Africa as a

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<sup>56</sup> However, this does not mean that sub-Saharan African communal ethics, in particular Zambian ones, overlook the rights of individual humans. Instead, traditional African decision-making is diffused as opposed to being centralised. What I mean by being ‘diffused’ is that in indigenous sub-Saharan Africa *modus operandi*, decision-making is not entrusted in the hands of the elite or a single representative; rather, decisions-making is a product of the discussions of all the mature people from within a concerned community (Colson, 1967, cited in, Silavwe, 1995, p. 74). This means that communal decisions are a product of negotiations amongst all the adult members in a given community. Silavwe reports that all the adults attending such community decision-making gatherings, and have something to say, are entitled to have their say heard.

whole; as it [self-determination] was developed in a specific culture, and was devoid of cross-cultural and cross-class considerations” (Silavwe, 1995, p. 73).

The sentiments expressed by Silavwe regarding the suitability of the application of Western values and ethics without due consideration of the Zambian reality and experience, are not in isolation. Most of the African authors considered in the immediate preceding chapter have, in fact, also argued for a pluralistic approach which reflects local culture, reality and experience. I would like to argue that this re-emphasised perspective which argues for a regime of human rights which are hinged upon societal needs is persuasive. It is persuasive because the adoption and sustenance of disjunctive foreign values can have sad ramifications on the quality of life of the people for whom a given value is intended to benefit.

Indeed, an HIV testing regime premised on individual autonomy can be problematic in the Zambian context because, for example, unlike in the West where an individual is entitled to have access to state or local authority social care when incapacitated by illness or other perils of life, in Zambia the individual will depend on family members and friends for care and sustenance – and thus, individual dignity (there are no state benefits in Zambia). Hence, the universalisation of HIV informed consent requirements (requirements which are premised on individual autonomy) can be harmful or inappropriate in the Zambian context, for the very reason that the current regime of such requirements in Zambia does not at the same time seek to protect or facilitate the common good of both the PLWHA and the future carers (family members and friends of PLWHA) in the country. In other words, it is arguably inappropriate because it fails to address the real needs of the common good.

#### **5. 4 Enduring Zambian culture**

Taylor focusses his thesis on culture and customs in Zambia. He states that Zambia has essentially remained Zambian despite what he identifies to be the late nineteenth century influences of colonialism and Christianity which discouraged or even banned cultural practices (Taylor, 2006, p. 109), and also due to the current impact of local environmental hardships, and globalisation:



... despite a largely hostile environment characterised by the twin pressures of globalisation and domestic hardship – or perhaps because of it – many Zambians, both urban and rural, are finding solace, as well as economic opportunity in their traditions. Thus, a number of Zambia’s social customs and traditions are proving surprisingly resilient, if not expansionary... Indeed, many have argued that the embrace of these traditions helps Zambians remain stable in turbulent times. Despite rampant poverty, the ravages of HIV/AIDS and changing lifestyles, people have sought to reconnect with their past as a source of stability and identity (Taylor, 2006, p. 110).

Put differently, Taylor (2006) explains that even though the peoples of Zambia have had their way of life affected by Christianity, Western ideas, local environmental hardships, and globalisation, the present-day Zambian’s worldview is a mixture of modernism and communalism. This entails that the peoples of Zambia have adapted some of their traditional ways of doing things only to a degree that such transpositions address present-day challenges.

That is, although imported individualism has affected some relationships within the Zambian society, pre-colonial traditional beliefs and practices still influence the cultural norms and practices of the modern-day peoples of Zambia (Taylor, 2006). He explains that “in Zambia today, as in much of Africa, tradition and modernity does not only exist side by side, but also what is modern becomes thoroughly endogenized, and the traditional is altered and adapted as well” (Taylor, 2006, p. x). Indeed, despite the country’s culture going through some changes as a result of Western influences, the people of Zambia have continued to hold on and practice values and ethics passed to them by their ancestral sages (Kaunda, 1993; Phiri, 2008). The common good value is one of the values which has been retained in present-day Zambia (Baldwin, 2013).

The foregoing observations confirm Khinduka’s and Healy’s theses, as established above. Indeed, like other developing countries around the world, the peoples of Zambia have preferred to embrace and practice their ancestors’ traditions, because they have found common value in them. These observations regarding the perennial communal situation of Zambia are also consistent with Michael Kelly and Geoffrey Silavwe’s conclusions noted above.

Undoubtedly, Zambian peoples' perspectives of their environment and who they are, like many other people in the world, are influenced by their own common experiences and circumstances, among other things (Taylor, 2006). Thus, arguably, it is justified for them to modify their traditions and morality only to a degree that such alterations do not interfere with the wellbeing of their shared humanity. A common good necessitated by natural human sociality, interconnectedness and interdependence.

Thus, Taylor concludes that the preservation of the common good resonates with the majority of the peoples of Zambia. For example, to underscore this perennial reality, he notes that in effect, the pronoun 'family' in Zambian cultures is not taken to mean the nuclear family of father, mother and children, but it includes aunts, uncles, cousins, grandparents and other biologically associated members. The members of such units have shared obligations and responsibilities towards each other (and, on a macro level towards their communities and fellow countrymen and women) (Kaunda, 1973).

In fact, traditionally, even when it comes to children, it is a collective responsibility of every adult member of the 'family' to assist in raising and disciplining children for the common good of the community (Taylor, 2006). Hence, according to the same author, "the shared responsibility meant that... wives were never really widowed and children were never orphaned because they were absorbed into the larger family groupings" (Taylor, 2006, p. 107). A social responsibility tradition, among other social obligations, of which has been transmitted by Zambian's ancestors to the present generation.

Like most African countries, Zambia's traditions have been orally transmitted from one generation to another, through folktales, proverbs, songs and dances, and myths. Taylor reports that even though oral tradition has now been accompanied by a written culture, "the addition of writing serves as a compliment to the oral histories rather than supplanting them" (Taylor, 2006, p. 43). He explains that modern Zambia still has storytellers who communicate the country's pre-colonial ideals to present-day Zambians, who are in turn expected to impart it to upcoming generations:

Unlike in West African cultures, where this is designated intergenerationally (and usually limited to males), in Zambian villages storytellers are simply men and women who have the ability to tell a good story to captivate an audience... Stories are generally told at home in the evening following the meal. Thus the stories tend to

serve as both entertainment and, importantly, as a means of transmitting norms, values, and traditions important to and about the various cultures (Taylor, 2006, p. 43).<sup>57</sup>

Indeed, the foregoing sentiments suggest that Zambia's socio-cultural ontology is related to that of other sub-Saharan African countries, as discussed in the previous chapter.

## **5. 5 HIV, human rights, and justice**

Kelly has suggested that the safeguarding of dignity of individuals and other human rights is paramount in our response to HIV. He argues that an environment where the rights of human individuals are upheld ensures that HIV/AIDS vulnerability is reduced, ensures that PLWHA and those affected live a life of dignity without discrimination, and it ensures that the impact of HIV/AIDS on the society is alleviated (Kelly, 2011, p. 11). It is worth noting here that when Kelly writes about the importance of human dignity and other human rights, he also includes the rights of those who are affected, and the rights of the larger society. I wish to argue that this perspective does not sit well with the requirements of informed consent in HIV testing in Zambia, which are almost entirely premised on individual choice, and the making of testing decisions exclusively based on what is best for the putative autonomous decision-maker.

My thesis does not reject the premise that every individual has inherent and inalienable rights, by virtue of being a human being. However, my study reviews how far the right to self-determination or autonomy, if it is even makes sense and is universally applicable, can be applied in Zambia, a country where HIV prevalence and incidence is very high, and where

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<sup>57</sup> I can personally relate to this. When I was growing up as a young boy in Zambezi, Zambia, after the evening meal we used to assemble together at home as a family, sometimes with neighbours or visiting extended family members. During such assemblies, the elderly would tell stories, sing, and throw riddles at the assembling audience to solve. Our elders would normally tell us children moral implicating tales (animals like tortoise, hare, lions, elephants, crocodiles, hyenas and mouse were the main characters in such tales). Having told a story or solved their own riddles, the elders would then ask us to explain the moral imperative to be drawn. Where we failed to give a satisfactory explanation to 'the moral of the story', our elders came to our aid. In my language such story-telling is called "*chwanu*". The tradition of riddles and proverbs in African society serves the role of enabling children to appreciate their history, human condition and African experience (Finnegan, 2012).

the HIV epidemic does not only affect PLWHA, but also family members and the society at large. Professor Michael Kelly observes:

Rights must be counterbalanced by obligations and duties... [It is] a contradiction to affirm rights without acknowledging corresponding responsibilities. The human person is certainly free, but this freedom is not unlimited (Kelly, 2011, p. 25).

Kate Turner has concluded:

[T]he strongest foundation for effective HIV policy and practice is an ethical foundation... It is also argued that the Charter [the African Charter on Human and Peoples' Rights] constitutes a foundation not only for ethical but also for effective HIV policy and practice in Africa. It is also argued that effective and sustainable HIV policy and practice will include the application of the rights and responsibilities set out in the African Charter in every aspect of HIV policy and practice (Turner, 1994, p. 90).<sup>58</sup>

The present discussion is to do with questions of the extent to which members of the community (people affected by HIV/AIDS) are entitled to protect themselves in the light of the rights of individuals who are held to be autonomous. The question becomes, since HIV testing can lead to behavioural change, reduction in HIV infections, and access to ART which has been found to prolong life, is individual autonomy in HIV testing, even from the human rights perspective, justified in the light of the impact that HIV has not only on the life of a PLWHA, but also the community (and also taking into consideration the reality, experience and culture of the peoples of Zambia)?

Proponents of individual autonomy, as discussed in chapter 3, have suggested that individual persons are 'sovereign' so they have a right to make decisions which they see fit for the direction of their own lives. This directly states and implies that failure to uphold individual self-determination will inevitably result in violation of an individual's human right (Malila, 2012).

These proponents, in regards to HIV testing, have stated that a person has a right to privacy. This particular right is mostly referenced to the *Universal Declaration of Human Rights*,

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<sup>58</sup> Kate Turner says that she has lived most of her adult life in Zambia than in any other country. She calls herself both an insider and outsider "to the cultures and the social, economic and political structures and institutions of one part of Africa" (Turner, 1994, p. 91).

which was adopted by the United Nations General Assembly in 1948. Article 12 of the said declaration, among other things, safeguards individual human beings from arbitrary interference with one's privacy, family or correspondence. The *International Covenant on Civil and Political Rights*, is another instrument which protects against arbitrary interference with a person's privacy. In fact, Zambia is a signatory to the *International Covenant on Civil and Political Rights*, among other international and regional instruments (Mwansa, 2008). Fletcher observes that "when individuals consent to undergo medical operations, engage in sexual intercourse, ...open their homes to the police searches, or... testify against themselves in court, they convert what otherwise would be an invasion of their person or their rights into a harmless or justified activity" (Fletcher, 1996, cited in, Beyleveld & Brownsword, 2007, p. 5).

However, besides the conclusions shown above to the effect that individual autonomy does not reflect dominant sub-Saharan African reality and experience, there is equally a debate to the effect that Western perspectives or culture "dominated the formulation of early international standards of human rights", until after the 1960s when newly independent African countries started participating in the drafting of the international instruments (Leary, 1990, p. 15). In fact, Donnelly suggests that individual autonomy-based human rights are a liberal conception of human rights which rest "on a definition of a person as an isolated, autonomous individual ... with inherent rights in the domain of the civil and the political..." (Donnelly, 1990, p. 31).

Owing to the foregoing, it would thus be problematic to argue that individual human rights ought to be protected because humans are autonomous. Representative sub-Saharan ontology does not regard individual humans to be autonomous. My thesis has so far shown that the concept of individual autonomy is not universally held. This entails that the application of 'universal' ethics in HIV testing in Zambia may, in fact, be problematic because that country in the reality of its experience and reality generally holds a socialistic understanding of human condition.

## **5.6 Informed consent requirements in a Christian Zambia**

The influences of Christianity were considered in this study because the majority (over 90%) of Zambians are overwhelmingly professing Christians. According to the interpreted traditional biblical system of law, patients do not have an absolute right to select their own medical therapy; it is held that the body of the individual person “does not belong to the individual”, instead it is held to be a trust given to human beings by God; a human being is thus held to have an obligation to respect and preserve the body (Walter, 1999, p. 357). The implication of such a perspective is that humans are merely trustees of the body which God made, hence during the biblical judgment day individual humans will be required to account for how they treated their bodies and life of which God put in their trust.

Put differently, individual consent in biblical law is not necessary when a procedure is beneficial to the individual, or where a procedure is harmful. Its exercise is only allowed in instances which involve “uncertain outcome, or in cases of equivalent choice” (Walter, 1999, p. 363). According to the same author, biblical doctrine does not discriminate between the competent and incompetent health service-user, rather medical interventions are sanctioned on the basis of the assessment of benefit versus risk.

In fact, the conception of “creation of all persons by one God, the universal graciousness of God toward all, the redemption of all by Christ, and the call of all persons to share in the mystery of Christ’s death and resurrection – all these are the foundation of a conception of mutual love and human solidarity” which are respected and promoted in Christian doctrine and ethos (Little, 1990. P. 61). This doctrine does not only require an individual to protect and preserve one’s own body and life from injury and death, but also to act responsibly towards others (Little, 1990). To this degree, the Christian doctrine on human relationships is similar to traditional African ontology.

## **5.7 Foreign aid and influence**

Zambia, like many sub-Saharan African countries, is dependent upon foreign aid, also known as “official development assistance” (Rena, 2013; Masaki, 2015; Sindzingre, 2015; The Mast, 2017). Currently, Zambia is dominated by many NGOs, organisations which to the very

NGOs' credit have been established, among other things, to fight poverty, disease, and promote good governance. Additionally, aid has also been granted, as a contribution to the Zambian government's budget, over several years. For example, it is reported that between 2000 and 2005 foreign aid accounted for 43% of that country's total national budget per annum (Rakner, 2012).

In fact, Zambia's dependence on foreign aid started from mid-1960s, in that, aid has even been called a strong political player in the nation (Carlsson, et al., 2000; The Mast, 2017; Sosala, 2017). Indeed, even in the light of the emergence of the HIV epidemic, many Western countries have contributed huge amounts of financial and technical aid to Zambia, to help the country in its response to the epidemic.

As already alluded to, donor countries provide both technical and financial support for HIV programmes in Zambia (Kalibala & Mulenga, 2011). These donor programmes are run through international and local NGOs. The United States of America (U.S.A) ranks as one of the country's major donors (Avert, 2016). For the year 2012, Zambia was given by the U.S.A government aid totalling US\$222 million. USAID reports that Zambia's partnership with the U.S.A was formalised through the establishment of USAID in 1977. Current aid from USAID is reportedly aimed, inter alia, at reducing the incidence and impact of HIV/AIDS (USAID, 2016).

PEPFAR, a U.S.A commitment or initiative in response to the HIV epidemic created in 2003, currently aids Zambia's response to the HIV epidemic. It provides technical support and direct service delivery (PEPFAR, 2016). In 2011, Zambia received a total amount of US\$306 Million through PEPFAR as assistance towards HIV prevention, treatment, care and support (U.S. Embassy in Zambia, n.d.).

My analysis of foreign aid conditions to sub-Saharan African countries makes me fear that informed consent requirements in Zambian HIV testing law and policy are a product of Western influence (Human rights Watch, 2005; Kalibila & Mulenga, 2011, Rakner, 2012; Sosala, 2017). In fact, even from as early as 1984, Ved Prukash Torul provides in his thesis on *Zambia and the Universal Declaration of Human Rights...* that Zambia has through its Constitution provisions and sustained legislative efforts given effect to individual civil and political rights established in the United Nations Universal Declaration (Torul, 1984). Some

of these provisions (for example, the right to privacy under Article 17 of the Zambian constitution) are based on the said universal instrument (*Kingaipe* and *Chookole v Attorney-General*, 2010; Malila, 2012). In fact, in the *Kingaipe* case the Court accepted Article 3 of the Universal Declaration and Articles 6 and 9 of ICCPR as authoritative (Malila, 2012).

Silavwe (1995) has advanced that the solution to Zambia's problems does not lie in the adoption of Western values which do not match with Zambian needs and wants. He argues that Zambia's reliance on developed countries' advice and expertise has become difficult to get rid of (Silavwe, 1995, p. 78). The author notes that "even when changes are needed and advocated, the change agents usually come from outside (for example United Nations experts and other experts from countries offering bilateral aid, etc.)" (Silavwe, 1995, p. 78). He advances that the reliance on foreign experts who are contracted to assist in finding solutions to Zambian problems (solutions of which he argues are either rejected by the people of Zambia or by their nature are counterproductive) is problematic. He adds:

These foreign recipes and borrowed tools fail not simply because they come from outside the system in which they are applied; rather it is because they have not been sufficiently integrated into such systems. In the majority of cases, they are products of assumptions and conditions that are totally different from those obtaining in the system in which they are expected to function. For such tools to be at all effective, they must be adapted to the local conditions in which they are applied (Silavwe, 1995, pp. 78-79).

## **5.8 Relationship of this study to other studies**

Studies done in Zambia that are closest to the present study are studies by Denison, et al. (2014), Denison, et al. (2006), a study by Topp, et al. (2011), also by Njeru, et al. (2011), and by Mburu, et al. (2014). The topics of study for the identified researches ranged from "*social relationships and adolescent HIV testing behaviours in Ndola, Zambia*" (Denison, et al., 2014), "*social relationships and adolescents' HIV counselling and testing decisions in Zambia*", (Denison, et al., 2006), "*opt-out provider-initiated HIV testing and counselling in primary care outpatients in Zambia*" (Topp, et al., 2011), "*practicing provider-initiated HIV testing in high prevalence settings: consent concerns and missed preventive opportunities*", (Njeru, et al., 2011), and "*responding to adolescents living with HIV in Zambia: a social-ecological approach*" (Mburu, et al., 2014).



Denison, et al., (2014) and Denison, et al., (2006)'s studies which concern social relationships and HIV testing behaviours amongst adolescents found that family factors are important in the implementation and evaluation of HIV testing. Discussing HIV testing with one's family members was found to be significantly related to people seeking to test for HIV (Denison, et al., 2014, p.136). In an earlier study, Denison, et al., (2006) found that adolescents often delayed going for VCT until a family member or friend who supported the idea of going to test for HIV was found.

These studies show that "family discussions correlated strongly with untested adolescents intentions to learn his/ her status" (Denison, et al., 2014, p. 136). Peer pressure, accessibility, cost, and quality to HIV testing services did not correlate with actual testing behaviour (Denison, et al. 2014, p. 136). In fact, the 2006 study found that data from household surveys shows that: "youth who discussed getting tested with their family members were six times more likely to plan to take an HIV test"; that, participants were more likely to get tested for HIV if they believed that their family members would not get upset with them if they found out that they had tested for HIV; and also found that, "perceived negative reactions of family and friends, and fear of HIV-related stigma prevent youth from seeking VCT" (Denison, et al., 2006, pp. 4-5).

When it comes to adhering to treatment, Mburu, et al. (2014, p. 7) in their study in Zambia report that "family and peers were noted to influence adherence by creating an environment that enable adolescents to adjust to new drug-taking routines and cope with the side effects." According to the same authors, their study's findings are consistent with other studies which have shown that support from trusted adults, e.g. parents and guardians, and peers has a positive influence on how adolescents adhere to treatment, as well as uptake of other services, and coping strategies.

On the other hand, Topp, et al. (2011, p. 328) found in their study in Zambia that when PITC was added to VCT, that the number of people who tested for HIV in the clinics of study was double the number going to VCT. However, a study by Njeru, et al. (2011, pp. 7-9) in Zambia, regarding PITC, indicate that a large number of study participants expressed frustrations in the new PITC approach. The authors observe:

Despite the fact that the option to opt-out or decline a test is part of the PITC model, our informants explained that it was in practice not possible to decline HIV testing at the ANC. Opting out implied that further care is declined (Njeru, 2011, p. 8).

Two issues arise from the studies cited under this section: a) adolescents testing for HIV owing to prior discussions and encouragements from family members and friends; and, b) more people testing for HIV after the introduction of PITC. Such results suggested to me that the trend of more adolescents testing for HIV because of family support is not indicative of individual autonomy.

However, what can be observed from the studies in question is that the majority of participants were between 10-19 years old. Given that participants below the age of 16 may not have fully developed mental capacities, one can argue that the findings are not reflective of people above the age of 18 who have developed mental faculties.

In my fieldwork, I interviewed an older age group above the age of 18 to find out why people test or have not tested for HIV. In this vein, I sought to find out the role that individual autonomy plays in such decisions.

Unlike the above mentioned studies which were concerned with the implementation of PITC, and, in general, the impact of family members on adolescents' decisions to test to HIV, this study is concerned with investigating the place of autonomy in HIV testing decisions and how participants in Lusaka and Chongwe above the age of 18 view autonomy.

## **Conclusion**

This discussion has revealed that Zambian socio-cultural traditional theory is communal in nature. It has also been argued that the HIV epidemic in Zambia does not only affect PLWHA, but also one's immediate family and the society at large. Hence, it has been advanced that the doctrine of individual self-determination's application in the Zambian context is problematic, because Western liberal autonomy protagonists and followers erroneously assume that individuals are sovereigns, when the reality is that individuals are social creatures, who are interconnected and interdependent.

Thus, I have suggested that individual human rights imperatives should be counterbalanced with corresponding individual obligations and duties to society due to human interdependence. That is, common good rights also ought to be recognized and respected in the Zambian context where the people of that country's outlook is still communitarian. Indeed, studies done in Zambia, among adolescents, indicate that the peoples of Zambia are still attached to that country's indigenous socio-cultural traditions.

# 6

## **Informed consent: participants share their experiences**

The data show that HIV testing medical practices in Chongwe and Lusaka undermine universal informed consent standards. A majority of pregnant women who go for antenatal services and people who are taken ill at public health facilities are routinely tested for HIV without their informed consent. It will also be shown that the majority of nurses and HIV counsellors have difficulties understanding the practical requirements of informed consent. For example, when asked about what information they provided to service-users prior to an HIV test, they said that they tell them about the “benefits of HIV testing”. This clearly ignores the requirement of disclosure of both benefits and risks of an HIV test. Nonetheless, medical doctors and policy makers’ knowledge of informed consent requirements reflected a good understanding of the doctrine, and its correct application in HIV testing.

This chapter reports what research participants shared during fieldwork regarding their experiences of informed consent in HIV testing. Before presenting these experiences, I will begin by sharing the current legal and policy framework of informed consent requirements in Zambia. This will inform our understanding of how Zambian legal and policy requirements of the doctrine compares with actual practice and implementation. Having provided this background, I will then provide a general overview of my findings before analysing participants’ understandings, experiences, and views on the requirements and practice of informed consent in HIV testing.

### **6. 1 Informed consent: law and policy**

Eba (2015) states that the concept of informed consent has been adopted in HIV testing policies in sub-Saharan African countries. As mentioned in chapter 3, the doctrine has two elements, access to information and knowledge, and full consent (Eba, 2015).

Zambian law holds that testing an individual for HIV without informed consent is an infringement of that individual's rights under Articles 15 and 17 of the Zambian constitution. The rights protected under Article 15 and 17 of the constitution are protection against inhuman and degrading treatment, and right to privacy:

**Article 15. [Protection from inhuman treatment]...** No person shall be subjected to torture, or to inhuman or degrading punishment or other like treatment. ... **Article 17. [Protection for privacy of home and other property]** ... (1) Except with his own consent, no person shall be subjected to the search of his person or his property or the entry by others on his premises. ... (GRZ, 1991).

In the Zambian landmark High Court judgment (*Kingaipe and Chookole v Attorney-General, 2010*), Muyovwe J. ruled that testing individuals for HIV without their informed consent is unlawful.<sup>59</sup> Following this case, it can now be said for certain that testing a person in Zambia without informed consent is unlawful (Alikipo, 2013). This case has established a critical legal precedence in Zambia because the Court for the first time added "its voice to the chorus of recent *obiter dicta* from several jurisdictions in the African region which have declared that HIV testing without consent is a violation of human rights as set out in international human rights treaties and other normative instruments" (Malila, 2012). The *Kingaipe* case is especially notable because the Zambian Court considered an individual's right to privacy in the context of HIV testing (Malila, 2012).

Besides the application of Article 15 and 17 of the constitution, the Court also recognised and applied international human rights conventions and standards to the case. In passing its judgment, the Court referenced (besides the Zambian legislation, domestic case law and policy statements) foreign legal precedents and international instruments and standards. The judge in passing her judgment, among other sources, cited Lord Mustill in the *Airedale NHS Trust vs. Bland [1993]* where the law Lord said this regarding "paramountcy" of a patient's choice:

If the patient is capable of making a decision on whether to permit treatment and decides not to permit it his choice must be obeyed, even if on any objective view it is

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<sup>59</sup> In this case two petitioners had been tested for HIV and put on treatment without their knowledge and consent. The Judge ruled that the claimants have personal rights to make a decision whether to test for HIV or not. She ruled that testing and treatment of an individual without one's knowledge and consent is unlawful.

contrary to his best interests. A doctor has no right to proceed in the face of objection, even if it is plain to all, including the patient, that adverse consequences and death will or may ensue (*Airedale NHS Trust vs. Bland (Acting by His Guardian ad litem)*, 1993).

Also cited was the case of *Diau vs. Botswana Building Society (BBS) 2003 (2) BLR 409 (BwIC)*, where the Court held that “the person to be tested, must not just consent, but must give informed consent”, and concluded:

Informed consent is premised on the view that the person to be tested is the master of his own life and body... The purpose of informed consent is to honour a person’s right to self-determination and freedom of choice (*Diau v Botswana Building Society (BBS), 2003*).

The Zambian High Court Judge concluded that individual privacy and dignity belong to every human being, and that every person who has a legally recognised mental capacity has a right to make one’s own choice when it comes to deciding whether to test for HIV or not.

Correspondingly, the Ministry of Health in its official policy requires that no individual human being should be tested without her informed consent. Re-emphasising the unlawfulness of disregarding informed consent requirements in HIV testing, the Ministry of Health guidelines provide:

Individuals must give informed consent for HTC and should be told their right to decline testing. Mandatory or coerced testing is never appropriate, whether that coercion comes from a health care worker, partner, or family member (Ministry of Health, Zambia, 2013, p. 9).

So, the question that follows from this is how far this law and policy on HIV testing is followed in practice. In the remainder of this chapter I will seek to share my findings on research participants’ experiences.

## 6.2 A quick snapshot

The majority of participants interviewed told me they had tested for HIV. For female participants, the common reason was pregnancy.<sup>60</sup> In Zambia, the government adopted the PMTCT initiative which has proven very successful in testing pregnant women for HIV. A 2010 report by UNICEF reveals that virtually all pregnant women who present themselves for antenatal services are tested for HIV. In 2009 it was reported that 95% of pregnant women were tested, an 83% increase from 2004 when only 12% of pregnant women were tested (UNICEF, 2010). In Zambia, this scale-up of testing of pregnant mothers is reported to have led to the halving of mother-to-child transmission of HIV from 24% in 2009 to 12% in 2012 (AVERT, 2016).

This shows that increased uptake of HIV testing amongst pregnant women can result in prevention of HIV from pregnant women to their fetuses. In other words, it shows that HIV testing is a critical tool in response to the epidemic.

However, during fieldwork I came to learn that HIV testing in Lusaka and Chongwe's health facilities was not really voluntary. The data gathered suggest that informed consent requirements are hardly respected (especially in regards to pregnant women) in clinical practice. These findings find support in Zambian media reports which have indicated that HIV testing amongst pregnant women and people who present as ill at public health facilities is increasingly becoming compulsory (Phiri, 2014; Southern African News, 2014; Lusaka Times, 2015; Phiri, 2015; Mwanza, 2015; Lusaka Times, 2017).

For example, it was reported that the University Teaching Hospital (UTH) in Lusaka has been carrying out mandatory HIV testing on all its in-patients. Citing doctors from the institution who chose to remain anonymous, doctors at the facility reportedly test patients for HIV without knowledge and/or consent. One of the doctors interviewed is reported to have said:

Yes, we do test all the patients who are admitted but we do not tell them, we do it just to know as doctors but we do ask the patient if we can test for HIV but if the

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<sup>60</sup> Participants also shared that they tested for HIV when they were planning to get married, when they had an illness which persisted for a long time without relief, when they had accidental exposure to HIV through a needle prick, when they sought male circumcision, when they applied for travel visas to certain countries, when they worked as HIV counsellors, when influenced by other people who tested, or/ and when they wanted to lead by example as a way of encouraging other people to test.

patient refuses, we do the test and just not tell them it was done or the results. It is confidential information for the doctor..." (Phiri, 2015).

Also, the Southern African News reports that nurses have increasingly been forcing pregnant women to undergo HIV testing. Lydia Nachila, one of the cited participants, narrated that during her first antenatal visit, she was told that before she could be given an antenatal card she had to test for HIV. A participant, Nachila, who has five children, shared that "she, like other pregnant women, has always been told to test before she could be attended to, and that it is only the women who agree to test who are allowed to attend antenatal sessions" (Southern African News, 2014).

### **6.3 Knowledge and attitudes: health workers and policymakers share how they respect consent requirements**

Doctors and policymakers I interviewed had good knowledge of the doctrine of informed consent. For example, a senior medical doctor/policymaker provided:

Well, I mean informed consent really means that the person understands what you are talking about. They understand what you are talking about and then you should have given them an opportunity to ask questions. So that they are clear, and there shouldn't be coercion. They should be left to decide after you talked to them the pre-counselling bit, and say that this is what it entails and you know you carry the discussion. And when they are comfortable and they say "OK, I am willing to test", so really an informed consent is that an individual should understand what it is all about, and they should also be given an opportunity to ask questions (II/MD/LSK/65).

Another participant, a policymaker,<sup>61</sup> shared that the informed consent requirement entails that service-users are given information about the benefits and harms of a medical procedure prior to carrying out an intervention. He added that HIV testing in Zambia requires consent as per WHO and UNAIDS guidelines. Qualifying the provision of

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<sup>61</sup> II/PM/LSK/80 at the time of interview worked at a USAID funded organisation, as the Development and Policy Manager. The organization at the time of the interview was involved in HIV policy initiation in Zambia.



information to clients as one aspect of informed consent, he observed that making information available to a service-user is also important for behavioural change.

Another participant, a senior doctor/policymaker,<sup>62</sup> explained:

...when we talk about informed consent we might start with parties to that consent. So, there is the person, or the institution requesting for that consent. It could be a doctor, a health practitioner or anybody else. Then there is the potential beneficiary, who I am going to call the client. Then the common denominator is the condition that is calling for the informed consent. So my understanding of informed consent is that; 1) the condition that is calling for that consent first must be understood clearly by both parties. The person calling for the consent must explain very clearly what that condition is. And the person being explained to, the client, must also understand that condition. 2) The procedure that is about to be conducted must be understood by the person who will be carrying out that procedure but the beneficiary must also understand what sort of procedure is going to be done on them. Secondly, the potential complications of that procedure must be explained, and, to the client. Any fears which the client has, the client must be allowed to bring out any fears they might have from their new understanding of the condition and those fears must be allayed. And so that the person who is about to undergo a procedure is comfortable with the procedure (II/D-PM/LSK/81).

He continued:

In fact they must get to a point where they even look forward to going through the procedure because it's for their own good. Not because the person performing says it's good, but because they have understood it's good for them and they need it. That's what I understand by informed by informed consent. If they say yes, let us go ahead, from this perspective, then they have been informed about the condition, they know about the condition, and they have agreed to the condition. Including the consequences that might come from there, be it positive or negative (II/D-PM/LSK/81).

