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THE BIOETHICAL AND HUMAN RIGHTS CHALLENGES SURROUNDING THE HIV TESTING OF WOMEN IN SOUTH AFRICA AND OTHER SUB-SAHARAN AFRICAN COUNTRIES

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A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, in fulfilment for the requirements for the degree
of
Doctor of Philosophy

Johannesburg, 2015

DECLARATION

I, Mary Josephine O'Grady, declare that this thesis is my own work. It is being submitted for the degree of Doctor of Philosophy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

14th day of September, 2015

This thesis is dedicated to my parents.

ABSTRACT

The purpose of this thesis is to explore the current HIV testing protocols, especially provider-initiated counselling and testing, otherwise known as 'routine testing,' under implementation in sub-Saharan African countries and examine whether and how they transgress bioethical and philosophical principles and the human rights of women in the current context of the highly stigmatised HIV epidemic. The research method employed is mainly a literature review partly based on my 20 years of experience working on HIV testing programmes and programmatic evaluations in sub-Saharan African countries, from which earlier background papers and this thesis topic grew. Included in this primarily moral examination are the historical philosophical and present bioethical principles of autonomy, beneficence, justice, and non-maleficence, the philosophical right to self-preservation, and relevant human rights principles and recent examples of human rights infringements related to the HV testing, in particular, the routine testing of women in sub-Saharan African countries. A conclusion is reached that where HIV testing is practiced in sub-Saharan African countries, and anywhere for that matter, without alignment with the bioethical principles of respect for autonomy, justice, beneficence, and non-maleficence, and without protecting the human rights of individuals testing for HIV, including the provision of pre- and post-test counselling, implementing the informed consent process, maintaining the confidentiality of test results, and making referrals to other services available to all individuals who test negative or positive, as well as making antiretroviral therapy (ART) available to anyone who tests HIV-positive, such testing is unethical. Thus I posit that without the aforementioned conditions, the routine testing for HIV of all individuals presenting to a clinic for healthcare—and the routine testing of all pregnant women for HIV—amidst the highly stigmatised HIV epidemic in sub-Saharan Africa is unethical.

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ACRONYMS

ACHPR	African Commission on Human and Peoples' Rights
ART	Antiretroviral therapy
ARV	Antiretroviral
BONELA	Botswana Network on Ethics, Law and HIV/AIDS
CDC	Centers for Disease Control and Prevention of the United States
CICT	Client-initiated counselling and testing
DOH	Department of Health of South Africa
DRC	Democratic Republic of Congo
GBD	Global Burden of Disease Study
GBV	Gender-based violence
GTZ	Deutsch Gesellschaft fur Technische Zusammenabeit
HIV	Human immunodeficiency virus
hrHPV	High-risk human papillomavirus
IPV	Interpersonal violence
NDOH	National Department of Health, South Africa
NNRTI	Non-nucleoside reverse transcriptase inhibitor
OAU	Organisation of African Unity
OHCHR	Office of the High Commissioner on Human Rights of the United Nations
OI	Opportunistic infection
OSI	Open Society Institute
PEP	Post-exposure prophylaxis for HIV
PICT	Provider-initiated counselling and testing
PITC	Provider-initiated testing and counselling
PLHIV	People living with HIV
PMTCT	Prevention of mother-to-child transmission of HIV

SADC	Southern African Development Community
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TB	Tuberculosis
UDHR	United Nations Declaration on Human Rights
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
US	United States of America
VCT	Voluntary counselling and testing
WHO	World Health Organization
WMA	World Medical Association

CHAPTER 1: DEFINING THE ETHICAL IMPLICATIONS OF THE HIV TESTING OF WOMEN AND GIRLS

1.0 INTRODUCTION

This thesis explores the ethical implications and impacts on women and girls of various types of human immunodeficiency virus (HIV) testing under implementation in or consideration for South Africa and other countries in sub-Saharan Africa. This research on the ethics of HIV testing supports the necessity of protecting and realising the rights of individuals amidst the HIV epidemic response, in particular individual women who are more vulnerable to HIV infection, and who may or already be living with "possibly the most stigmatised disease in history" (Cameron, 2010, p. 6). Through the implementation of ethical HIV testing protocols in South Africa and other sub-Saharan African countries, the rights of individuals, including women and girls, will receive greater protection. Moreover, the research argues that by protecting the rights of individual women in regard to HIV testing and in the overall HIV response, there will be a better chance of reaching the public health goal of decreasing the rate of new HIV infections overall. That is, by respecting the health and human rights of individuals, especially individual women and girls, society itself will benefit—although the aim of the research will not be to try to prove the latter hypothesis (Mann, 1996, p. 924).

To override the individual rights of women to achieve public health objectives in this highly stigmatized HIV epidemic does not seem like a just, moral, or caring objective, especially as women biologically are more vulnerable to HIV infection than men due to anatomical, physiological, and reproductive health reasons (Chersich and Rees, 2008, p. S29). Moreover, women have lower socioeconomic and sociocultural status than men,

putting them at greater risk of infection due to various factors that this thesis will describe (ibid., p. S35). Yet HIV testing protocols currently focus on testing more people for HIV infection rather than making undergoing an HIV test a truly voluntary act and well-informed decision and do not necessarily provide access to antiretroviral therapy (ART) if an individual tests HIV-positive. Since women have a greater need to access health care than men due to their reproductive health issues, which also can make them biologically more vulnerable to HIV infection, they are more likely to be tested for HIV, whether or not such testing is voluntary and truly informed and results in ART provision, if needed.

Women are tested for HIV more frequently than men for a variety of reasons, including testing during pregnancy and because more women than men voluntarily undergo HIV testing due to their health concerns (Young, Hlavka, Modiba, et al., 2010, p. 621). Some have described these factors as placing the burden of HIV testing on women (Knight, Shoveller, Greyson, et al., 2013, p. 7). Thus women are subject more than men to any unethical practices surrounding HIV testing simply because more women than men are tested for HIV. Also, the inferior social position of women in African society means that they have less individual agency and autonomy than men (Jewkes, Dunkle, Nduna, et al., 2010, p. 48). Consequently, women in Africa have less power to object to any unethical practices they may undergo under the guise of 'voluntary' HIV testing. The unethical practices some women encounter range from the use of coercion to test for HIV, the lack of informed consent or any consent, the lack of information provision and counselling to explain the testing procedure, the meaning of the potential testing results, and any availability of health care they may need or wish to access, or the lack of confidentiality about the result of their HIV test (Angotti, Dionne and Gaydosh, 2010, pp. 1, 8; Orza, Welbourn, Bewley, et al., 2015, pp. 16-17).

1.0.1 Brief History of HIV Testing and Impact of Stigma

The first HIV tests became available in 1985, a few years after HIV was discovered in 1981 (Staveteig, Wang, Head, et al., 2013, p. 1). At that time before ART was available to treat HIV and AIDS effectively, the benefits of HIV testing were questioned and ethical concerns were raised by many around the world based on the substantial stigma toward and discrimination against people living with HIV (ibid.). Unfortunately, the stigmatisation and discrimination regarding people living with HIV has not abated in many places and is still widespread in sub-Saharan Africa (Logan, Plank, Bogart, et al., 2013, p. 1). The stigma toward and discrimination against people living with HIV is particularly directed toward women, who are the most vulnerable to HIV infection due to their greater biological vulnerability, which is exacerbated by the gender inequality and lower socioeconomic and socio-cultural status of women in African societies (UNDP, 2012, p. 68; Gari, Malungo, Martin-Hilber, et al., 2013, p. 1; Horwood, Butler, Haskins, et al., 2013, p. 1; UNAIDS, 2013, p. 79). Also, the prevalence of gender-based violence (GBV) in many African countries increases women's risk of HIV infection from HIV-positive partners (Jewkes, Dunkle, Nduna, et al., 2010, p. 48; Adimora, Ramirez, Auerbach, et al., 2013, p. S169). Behavioural evidence has shown that men who practice GBV against their partners also tend to practice HIV-risk behaviours, such as having multiple sex partners, frequent alcohol use, and having a sexually transmitted infection (STI), which increase their partners' risk of HIV infection (Garcia-Moreno, Pallitto, Devries, et al., 2013, p. 21). The possibility of suffering from GBV, abandonment, loss of economic support, family disruption, community marginalisation, and losing one's place of residence are all barriers to HIV testing because of the fear of many women that their test result may be positive (Medley, Garcia-Moreno, McGill, et al., 2004, p. 300).

1.0.2 The HIV Epidemic in South Africa and in Sub-Saharan Africa

Sub-Saharan African countries have the largest HIV epidemics in the world, and South Africa has the world's largest number of people living with HIV in any country in the world, estimated at 5.9 million people in 2013 (UNAIDS, 2014b, p. A27). Moreover, more women than men are living with HIV in Africa, with women making up nearly 60% of the people living with HIV on the continent (UNAIDS, 2012, p. 3). Not only is it important to protect the rights of people living with HIV, but it is especially important to protect the rights of women living with HIV because of their greater vulnerabilities, including vulnerability to unethical testing protocols and practices.

1.1 RATIONALE FOR THE RESEARCH

The rationale for the research is that it is important to understand the potential bioethical and human rights ramifications of the approaches and content of various HIV testing protocols for the following reasons:

- To be able to design HIV testing protocols that are ethically sound;
- To not infringe on the individual rights of anyone testing for HIV;
- To not infringe on the rights of any groups particularly vulnerable to HIV infection, such as women, based on their heightened biological, socio-economic, and socio-cultural vulnerability to the virus;
- To allow for the provision of the necessary level of care to anyone refusing to test for HIV, including pregnant women, due to their fear of the greater potential for intensified stigma and discrimination if testing HIV-positive, including by sex partners, family members and community members;

- To prevent stigmatization toward or discrimination against individuals who undergo testing after potential exposure to HIV, including rape survivors, and especially girls and female adolescents;
- To not deter anyone who is ill from seeking health care due to the fear of 'routine' HIV testing, as an increasing fear of testing for HIV could have a deleterious impact on the spread of HIV amidst the global pandemic and the world's largest HIV epidemic, in South Africa.

By reviewing the various HIV testing methods and protocols and the ethics surrounding these approaches and protocols and how the testing protocols are implemented, this thesis will examine potential unethical testing approaches and protocols and possible human rights infringements relating in particular to the HIV testing of women and girls.

1.2 DEFINITIONS OF HIV TESTING PROTOCOLS

Each of the HIV testing protocols will be defined. These include: HIV voluntary counselling and testing (VCT); provider-initiated testing and counselling (PITC), also called 'routine testing'; a request for HIV testing by a patient from a private health care practitioner or by a health care practitioner to a patient for diagnostic purposes; mandatory or compulsory testing; and the latest, universal testing or 'test and treat'.

In South Africa, "HCT" is the acronym used by the Department of Health (DOH) for any type of HIV counselling and testing, while "HTC" is the common short form acronym used in a number of other sub-Saharan African countries for any form of HIV testing (Republic of South Africa, Department of Health, 2014, p. 20). In 2015 South Africa's DOH distinguished between only two forms of HCT, client-initiated counselling and testing (CICT) and provider-initiated counselling and testing (PICT), although the national

HIV guidelines state that “all forms of HCT should be voluntary” (ibid.). However, for the purposes of this paper, I have broken down HIV testing and counselling into more categories, as follows.