Another participant, for example, in the doctors/ policymakers category, who shared her understanding of informed consent was a senior medical consultant.<sup>63</sup> When I asked her if

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<sup>62</sup> II/D-PM/LSK/81 was at the time of this interview a deputy presiding officer of a USAID funded organisation. (Note: I have used the verb 'was' in my referencing of participant demographics in the result sections to refer to the demographic statuses of participants at the time of interview.)

she would disclose information to a client, information that could jeopardise her client's chances of consenting to a medical procedure or treatment, she responded that she would actually disclose any information that is necessary for consent purposes. She argued that as a doctor she is required to disclose all the information which should not only include the benefits of a proposed intervention, but also the risks. She noted that consent prior to carrying out an HIV test is very important in her line of duty. And when I asked her the question about how she can determine whether her clients understand enough to make a meaningful informed consent, she responded:

...sometimes because of the certain terms that we are explaining, we may want to know the level of education for this client, so that we are able to explain the terms appropriately for their level. So from there we are able to know whether they actually understand or not... Then as part of the counselling you are normally also expected to offer the client an opportunity to ask questions. So from there, even judging from the kind of questions and the kind of responses of the engagement, I think you are able to know that the client actually understands. And when you look at the issue of HIV, I think in our country, especially this day and era, ah, most of our patients have had experiences with family members, friends who have had the symptoms or may have died. So most of them would fairly understand during the session (II/D/LSK/70).

Amongst the medical doctors interviewed only one participant,<sup>64</sup> and three trainee doctors, confused DCT with mandatory HIV testing. They held DCT to be synonymous with compulsory testing.<sup>65</sup> Compounding this, I also found that the majority of nurses and HIV counsellors did not fully grasp the *modus operandi* of the informed consent doctrine.

It was also apparent that the majority of nurses and HIV counsellors had difficulties appreciating the practical application of the doctrine. I found this troubling. Firstly, a large majority of nurses and HIV counsellors told me that when 'inviting' service-users to test for

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<sup>63</sup> II/D/LSK/70 was a senior medical doctor.

<sup>64</sup> II/M/LSK/69 was a medical doctor at a hospital in Lusaka.

<sup>65</sup> Unfortunately, this error was not only limited to this junior doctor, and the three trainee doctors. A number of other health workers interviewed also thought that DCT legitimises compulsory HIV testing. As an example, an ART Adherence Officer (II/CW/LSK/51) told me that the health institution where she works at has DCT, and because of this an individual has to test for HIV with or without consent.

HIV they only disclosed to clients the benefits of HIV testing. The problem with this practice was that service-users were tested for HIV without equally informing them about the risks of HIV testing. It was done as though disclosure of the “benefits of an HIV test” is the only requirement to be satisfied in order to fulfil informed consent requirements. The implication of such practices is that service-users’ did not enjoy their right to be informed about material facts concerning an HIV test. Thus, they were denied an opportunity to make an informed decision.

The second concern which came up during interviews was that when nurses and HIV counsellors spoke about pregnant women, most of them shared that if a pregnant woman went for antenatal services but refused to test for HIV, they (as nurses or HIV counsellors at an antenatal centre) would continue counselling her until she agrees to test. This, to my understanding, suggested that the majority of interviewed nurses and HIV counsellors were not prepared to accept a pregnant woman’s refusal to test for HIV. This raises the question whether the ethos of counselling pregnant women who already said “no” to HIV testing could amount to coercion (Groves, Maman, Msomi, Makhanya, & Moodley, 2010), besides exemplifying a contemptuous disregard for personal choice.

To illustrate this, during the nurses’ FG<sup>66</sup> discussion I asked participants to share about what information they disclose to service-users for informed consent purposes. Addressing this question, one participant, for instance, responded:

...sometimes what we usually do, we don’t talk much about the negatives [risks]... We are going to concentrate much on the positives [benefits]. Let’s say someone wants to go for theatre and we know that some anaesthesia can cause someone to sleep for good [can make a person die], we are not going to talk about effects of anaesthesia, we are going to talk about the advantages of going for that operation so that we save that client. Yes. We don’t highlight much on the negatives. So that in some way we pursue that client to accept the procedure, so that we can save that client (FG/LSK/Nurses).

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<sup>66</sup> FG/LSK/Nurses was the nurses’ focus discussion group. There were 6 participants in this FG. All the nurses interviewed in this particular intercourse were senior midwives, who had many years of experience in nursing and midwifery.

Rephrasing the question, I asked the FG members to talk about “whether they would or would not disclose certain information to a client, if they knew that disclosure of such information has a likelihood of making a client refuse life-saving treatment”. Discussing this issue, a participant said:

That is why I was saying in short we don't disclose, that's why we are not going to talk about the negatives. We are only going to highlight the benefits so that that client is influenced to accept that treatment. Yes. We are not going to disclose... (FG/LSK/Nurses).

I pressed the participants to elaborate why they would not disclose such information to a service-user. The discussants responded, as noted by one participant:

We want to save that client because once we disclose to them; “if you go in theatre we are going to give you medicine that will make you sleep, then with that medicine sometimes you might not wake up”, that client will think twice. If “I go and then I sleep for good [die] what will happen?” Yes, so we are not going to disclose so that we help that client to choose that type of treatment that will save her life (FG/LSK/Nurses).

Since I was dealing with midwives during this particular FG interview, I particularly became interested to learn from them about how they would respond to a situation where a pregnant woman who has come to their department for antenatal services refuses to test for HIV, and what information they normally relay to pregnant women during counselling sessions. Participants stated:

Participant 1:<sup>67</sup> In such situations, *ayi* [translated “yes”], what is needed is counselling. Proper counselling, *ayi*. A proper mother cannot accept or cannot allow the child, innocent, get the virus from the mother. If you give proper counselling

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<sup>67</sup> I have in some FG quotations in the result sections included more than a single response from participants to illustrate the result of a given discussion. Where I have quoted several responses from different participants in a given FG quotation, I have numbered the various participants (e.g., participant 1 or 2 or 3, etc.) to indicate the various participants' responses. This FG responses numbering does not entail that a participant who is assigned a given number (e.g., participant 1) is the same participant in another given quotation; the numbering simply identify how many FG participants have been quoted in a given single quotation.

usually the mother they accept... so that she saves the unborn child. What is important is proper counselling... The other things we are going to tell this pregnant woman is how HIV is transmitted. Second we are going to tell them the importance of knowing their status. Then thirdly we are going to tell them in case they are found positive what measures are we going to take so that the unborn child doesn't get the infection from the mother. That is the information we are going to give. And usually mothers they would not want their babies to be born with HIV, so they usually agree...

Participant 2: And also tell them [pregnant women] that it is for their own benefit. If they are diagnosed early with HIV, then we will serve ART (FG/LSK/Nurses).

A participant also explained:

There are some people [service-users] who can tell you "we have refused this", so there is nothing you can do. Then we discharge them. So when you [they] hear that they say "where else can we go since you say that I have been discharged?" [Medical staff would then respond] "Because this is your only treatment we can offer, so we are discharging you" (FG/LSK/Nurses).

From the above conversation, it can be seen that the nurses interviewed do not regard the sharing of risks of HIV testing or any medical procedure as critical, would not take a "no" to test for HIV for an answer, and would even threaten service-users with discharge from health facilities when they refuse to oblige to an HIV test or treatment. These views were shared among nurses and HIV counsellors in both in-depth and FG interviews. Indeed, when it comes to the issues of continuing to ask pregnant women to test for HIV (even when they have already said "no" to a test) even some views shared by some doctors indicate that health workers find it hard to accept a pregnant woman's refusal to test:

When a pregnant woman comes in and we say to them what we are offering and everything, some of them don't agree the very first time. They will say "let me go and think about it. No, let me go and consult my mother or my husband." So when they come for the second visit you still bring out the promise in the notes. "So since last time you have had chance to talk to anyone?" So sometimes some people get tested; a lot of them get tested on the second time. Some of them even on the third time; so you shouldn't give up if they had said "no" one time. So when these people come we test them (II/MD/LSK/65).

Another senior medical doctor reported:

...we offer HIV counselling and testing to all women and we try to offer it in an environment which is suitable. And because of that the turnout has been 100%. That one we can even refer from our records. So it's [HIV testing is] not compulsory, but we just offer HIV counselling and testing appropriately and we offer. If a mother, for instance, the first time refuse and they are not keen [to test for HIV], we make a record. They are going to come through again for the antenatal, and we will find an appropriate way of introducing the topic again, so that we do the counselling again. And you find that by the end of the entire antenatal period, all the mothers actually accept to test because they can understand the benefits, they can understand the benefits for themselves and for their unborn baby (II/MD/LSK/70).

A participant, a midwife<sup>68</sup>, when asked to share with me what she would do if a pregnant woman who comes for antenatal services refuses to test for HIV, responded that a client has got a right to refuse to test. She said that as a medical professional if she found herself in such a situation she will tell the pregnant women about the benefits of PMTCT and the benefits of ART. She explained that she will tell the pregnant woman who has refused to test for HIV that she will have a prolonged life if tested for HIV and tested positive, because she would be put on ART. She argued that once she has given the pregnant woman such information, she would then leave it up to her to choose between testing and not testing. If the pregnant woman continues to refuse to test even after she has been counselled, the midwife told me that staff at the hospital will continue counselling her until she accepts to test.

Another midwife<sup>69</sup> said that when it comes to those pregnant women who decline to test for HIV (she said very few pregnant women refuse), midwives and HIV counsellors schedule extra appointments in order to "*convince*"<sup>70</sup> them to test. If a pregnant woman continues to refuse testing, the nurses will not give up asking her to test, even beyond post-natal, the participant told me.

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<sup>68</sup> II/MW-C/LSK/38 was also an HIV counsellor. She was in her 60s (age). I conducted this interview with the informant at her office after she finished attending to women attending antenatal.

<sup>69</sup> II/MW/LSK/36 was in her 40s.

<sup>70</sup> The word "*convince*" was used by the midwife. Emphasis mine.

When I asked the same participant to inform me about whether she would withhold information necessary for informed consent purposes (if she is aware that disclosing such information may lead a service-user to refuse to test for HIV), she responded that it is not permitted to withhold information from a client. She stated that when one is involved in counselling one should not withhold information. HIV testing in Zambia requires consent from the person to be tested, she declared. She argued that human beings need to be treated with respect. What a health professional needs to do is to provide service-users with information on the importance of testing, and once counselled people can test, she retorted.

On disclosure of information, a midwife<sup>71</sup> from the same hospital held similar views. She told me that if she suspects that a pregnant woman who visits the health centre could be living with HIV, she would provide information to the pregnant woman. She said that she would not withhold information regarding HIV testing, arguing that she has to respect the service-user as a person and give her the quality service she deserves. Clients have a right to information, a right to choice and a right to privacy, she asserted.

However, like several other nurses and HIV counsellors who suggested that disclosure of information for informed consent is synonymous with sharing “benefits of HIV testing”, this participant, who earlier correctly explained the importance of informed consent requirements, never mentioned during the interview that besides disclosure of benefits of an HIV test the concept of informed consent also requires health workers to share with service-users the risks of testing. Moreover, she also added that if a pregnant woman refused to test for HIV, she will keep on counselling her until when she agrees to test.

#### **6.4 Informed consent in practice: service-users**

When participants were asked about their experiences during the times when they visited health facilities (when pregnant or ill), I came to learn that service-users, especially pregnant women, were in most cases not given an opportunity to give or withhold consent to an HIV

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<sup>71</sup> II/MW/LSK/37 was in her 30s

test. HIV testing was presented to service-users as though it was compulsory. The majority of men and women interviewed believed that antenatal HIV testing is compulsory. Those women who correctly pointed out that HIV testing in Zambia requires consent, however, confessed that refusing to test for HIV in medical facilities when pregnant is not easy for women; some even mentioned that medical staff told them HIV testing during pregnancy is compulsory.

Men and women shared personal stories of how medical staff attended to them when they presented at hospitals or clinics when pregnant, or were taken sick, or took a relative to a clinic or hospital, or when they sought male circumcision. Some service-users who were tested for HIV when they presented at the hospital with an illness were even never told that they were tested. In other words, the experiences shared by service-users show that HIV testing for pregnant women and people who are taken sick at public health facilities undermines informed consent requirements.

Generally speaking, the informed consent requirements which the *Kingaibe* Court established are hardly followed in practice, more so when it comes to antenatal testing. The various experiences shared by participants in this study suggest that official informed consent requirements in Lusaka and Chongwe resemble a “paper tiger”.

One participant<sup>72</sup> told me that HIV testing policy in Zambia has changed. She stated that years back HIV testing used to be voluntary, but it has now become mandatory. She shared that when she was pregnant and went for antenatal services all pregnant women were required to test. She recounted that pregnant women, including herself, were never given an opportunity to give or withhold consent. Every pregnant mother was screened for STIs, HIV and TB, she reported. She added that when one is sick and goes to the hospital or clinic, one is told to test for HIV whether one likes it or not.

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<sup>72</sup> II/M/LSK-LA/01 was a middle-aged woman. She works for a government department in Lusaka. She told me, with pride, that she has served the government for many years. She is a mother, married, and a devout Christian.



Recounting her own experience of being tested for HIV when taken sick at the hospital, she related a story about her husband who was tested for HIV without his knowledge and consent. She explained that prior to her marriage she was in courtship with a pastor of a church. In the two years of courtship with this pastor she never had any sexual contact with him or any other man. But then came a time when her fiancé became ill with what both of them suspected to be malaria. Owing to their fear that he had malaria, she went with him to a hospital. At the hospital the participant informed the doctor that she is widowed and the man whom she went to the hospital with is her fiancé whom she wanted to marry. They had their blood taken for malaria testing (at least, that is what the service-users thought). However, after tests were done, the doctor secretly called the participant and told her that he (the doctor) had also tested them for HIV when conducting other tests. The doctor then revealed to the participant that she needed to know that the HIV test result for her fiancé came out reactive. This participant told me that since her fiancé did not know that he was also tested for HIV by the doctor, she kept this revelation a secret from her fiancé. After revealing the results the doctor had cautioned the participant that the disclosure of the HIV results of her fiancé was in confidence.

Another participant<sup>73</sup> told a similar story. The participant recalled an event when her baby was tested for HIV without her consent. This happened when her baby was admitted at the University Teaching Hospital in Lusaka (UTH). She told me that she was alarmed when she later read through hospital paperwork belonging to her child only to discover that her child was tested for HIV without her as the parent's knowledge. She told me that she was not consulted or asked for consent prior to testing her child even when she was at the bedside most of the time.

She also recounted that she tested for HIV several times during her previous pregnancies. She said that when she went for antenatal services she was told that all pregnant mothers have to test for HIV for PMTCT purposes. She said that HIV testing requires individual consent, apart from pregnant women and sick people (in hospitals) who are mandatorily tested. She told me that when doctors and other health personnel test in and out-patients

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<sup>73</sup> II/M/LSK-RGW/11 was a 28 year-old housewife. Her husband at the time of the interview was a nurse. She had two young children.

at the hospital, they normally don't disclose to them that they have been tested. *"They do it secretly; they don't indicate to the patient that she is being tested or has been tested for HIV"*, the participant stated.

Another participant, a senior lawyer at one of Lusaka's reputable law firms, also shared that on two occasions he found himself tested for HIV without his knowledge and consent:

...it is where I have actually gone to a clinic and then I have just been asked "would you mind if we did an HIV test"? That is all... But other is where I have encountered a situation where I have not even been told that I am being tested for HIV. But my blood is just collected. But when the tests are being done the HIV test is also done. And this was the situation where our son [his son] was not particularly well, and he had a recurring condition. And I think in the doctor's mind the immunity of the child was being compromised by the fact that [the doctor wrongly assumed] we had transmitted HIV virus to our child. And when I found out later I felt cheated actually... And, we encounter that a lot in clinics and hospitals, when the doctor feels that all the treatment are being given, but it looks like the patient is not improving... (II/B/LSK/75).

Another participant, a University of Zambia lecturer and researcher, reported:

... What I have heard is that for every pregnant woman when they go to health facilities it has become almost mandatory that they get tested for HIV. So, I guess they don't even need to consent. The health personnel just go ahead and do that. Whether with or without their [service-users'] knowledge. Except in cases where maybe the respective individual insists not to be tested. But in any case it's possible that if blood sample is taken from that individual, from other tests, it's possible the health facility could do without their knowledge. Also go ahead establish whether they are HIV positive or not for their records. Since health facilities hold documents with the highest confidentiality possible (II/T/LSK/77).

During the teachers FG<sup>74</sup> interview, I asked participants to share with me their knowledge on HIV testing policies in Zambia. The teachers unanimously agreed that HIV testing in Zambia in theory requires consent. However, they also said that HIV testing is compulsory:

But there are some cases you go to the hospital but they will not force you... There are some instances whereby they want to test maybe for statistics. They would come... They will test you without your consent. Then they will not say this one is

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<sup>74</sup> FG/MT/LSK/Teachers. The teachers group had six participants. The ages of the participants ranged between 35 and 50 years.

positive or not... It is done unknowingly to say they want the statistics. You can go for malaria but they are doing both [test for malaria and HIV]. But they will even treat you for malaria... There is a situation where you are very sick in the hospital. Admitted. They try this and that, nothing. They will come to you. The doctors will even maybe do it [test for HIV] without you knowing. Then they will discuss there that he is positive or she is positive. Now they cannot just come to tell you that you are positive... Then someone will come to counsel you. ... (FG/MT/LSK/Teachers).

Similarly, another participant added:

Let me come in *boi* [translated: my friend]. I went to my brother's... he has a medical scheme for some hospital which I am not going to mention. Now at that *ka* [translated; "the"] hospital what happens is when you go there they do all the necessary check-ups before they put you on medication. They could be giving you Panadol while the problem is different. So now in that case what is important there is are you ready to refuse, that is why the voluntary is on the part of accepting to be told if you are positive or negative or not. That's the issue. You could be tested but as long as you are not told ... that's the thing. But they will make sure that they make all the necessary tests before they start wasting *munkwala* [translated: "medication"]... (FG/MT/LSK/Teachers).

In relation to compulsory HIV testing for pregnant women, a participant said:

Me I have worked in rural areas. There was like people are told to say when you are coming for antenatal clinic you should come with your husbands... So now people started shunning to go for antenatal, to say [people would say] when we go for antenatal they will force us to go for HIV testing, which they [service-users] were afraid of. So it brought issues. Until [the] government came in, it [the government] has tried to educate people, but even ladies, our women in some parts of the country they demonstrated [protested] to say that why are we being forced? So then it [officials from the government] came to say "no, the governments wants to protect the unborn child". And they thought the unborn child is more important than the already existing, even the pregnant mother herself... They are still doing it [compulsory HIV testing of pregnant women] ... (FG/MT/LSK/Teachers).

Another participant, a school teacher,<sup>75</sup> during a one-to one interview expressed doubt regarding how informed consent requirements are implemented in Zambian medical facilities. She was not the only woman who expressed such doubt. Another participant, a

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<sup>75</sup> II/T/LSK/82 was a primary school teacher, an HIV counsellor, married, and had a child. She was in her late 20s.

single female,<sup>76</sup> talking about PMTCT, said she was not sure whether pregnant mothers who go for antenatal services can be in a position to give genuine consent. Pregnant mothers, she said, are afraid to refuse testing for HIV at antenatal clinics because they feel they will be denied antenatal services if they refuse to test. Pregnant mothers have no option but to test for HIV at antenatal clinics when HIV testing is offered to them; “this cannot be consent”, she argued.<sup>77</sup>

On the whole, the majority of men and women interviewed told me that HIV testing of pregnant women and in-patients does not require informed consent. In fact, in the churchgoers FG<sup>78</sup> discussion, all the participants seconded when a participant told me that HIV testing at antenatal centres around the country is mandatory. She explained that when a woman gets pregnant, she is required the first day she attends antenatal services to test for HIV. I asked the participants to substantiate their claim of compulsory HIV testing in Zambian antenatal settings. I was interested to know what made them conclude that HIV testing for expecting mothers is compulsory. Then, they explained that their daughters who have attended antenatal services have told them this to be the reality:

[W]e have friends who are nurses, some who are doctors and when we have workshops<sup>79</sup> these are the things they tell us. Even if you go out there you meet women who are pregnant and they are scared to go to the hospital. They are just wasting their time because any day they will go there they will be tested whether they like it or not because they want to protect [the foetus]. They even encourage to go early so that they can protect the child... [And later talking about HIV testing of patients she said] ... when you are sick you go to the hospital; whether you like it or not the first test they [people who are taken ill] get is HIV (FG/LSK/Churchgoers).

Similarly, another participant said:

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<sup>76</sup> II/SF/ LSK-LND/22, a young female, was at the time of interview aged 26 years old. She was working as a pharmacy technologist. She was single with no children.

<sup>77</sup> II/SF/ LSK-LND/22

<sup>78</sup> FG/LSK/Churchgoers was the churchgoers FG. Six participants made up this group. It comprised of different professionals, some of whom were already retirees. The youngest participant in this group was 55, and the oldest was 73 years old.

<sup>79</sup> The churchgoers FG exclusively comprised of members involved in outreach to PLWHA. These members now and then, they told me, they hold workshops with doctors and other medical staff on how to care for PLWHA.

There is also [when one goes] to the clinic when you are sick, whether you like it or not the first thing you are tested for [is] HIV. So that the doctors will know if you are positive or negative (FG/LSK/Churchgoers).

And a participant explained (it is apparent, in an effort to justify compulsory HIV testing):

You know people have come to learn [that] knowing [one's HIV] status is something that is very important. Because that ignorance which was there that "I cannot be tested" a lot of people risk their lives. Now with this generation where there is now medication which people can take, they want to be tested so that they know their status. If they are positive they start medicine and their life is prolonged. So, they want to live, also they don't want to die. Because when they take the medication your life is [their lives are] prolonged. You live ten fifteen years more. People want to be alive, no one wants to die. Even us we are also saying if this medication was there in the past, some of our relatives would not have died... So it is important to be tested because if you know the status and you will know how to live (FG/LSK/Churchgoers).

The experiences which the members of the Chongwe rural FG group<sup>80</sup> shared also brought the implementation of informed consent requirements in public health facilities into disrepute:

Participant 1: If you go to the clinic and with a malaria complaint, the doctors get angry if you say you have malaria. The doctor will say "we need to test the blood to see what is causing the ailment..." The doctors will test your blood to see if you have malaria. But if no malaria is found then they will test you for HIV... The doctors will tell you that you are not supposed to refuse testing because "we need to find the problem in your body".

Participant 2: As for us women, us the women whether we like it or not we are supposed to be tested. As a person who is pregnant, whether you like it or not you will be tested... First they test you for other STDs, next HIV... whether you like it or not... They want to protect the child in the womb (FG/CN/Chongwe Rural).

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<sup>80</sup> FG/CN/Chongwe Rural Group was the Chongwe rural area FG. This group comprised of 6 participants. All the members in this group came from a very remote village in Chongwe. Also in attendance as a participant was their Village Headman. The FG comprised of 3 men and 3 women. The age of the participants ranged from mid 20s to late 60s. This village and the surrounding villages do not have amenities such as running water and electricity.

I also had the privilege to interview a rich group of women, who comprised the women FG.<sup>81</sup>

The accounts of the women confirmed the accounts shared above:

Even at Chainama<sup>82</sup> where I delivered [gave birth to] my son; the time I was pregnant for my first born daughter, they had not yet introduced the same system. But the time I had the pregnancy for my second born son I found that they have already introduced compulsory testing... It is mandatory. Whether you like it not they were testing, as what all the speakers have unanimously said here. We were counselled first then they tested us. Then they indicated one's HIV status on the antenatal card. Yes... They tell us that "testing for HIV is important because you will then know your HIV status and you will know how to live. And it helps to protect the child from getting HIV. Because the HIV epidemic is too high. So we want to protect the unborn child, and also to tell you how to look after yourself whether found positive or not." These are the things they tell us. After the lessons we are then called into the room one by one for testing. They draw our blood... When I was being tested, I was not told anything. They don't tell you just then... If they find you positive that is when they will tell now and then. For me because I was found negative they did not tell me anything. They just indicated on the antenatal card, though I did not know... (FG/LSK/Women).

Another participant explained:

They just indicate if you are reactive they put "R", if non-reactive they write "NR"... "Why is it mandatory for pregnant?" I think because some of the women refuse to be tested. So it is better when they go there whether they like it or not they test them. In order to protect the child... (FG/LSK/Women).

I asked interviewees if they knew what the HIV testing policies are, and a participant stated:

It is voluntary, it's confidential... [But] At clinics and hospitals they don't follow the official HIV testing policy. It is because they want to reduce HIV... (FG/LSK/Women).

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<sup>81</sup> FG/LSK/Women group is the women FG. This group comprised of 5 participants. Among the participants were two pregnant women, three mothers, and two single women. Also present among the 5 participants was a nurse, and one HIV counsellor. The age for the participants ranged from early 20s to early 30s.

<sup>82</sup> Chainama is a public hospital in Lusaka.

Over and over, participants' accounts regarding clinical experiences were consistent.

Recounting her pregnancy experience, a participant<sup>83</sup> said:

It is whether you want or you don't want, you have to [test for HIV]. When one is pregnant, when you are pregnant they would test you. Whether you want or you don't want but, it is a must you will be tested. They are supposed to check everything... So that you know your status... So that if you know that you are sick, you can start taking medication (II/PM/LSK/63).

Some participants told me that they did not even know that the HIV testing policies in Zambia requires consent. Some of these women who expressed ignorance have gone through HIV testing at antenatal clinics before. It is apparent that even though they had counselling at antenatal clinics, they still tested believing that HIV testing was compulsory. This suggests that medical staff never informed these service-users of their right to informed consent.

One participant<sup>84</sup> argued that all pregnant women are supposed to be tested for HIV. She informed me that when she was pregnant, all pregnant women were tested for HIV "whether one [a pregnant woman] likes it or not". They were told that they were being tested in order to protect the unborn child. This participant also believed that HIV testing of pregnant women in Zambia is officially compulsory.<sup>85</sup> She argued that compulsory HIV testing is the law. The law is that all pregnant women should be tested for HIV, she declared. All pregnant women are required to test for HIV so that pregnant women are told about how to maintain the well-being of the unborn child during pregnancy, the participant

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<sup>83</sup> II/PM/LSK/63 was 19 years old, was pregnant at the time of the interview, and a housewife.

<sup>84</sup> II/M/CN/55 was a married woman aged 32 years old. She has two children. She was a merchant. She told me that she has attained no further than primary education.

<sup>85</sup> These findings are consistent with findings, for example, in a Kenyan cross-sectional study: "None of the 900 pregnant women included in this study declined HIV testing under the routine 'opt-out' approach. A majority (83%) had not understood that HIV testing was optional... The midwives did provide correct information regarding the importance of HIV testing in the first trimester of pregnancy, but the great majority of women (83%) never understood that it [HIV testing] was optional... Our findings showed that it was difficult for the providers to remain neutral when informing about routine HIV testing... The reason given during the sessions for having the test was the need to protect the child, while nothing was said about HIV testing being optional" (Ujiji, et al., 2011, pp. 4-5).

concluded. Another participant<sup>86</sup> explained that when a pregnant mother goes to a clinic or hospital for antenatal services, she is tested for HIV, syphilis, and malaria. She told me that testing for HIV for pregnant women at clinics or hospitals is mandatory. For as long as one wishes to use antenatal services, one has to be tested for HIV, the participant related.

In fact, it appeared that service-users were afraid to refuse HIV testing when 'requested' by medical staff. Participants from women's group discussions shared about the implication of refusal to oblige to 'requests' to test for HIV in the clinical setting:

Participant 1: They will chase you [a pregnant woman who refuses to test] from the facility. And they will not give you an antenatal card. And the way it is here in Lusaka you cannot go for child delivery if you do not have antenatal card.

Participant 2 added: They would want to see your antenatal card when you go for delivery (FG/LSK/Women).

A mother<sup>87</sup> said that she had tested for HIV multiple times. And when I asked her to share the reason(s) behind her testing for HIV, she told me that she had no choice but to test. She responded that when someone is pregnant it is a must to test for HIV for the welfare of the child. She said that she was not given an opportunity to refuse to test for HIV, as she was told on the two occasions she was pregnant that she was going to be tested because she was pregnant. Nurses informed her and other pregnant women that medical professionals were ready to test those who were ready to be tested on the day of counselling; they were told that those who were not ready to test on the day can be tested on a different day. Those pregnant mothers who were afraid to test on the day received lessons and were tested on a later date, she related. She argued that this sort of HIV testing is not voluntary, but mandatory. This shows that medical staff, indeed, did not give up until service-users agreed to test. A process was followed, as alluded to, to ensure that all service-users were tested.

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<sup>86</sup> II/M/LSK-K/19 was a young woman in her early 30s. She was married with 3 children. Her education was minimal (not more than primary education). At the time of interview she worked as a baby-sitter.

<sup>87</sup> II/M/LSK-KML/07 was a married woman in her 30. She had two children, and was a housewife. Her level of education at the time of interview was college.



Thus, I became interested to learn about the processes these women went through prior to an HIV test. A participant<sup>88</sup> recalled that when she went for antenatal she was not counselled. Medical staff took blood from her finger for HIV testing. After that, they asked her to wait. She waited for about 15 minutes for the test results. She told me that she was informed that since she was pregnant she had to test for HIV in order to protect unborn child, should she test positive. A person cannot refuse to test for HIV when one goes for antenatal services, she declared.

Another participant<sup>89</sup> explained that when she went for antenatal services a nurse drew blood from her. When drawing the blood, the said nurse did not tell her anything. This participant informed me that she had not only experienced this process once, but also on the day this interview took place. Describing the testing process, she related that they had group counselling after which they started calling them (pregnant women) one by one into an office. She said medical staff drew blood from each one of them and were tested for STIs, HIV and HB. This participant, like many others, said that testing of pregnant women for HIV is mandatory. When a woman is pregnant, it is a must that one tests for HIV, she stated. She told me that she has never heard of a case where a pregnant woman refused to test for HIV, adding that it is not possible to refuse to test. I asked the participant to point out for me the authority which informed her that HIV testing for pregnant women is compulsory. She responded that people usually say that, that, even doctors say so, and that even nurses at the clinic from where I interviewed her told her and other pregnant women that all the pregnant women attending antenatal services have to test. They told them that all pregnant women will test; no one is allowed to refuse, she narrated.

Indeed, when I was conducting interviews at one of the health centres I had to stop interviewing one participant<sup>90</sup> mid-way because his wife came to tell him that a midwife had called the number he was assigned to go with into an office. (He had accompanied his wife

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<sup>88</sup> II/PM/LSK –CZN/ 62. The participant was a female in her 20s. She was pregnant and had one child. She was a high school graduate.

<sup>89</sup> II/M/LSK/67 was a female aged 22 years. She was married and had one child. She was also pregnant at the time of interview. She had studied up to grade 9 (year 9).

<sup>90</sup> II/F/LSK/66 was an expecting father. He was 23 years old, and married. His education attainments are up to grade 9. He was self-employed at the time of interview.

for antenatal services). Before the participant left, I asked him if it was possible to continue my interview with him once he has been attended to and finished the business for which the midwife had called him. He agreed. Later on when he came back, I asked him if he went to test for HIV, and he said “yes”. I then asked him to share with me, if possible, about what transpired when he went into the midwife’s office. He accounted that when he went into the office he was told that his wife had asked him to go to the clinic so that he can be tested for HIV. He told me that he was not given an option to refuse the test. They just drew his blood for testing, and later tested it.

To sum up this section, I wish to quote what a participant (a nurse) from the women FG said, who, in my opinion, summarises and confirms what has been shared in this section. It is also interesting to observe her rationale, as a nurse, behind compulsory HIV testing<sup>91</sup>:

On the part of voluntary, I think they [medical staff at public health facilities] have stopped using voluntary testing especially on pregnant women and those that come with opportunistic infections like TB. They are calling it diagnostic counselling and testing. Once they see that you are presenting with such, they just tell you and test. It is for diagnostic purposes. So like in Mumbwa<sup>92</sup> when they [pregnant women] come for antenatal what they [health workers] do is they teach them. They have to first teach them. And then they will call counsellors. That is Mumbwa. They will call counsellors those that have been trained... They will counsel them and then they will test... Somehow it is mandatory. But you see when you are testing that is mandatory, but what they are testing for it is HIV. They will first explain to you [service-users] about HIV, ask you what you know about HIV and then they will start now calling you one by one. Those that have come with partners they ask them to go in with their partners. Those [pregnant women] that came alone again they have to test them. And it has to indicate on the antenatal card that their status... (FG/LSK/Women).

And, she reasoned:

On the voluntary and mandatory if I am not pregnant it is voluntary because they will not come to my home and say “let’s go”. Even when again I am pregnant and I don’t

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<sup>91</sup> This will lead us to the next question; where I have shared what medical staff said in relation to the experiences shared in this section.

<sup>92</sup> Mumbwa is a district in Central province, Zambia. The Central Province is one of the ten provinces in Zambia. Lusaka is also a province; but also the capital city of Zambia.

decide to start antenatal they won't test me for HIV. But if I decide to go to the clinic there now for pregnant women it becomes mandatory. Again not only for pregnant women, I know we are doing it on pregnant women. But on the mandatory part [also compulsory] if you as a man go to the hospital and present with some optimistic infections... So for pregnant women when they go for antenatal yes it is mandatory. But if you are not pregnant as a woman it is not mandatory because no one will pick me out from home. Unless I go. Again, when I go they will look at what I have presented... with Mumbwa when you have patients in the ward counsellors will come and talk to individual patients. They will talk to them. And it is a requirement you need to test... Now if they were not tested it becomes also a danger to the ones that are working, the nurses and everyone or maybe you can just be treating a cough, yet it's not just a cough the immunity of this individual has gone low, he is got TB (FG/LSK/Women).

Indeed, the foregoing discussion indicates that HIV testing in Lusaka and Chongwe undermines informed consent requirements. This shows that individual's autonomies in HIV testing are not respected in these parts of the country. In the following section, I will share what medical professionals from the very locations where I interviewed the above participants said about their own experiences regarding HIV testing. I deliberately separated service-users and medical professionals' experiences into different sections because I felt that each demographic demanded separate sections. This has enabled me to focus (in my reporting) on the different experiences by these two demographics (the people whose individual autonomies ought to be respected, on the one hand, and those who are required to respect and promote such autonomies, on the other hand). This has, indeed, aided me in focussing my mind and separately appreciating what the results from each of these two demographics actually show, and also enables me to separately assess the implication of the un-conflated findings on HIV informed consent requirements.

## **6.5 Informed consent: medical staff**

Besides listening to service-users' experiences regarding HIV testing in public hospitals and clinics, it was imperative to check with medical staff on their own experiences regarding the same. Nearly all, if not all, medical staff – who included doctors, nurses, midwives, and HIV counsellors – told me that HIV testing, especially of pregnant women, is compulsory in practice. Some medical staff (mostly midwives) even thought that HIV testing of pregnant

women was legally compulsory, with some confusing PITC and DCT with mandatory HIV testing.

The experiences shared by the medical staff are consistent with the experiences shared by service-users. That is, they confirmed in their own words that at antenatal clinics pregnant women are compulsorily tested for HIV. They also shared that patients who present with illnesses at health centres are tested without following laid down official HIV testing informed consent procedures. An HIV counsellor in Lusaka, generally explaining about compulsory HIV testing, stated:

... In spite of it [PMTCT] being voluntary they have advanced further where, initially when they introduced it they said it was voluntary, you volunteer. But what they are doing now it is very tricky because every pregnant woman, girls, or whatever they can be, they are now subjected to an HIV test. OK... Of which case every pregnant mother is expected now to go through the test. OK. Not only are they actually encouraging that. They are also encouraging that the first visit that you make to an antenatal, for antenatal visits, you go with whoever, either your husband or your boyfriend. Whoever has impregnated you must go with you. And they have incorporated counselling in that same visit and later on the test itself... Because again in the hospital, just adding to that we say the policy of voluntary, which policy is still standing. But certain times when you go to the hospital sometimes even without your consent or your consent of your family what they do is they will just look at you, even get blood and test you without consent. Later on, all they need now to do is just to tell you to just counsel you. They already know what your situation is. And they have decided whether you like it or not, they will tell you. They just begin to just counsel you. Tell you one two three four five things. Even break news to you. It is no longer voluntary (II/C/LSK/83).<sup>93</sup>

When I asked another HIV counsellor<sup>94</sup> in a separate interview about whether HIV testing consent requirements apply to all populations groups in Zambia (this was after he correctly told me that HIV testing in Zambia requires informed consent), he responded:

I think there is another group. Babies born from mothers living with HIV. Though the consent would come from mothers, but I think it's not voluntary. We just test them to see if they are sick... Babies born from mothers living with HIV... And I think also

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<sup>93</sup> The participant was 39 years old, married, and had children.

<sup>94</sup> II/C/LSK/48 was an HIV (male circumcision) counsellor. He was in his mid-30s.

the issue of abuse. Child abuse. Children who have been abused. I think they would also most times it's not voluntary... Also in men, we have a certain group of men who would be tested involuntarily. Especially when they are, for male circumcision.<sup>95</sup> Now this one is a little bit tricky. Ok. Though it is not voluntary, but at the end of the talk one would volunteer to do an HIV test. Because we will tell them the reasons as to why they are being tested for HIV before they undergo male circumcision. So that's another group that probably they wouldn't have volunteered coming from home say "I am going to do an HIV test". They would come to the clinic wanting to do male circumcision then they find that before you get to do male circumcision you have to do an HIV test... So I think that doesn't qualify to be voluntary. Even if they say "ok I think I will do it", I am sure they would not have volunteered in the first place (II/C/LSK/48).

This participant also informed me that pregnant women are compulsorily tested for HIV at antenatal clinics. This brings me, firstly, to reporting on experiences regarding testing pregnant women. For examples, on testing pregnant women for HIV a participant, a midwife,<sup>96</sup> said:

I don't know if it [the practiced compulsory HIV testing] is a government policy or not. Here at our health institution testing pregnant mothers who are in labour is mandatory. In the labour ward all pregnant women are tested for HIV. This also happens in post-natal. We counsel then test them. We tell them that it is a must that they test in order for us to know how to handle the mother and child. This is why we make it mandatory (II/MW/LSK/36).

When I asked a participant, an HIV counsellor,<sup>97</sup> how he would respond if a relative who is pregnant refuses to test for HIV, argued:

When the mother goes for antenatal, for the first time registration. Whether you like it or not mothers have to be tested for HIV, for haemoglobin which is anaemia, and

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<sup>95</sup> Circumcision was the other reason given by some participants for compulsory testing. Voluntary medical male circumcision was launched in Zambia in the year 2009 as an HIV prevention strategy. For example, talking about HIV testing experience another participant, II/SM/LSK-LIA/18, told me that male circumcision requires mandatory HIV testing. He said he experienced this, first hand. He told me that the medical staff at the facility where he was circumcised told him that if he wanted circumcision then he was required to test for HIV prior to being circumcised. He says he was told that "no testing for HIV, no circumcision". II/SM/LSK-LIA/18 was 29 years old, father of one child, not married, and at the time of the interview worked as a landscaper and cleaner.

<sup>96</sup> The participant was a nurse (midwife). She was in her 40s.

<sup>97</sup> The participant was male in his mid-20s. He was an HIV counsellor.

for syphilis ... all those tests have to be done. It is a must, ok. It's, that is just the rule of the clinic now. Every mother has to be tested for the first time. Every time they go for their antenatal visits for the first time they have to be tested for HIV ... for anaemia, for syphilis as well. So that they know their status. Because the main reason why they do that, it's for the protection of the child. To make sure that the child is safe, the child is protected... (II/C/LSK/28).

This participant even believed that compulsorily testing pregnant women for HIV did not breach informed consent requirements. Firstly, when I asked him whether HIV testing in Zambia is mandatory or not, he responded:

Testing in Zambia is voluntary. It is voluntary. A person has a right to test. Every person has to test or not to test... We say it's optional (11/C/LSK/28).

However, when I asked him to tell me whether the practices he has described above violate pregnant women's autonomy to accept or withhold consent in HIV testing, he surprisingly responded that they don't. He maintained that such mandatory tests are still consensual, and appropriate:

That is voluntary because you see before we do the testing for the mothers we ensure that for the safety of the child. Because we have understood that every mother, every mother wants their baby to be born safe and sound. Once a baby who is health, that's the most important thing. So if we say all the mothers have to be tested when they go for their first antenatal visits, it's mandatory. It does not involve other people, it involves them. It is about them, and not about them but also about the child. So we are just, the reason why this HIV testing was arranged that every time a mother goes for antenatal pregnant mothers they have to be tested for HIV, for syphilis, for HB, for haemoglobin... The main thing is to reduce the number of children born positive. That's the main thing... So that's the reason why the Ministry of Health here came up with this each and every mother that goes for antenatal for the first time is to make sure that all the mothers are protected and to know their status (II/C/LSK/28).

Moving on, another participant, a midwife,<sup>98</sup> shared that at the facility where she works every pregnant woman is tested for HIV. Likewise, she stated that every pregnant woman is tested because it leads to babies being born HIV negative and healthy. She emphasized that

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<sup>98</sup> II/MW/LSK/45 was a midwife in her 40s.

testing for HIV during antenatal is mandatory. She stated that the voluntary part when it comes to consent is only when it comes to collection of HIV test results; here service-users can choose not to collect their HIV test results. The participant also confirmed that because of mandatory testing, pregnant women also are required to come with their spouses when they attend antenatal. She told me that about 70 to 80% of men agree to test for HIV when summoned through their wives or partners. She jibed that unlike in the UK, it is rare in Zambia for service-users to disagree with a nurse or doctor's recommendations or wishes. Indeed, literature suggests that due to power inequity between medical staff and service-users, it is hard for the latter to exercise their autonomy when it comes to medical decision-making (Rennie & Behets, 2006).

Indeed, it is not easy not to oblige to medical professionals' wishes when one with a medical condition finds oneself in a clinical environment (Wear, 1998), more especially when it comes to service-users who are disadvantaged economically and education-wise. I asked participants in a focus group to discuss whether it is easy for service-users to refuse treatment or any medical interventions recommended by medical staff:

We have individuals who decline. We have few. But mostly they don't, but we have few. Especially those, the learned ones, they are the problem. Then they know that each patient they have rights, so they have the right to refuse treatment, they have to refuse whatever advice you are giving them, yes. But those who are coming from the compound [from economical and literacy disadvantaged areas] are very good clients. Whatever you tell them they believe... Because right now, like in our set-up [at the health institution where the participants work] every mother who is pregnant they are supposed to do HIV testing. It is like they have made [antenatal HIV testing] mandatory here. But it is not mandatory, it is voluntary. But the way we treat them it's mandatory... When they [pregnant women] are starting antenatal they have to have HIV testing... [And later again added] We don't pronounce the options [they don't inform service-users about consent requirements]... We don't talk about the negatives [risks of a test]. We don't pronounce that we have options. We just say everyone who is pregnant they have come they have to start antenatal they have to undergo testing. Even in the [name of department withheld]<sup>99</sup> they have now started everyone who is sick they do testing before they see the doctor... Before they see the doctor they have to see the counsellors and get tested (FG/LSK/Nurses).

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<sup>99</sup> The department withheld is responsible for screening in and out-patient service-users. What this participant told me is that when service-users with various medical complaints go there, one of the test which is done is compulsory HIV testing.

During a one-to-one interview a participant, a midwife<sup>100</sup> related that pregnant women are scared to refuse testing for HIV at antenatal clinics. They are scared to refuse because they know that when they visit the same health facility next time a nurse or midwife is going to ask them the question, “mummy, why have you not tested for HIV?”, the midwife said. She also said that pregnant women are afraid because they worry that if they refuse to test they will fall out of favour with medical staff and they might not receive a good service from them should they choose to continue using health services from a concerned health facility. Such findings are consistent with what other studies done in sub-Saharan African countries have reported (Molyneux, Peshu, & Marsh, 2004; Angotti, Dionne, & Gaydosh, 2010; Groves, Maman, Msomi, Makhanya, & Moodley, 2010; Odimegwu, Adedini, & Ononokpono, 2013).

This participant<sup>101</sup> gave an account of her experiences of what happens when pregnant women attend antenatal services. She recounted that when pregnant women go for antenatal services at the facility where she works, she and her colleagues counsel each one of them. She told me that they would counsel the pregnant women in a group, give them information concerning the benefits of testing for HIV, and would tell them that they needed to take care of themselves and their babies.

She said that, as for her, she personally tells pregnant women that they have a right to refuse testing, but then added that not all concerned health personnel mention to pregnant women about their right to refuse testing for HIV. She argued that midwives and other health workers do not tell pregnant women about their right to refuse because they (health workers) believe that if such was mentioned some pregnant women will refuse to test.

This participant<sup>102</sup> also talked about what she called “group psychology” in HIV testing. She explained that since pregnant women at antenatal services are counselled in groups, this has a psychological influence on their ultimate decisions. Group counselling causes pregnant

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<sup>100</sup> II/MW/LSK/37

<sup>101</sup> II/MW/LSK/37

<sup>102</sup> II/MW/LSK/37



women to test, she declared. Supporting her claim, she said that it should be noted that when a pregnant woman at antenatal services has her blood drawn from her arm, medical staff medically cover tissues punctured by a needle when drawing blood. This is done to prevent bleeding after blood has been drawn, she noted. Owing to this medical process other pregnant mothers are able to know whether a fellow pregnant woman with whom they were counselled together has tested for HIV or not when one emerges from the testing room with or without the “evidence” of having one’s blood drawn, the nurse stated. She explained that without physical evidence other pregnant women will be able to see this and be suspicious as to why the other person has not tested. Owing to this, a pregnant woman who may be thinking of refusing to test will be ashamed to think how other pregnant women would react if she emerged from “the testing room” without the “evidence”. The participant told me that those who have tested may think the person who has not emerged with testing “evidence” has not tested because she is trying to hide something; they may conclude that she is living with HIV. Owing to such apprehension, pregnant women are forced to test out of shame and fear, she argued. She then added that she does not know if this should be called VCT. Maybe it should be called a different name, she suggested. I would call it testing for HIV by virtue of fear for stigma.

The difficulty to decline instructions or recommendations from medical staff when it comes to testing for HIV was also illustrated in accounts given, among others, by an HIV counsellor<sup>103</sup> and a nurse<sup>104</sup> at two of Zambia’s biggest health facilities. The HIV counsellor related:

What I do is I call them [pregnant women] together into a counselling room. I counsel them together in a group and test them one by one. After I counsel them all the women agree to test for HIV. But once inside my office for testing others start complaining that “this HIV testing of yours has become too much. It is now every day” (II/C/LSK/40).

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<sup>103</sup> The participant was a female in her 30s. She told me she studied psychosocial counselling before taking up her appointment at the health institution where I recruited her for an interview. At the time of interview, she had already worked as a counsellor for many years, she told me. She was a counsellor for pregnant women, and post-natal mothers.

<sup>104</sup> II/MW/LSK/44 was in her 30s. At the time of interview she was the sister-in-charge of antenatal, post-natal, under-five and family planning departments.

As can be seen from the above quote, this HIV counsellor appears to suggest that pregnant women are getting fed-up of being compulsorily tested for HIV. If, indeed, HIV testing was voluntary at antenatal services, I don't see why people who have autonomy in such clinical settings would make such complaints. This, to me, also implies that service-users were fearful of refusing to test; rather, they deferred to medical workers' wishes. It is apparent that fear of others plays a significant role in HIV testing decisions. This is because if, indeed, these women whom this participant referred to were autonomous, there was no need for them to complain about HIV testing. All that they could have been doing is to tell the HIV counsellor that "I am not going to test because this is what I have chosen for the direction of my own life".

The nurse recounted:

We get consent from pregnant mothers. [The participant said this after I had explained to her that HIV testing requires individual consent]. It is just that, maybe, they [pregnant women] fail to say 'no' to test for HIV because they are afraid of us. Maybe we use coercive means so they are afraid to say "no". Some just have a fear of nurses and say "when a nurse says something it is better to follow what she [a nurse] has said" (II/MW/LSK/44).

Moreover, it was also obvious that health workers did not make any things better for service-users. It was apparent that they presented an HIV test to pregnant women, those who sought male circumcision, and people taken ill as though HIV testing was mandatory in Zambia. Some medical staff even confused PITC with compulsory HIV testing. They argued that diagnostic HIV testing does not require consent from service-users. In this sense, they attempted to justify their practices of testing pregnant women and people who present ill at health facilities. Hence, it would be instructive to hear an account to this effect of what a participant, a midwife,<sup>105</sup> among other health workers, narrated.

According to her account, in clinics health workers are strict with couple HIV testing to prevent reinfections. She said that sometimes those pregnant women who go for antenatal

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<sup>105</sup> II/MW/LSK/41 was a midwife at a health facility in Zambia. She was in her 50s, with many years of medical experience.

services without their husbands are sent back home to inform their husbands to accompany them. She related that testing of pregnant women for HIV in her department at the institution where she works is compulsory. The participant declared that HIV testing in Zambia requires consent, on the hand, but it is also diagnostic. She explained that one policy requires consent prior to testing an individual, and another policy is that HIV testing is diagnostic. With diagnostic HIV testing policy, testing does not require consent from an individual; the aim of diagnostic testing is to ensure that an individual who is ill survives, the participant stated. She told me that diagnostic HIV testing is done in order to rule-out other diseases. That is, a person who is to be tested is told that she will be tested, however, she is not given an option to refuse, the participant explained. Relating DCT to pregnant women, she asserted that with pregnant women HIV testing is some sort of diagnostic because HIV testing has to be done on every pregnant woman and every woman who tests positive for HIV is put on treatment.

Thus, it has been demonstrated that the implementation of PITC and DCT in sub-Saharan African countries<sup>106</sup> clinical settings has made informed consent in HIV testing a meaningless concept in practice (Bain, et al., 2015). Indeed, my fieldwork analysis and other studies confirm this to be the case. It confirms that as a result of the introduction of DCT in medical facilities in Zambia, service-users, especially pregnant women, agree to test under a degree “of implicit or “involuntary” coercion” (Bain, et al., 2015, p. 2).

An HIV counsellor<sup>107</sup> shared a similar story to the one above. She told me that one day she had a case where a woman came with her daughter-in-law to test for HIV. A doctor had sent them (daughter and mother-in law) to her department to test for HIV for “DCT” purposes. She explained that the mother-in-law was required to undergo all the listed tests by the doctor. She stated that when the two women went to her department they told her (the participant) that they were forced to go to her department and test for DCT purposes. These service-users did not desire or want to test, but they had to test, the participant narrated.

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<sup>106</sup> Such practices are not new, and cannot be restricted to sub-Saharan African experience (Magnusson, 1996). No wonder, Bennett has concluded that “routine antenatal testing regimes are incompatible with requirements for informed consent”; the author argues that marrying informed consent with routine HIV testing is incompatible, in that, “combining them in this way not only puts implementing the policy in an impossible situation, but also effectively masks an ethically problematic policy” (Bennett, 2007, p. 446).

<sup>107</sup> II/C/LSK/47 was in her 20s. She was a counsellor at a public health facility in Lusaka.

The participant told me that she told the two women that since it is the doctor who sent them to her office for testing, she was required to conduct the test as instructed. The mother-in-law was tested and her test results came out HIV-positive.

### **6.5.1 HIV policymakers responses**

Having heard such various but consistent accounts from service-users and medical staff on HIV testing, I decided to seek audience from HIV policymakers. I was interested to learn from them about their knowledge, experiences, and views about the practice of informed consent described by service-users and health workers. That is, I wanted to know whether they were aware about such practices or not. Thus, I asked an HIV policymaker/senior medical to inform me if HIV testing has become mandatory in Zambia, and he responded:

I will answer that question at basically two levels. HIV testing in Zambia is voluntary. Meaning it is not forced, it is not coerced. There is the other aspect, I said "I will answer it at two levels". There is the aspect of prevention of mother to child transmission of HIV, where mothers who go for antenatal visits are tested. It is said it is voluntary, but all mothers are now being tested. So the voluntary aspect is quote and quotes "voluntary". If they are testing everybody, probably they don't have a choice... Antenatal mothers, every antenatal mother now is going through the testing (II/D-PM/LSK/81).

I asked the participant about any awareness he has of any different approaches, if any, of compulsory HIV testing in health facilities around the country, he replied:

...Two scenarios. One in the antenatal clinics, there are some clinics. Apparent in my full time job I head the policy and legal input of the project, and we do receive sometimes complaints... There are clinics which are testing particularly women without any informed consent. They do group counselling and all of them are tested. And those who test positive are put in one group, and those test negative are put in another group, or they are given an antenatal card which has a different color. And, people are able to decode, and to tell that "those with a yellow one or a pink one they are HIV positive. Those without they are HIV negative". But yes, this is where we have gone against the policy of informed consent. They never consented to the test. They were not informed that it is HIV test being done. Everyone has blood drawn and everyone is tested and the results are given. And, our people are accepting that as normal practice, by the way. Because they have to continue

reproducing, procreating, yah. Second, where there is defilement. If a man defiles a girl, which is becoming common, I know that one of the test being done on the defiler, on the accused is the HIV test, with or without consent. Because they want to determine whether there is willful transmission or something like that. It helps them in establishing all these court cases. Those are the two situations. The other one, there is what we call post exposure prophylaxis. Because it happens so quickly, sometimes we have no time to counsel. We first do the test then we counsel later. Because it's for the good of the patient. It is like accidental pricking. Things like rape, a person who is raped again, we have to put them on post exposure prophylaxis. But in order for us to do that we have to do the test... (II/D-PM/LSK/81).

When I asked a senior HIV policy coordinator the question "Are you aware about how the PITC regime is being implemented in the clinics around Lusaka?" she responded:

It is not just PITC it's a lot of things that are not implemented properly. Uh, we, the National AIDS Council have got very clear guidelines. And if you look at the 2006 guidelines... But the problem is, how many people read guidelines? I think that is the biggest problem, including doctors. Very few doctors or anybody for that matter read guidelines. So they are not being done properly; that is number one. Number two; for people to effectively do counselling they have to undergo 6 weeks counselling course. But most of our doctors have not undergone that. And then we don't teach counselling in our medical school... For me what to do is that we have people who are trained counsellors. Nurse Counsellors, nurse trainer of trainers, so these are the people that we use and they know exactly what is supposed to happen. So, we do get reports and some I am sorry to say that they are not really being done very, very well. So this is another cycle, we are going to start again for the next three four months. Our nurses are going to go into primary health facilities and see (II/MD/LSK/65).

I asked another HIV policy-maker<sup>108</sup> the question "are you aware of any variation in approaches of HIV testing of different populations, in different clinics?" I told the participant that I had had some earlier participants tell me that clinic/ hospital staff tested them for HIV without informed consent. The following was his response:

I am aware about antenatal testing. It is not voluntary. Counselling is done in groups. When the nurses at the antenatal tell the pregnant women that it is now time to test it, it becomes difficult to opt-out. In that sense, everyone pregnant goes to test. Group counselling makes it difficult for one to opt-out. Pregnant mothers are scared

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<sup>108</sup> II/P/LSK/30 was a male in his 50s. He was at the time of interview a policy manager at one of the government's policy planning agencies.

of being stigmatized or discriminated against by others and the nurses for refusal to test. People would say, “Why did that pregnant woman refuse to test? She is hiding something” (II/P/LSK/30).

These accounts by policymakers corroborate the experiences which were consistently shared by service-users and health providers. These accounts suggest that HIV testing among pregnant women, people taken ill, and those seeking male circumcision undermine informed consent requirements. In other words, service-users’ autonomies are not respected through such practices.

## **Conclusion**

Zambia adopted informed consent requirements in HIV testing. Case law and HIV policy-guidelines in that country have also confirmed this.

However, despite the clear guidelines on informed consent, findings from my fieldwork reveal that informed consent requirements are hardly respected in practice. From experiences shared by service-users, health workers, and confirmed by policymakers, it is apparent that informed consent requirements are not strictly adhered to in HIV testing practices especially among pregnant women and people who are taken sick at health facilities.

# 7

## **Autonomy: participants share their views on human agency**

In the previous chapter we saw what participants shared regarding HIV testing at antenatal services and other clinical settings. We saw that despite the adoption of informed consent requirements in HIV testing by the Zambian government its implementation in clinical settings and its acceptance by the general public is problematic. We saw that pregnant women, men seeking male circumcision, and ill people taken to public health centres do not *per se* enjoy their right to informed consent when they visit public health facilities as service-users. In other words, individual autonomy – the right which informed consent requirements are supposed to protect – is undermined in clinical practice.

In this chapter I am going to share what participants said concerning the value of autonomy. Sharing the views of service-users and service-providers, I wish to suggest, will enable us to appreciate the underlying motivations behind the participants' attitudes shared in chapter 6. Put differently, having shared in the previous chapter that nearly all participants reported that there was a gap between informed consent requirements in the Zambian law and policy books and clinical practice, I felt that it would be relevant to report on what participants said about this gap.

My research indicates that the majority of participants were happy with compulsory HIV testing of pregnant women, close relatives, and to a large degree people taken ill. Even though participants generally argued that informed consent requirements in HIV testing are acceptable, the dominant view was that these requirements should not be strictly adhered to because doing so would be detrimental to foetal 'rights', injure the welfare of one's immediate family and community, impede correct diagnosis and treatment, hinder appropriate national health planning, and harm the socio-economic well-being of the country. Moreover, some participants even indicated that informed consent requirements are foreign to Zambian traditional and contemporary way of life.

In rejecting individual autonomy, the most common words and various phrases employed by participants were: the foetus “is innocent”, “protect the unborn child”, preservation of “future generation”, “if you are not infected you are affected”, human beings are not autonomous “because people are dependent on each other”, “no man is an island”, when “my daughter [or relative who refuses to test for HIV] becomes sick I will be the one to look after her”, African and Zambian culture make an adult child or relative “listen to [submit to] advice” from parents, HIV testing would enable the “government to plan”, “rights have got limits”, individual “rights must be balanced with obligations”, “the community is important”, and some people don’t test for “HIV because of fear”, etc. Participants suggested that the application of individual autonomy in a human society is based on an illusion, impractical, and/or immoral.

The themes which emerged from the data reveal lived experiences and perspectives of a people whose way of life is grounded on the idea of the common good. These results are consistent with Zambian traditional philosophy and morality which is not based on individualism and competition, but on cooperation and preservation of the wellbeing of the whole (Olivier, 1981; Kaunda, 1973; Colson, 2006; Taylor, 2006). Put differently, the data indicate that the majority of participants embraced the dominant traditional African approach to human rights which view human beings to be interlinked, essentially relational, and interdependent and thus socially autonomous and philosophically and morally expected to respect and promote the common good.

Traditional sub-Saharan African (Zambian) ontology views human beings as naturally conditioned for togetherness, for family, for fellowship, and to exist in a tender network of interdependence (Woods, 2002-2004). Unlike the ‘universal’ regime of human rights which are premised on individualism (Donnelly, 1990; Niekerk, 1998; Gaylin & Jennings, 2003), the data reveal a people who viewed themselves to be naturally and essentially social beings who are naturally and morally obliged to preserve the present and future wellbeing of their communities; they saw themselves as made for co-operation, reciprocity, and sharing. The dominant Western liberal approach to human rights encourages self-centredness, is focussed on the present satisfaction of an individual’s rights, is grounded on individual competition, is premised on individual privacy or boundary-ness, and is secular in outlook (Donnelly, 1990; Silavwe, 1995; Healy, 2007). This chapter will focus on reporting thematic



views and experiences of participants, views and experiences which can be distinguished from the Western liberal ideal of human agency and rights.

## **7.1 Natural sociality and common good**

Firstly, my fieldwork findings indicate that the majority of participants viewed themselves to be social human beings. In their individual responses to fieldwork questions they put forward an ontology of human interconnectedness, interdependence, shared vulnerability, mutual love, mutual responsibility, and common good. These participant views and lived experiences demonstrated a mismatch with 'universal' human rights values which inspire individual solitariness and self-centredness.

Human interconnectedness and interdependence, as opposed to individual autonomy, was advanced and celebrated by the majority of participants during interviews. These findings confirm conclusions reached by both African and Western anthropological and contemporary research which has established that the peoples of Africa are communal in outlook and practice (Senghor, 1964; Nyerere, 1968; Kaunda, 1973; Kwesi, 1977; Kenyatta, 1984; Diop, 1991; Silavwe, 1995; Gyekye, 1997; Battle, 1997; Tutu, 1999; Masina, 2000; Colson, 2006; Taylor, 2006; Healy, 2007; Achebe, 2008; Imasiku, 2009; Agulanna, 2010; Metz, 2011; Denison, et al., 2014). Similar to indigenous African communitarian ontology, the majority of participants held that an individual cannot exist or survive outside the social setting (Nussbaum, 2003; Agulanna, 2010).

The results from my fieldwork study indicate that sub-Saharan African peoples, in general, embrace and celebrate social living over individualism, a legacy which can be safely attributed to indigenous African civilisation: an African enduring social order which colonialism, apartheid and capitalism failed to supplant (An-Naim & Deng, 1990; Kaunda, 1993; Masina, 2000; Woods, 2002-2004; Maluleki, 2012; Omaswa, 2014). Below I have provided examples of the elements of this social outlook from participants' responses:

A charitable church group told me that they provide home care to PLWHA. I asked them to share why they do so:

Participant 1: [W]henever you are alone you cannot be a person; you need other people around you. So even if they [the suffering PLWHA] don't give you anything, but that closeness with people the person [PLWHA] gets healed because he knows I have somebody near me, who loves me...

Participant 2: These [PLWHA] are people just like ourselves... Jesus gave an example that these are our brothers and sisters... So even us as Christians these are the things we should, sometimes when people are neglected they die quickly, but when we associate with them, talk with them, chat with them, show them love you find they live, you know... (FG/LSK/Churchgoers).

The majority of participants saw themselves as dependent beings who by virtue of their natural human condition mutually need affection, love, aid and care from others. I asked a policymaker/medical doctor the question "are individual human beings autonomous?" She responded:

I don't think so. We need each other. I think so, we need each other. I think even me, I mean ok I am old enough I know exactly what I need in life. [But] Once in a while I want to sit with my sister and talk. We just have a good laugh once in a while. When you are sick somebody will come in and help you out. Yah, we need each other... Is there anybody who just think that "I don't need anyone?" That is the same mistake that people make. And then when you are in trouble then somebody comes and helps you out. And you get so surprised that some people can actually come. But generally, Africans will tend to depend on each other. I have seen, I mean I have lived in America where you can be here and where you don't even know your neighbours... (II/MD/LSK/65).

In this response one can see that the participant brought out the dominant African ontological perspective of natural sociality of humans, human interconnectedness and interdependence. This perspective of the social connectedness and dependence of humans is overlooked in the current universalised regime of individual human rights. Individual choice is celebrated by the Western liberal and libertarian lawyer without due appreciation of the impact such an approach would constitute against the common good.