1.2.1 Voluntary Counselling and Testing (VCT)

Voluntary counselling and testing (VCT) is when an individual either voluntarily goes to a health-care or community-based centre where VCT is provided and requests an HIV test, or when an individual requests an HIV test if home-based HIV testing is available in the community (WHO, UNAIDS, GTZ, et al., 2004; Doherty, Tabana, Jackson, et al., 2013, p. 3). In this protocol, available in developing countries for some 20 years, pre-test information and counselling is provided on an individual, confidential basis and can include personal risk-reduction identification by a trained counsellor to help the person understand her risk of HIV infection and devise strategies to reduce her risk, including HIV prevention methods (WHO, UNAIDS, GTZ, et al., 2004, p. 34). The HIV test is performed by the provider with a rapid test kit, taking a pin prick of blood from the client’s finger. Some 20 minutes later after the test result is visible, the result is provided confidentially to the client, explained, and post-test counselling is provided, whether the person has tested negative or positive (ibid.). The provider describes the implications of the test result and discusses risk-reduction counselling to prevent future HIV infection if the person has tested negative or onward transmission of HIV if the person has tested positive (O’Grady, 2005, p. 27). For a person testing positive, the provider writes a referral to a health-care centre or laboratory for a CD4+ cell count (if this service is available) to test the person’s immune system level and whether she should start antiretroviral therapy (ART), if available, if she has reached the threshold for treatment in her country through the public-health system. In some countries, ART can be made available as soon as

possible after a person tests HIV-positive if funding is not an issue and the health system will support the immediate availability of and access to lifelong ART. In South Africa, for example, the 2015 HIV guidelines recommend ART initiation at a CD4 count of ≤ 500 cells/mm^3, which is consistent with the latest WHO guidelines from 2013, but in fact in 2015 the country is still struggling to meet WHO's previous guidelines for ART initiation for individuals testing HIV-positive at ≤ 350 cells/mm^3 with some 3 million people accessing ART in early 2015, or less than 50% of the 6.8 million South Africans estimated by UNAIDS to be living with HIV (RSA, DOH, 2014, p. 15; Bekker, Venter, Cohen, et al., 2014, p. 105; UNAIDS, 2015, p. 1).

1.2.2 Provider-Initiated Testing and Counselling (PITC)/Routing Testing

Provider-initiated or routine HIV testing has been recommended in the United States of America (USA) by the U.S. Centers for Disease Control and Prevention (CDC) since 2006 and the World Health Organization (WHO) for countries with generalised HIV epidemics, most countries in sub-Saharan Africa, since 2007 (Branson, Handsfield, Lampe, et al., 2006; WHO, 2007). Routine testing is when an individual goes to a health-care practitioner or clinic for diagnosis, care, or treatment of any illness, for a health check-up, or a pregnant woman for antenatal care, and the health-care practitioner states the individual will be tested for HIV unless she declines the HIV test, known as 'opting out' (WHO, 2007, p. 20). Test-related information is provided before the HIV test is performed rather than specific pre-test counselling; the information given varies in the level of detail by the facility and provider, although related guidelines were released in 2007 by the WHO (ibid., p. 36). If an individual 'opts out' of routine testing stating she does not want to be tested for HIV, the provider should not test her. Post-test counselling generally is provided only

to individuals who test HIV-positive through routine testing, although the WHO recommended in 2007 post-test counselling for anyone testing for HIV (ibid., p. 39).

1.2.3 Diagnostic Testing

Individuals seeking health care through a private provider or at some public health clinics in sub-Saharan African countries can request an HIV test, but counselling generally is not offered. The WHO calls testing based on specific signs and symptoms, the approach generally used for most medical tests, "diagnostic testing," or diagnostic testing and counselling" if counselling is offered (WHO, 2012, p. 18).

1.2.4 Mandatory Testing

Mandatory or compulsory HIV testing is when all adults or the whole population of a country are tested without an opportunity to decline the HIV test, as was done in the former Soviet Union in the late 1980s/early 1990s (UNESCO, 2005, p. 16). Mandatory HIV testing of individuals occurs in some countries in southern Africa to obtain insurance, to enter the military, before blood and organ donation, and for immigration purposes (Armstrong, 2008, p. 6). Mandatory HIV testing has not been linked to treatment for HIV, which complicates its ethical implications by potentially diagnosing an individual with a dreaded, deadly disease without providing any access to treatment for it. In 2013 mandatory testing was suggested by Zimbabwean President Robert Mugabe and several Southern African Development Community (SADC) leaders as a viable strategy to curb the spread of HIV, showing that this testing approach may be seeing a resurgence of support by policy makers (Mbanje, 2013, p. 1).

1.2.5 Universal Testing

Voluntary universal testing for HIV emerged conceptually in 2009. In theory, voluntary universal testing of HIV is linked to universal treatment for anyone testing HIV-positive (Granich, Gilks, Dye, et al., 2009, p. 48). However, this hypothetical approach is based on a controversial mathematical model supposedly verifying effectiveness, the validity and public health value of which many have questioned. Several published responses to this study questioned the ethics behind the mathematical model using data from South Africa's generalised HIV epidemic (and admitted guesswork) in which adults 15 and older would be tested for HIV annually and started on ART immediately if testing HIV-positive (Jurgens, Cohen, Tarantola, et al., 2009, p. 1079; Cairns, 2009, p. 3). The model also had significant problems in its epidemiological assumptions and design, according to several respondents (Ruark, Shelton, Halperin, et al., 2009, p. 1078; Hsieh & de Arazoza, 2009, p. 1079). Moreover, the cost that such an HIV testing approach would involve, including the necessary human resources and funding for massive testing and lifelong ART for many millions of people, was felt by some to be prohibitive (Bartlett, 2009, p. 1). Other modelling study results published in 2010 show that universal testing and immediate treatment with ART for individuals testing HIV-positive could promote greater proliferation of drug-resistant strains of HIV, which would defeat its public health objective (Smith, Okano, Kahn, et al., 2010, p. 1). Resistance of HIV to ART is causing clinical and public health problems in Europe and the USA, and resistant strains are growing in developing countries, where the deleterious impact could be much greater in resource-constrained settings with larger epidemics (ibid.).

1.3 HIV TESTING AND ETHICAL PRINCIPLES

I will argue that it is essential for South Africa and other countries in sub-Saharan Africa to encompass the bioethical principles of respect for autonomy, beneficence, non-

maleficence, and justice, and the related sub-issues of informed consent and privacy and confidentiality, in their HIV testing protocols and for HIV testing to be ethically beneficial on both the individual and population levels. And sometimes there will not be an easy union of individual and common good. Exploring and answering questions about the ethical content of HIV testing protocols, including voluntary counseling and testing, provider-initiated or 'routine' testing, mandatory testing and universal testing or the 'test and treat' approach, will shed light on whether these interventions are indeed ethical and respectful of human rights, especially the rights of individual women. (In South Africa and some other countries HIV counselling and testing (HCT), or HIV testing and counseling (HTC), is the 'blanket' term used to encompass the various types of testing-related interventions available.)

Identifying the most ethical testing methods to use amidst the world's largest HIV epidemic, here in South Africa, where a massive testing campaign was introduced by the government in April 2010, could also help identify the protocols potentially most beneficial for reaching public health objectives. Moreover, examining the essential ethical content of routine testing and other HIV testing interventions could help guide the evolution of an optimal testing intervention or the optimum range of testing interventions for South Africa and other countries in the region in the future as the HIV epidemic and the responses to it continue to unfold. It is important to recognize that in medicine and public health, "there is no universally accepted way to do ethics", according to a prominent ethicist (Sokol, 2010, p. c3256). Thus identifying the full range of ethical issues evident in the various HIV testing protocols and describing where and how they impede the implementation of recognised bioethical principles and veer off into human rights

infringements or outright violations related to women and girls would advance the fields of both bioethics and human rights.

Reducing HIV transmission is a primary rationale for HIV testing. Emphasising the need for voluntariness, good counselling both before and after HIV testing, and accessible ART provision supports HIV testing as an entry point to both prevention and care. Interrogating the ethical issues surrounding current HIV testing protocols and making recommendations for the future also could help countries provide not only more humane services, but lead to greater uptake of testing and the necessary referral services to prevention, treatment, care, and support services—resulting in beneficial impact for individuals and public health by decreasing the number of new HIV infections—especially in women and girls.

The bioethical principles to be examined regarding HIV testing include respect for autonomy, beneficence, non-maleficence, and justice. The following definitions by Beauchamp and Childress will be used for these principles: respect for autonomy, as a norm respecting the decision-making capacities of autonomous persons; non-maleficence as a norm of avoiding the causation of harm; beneficence as a group of norms for providing benefits and balancing benefits against risks and costs; and, distributive justice as a group of norms for distributing benefits, risks, and costs fairly (Beauchamp and Childress, 2001, p. 12). However, the philosophical views of autonomy and that autonomy involves liberty of action will also be explicated; and, views of justice beyond distributive justice, including justice as fairness and social justice, will be reviewed. The two most important ethical issues challenged by some current HIV testing protocols are autonomy and justice. Autonomy is challenged when HIV testing is not voluntary, or is perceived not to be a matter of choice through the lack of including an informed consent process prior to testing, or if testing appears to be coercive and individual agency is overridden. In these

cases, autonomy is overridden because of the end, that is, testing more people for HIV, justifying the means of involuntary testing. Justice is challenged when HIV testing results are not kept confidential in the current social environment of stigma toward and discrimination against people living with HIV (PLHIV), or no counselling is accessible surrounding HIV testing, or testing is forced without access to HIV care and treatment if one tests positive. The occurrence of the events also show a lack of beneficence and indeed are maleficent. Other ethical issues to be interrogated with respect to HIV testing include human rights, specifically the right to self-preservation, related to the right to health care and argued by some to be a socioeconomic right and by others to be encompassed by the concept of social justice. Yet self-preservation can be perceived as a more basic right than either of those concepts encompass. Any of these rights are profoundly dense and complex matters.

1.4 LITERATURE SURVEY

The current debate about the efficacy of various HIV testing methods centres around a utilitarian justification of aiming to reach a public health objective of fewer new HIV infections through the use of a routine testing approach for HIV, which some believe infringes on human rights. This thesis will make a rights-based argument related to the ethics of various HIV testing protocols, which bioethical principles help expand beyond the common human rights framework normally discussed because they encompass explicit rights of patients and duties of health-care providers. The following literature review includes literature related to these two areas most prominently and more selectively to the key issues and the most important points related to the ethics of these testing protocols regarding the rights of women and girls, starting with routine HIV testing.

1.4.1 Views on the Ethics and Bioethics of Routine HIV Testing

Several authors have raised ethical questions about routine HIV testing in medical journal articles since 2006. Yet they have not necessarily linked their questions to bioethical principles. While not identifying the principle of autonomy, Rennie and Behets reviewed informed consent for HIV testing in developing countries, where disempowerment is common and the 'voluntariness' of routine testing and choice can be questionable based on power differentials between patients and health-care practitioners, especially when the patients are women (Rennie and Behets, 2006, p. 54). However, power differentials between patients and health-care practitioners are not limited to developing countries. Rennie and Behets, Maman and King, and Bassett and Walensky focused on gender inequalities specifically in developing countries and the commonality of women who test HIV-positive facing stigma, violence, and abuse in these countries, emphasising that routine testing may expose women and girls to significant harm or maleficence (ibid., pp. 54-55; Maman and King, 2008, p. 198; Bassett and Walensky, 2010, p. S81).