I asked a similar question (whether individual human beings are autonomous or not) to a university lecturer/ researcher. He answered:

... I already established or underscored much earlier that human beings co-exist. Yah, so if they co-exist then being self-sufficient is a relative concept as well. You cannot be an island, if self-sufficiency is more the less close to being an island then it [individual autonomy] is not possible. But if self-sufficiency means a relative term which will imply that you are able to develop your capability based on other people

in society, who will be your source of knowledge, your source of understanding, and the field within which you express your abilities, then it means that one thing will lead to another. So autonomy means that, in a way, autonomy will be closely related to empowerment. When you are empowered you are able to make decisions independently, and not being forced by anyone (II/T/LSK/77).

Similarly, a church elder/managing partner at a private economic research firm replied to the question of whether individuals are autonomous or not:

I would say “no”. And the reason is that really people were created in God’s image and were created in such a way that we must belong to others. Yah, as long as we are image bearers of God we are not meant to live as “I”. We must live in a communal way and depend on one another. An individual cannot have all it takes for them to really be able to be fulfilled in life, yes. So it’s really, it’s a corporate affair, it’s a corporate experience. And that matter becomes more pronounced when a person becomes a Christian. Because God joins you to the body of his son. And that body has many parts. So that by default you are joined to a community of God’s people. And hence you know you are created in such a way that the recreation is that you are created in such a way that you are a belonging being. Yah!  
(II/CG/LSK/58).<sup>109</sup>

Responding to a similar question, an HIV counsellor argued:

It’s true you can accept somebody to live their [own] life. But it is depending again on the kind of decision that they are making. Sometimes it’s important you make them [people who embrace individual autonomy] understand that life is not about autonomy. Life is not about living my own life. Not at all! Ok? Because no man is an island. You may say “I am autonomous, I can live my own life”, but in this world you do not live alone. You live amongst people, you live with people and all that kind of arrangement. Now you are looking at a situation where once I begin to say “no I can live my own life” then I am heading for disaster. OK? People must begin to understand to say life is not all about myself and myself and everything to do with me. People, “it’s to do with me and other people,” OK? That is how come even people that are born in a single family they go looking for family elsewhere. So that they can live with people. It’s not all about myself, and myself, and living and everything that surrounds me, it’s all to me. No. It’s about me and the other people as well (II/C/LSK/83).

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<sup>109</sup> The participant was a development consultant/ managing partner at a research firm, and also a church elder at one of Lusaka’s biggest and affluent churches. He was in his 50s.

During a focus interview with school teachers, I explained to participants what autonomy is.<sup>110</sup> This was especially because during several interviews some participants (including some within this FG) indicated to me either that they did not know what autonomy entails, or they have never heard of the word “autonomy” before.<sup>111</sup> So having established the working definition<sup>112</sup> of the concept, I asked the participants a similar question as above (that is, are individual human beings autonomous). Participants indicated that individual humans are not autonomous:

Not very much... You cannot live in isolation. Even in regards with, you know, they say “no man is an Island, ayi [translated: true or right]”. You cannot live, you cannot be autonomous. You know in every aspect you need to have someone where you can lean on, you can ring... (FG/MT/LSK/Teachers).

And, in the nurses FG, responding to a similar question, participants argued:

Participant 1: All of us need each other at one time or another. We need someone to help us in the other [one] way or another. Because you might say I am myself, but there are sometimes when we need someone also because you are in need. When you are sick you need people to come around because you are helpless...

Participant 2: No man is an Island.

Participant 3: What they are saying is “no man is an Island.” You can have everything, ayi. Especially those people who have money. They may think that they are self-sufficient, they can rule themselves because of the money. But somehow they need some people to help them to give them directions. That is why we even go to churches so that they give us direction which way to go. Someone who is not a medical personnel, they cannot say that “it is my right”... (FG/LSK/Nurses).

These representative extracts suggest that the participants have a very strong sense of human interconnectedness and interdependence. These participants indicated that individual human beings are incapable of individual autonomy because they are social in nature. The reality of natural human sociality, interconnectedness and interdependence is hardly, if at all, acknowledged by protagonists and proponents of individual autonomy. The dominant Western liberal and libertarian ideal of human agency dismembers an individual

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<sup>110</sup> I explained to participants that to be autonomous is to be self-governing.

<sup>111</sup> A vast number of participants during the interviews in Lusaka and Chongwe did not know what autonomy is. It was their first time hearing about the doctrine. I had to explain it to them. It would be seen in this thesis that even after I explained the concept some participants still referred to autonomy as if it was a noun, or erroneously referred to it as “autonomy”.

<sup>112</sup> See chapter 3 for my working definition.

from her natural sociality and interconnectedness with other people, hence it is not concerned with the protection and promotion of the common good. In other words, the liberal and libertarian ontology of human nature fails to acknowledge the corporate nature of human existence. Unlike the Kantian conception of individual sovereignty, participants in Chongwe and Lusaka viewed interdependence, not autonomy, to be an essential characteristic of human condition (Wood, 2002-2004). And consequently, as will be later shown below, even when it came to the idea of human rights, the majority of participants identified “the jurisprudential sources of rights not in the capacity for reason, but in that very interdependence, which is reflected in the saying “a genuine human need carries the right to satisfaction” (Wood, 2002-2004, pp. 57).

This brings me to the next theme generated from my fieldwork results: the common good. I have referred to it as the common good value, an ethic which the majority of participants brought to the fore during my fieldwork study in Lusaka and Chongwe. Participants argued that HIV testing and knowledge of one’s HIV status is critical in the promotion of the well-being of the Zambian society. The promotion of the common good was held by the majority of participants to be critical, by reason of an individual being born into the community, human interconnectedness and interdependence. Participants regarded collective guarding of the common good as necessary for protection or promotion of present and future mutual wellbeing and happiness of individual members of their society.

### **7.1.1 Common good**

I asked participants in a group interview why they reiterated that the community is important to them as individuals. During the discussions, a participant particularly responded:

Then again just coming on the community aspect where you have just asked, you know when you look at a social family, the social family begins with an individual family, from an individual family we go to a community, from a community to a nation. And from the communities if we are not sensitized about it [HIV], and if we are not helping each other, then meaning we are going to decline.<sup>113</sup> And you know

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<sup>113</sup> On community decline a participant, a senior police officer, argued that all people should be compulsorily tested for HIV. He explained that failure to make HIV testing compulsory could make a

what I mean, we are going to decline. Whereby there will be no teachers. Important people in life will die... (FG/MT/LSK/Teachers).

Talking about collective necessity to promote the common good, an HIV counsellor shared:

There are people who take that message, and people who won't take that message. But those people who take that message will benefit from that message... So the community is very important because a community builds... Development comes from a community (II/C/LSK/28).

An HIV counsellor shared why he promotes the common good in society. He shared that he does things to make himself useful to the society in which he lives in because the state of a society engenders the ultimate welfare of each human being living therein. Talking about how a given state of affairs of his society has inescapable ramifications on him and others, he explained:

The society is extremely important because we can't take ourselves out of society. We are one and part of the society. Whatever happens in the society affects us. In an indirect way or directly, OK? ...to about 30% of indirect way. In a direct is about 70% it is affecting us directly. Ok? But morals of this society are affecting us, the good morals are affecting us. Each and every other thing is affecting us because we are living in a society, there is no way that will take us out of society until death... (II/C/LSK/83).

Similarly, a police officer argued:

The community is part of us. A community it's, you cannot do anything without the community. The community affects our well-being. The community is part of us. Do you see? Yes, we cannot do without the community. Because we are, human beings are interdependent. I depend on you, you depend on me. Have you seen? This interview, "why didn't you go to animals?" You chose to come and interview me, a human being. You understand. Because you knew I would offer a more reasonable thinking. You know. Which would help us make our community habitable. You get my reasoning? ... The community is the society we live in. The whole, for example, our community, our country, our, it's where the humans survive. You see?

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community of people become extinct. He riposted: *"Regarding HIV testing, for example, I want people to be healthy in the community. Testing for HIV in the family/ community will lessen unnecessary deaths. In this manner, my community will not go into extinction because of AIDS. Individuals, even when they can claim individual rights to make choices, do not live in a vacuum. Their daily decisions have an impact on the community in which they live in. When I say community, this also includes the country. Zambia as nation is a community of people"* (II/F/LSK-KML/09). Prevention of deaths and subsequent communal extinction due to AIDS is a common good, according to this participant.

Community is, the community is the world we live in. Our country, our villages, our towns. You understand? ... These are our communities. How do they affect us? You understand? So such situations like the HIV positive-ness really affects these our countries, our towns, our. How do they develop if you are, if you find our health is not up to date [sic]? It will be very difficult to develop our town. It will be very difficult for our village to expand. You understand? Because the health of the human being will even determine at which rate the economy is growing. You understand? (II/F/LSK/01).

This participant argued that securing of the common good is dependent upon individual effort and contribution. He considered the preservation of individual health to be a common good. Indeed, the wellbeing and productivity of an individual is celebrated as being of benefit to the common good. That is, health individuals are seen to advance a health society, and vice versa.

In the women FG participants explained:

Participant 1: ... If we are all healthy our country will develop. If we are not healthy how is our country going to develop? That is the answer I can give.

Participant 2: HIV and AIDS. You know this is something that has just come... We know that if we put measures this person will not die. Like she said... We want this human resource. We want our nation to go forward. Now if we keep on losing people every day over something [AIDS-related deaths] that we can even prevent, are we being fair? ... (FG/LSK/Women).

I asked participants from the nurses' FG if the health of the people from their communities matter:

Participant 1: Very important because there will be less trouble for us. If the community is healthy, then there will be no pressure on us. But if the community is sickly, there will pressure for us.

Participant 2: It is very important... (FG/LSK/Nurses).

Indeed, such arguments for the promotion of the common good and need for collective HIV testing were shared amongst the majority of participants. The shared perspectives suggested that a practice of individual autonomy in HIV testing without due respect for communal good would have deleterious ramifications on both society and individual. The suffering or death of an individual in a community was considered to cause suffering and loss to society, and vice versa.

The promotion of the common good, as opposed to individual autonomy, the participants indicated, provides an appropriate “foundation for a human rights paradigm that is capable of addressing the broad panoply of claims that are vital to the full attainment of human dignity...” (Wood, 2002-2004, pp. 55-56). In fact, sub-Saharan African communitarian moral and political theory, which the majority of participants arguably advanced, advocates the politics of the common good which is inspired by the elements of our shared humanity (Gyekye, 1997). Hence, according to the views of several participants, our natural human sociality “implicates the individual in a web of moral obligations, commitments, and responsibilities to be fulfilled in pursuit of the common good or the general welfare” (Gyekye, 1997, p. 71).

When I asked various participants a question to the effect that should an individual’s right to know or not to know one’s HIV status always be respected whatever the circumstances, the dominant view was that the common good of a community should equally be respected.

Responding to the question should an individual’s right to know or not to know one’s HIV status always be respected whatever the circumstances, a participant answered:

No, I don’t agree with that statement. HIV is not an ordinary disease. Condition. It is something that is transmitted sexually. And in a country like ours where one of the key drivers is multiple and concurrent sexual partnerships, I think that it is important, and we need to get a stage where every sexually active adult knows their status. And as long as the person wants to engage in sex, they have to disclose their status to their sexual partner. And I think that is the only way we are going to break the cycle of HIV infection. Living the option to people to disclose or not to disclose, I think in our setting it is counterproductive. If it was very low HIV prevalence I wouldn’t mind. But with a prevalence of 13.3% in the reproductive group, sexually active, we have to do something about it. That is my very honest personal opinion. Also in medical conditions, there are so many conditions, we conduct operations in hospitals. And knowing the HIV status sometimes is very important. And, because it has a bearing on the prognosis of certain operations... (II/D-PM/LSK/81).

Asked a similar question, a participant, a medical doctor responded:

I think I would say yes and no on that one. If there is no one else who is going to be affected by that individual not knowing their status. Or if somebody else is going to be affected but that is the person who has got the ability to make decisions, to agree whether for instance to engage in a sexual activity with person unprotected or



protected. I think that is final, we need to respect the individual's rights. But where other people's lives are at risk, I think that's a statement that probably needs to be rephrased. If you see children with HIV I don't think they deserve to go through what they go through. And I don't think they deserve that especially if their mothers had the opportunity to actually prevent HIV. So I think that is a question of yes and no. We need to respect individual circumstances, individual rights, but those individual rights obviously go with responsibilities. I think for pregnant mothers we probably need to rethink that issue for the sake of the unborn child, and even for sake of this mother who we are going to help remove the burden of looking after a sick child... (II/MD/LSK/70).

### **7.1.1.2 Common good and solidarity rights**

The majority of participants, as alluded to above, indicated that strictly giving effect to individual autonomy in practice is problematic because it impinges upon the common good. The common good was seen by participants to protect both individual and communal rights.

Participants argued that informed consent requirements in HIV testing overlook the rights of others (family members, community, and society with which an individual is socially connected). Thus, they rejected the current universal regime of human rights which does not with the same force it promotes individual rights promote solidarity rights. Put differently, according to participants, the current universalised regime of individual rights is problematic because it does not reflect Zambian peoples' lived experiences in relation to the HIV epidemic. They, among other things, argued that since a person suffering from AIDS will inevitably depend on others for care by virtue of human interdependence, people ought to test for HIV in an effort to prevent affecting the lives of others.

The preservation of the health of the individual through HIV testing and treatment was seen to be a common good. A healthy individual would not affect the lives of others because she would be able to take care of herself and those who depend on her and, thus, would contribute to the common good. The implication of such a perspective, as seen by the participants, is that human rights in Zambia ought to be common good-oriented – they ought to recognise and protect the interests of the whole.

For example, an HIV policymaker informed me that she was not happy with informed consent requirements. She argued that such values do not at the same protect the rights of relatives or medical staff:

There is the aspect of care. It is maybe a wife, a doctor, and if somebody is refusing to take the test or consenting to HIV testing it is unfair to the people who are taking care of them. Because if you are found positive and maybe the caregivers they have nothing to protect themselves, maybe use of gloves, they just take it that our relative has got malaria. They are, you know, coming into contact with fluid or blood, in the end I think that is where you feel it is not fair for somebody to refuse to consent for HIV testing (II/M/LSK/42).

Having heard this, I asked the participant that since she argues as such, what happens to individual choice, or autonomy: that is, shouldn't an individual's choice be primary? She retorted:

Yes, they can be prioritized. That is OK. But this thing should be looked at not just from the rights of the person. What of the rights of the other people? Because you are looking at a person who is still being taken care of...<sup>114</sup> I don't know whether I will put it as rights of the people who are taking care of you? Because I feel it is better to prevent that infection from continuing. If it is continuing, it is [better contained] in the family than to let it spread to others. Just like for instance if you had the case of cholera, a person decides to say no... but that is epidemic prone disease. If you refuse... what is going to happen? That will end up being an epidemic. It will affect a lot of people (II/M/LSK/42).

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<sup>114</sup> In dismissing autonomy, several participants indicated that the value of autonomy, which in itself is premised on a fiction, ignores other people's rights. They suggested that since we need others (we are interdependent) the protection of health of every individual should not be premised on individual autonomy. For examples, a participant argued: *"An individual is not autonomous. We need others – counselling and palliative care for people with HIV/ AIDS underscores my argument. [At this point the participant paused, then cuddling her baby who was crying for her attention, pointed at her child and announced:] "This is why we are saying that we are not autonomous"* (II/T/LSK/82). Another participant responded: *"I agree with individual autonomy 50%. There are things which require individual autonomy and things which require community autonomy. In the case of HIV/ AIDS; if I have a daughter who refuses to test for HIV by appealing to individual autonomy, is that acceptable? When my daughter becomes ill of AIDS she will be helpless, she will have to be fed, to be bathed; where is autonomy in such a case? Does also not her individual autonomy to refuse to test subsequently affect me? I will tell you that such things as testing for HIV shouldn't need require individual autonomy. However, the individual autonomy right should be promoted when it comes to rights that concern right of speech and expression, right of movement, etc."* (II/F/LSK-KML/09).

Several participants reasoned that individual rights must be balanced against communal rights. These views suggest that participants were not willing to embrace informed consent requirements which are exclusively premised on individualism. When I asked a participant why he insisted on having pregnant women compulsorily tested for HIV, he answered:

The issue is we are trying to promote human rights, but human rights or rights in general they come with obligations. So yes, women need to have rights, and their rights need to be promoted, yes. But they also have obligations. Some of those obligations are natural, other are social or economic... Like you are from a legal background. I have seen most lawyers like using some kind of, is it a scale? It has two weights. So, that needs to balance. On one hand you have the rights. On the other hand you have obligations. There has to be that balance. So there is no way you can promote just one side, then for a lack of a better term, you become an extremist. I think that's my simple understanding... [And later on directly speaking about informed consent participant said:] So it's very hard to say informed consent should be absolute. It's not a natural law. A law of nature where will say if you throw something up it will come down because of gravity. It becomes hard. So it's all about striking a balance between different factors, and having something ideal for the common good<sup>115</sup> again. It comes to the common good even if we are promoting individual rights (II/T/LSK/77).<sup>116</sup>

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<sup>115</sup> I asked the participant what he meant by 'common good' and he responded: "...again when we say common good, it comes back to the scale issue. So you have, how could we explain this? Naturally, even using mathematical laws, you have the majority resolving around the centre. Right? They are clustered around the centre. That means it's where the scale is balancing. So that becomes the common good. Yah. So, if you go far away, then you are going to the outliers. Those are the extremes. Becomes extremes. So you have to structure or to come up with policies which are neither respecting individuals so much, nor respecting collective kind of arrangement so much. But something which is in-between. To allow for flexibility because if you respect, say individuals so much you reach extremes where your laws will end up being like Islamic countries where there is Sharia, where you can even be killed..." (II/T/LSK/77).

<sup>116</sup> When I emphasise solidarity as being critical in indigenous sub-Saharan African thought, I do not mean to say that the Western approach to human rights does not recognise that rights come with obligations and responsibilities (Council of Europe, 2017). Rather, my emphasis on indigenous African rights are necessitated by the perspective that in addition to civil and political rights European social rights are still centred on the rights of an individual. The relationship that exists between an individual and society in the Western approach to human rights is such that a state or an organisation owes and should respect an individual's rights, and the individual is entitled to enjoy such rights for her own good. Sub-Saharan African solidarity rights require both ends (the individual and the state) to respect the other's rights; the individual ought to promote the common good, and the state an individual's rights. It is a give and take mutual relationship. And secondly, when I argue that dominant sub-Saharan African ontology is communalistic, this does mean that sub-Saharan African outlook does not respect individualistic values. Rather, what this entails is that the promotion of common good (as opposed to individualism) is of primary value in sub-Saharan African traditional thought. The same is not true about the dominant Western (Kantian, Millan and Rawlsian) perspective; as promoted in informed consent requirements in HIV testing. According to

When I asked members of Chongwe rural FG to tell me what they would or wouldn't do if they have a very close relative who refuses to test for HIV before marriage - their relative invokes her rights to choose what is best for her own life, a participant responded:

She can have rights, but as long as we remain parents to her, even us we have got rights to advise her. She needs to follow what we tell her as parents. It does not mean that she has got power in this matter, "no". All the rights have limits. It does not mean that because she has got rights then we oblige, no! She needs to listen to the advice we give her... (FG/CN/Chongwe Rural).

Similarly, responding to a question where a pregnant daughter refuses to test for HIV and invokes her rights to informed consent, a participant from women's FG, in addition to what another participant earlier said, stated:

What she is saying is when you are not infected you are affected. Yes. It is either you are infected or affected. When a family member is sick, it is not just about the person. When making the decision a person can say "it is my right." But when they are sick it is not their right. The right will not be there anymore because that person will be bedridden, hopeless. And they will need your help... You don't have the right to say that "it is my life it is my choice." But when there is a calamity falls, a calamity falls, it is not just for one person. We will not neglect that person because they answered us in a bad way (FG/LSK/Women).

Several participants further advanced that individual informed consent requirements are alien to Zambian traditional and contemporary way of life:

This [individual informed consent] is a totally a borrowed, a question of a borrowed bucket. We are drawing water using a borrowed bucket. As you know when we have borrowed a bucket we are not going to put in enough water for fear of, sometimes we may not know how to carry the bucket properly. The type of consent we have, informed consent is borrowed. Of course it is founded on the principles of universal human rights. And, but we have a culture, we have a way of living. I just gave you an example of the rural setting; people don't exist as individual beings.<sup>117</sup> They exist as

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dominant Western liberal conceptions of autonomy, the promotion and protection of individual sovereignty is primary.

<sup>117</sup> Earlier I asked the participant, since he was at the time an HIV Policymaker, if, in relation to informed consent requirements, he had any knowledge about service-users' experiences of HIV testing in Zambian health facilities. He responded: "We work in chiefdoms. My component works in chiefdoms. And in the chiefdoms we are trying to galvanise traditional leadership, and ignite traditional communities... Consent at those levels it appears is very different because in a typical

families. There is a social safety net that is responsible for decision-making. Decisions are made in a very consultative process, including marriage... It's done in an extremely consultative manner. Consent at that level, in its present form is actually inappropriate. Because the person who is asked to make decisions is not responsible for the final decision-making. It is done in consultation with others, that's just the way we live. And we shouldn't be judged primitive or otherwise. That's just the way we are. And that way should be respected (II/D-PM/LSK/81).

He continued:

I have seen for myself a lot of benefits when I worked in the rural setting from communal, is it a shared consent, I don't know what to call it... But in a nutshell, I think for educated people like ourselves it will not make sense ... Individual feelings, being all the time being responsible for my health, and "yah I must be respected, and people should only know when I feel they should know." But in our traditional setting that's not. Ah, people share almost everything. And HIV testing is no exception. From a hospital point of view also we must treat it like any other. A person who walks in the hospital it is an opportunity. Let's test it together with the other blood tests without making a big fuss out of it (II/D-PM/LSK/81).

As can be seen above, it is apparent that participants saw themselves as mutual guardians of their common welfare. They rejected the current regime of 'universal' human rights which only recognize the rights of an individual. One individual's calamity or misfortune was considered to be a calamity of the whole. In other words, due to perceived human social attachments participants indicated that one person's pain becomes another's pain. In fact, it was also apparent from the majority of responses I got that what moved the participants to

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rural community at chiefdom level, people exist yes as individuals, but more so as communities, as families. And decisions are not based on personal opinion, it is on communal opinions, shared opinions, and shared values. There I have seen the way consent is given. There are so many people involved in agreeing in or disagreeing to consent. I will give an example. A person might be sickly, in the village they will just say we are taking you to the hospital. And when they arrive at the hospital they will just tell the doctor "test this our child," not my child, "our child." The uncle, the father, the mother, the brothers, they are all there to give moral support to each other. And consent, everyone agrees, not just, if you ask the guy who is supposed to receive the test he just say "ask my uncle, ask my father, ask my elder brother." And we don't have in the guides, ah spaces for this communal consent. Let me call it communal consent, or is it family consent... And I never had problems. For 10 years I worked in that environment and I have never had a problem. Once we agreed if the outcome was not favourable I will have explained to the family, they will have understood. If it was favourable, they will still appreciate, and say "thank you doctor" ... In that regard even when a person dies the family already knows that "the doctor explained to us" and they would be there with you. That's the difference I have seen in a typical rural setting like a chiefdom where people still value their traditions and customs, and decision-making is collective" (II/D-PM/LSK/81).

dismiss the appropriateness of individualized informed consent requirements in HIV testing was not only the need to protect the common good, but were also moved by their love for their family members, friends and community with whom they identified as being interconnected:

We have attachments to patients. One will look at a patient and see a human being; so you want the best for that individual. Sometimes you will have to put away the policy [informed consent requirements in HIV testing] to help an individual. This is what happens in practice. In practice we apply a human face. We see an individual as having a family; so needs to be helped. That person will even later thank you for doing the right thing for them (II/P/LSK/30).<sup>118</sup>

A participant in expressing her views on unofficial HIV testing practices in Lusaka said:

These people [HIV counsellors and midwives] who test us when we are pregnant help us. They are interested in our well-being. They are right to force us to test for HIV. They should be concerned about the well-being of my unborn child because when my child gets ill the hospital will have to spend their time and resources to look after my child. To know one's HIV status is to protect one's child. Nurses say they feel bad when they see a mother with a child born HIV positive. They say they are also mothers so they feel the pain the mother of an HIV positive may feel. Not only are they interested in protecting the unborn child, but the mother as well. Not only does a baby born HIV positive trouble the hospital; it also troubles family members too. Family members will worry, they will have to spend money to travel to see the sick child, and, and will have to spend time looking after a sick child (II/M/LSK-K/19).

A midwife<sup>119</sup> shared:

We are happy with pregnant being mandatorily tested for HIV. However, testing the rest of the population groups for HIV should remain as it is; it should require consent... For those women who test and they test positive their children are born HIV free after we put them on ART. We feel good when we see healthy children. In 10 women tested for HIV, one can be HIV positive. Once we test a pregnant mother and she tests positive we immediately put them on ART. With B+ option every pregnant woman who tests HIV positive is put on HIV treatment, immediately. If she (pregnant mother) says "I need to go consult my husband or others before I can start taking this medication", we give such a woman time so that she can go talk to her relatives first before commencing treatment (II/MW/LSK/43).

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<sup>118</sup> The participant was an HIV policymaker.

<sup>119</sup> She was in her 50s.

A midwife noting pregnant women's behavior after being tested for HIV explained:

For pregnant women they later come thanking us saying "thank you, you helped me. If you left me to myself to decide whether to test for HIV or not when I was pregnant I was not going to test." That is what all of them say to us afterwards. That is a plus to the nation. It is now rare to find HIV positive new-born babies. Numbers of HIV positive new-born babies have reduced. A lot of mothers would tell us that if you left us to ourselves to make HIV testing decisions, we could have refused to test for HIV... Unlike in the UK where you come from, it is rare here for health clients to disagree with a nurse or doctor's recommendations here. They (health clients in Zambia) want to be helped (II/MW/LSK/45).

I asked a senior doctor/ policymaker what she thinks about the current HIV informed consent requirements in Zambia, and she responded:

I think for the time being I am very happy for what it is. But if you look at the WHO, Zambia is highly endemic. We are over 10% [the Zambian population living with HIV]; so we are highly endemic. Should we sit and see young people getting infected when we can prevent it? And you can only prevent it when you know your status. Should we let people die because they have got the right to die? We are saying no to euthanasia, isn't it? But in the same time we are allowing people to die, because they have got their own right. So it is very complicated. It is truly very complicated. Because I think you know like in a highly endemic area like this and if we are trying to; we are saying zero tolerance to HIV, that is our motto, how are we going to achieve that? If all of us do not know our HIV status...? (II/MD/LSK/65).

During an interview with this participant, she became passionate when she spoke about how free HIV treatment has helped a lot of children whom she said could have perished had the government not rolled out free HIV treatment. Due to my witnessing of her being emotional as she was narrating how some children who were born with HIV are now "becoming lawyers and medical doctors" due to the availability of free HIV treatment, and her intimations to me about the amount of her personal effort and time she had put in over the years to help these young people live healthy lives and aspire, I asked her why she was concerned about the welfare of these young people. She answered:

We are Africans. Have you become a white man? ... You just say Ubuntu! Some of us we just love people. And even someday I am always the last to leave here [the office] because I have so much work to do... Like somebody was saying "since you have got everything why do you work so late?" ... People think if you are rich, you have got a house, you have got a car that is enough. But some other outlook is that I am making a difference in someone's life, yah? And the more people I make a

difference in, the better I feel. That is, I don't drink, I don't smoke, so that is my narcotic just to see that children are healthy... So yes, I get a kick out of it. I am helping kids (II/MD/LSK/65).

The above quoted examples, under this section, indicate that the participants' rejection of human rights which are premised on individual autonomy is influenced by their embrace of an ontology of the natural sociality of man, human interconnectedness, interdependency, and shared vulnerability and frailty. This view is consistent with sub-Saharan African traditional and moral ontology. The largely imported current regime of individual human rights in HIV testing in Zambia is only concerned with the protection of an individual; they are indifferent to communal good.

Moreover, it was also apparent that participants equally embraced the Christian view of human condition. Hence, it would be appropriate to suggest that the majority participants' views on individual autonomy reflected an Afro-Christian view of human nature.

## **7.2 Religion and autonomy**

I wish to slightly digress from the present discussion<sup>120</sup> by advancing that the participants in Lusaka and Chongwe's lived experiences and perspectives were not only influenced by sub-Saharan African communitarian and moral thought, but also by Christian ontology. A lot of participants referenced their faith during interviews. Almost all the participants who took part in this study were Christian.

It has been shown that Africans are deeply religious peoples. Even prior to colonization and subsequent Christianization of Zambia, it has been reported that the peoples of sub-Saharan African countries have always been deeply religious (Kaunda, 1973; Gyekye, 1995; Colson, 2006). Thus, it was not surprising that participants referenced their religious beliefs in their responses to interview questions.

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<sup>120</sup> From section 7.3 I have continued to explore the other themes that emerged from my study: themes of participants' views experiences which indicate an outlook which besides being communal (as shown in the current section), is concerned with preservation of future legacy, is not premised on privacy or boundary-ness (but on openness, talking, trust, and sharing), and promotes co-operation and reciprocity between human beings (as opposed to self-centredness). In the present sub-section I share what I found regarding the religious influences on participants' ethos and outlook.



I asked participants in the churchgoers' forum group why they were passionate about helping PLWHA, sometimes at their own detriment. They responded:

Participant 1: You take yourself as a Christian did [does], what Jesus is doing [did]. When he was going around [he was] healing the sick and so forth.

Participant 2: As we have said that if you are not infected you are affected... (FG/LSK/Churchgoers).

I asked a church elder why he was so concerned about the welfare of individual members of the church in which he is a minister, in that, he desired that everyone is compulsorily tested for HIV so that those who test positive are put on treatment. He answered:<sup>121</sup>

Yah, it actually is a Christian mandate. As a matter of fact it goes beyond just the church members, in my view... You know as God's people it's about God-given responsibility to take care of life and by that we look not only at the spiritual part but also the physical. You know Christ, our Lord... gave the best example. He was concerned about the spiritual as well as the physical. The physical as demonstrated in the way that he would feed the hungry, he would heal the sick, yah. But also to be frank when I look at the suffering that you might, you know, go through it makes me very very very upset... (II/CG/LSK/58).

During an interview with school teachers some participants kept on mentioning the community in their responses. Therefore, I asked the participants if community involvement is important in responding to the HIV epidemic; and a participant particularly responded:

Very much! That is why I am saying without the community you cannot have a bigger part which is the nation. That is why I started with "we have a smaller one which is a family unit, from the family unit we go to the community unit." The community is very much important because in the end we have more important people to represent the nation at highest level. If at community level we are destroyed, meaning even on the top there we are destroyed. [The participant latter added:]... 80% of the people that live in Zambia are Christians. We feel for each other, and like I earlier on said if you are not maybe considering the importance of helping each other we cannot develop as a country. We will never develop as a country... (FG/MT/LSK/Teachers).

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<sup>121</sup> This participant had shared with me during the interview that the church membership in which he is a minister used to pull their resources together to pay for the medication of any of its members who tested HIV-positive at the time when ARVs in Zambia were prohibitively expensive.