A Kantian-based examination of routine testing was done by Metz, although he also used a utilitarian lens in reaching his conclusion. Metz determined that routine testing does not violate rights, can promote health, and is morally justified even where ART is unavailable or unaffordable (Metz, 2005, p. 397). He based his conclusion on assumptions promoted by public health advocates on the potential benefits of routine HIV testing to result in fewer HIV infections in the future (ibid.). He cited support for his statements that people who test HIV-positive subsequently engage in safe sex from an article published in 1991, when advocates hoped VCT would result in disclosure of positive status and the practice of safer sex (i.e., using a condom) by PLHIV and have an impact on the spread of HIV (ibid.). These assumptions from more than 20 years ago have not been proven by research

results supporting such outcomes, although to gain additional information intrusive measures might have to be used. Research has shown that disclosure of positive HIV status remains limited, mainly because of HIV-related stigma and discrimination, including in South Africa (Wong, Van Rooyen, Modiba, et al., 2009, p. 220). Metz supported routine testing as a "means" likely to justify achieving the public health goals of reducing HIV transmission and improving access to ART, stating that such testing is justified even if ART is not available (Metz, 2005, p. 405). Ironically, he justified routine testing mainly on utilitarian grounds rather than on the Kantian principle of autonomy, which does not support the end justifying the means.

Knight and colleagues reviewed several ethical issues related to HIV testing approaches in peer-reviewed literature and how they pertained to public health and/or individual interests. Among the issues they reviewed were John Stuart Mill's principle of preventing harm to others; the impact of stigma on HIV testing; and, mandatory testing (Knight, et al., 2013, pp. 2, 4, 7). They determined that consequentialist arguments focusing on whether testing approaches were morally permissible or not had neither robust empirical or theoretical underpinnings related to the needs of individuals or public health. Knight and colleagues did not examine gender issues related to HIV testing, although they reviewed the issue of pregnant women and coercive or mandatory testing and the rights of the foetus versus the rights of these women (ibid., p. 7). Noting that forms of ethics emphasising equity, justice, and the structural distribution of health and illness had not been included in the testing literature they reviewed, Knight and colleagues recommended the need for continued articulation of both evidence- and theory-based ethics regarding HIV testing (ibid., p. 10).

1.4.2 Autonomy and HIV Testing

Kant's principle of respect for human dignity and that every human being is of "absolute and incomparable worth" is the basis for respecting the autonomy of each and every human being, i.e., respecting an individual's right to make her own decisions about her actions and her life (Kant, 1996, pp. xvii, xxii). The bioethical principle of autonomy is based on the Kantian principle of autonomy: the ability to make a choice, to weigh the specific factors involved, to make a determination about a present or future action, and to take action based on one's decision, all of which are dependent on rationality, the human ability to reason. Exercising autonomy recognises the right to liberty of action. Contemporary philosophical notions of individual autonomy also encompass conditions influencing decision-making other than the necessity of choosing what could be considered ethical for everyone, such as psychological and social factors enabling or delimiting autonomy (Oshana, 2006, pp. 87-88). Fundamental to autonomy is the opportunity for choice.

For health-care practitioners, respect for autonomy obligates them to disclose information to the patient pertinent to a procedure or intervention they recommend, including the potential benefits and harms of the procedure; to probe for and ensure patient understanding and voluntary agreement to undergo the procedure; and, to foster adequate decision-making by the patient about whether she freely gives consent for the procedure (Beauchamp and Childress, 2001, p. 64). Some may see this as a controversial claim regarding HIV testing, pitting individual autonomy against collective autonomy, or the individual's rights against a public health prerogative. Yet HIV testing is in invasive procedure.

In interrogating whether routine testing encompasses respect for autonomy, I will examine whether a health care practitioner stating to a patient she will be tested for HIV unless she declines indeed respects patient autonomy. If there are no signs and symptoms of HIV disease in a patient, yet the healthcare provider states she will test the patient for HIV simply because the person lives in a country with a generalised HIV epidemic, this approach may discriminate against individuals living in these countries even though WHO's rationale for routine testing is to protect more people from HIV infection (see Chapter 2). If the patient has seconds to decide if she wants to be tested for HIV and has to immediately decline if she objects, this testing process does not seem to respect autonomous decision-making involving the time needed to make an individual choice. If the patient has no prior relationship with the healthcare practitioner who states she will be testing the person for HIV, the average patient may not feel she is in a position to decline the test the more powerful health care provider intends to conduct. For example, 68% of individuals who tested for HIV within 11 months of Botswana adopting HIV routine testing as its national policy reported they felt they could not refuse the test (Maman & King, 2008, p. 197). In Malawi in 2007, rural women who were interviewed did not perceive HIV testing as a choice, but as compulsory to be able to receive antenatal care (Angotti, Dionne and Gaydosh, 2010, p. 1). In 2010, personal reports from a few South African provinces showed that "people are being told that unless they agree to be tested, they will not be provided with healthcare" (IRIN Plus News, 2010, p. 2). Routine testing may infringe on freedom and equality, conditions for autonomy.

1.4.3 Autonomy as the Basis for Informed Consent

If an individual is given limited information about the HIV test before it is performed, does this show respect for autonomy by following an 'informed consent' process, the standard

manifestation of respect for patient autonomy in medical care? According to Manson and O'Neill, informed consent is voluntary consent for a course of action under which those requesting consent must provide an explicit statement of the nature and purposes of the proposed action, including its effects, risks and other features, to an individual whose consent is sought (Manson & O'Neill, 2007, p. 10). Consent may not be "informed" if it is based on limited information provision. If an 'opt-out' process is used, whereby a patient has to quickly orally object to the performance of the test, rather than the use of an 'opt-in' process, whereby the patient would have to say, "Yes, I do want to be tested for HIV" before the test is administered, consent may be questionable. The approach of the health care provider stating, "I am going to test you for HIV unless you say no," could appear coercive or manipulative, especially where personal power differentials are great. The use of coercion voids autonomy in bioethics (Beauchamp and Childress, 2001, p. 94). Routine testing also could be seen as an example of a positive 'framing effect,' that is, framing a wish in such a way to guide the patient to make a specific decision as an apparent positive gain (Gonzalez, Dana, Koshino, et al., 2005, p. 2). In bioethics, use of the framing effect is considered a barrier to informed consent (Beauchamp and Childress, 2001, p. 95). The opt-out routine testing protocol does not seem to show sufficient respect for patient autonomy to be considered morally just, according to both the bioethical and Kantian principles of autonomy, an argument I will develop more fully in Chapter 2.

Regarding mandatory testing, respect for autonomy is not even at issue, as the protocol overrides respect for autonomy based on its non-voluntariness. Yet whether this testing protocol would be advisable in some HIV epidemic circumstances and thus warranted in overriding respect for autonomy to protect public health, a utilitarian or consequentialist goal, will be examined. Mandatory testing is important to investigate ethically based on

several new legislative bills in African countries designed to establish and implement mandatory testing measures and other controversial HIV-related legal amendments. One of the bills was passed by Uganda's Parliament in 2014 and signed into law by Ugandan President Yoweri Museveni on 31 July 2014 (Barton, 2014, p. 2). The new Ugandan law enacted in 2014 permits mandatory HIV testing of pregnant women and their sex partners, and survivors of GBV, and it enables the courts to release the HIV status of these individuals against their will and without their consent, potentially exposing them to physical violence from sex partners and other family or community members (Burnett, 2014, p. 1).

1.4.4 Beneficence and HIV Testing

Beneficence requires the balancing of benefits and harms that may result from an action to determine whether or not, on balance, the action is beneficial (Kass and Gielen, 1998, p. 92). With respect to beneficence and VCT, the patient already has decided getting tested for HIV is in her best interest, with such beneficence dependent on autonomous decision-making. Thus VCT can be considered a beneficent HIV testing protocol on this basis. The same rationale can be used for beneficence in regard to a patient requesting an HIV test without counselling from a private health care practitioner.

With respect to routine HIV testing, however, the rationale is that it is in the best interests of society, or in the interests of public health, that people be tested for HIV, rather than in the best interests of the individual. Where ART is accessible after an individual tests HIV-positive, there is an individual benefit in testing: the ability to start treatment and prolong life if one tests positive. The public health benefit in these circumstances is that taking ART lowers an individual's HIV infectiousness. The results of one study suggested that if

many people infected with HIV are taking ART, fewer people will become infected with HIV in the future (Das Douglas, Chu, Santos, et al., 2010, p. 1). However, the results of another study showed that while expanded HIV testing and treatment will increase the life-expectancy of people living with HIV (PLHIV), it will have only a modest impact on HIV transmission and thus is unlikely to halt the epidemic (Walensky, Paltiel, Losina, et al., 2010, p. 1). Consequently, there may be a public health benefit from routine testing if it results in more people accessing ART and thus fewer people living with HIV who will remain highly infectious. But whether routine testing for HIV definitely will have a positive impact on public health is unclear, especially in areas where there may not be many people living with HIV.

Taking a test for an infectious disease, including HIV, does not in itself lower an individual's infectiousness. Moreover, empirical evidence shows that individuals do not necessarily practice safe sex after they learn they are HIV-infected, and one may wonder why they are not. According to Simoni and Pantalone, some are afraid of rejection and abandonment, or violence and other forms of abuse from their partner (2004, p. 110). While the reasons behind this outcome vary, it is mainly because the rampant stigma toward and discrimination against PLHIV prompt many people not to disclose their HIV-positive status to their sex partners, and some to no one at all (Sullivan, 2005, p. 33; Niccolai, King, d'Entremont, et al., 2006, p. 102; Wong, et al., 2009, p. 220).

Routine testing may not be beneficent where counselling is not available to patients testing negative, thus providing no HIV prevention benefit to them. Its beneficence also is questionable where ART is not accessible to patients testing positive, providing no treatment benefit, or where a threshold has to be reached in an individual's CD4+ cell

count before ART is provided through a public health system, especially where there are waiting lists of up to a year for patients who have reached the threshold for treatment (during the course of which some die), or in countries where ART is largely unavailable. Mandatory testing also is not in itself a beneficent HIV testing protocol.

Whether routine testing on its own can be in the individual patient's best interest is debatable. Before ART became available in 1996 in developed countries and in 2004 through the South African public health system to patients who reach the necessary low CD4+ count threshold, the beneficence of VCT for individuals was debated. The theory at the time of initial availability of VCT and which remains in the era of routine testing is that if patients learn they are HIV-positive but do not have access to ART, at least they will know they have weakened immune systems. Then they promptly can seek treatment if they are infected with an opportunistic infection (OI), such as pneumonia or tuberculosis (TB). Yet this theory assumes OI treatment will be accessible to all PLHIV, that they will be able to afford to go wherever the treatment is available for their specific OI (of which there are many), be able to pay for treatment or access it through the public health arena, and perhaps be cured of whatever infection they have developed. Recent research results show, however, that these assumptions are not valid for many Africans (Irin PlusNews, 2010, p.1).

I believe that whether HIV testing seems beneficent for an individual should be a decision made by the individual. When routine testing is not linked to counselling for individuals testing negative and not linked directly to treatment for individuals testing positive, this protocol appears to be deficient in beneficence and justice, unless the procedure is fully voluntary whereby the individual has decided in advance that knowing her HIV status will

be in her best interest—underscoring the autonomy of the decision—whether or not treatment will be available afterward. Unless a woman is pregnant, it is unlikely she would have decided to be tested for HIV and not already gone for HIV testing at a facility offering VCT unless other issues precluded it, such as lack of transport funds to reach a facility or the lack of necessary childcare assistance.

Knowing one's HIV-positive status despite lacking access to ART is presumed to be beneficial for mothers living with HIV who are approaching death and want to prepare themselves and their children for their deaths to try to lessen emotional pain and promote greater child stability. Yet it is hard to imagine how *routinely* testing a patient for HIV and telling her she has a fatal illness if ART is not available is in her best interest. Is routine testing really a public health protocol designed to control the HIV epidemic, as I believe, and beneficent to individuals and public health only if ART accompanies routine testing?

Along with examining HIV testing issues from the individual woman's viewpoint, I will examine whether the public health goal of routine testing—the utilitarian goal of substantially decreasing the number of new HIV infections—is an ethical rationale. Currently, there is no evidence to show that routine testing itself lowers the prevalence rate (percent of the population at risk who are infected) or the incidence rate (percent of new infections in the population at risk in one year) of HIV anywhere. The rationale for routine testing relies on the public health assumption that testing more people for HIV will result in lessening viral spread, a beneficent public health goal, but also a questionable outcome (WHO, 2012, p. 12).

A caveat regarding the efficacy of routine testing is when it is linked to the prevention of mother-to-child transmission (PMTCT) of HIV, which connects testing with treatment to help prevent transmission of the virus from the mother to the foetus or baby. The WHO guidelines on PMTCT recommend full ART provision to the mother, making the PMTCT protocol beneficent both for the baby and for the mother (WHO, 2009, p. 5). Previously, PMTCT focused on reducing the risk of transmission to the baby and physically benefitted only the foetus or baby. Yet it benefitted the mother emotionally by reducing her risk of passing her infection to her baby, which some pregnant women who knew they were infected with HIV were concerned about (Bello, Ogunbode, Adesina, et al., 2011, p. 33; Hamela, Tembo, Rosenberg, et al., 2013, p. 37). It is important to note that the latest PMTCT protocol includes treatment for both mother and baby, including lifelong ART for the mother in countries with generalised HIV epidemics, not only a routine test for HIV for the mother (WHO, 2013a, p. 100).

1.4.5 Non-Maleficence and HIV Testing

For 2,000 years, "primum non nocere," or "first do no harm," echoed in the 'Hippocratic Oath,' has been the fundamental guideline of Western medicine (Pappas, Kiriaze & Falagas, 2008, p. 347). Non-maleficence in bioethics means that no matter what you do to a patient, do not harm the person, or at least do not leave the person worse off than before you started to intervene (Jonsen, 1975, p. 27). Non-maleficence is important for health care practitioners to keep in mind regarding a patient's emotional and psychological, as well as physical health. More than 35 years ago, six years before HIV was discovered, internationally renowned bioethicist Edmund D. Pellegrino asked, "Where is the delicate balance drawn between assuming moral authority on the justification of an emergency and overstepping the patient's moral agency?" (Pellegrino, 1975, p. 215). This question

addresses both respect for patient autonomy as well as the need for non-maleficence by the health-care provider. Such a question is central to ethical decisions that have to be made by individual health-care providers, agencies, and nations about the necessary response to the HIV epidemic. It also shows there is overlap in bioethical principles relating to individual rights versus public health.

Regarding the possibility of having to give a patient bad news about being infected with a fatal or at least long-term chronic disease, it is important to reflect on the difference for the patient between voluntarily requesting an HIV test and the potential result, versus a patient being told by a health-care practitioner she will be tested for HIV unless she refuses with a possible resulting diagnosis of HIV infection. Some have speculated that once it becomes common knowledge that HIV testing will be conducted when anyone goes to a clinic or practitioner for health care, fewer people will access health care because they will fear being tested for HIV. This worry has been expressed by a number of health care practitioners in journals and by some southern Africans themselves in recent surveys (Weiser, Heisler, Leiter, et al., 2006, p. 1017; Wynia, 2006, p. 5; Becker, Tsague, Sahabo, et al., 2009, p. 3).

Imagine a young South African woman in her early 20s who goes to a public health clinic because her nose is blocked and has been blocked for ten days. She feels tired all the time, and her body aches. She doesn't want to get out of bed each morning, and she's worried because her infection is affecting her work productivity as a domestic. She wants 'tablets' to make it go away. When she finally sees a health care practitioner after standing in the long queue of patients at the clinic, she is told by the practitioner she will be tested for HIV unless she refuses. She is glad to see the practitioner and she is too scared to say no,

although she doesn't really understand what the practitioner has said about the test. She is tested for HIV. Twenty minutes later she is told by the practitioner she is HIV-positive, and she must go to another clinic in a city to have her CD4+ count tested to see if she can be put on ART. She is asked if she has any questions. But she is too stunned to know what to ask. She sits in the chair in shock and tries to listen to what the health care practitioner is saying. All she can think of is that she may die soon, and then who will take care of her young daughter?

This is how routine HIV testing works, using the opt-out approach, which is supposed to be implemented across South Africa, was recommended in the USA in 2006, and has been implemented in Botswana since 2004 (Branson, et al., 2006, p. 4; Kenyon, 2005, p. 21). In Botswana, though, the original routine testing protocol was 'opt in' by the patient, rather than 'opt out' (CDC, 2004, p. 1). Consideration of all the impacts of routine testing on individuals is needed to make an ethical determination. For example, does routine testing for HIV of the young South African woman, telling her she is HIV-positive, and giving her a referral note for a clinic in the closest city to have her CD4+ cell count tested appear to be a largely beneficial intervention, without any detrimental impact to her emotionally or psychologically? According to bioethicist Albert Jonsen, "To benefit is to balance; to harm is to unbalance or fail to balance" (1975, p. 28).

While patients may be no worse off physically after being tested for HIV, many patients are worse off emotionally and psychologically based on stigma toward and discrimination against PLHIV (Hensen, Baggaley, Wong, et al., 2012, p. 67; Loutfy, Sherr, Sonnenberg-Schwan, et al., 2013, p. 5). They can be denied job opportunities, their relationships or marriages can deteriorate, and they can experience verbal abuse or physical violence if

others find out they are HIV-positive (Gaillard, Melis, Mwanyumba, et al., 2001, p. 938; April, 2010, p. 4). Stigma also includes the internal stigma many PLHIV feel on which Edwin Cameron has written so cogently (Cameron, 2005, p. 53). Many individuals feel they have no one to turn to for support. Indeed many may not, as recent study results on HIV disclosure in two locations in South Africa showed (Wong, et al., 2009, p. 216). Even if a person has a family member or friend to turn to after she learns she is HIV-positive, the psychosocial support system available in most sub-Saharan African countries through public health systems is minimal at best. The availability of support or lack thereof is relevant because of the commonality of depression in PLHIV, especially to individuals after learning they have tested HIV-positive. Another recent study in South Africa showed that 22.5% of HIV-infected patients had thought about suicide, and 69% of these patients had thought about it as a result of testing HIV-positive (Thom, 2009, p. 11). I believe routine testing interventions cannot be considered non-maleficent in and of themselves even if they are linked to the provision of ART to patients who test HIV-positive. The potential for negative psychological and emotional impact on a patient after testing HIV-positive is one of the reasons why the voluntariness of HIV testing is crucial.

1.4.6 Justice and HIV Testing

I now turn to justice, including justice as fairness, distributive justice, and social justice. In regard to giving someone her due, is it just to tell her you are going to test her for a dreaded disease unless she refuses because she has come to a health clinic? Doesn't this seem like it could be considered discriminatory practice toward individuals who are sick, or women who are pregnant, or anyone living in a country with a generalised HIV epidemic? I do not believe it is fair to tell a patient you plan to test her for a dreaded, stigmatised disease if you do not plan to offer her treatment for the disease if she is

diagnosed with it. Such a notion of fairness is aligned with that of Rawls, which is that all obligations to others arise from the principle of fairness, a theory of justice; that "each person has an equal right to a fully adequate scheme of equal basic rights and liberties," and "that when justice as fairness is fully realized in a well-ordered society, the value of full autonomy is likewise realized" (Rawls, 1999a, pp. 226, 301; Rawls, 2000, pp. 341, 344). Leaving someone on her own to suffer whatever negative consequences she may have to contend with after testing HIV-positive seems unjust.

Perhaps routine testing could be considered a just protocol only if it is linked to access to ART and other health-care support for all individuals testing HIV-positive and available support for all individuals who test HIV-negative. If this is done, routine testing will comply with at least one of the factors ensuring a rights-based approach in the policy statement on HIV testing released in 2004 by UNAIDS/WHO before the routine testing/PITC guidelines were released (2004, p. 3). With regard to linking routine testing to treatment and care, justice equates with the right to health care, which many argue is a human right and with which I agree (Shue, 1996, p. 171; Rawls, 1999b, p. 50; Ashford, 2007, p. 185; Gewirth, 2007, pp. 221, 225; Pogge, 2008, p. 74).

Some bioethicists believe that in addition to justice, the bioethical principles of beneficence and non-maleficence also underlie the societal obligation to provide "a decent minimum of health care" (Beauchamp and Faden, 1979, p. 128). Whether routine testing when not linked to health care can be shown to be morally unjust, and lacking in beneficence and non-maleficence, will be included in my interrogation. Others believe that health care should be subsumed under a principle of justice that guarantees the fair equality of opportunity, or distributive justice (Daniels, 1981, p. 95; Daniels, 2009, p. 37).

Linking routine testing to treatment also is a distributive justice issue regarding the resources needed for ART provision in developing countries. One has to question whether implementing routine testing in countries that cannot afford to make ART available to those who test HIV-positive is not only morally unjust, but lacking in pragmatism. Routine testing does not seem just even to the majority if the rationale is simply to test as many people for HIV as possible. Testing people for an infectious disease without any access to treatment or care if they have the infection has no real public health value, nor will it make the majority of people happier, or promote the greater well-being of all, other utilitarian goals. Awareness of the levels and impacts of HIV epidemics by public health professionals has been known for more than ten years. Testing more people for HIV to find out more about the epidemic, how to prevent more infections, and how to treat people for this illness is unnecessary even from a utilitarian point of view. Thus routine testing without access to ART does not seem efficacious as a valid utilitarian approach beyond whether it is morally just or unjust on the individual level.

Another current issue related to justice is that some believe treatment for HIV in developing countries with the largest epidemics in the world should be supported primarily by resources emanating from developed countries. Their belief is premised on a duty of implementing social justice to individuals born in countries lacking or with huge disparities in socioeconomic equity (Pogge, 2008, p.79; Selgelid, 2008, p. 124).

These are a few questions I will examine related to justice, distributive justice, and social justice. However, I believe developing countries have health care-related duties to their citizens and the issue is not only a cosmopolitan one related to the responsibilities of

countries—developed and developing. The duty not to impose unjust social institutions on other human beings, or an unjust social order as aligned with Pogge's concept of cosmopolitanism, surely not only transcends borders but is relevant within one's own national borders and is a responsibility of any government (Pogge, 2002, p. 86).

1.5 RESEARCH METHOD LIMITATIONS

It is important to note that this thesis does not draw on new empirical research, but is based on the available literature and my work on HIV testing, which began in 1995. The research undertaken for the thesis is primarily theoretical, yet includes some important, relevant results from recent empirical studies. The study design involved a review of literature related to ethics, human rights, bioethical principles, autonomy, justice and social justice, welfare, the HIV epidemic, stigma and discrimination against PLHIV, the history of HIV counselling and testing, current and historical HIV testing guidelines, and related emerging and evolving issues surrounding current modes of testing, as well as potential HIV testing methods projected for use in the future.

The research method that was used entailed the exploration of routine testing and other HIV testing methods as a moral problem. Concerning empirical inquiry, the method employed was theoretical. The range of approaches available for HIV testing and the ethical issues these approaches encompass is a current ethical and public health problem that may be better understood through examination and explication. Ethical inquiry, including analysis of the means (reasonable and ethical actions by individuals and groups) and ends (a just and good goal for individuals and groups), was undertaken. The method involved clarification of the issues, concepts (ideas), logic (the relationships between the way decisions are made by individuals and determinations made for public health

purposes), and criticism of intent (how experience is conceptualised, described, and acted on). The relevant issues are identified in the thesis, and how they relate to human dignity and individual rights are described. Related developments in rights theory from the 1600s to the present day are reviewed and referenced. The facts surrounding ethical and public health issues related to routine HIV testing and other testing protocols are outlined. Examples from published research study results and other relevant journal articles are provided.