For a final example on the theme of Christian influence on HIV testing among participants, my own experience of witnessing a Christian worship and praise gathering which subsequently led to testing of pregnant women, something I witnessed during the times I was moving around from one clinic to another seeking for participants to interview, is worth mentioning. On three occasions at some clinics, I heard and saw pregnant women, HIV counsellors, and nurses singing Christian praise and worship songs. When I first heard the singing at the first clinic I assumed there was a church service going on within the facility. The singing was followed by prayer where every member who had earlier made up the singing party started praying; they all prayed at the same time. When I drew closer to the location of the gathering I learned that it was a group of pregnant mothers who had come for antenatal services. I was surprised! I thought that this was an exclusive practice at this particular health facility until I witnessed the same at other clinics.

During one of my interviews at one of these clinics I asked a participant<sup>122</sup> who was earlier among the singing and praying party to share with me the significance of what I witnessed. She attributed the source of the singing and praying I heard to herself, other expecting mothers, and health workers within the antenatal department. She informed me that they sang and prayed during antenatal clinics because they know that a pregnancy is a gift from God. She asserted that God made it possible for her and her fellow pregnant women to be pregnant and for this reason their singing and praying was a token of thanks, and at the same time a petition to God to enable them appreciate what will be taught to them during group counselling. The participant explained that the foetus is a gift from God, so they needed to praise God for the gift of life and ask for blessings before they could proceed to test for HIV and other health conditions. She stated that pregnant women are stewards who will one day give an account to God.

### **7.3 Co-operation, mutual responsibility and reciprocity**

In section 7.1 I have reported that individualism was looked down upon by participants in Lusaka and Chongwe. The majority of participants considered the promotion of individual autonomy in the Zambian society to be illusory, immoral, un-Zambian and/ or un-Christian.

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<sup>122</sup> II/M/LSK/67

Participants saw themselves to be social beings who are naturally and essentially interconnected with other human beings and interdependent. They rejected the universalised version of human rights which imbue selfishness and solitariness and instead advanced an African traditional ontology which propagate that since human beings are social in nature and share common vulnerabilities, they have mutual obligations to preserve their common good for their corporate wellbeing. In this section, I have shared another theme which emerged from the data: co-operation, mutual responsibility and reciprocity. Participants indicated that the current regime of human rights is biased towards individual self-centredness. Individualism was viewed to “diminish the importance of caring, reciprocity, community building, generosity and cooperation” (Healy, 2007, p. 24). In that, human rights which are exclusively based on individual autonomy tend to overlook that “no society can rest on autonomy alone”; participants suggested that “our humanity is fulfilled by conjoining rights and responsibilities, autonomy and relationships, independence and interdependence” (Gaylin & Jennings, 2003, p. 67). The following responses from participants show the place that cooperation, responsibility and reciprocity occupied in their lives, as opposed to self-centred living:

When a participant indicated that her pregnant daughter would comply with his wishes to test for HIV by virtue of cultural conventions, I proceeded to ask him to elaborate on what he meant when he referenced culture. He responded:

There is this notion that under the shot [instructions] of your father you do as the father says. But in this case it wouldn't be me dictating saying “you do this”. The African culture is about listening to what your parents say. Whether you like it or not, whether they are right or wrong you just go with it. But I think as time is moving things are changing. We are getting to levels where parents are actually sitting down to talk with their children... Sit down with her and say “my friend this is reality [HIV is real]. Possibility of you being negative is there, possibility of you being positive is there, so the best is let's take a test. It's not about your rights. Your rights will come in but what happens when you get sick tomorrow? ... (II/SNMC/LSK-KL/08).

I again asked the participant if culture can have influence on her daughter's choices. He retorted:

Automatically yes, automatically! She would agree. There wouldn't be any negotiations; coming from the culture that we have. Human rights like I said in our

Zambian culture don't really come to play.<sup>123</sup> I think I have heard of incidences where somebody is HIV positive and they didn't know but the parents will test and then tell them later. Obviously they will think of "OK, why did you do it without my consent?" But you can't really approach your parents because of the culture that we have come from. It's different from the culture in the West or say in Europe where you actually negotiate and say "ok, these are my rights I can do this, I can't do that." Here it's different. The culture will definitely influence automatically my child will listen to what I will have to say. We have been brought up in a culture which I don't know if it's good or bad. In some way it's good in some way it's bad. It's just knowing how to strike a balance... (II/SNMC/LSK-KL/08).

Talking about mutual responsibility, a participant in the teachers' forum when responding to a question of whether individuals are autonomous or not responded:

But now the autonomous [autonomy] you are talking about is about life and death, on the HIV thing. You see that right? So, for me autonomous should be in other areas not in the area of life and death.<sup>124</sup> I cannot just say "whether I don't test or". What, who knows maybe it is me who is spreading it [HIV] around the community we are talking about. That is what the problem is. Ah, because of the policies have come up with they say, ok, autonomy. Autonomy [sic] in other things but not when it comes to HIV. Because they say "if you are not infected you are affected" [All the participants joined in and 'chanted' "if you are not infected you are affected]... (FG/MT/LSK/Teachers).

When disputing an individual's capacity to be an autonomous agent a midwife added:

Someone is sick, you say "you need this treatment" then they are saying "it is my right." Me [talking about himself] I am a medical personnel I know what they are suffering from. And they haven't gotten the treatment, I know where they are going. Ayi. But them because they are not medical personnel they are underestimating

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<sup>123</sup> Meaning: The current regime of individualised human rights is not really respected due to the Zambian communitarian ontology.

<sup>124</sup> Some participants argued that informed consent should not be a priority in HIV testing because of the need, on the other hand, to protect the lives of unborn children, the very person who may be living with HIV, potential caregivers, and the communal good. For example, a participant in regards to what she explained to be the primacy of life in relation to individual autonomy argued that an individual might say "*it is my life, but when such a one [the person who has refused to test for HIV] gets ill she will be the trouble of the family and community. So why as a family and community should we wait for such trouble when we can prevent it? No one has a right to take one's own life. Isn't suicide, for example, a criminal offence in Zambia? So then what about taking one's life through AIDS? So a doctor tests without consent so that he can prevent a death; life is more important than informed consent. A right to life is also a right which needs protection. A mother and her unborn child's lives are more important; so in such cases individual consent should be thrown through the window*", the participant concluded (II/C/ LSK – KLNLN/10). This participant saw herself as responsible for protecting the common good.

what they have, ayi. So there is no one who can stand on his or her own... (FG/LSK/Nurses).

Sharing about what the community means to him and how he reciprocates, a participant, an HIV counsellor said:

Personally the community is very important to me. It is very important because everybody comes from a community. Everybody does come from the community. What makes a community is people. And for a community to be there people have to be working together for the community to succeed... It's a matter of working together, OK... And I have got friends in the community, I have got a lot of people in the community, and these people have to help out. OK. We face a lot of situations in the community. And I learn a lot of things from the community. The community first of all teaches me. If the community is working together, it's co-operated, united, what does it teach me? It teaches me to be organised, to be united with other people... Now I am a counsellor, I also contribute to the community because it is very important for me... For the community to develop everybody they have to contribute to the development of the community. So my contribution to the community as a counsellor with my information. The information that I have now I share it with the community. My knowledge about testing and counselling I share it with the community. I don't build myself, but I also build a community ... (II/C/LSK/28).

Talking about communal responsibility, a participant, another HIV counsellor, said that he is responsible for his friends' welfare. Sharing about the degree of his responsibilities towards his friends and relatives he said that "I will say not every time, but most of the time."<sup>125</sup> This participant reported that as counsellors, in collaboration with other medical staff, they work under 'ethics' where "sometimes" a service-user's right to informed consent is never sought before conducting an HIV test for diagnostic purposes. He argued that such practices are important in aiding medical staff to diagnose what medical condition(s) a service-user may be suffering from. He shared that "We don't get consent from the clients; we just go there because we want to save someone's life."<sup>126</sup> Moreover, the participant reported that when he is in community, when not a work, he goes about sensitizing his friends about HIV. When asked about why he is concerned about the welfare of others, he responded:

...biblically, I will say, even the Bible says "be a brother's keeper." OK, so it's not only because I am concerned about what they [people] do or what they think is right, "no". It's because I know, "how am I going to be someone who is this important to

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<sup>125</sup> II/C/LSK/46 was a VCT head of department at a governmental health facility. He was in his 20s.

<sup>126</sup> II/C/LSK/46

the community or in my country I come from?" I see myself, even though others don't see this, I see myself to be someone who can really do something that will develop our country, ok. At least something that at the end of the day someone will be able to appreciate to say at least this person was able to do something. Yes, it is difficult. I think, it's not only me, to say "I don't care about this person, let me concentrate on my life," ok? I am also looking at it because if I change the way my friends think, ok, it means that if the people who are close to them were able to do that as well, ok, once they see the importance of me talking about change, I am sure they will be able to save the other people. And the other people will be able to save others. Information will be transmitted just like that. Meaning that if information is being transmitted like that it means, one, we are looking at reducing the spread of HIV... (II/C/LSK/46).

When I asked a church elder whether he would or wouldn't officiate a marriage where the bride refused to test for HIV, he answered:

Yah, the first thing that I would do is to help her, I would begin some counselling sessions, to put it simply, because in my view she would need to be assisted to realise that really, you know, she ah, this condition does not only affect herself. Yah. If, for example, it was discovered that she had it [tested HIV-positive] other people get affected. Yah, and as, and if she is a Christian person the Bible teaches strongly the matter of stewardship. That stewardship includes the stewardship relating to how we must take care of ourselves, and how we must take care of, you know, the other people round about us. It is a God given mandate to do that... (II/CG/LSK/58).

Indeed, what the results in this section show is that the participants were opposed to self-centered practices: a universalized value which is evidently promoted in HIV testing individual autonomy requirements. Rather, they considered themselves as moral agents, who by virtue of their natural sociality have obligations to co-operate with other human beings, to act responsibly towards each other, and reciprocate in order to ensure the common good.

When I was driving through Chongwe-rural I noticed that there were homesteads along the dust roads I was driving through. I cannot remember seeing a place where there was only one hut for one family or an individual person, even when I saw a lot of virgin land, areas where individuals could have elected to live on their own. Thus, during an interview from the area I asked participants and their village headman why they decided to live together at the village as a people; that is, why don't they live solitary lives as individual persons or as separate families units away from the communal village? The participants responded:

Participant 1: Living with other people is something which is good. You cannot choose to live alone separate from everyone in the bush. You cannot only live with your husband, it is not good. That is when we saw that living with other people is good. Living with your neighbour is a good thing. This is because if I am sick my neighbour will care for me. If I am suffering, my neighbour will help me, if I have no salt, my neighbour will give me salt. For anything which I am lacking, we will help each other with my neighbour. So it is a good thing to live amongst people, to live with people, to cooperate with people. If you live alone you will be sick and you will die on your own. You will not have anyone to care for you.

Participant 2: The reason we chose to live with people is because you cannot know anything without other people. You can know nothing. That is why we have this information because we are finding ourselves among other people. If I was living only with my wife I will have no access to such information. That is why it is important to live with other people.

Participant 3: Living with other people is very important. If I was living alone, I wouldn't have known that you have come to our village... You cannot live by yourself you cannot know things... (FG/CN/Chongwe Rural).

#### **7.4 Futurism and legacy**

As opposed to universalised individual autonomy which evidently protects and promotes an individual's right to secure present fulfilment of her desires and wellbeing, I found that the majority of participants' outlook was not exclusively grounded on present satisfaction of an individual's autonomy. In addition to securing present wellbeing and rights of an individual, a large majority of participants were more concerned with a preservation of the common good and wellbeing of future generations (Senghor, 1964; Kaunda, 1973; Kenyatta, 1985; Kurtz, 2000; Woods, 2002-2004; Angotti, 2010). This behaviour is consistent with human nature: "Human behaviour is not random, it is purposeful; it is future – as well past – oriented" (Gaylin & Jennings, 2003, pp. 144-145). The participants' concept of autonomy, human rights and wellbeing was thus futuristic.

The current universalised regime of HIV testing informed consent requirements are concerned with present satisfaction of an individual's autonomy in total indifference to the future consequences of fulfilling such rights. Participants in Lusaka and Chongwe argued that human rights ought to protect future generations and the environment.

I asked the participant about what happens to an individual's rights to self-govern since the participant argued for collective HIV testing of pregnant women. This was especially after the participant insisted that if her pregnant daughter refused to test for HIV he would still have her tested without obtaining her consent:

I think it [voluntary HIV testing] was like that before PMTCT was introduced. People would decide whether to go ahead and test. And where they don't want they wouldn't test, they will just continue living their lives. But the rate of HIV was getting higher and higher at the end of the day. So the policies had to be put in place. So regardless of culture, certain things I think, there are certain things that you can have a place to negotiate over; "let's debate over this", but certain things don't even need that, just put your foot down and say "ok we will do it this way."<sup>127</sup> At the end of the day you are looking at the welfare of the entire nation. Because we are looking at a possibility of having a wipe-out of the entire country. So this policy [compulsory HIV testing] has actually helped. So regardless of what culture says this has helped. You see it when you go to the clinics, and you see how many people are on pills and how many people are getting medication (II/SMNC/LSK-KL/08).

As already alluded to expressly or implied in the foregoing conversations from chapter 6, several participants suggested that individual rights should be balanced against the common good. When I asked a participant, the university lecturer/ researcher, why he insisted on having pregnant women compulsorily tested for HIV, he responded:

The context here is not what I want, or that to be mandatory. It's based on the practice. In practice that's what is happening. Pregnant women have been tested. Much more in a mandatory manner. So it is not that I want that to be mandatory for

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<sup>127</sup> When it comes to pregnant women the majority of participants argued that it is important to test all pregnant women for HIV because leaving the decision to a pregnant woman who may refuse to test may have a bearing on the woman herself, the child, but also close relatives. For examples, a participant, a school teacher/ HIV counsellor who told me that she would secretly have her pregnant daughter who has refused to test for HIV at antenatal tested by a midwife without pregnant daughter's informed consent later argued: "...no matter her age she [pregnant daughter] will always remain a daughter to me; once a child forever a child. The other thing is that when my daughter gets ill, I will be the one who is going to look after her as a mother – she will not be the law's responsibility" (II/T/LSK/82). Taking about human rights, I asked a housewife why she said to me that if her own daughter who is above the age of consent refused to test for HIV she would ask her friend to secretly test daughter for HIV; that is, what happens to daughter's right to informed consent? She riposted: "Because I want to protect the unborn child. Also all the problems my daughter will face will eventually come to be my problems. If my daughter refuses to listen to what I tell her, then I will tell her to go out of my site. My Daughter can have rights but she will forget about them when she is in trouble. She will come rushing to me seeking for help; she will say "mother help". So what has happened to her rights now that she seeks help from me?" (II/M/LSK-RGW/13). (II/M/LSK-RGW/13) was in her 30s.



them, but we are looking at what is happening on the ground. In as much as we want to promote rights and say they have the right to do this, they have the right to make the decisions, we have more the less [we have] the government which is supposed to be the protector of everyone's rights. It's already establishing some kind of norm. The norm is that pregnant women have to be tested for HIV. In as much as they want it to be voluntary but it's done in a mandatory manner... So, and this we know that society grows or, reproduces itself through procreation where women are the ones who are responsible for child bearing. So, this means that we want to ensure that our society, our country lives on, or grows. Then the health of women is improved, it has significant natural effects on the rest of society, and the rest of society. So in this regard women become a special case, not just because of HIV issues, but a special case because of their natural and even social and economic roles in society... (II/T/LSK/77).

When responding to a question of individual's autonomy, an HIV counsellor began by arguing that individual autonomy is conditional, then added:

As much as we can respect them [individuals] to live their life, do whatever they want to do, certain things are not even a matter of respect towards them... Now you begin to tell them to say "no, yes fine you can live your own life, make your own decisions and stuff like that, but one thing you are supposed to know is that in this life there is also sicknesses, there are illnesses. Ok? That have different levels and different magnitudes that will come upon your life. Depending on what, the kind of life that you live. Just as much as they say speed kills. Speed is good enough to take you to the destination you want. But the same speed can as well kill you. What can take you quickly to the destination you want, can as be detrimental to your own life" (II/C/LSK/83).

When sharing about how he feels individually responsible for the advancement of his community's wellbeing, as opposed to only caring for his own wellbeing and rights, a participant later added:

And then certainly you see within the friends you go out with, sometimes you don't know they may even be going out with [dating] our sisters. Or even brothers; we don't know. So by doing that [sensitizing community members about HIV, and testing] we are protecting part of your family, even part of your relatives, part of your close friends, even, part of people who are going to be future leaders. So we are talking about, we are not only being concerned because these are your friends, we are looking at the thing that is valuable; that add value to our government (II/C/LSK/46).

Responding to a question where a pregnant daughter refuses to test for HIV and invokes her right to autonomy, a participant in the women's FG answered:

On that I will emphasise that "yes they are your rights. But if you get sick it is me who is going to suffer as a mother." I will even explain "when your CD4 count drops", because when a pregnancy is four months old and above the CD4 drops when someone is not taking ARVs. I will tell her that "I am a widow I am not working. Where can I find 13 million to buy you CD4 count at UTH? This will mean that you will die. And if you died, the funeral expenses will be 10,000 Zambian Kwacha." So then I will convince her I will talk to her that "yes they are your rights but you need to consider the implication of your decision on yourself, your child and me you parent. And I am your parent. Me I am your parent, you cannot ignore what I am saying." A parent is a parent (FG/LSK/Women).

I asked the members of the rural FG to tell me what they would or wouldn't do if they have a very close relative who refuses to test for HIV before marriage; their relative invokes her rights to choose what is best for her life, a participant responded:

In most cases I would say that it is parents who end up suffering. You will find one saying "it is my life, or if I perish it is my own body, so I can do what I want." But one forgets that it is parents who suffer when one gets ill. Because once one gets ill all those things will not be there, "saying that I have got rights I can do what I want." It is the parents who are going to suffer because they will be the ones looking after their sick child. That is why parents have to insist a lot that a child tests (FG/CN/Chongwe Rural).

Similarly, when I asked the participants from another FG the question about what as individuals they could say to a person who refuses to test for HIV, arguing that she can choose as she sees fitting because she is entitled to her choices, that is, she is the sovereign of her own body and life, some participants responded:

Participant 1: You [one] will tell her that "yes it is your life, but if you died I will be affected. I will never be happy. My life is just the same, if I died today, won't you be sad? That's why I want you to test for the sake of your life..." In the family how it is [In reality the way it is in families is that] if one is sick, everyone just the same won't be well...

Participant 2: If you are not infected you are affected. And sometimes these rights which are there we abuse them. We abuse our rights sometimes. Because I can say "it's my choice it's my right you know!" I don't even know the consequences that are there when I am saying "it is my right it is my choice." Yes, it your right it is your choice, but when problems come we are all affected. But you were saying it is your right it is your choice, you know... So these rights sometimes we abuse them and

they are bringing problems in homes... These rights which have just come...  
Participant 3: In fact we can say rights were there. But we were very obedient to our parents. In Bemba they say *uwuumi wa muntu waba mkutwi* [translated: the life of the person is in the ear or in hearing]. You need to listen to what people are saying. As an elderly person knows why he is saying this thing is bad...  
(FG/LSK/Churchgoers).

When all participants from the PLWHA FG, apart from one, told me that they would prefer that HIV testing in Zambia is compulsory I asked the participants that since they say so, then what happens to an individual's right to choose what is best for his own life. Participants, for example, argued:

Participant 1: Their rights could be there quite alright. But if you know that this person if you can't force [test him without consent] he is going to die, it is better we put away the rights.

Participant 2: Because if you are going to die that right won't be there [if a person dies she cannot in the future enjoy the right to choose what is best for oneself]...

Participant 3: If there was ignorance about the testing, because the time I was doing my pregnancy antenatal my CD4 was as low as 9. Yes. So now I imagine if I was ignorant... So it should be mandatory.

Participant 4: It is like what the others have said... When you tell these people do this and this and this. They refuse in these compounds. People run away...  
(FG/LSK/PLWHA).

In other words, as indicated above, the majority of fieldwork participants shared that they tested for HIV, or would test, or would cause others to test for HIV not because it is what the participants thought is best for themselves, but apparently for mutual benefits or solely so as to protect others, e.g., unborn babies. In other words, such testing is done or would be done not because the individual thought it is best for her own good, but also because of consideration of the present and future welfare of others. When I asked participants to share what they would do if their partners asked them to test for HIV because of pregnancy, a participant answered:

Me just, I would [test for HIV] just like the reasons we are giving you. If it's me and my spouse it would be much better to live for a long time while we are taking care of those kids [participant held that testing for HIV would enable her and his spouse to access HIV treatment which would prolong their lives]. We cannot just die 3 years from now! Moreover, my first born is still at pre-grade so if I die today how is he going up to college. And you know the way it is here... If I found out that me and my

wife we are positive, I mean the doctors and whoever will tell us that you are this and this. If you want to stay for a long time try to this and this. I am not talking from without (FG/MT/LSK/Teachers).

What this participant said is that he will test for HIV in order to ensure the future security of his young children. Put differently, his readiness to test for HIV is not only about what is good for himself, but also his toddlers.

I asked participants in the women forum discussion if they could have still tested for HIV if HIV testing in practice was not compulsory.<sup>128</sup>

Participant 1: As for me, in accordance with the counselling we received I could have volunteered to test because I thought that the health of my child is a priority... If I test, the way I thought, I will prevent my child from getting the disease. Because that child once he is born he can have many more years to his life. But for me, me I am old I can know how to look after myself. But that child is innocent. So since I am the one who got the disease I will not want my child to get infected. So on my own I thought that if I tested as a volunteer just to protect my innocent child...

Participant 2: As for me, when I had my first born I was so scared. When I became pregnant with my first child. I was so scared that "I go to the hospital to test? No, I will not go there. To go and test, no I will not go there"<sup>129</sup> But when I went and at the moment they were testing me I was so scared, I thought I will get killed when drawing the blood... When I had my second child, my son, I said "I am used... Even if I am scared I will test so that my child will be well, so that if I am sick the child will be well. I don't want my child to have HIV" (FG/LSK/Women).

Participants from this forum continued to share:

Participant 1: ... I want to know my HIV status because there are so many diseases. Testing is important so that I can know how to look after that child...

Participant 2: Yes now I can test, but I was also not so comfortable with the idea of every pregnant women going for testing. But I have looked at the benefits, it is very important... When you go back in 1991 before this idea of voluntary coming, mandatory testing pregnant women came in 2 pin [2 pin is a Lusaka slang which in this case means "the year 2000"]. We see a lot of children who were born during that period. They are positive today and it is very sad. If they started testing compulsorily back then, I think today we are going to say that children who are positive would be few... (FG/LSK/Women).

An HIV counsellor talking about pregnant women's autonomy in HIV testing argued:

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<sup>128</sup> These participants had told me that HIV testing for pregnant women is compulsory in Zambia.

<sup>129</sup> Participant reasoned with herself.

Now that she [a person who is pregnant] has a child, she is not alone. She has a child and she has a dependant now.<sup>130</sup> She just has to go for testing which is the most important thing... I will advise her on the counselling process, and the testing process which is the most important thing. And not for her but for the child as well. That is the most important thing, for the child. Most for the child. I will do that for the child... (II/C/LSK/28).

Indeed, as I indicated earlier, the majority of participants were in favour of compulsory HIV testing in certain cases. These cases included pregnant women and people who are taken ill at a hospital or clinic. In this vein, for example, when I challenged a participant to explain why he desired HIV testing to be compulsory to every service-user who visits a hospital or clinic in Zambia, the participant, a police officer, argued:

I already said it, it [HIV] will be very easy to control. Because that will help us to know if really we are fighting the HIV AIDS; if our fight against HIV and AIDS is going in the right direction. Or we are not doing anything? Can you see? Because you cannot have the good information [statistics]. You might think you are fighting AIDS, you might think you are the conqueror, but you are the most conquered. You get my reasoning? You might think that, for example, as a ministry, take it to [for example] the Ministry of Health. The way they don't do it [compulsory HIV testing]], they don't do it to everyone who just goes to the hospital, how can you have the information that you are really fighting AIDS? Because you just test some people for malaria, but the actual thing he is suffering from is HIV and AIDS? You see? He goes, this one comes, you just test for something. The actual thing you are living with it [testing for other illnesses when the real illness is HIV]... You end up just giving wrong medicine. The disease and even death rate will just continue rising... (II/F/LSK/01).

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<sup>130</sup> Several participants argued that pregnant women should test because they are 'no longer alone'. For example, a hotel cook, a woman who was tested several times without informed consent on two occasions when she was pregnant argued that it is a good initiative to force expecting mothers to test for HIV for the sake of the welfare of an unborn child and that of a given community. She explained that *"a child is a soul which expecting mothers carry", and that forced testing for HIV is convenient because the case of pregnant mothers involves two lives as opposed to one life. It is about saving the life of the mother and that of the unborn child; not just to be centred on the rights of the mother, the informant argued. She lamented that decisions which do not consider the well-being of the unborn child are selfish in nature. Furthermore, she argued that forced HIV testing at the antenatal clinics is a good practice because many ignorant pregnant women come to know their HIV statuses through such initiative. She also stated that knowing one's status gives an opportunity to other people, e.g., relatives to know that one of theirs is ill. "It is important that one tests in light of one's relationships with others because in the end it will be relatives who will suffer taking care of a relative who has developed AIDS and a child orphaned by AIDS", the participant (II/M/LSK-LA/02) argued. II/M/LSK-LA/02 was a housewife, had children, and trained in hotel and catering management. She was in her late 20s.*

## Conclusion

The findings from my fieldwork study in Lusaka and Chongwe suggest that the value of individual autonomy was dismissed by the majority of my study participants, in preference to the common value good. The participants' embrace of solidarity, sharing, caring and trust was connected to their idea to protect and promote the common good value – a value, which according to participants is necessitated by shared human frailty, vulnerability, connectedness and interdependence. This view reflects a people who favour living in relationships with others. It rejects human rights values which are exclusively premised on individualism, exclusively focused on present satisfaction of individual rights at the expense of the future legacy, promote self-centeredness and imbue competition at the cost of the common good, create boundaries between human beings, and advance that human beings are rational actors and self-sustaining.

My findings expose a people who valued, embraced and perpetuated Ubuntu. In the following chapter, as a part of the discussion in the light of the results shown in this chapter, I have argued that the participants' rejection of individual autonomy suggests that people in Lusaka and Chongwe are followers of Ubuntu. In other words, I have considered the participants' opposition to the value of autonomy as influenced by sub-Saharan African communalistic ontology and way of life. According to dominant sub-Saharan African traditional and moral outlook, "human beings have a dignity by virtue of their capacity for community, understood as the combination of identifying with others and exhibiting solidarity with them" (Metz, 2011, p. 532):

The hallmark of Ubuntu is about listening to and affirming others with the help of processes that create trust, fairness, shared understanding and dignity and harmony in relationships... Ubuntu consciousness is about the desire to build a caring, sustainable and just response to the community – whether that be company, village, city, nation or our global village... The African view of personhood denies that a person can be described solely in terms of physical and psychological properties (Nussbaum, 2003, p.3).

# 8

## Discussion

The purpose of this dissertation was to analyze the value of autonomy from theoretical and empirical perspectives in the context of HIV informed consent testing requirements in Zambia. My analysis of autonomy was relevant because informed consent requirements in HIV testing are premised on it. Hence, it was imperative that chapter 3, which I made the basis of my literature review, was devoted to an analytical discussion of historical, philosophical, and ethical dimensions of autonomy. This was necessary because only by first appreciating the power of the value of autonomy was this study then enabled to comprehend its strengths and limitations (Gaylin & Jennings, 2003). Thus, it was first necessary to establish what the concept of autonomy entails (theoretically) before legitimately comparing and contrasting its understood nature with people's lived experiences and views. My literature and fieldwork analysis indicates that the employment of individual autonomy in HIV testing is problematic; the value is illusory, and its employment in Zambia impractical and/or morally inappropriate.

In chapters 3, 4 and 5 it was observed that the concept of autonomy has its roots in the individualistic Western liberal conception of what it means to be a human being. Then, it was noted that sub-Saharan African governments (Zambian in particular) have adopted these very individualistic values in their HIV testing laws and/or policies (Ujiji, et al., 2011; Eba, 2015). It was argued that such approaches have been aided by a mistaken or pretended view that individualistic values are universal human ideals, and compounded by the view that sub-Saharan African values are non-existent or inferior. Such a view has made it fitting for Western countries and international institutions, e.g., the Bretton institutions, to demand that African political and civil leaders adopt individualistic values into law and policy as a condition for monetary and technical support, and cooperation (Torul, 1984; Human Rights Watch, 1997; Pahuja, 2012; Omaswa & Crisp, 2014; Sosala, 2017; The Mast, 2017).

However, this study and other studies done in Africa by both African and other scholars suggest that the internationalization of individualistic values in sub-Saharan African countries is inappropriate. They show that African peoples, in general, have their own way of life and reality of which my study has found to be disjunctive with the current universalized autonomy requirements in HIV testing.

Studies (this one included) have shown that individualistic values have continued to be rejected by ordinary African peoples, in particular in HIV testing. The reason for such rejections is practical; the dominant sub-Saharan African peoples' way of life is ontologically communalistic. It places a greater emphasis on the need to preserve the common good. In contrast to the liberal Western conception of human rights which are exclusively centered on individual choice and wellbeing, the African indigenous humanistic perspective in addition holds that the promotion of the common good value is equally critical – by virtue of natural human sociality, interdependence and interconnectedness.

Thus, this study will conclude that it would be more appropriate and effective to apply indigenous African human rights values to HIV testing in Zambia, instead of liberal Western values. Indeed, as opposed to the view that Africa is a dark continent which needs to be civilized through, among things, the application of Western notions of human rights, my study has found that sub-Saharan African countries have an indigenous regime of human rights which is more suited to address African human rights issues.

Africa as a continent has been globally pitied as poor and incapable of managing its own affairs (Doyle, 2009; Omaswa, 2014; Gelman, 2016). It is represented as a Dark Continent which needs salvation from the industrialized, enlightened, and progressive Western world. Indeed, taking into consideration that African countries have over the years been buffeted by poverty, famines and wars, it would be correct at first glance to indict Africans as a peoples who are incapable of managing their own affairs and fostering a future which could equal or even imitate the present Western 'civilization'. Politically, this picture has inevitably been aggravated by some African political leaders who, due to insatiable greed and power, have clung on to political power at the expense of respect for basic human rights of the peoples whom they claim to represent and serve (Magnarella, 2000; BBC Africa HYS Team,



2011; Somerville, 2016).<sup>131</sup> In this light, it is correct to construe Africa as a continent to pity, one which if left to its own devices is incapable of managing its own welfare and future. The African continent continues to be seen as a region possessing a people who need help from outside, help in form of financial aid, “worse still, for ideas and solutions as well” (Omaswa, 2014, p. 13).

This study shows a different picture of ordinary African peoples. It shows that the generalized picture of an African peoples who are incapable of managing their own future is only true as far as greed, corruption and authoritarianism perpetuated by some African political leaders, their minions, and surrogates is concerned. African traditional and moral thought which requires every human being to promote and respect one other’s human rights contradicts prevailing and reported political and human rights abuses in some African countries. People in some African countries’ basic rights are routinely violated not because African civilization lacks an indigenous humane and decent regime of human rights, but it is because those involved in human rights violation (immersed in achieving selfish ends) in African countries simply fail to respect Ubuntu.

It is this Ubuntu which I sought to establish in chapters 4 and 5, and was confirmed by participants in chapters 6 and 7. A theory which, I argue, ought to be acknowledged and integrated in HIV testing informed consent requirements: a traditional and moral theory which holds that individuals are unique, possessing inherent dignity and worth, and yet at the same time are social in nature; a philosophy which celebrates both the individuality of every human being and equally underscores the need to protect our shared humanity. It preaches that an individual’s pain is another person’s pain. The application of this philosophy to HIV testing policy in Zambia would entail that HIV testing would be seen to be a common good.