The groups and individuals having a stake in HIV testing and the outcomes, and their special needs and obligations, especially those of women and girls, are characterised. The options for taking specific approaches to HIV testing related to ethics and public health are summarised. The ethical reasons for and against taking specific approaches, including voluntary counselling and testing, routine testing, mandatory HIV testing, 'universal' testing, and potentially other new approaches to HIV testing, are examined.

The main focus is on the options regarding HIV testing that will produce the least harm to an individual, especially an individual woman or girl in sub-Saharan Africa, without compromising public health. Common individual and gender-based circumstances related to HIV testing in the present epidemic environment, especially in sub-Saharan Africa, are an important focus. A conclusion regarding the ethical basis for and ethically appropriate methods of HIV testing of women is reached, including relevant recommendations for the future. Several health-care and legal professionals have identified a few human rights concerns regarding HIV testing over the last five or more years. Yet to my knowledge, an extensive examination of the relevant bioethical principles and human rights and the ethical implications of HIV testing protocols, with recommendations on revisions

specifically to routine testing to make it a more ethical intervention, especially for women and girls, has not been undertaken previously.

Books, journal articles (both electronic and hard copy), and other related philosophical and health publications have been used for the research and writing. A 'snowball' approach has been used, i.e., reviewing references in the most important related publications, both books—classics through contemporary—and journal articles to expand the information sources and the ethical underpinnings, and relevant research study results published prior to and during the research period. All information search engines available through the Wits Library's electronic catalogue and books from the Wits libraries, as well as other lending libraries available through other universities, were accessed. Google Scholar and other search engines such as ProQuest, Science Digest, etc., were used to include other relevant source materials.

Historical and contemporary ethics, medical ethics, human rights, and bioethics theories and practices have been assessed related to HIV testing, particularly of women in sub-Saharan Africa. Where relevant, data from the results of published empirical studies was examined regarding specific ethical issues related to epidemic status and trends, HIV testing, vulnerability to HIV infection, secondary and tertiary socioeconomic vulnerability and status, and other emerging issues within the research itself. Key data has been used to defend or refute ethical arguments, where relevant, along with the most important ethical and human rights theories, policies, and potentially existing or planned programming. Data include those relevant to the ethical issues surrounding HIV testing methods and policies under discussion for the future in sub-Saharan Africa and their potential implications for and impact on women and girls in the region.

CHAPTER 2: STIGMA AND ROUTINE TESTING

2.0 INTRODUCTION TO STIGMA AND DICRIMINATION AND HIV

Stigma and discrimination related to HIV infection and HIV testing have been issues of serious concern for individuals and vulnerable groups since the HIV epidemic began (April, 2010, p. 4). They remain issues causing anxiety to many today. A recent study in Zambia showed that discrimination against people living with HIV by health-care workers and stigmatising attitudes toward them by community members continue to be common barriers for individuals in deciding whether to be tested for HIV (Gari, et al., 2013, p. 1). The study investigators also hypothesised that because of the level of tolerance of GBV in Zambia, to which women living with HIV are highly vulnerable, women's fear of potential abuse can govern their decisions about HIV testing (ibid.). Moreover, the study noted that other studies in Zambia have shown that women who are living with HIV and who have suffered from GBV are more likely not to receive treatment for their disease because of their fear of further violence and abandonment by their families (ibid.). Such findings are not limited to women in Africa. A recent literature review of articles published in Africa, Canada, Europe, and the USA from 1980 to 2012 found that the emotional well-being of women is affected by stigma, discrimination, violence, lack of self-resilience, and post-traumatic stress, resulting in an impaired quality of life and lack of adherence to HIV medication, negatively affecting clinical outcomes (Loutfy, et al., 2013, p. 11).

This chapter will explore autonomy as an ethical issue and its relationship to HIV testing, the impact of GBV on women related to HIV and testing, the criminalisation of HIV transmission, the HIV testing policies of the WHO and the U.S. Centers for Disease Control and Prevention (CDC), informed consent and HIV testing, pre- and post-test

counselling as integral parts of HIV testing, and HIV testing as a gateway to care, with linkages to HIV prevention and care interventions.

2.1 AUTONOMY AS AN ETHICAL ISSUE IN HIV TESTING

Autonomy is derived from two Greek words, *autos*, which means 'self,' and *nomos*, which means 'laws' or 'rule,' and the word originally referred to the self-governing city-states in ancient Greece (Elander & Hermeren, 2013, p. 153). The contemporary use of the word autonomy related to individuals connotes different meanings to different philosophers. A number of differing frameworks for autonomy have been advanced by philosophers, as well as various types of autonomy, such as moral autonomy, personal autonomy, ethical autonomy, legal autonomy, political autonomy and social autonomy, among others (Christman & Anderson, 2005, pp. 2, 15). Only a few descriptions of autonomy will be examined briefly here, those that seem most relevant to the ethical principle of respect for autonomy and its importance in HIV testing.

To many philosophers, such as Immanuel Kant and his followers, autonomy is used to denote self-government, related to an individual who is self-governing, thus referring back to the original meaning of the word (Gregor, 1996, p. xxiv). To be self-governing to some philosophers means the ability to make choices for oneself and the action of making such choices without interference by others. However, autonomy is used by other philosophers, such as contemporary philosopher Marilyn Friedman, to connote self-direction, giving the sense of a more long-term planning process by an individual for her life, which would involve making choices, some important and long-lasting and others more immediate and mundane, but with an idea in mind of the path her life should take (Friedman, 2005, p. 156). Both of these senses of autonomy are important, even though none of us is truly self-

governing and no one can be solely self-directing. All human beings live in some country that governs its citizens; and, all human beings are dependent on others and individual life circumstances, as well as the surrounding social, political, and environmental conditions, which are crucial factors in the range of self-directing choices and actions that are available to anyone.

Contemporary versions of autonomy generally entail reference in some way to philosopher Immanuel Kant's 'principle of autonomy' (Kant, 1996, p. xxii). The ability to make a choice, to weigh the specific factors involved, to make a determination about a present or future action, and to take action based on one's decision is dependent on rationality, the ability to reason. In his writings, Kant explored the unique human capacity for "practical reason" and that such rationality influencing the will is what separates humans as "intelligible beings" from other "non-rational beings" (ibid., p. 544; Kant, 1991, pp. 90-91). Moreover, Kant wrote that the rational nature of human beings is what makes persons "ends in themselves," not just the "means" for achieving ends—and that all actions must harmonise with this principle of humanity (ibid., pp. 92-93). Kant's respect for human dignity and that every human being is of "absolute and incomparable worth" is the basis for respecting the autonomy of each and every human being, that is, respecting an individual's right to make her own decisions about her actions and her own life (Kant, 1996, pp. xvii, xxii).

What is important to understand about Kant is that his principle of autonomy centres morality within rationality, and that human reason is the source of moral legislation (ibid.). But Kant did not mean that every person makes her own morality. Rather, in identifying "the Idea of the will of every rational being as a will which makes universal law," Kant

meant that the moral principle(s) an individual follows in determining actions of the will should be the same moral principle(s) that any individual would follow in the same circumstances of determining right action (Kant, 1991, pp. 90-91). Thus, the ability to universalise a right action, or the capacity to make a rational determination and attribute one's chosen action morally to what anyone would choose, is a key concept in Kant's moral philosophy. The universality of right action is what unites his notion of autonomy to rationality (reason) and the dignity inherent in each human being, since the "moral law," or "universal law of right," resides within each person (Kant, 1996, pp. 269, 388).

Kant's idea of autonomy is considered by many to be idealistic and not a practical way to make decisions concerning individual circumstances involving the weighing of a variety of pluses and minuses before making a determination and taking action. Indeed, Kant was more focused on a "distinctive conception of autonomy" (O'Neill, 2002, p. 74). Kant's conception might be called moral autonomy as it conceptualises an overall moral basis, or perhaps more rightly a moral method for living, whereas individual autonomy can involve choices, decisions, and actions that are not fundamentally based on moral principles, or methods of decision-making that would fall into the moral realm, as well as others that would be morally based. Indeed, more contemporary notions of individual autonomy encompass conditions influencing decision-making other than the necessity of choosing what could be considered ethically universal for everyone, such as psychological and social factors enabling or delimiting autonomy (Oshana, 2008, pp. 87-88). Yet it is the Kantian concept of autonomy that lies behind the contemporary bioethical principle of respect for autonomy that is used in medicine today, as one of four bioethical principles central to medical ethics and which shall be examined later in this chapter and in subsequent chapters of this paper, where relevant (Beauchamp and Childress, 2001, p. 63).

2.2 THE IMPACT OF GENDER-BASED VIOLENCE (GBV)

The lower socioeconomic status of women than men also limits their personal autonomy and ability to access the care they need if they have to make time during the day while caring for their family and home and/or somehow find transportation funds to travel to a clinic, both of which can be factors impeding HIV testing (April, 2010, p. 4). These inhibiting factors are of central importance in the case of rape when access to antiretroviral therapy (ART) to prevent HIV infection is essential within 72 hours (WHO, 2013d, p. 4). The fear of HIV testing because of potential GBV after one tests HIV-positive means that many women do not possess the personal autonomy and self-efficacy needed to access HIV testing and the treatment and care needed afterwards if they test positive. According to Gari, et al., the lack of being able to freely decide to test for HIV due to the fear of violence or social exclusion is a human rights violation (2003, p. 8). Moreover, the fear of violence as the impetus for HIV testing violates Article 3 of the Universal Declaration of Human Rights, which states, “Everyone has the right to life, liberty and security of person” (UN, 1948, p. 1).

According to the WHO, the lifetime prevalence of intimate partner violence (physical and/or sexual) or non-partner sexual violence against women aged 15 and over in Africa is 45.6%, a strikingly high percentage and the highest of any region (2013b, p. 20). That 57% of the people living with HIV (PLHIV) in Africa, the epicentre of the global HIV epidemic, are women emphasises the heightened vulnerability of women in Africa to both GBV and HIV infection (UNAIDS, 2014b, p. 78). Gender-based violence increases the risk of HIV infection to women physiologically through traumatic injury to genitalia, with an even greater physiological susceptibility to infection by children and adolescents who

undergo sexual violence (ibid., p. 81). Women who have suffered sexual violence as children or adolescents are susceptible to HIV infection later in life as they have enhanced social and psychological vulnerability to infection due to their potential for increased sexual risk-taking based on the experience of violence in their youth (ibid.1). Indeed, recent studies of women in Uganda and young women in South Africa found that women who had experienced intimate partner violence were 50% more likely to be HIV-infected than women who had not experienced violence (ibid., p. 80). A study by the WHO in 2005 found that men who were violent toward their female sex partners were also more likely to have multiple sex partners and be infected with HIV (UNDP, 2012, p. 64). Of additional concern is that another study in Uganda found that 29% of the surveyed women living with HIV reported they had undergone intimate-partner sexual violence in the last year, and those on ART were twice as likely to report such violence (UNAIDS, 2013, p. 81). These recent statistics underscore that while there are some reports of decreasing stigma and discrimination against PLHIV in some places, a high degree of stigma and discrimination exists in Africa to which many women living with HIV attest. It is not surprising that African women who previously have suffered GBV or who feel they are at risk of it would hesitate to be tested for HIV.