To this effect, the present study laments that had some African political and civil leaders searched and heeded the common humanity theory of its precolonial sages, the African continent would not be wearing its current pitiable reputation. And most likely, there

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<sup>131</sup> Besides political corruption, African countries’ poor human rights records is attributed to post-colonialism, ignorance, poverty, disease, internal conflicts, racism, debt, bad management, lack of judicial and press autonomy, religious intolerance, and border conflicts (Magnarella, 2000). However, corruption is not restricted to the political elite; it is commonplace across the public sector in African countries (McCool, 2015).

wouldn't be a mismatch between HIV testing law and policy and clinical practice in sub-Saharan African countries. It is celebrated in this thesis that sub-Saharan African countries have an indigenous philosophy which is incompatible with the colonial image and contemporary media portrayal of an uncultivated and uncivilized peoples, and on the other hand, regretted that such an indigenous philosophy is not reflected in HIV informed consent requirements in Zambia.

## **8.1 Summary of my fieldwork findings**

Diop observed:

The historical factor is the cultural cement that unifies the disparate elements of a people to make them into a whole, by the particular slant of the feeling of historical continuity lived by the totality of the collective... It is the historical conscience thus engendered that allows a people to distinguish itself from a population, whose elements, by definition, are foreign... The historical conscience, through the feeling of cohesion that it creates, constitutes the safest and the most solid shield of cultural security for a people (Diop, 1991, p. 212).

This study has shown that sub-Saharan Africa is communitarian in outlook. Ubuntu is a historical conscience of sub-Saharan African peoples – indeed, a conscience which at present still enables these peoples to distinguish themselves from non-African conceptions of what it means to be a human being. This conscience, my study has found, is not reflected in HIV testing informed consent requirements. In fact, my fieldwork findings have shown that this representative indigenous African communitarian outlook, a way of life transmitted by the peoples of sub-Saharan Africa from one generation to another through tales, songs, dances, proverbs, aphorisms, drawings, etc., can still be found in attitudes and views amongst ordinary peoples living in Lusaka and Chongwe.

Besides literature analysis, this study set out to find out about participant experiences and views regarding living an autonomous life. This approach was in part necessary in order to appreciate how the peoples in the areas of my fieldwork relate to the reported historical African Ubuntu conscience, if they did at all. In this vein, my fieldwork interview questions were designed in such a manner so as to access participants' present practices and appreciate the dominant assumptions and motivations underlying those practices. It is this

approach which has in fact aided my study to identify the dominant ethos and ontological outlook of my study participants, findings of which I have compared and contrasted with the historical Ubuntu conscience discussed in chapters 4 and 5.

The discussions and conclusions of my fieldwork study are thus drawn from the participants':

"...ethos, that is, their qualities, temperament or attitudinal inclinations, their dominant assumptions, their underlying sentiments that inform their beliefs, customs and practices." What is here suggested is that there are some dominant attitudes or recurring elements of life, which define the cultural pattern of any given race, or people, which can be identified in the way they act, interact or behave (Agulanna, 2010, p. 290).

The main findings of my fieldwork are that Ubuntu values are still respected and practiced in Zambia. I identified this practice from participants' attitudes towards life and ethos:

Cultural norms are not the only determinants of behavior. Cultural habits are conceptualized as ideal norms or patterns of behavior. Since a person behaves in response to his or her perception on the total situation, including physical stimuli and psychological factors such as the degree of the person's identification with the cultural model, actual behavior may not necessarily coincide with ideal norms or patterns of behavior... (An-Naim, 1990, pp. 337-338).

The study indicates that HIV testing practices and views in Lusaka and Chongwe do not conform to universal informed consent standards. It is especially apparent from data showing that pregnant women who go for antenatal services, and people who present ill at clinics and hospitals are routinely tested for HIV without their informed consent. This behavior by medical workers contradicts official informed consent requirements; requirements intended to protect individual autonomy. Moreover, these very unofficial medical practices can arguably be said to have contributed to an increase in HIV testing, especially amongst pregnant women.<sup>132</sup>

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<sup>132</sup> Prior to the introduction of PITC only 12% of pregnant were tested for HIV in 2004; this figure jumped to 95% within 5 years (in 2009) – an increase of 83% (UNICEF, 2010).

### **8.1.1 A disjunction between HIV testing law and practice**

My fieldwork results show that there is a gap between HIV testing in the Zambian law books and practice. The mismatch was not only observed in the practice of medical staff, equally non-medical staff (non-medical participants) expressed approval of the unofficial HIV testing practices. Men and women shared with this study how medical staff attended to them when they presented pregnant at antenatal clinics, presented ill at a clinic or hospital, sought male circumcision, or took a partner or a family member to a hospital for medical attention, or what happened to a friend or another relative who went to seek medical attention at a health facility. The pattern of their stories show that HIV testing informed consent requirements are routinely undermined in medical practice in clinics and hospitals around Lusaka and Chongwe. And, when I asked them why they agreed to test or would coerce a relative (or a service-user) to test, the majority invoked the common good premise as a reason for their behaviour or view. When I emphasized to them during interviews that per Zambian law and policy HIV testing requires informed consent, the majority of participants argued that it was right to compulsorily test certain categories of people (for example, pregnant women and people who present ill at medical facilities – others even suggested that HIV testing should be mandatory) in order to preserve the collective welfare. The dominant view from the participants was that individual rights should be balanced with social obligations.

The majority of participants underscored their views by arguing that individuals are not 'islands' but interconnected with others. They argued that all human beings by their nature co-exist and are interdependent, and that as a consequence individual choices have inescapable ramifications on the well-being of others. Put differently, participants saw themselves as naturally and essentially connected with other human beings, indicated that to strictly adhere to informed consent requirements would be immoral/ impractical, and also dismissed the value of individual autonomy as un-African (un-Zambian). All things considered, the dominant view of fieldwork participants suggest that informed consent requirements which are based on a Western model of autonomy hardly have resonance and internal validation in Zambia.

## 8.2 My fieldwork findings compared with existing research

On the whole, the theme that has come out from both my literature and data analysis is that the application of the principle of individual autonomy in HIV testing in Zambia is problematic. These results show for the first time that the universalization of informed consent requirements in HIV testing in Zambia is inappropriate. The majority of participants did not hold individual human beings to be autonomous; the two dominant views were that individual human beings are incapable of autonomy, and/or that the application of the value is impractical/ immoral (Gaylin & Jennings, 2003).

This human incapacity to be autonomous and impracticality of autonomy was confirmed by participants when participants shared with me about: what makes a lot of individuals not test for HIV; about the challenge of stigma and discrimination; about fear of refusing to test in the clinical setting due to the perception that refusal would incest a physician; about coercion in medical practice; and about participants being complacent in or favoring of coercive HIV testing practices.

Firstly, mere fear of testing, and anticipated self and social stigma were some of main reasons identified by participants as responsible for preventing people from volunteering to test for HIV. These findings are consistent with, for examples, Musheke's whose study has found stigma and discrimination, perceived psychological burden of living with AIDS, and fear of losing social support networks among the key factors which prevent people from testing (Musheke, 2013). An earlier Zambian study confirms "perceived negative reactions of family and friends, and fear of HIV-related stigma" as responsible for preventing the youth from seeking VCT (Denison, Lungu, Dunnett-Dag, McCauley, & Sweat, 2006, pp. 4-5). Another Zambian study concluded that when the level of social support among friends or family members is perceived to be high by a PLWHA, a person's health improves (Imasiku, 2009).

These studies indicate that mere psychological fear and fear of stigma and discrimination can inhibit people from testing for HIV (Mburu, et al., 2014). This suggests that human fear, as opposed to acting rationally, can impede HIV testing uptake. This demystifies the illusion that people can always act rationally for their own best interests. My thesis has shown the opposite; HIV testing uptake is significantly correlated with family members or medical staff

supporting the idea of testing and guaranteeing support that one will be still accepted and supported if tested HIV-positive (Denison, Lungu, Dunnett-Dag, McCauley, & Sweat, 2006; Imasiku, 2009; Musheke, 2013; Denison, McCauley, Lungu, & Sweat, 2014). This to me indicates an HIV testing by virtue of social autonomy, as opposed to individual autonomy. In other words, a person's experiences of living with HIV or willingness to test are determined by factors located within and beyond oneself, including factors at the family and peer level, community level and structural level (Mburu, et al., 2014, p. 16).

Two conclusions can be drawn from this: human beings are ruled by fear, and secondly, human choice is susceptible to both internal and external influences from which one has no control (Crittenden, 1993; Oshana, 1998; Gaylin & Jennings, 2003). Thus, it follows that human actions are a product of internal and external environments, not merely the rational self.

I wish to suggest that fear of self and social stigma is a product of socialization, internalization,<sup>133</sup> and biological factors. This perspective has been necessitated by research which has shown that people fear to test for HIV because of fear of a psychological burden of living with HIV, or fear of being rejected by others. People grow up being told that HIV is leprous and an immoral disease; they internalize this falsehood, and eventually become fearful of testing. These subtle socializations and internalizations compromise individual autonomy; it makes a person identify with and treat deformed ideologies and desires as natural, factual, and rational (Morison, 1984; Crittenden, 1993; Gaylin, 1996; Konner, 2002; Killmister, 2013; Mburu, et al., 2014).

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<sup>133</sup> HIV/AIDS stigma is a social construction. HIV stigma is shaped (in the sub-Saharan African context) by a view that an infection is God's retribution against man, and also shaped by pre-existing cultural values and beliefs surrounding sexuality. PLWHA "are usually considered deviant or shameful and as a result are shunned, avoided, discredited, rejected, restrained and or penalized" (Odimegwu, Adedini, & Ononokpono, 2013, p. 2). This can cause anxiety and fear among the socialized, and prevent one from choosing to know one's HIV status (Pebody, 2015). Indeed, understanding the nature of the underlying factors behind self and social stigma is critical; understanding such has both sociological and policy implications on how we view individual autonomy in HIV testing. People may refuse to test for HIV not because they are exercising their autonomy, but because they are scared of stigma if an HIV test comes out reactive. In other words, "stigma and discrimination have been reported as factors constituting a serious impediment for VCT uptake and HIV prevention... (Odimegwu, Adedini, & Ononokpono, 2013, p. 2). Studies have demonstrated that social influence affect human development and behaviour (Cook, Herman, Philips, & Settersten JR, 2002).

A person who is sovereign and a law to self would not resemble one whose decisions are influenced by fear or factors against which he has no control. Since autonomous individuals are self-governing, shouldn't their actions also be original and influenced by the self? "Self-governance must surely be taken to mean both governance by the self, and governance of the self" (Killmister, 2013, p. 111). Shouldn't it? A perfectly autonomous person is thus the human being who is most perfectly isolated from the natural society of others (Crittenden, 1993), and one who is an authentic sovereign of one's natural appetites and fears.

In this vein, wouldn't it, therefore, be fitting to draft laws and policies which encourage people to test for HIV (and encouraging others to support PLWHA) by informing or reminding them about the true facts of what it means to be a human being living with HIV or AIDS, by telling individuals that 'I am because you are' and 'we are because you are' – instead of what is told to them that they are autonomous HIV testing decision-makers? Existing research has demonstrated that community based interventions can change negative perceptions and create a positive environment for HIV testing (Mburu, et al., 2014). So, as opposed to promoting individual autonomy, shouldn't the lawmaker be finding ways to desocialize stigma in order to promote HIV testing scale-up? HIV testing is one of the tools that can be used to normalize HIV testing (De-Cock & Johnson, 1998; World Health Organisation, 2005; Pebody, 2015; Chan, Tsai, & Siedner, 2015).

Secondly, this study also found that some participants were tested for HIV (and other participants said that they know of relatives or friends or colleagues) who tested for because they were afraid to say 'no' to a test recommended by health-providers. Participants shared and reasoned that refusing to accede to a medical practitioner's 'request' could lead them to losing favour with practitioners, and might also impinge upon being able to access future health services. Because of this participants and other service-users have been tested or are susceptible to be tested for HIV. Other participants even shared that it is proper to accede to medical staff's 'requests' to test because physicians know what is best for service-users.

These findings confirm studies which have demonstrated that power imbalance and trust of medical professionals make the achievement of autonomy in medical decision-making difficult (Faden & Beauchamp, 1986; Molyneux, Peshu, & Marsh, 2004; Wear, 1998; Angotti, 2010; Groves, Maman, Msomi, Makhanya, & Moodley, 2010). Lack of education, feelings of

inferiority, disadvantaged economic status also contribute to feelings of powerlessness and lead to doctor deference when it comes to medical decision-making (Molyneux, Peshu, & Marsh, 2004; Larsson, et al., 2012). To question a physician's advice and proposed intervention could also be culturally viewed to be inappropriate within the sub-Saharan African region (Kenyatta, 1985; Molyneux, Peshu, & Marsh, 2004; Darley, Luethge, & Blankson, 2013). A participant in the Kenyan study even shared that it would be a miracle if a service-user refused to heed a doctor's advice to accept a proposed intervention (Molyneux, Peshu, & Marsh, 2004). It was thus not surprising when a midwife, among others, during an interview in Lusaka shared that as a hospital they have very few service-users who refuse to test for HIV when invited to do so by medical staff (FG/LSK/Nurses). These results indicate that rational choice hardly influences decision-making in human beings.

This further complicates the claim that informed consent requirements protect individual autonomy. What can be seen in the foregoing discussion is that service-users are tested because of fear, in that, they believe that refusal to accept an invitation from medical staff to test for HIV could affect the seeking of future medical therapy. Also, some test for HIV by deferring to medical staff's wishes as they regard medical professionals to be experts and beneficent actors:

Distilled from a host of conversations with my clinical colleagues over two decades, the prevailing clinician perspective on patient autonomy and informed consent would seem to be this: most patients come to physicians for their expertise in identifying and resolving problems that the patient no longer wants to grin and bear... They usually do not come to be educated, often not listening to whatever information is provided, and do not see themselves as decision makers regarding matters about which they have no expertise and of which they are often quiet ignorant... (Wear, 1998, p. 50).

My literature analysis and fieldwork findings suggest that service-users generally go to "their physicians for expertise and reassurance, not knowledge and power...; they want to be fixed and reassured" (Wear, 1998, p. 3). What this indicates is that the behaviour I found amongst my fieldwork participants is not unique to Zambia. It is apparent from Wear's research and other discussions in this thesis that the empowerment of patients by appealing to individual autonomy can hardly be achieved in the clinical environment. If fear of losing favour with a



health worker does not coerce a service-user to accept a proposed medical intervention, trust in the beneficence or deference to the expertise of a physician can. Studies have shown that even for those who are provided with full informed consent information and have a real choice to decline an envisaged medical intervention, they still prefer to defer the determination of the direction of a given intervention to physicians (Wear, 1998; Molyneux, Peshu, & Marsh, 2004).

In other words, consent to medical interventions by patients is hardly founded on a full understanding of informed consent information, rather on trust or mistrust, or on one's priorities (Wear, 1998; Molyneux, Peshu, & Marsh, 2004). For example, in a Kenyan study, most participants made the decision to participate in the study not based on the information disclosed to inform consent, but on their trust of the health and research institution (KEMRI) which was carrying out the research, or due to perceived fear of being excluded from using the health facility if they refused to participate, and/or, they saw their participation as a way to reciprocate the generosity or benefits gained from KEMRI's treatment and, other accrued benefits (Molyneux, Peshu, & Marsh, 2004). Compounding this is that health workers equally see themselves to be patient benefactors and contributors to the common good (Kinsinger, 2009).

In fact, medical staff whom I interviewed for this research tended to see themselves as the health guardians of their communities, and showed indifference to their lack of respect for informed consent requirements in HIV testing. They tended to be lukewarm towards, if not against, individual autonomy in medical practice. This has led me to conclude that no matter how much:

“...bioethicists and lawyers may consider the issue of informed consent to be beyond debate, many of those who must provide it remain unconvinced (and crucially, uncommitted to it). Mention informed consent to a clinician and my experience is that you are more likely to get a groan, as well as talk about the “myth of informed consent”... informed consent is not yet adequately fashioned to be successfully grafted into the heart of clinical practice. As a result, the practice, it is too often little more than a ritual, is offered grudgingly and without conviction by clinicians (Wear, 1998, pp. 2 & 4).

The foregoing observations only reinforce the view that “informed consent is thus a fiction masking a much simpler reality – that of the patient who chooses whether or not to trust in

his physician's judgment" (Wear, 1998, p. 50). Individual autonomy in HIV testing in Zambian clinical practice is an 'emperor's new clothes'.

Thirdly, the majority of participants shared that they tested for HIV because someone else required them to or coerced them into doing so. Put differently, participants and others in Zambia have been tested for HIV through coercion or due to medical staff having a mistaken understanding that HIV testing in Zambia among certain demographics is mandatory (or that PITC requires mandatory testing). Alternatively it was the service-users themselves who tested in the false belief that it is compulsory to do so. These findings confirm other research and media reports in Zambia which have shown that HIV testing amongst pregnant women and people who are taken ill at medical facilities are routinely carried out without informed consent (Mutombo, 2007; Imasiku, 2009; Musheke, Bond, & Merten, 2013; Phiri, 2014; Southern African News, 2014; Lusaka Times, 2015; Mwanza, 2015; Lusaka Times, 2017). These findings on coercion in HIV testing are also consistent with studies done, for examples, in Malawi, Kenya, Nigeria and South Africa where pregnant women especially have been found to being tested for HIV without informed consent (Molyneux, Peshu, & Marsh, 2004; Ordinioha, 2008; Groves, Maman, Msomi, Makhanya, & Moodley, 2010; Angotti, Dionne, & Gaydosh, 2010; Angotti, 2010; Odimegwu, Adedini, & Ononokpono, 2013).

In relation to the introduction of PITC in health facilities around Africa, studies done in sub-Saharan African countries have shown that HIV testing uptake during antenatal may increase by 80% due to the introduction of PITC (Larsson, et al., 2012), and others, for example, the one done in Lusaka demonstrate that the introduction of PITC in hospitals may lead to as much as 98.5% of inpatients agreeing to testing for HIV (Kancheya, Jordan, Zulu, Chanda, & Vermund, 2010). My study confirms a trend of increased HIV uptake since the introduction of the opt-out testing regime in Zambian health facilities.<sup>134</sup> These trends suggest that this increased HIV uptake amongst pregnant women during antenatal and other service-users who visit health facilities is connected to routine disregard of HIV testing

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<sup>134</sup> In Zambia, the government adopted the PMTCT initiative which has proved very successful in testing pregnant women for HIV. A 2010 report by UNICEF reveals that virtually all pregnant women who present themselves for antenatal are tested for HIV. In 2009 it was reported that 95% of pregnant women were tested; an 83% increase from 2004 when only 12% of pregnant women were tested (UNICEF, 2010). This scale-up of testing of pregnant mothers is reported to have led to the halving of mother-to-child transmission of HIV from 24% in 2009 to 12% in 2012 (AVERT, 2016).

informed consent standards in health facilities. In my fieldwork findings, it is either the PITC testing was mistaken for compulsory HIV testing by medical staff and other participants, therefore, leading to participants testing for HIV, and/or testing was effected simply through coercion or appeals to morality. In other words, “Provider-oriented testing, other than testing out of one’s own volition, is the major factor making people test for HIV in Zambia” (Mutombo, 2007, p. 17; Musheke, Bond, & Merten, 2013; Southern African News, 2014; Post Zambia, 2015).

These studies generally show that the choice whether to test or not to test, especially amongst pregnant women attending antenatal, is not for pregnant women to make. Put in the Zambian context, HIV testing in Lusaka and Chongwe health facilities does not appear to promote autonomy across all the population demographics because: pregnant women are misinformed prior to attending antenatal services that refusal to test for HIV is not allowed under the PITC regime (this misconception is not corrected by midwives and counsellors during antenatal information sessions); HIV testing service-users in medical facilities are hardly informed about their right to choose prior to HIV testing; some service-users, in general, do not know what PITC means (they end up mistaking it for compulsory testing); service-users are coerced into testing by being reminded about a moral duty to protect fetuses and other common good responsibilities; some medical staff compulsorily test individuals because they think PITC means compulsory HIV testing or just routinely ignore informed consent requirements; most service-users are afraid to ‘refuse’ to test when they find themselves in the clinical environment because of the perceived authority and/or beneficence of medical staff; and, some service-users are even tested without their knowledge and consent (Angotti, Dionne, & Gaydosh, 2010; Groves, Maman, Msomi, Makhanya, & Moodley, 2010; Larsson, et al., 2012; Musheke, Bond, & Merten, 2013; Lusaka Times, 2015).

This study confirms that there is in fact a gap between international informed consent standards in HIV testing and their application in sub-Saharan African countries. The importance of the notion of informed consent in the communitarian sub-Saharan African

countries' clinical practice is apparently trumped by other factors which either service-users or medical staff deem more critical and urgent.<sup>135</sup>

My study concludes that HIV testing 'universal' individual human rights are being disrespected in sub-Saharan African countries because they are premised on individualism, focussed on present benefits and harms to an individual, encourage self-centredness, are secular in outlook, imbue privacy and confidentiality, and are seen to promote distrust between medical staff and service-users (An-Naim & Deng, 1990; Silavwe, 1995; Taylor, 2006; Colson, 2006, Healy, 2007; Mutombo, 2007; Omaswa & Crisp, 2014). Indigenous African regimes of human rights were favoured amongst the majority of participants. African values were favoured because, according to the participants, these values reflect human reality and protect the common good. Contemporary Zambian cultural ontology is dominantly social in nature, futuristic in outlook, encourages co-operation and reciprocity (is relational in nature), is influenced by both African traditional and contemporary religions (especially Christianity). Whereas 'universal' human rights encourage privacy (boundary-ness or confidentiality), African human rights inspire sharing, talking and openness, and trust between service-users and medical staff. My fieldwork findings indicate that the participants' perspectives and actions are influenced by both African traditional ontology and the Christian outlook. The current regime of HIV testing informed consent requirements in Zambia does not reflect the African and Christian outlook.

So, if individual autonomy means "personal rule of the self that is free from both controlling interferences by others and from personal limitations that prevent meaningful choice" (Pantilat, 2008), then the majority of participants from my fieldwork study exhibited through their attitudes, actions, and behaviours that individual autonomy is an illusion and impractical. That is to say, that their practices and views suggest that informed consent requirements in HIV testing in Zambia are premised on an illusory and impractical edifice.

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<sup>135</sup> It would be thus, when it comes to HIV testing, be sensible to heed what the authors in a journal article of the *Journal of Global Marketing* had to say about advertising in sub-Saharan Africa (Darley, Luethge, & Blankson, 2013). The authors of this article concluded that advertising appeals in sub-Saharan African countries should be focussed on the society. That is, they recommended that advertisement appeals should be focussed on presenting the individual as a member of the community, due to the sub-Saharan African communal culture of belongingness.

Levine argues that “imposition of these [informed consent] standards as they are now written will not accomplish their purposes; i.e., they will not guide physicians in their efforts to show respect for persons because they do not reflect adequately the views held in the cultures of the nature of the person in his or her relationship to society (Levine, 1991, p. 209). Angotti has concluded that counsellors do not strictly follow the principle of consent as established and understood by international and national guidelines because, firstly, counsellors think that “families have legitimate claims on their members - claims which may override individual rights” (Angotti, 2010, p. 989). For example, she invokes a case where a counsellor (Harold; a participant in her study) was advised by a more senior counsellor on how to deal with cases in which parents send their children to be tested for HIV at the clinic. The senior counsellor explained to Harold that the latter may get cases where parents send their children to be tested for HIV in order for parents to know their children’s HIV status. In such cases, the senior counsellor explained, Harold must not refuse to test them because there is a reason why the children have been sent by their parents for the test.

Angotti reports that Harold empathised with the parents in their reasons for sending their children to test for HIV; “he [Harold] also articulates a different ideological heritage from the individualism of the West: rather than the autonomous individual” (Angotti, 2010, p.989). The author indicates that African peoples want to know the HIV status of their social others because they think like families. Where children may refuse to be tested for HIV, the senior colleague, according to Angotti, advised Harold to persuade children to test by telling them during counselling that the reason their father had sent to test for HIV is not malicious, but it is because their father is thinking of their future.

HIV health workers in Zambia disregard, alter, or adapt consent requirements because these health workers see themselves as guardians and benefactors of the health of their communities. When health workers realised that ‘universal’ informed consent requirements come into conflict with African and Christian morality, and against a desire to conduct oneself in a way consistent with one’s sense of morality, certain requirements of informed consent were thus ignored. Angotti notes that since HIV counsellors “implement the policies of consent, confidentiality and counselling, policies that they themselves [counsellors] have not designed – and indeed, had their origin far from rural sub-Saharan Africa – they must actively interpret and reframe them”(Angotti, 2010, p. 992).

These findings demonstrate that health workers adapt (or ignore) testing norms in an effort to reconcile such with what they perceive to be in accordance with their community or social responsibilities, as Africans and Christians. Medical staff participants see themselves as having extra-‘professional’ lives; that is, they see themselves as a people who have other competing roles owed to a family member, a friend, a village neighbour or a fellow Christian (Angotti, 2010). The majority of the participants across the all the demographics in my fieldwork study viewed themselves as missionaries of the common good (Angotti, 2010).<sup>136</sup>

### **8.3 Limitation of this study**

Firstly, my fieldwork was limited to Lusaka and Chongwe. I did not have time, resources and even the need to interview people from the other provinces of Zambia. Hence, I wish to emphasize that my findings from Lusaka and Chongwe may not necessarily represent the views of the peoples of Zambia. However, I am satisfied that even if I did not carry out any interviews in the other parts of the country, my study’s finding’s generalizations have support from newspaper reports and academic studies done in Zambia, which have found that informed consent requirements in HIV testing in Zambian clinics and hospitals are in practice routinely ignored.

I did not embark upon this study to find out how the majority of Zambians conceive autonomy in HIV testing, rather what the majority of interviewed people from Lusaka and Chongwe from across demographics perceive and experience autonomy; I went to Zambia to empirically test the hypothesis of my research. The objective of this study was to provide

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<sup>136</sup> Talking about the need for a moral response to protect the common good by reasons of our shared humanity, it has been observed: “The vulnerability and dependence of the other call forth in us a moral response... That moral response elicited by the vulnerability of others and our connectedness with them... It is a sense of a shared humanity and a sense of our own vulnerability and mortality; moral common sense is a sense of what we have in common with other members of the human moral community. Without these other values that pertain and respond to interdependence, autonomy alone does not provide an acceptable moral understanding of the human good, or of the fabric of our lives as moral beings. The social emotions are not symptoms of moral childishness; they are the signs of the moral engagement, embeddedness, and maturity... (Gaylin & Jennings, 2003, p. 254). Thus, I wish to suggest that the reported behaviour of sub-Saharan African (in particular, Zambian) attitude towards individual autonomy in HIV testing is synonymous with a people who are morally engaged and embedded in their socio-culture which celebrates our shared humanity.

a rich and contextualized understanding of a range of peoples across demographics in Lusaka and Chongwe in an effort to empirically appreciate their lived experiences and personal views.<sup>137</sup> Hence, the conclusions and careful generalizations drawn in this study are supported by evidence from both my fieldwork study (in-depth, rich and contextualized empirical data) and literature review findings (Polit & Beck, 2010).

And, lastly, in the previous chapter I indicated that the majority of participants shared that they were in favour of informed consent in HIV testing. It may appear biased that I have not included a chapter or even a paragraph exploring this view. However, I wish to establish that I did not explore or devote a chapter or paragraph to this view because when the very participants were asked follow-up questions which related to a family member or a service-user refusing to test for HIV, they were quick to either directly or indirectly denounce autonomy in HIV testing. Their denouncements of individual autonomy clearly indicated to this research a people who are in favour of balancing individual and collective rights in HIV testing.

#### **8.4 Recommendations for further research**

To sum up, this study does not make a claim that the views shared by participants in my study are representative of the population of Lusaka and Chongwe, rather, it suggests that the shared experiences and views found from fieldwork responses represent the majority experiences and views of the people in Lusaka and Chongwe who were randomly chosen for this study. In this vein, I therefore encourage further studies to be conducted in the other parts of the country which should adopt a quantitative or a mixed research methodology approach on the question of this research. I am confident such studies will contribute to our knowledge of informed consent, and further enriching the debate surrounding the appropriateness of individualized HIV testing informed consent requirements. Future larger studies with statistical analysis on the practice of informed consent in Zambia as a whole would be of interest.

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<sup>137</sup> “Qualitative researchers seldom worry explicitly about the issue of generalizability. The goal of most qualitative studies is to provide a rich, contextualised understanding of human experience through the intensive study of particular cases” (Polit & Beck, 2010, p. 1452).

Moreover, the analysis in this thesis does not enable us to determine whether there could be a link between the adoption of African human rights and increased HIV uptake. What this study has indicated is that there has been increased uptake of HIV testing in health facilities in Zambia, and this could be linked to routine coerced HIV testing. A study devoted to this end would also be welcomed.

## **Conclusion**

All things considered, if the world hopes to see a prosperous Africa, it should recognize that transplanting Western values into the African reality – values which are generally a product of Western experience and reality – will hardly develop the welfare of that continent's peoples. It is thus contended that the solution to African problems lie in tapping into African solutions, solutions which were developed by African sages on the basis of African experience and reality. The appropriate approach to HIV testing in Zambia, and in sub-Saharan African countries, lies in recognizing and respecting this African reality and experience. My thesis proposes for an HIV testing regime which acknowledges and respects the dominant humanistic African reality, and embraces the contemporary experience of the impact the HIV epidemic has had on the peoples of sub-Saharan Africa, and Zambia in particular.

Indeed, in Zambia AIDS has affected almost every living family. When one meets any random Zambian person and asks her about her experience with HIV, there is always a sad story behind every response. It is either the person asked is herself living with HIV, or a very close relative or friend or acquaintance is suffering or died of AIDS. This reality is different from that in the Western world where HIV prevalence is very low. Adumbrating the genesis of the HIV epidemic in Zambia, Colson correctly paints a horrifying picture of the devastation of the disease in that country:

From the 1980s on, AIDS became an increasing drain on resources, as people came home from the towns to die, and HIV infection spread through the villages... By the end of the century, it was estimated that 21% of Zambian population, between the ages of 15 and 49, was infected with HIV... Death became more salient, everywhere, as the number of deaths rose, and funerals absorbed an ever greater proportion of time and other resources. Wailing became the common background sound against



which daily life was lived out. I have heard it suggested that many Zambians, by 2000, were behaving as though they suffered from clinical depression. They had reason to be depressed. Many were ill, or worn out with caring for the ill, and the poor felt their poverty more severely, contrasting this with their earlier hopes and achievements... (Colson, 2006, pp. 226-227).

It would not be correct to say that the Western world from where HIV testing individualized consent requirements have been largely imported share this Zambian reality and experience. It would not be true to say that Western countries have similar experiences in relation to the experiences and impact of AIDS in African countries, hence my objection to the transplantation of Westernized autonomy in HIV testing in the African sub-region. Moreover, the conception of individual autonomy is philosophically problematic. African jurisdictions in their legislation and court rulings ought not to gamble with a value which is not only elusive, but also inappropriate in the African context in the light of the dangers that the HIV epidemic poses against the common good of its peoples.