It seems to be a moral dilemma in the context of substantial stigma toward and discrimination against women living with HIV in Africa and the growing awareness of their heightened risk of GBV that pregnant women are routinely tested for HIV in many clinics, at a time when they are extremely vulnerable in a variety of ways. Yet only half of countries collect data on the linkages between HIV and GBV, so while awareness of the links is growing it does not seem to be widespread (ibid., p. 82). Recently, the Global Commission on HIV and the Law found that:

> "Coercive and discriminatory practices in health care settings are rife, including forced HIV testing, breaches of confidentiality and the denial of health care services, as well as forced sterilisations and abortions (UNDP, 2012, p. 65).

These apparently unethical practices focus specifically on women. Reports on forced sterilisation and abortion among women living with HIV have emerged from Kenya, Namibia, South Africa, Tanzania, Uganda, and Zambia, among other countries and, according to the Commission, some of the women claimed they were denied access to HIV-related health services unless they agreed to abortion or sterilisation (ibid., p. 66). In late 2013 the African Commission on Human and Peoples' Rights (ACHPR) condemned coerced sterilisation as a blatant violation of the fundamental rights of women living with HIV, rights that are guaranteed under the Africa Charter on Human and Peoples' Rights (Southern Africa Litigation Centre, 2013, p. 1). The African Commission based their pronouncement on coerced sterilisation of women in Kenya and Namibia who were challenging the practice in court. These reports belie HIV testing as voluntary, and all the practices identified by the women and the commissions are human rights violations. These practices reinforce why women can fear HIV testing, especially where HIV exposure and transmission are criminalised and mothers living with HIV can be prosecuted for passing on the virus to their children, such as in West and Central Africa (UNDP, 2012, p. 23). The transmission of HIV from an infected mother to her child can occur during pregnancy, labour, delivery, or breastfeeding (WHO, 2013d, p. 4). If a pregnant woman does not know she is infected with HIV and passes on the virus to her child, it is unjust to criminalise her for such transmission. Yet the laws in some countries do not take this circumstance into account. Indeed, the plural legal systems of constitutional law and codified customary/religious law concerning private and family life in some countries in Africa can

perpetuate gender inequality and discriminatory practices and have “negative implications for women’s sexual health” (UNDP, 2012, p. 63).

2.3 EXAMPLES OF CRIMINALISATION OF HIV

Despite interventions by several civil society organizations, in April 2013 Botswana’s Parliament passed a bill that allows medical practitioners to test for HIV without patients’ consent, to force patients to be tested for HIV, to test patients for HIV before deciding whether to carry out non-urgent procedures, and to allow doctors to disclose patients’ HIV status to their sex partners (Bernard & Cameron, 2013, p. 25). Botswana’s Public Health Bill was signed into an Act of Parliament in September 2013 (News Botswana, 2013, p. 1). The intent of the law in Botswana was to isolate people infected with HIV who knowingly infect others with the virus, which in theory has some merit, but as it also allows doctors to force individuals to be tested for HIV through a court order, and it enables the situation of mandatory HIV testing of an individual against her will (Botswana Network on Ethics, Law and HIV/AIDS (BONELA), 2013, p. 1). Kenya criminalises HIV transmission in its Sexual Offences Act, which one Kenyan woman lawyer said will lead to most pregnant women wanting to deliver at home, risking a dangerous delivery, to avoid antenatal care and HIV testing and reprisal from health-care providers (ibid., p. 66). Uganda drafted its HIV Prevention and Control Bill 2010 to include mandatory HIV testing of pregnant women, their partners, and survivors of sexual offences, discretion by medical personnel to disclose one’s HIV status to one’s sex partner, and criminalisation of intentional and attempted transmission of HIV/AIDS, among other clauses. The controversial law was passed unanimously by Parliament in mid-May 2014, and was assented to by President Yoweri Museveni at the end of July 2014, despite 43 civil-society organisations attempting to have it reworded to delete mandatory testing (Agaba, 2013, p. 1; Fallon, 2014, p. 1).

These examples of laws criminalising HIV transmission are only a few of those that have been under discussion by legislators in African countries in the last five years. There is a movement to criminalise HIV transmission arising in some countries even though since 2010 there have been successes in restricting the use of criminal law to cases of intentional transmission of HIV in Congo, Guinea, Senegal, and Togo (Bernard and Cameron, 2013, p. 25).

It is understandable that pregnant women would not only fear the potential of being imprisoned if they pass on the virus to their child, but also the possibility of having to go to court to defend themselves when they may not have known they were infected with the virus or were unable to prevent HIV transmission. While the criminalisation of HIV transmission may seem to some to be a very good reason why pregnant women should get tested for HIV, the existing interventions to prevent mother-to-child transmission (PMTCT) of HIV are not available everywhere in Africa. Nor is HIV testing itself available in every clinic where women deliver babies, especially in rural areas. For example, only 41% of 96 public health facilities surveyed in an evaluation in the Democratic Republic of Congo in 2013 provided HIV testing for PMTCT (O'Grady, Sadaphal, Mandjo, et al., 2013, p. xiii). Of those 39 clinics offering HIV tests, only 59% of them, or 23, which is about 25% of all the clinics surveyed, provided antiretrovirals (ARVs) for PMTCT (ibid.). Thus if ARVs to prevent HIV transmission are unavailable, it is impossible for women in some areas to prevent the transmission of their HIV infection to their baby even if they know they are infected with the virus. In countries where home deliveries remain common, preventing the transmission of HIV to the baby at birth can be impossible if the mother is infected with the virus and gives birth at home—whether she knows she is infected or not. Thus in some areas HIV testing may be a futile prevention

intervention where antiretrovirals remain unavailable. Moreover, mandatory testing does not prevent HIV infection.

2.4 WORLD HEALTH ORGANIZATION (WHO)'S HIV TESTING POLICY

Since 2007 the WHO has recommended routine HIV testing in countries with generalised HIV epidemics, including routine testing of pregnant women (WHO, 2007). The view of the WHO was that routine testing should be standard clinical practice where patients present with symptoms of HIV and where ART is available or the country's national plan states it would be made available eventually (Baggaley, Hensen, Ajose, et al., 2012, p. 1). However, what "eventually" meant went unexplained by the WHO in 2007, and some countries did not make ART available to anyone testing HIV-positive, including individuals meeting the WHO guidelines for ART of having a CD4+ call count below 200. In 2007 only 31% of individuals estimated to be in need of ART according to the WHO guidelines received it of the estimated 33 million people living with HIV (WHO, 2008 p.1). In 2013 the WHO revised its clinical guidelines for HIV to include initiating ART for all HIV-positive pregnant women and HIV-positive women who are breastfeeding and other HIV-positive adults and adolescents with a CD4+ cell count of 500 or below (the CD4+ cell count of an individual is an indicator of the progress of an HIV infection) (WHO, 2013a, p. 92). Obviously, the WHO's revised guidelines assume that ART will be available in clinics, a false assumption for many areas in Africa. Thus the WHO made a recommendation in 2013 that many countries did not have the resources to act on. More progressively, in 2013 the U.S. National Institutes of Health (NIH) made a "moderate recommendation" for HIV-positive individuals to start ART even if their CD4 cell count is over 500, meaning that individuals can start treatment as soon as they are diagnosed HIV-positive and can continue it lifelong (NIH, 2013, p. E1). The new guidelines by the WHO

and NIH for HIV treatment are excellent in that they support provision of ART to PLHIV and pregnant and breastfeeding women who are HIV-positive.

Despite the recent progressive guidelines issued by the WHO and the NIH, in some areas in Africa treatment may not be available if women test HIV-positive, and PMTCT may not be available for pregnant women who test positive (UNAIDS, 2014b, pp. A63, A67-A68). A study published in 2011 found that less than half of HIV-infected women in sub-Saharan Africa receive PMTCT interventions (Turan, Bukusi, Onono, et al., 2011, p. 7). In areas where ART is not available and stigma toward and discrimination against PLHIV is rife, telling a pregnant woman she will be tested for HIV unless she refuses it, giving her perhaps 10 seconds to make up her mind, and afterward potentially telling her she is infected with a virus she may believe is a 'death sentence' does not seem like an ethical act by a health-care provider. Yet this is the unenviable position the WHO has recommended that has put many nurses in clinics in Africa where resources, including ART, are scarce. After a testing situation that may be experienced by a woman as coerced if access to treatment is not available if she tests HIV-positive, this might be considered a human rights violation. As explored earlier in Chapter 1, many nurses in such situations claimed they were following orders, focusing on reaching testing targets, and dealing with long waiting-room queues as rationales for carrying out routine testing on pregnant women where the women may have felt the decision was coerced (Maman & King, 2008, p. 197; Angotti, et al., 2010, p. 1). Yet it is important to explore the reasons why and the rationale behind the current practice of coercive HIV testing.

Health-care providers generally describe routine testing as an "offer" to test a person for HIV (Turan, et al., 2011, 7). However, the 'opt-out' protocol used for routine testing at

clinics consists of telling a woman she will be tested for HIV unless she explicitly refuses (Topp, Chipukuma, Chiko, et al., 2011, p. 1). Thus routine testing using the 'opt-out' approach is not an "offer" to test a person for HIV. Rather, it consists of telling a patient in a vulnerable position in relation to a health-care provider in the more powerful position that s/he will take a blood sample for an HIV test through a finger-prick, an invasive action, unless she refuses (Hardon, Vernooij, Bongololo-Mbera, et al., 2012, p. 9). Anyone seeking health care is in a vulnerable position in comparison to the health-care provider. According to a nurse in Kenya, "The patients are so innocent, they trust that whatever you are doing is for his own good" (Evans and Ndirangu, 2011, p. 8). Indeed, trust is one of the most important concepts in health care. According to the World Medical Association (WMA), "Trust is an essential part of the physician-patient relationship" (2005, p. 52). Yet health care providers are in the position of being able to betray a patient's trust by disregarding it for what they perceive to be as one or more expedient reasons, for example, they work in a busy clinic with a long queue of patients, too few health care providers, and they see 50 or more patients per day. Thus their focus can be on quantity rather than quality of care. Moreover, they may even realise that patient trust can be an important factor in the healing process and that a lack of trust can hinder the effective delivery of health interventions designed to achieve public health goals over the long term (ibid., pp. 39, 52). Pregnant women are especially vulnerable patients due to their pregnancy, a condition that can cause multiple health risks for the mother or the baby (CDC, 2013, p. 1). Moreover, pregnant women in countries where HIV is more common than elsewhere are even more vulnerable to the emotional impact of being told they will be tested for HIV unless they decline because there is a greater likelihood they may test positive in an environment they know is rife with stigma and discrimination surrounding the virus.

What also is notable about WHO's 2013 HIV guidelines is that there are new and more specific guidelines regarding HIV counselling and testing. The guidelines support the need for voluntary HIV testing: "Mandatory or coerced testing is never appropriate, whether that coercion comes from a health care provider or from a partner or family member" (WHO, 2013a, p. 69). Clearly, the new guidelines exhibit cognisance that HIV testing can be coercive by health care providers. The WHO guidelines state that informed consent must be given by people receiving counselling and testing, that individuals must be informed about the process of counselling and testing in advance and their right to decline HIV testing, and that the services are confidential (ibid.). These counselling and testing prerequisites are not new, but they are not necessarily followed across all clinics providing routine testing. What WHO's guidelines also state is that high-quality pre-test information must be given and post-test counselling provided to everyone (ibid.). However, post-test counselling is provided in many facilities in Africa only if a person tests HIV-positive, a common flaw noted by many since routine testing commenced (Hardon, et al., 2012, p. 5). For example, South Africa's HIV counselling and testing guidelines published in 2009 suggest an offer of post-test counselling to individuals who test negative, but state that post-test counselling is vital for individuals who test HIV-positive (National Department of Health, 2009, p. 46).