It has been demonstrated that human beings are incapable of being autonomous due to reasons owing to their natural sociality since birth, and due to biological factors. In this vein, rational choice or self-reflection theories or any other self-determination theories which place a human as a sovereign of her choices and life have been found to be incoherent, at best. My study understands that human beings' decisions are influenced by a conflation of biosocial and psychological factors. It is these internal and external factors which make up the "self" – the "self" is made up of environmental facets. Thus, we cannot comfortably talk of such a thing as an individual self; rather to talk about a "socio-relational self".

Moreover, even if individual autonomy was not an illusion – that is, if it was achievable in real life – this study, in the light of African ontology, still argues that human beings by virtue of their natural sociality and interdependence have moral obligations towards each other. Indeed, such an understanding would have inescapable ramifications on the way we view ourselves when it comes to making HIV testing decisions; the HIV epidemic is a menace to our common humanity. Currently it is only by means of HIV testing that we will be able to prevent the fruition of this real humanitarian danger. The African ontological perspective that demands reciprocity and shared responsibility would require that people in Zambia and other sub-Saharan African countries shouldn't exclusively claim for individual rights goods

but also respect the rights of others (the common good); it establishes that individual rights and obligations are not mutually exclusive, but are to be enjoyed simultaneously.

The evolution of self-determination from city autonomy to individual rights involving participation in civil and political governance, entitlements to economic, social and cultural welfare have broadened the rights of individuals almost in total denigration of individuals' moral obligation to the common good. In fact, as a consequence of the horrors of Nazi experimentations and murders, and other inexcusable premeditated inhuman deeds like the Tuskegee syphilis experiment, informed consent requirements have over the years eventually been extended to individuals in medical decision-making, and subsequently to HIV testing.<sup>138</sup> The present dominant discourse of human rights is that an individual cannot be tested for HIV without informing her of the benefits and harms of the test, without being told about any alternative treatment, and without being informed about her inalienable right to refuse to test.

The individual who is surrounded by multiple factors, and whose illness (if she is living with AIDS) could affect other people is here told and celebrated as a sovereign of her own medical therapy and life. She is told that she can choose to test or not to test because she is her own person, and an author of her own life and destiny. According to this discourse, the individual's rights and course of actions are primary; collective rights are recognized only to the extent that they support the enjoyment and protection of individual rights and choices (Woods, 2002-2004). This view is indeed problematic and/or incoherent.

In fact, in the light of the International Conventions on human rights and the Universal Declaration of Human Rights, it is apparent that such an outlook represents an understanding to the effect that to be a human being is to demand protection and require help from others. Ironically, social responsibility (even when these same international instruments imply that human beings are interdependent) is relegated to a mere interference with the value of an individual's autonomy. That is, these instruments (which have been adopted in HIV consent requirements) advise us that we can only participate in

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<sup>138</sup> The value of informed consent first appeared in a recognisable and robust form since 1957 (Schuck, 1994). Indeed, "[t]he great philosopher of medicine, Hippocrates, would [indeed] be shocked by the world of modern medicine and possibly hounded out of the medical profession and driven into poverty by" the current informed consent requirements in HIV testing (Kurtz, 2000, p. 1243).

the sphere of another person's life if she permits us to; if she doesn't, then we should mind our own business.<sup>139</sup> We should tell a spouse, son, daughter, parent, friend, or health service-user that she has a right to test for HIV because besides being a law unto herself, she is a rational human being who should choose what is best for herself.

The individual human is here epitomized and celebrated as a self-moral agent to whom we owe recognition and protection of her rational self and bodily self. Individual rights become individual claims to be protected from the interferences of other people (Niekerk, 1998).<sup>140</sup> It is indeed troubling to appreciate that man who was once pitied to be naturally dependent, vulnerable, fallible, and a moral agent is now declared and celebrated to be a rational and/or a sovereign and one's own; thus, she is proclaimed empowered by her 'inherent' individual autonomy to choose and direct her own HIV medical therapy without interference from others.

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<sup>139</sup> Schuck observes that genuine respect for the dignity of the autonomous individual requires that a broad deference to her choices is upheld and promoted. That, "it is to say that she [the autonomous individual] alone can define the nature of her relationships with others..." (Schuck, 1994, p. 900).

<sup>140</sup> Donnelly observes that "[t]he idea of human rights does entail a certain individualism... the human rights establish special and particularly strong obligations owed specifically and directly to each individual by every other person or group and, in particular, by the state. Each person, simply as a human being, is specifically entitled to the treatment demanded by human rights" (Donnelly, 1990, p. 35).

# 9

## Conclusion

In this study, I set out to investigate the appropriateness of individual autonomy in HIV testing in Zambia, and in general in sub-Saharan African countries. I built my hypothesis on the premise that the universalization of informed consent requirements could be problematic because, firstly, individual autonomy could be an illusion, and secondly, that it may not be appropriate to apply this value in the Zambian context because of the peoples of that country's lived socio-cultural reality and experience. In other words, after I witnessed friends, family and community members suffer because of not testing for HIV, I began to question if people are in fact autonomous as individuals, and if so, whether individuals' autonomous right to test or not to test for HIV should still always take priority over the common good.

To investigate this question, in the first part of my thesis, firstly, I sought to analyze autonomy and its relationship with informed consent from a Western perspective (chapter 3). Secondly, I reviewed the ontological perspective of traditional sub-Saharan Africa on the question (chapter 4). The final part of the first part of the investigation was devoted to an exploration of Zambia's socio-cultural and economic reality, in an effort to analyze the appropriateness of HIV testing autonomy in the Zambian context (Chapter 5).

The second part of this study was concerned with reporting the results of my fieldwork data. In chapter 6 I shared my findings on participants' experiences with HIV informed consent requirements, and in chapter 7 I reported on the attitudes my fieldwork participants held towards the application of individual autonomy in HIV testing.

My literature analysis and fieldwork findings demonstrate that individual autonomy is an illusion, and its employment in Zambian HIV testing informed consent requirements is inappropriate. It was found that individual identity is a product of biosocial and psychological factors. These findings indicate for the first time the inappropriateness of the application of informed consent requirements (premised on individual autonomy) in HIV testing.

## 9.1 Individual autonomy: “an emperor’s new clothes”?

My literature analysis and fieldwork findings indicate that a theory that holds that an individual person is capable of choosing their behavior autonomously, “and that the conduct of others can generally be modified through rational argument”, or through self-reflection, is an illusion (Gaylin & Jennings, 2003, p. 7). Indeed, subscribing to a perspective of an autonomous human being “reflects an inadequate understanding of human motivation, and ultimately is philosophically and morally untenable” (Gaylin & Jennings, 2003, p. 7).

Instructively, even public health regulations and law, national security pronouncements by politicians, and the International Convention on Economic, Social, and Cultural Rights paint a different picture of human condition; a human being is implicated by these instruments as one who is dependent, and who is to be taken care of by others for her own good.

Surprisingly, it is still pretended or implied in these very texts that man is autonomous:

Autonomy understood as negative liberty appeals to metaphors of space. It wants elbowroom – a place of its own. It is the single-family dwelling of ethics. Negative liberty requires fences and boundaries for protection against outside intruders. It rests on a conflict-ridden and antagonistic picture of social existence, in which each individual struggles with everyone else to control his own patch of ground... Autonomy as positive liberty rests on the insight that human self-sufficiency is limited and that freedom often requires the assistance of others. This insight has led to an expansion of the concept of rights into what has been called positive rights... Rights are moral (or legal) claims that a person makes against one or more other people to protect or promote his or her freedom... Positive rights are sometimes called “welfare rights” or “social rights”... A woman’s negative right not to be hindered from having an abortion would have to become a positive right to be helped in having one (Gaylin & Jennings, 2003, pp.40-43).

Moreover, it is apparent that even if individual autonomy is promoted in Western countries, these same countries seem to acknowledge the limits of the doctrine in their public policy, laws and regulations, through their (Western political leaders’) frequent invocations of interest and security, and even in court judgments (Hill, 2006). The presence of these public policies, interests, security and judicial justifications suggest to me that individuals are only allowed to be autonomous as far as a government authority deems appropriate. This begs the question: if autonomy is in fact objectively natural and inherent, then how can an

inherently sovereign individual be told by others she cannot be autonomous in given circumstances (?):

...the supremacy of absolute individual freedom in western law is faltering. And its protection is countered through the application of the principles of public policy, public interest, *boni mores* and equity. Although individualism is still reflected in these principles, the position of the individual as a part of a larger whole is coming to the fore, thus limiting the absolute primacy of individual freedom... If the western idea of freedom is to mean something other than the satisfaction of individual desires, it must include solidarity with others through participation (Niekerk, 1998, p. 172).

My research has shown that self-reflection or rationalizations do not make individuals autonomous. The individual who is born into society, dependent on society, is naturally susceptible to sociological, bio and psychological drives and impulses which compromise rational choice. A person who is inextricably faced with one's family and society's formidable capacity to instill and enforce conformity cannot legitimately claim to be sovereign or a law to herself. She can even pretend to be a self-made anarchist, yet once her ideas of her 'ism' are closely inspected, one will be disappointed to find that the very 'self-made' anarchist is actually not the originator of her ideas. Furthermore, if it happens that the anarchist is arrested for a public nuisance or breach of peace offence, in the defense of her actions she is more likely going to plead that she suffered from temporal lapse of judgment or that her actions were intended to highlight an injustice against humanity, or that her actions are synonymous with human weakness:

Whereas the individual may succumb to deviant impulses and drives in private, and may even consider rebellion against the established ideal, open deviance and rebellion are rare. The powerful force of conforming to the established ideas by the fact that most people seek to keep their deviant behavior secret and, if discovered, try to explain them as temporary lapses in judgment rather than deliberate rejection of the ideal norm or pattern of behavior. Even the few who choose to come out in open revolt, whether or not they claim a commitment to an already alternative model, would normally attempt to explain or rationalize their position as reflecting a more genuine commitment to the ideals of society, or as resulting from a reinterpretation of those ideals... Many scholars have recognized that our perception of the world is conditioned by our pre-existing conceptual categories... This generally accepted proposition applies to many facets of life, such as perceptions of beauty... (An-Naim, 1990, pp. 338-339).

Indeed, there is a mismatch between the theory and reality of autonomy. Is it not time we appreciated that we are products of our environments, and that individual autonomy is “an emperor’s new clothes”? This is what the first part of this thesis (chapter 3) found. By virtue of the reality of various internal and external environmental factors, individual autonomy is an illusion.

### **9.1.1 Individualism rejected**

Secondly, the promotion of autonomy solely from the perspective of individual choice impinges upon the necessity to respect and sustain our shared humanity, and is therefore immoral. We need each other as human beings for our wellbeing and survival. Individualistic values “have contributed to the creation of societies of cold isolation, with individuals and groups pitted against each other for their survival”, the result of which “has been social anomie, apathy and despair” (Felice, 1996, cited in, Woods, 2002-2004, p. 54). As Healy has lamented, “individualism, especially in its rugged and competitive forms, diminishes the importance of caring, reciprocity, community building, generosity and cooperation” (Healy, 2007, p. 24).

Put differently, “the protection of the individual has become a reasoned process which is sadly devoid of human feeling, emotion and compassion” whereby individuals do not only stand in radical isolation, but they are also objectified to resemble cold self-made and programmed automatons (Niekerk, 1998, p.171). Van Niekerk argues that human rights have become individual rights without reference to the relationships which individuals have with society. Health professionals, thanks to Kantian and Millian autonomy, are now told that they have to respect and promote unique values, priorities and preferences of individuals in HIV testing because an individual is a master over herself (a sovereign of her mind and body). Even when an individual is surrounded by multiple realities (e.g., he is a father who is emotionally, physically and materially depended upon by his young children), his decision not to test for HIV must be celebrated as his right to autonomy.

Western liberalism’s individualism is “a radical, competitive, atomising individualism that is both phenomenologically inaccurate and morally indefensible” because the only reality it perceives is the reality of the individual (Donnelly, 1990, pp. 35-36). Indeed, various authors

I reviewed in chapters 3, 4 and 5 find individual autonomy to be philosophically and morally indefensible, as did my fieldwork participants as shown in chapters 6 and 7 of this thesis.

My literature analysis and fieldwork findings have indicated that it is detrimental and immoral to atomize or isolate a human being by telling her that she can do whatever she wants with her own body and life or decide her own medical therapy, without at the same time telling her that her actions have ramifications on the lives of others. The current informed consent requirements do not require physicians to emphasize to a service-user that her refusal to test for HIV will add to the workload of the already overwhelmed Zambian medical staff at the hospital who will have to medically nurse her when her potential undiagnosed treatable HIV status develops into AIDS due to lack of treatment. The service-user is not told that her refusal to test for HIV has the potential of her late diagnosis being too late for treatment therefore leading to her demise which could expose her children or dependent family members to contempt, poverty, suffering, or even push them into their early graves. She is not told that when she becomes very ill due to AIDS, it's her close relatives and friends who are most likely going to nurse her, who will work to make her pain and suffering at least bearable. She is not told that her pain due to illness will be also her close relatives' pain and cause them suffering, and her demise their loss, etc.

What is overlooked in such policies is that close inspections of our lives show that as human beings we are what we are because of others; we are neither self-made nor independent. That is, since the time of our conception our lives have been interlinked with others' lives. It is these others who nursed us after conception, nourished, protected and led us through our childhood years', and now encourage, love, befriend, illumine and morally support us in our adult years. Therefore, is such a reality not enough to make us pause, reflect, sober up, and renounce the seduction of individual autonomy? Indeed, my literature review and fieldwork data suggest that as non-autonomous and interdependent individuals, our shared humanity morally obligates us to act responsibly in order to preserve the common good.

Hence, I have argued that as human beings it is not enough to pursue our own goals and perceived happiness without due consideration to the call of our shared humanity. This study has shown that divorcing ourselves from an inextricable reality to guard our shared humanity will not only isolate us from our significant others and lifeline (leaving us isolated, cold, despairing, and individually exposed to the perils of our common human vulnerabilities



and frailty; we would have bitten off the very finger that feeds, aids, nourishes and dignifies us as human beings), but, as demonstrated in chapter 3, such a divorce will also leave us holding on to an illusion of individual autonomy.

In fact, I wish to suggest that whenever we are faced with the temptation to celebrate our 'individual sovereign rights' we should pause, consider, and remember that we 'are' because of the humanity of others: our birth came through others, our name was given to us by others, we have been educated by others, the respect we demand is given by others, the first bath we have ever had was given to us by others when we were born, our last bath will be given by others, our funeral and potentially dignified burial will be organized and conducted by others, and, everything we have owned will be inherited by others once we are dead.<sup>141</sup> We are simply not autonomous as individuals; we are but interdependent and interconnected social creatures. Thus, morally we cannot operate as if we live in a vacuum.

Unfortunately, this moral imperative to provide for our common good, strictly speaking, is not promoted in HIV informed consent requirements due to the holding of individuals as sovereigns of their lives. When I speak about common good values, I mean values which:

... relate to the human condition of interdependence, and they find a basis for a fabric of life together in precisely those aspects of life and experience that the culture of autonomy disdains and ignores. Foremost, among those aspects are need, vulnerability, frailty, fallibility, weakness, and mortality. Autonomy forgets that the human being is incomplete without the mutuality of others (Gaylin & Jennings, 2003, p. 253).

It is in this vein that this study endorses the African traditional communitarian moral ontology which advances that the self is part of the whole. This philosophy departs from atomizing an individual by seeing the need for involvement of others in her life in order to protect and promote mutual dignity, happiness, and survival. This philosophical outlook does not seem to me to be merely a product of a peoples who are ruled by their hearts instead of their brains, but a people who understood (and still understand) their environment and intricacies of human condition. A philosophy which would see HIV testing as morally imperative because of our common humanity. In other words, in the light of my thesis's findings, I have embraced the indigenous African thesis of human condition.

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<sup>141</sup> The ideas in this sentence that we are because of others are not originally mine. I have adapted them from a WhatsApp text message which one of my siblings shared in a Group chat.

## 9.2 The 'civilizing' of an African

African colonizers, some Christian missionaries, and even early Western academics held Africans to be savages whose way of life was considered "inferior or even worse: evil and sinful" (Omaswa, 2014, p. 29). Even as early as the second century A.D., a Greek physician, Galen of Pergamon, merely reduced the characteristics of the black African to one whose length of his penis is inordinate, has a strong propensity for laughter, and hilarity (Diop, 1991, p. 216). These prejudices have since pre-colonization called for the civilization of these peoples. Shall we therefore be surprised when we see a Zambian trying to 'civilize' herself? Similarly, should we protest when we behold a Zambian being 're-educated' through universalized liberal instruments that she is an autonomous individual – instruments which have since been transposed into the Zambian constitution and pronounced in legal precedence (Torul, 1984).

Kenneth Kaunda, discussing colonizing powers' appetite to civilize the African, reports and concludes:

...the Portuguese believed that the African could, in time and with patience, be assimilated into the Portuguese culture as "assimilados," and be molded into versions of the Metropolitan Portuguese. Similarly, the French held that with adequate acculturation, the African could quite easily rise above his "inadequacies" and become a Frenchman... The African has never really been allowed by non-Africans to be African in both thought and deed (Kaunda, 1993, p. 835).

My thesis in chapters 4 and 5 has shown that informed consent requirements in HIV testing are not representative of sub-Saharan African thought and experiences; indigenous African ontology considers a human being to be socially autonomous. HIV informed consent requirements are a legacy of Western influences. The communal facets of Zambian indigenous and moral thought are not reflected in HIV testing requirements. Rather, it is the primacy of individual needs and goals which are legalized in HIV testing consent requirements. Zambian ontological collective rights are ignored, if not denigrated. Western liberal individualistic ethics are declared universal human values and celebrated. This trend is not a new one.

The African colonial rulers believed that their Eurocentric ideologies conceived a better world. Colonial administrators and missionaries were not in Africa to equally learn about the

African's ways of life, but to civilize black Africa (Silavwe, 1995). As a consequence, African colonial civil, political, economic, social and cultural systems were largely never based on local conditions and knowledge, in the same way the current informed consent requirements in HIV testing in Zambia do not reflect that country's peoples' socio-cultural outlook and ethos.

Silavwe has argued that the current solution to this misconception of African ontology lies in dismantling unsuitable Western liberal and libertarian values by replacing them with new ones that are a product of Zambian needs and wants (Silavwe, 1995, p. 78). This study has established that, in fact, Zambia has a civilization of its own which even today reflects sub-Saharan African reality and experience.

In chapters 4, 5, 7 and 8, it was argued that this universalization of Western values (ethics which are not bad in themselves) has continued today in sub-Saharan African countries. Africa being dependent on foreign financial, and to a degree technical, aid receives some of such assistance with attached conditions (Torul, 1984; Silavwe, 1995; Human Rights Watch, 1997; Lee, 2011; Pahuja, 2012; Omaswa & Crisp, 2014; Sosala, 2017; The Mast, 2017).<sup>142</sup> Looking at the poor human rights records for some of the African countries, it is actually appropriate that certain conditions are attached to aid. After all, such conditions could coerce those undemocratic, authoritarian, power-possessed, and greedy political, military and civic leaders who violate their peoples' human rights – thereby defiling our common humanity with impunity – to rethink their ways.<sup>143</sup>

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<sup>142</sup> Talking about dependence on foreign aid, even as recent as April 2017 The Mast Newspaper editorial mentions and laments this legacy. It notes that Zambia as a country has become so dependent on foreign aid for everything that includes economic, political and social wellbeing. In that, donors even design the country's economic policies, and they are the only ones who at the moment are capable of moderating the behaviour of political leaders because they can leverage their budgetary support to demand for good governance. In relation to HIV, the over 1.2 million Zambians living with HIV are not supported by the national budget. Rather, their lives have been left in the hands of donors, in that, should donors decide to stop funding HIV programmes, the majority of Zambians living with HIV will no longer be able to afford ART. Similarly, like Silavwe and Omaswa, the editorial concludes that if Zambia "want to live well in justice, in equity and in peace, it is the members of the Zambian society who should learn to do for themselves "all the things that are needed to build such a society". That is, such a just, fair and humane society will not come by itself, and "reliance on donors for good governance, respect for human rights, rule of law" won't do (The Mast, 2017).

<sup>143</sup> Unfortunately, as the Mast has also correctly observed, even donors themselves are not always interested to intervene when some African political leaders violate the basic human rights of their

The Bretton Woods institutions to which African political leaders have gone – and still go – begging for financial aid and advice give conditions for assistance which has resulted in many African countries sacrificing some of their core traditional cultural values on the altar of expediency (Pahuja, 2012; Omaswa, 2014).<sup>144</sup> In other words, besides the political, military, and civic violations of already existing Western influenced human rights, in order to get much needed foreign aid, African politicians and technocrats have over the years implemented solutions from their donor counterparts which the African technocrat and politician knows would not work in the African context:

The new order dictated that Africans were told what to do and how by foreign technocrats and politicians who did not have the same depth of understanding of the African situation as the locals. Studies were frequently commissioned as part of analytical work to define the problems and identify solutions. Often, however, these were designed and carried out by external experts whose contextualization of the issues was misplaced, resulting in the generation of findings and recommendations that were out of context and solutions that did not solve the problems (Omaswa, 2014, pp. 10-11).

The Bretton Woods institutions, through their measure to address African countries' underdevelopment after colonialism, require that African countries adopt structural adjustment programmes, policy reforms which are regrettably "based on narrow quantitative concern for economic growth and macro-economic stability", in that, there is

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peoples, where the violations by the latter are not equally packaged with "adverse economic policies that touch on safety, viability and profitability of their [donors'] transnational corporations and the neoliberal economic policies..." (The Mast, 2017). This indicates that we can neither wholly depend on politicians nor donors for appropriate human rights policies and their protection; rather, it is the empowerment of the peoples of Africa in law-making and the contextualisation of their plights and experiences in law and policy that is needed to ensure the protection of human rights.

<sup>144</sup> Talking and lamenting about technical support, Silavwe notes: "Another habit that has been found difficult to get rid of is the reliance of developing nations on advice and expertise from developed and industrialized nations. Zambia, like other developing nations, is striving hard to snap out of this habit, but not with immediate success... Even when changes are needed and advocated, the change agents usually come from outside (for example United Nations experts, and other experts from countries offering bilateral aid, etc.) Continued reliance on foreign recipes and borrowed tools in the planning and delivery of social services leads to the production of services and service delivery mechanisms that are either rejected by the people or, when foisted upon the clientele, are counterproductive... For such tools to be at all effective, they must be adapted to the local conditions in which they are applied. And if they cannot be adapted, they must be abandoned..." (Silavwe, 1995, pp. 78-79).

little to no concern for questions of equity, livelihoods, and human security in these programmes (Gawanas, 2014, p. 147). Such policy reforms conceive a human being who:

...cannot even properly address the problems our country [e.g., Zambia's HIV epidemic] now faces, much less solve them; what is needed now are empathetic and compassionate persons interrelated rather than independent, and encumbered by responsibilities to other human beings, from family and kin outward to encompass the whole world. But such persons will embrace, must embrace, a different ordering of values than is the case for the competitive autonomous individuals... The ideology of the autonomous individual has become so deeply ingrained in us [at least in the minds of most people from the West] that it is almost impossible to think in other than individualistic terms (Of course I'm an individual! And free! What else could I be? Or want to be?) (Rosemont-Jr, 2016).

This study reminisces about what could have been the case now if the needs, reality and protection of human rights of the African peoples was the bedrock of African countries' economic, political, and social policies, especially in response to the HIV epidemic - that is, if the Ubuntu philosophy was reflected in HIV law and policies, its implementation was made the condition for foreign aid, and officially enforced in clinical HIV testing practice.

Nevertheless, this thesis celebrates that the powerful influences of liberal Western civilization, forces of current globalization, and human rights abuses by some African political leaders have not managed to obliterate or manipulate Ubuntu ethos among ordinary African peoples, in particular Zambia (Maluleke, 2012). Ubuntu, or African humanism still holds relevance in African societies today, my study has found. It is this practical indigenous philosophy which this study has proposed ought to be recognized in HIV testing informed consent law and policy in Zambia.

### **9.3 The sub-Saharan African (Zambian) Ubuntu**

Sub-Saharan African countries' socio-cultural outlook is dominantly communal in nature. The question as to whether the general society in African countries is communitarian or not has been discussed in chapters 4 and 5. Common ancestry and historical contact have been identified to account for shared cultural features or ethos amongst sub-Saharan African peoples (Gyekye, 1995; Colson, 2006). This African traditional communitarian philosophy has even been recognized in the African Charter on Human and Peoples' Rights, an

instrument which recognizes solidarity rights (Niekerk, 1998; Woods, 2002-2004). The African Charter solidarity rights which promote compassion, solidarity and community are “ascertainable among most precolonial African societies” (Winks, 2011, p. 456), and I also found such values practiced and celebrated amongst the majority of my fieldwork participants. According to this outlook, “the identity and morality of the individual are inextricably bound by her or his relationships with others in society” (Winks, 2011, p. 456).

Therefore, as opposed to the perceptions that African societies have a primitive or undeveloped philosophical or legal system, in fact an indigenous African jurisprudence and legal order established and perpetuated by African precolonial societies has been shown to exist (Niekerk, 1998). This philosophy has been called different names by African, European and American anthropologists, philosophers and writers; it has been called African socialism, African humanism, African communitarianism, African communalism, or Ubuntu.

This philosophy has since time immemorial been so critical to African ways of life that when, due to epidemics, wars, genocide, and social upheavals, there was shortage of men a son was allowed to marry his deceased father’s wife in order to ameliorate social solitude (Diop, 1991, p. 118). According to the same author, polygamy in the African society was premised on the same social perpetuating principle. Even the African indigenous justice system was instituted in such a way so as to promote and restore peace, relationships, and promote social harmony disrupted or ruptured by conflict (Elechi, Morris , & Schauer, 2010, p. 80). As opposed to retributive and punitive justice, African indigenous justice emphasizes reconciliation and restoration (Himonga, Taylor, & Pope, 2013).

This shows that the peoples of Africa have since time immemorial thought “about the nature of their world, the meaning of their own lives, and the sources of good and evil” in the light of their own realities and experiences (Colson, 2006, p. 3). The promotion of the common good is one of the products of the African peoples’ thinking about their place as human beings in a world full of good and evil.

African indigenous moral philosophy which has been passed orally from one generation to another preaches “that it is in the community of other human beings that the life of the individual can have meaning and significance”, in that, “both as individuals and as groups, people need the protective cover that the community life offers if their lives are to have any

meaning or significance” (Agulanna, 2010, p. 282). Communal responsibility is held to be an essential means by which people can effect and realize their individual and social aspirations and goals. Applied to HIV testing, the problems that come with living with HIV are not seen to only affect PLWHA, but also one’s family and community.

This dominant outlook acknowledges and advances that neither the individual nor the community can survive without the other, and that since the individual cannot live outside the social setting, she has a duty to contribute to the preservation and well-being of our common humanity. Kaunda notes that African humanism (which means, being human and glory for all) which is concerned with the promotion of the well-being of all humans defines what African ontology accepts to be normal human behaviour and decency (Kaunda, 1993).

The views and practices of my fieldwork participants are consistent with this perspective. Like the Igbo people of sub-Saharan Nigeria who are reported to hold that “no individual is an island unto himself” and who regard mutual responsibility and obligation to be “beneficial reciprocity” (Agulanna, 2010, p. 292), the majority of individual participants in the fieldwork saw themselves as essentially a ‘brother’s keeper’, and reiterated what became a slogan of ‘no man is an island’ in their responses to field questions which pertained to individual autonomy. These views confirm the African indigenous moral theory which holds that individual human beings affirm their humanity by recognizing the humanity of others and teaches for the need to respect and have compassion towards others (Elechi, Morris , & Schauer, 2010).

In opposing isolationism, indigenous African moral thought implores every human being in society to co-exist harmoniously with others through respect and protection of individual interests, as a component of the collective (Niekerk, 1998, p. 168). This may explain why most health workers and other participants during my fieldwork who were in favour of the idea of informed consent were quick to dismiss its pure individualistic outlook. To them ‘no man is an island’; a human being is a person through others, and a human being has a moral obligation to reciprocate. To the majority of participants, an individual is a part of the whole. That means a family or community cannot be whole without an individual, and equally an individual cannot be whole without family or a community of people. This African ontology

which enjoins the preservation of the common good finds semblance in the metaphor in Saint Paul's letter to the Romans.<sup>145</sup>

The common good is illustrated by the Akan people by using a symbol of a Siamese crocodile. The common good is depicted in this symbol as a crocodile who has two heads with a common stomach (Gyekye, 1995). The common stomach, according to Gyekye, recognizes that human beings' basic needs are identical. That, just as the feeding of the common stomach by each of the Siamese heads of the crocodile results in the common stomach becoming bigger, so is the wellbeing of a society and an individual secured through individual contributions. It will be detrimental for the Siamese crocodiles who share a common stomach to fight over food because their common good is achieved through both heads putting food in their common stomach:

The individual's dignity, health and social welfare should be protected. But her welfare is only one side of the coin, the other side is being the welfare of the community. And in that lies the essence of Ubuntu: the welfare of the individual is inextricably linked to the welfare of the collectivity and that, in turn, is inextricably linked to an harmonious relationship with the ancestors and with nature. Although man is at the centre of things, man can be defined only in relation to other men. And the community can likewise be defined only with reference to its individual members... (Niekerk, 1998, p. 168).

In the light of this human reality, no wonder the inculcation of the sense of community bonds is seen as a critical resource in sub-Saharan African ontology. Emphasis on individual interconnectedness or natural bonds, which call for reciprocal hospitality, mutual care and responsibility, marks indigenous African moral thought from the present Western liberal philosophical and moral conception of man. Human interdependence, as opposed to individual autonomy, is celebrated in indigenous African ontology and practiced amongst the ordinary peoples of sub-Saharan African countries.

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<sup>145</sup> Saint Paul uses the human body to illustrate the imperative to promote the common good (Bible Study Tools, 2017). He tells Christians that just as the human body has many parts, so are human beings who make up a community. A community of human beings is seen to be like the human body which has many parts but different functions. Paul, enjoins Christians, as a body of Christ, to imitate the way human body parts work; for the common good. He instructs them, among other things, to live in harmony with each other, to love each other, be devoted to one another, "to rejoice with those who rejoice", "mourn with those who mourn", not to be proud, and to do what is right in the eyes of every human being (Bible Study Tools, 2017). Paul's metaphor of the common good is synonymous with that of the Akan people of West Africa. I have shared more on Christian socio-cultural influences on Zambian socio-culture in the next section.



Reporting on the way of life of the Tonga people of Zambia and Zimbabwe, Colson notes:

Funeral rituals once encoded much of Tonga thought about the human condition... The basic theme is summing up of human life, and the variations from one area to another do not obscure this fundamental message. The rituals celebrate the status achieved and the various sets of relationships created over a lifetime by the deceased, the importance of kinship in general and the continuity of the lineage, and the value of neighborliness... (Colson, 2006, p. 173).

#### **9.4 The implication of Ubuntu, Christianity, and illusion of autonomy**

The Afro-Christian perspective on human nature and consequent obligations cannot be safely dismissed or regarded as antithetical to human nature and morality. Even common sense shows the foregoing thesis of human condition and need to be sensible, unlike the unconvincing account of individual sovereignty or atomism:

Common sense tells us to reach out to those in need, to step up and take charge of the situation when we can clearly see disaster impeding or needless hurt coming... Moral sense would have us reach out to help, to do what it knows right... It respects the humanity of others by sensing connectedness with them and with their vulnerability... A natural sensibility impels us to see ourselves in relationships of interdependence with other people and to take responsibility both for our own lives and for what happens to others as well. We are our brother's keepers... Common sense often tells us to intervene, get involved, use persuasion, inducements, pressure, or coercion, if necessary, to turn a bad situation around, to stave off foreseeable evil (Gaylin & Jennings, 2003, pp. 3-4).