2.5 CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC's) HIV TESTING POLICY

The U.S. CDC's routine testing recommendations published in 2006 state that providing counselling related to HIV testing in clinical settings is not necessary at all, although the CDC still recommends counselling provision at non-clinical testing sites (Branson, et al., 2006, p. 2; CDC, 2011, p. 9). Of interest is that ethics seemed to play little role in CDC's

issuance of revised guidelines for HIV testing in 2006. The rationale given by the CDC for routine testing at clinics was that the cost of testing often is not reimbursed to providers, providers might perceive counselling requirements as a barrier to providing testing, and HIV prevalence information is not available to guide where testing should be provided (Branson, et al., 2006, p. 9). Since the CDC already had overridden providing pretest counselling to pregnant women and the need for their written informed consent for testing in 2001, one might think that the CDC was already on a slippery slope regarding the positioning of ethics as a high priority in its decision-making for HIV testing recommendations (ibid., p. 4). However, the difference between the CDC in issuing its routine testing guidance in 2006 and the WHO's issuance of its routine testing guidance in 2007 is in stating as the objective for the revised guidelines to be able to link HIV-infected persons to treatment and prevent more new infections. There was a much greater chance of PLHIV in the USA to access ART based on the CDC's testing recommendations than there still is at the present time for PLHIV in Africa based on the WHO's counselling and testing recommendations the following year. Thus there was a stronger rationale for the CDC to issue its routine testing guidance in 2006 given the greater access to ART for patients in the USA than there was in 2007 and indeed still is for patients in Africa as the treatment-focused rationale for the WHO releasing its routine testing guidance in 2007.

Another new item in WHO's guidelines issued in 2013 is the inclusion of community-based HIV counselling and testing, which the WHO recently recognised is especially important in Africa, where non-governmental organisations (NGOs) often provide the bulk of HIV counselling and testing services. The WHO guidelines also note the need for a referral after counselling and testing to "appropriate follow-up services as indicated" for clinics and for community-based organisations, which includes referral to prevention as

well as treatment services (WHO, 2007, p. 69). Where no treatment for HIV is available, there will be no referral made for ART. Yet clinics may not make referrals for prevention services or condoms either, where these commodities and services are not available or where making referrals is not a standard operating procedure. It is not difficult to understand that in many clinics in Africa the WHO guidelines for HIV counselling and testing are more aspirational than strictly followed. This situation is ironic as 42 countries in Africa had adopted a policy on the routine testing of pregnant women at antenatal clinics or via PMTCT services by 2010 (Baggaley, et al., 2012, p. 3). Yet this policy also seems to have been more aspirational than enforced in various countries.

2.6 INFORMED CONSENT AND HIV TESTING

The routine testing of pregnant women in South Africa, which adopted opt-out routine testing as a national policy in 2009 (previously South Africa implemented an opt-in routine testing policy for pregnant women), is illustrative of what can happen in regard to securing informed consent when opt-out routine testing is implemented in clinics (National Department of Health, 2009, p. 42). A study in an antenatal clinic in Durban, published in 2011, found that only 50% of the pregnant study participants described having a clear choice in making the decision to test for HIV. Others were less clear about whether they had been given a choice to test or not; and, the rest felt that had been given no choice in testing for HIV (Groves, Maman, Msomi, et al., 2011, p. 3). A number of these women felt pressured by the nurses to test for HIV, a few felt they were forced to test, and most who did not feel they had a choice to test had not thought about testing for HIV before coming to the clinic, illustrating that having time to consider one's testing decision is important (ibid., p. 5). These findings show that informed consent for HIV testing of the study participants was either not sought at all in some cases; or some women were not told they

could decline the test; or the testing procedure happened so quickly, some women did not feel they were given the choice to test or not. And, similar to other study findings, some women felt they could not decline the test and still receive adequate care at the clinic (ibid.). Some of the pregnant women who had come for antenatal care did not know they would be asked to test for HIV at the clinic and said they were totally unprepared to decide to test or not, including most of the women who did not feel they had a choice about testing (ibid., pp. 4, 5). These study findings are not unique, as similar findings were presented in Chapter 1 in this paper. Other researchers have found similar results about the ability of pregnant women in Botswana to decline an HIV test at routine testing sites (Weiser, et al., 2006, p. 1013). De Zulueta and Boulton went as far as to suggest in 2007 that if informed consent is to be eroded in routine testing to protect third parties—foetuses—from preventable disease, "such a policy should be made transparent, debated in the public domain and negotiated with women seeking antenatal care" (p. 329). They did not focus on the erosion of informed consent due to the desire to save time and test more people for HIV, as some have done including the CDC, or the lack of professional competence or responsibility, which also are potential factors inhibiting the proper implementation of the informed consent process. A recent study of informed consent, counseling and confidentiality conducted in Burkina Faso, Kenya, Malawi and Uganda found that some pregnant women said the testing process was coercive, and 79% of the women testing positive reported they kept their HIV-positive status secret because of their fear of stigma and discrimination (Hardon, et al., 2012, p. 13).

Others have focused on the importance of proper implementation of the informed consent process for HIV testing during labour, when women may be constrained physically or mentally to process the range of issues needed to provide fully informed consent (Gruskin,

Ahmed and Ferguson, 2008, p. 28). For a woman to be told during labour that she will be tested for HIV unless she declines, especially if she has not thought about HIV testing previously, could be an upsetting situation—in addition to the physical and emotional stress she already is undergoing due to her labour. Health-care providers should be especially sensitive to ensuring that not only is the informed consent process carried out for women in labour, but that these women understand why HIV testing is recommended at this time, what the testing process consists of, what the results mean, and the type of care they will receive if they test positive and the related referrals available, as well as the related referrals available if they test negative. It is overly optimistic to imagine that HIV testing, informed consent, and the information communication and counselling process is implemented comprehensively for all women in labour in routine testing environments in Africa. In fact, the study by Hardon, et al. showed that counselling and testing processes are not implemented comprehensively even in antenatal care in some clinics, with some health care workers telling pregnant women in Kenya and Uganda that mandatory testing of pregnant women is the government policy (2012, p. 9). While "There are substantial complexities…associated with HIV counselling and testing in labour"…and "this obviously is not the preferred time to be counselling a woman about HIV and obtaining consent for HIV testing," such counselling and obtaining her informed consent is her human right, whether or not she is in a sub-optimal condition to give it (Forsyth, Barringer, Walls, et al., 2004, p. 154). Of course, efforts taken earlier in antenatal care, when and where possible, to offer an HIV test—where ART to prevent mother-to-child transmission of HIV is available—via 'opting in' rather than 'opting out' have a greater likelihood of receiving a pregnant woman's fully informed consent, whether she decides to test for HIV or not, than during labour (ibid.).

Nonetheless, the results from a few recent studies in African countries have shown it is possible to provide comprehensive HIV testing and counselling services to women in labour, at least when they are in the early stages of it (Hamela, Tembo, Rosenberg, et al., 2013, p. 38). As labour progresses and women experience more pain, some mothers participating in a study in Malawi felt that women would not be able to engage in meaningful communication with a counselling and testing provider, understand the information they were told, or give truly informed consent (van Lettow, Kapito-Tembo, Kaunda-Khangamwa, et al., 2012, p. 9). A study at a hospital in Nigeria found that 86% of the women in the study accepted HIV counselling and testing during labour, but the investigators noted that women may feel obliged to accept it while in labour because of their fear of victimisation by health-care providers or withdrawal of the emergency care they had sought for delivery (Bello, Ogunbode, Adesina, et al., 2011, p. 30). The study conducted in Nigeria did not investigate stigma and discrimination surrounding HIV as a possible reason why some women in labour declined to be tested, but fear of stigma and discrimination was a prominent reason for refusing HIV testing during labour by women in Malawi (van Lettow, et al., 2012, p. 9).

In addition to their fear of stigma by health-care providers if testing HIV-positive, some women in Malawi expressed fear of their partner learning their positive status, or that they had been tested for HIV without receiving their partner's approval (ibid., p. 11). In the four-country study conducted by Hardon, et al. only one in three of the pregnant women who tested positive disclosed their HIV status to their partner (2012, p. 10). In fact, the study showed that some of the women who had disclosed their HIV status to their partners were abandoned or divorced by their partners (ibid., p. 11). These findings support the

continuing impact stigma and discrimination have on testing decisions, especially for women, in their inferior position to men due to gender inequality.

2.7 THE IMPORTANCE OF COUNSELLING

Findings from interviews with women in Malawi in another study highlighted how important the counselling aspect of HIV counselling and testing is to women in labour. What was found to be most significant to both the study participants and the study investigators was the pre-test counselling that was provided, which outlined the advantages and disadvantages of testing for the women in labour and helped to enable them to accept the HIV test (Hamela, et al., 2012, pp. 36, 38). The pre-test counselling also included discussion of the possible results of the HIV test to prepare the women for the potential of receiving a positive result (ibid., p. 37). Preparing clients for the possibility of receiving a positive test result is one of the most important aspects of HIV counselling and testing and why I believe pre-test counselling is a crucial element of counselling and service. It also is important to note that the studies cited here addressed the ethical importance of securing informed consent for routine testing from women in labour, the issues of their particular vulnerability and its potential impact on the validity of their consent, and their fear of the loss of health-care provision if they declined the test.

While women who are in labour may seem like a special case regarding the informed consent needed for routine testing based on their heightened vulnerability, individuals who present for health care also are in a heightened state of vulnerability to the more powerful health-care providers from whom they seek care. Individuals seeking health care also are targeted for routine testing by the WHO, the CDC, and some countries in Africa, including South Africa (National Department of Health, 2009, p. 42). As documented herein

previously, the rationale given for routine testing by these institutions is to provide individuals who test HIV-positive with appropriate care and treatment and to decrease HIV infections, as well as help to prevent mother-to-child transmission of HIV. However, ART is not immediately available to everyone who tests HIV-positive in any country as a recent study of ART eligibility in 70 countries showed, whether the country's HIV policy is consistent with the WHO recommendations or not (Gupta, Granich, Suthar, et al., 2013, p. e87). For example, ART is not available to individuals who do not meet South Africa's eligibility criteria for treatment. The country's new eligibility criteria for ART in 2015 includes: a CD4 count of 500 per cubic millimeter or under; lifelong ART for pregnant women, breastfeeding women and women within one year post-partum; ART initiation for HIV/TB co-infected patients; (Department of Health, South Africa, 2014, pp. 14-15). However, it is important to point out that in early 2015 South Africa is still trying to provide ART initiation to individuals testing HIV-positive with CD4 counts of 350 or under to meet the country's 2010 guidelines. Less than half of the people estimated to be living with HIV in South Africa in 2015 have access to ART. A study conducted in Côte d'Ivoire, Thailand, and Uganda in 2008 found that on average it takes six years from HIV seroconversion for an individual to reach ART eligibility in countries with an eligibility threshold of 200 CD4 count per cubic millimeters or less, and it takes on average only two years from reaching that eligibility criterion to death (Wandel, Egger, Rangsin, et al., 2008, p. i31).

2.8 HIV TESTING AS THE GATEWAY TO CARE

While HIV testing potentially is a 'gateway to care,' as many have described it for more than a decade, the queue before that gateway opens to ART provision can be long indeed (Hardon et al., 2012, p. 2; Hensen, et al., 2011, p. 59; Branson, Viall and Marum, 2013, p.