An Afro-Christian approach to HIV testing would expect us to remind those who have been exposed to HIV to test by assuring them that our intervention in their lives is necessitated by our natural connectedness to them and common sense morality: that, we are each other's brother and keeper; that, our wellbeing as a friend or relative is interlinked with their wellbeing; that it is only through HIV testing and treatment that as a corporate body we can all continue to enjoy other's personal human rights:

Our [common] humanity is fulfilled by conjoining rights and responsibilities, autonomy and relationships, independence and interdependence. The tools of each are essential to being and becoming the kind of creatures we are. [Hence] How each of us as an individual and how our society as a whole understands the connection

between these two poles of our moral being is therefore of crucial significance (Gaylin & Jennings, 2003, p. 68).

Our shared humanity cannot be exclusively fulfilled by mere self-improvement and actualization. Embrace of the seduction of individual autonomy, without due consideration to the threats posed against our common humanity by epidemics such as HIV, is injurious to our human identity.

Moreover, even if there was no Afro-Christian moral imperative to remind us to act unselfishly in order to protect and promote our common humanity, as referred to over and over again, human beings are incapable of being individually autonomous, even theoretically speaking.<sup>146</sup> We are a product of our upbringing, culture and biology (Endleman, 1967); even our choices are often times influenced or motivated by fear, guilt, shame, and pride:

The prolonged period of dependence imposed on the human infant not only binds adults to the infant but gives them the opportunity to indoctrinate the child with values...The social emotions of guilt, shame, and pride – uniquely human, are such powerful motivators, when they are present, that they can be exploited by parent and community to shape decency and moral conduct... (Gaylin & Jennings, 2003, pp. 99-100).

Thus, it does not make sense to base a regime of HIV testing on an edifice which is illusory, especially when HIV testing scale-up is a critical response to the HIV epidemic.

Instead, it would be fitting to base HIV testing consent requirements on the need to protect and promote an objective reality: our socio-relational autonomy. As people, even our very behaviours testify that we are not autonomous: we want to quit smoking yet we fail to do so; sometimes we don't want to wake up in the morning to go to work or school, yet we force ourselves to go because we are fearful we may not get our wage at the end of the month, or may fail an exam, lose our job, lose our place at a university; we feel guilt, are fearful, or anticipate the feeling of shame of how our work colleagues or tutors will regard our absence. Generally, we are susceptible to despair, get angry, get depressed, curse, swear, get stressed, feel sad, cry, and feel helpless or hopeless. This human reality cannot support our claimed individual autonomy, but reminds us that we are not in charge of our

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<sup>146</sup> See chapter 3 for this conclusion

own lives and we just cannot control things in our own lives. “The culture of autonomy stubbornly denies the very psychology that the average person uses in her commonsense approach to her colleagues at work”, her spouse, relatives, friends, children at home, etc. (Gaylin & Jennings, 2003, p. 146).

Besides the value of individual autonomy being theoretically problematic, its application is also impractical in the sub-Saharan African context because an individual in Africa is dependent upon the support of other members of the community. There are no social welfare packages in African countries, unlike in the developed Western world where the poor or the less privileged are entitled to social welfare benefits from their governments.<sup>147</sup> In African countries “it is family or community that fulfils this role of government...” (Agulanna, 2010, p. 291). This entails that a person living in Zambia whose illness has developed into AIDS will be dependent on her family and well-wishers to nurse her and provide personal care. This makes the application of individualized informed consent standards in the Zambian context equally morally offensive.

Moreover, Africans did not have input into the universal values. The universal ideals have their roots in the Universal Declaration of Human Rights, ideals to which no sub-Saharan African country had any input (Mapaure, 2011). Hence, for this reason one can, in addition to what has already been argued, say that some so-called universal fundamental human rights (the value of individual autonomy being one of them) are not grounded on an ideologically neutral philosophy. They are premised on Western liberal conceptions of what it means to be a human being. Any claim that the current regime of international human rights is universal is disproved by the very fact “that most African nations were still under the yoke of colonialism, hence not members of the United Nations, when the Universal Declaration of Human Rights, the embodiment of western values, was adopted, and [sub-Saharan Africans] had no input in its formulation” (Woods, 2002-2004, p. 53). It would be a mistake to argue that Western norms are universal in form and content, therefore, it doesn’t matter whether African countries participated in their formulation and institution or not. This study has shown that the Western liberal norm of individual autonomy is not

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<sup>147</sup> Even with this Western approach to help the less able of society, can we not call it Western socialism? Where is individualism in such ethos?

universal in form and content, therefore cannot be safely appropriated in HIV informed consent requirements in Zambia to the letter.

Writing on the value of informed consent, Levine argues that the American (U.S) conception of personhood though it places high value on a universalistic definition of worth, dignity and equality of every individual person is culturally particularistic and ethnocentric. “[I]t rests on the implicit assumption that ideas about personhood are common to many, if not most, other societies and cultures” in that “it assumes that the American way of thinking about a person represents the way men and women of all societies and cultures should and do think about personhood when they are being supremely rational and moral” (Levine, 1991, p. 210). The same author concludes:

Thus, it would not be prudent to trust an American to provide a universally applicable definition of informed consent. I suggest further, that it would not be prudent to rely on any person situated in any culture to provide a universally applicable definition of informed consent (Levine, 1991, p. 210).<sup>148</sup>

Levine establishes that “[p]luralists call to attention the fact that the Declaration of Helsinki, although widely endorsed by the nations of the world, reflects a uniquely Western view of the nature of the person; as such it [pluralism] does adequately guide the investigators in ways to show respect for all persons in the world” (Levine, 1991, p. 211).

It is here argued that the universal ‘one size fits all’ does not ‘fit all’ when applied to individual autonomy in HIV testing. Put differently, since the culture of autonomy has been identified to emerge from the Western liberal and libertarian moral ideologies of individualism, materialism, and rationalism, and is incompatible with African way of life, it would it be problematic to hold the African peoples living in Africa to a moral or

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<sup>148</sup> Thus, An-Naim offers a solution to this predicament; he argues for a pluralistic approach. He observes that cultural pluralism “is aimed at getting people to admit that although it may seem to them that their moral principles are self-evidently true, and hence seem to be grounds for passing judgments on other peoples, in fact the self-evidence of these principles is a kind of illusion” ... [C]ultural relativism acknowledges the equal validity of life, and lays “stress on the dignity inherent in every body of custom, and on the need for tolerance of conventions though they may differ from one’s own” (An-Naim, 1990, pp. 339-340).

philosophical standard which offends the very identity of who they are as human beings in the light of their shared experience and reality.<sup>149</sup>

## 9.5 In defence of African indigenous human rights

One of the arguments against communitarian ethos is that they suffocate individual human rights. This study argues that African humanism protects individual rights. Unlike under the Nazi Gestapo regime where an individual was seen to be of no consequence, apart from being used as a means to achieve racial and economic ends, the individual in African indigenous thought is not a mere means to serve social goals and expectations, but is an essential part of the whole – who as an individual is celebrated to have inherent worth and dignity (Agulanna, 2010). Even though African traditional and moral theory emphasizes the communal nature of human beings, “it does not by that token deny individual liberty or the idea of every human being unique and important” (Agulanna, 2010, p. 288). One’s loyalty to one’s family, community, or clan in African indigenous moral thought does not entail abandonment or discouragement of individual self-development, personal creativity, self-reliance and actualization (Gyekye, 1997; Colson, 2006; Agulanna, 2010).

African humanism puts value on human life and dignity, entailing that respect of an individual’s person, life and dignity is an integral humane imperative. It is to this effect that it has been noted that although Western scholarship and media is replete with a general mistaken belief that Africans love violence and conflict or disregard human rights, actually during such times of violence, conflict, and human rights abuses, “distraught members of [the African] society decry the loss of Ubuntu”; this is because Ubuntu recognizes an individual’s status as a unique human being who by virtue of being a human is entitled to unconditional respect, dignity, value and acceptance from the members of her community to which she belongs (Mapaure, 2011, p. 160). This shows that this regime of human rights sees every human being as one who has both intrinsic and material value; it advances a perspective of inherent good, worth and dignity of every individual human being (Elechi,

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<sup>149</sup> I have been using the phrase Western liberal thought not to implicate all Western liberal thinkers and their followers as having the same individualistic perspective. Some liberal and progressive thinkers have since the 1990s come to refer to themselves as communitarians (Gaylin & Jennings, 2003). This study understands that not all liberals are individualists.

Morris , & Schauer, 2010). It further “carries in it the ideas of humaneness, social justice and fairness” (Himonga, Taylor, & Pope, 2013, p. 379). It affirms the glory for all human beings despite their stations in life (Kaunda, 1993).

Moreover, the African communitarian version of human rights encompasses a wider range of rights; it is not restricted to individual rights, but also recognizes other people’s rights – an imperative to self-promote and improve, and yet at the same time to endeavor to preserve the present and future well-being of future generations and the environment. Sub-Saharan African indigenous human rights are predicated on a more inclusive panoply of rights; an individual’s rights are not exclusively treated without accommodating them “within a continuum of the dead, the living, and the yet unborn”:

... a perspective emphasizing a duty to community members “yet unborn” encompasses interests such as the “third generation” right to preservation of the environment for future generations... Kenneth Kaunda describes the tribal community as a “mutual society... organized to satisfy the basic human needs of all its members... Personhood [in the Akan conception] is inherently connected to community; its full attainment requires fulfilment of one’s obligations to self, family and community... (Woods, 2002-2004, pp. 55-57).

Thus, African indigenous human rights theory can be summarized as comprising the following elements:

[1] All persons have equal worth [2] Human beings are essentially inter-dependent [3] The source of rights is human need [4] The commonality of interests is paramount [5] Consensus decision-making maximizes human rights (Woods, 2002-2004, p. 58).

Thus, an African indigenous communitarian adherent would regard that “an injury to one person is an injury to all”, and yet at the same time hold that the survival and well-being of the community is dependent upon the well-being of the individual (Elechi, Morris , & Schauer, 2010, p. 75). Put differently, this regime of rights recognize and promote “the humanity of each person and the entitlement of all people to unconditional respect, value and acceptance from one’s community”, and at the same time holds that “every person has corresponding duty to show the same respect, dignity, value and acceptance to each member of that community”, thus, advancing a concept of co-responsibility and mutual enjoyment of rights by all (Himonga, Taylor, & Pope, 2013, pp. 379-380).

Therefore, to generalize that Africans love violence and conflict is not only blatantly prejudicial and ignorant, but also grievous to the ordinary peoples of African countries who are already distraught with the loss of Ubuntu in political practice:

Despite different and even conflicting normative judgments within the extensive literature on human rights in Africa, a remarkably consistent descriptive pattern emerges: traditional African society embodies values that are consistent with and supportive of human rights, but the effects of colonialism and the difficulties of nation building and development have contributed to an erosion of those values or, at least, bred disrespect for and abuse of human rights. Linking disrespect for human rights to authoritarianism, Dunstan Wai, for example, argues that “authoritarianism in modern Africa is not at all in accord with the spirit and practice of traditional political systems, but that its practices are aberrations facilitated by colonial legacies and reinforced by the agonies of “underdevelopment” (Silk, 1990, p. 292).<sup>150</sup>

Put differently, African indigenous human rights do not only protect and promote communal rights, but also individual human rights:

Focusing on whether specific rights were recognized and protected in traditional African society – and, if so whether they are consistent with Western or African conceptions – has led the discussion away from a consideration of a fundamental question. That question may be stated in negative or positive terms: is there something in traditional African culture that is inhospitable to basic international human rights, or is there some fundamental value in African traditional culture that can provide the basis for the protection of such basic human rights? (Silk, 1990, p. 291).

## **9.6 The gap between theory and clinical practice and views further enforces an argument for pluralism**

It is commonplace now to decry the unacceptable discrepancy between theory and practice of human rights. Despite the existence of elaborate and enlightened international standards of human rights for several decades, and despite the rhetoric of strong commitments to these standards by governments, which are often supported in or pressured into such commitment by an increasing number of nongovernmental organisations and groups, we continue to witness gross violations of human rights in all parts of the world. If we are to reduce this unacceptable

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<sup>150</sup> This study adds that political greed, the humanisation of profit, and the ills of underdevelopment are cumulatively responsible for human rights abuses in African countries; not a lack of indigenous African human rights.

discrepancy and promote and ensure greater respect for the full range of human rights throughout the world, then we must understand and combat not only the immediate causes of the discrepancy but also the underlying factors that contribute to it (An-Naim, 1990, p. 331).

This thesis advocates for a plural transposition of human rights in Zambia. It argues for an HIV human rights perspective which is coherent and consistent with the Ubuntu value system, a value system which has its roots in the experiences and reality of the peoples of Africa. I do not trash liberal Western ethical principles as wrong or wholly inappropriate, rather my thesis encourages contemporary African philosophers, political leaders, and policymakers to appreciate and learn from Western values, yet at the same time embrace such values in the light of their peoples' lived experience, reality, and Ubuntu.<sup>151</sup> In other words, in the light of our necessary globalized world, African philosophers and lawmakers ought to "think global and act local" when it comes to the adoption of 'universal values' like informed consent requirements in HIV testing (Mapaure, 2011). The corpus of the present thesis is against an approach where African, in particular Zambian, lawmakers transpose international values without due consideration of their nature, acceptability, viability, and appropriateness in the local context. I argue for an approach which would offer socio-cultural legitimacy to Zambian HIV law and policy, and aid the scale-up of HIV testing.

Sadly, it is as if lawmakers who adopt foreign values appear to ignore empirical evidence concerning the way of life of the peoples whose interests they claim to serve. They fail to translate available empirical evidence into a local regime of human rights that has a global outlook, but rooted in local experience and reality. Indeed, what can be said about the current regime of informed consent requirements in HIV testing in Zambia?

To reiterate, it is here proposed that when transposing international ideals into law or policy, it would be important for an African, in particular a Zambian lawmaker, to put on a

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<sup>151</sup> An-Naim argues that "... the difficulties in implementing established human rights effectively, and in recognizing other claims and interests as human rights and implementing them also, derive from the insufficiency of cultural support for the particular right or claim. Culture mediates power and acts as the framework within which self-interest is defined and realized in any community. Cultural legitimacy, moreover, cannot be deduced or assumed from the mere fact of official recognition of the claim as a human right in existing formal documents... the process through which the current international human rights standards were formulated and adopted did not address issues of cultural legitimacy in relation to most of the cultural traditions of the world" (An-Naim, 1990, p. 333).



pair of “Afrocentric goggles”, goggles which will enable her to build a realistic legal order which matches the lived reality and experiences of the people. A ‘think global and act local’ approach “considers African people, their values, cultures, histories, collective struggles, needs and aspirations” to be the central constitution of the pluralistic goggles through which the lawmaker is invited to look through when adopting new laws or policies for her country (Mapaure, 2011, p. 160). Indeed, the imposition of “formal mechanisms on communities without regard for local-level processes and informal legal systems may not only be ineffectual, but can actually create major problems”, in this case having an informed consent HIV testing regime which is disregarded in actual practice (Mapaure, 2011, p. 159). This study conceives that the lack of African peoples’ socio-cultural values in HIV informed consent requirements could explain the disjunction between HIV informed consent policy and practice in Zambia. Informed consent requirements which are based on an individual determining her own therapy for her own good hardly have internal validity in African sociological experience and reality:

The prime feature underlying cultural legitimacy is the authority and reverence derived from internal validity. A culturally legitimate norm or value is respected and observed by the members of the particular culture, presumably because it is assumed to bring satisfaction to those members...” (An-Naim, 1990, p. 336).

Similarly, Omaswa argues:

The foundation that makes ownership and accountability by Africans an imperative is the thesis that sustainable change is inherently endogenous and must come from within the country, the community, the people, or individuals who are the beneficiaries of the change... ‘Only that change that comes from the communities themselves is sustainable.’ ... ‘In Africa if it doesn’t happen in the communities, it doesn’t happen’” (Omaswa, 2014, p. 13).

## **9.7 A pluralistic HIV informed consent testing approach is proposed**

I wish to argue in the light of my findings and those of other studies cited in this research, that a regime of African communitarian human rights ought to be acknowledged and transposed into HIV informed consent requirements in sub-Saharan African jurisdictions, Zambia in particular. Failure to do so, it is apparent, will lead to a continued violation of the

current regime of universal consent requirements. I wish to suggest that the dominant African ontological view on the human condition offers a more plausible explanation of human nature. Not only does it represent a more coherent theory, but it also represents African experience and reality, a reality which ought to be reflected in HIV testing requirements in Zambia. Most importantly, African Ubuntu recognises and upholds both individual and collective human rights.

African Ubuntu embodies inclusivity (individual and social rights) and recognizes the reality of human inter-connectedness and interdependence. Its inclusion in HIV informed consent requirements would be suited for a development of a genuinely plural African or Zambian regime of HIV test which recognizes sub-Saharan African needs and reality. African indigenous ontology and human rights cannot be relegated to the periphery of indifference. The 'elephant in the room' of African peoples experiences and reality needs to be acknowledged and transposed into Zambian legal instruments so that health workers in Zambia's practices can equally have legal backing, and service-users' lives (and common good rights) can be protected without fear of legal sanctions.

Adopting a plural approach in policy or lawmaking in the light of the African peoples' socio-cultural reality and experiences would be an effective way to go (An-Naim & Deng, 1990). This approach would not only lend internal legitimacy to human rights, and consequently respect a given African peoples' rights in the light of their experiences and outlook because they can identify with the rights as necessary, but also realistically we need to appreciate that not every right that is included in the United Nations international human rights instruments is universal. Legitimization of an African regime of human rights for sub-Saharan African peoples in the African countries context, I propose, is necessary to bridge the gap created by individualistic HIV informed consent requirements and practice:

... if this discrepancy [law and practice gap] is to be reduced... the cultural legitimacy of the full range of human rights standards must be developed – that is, the concern for human rights as they figure in the standards of many different cultures should be enhanced. In particular, I believe it would be useful to challenge representations of some human rights as lacking genuine cultural legitimacy within a sociological system... The continuing processes of change and adjustment of political social, and economic relationships within a community mean that internal changes can be made to accommodate a given human right, if that right is shown to be legitimate within the culture of the particular community (An-Naim, 1990, p. 332).

In other words, since HIV informed consent requirements have not been universally accepted (due to different peoples around the world's unique experiences and realities), aborting them in the light of the Zambian reality and experience should be the way to go. Informed consent requirements in HIV testing in Zambia should accommodate empirical and anthropological evidence which reflect that country peoples' needs and socio-cultural reality and experience. I add that even if it could be granted that all human beings who make up the global human family share the same alienable rights, individual autonomy is not one of them; therefore, it should not be imposed on a way of life of a given people.

### **9.7.1 A sub-Saharan African informed consent requirements regime is proposed**

What form should the African (Zambian) regime of informed consent requirements take? In the light of Ubuntu values, I propose that in assessing whether an action to test for HIV is acceptable or warranted in Zambia what a lawmaker, a court of law, a philosopher, or an ordinary Zambian citizen should ask when assessing the validity of a health worker's actions should not be; 'did the health worker uphold the sovereignty of the individual prior to, during, or after carrying out an HIV test?' What ought to be asked, instead, is, 'were the actions of the HIV counsellor or health worker ethical, in the best interest of the service-user? That is, did they uphold the dignity of the service-user; and, at the same time secure the common good?' Put differently, were the actions of the HIV counsellor respectful of a service-user's dignity and worth; that is, were the deeds of the health worker motivated by common sense morality (an ontological morality shared in a concerned community by virtue of their shared experience and current reality) – a morality necessary to protect and preserve both the rights of an individual and the common good?'

Consent from an individual would still be necessary in this suggested approach because it will be immoral to force a person who has refused to test for HIV to test. Before conducting an HIV test, it would be imperative to ask a service-user or candidate whether they agree to test or not. However, as opposed to the Western liberal model of informed consent requirements which requires medical staff to inform service-users of material facts which

only relate to the benefits, risks and alternatives of an HIV test to the 'autonomous' service-user, a Zambian model should equally inform a service-user the benefits and consequences of acceptance of one's refusal to test one's family, friends and community.

Put differently, a Zambian model could be as follows: firstly, a service-user must be informed about the benefits of an HIV test to herself and others. Secondly, she must be informed about the long-term material consequences (harms which include physical, psychological, social, cultural and economic) to herself and others if she accepts or refuses to test for HIV. Thirdly, she must be reminded that according to the general sub-Saharan African ontology and morality, she is seen as a member of a wider family whose contribution to the common good is critical for its preservation. And lastly, but not the least, she must be informed that, if she still chooses not to test, no one will force her to do so against her will. In other words, she would be reminded that such an HIV testing intervention is necessary: in order to protect and ensure her continued enjoyment of her own life, individual worth and dignity; that her well-being or lack of it will also affect other people due to human interconnectedness and interdependence; that the reason for the intervention by others for her to test for HIV is necessitated by our common human need and common sense morality, not malice; and finally, that reciprocal protection and promotion of our shared needs and interests is contingent upon every individual member.<sup>152</sup>

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<sup>152</sup> This approach seems coercive or appears to be designed to invoke guilty. But, yes, granted that it is coercive, then is coercion evil in itself? Or it is sometimes a necessary evil? A closer look at human society shows us that we live in a world of coercion. Our laws are coercive, our road and traffic signs are coercive, announcements on flights before take-off are coercive, warning on cigarette packaging and alcoholic drinks are coercive, academic and other professional expectations are coercive, and the list is endless. So what would be unique about informing and warning people about the dangers of refusal to test for HIV? Indeed, coercion is sometimes a necessary evil (Gaylin & Jennings, 2003), provided it can be used to point an individual to an impending danger and its clear consequences. And, where the person exercising coercion as a tool of warning does not do so in an insensitive and arrogant manner; that is, where the coercing health provider does not when employing the tool in HIV testing "place little or no value on individual patients' opinions and values, and arrogates to" oneself "the absolute right to select therapy, under the guise of always knowing what is best for the" service-user (Glick, 2000). My HIV testing proposal is in favour of the use of 'coercion' strictly in the sense it is used on cigarette packaging. The health warning on cigarette packaging of "Tobacco is harmful to health" only reminds smokers of the reality of the dangers of smoking – it does not mandate them to stop smoking. The decision is left up to smokers and potential smokers to heed or ignore the warning. So, is the spirit of my proposed HIV testing approach; it also warns individuals the personal and communal realities of not testing for HIV.

A basic understanding of Zambian humanistic or social philosophy which represent that country's traditional culture can be found in Kenneth Kaunda's humanism works. Kaunda's philosophy is rooted in African indigenous society's philosophical and moral outlook; a society which was organized to satisfy basic human needs of all the members in the community, and discouraged individualism (Olivier, 1981). Hence, the suggested adaptation of informed consent requirements in Zambia is proposed so as to represent the non-individualistic Zambian socio-relational autonomy experience and current reality, an outlook which African sages organized in order to ensure that the basic human rights of all the members in a community are satisfied.

A Zambian HIV testing regime, premised on a Zambian reality, would appropriately and legitimately speak to the common experiences and needs of the Zambian peoples. It would acknowledge the Afro-Christian ontology which encourages the practice of reciprocity and mutual welfare,<sup>153</sup> values which have been overlooked in the current regime of HIV testing.

Moreover, in the light of the threat of HIV epidemic, the application of Afro-Christian values in HIV testing would also be useful because this perspective recognizes life as a mother of all rights (that is, it recognizes that without life one cannot enjoy the other rights) (Chengeta,

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<sup>153</sup> Pastor Ronald Kalifungwa correctly captures what this spirit of human sociality and reciprocity in Zambia entails. Despite the fact that this sermon was intended for the Christian community, there is a lot of material in it that resonates with sub-Saharan African ontology. Preaching on the book of 1 John 1 v 7, he observes: "Fellowship according to verse 7 happens in a "one another" context... Notice those words "one another". Those words "one another" when joined together form what we refer to as "a reciprocal pronoun". A reciprocal pronoun. Pronoun which describes and underlines the spirit and practice of unity, of considerateness, of companionship among brethren. The words "one another" in a sense are at the heart of the Christian life. When you think about it, without these two words, there would be no caring and no loving. There would be no unity and no serving. There would be no hospitality and no submission. For each of these activities requires that there be another person in order for them to be perfected. When you are commanded to love it is with respect to showing care and affection to another when we are called to serve. It is in the context of serving another. So there cannot be fellowship without another. Without sharing it with another. Without partnering with another. Without being with others. We need one another in order to achieve fellowship, indeed in order to achieve anything! It is for this reason that in Ecclesiastes and chapter 9 that Solomon says "two are better than one because they have a good return for their work. If one falls down his friend can help him up. But pity the man who falls and has no one to help him up. A cord of three strands is not quickly broken." ... You can't have fellowship just with yourself. You can't have fellowship in isolation. There is something wrong where life was just about yourself. To have life that way is to be unlike God. And God made you in His image... You are intended to be in company, to be in a plural arrangement. To be with others..." (Kalifungwa, 2015).

2016). The right to life and dignity are arguably the most critical rights to human beings because they are the source of other personal rights (Rosa, 1996, p. 139).

### **9.7.1.2 Informed consent in medical practice necessary, but needs amends to reflect the Zambian reality**

Overall, my thesis is not against the principle of informed consent in itself, but its premise on individual autonomy. Besides the doctrine of informed consent being premised on an illusion of autonomy and being largely not representative of sub-Saharan African ontology, my research has further shown that there is a gap between the doctrine as imagined and the manner the doctrine is actually implemented by physicians or medical staff (Schuck, 1994). In other words, there is a mismatch between the way informed consent requirements are established and emphasized in law books and the way they are implemented in practice in clinical deliberations. I am not convinced that the existence of this gap or mismatch can be rectified by conforming the law in action to the law in the books; I am inclined to appreciate that this gap simply demonstrates how impractical universalized consent requirements (premised on individualism) in medical practice are:

My skepticism about both the benefits of informed consent law in action and the prospects for the vigorous enforcement and efficacy of the law in books is not meant to suggest either that the informed consent process has been wholly meaningless or that it cannot be improved... The problem... may go beyond poor techniques and flawed implementation of the doctrine... [Rather, because physician to service-user] discussions are readily shaped by other entrenched social forces, including physicians' superior status and long-established professional traditions, and patients' anxiety and medical ignorance... (Schuck, 1994, pp. 937-938).

Moreover, the principal goal of informed consent can hardly be achieved (that is, in countries where it is even enforced). Often times health workers disclose information to service-users "in a more perfunctory manner without much regard to how well the patient comprehends the information", and on the other hand, "many patients appear to understand little of the risk information and, shortly after the discussion, to recall even less" (Schuck, 1994, p. 948). This is consistent with my fieldwork findings which show that despite women attending antenatal information sessions, they were never informed that they are

autonomous individuals who have a right to refuse HIV testing if they wish. The implication of such is that unless informed consent requirements are remodeled in the image of human experience and reality, individual autonomy promoting requirements will only continue to perpetuate a fiction or an illusion of service-user choice, at the expense of the common good:

...whatever strides the medical consumer movement has made among the healthy and educated, the sick still generally come to their physicians for expertise and reassurance, not knowledge and power. They want to be fixed and reassured, not educated and forced to make decisions about matters with which they are quite unfamiliar (Wear, 1998, p. 3).

## **Conclusion**

In conclusion, since human beings are interconnected and interdependent, and thus have reciprocal obligations to protect the common good, and secondly given that the HIV epidemic, more than in any other region of the world, threatens the common good of the peoples of sub-Saharan Africa, it would not be appropriate to continue to sustain a regime of human rights which is premised on individualism. Moreover, the current regime of informed consent requirements is premised on an illusion, and is not premised on dominant sub-Saharan African ontology and experience.

Individual autonomy in HIV testing in Zambia is an “emperor’s new clothes”. Hence, we are here encouraged to see, touch and recognize “the elephant in the room” (indigenous African ontology and peoples’ experiences and views) in our approaches to HIV testing in Zambia. I wish to suggest that an approach to testing which modifies/adapts/changes emphasis of informed consent that more fully reflects particularly African heritage and experience is more suited for sub-Saharan Africa, and particularly the Zambian context.

Moreover, my analyses of various theories and empirical data have shown that I am a “self beyond itself”. That is, I am “the We That Is I” and the “I That Is We” (Ravven, 2013, p. 366). Put differently, I am this:

A permeable and relational (as well as self-promoting, self-protecting, and self-furthering) rather than closed discrete, and playing out its [my] own internal program upon the world stage. ... For we not only discover the world within us but

also discover ourselves in the world, identifying ourselves with parts of it. ... The self as fully self-aware includes perspectives that were initially “other”: third-person perspectives now taken in as one’s own have relocated the self outside itself and in another. ... (Ravven, 2013, pp. 367-369).

Indeed, I found that I am a person through other persons (Battle, 1997; Tutu, 1999; Nussbaum, 2003). That is, I didn’t come into this world fully formed; I am a product of both socialization and biological limitations.

Reflectively, even our daily experiences show that we are wired “for fellowship, to exist in a tender network of interdependence” (Battle, 1997, p. 65). This reality inescapably poses a challenge to how I view my autonomy in HIV testing. The self, that is, the “I” in the first place emerged in relation to others:

The self in a sense “others” itself by casting itself into a world and finding itself there in the eyes of another. It returns to itself as including the other as *integrated within the I*. I discover myself in others’ eyes. I have a socially defined self resulting in a shared reality, a shared world (Ravven, 2013, p. 369).

In other words, according to the findings of this study, I am a “self” who is a product of biological limitations, and a social self due to early and ongoing relationships with my parents, siblings, friends, teachers, and others. These relationships and biological limitations which I have had since I was born do not only compromise my emotions, but also profoundly affect my motivations. Moreover, humans are essentially interconnected and interdependent.

However, my study also shows that these biological limitations and human interconnectedness and interdependence should never legitimize the forcing of individual humans to do what is against their will. Moreover, any policy or law that has the potential to violate human dignity and curtail individual choice has no place in traditional African ontology and human rights.

“[T]here is considerable evidence that decision by consensus was often the order of the day in African deliberations, and on principle” (Wiredu, 2002). In indigenous African society traditional authorities like Kings, Queens, local Chiefs, and Headmen and Women did not rule with absolute power, but governed through consultation, cooperation, negotiation,



compromise and consensus (Ajaegbo, 2014). Thus, it must be pointed out that as much as African sages saw it necessary for the “Siamese crocodile” to feed for the common good because the heads had one stomach, the African sages’ acknowledgement of the two heads suggest that they also acknowledged and respected the uniqueness of the two heads of the crocodile.

In this vein, I wish to observe that it would be inappropriate for the current executive government of Zambia to make HIV testing compulsory in the country. In fact, mandatory HIV testing would not only lead to the violation of an individual right to be treated with dignity, but would also offend traditional African democratic and human rights values, which I have argued above are premised on African experience and reality. Moreover, since stigma is still epidemic in Zambia, there is a danger that mandatory testing may just end up even annulling the positive achievements which the country has so far made towards HIV prevention, testing, treatment and care.

The government should adopt an HIV testing policy which reflects human reality, respects human rights, recognizes and seeks to address the problem of stigma, and is grounded on a premise which promotes both individual and the common good. Indeed, pursuing public health or individual ends at the expense of the rights of either side is counterproductive to stopping and ending HIV and AIDS by 2030. It is in this vein that I have proposed an HIV testing approach which acknowledges the dimensions of this critical relationship between the individual and society.

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