S117). That ART is not available at all clinics in many African countries, especially in rural areas, is important regarding positioning routine testing as a gateway to care in international or national policy (Rosen and Fox, 2011, p. 10). The rationale for routine testing by the WHO to be able to provide treatment to people testing positive in generalised epidemics seems to be secondary at best in countries where treatment is not provided to individuals testing positive unless they meet the ART eligibility criteria. The primary focus in many countries appears to be testing as many people as possible for HIV, with some opining that reaching testing targets can be the real priority, which can help a country to secure more donor funding for the national epidemic response (Evans and Ndirangu, 2011, p. 6; Buse, Eba, Sigurdson, et al., 2013, p. 103). Testing someone for HIV does not make them less infectious, but treating someone with ART soon after infection when the individual's CD4 cell count is 350 to 500 per cubic millimeter can make the person 96% less infectious, according to the results of a key international study published in 2011 (Cohen, Chen, McCauley, et al., 2011, p. 503).

It is sad and tragic that ART is so efficacious for treating HIV and prolonging life, yet there is still too little focus on the importance of linking people who test HIV-positive to treatment and care soon after they receive their test results. Rosen and Fox found in a review of 24 studies in Africa that only about 18% of patients who tested HIV-positive, yet did not meet the eligibility criteria for ART in their country, were retained continuously in care (2011, p. 1). They also noted that little care is offered to patients who test positive but are not eligible for ART, and it may be too expensive for them to come back to the clinic to have their CD4 count monitored, or they cannot take time off from work and jeopardise their jobs to do so, or they do not want to be seen visiting an HIV clinic due to the stigma and discrimination by community members (ibid., pp. 9-10). Rosen and Fox also noted

that some patients die before they can access ART even if they meet the eligibility criteria (ibid., p. 10). All of these reasons emphasise that testing for HIV is only step one in the cascade of care needed by people who test positive. It should not be the objective itself. It does not on its own lead to decreasing new HIV infections.

As already noted, testing HIV-positive can lead to substantial stigma and discrimination, including internal stigma, and it can lead to a painful and often lonely death without accessible treatment, care and support (WHO, 2006, p.1). Hardon, et al.'s four-country study results found that one in five women respondents said they felt worthless after testing HIV-positive, with an equal proportion saying they felt guilty (2012, p. 9). These women were worried about stigma by others, but they also were self-stigmatising themselves (ibid., p. 9). Some health professionals have written that "treatment availability should be a pre-condition for opt-out testing" even if they support routine testing as an approach (April, 2010, p. 2). This stance is based on the lack of survival gains if individuals testing positive do not have access to ART, which could be outweighed by the negative social consequences suffered by these individuals, especially African women who are more likely to be living with HIV and undergo testing (ibid., pp. 2, 4). Hensen, et al., straightforwardly wrote after their review of ten surveys of routine testing conducted in sub-Saharan Africa, "The benefits of testing, in the absence of effective linkages to PMTCT, treatment and care services, are limited" (2012, p. 68). Moreover, April has pointed out that while routine testing is expected to "yield a net benefit to populations, it is impossible to know whether the consequences of testing will bring more harm than benefit for each individual" (April, 2010, p. 5). This insightful understanding of the possible negative impact of routine testing on individuals, particularly women, emphasises the absolute necessity of a comprehensive informed consent process as an essential part of

routine testing so that testing is not coerced and clients understand what they agree to undergo.

2.9 CONFIDENTIALITY AND HIV TESTING

Anonymous surveys conducted in Cape Town, South Africa, found significant examples of stigma and discrimination toward PLHIV: one in five people infected with the virus had lost a job or a place to stay because of their HIV status, and more than one in three felt "dirty, ashamed or guilty" based on their status (Simbayi, Kalichman, Strebel, et al., 2007, p. 1823). These results also point to the need for confidentiality of HIV test results and the importance of limited self-disclosure by individuals testing positive. These findings also highlight the intense impact of testing HIV-positive on individual self-esteem, whether or not the individuals share the knowledge of their status with anyone else. They also underscore the issue of privacy and how important this can be to individuals regarding HIV test results, whether or not individual privacy has been a long-standing practice in an individual's culture. Privacy is indeed a protected right in many countries. For example, South Africa's Constitution protects individual privacy: "Everyone has the right to privacy" (Republic of South Africa, 1996, Constitution: 14).

Confidentiality is a general ethical obligation in medical practice, and the need for confidentiality of HIV test results has been a continuing concern of individuals and ethicists for many years as a general principle and because of HIV/AIDS-related stigma and discrimination (Piot, Kazatchkine, Dybul, et al., 2009, p. 1676; WHO, 2013a, p. 69). According to the WHO, test results and any discussions surrounding the results should not be disclosed to anyone else without the expressed consent of the person who was tested (ibid.). Thus the WHO counselling and testing guidelines also support the need for consent

related to test results for any disclosure to others by a health-care provider in addition to the need for informed consent given by the client before testing should occur. Despite the awareness of health-care providers in Africa of the need for confidentiality of HIV test results, some recent studies have shown that breaches of confidentiality by some providers still are occurring (Evans and Ndirangu, 2011, p. 8). These breaches have provoked stigma and discrimination by some health-care providers and by community members towards individuals. Some individuals have been denied care otherwise accessible after testing HIV-positive, and some counsellors have shared supposedly confidential test results with community members (Hardon, et al., 2012, pp. 9-10). In such environments, it is not surprising that 79% of the individuals who tested positive in Hardon et al.'s four-country study kept their HIV status secret (2012, p. 9).

Despite some breaches of the confidentiality of test results by counsellors, counselling before and after an HIV test is felt to be a crucial by some health-care providers in addition to individuals knowing their HIV status amidst major HIV epidemics, supporting the need for counselors to provide good counselling (Hardon, et al., pp. 9-10). Kelly noted the risk associated with "rapid-fire testing and insufficient counselling" by South Africa's national HIV testing campaign in 2010, which he said could result in much greater levels of anxiety, depression, and other mental health issues of people found to be HIV-positive, (Conway-Smith, 2010, p. 2). Kelly also noted that finding out one's HIV status is not a complete intervention: "we should not imagine that simply knowing your status is going to lead to HIV prevention or better access to care or a decrease in the degree of stigma, discrimination or denial" (ibid., p. 2).

One of the most tragic examples of HIV discrimination was the stoning and stabbing to death of HIV-positive Gugu Dlamini by community members in South Africa in 1998, a few weeks after she publicly announced her positive status (Cameron, 2005, pp. 53-54; April, 2010, p. 4). The death of Gugu Dlamini was international news at the time and is still remembered by many (Associated Press, 1998, p. 1). Based on the ongoing fear of stigma and discrimination surrounding positive HIV status, where confidentiality of test results cannot be assured, I believe routine testing should not be delivered as the standard protocol for every person coming to clinics for health care. This testing protocol is potentially dangerous for individuals, especially women, when the confidentiality of positive test results is breached. Also, not protecting the confidentiality of test results is unethical.

2.10 RESPECT FOR AUTONOMY AND HIV TESTING

Heywood has described routine testing as "implicitly less voluntary, less confidential, and with consent as opposed to informed consent" (2005, p. 14). Heywood wrote in 2005 before routine testing was recommended by the WHO in countries with generalised HIV epidemics, but was being considered:

> "From a human rights perspective, routine testing also carries the risks of becoming a war on "vulnerable groups"—and later on, people with HIV—who must be identified so that the state can "help them" (allegedly). This is paternalistic and coercive; and if the objective is improved HIV prevention and treatment, then routine testing most certainly will fail" (p. 18).

Challenging the point of view of some health-care providers who have described informed consent as a barrier to HIV testing, Heywood emphasised informed consent as a

"guarantor of respect for dignity" within the HIV testing process and obtaining it as an ethical duty of health-care providers (ibid., p. 16). Heywood recognised that health-care providers not enabling individuals to understand the testing process, the possible results, and given the choice to proceed with it assaults their autonomy and the Kantian principle of human dignity (Kant, 1996, pp. xvii, xxii). Philosopher Immanuel Kant wrote in 1785 that every human being has dignity and is of absolute and incomparable value, defining his principle of autonomy (1996, p. xvii). According to Kant, all human beings are equal to each other, and each rational human being is an end in itself and cannot be used as the means to an end (ibid., pp. xviii, 245). Kant also wrote that autonomy of the human will is the sole principle of moral laws and of the duties attached to them (ibid, p. 166). Thus according to Kantian autonomy, testing human beings without their informed consent and choice to be tested in order to promote the public health goal of reducing HIV infections would be a means to an end. This action would sacrifice their individual autonomy to what some may perceive as collective autonomy, yet to Kant it would be against moral law. Since respecting the autonomy of another human being is a human duty according to Kant, respect for autonomy should be a duty of health-care providers caring for other human beings.

That the informed consent process within routine testing should allow enough time for an individual to understand the process itself, the benefits and potential harms related to testing, the possible testing results and any related care opportunities available before making the decision to test or not is aligned with the whole notion of informed consent for a medical procedure and with Kantian autonomy. Nonetheless, that informed consent is a standard ethical responsibility of health-care providers does seem to be neglected or overlooked by some providers in relation to routine testing, despite the WHO stating that

HIV counselling and testing must be voluntary and involve informed consent (WHO, 2013a, p. 69). In fact, informed consent was one of the WHO's initial three C's—"consent, confidentiality and access to counselling"—necessary for HIV routine testing in 2007, which grew to five C's—"consent, confidentiality, counselling, correct test results, and connections to care" in the WHO routine testing guidance published in 2013 (WHO, 2011, p.17; WHO, 2013a, p. 69). It is important to note that the WHO's guidelines on HIV counselling and testing continue to evolve, which in part is a justification of the importance of some of the issues covered in this thesis. For example, in 2007 the WHO's routine testing implementation guidelines included the following,

> "Women may be more likely than men to experience discrimination, violence, abandonment or ostracism when their HIV status becomes known. Although a synthesis of studies on disclosure of HIV status among women in developing countries reported positive outcomes related to disclosure in most cases, disclosure-related violence does occur and preventive measures must be taken" (p. 30).

In its 2007 guidelines, the WHO recognised the possibility of 'compulsory' or coerced testing occurring and that it must be prevented along with unauthorised disclosure of test results, and that the possible negative outcomes of knowing one's status must be explained to the client, including possible discriminatory attitudes of health-care providers if the client tested positive (ibid.). Thus the world's largest health care policy-making body supports the necessity of informed consent for HIV counselling and testing at the same time it acknowledges possible infringements on the right of clients to maintain their autonomy through informed consent. Moreover, the WHO guidelines allude to the right to

the dignity of the person in the reference to possible discrimination by health-care providers. Thus, the erosion of the informed consent process taking place in some clinics in Kenya, Malawi, and Uganda documented by Hardon, et al. regarding pregnant women who are told that testing is mandatory, is a serious cause for concern because it goes against both international and national routine testing policy (2012, p. 9). Another recent study at a hospital in Uganda by Rujumba, et al. also found that most of the pregnant women participants understood the routine testing to be compulsory, as the possibility of opting out of it was seldom discussed with them by health workers (Rujumba, Neema, Tumwine, et al., 2013, p. 5). This alleged lack of providing informed consent infringes on the right of an individual to be autonomous in making an informed choice to test or not. It also is paternalistic because health-care workers decide HIV testing is in the woman's best interest without adequately considering the possible negative impacts of testing positive, such as stigma and discrimination, including GBV. The risk of GBV toward women by their partners or other community members if knowledge of their HIV-positive status becomes known can result in not only a physical assault, but it is also an assault to their human dignity, which the lack of informed consent can initiate.

The WHO's 2007 guidelines on routine testing focused on the need for pre-test information provision, which includes the informed consent process, rather than pre-test counselling (p. 36). The WHO also set standards in 2007 for what the pre-test information should include: why the testing is recommended; the benefits and potential risks of HIV testing, including discrimination, abandonment and violence; the confidentiality of the test results; whether ART is available if the patient tests positive; the patient's ability to decline the test otherwise s/he will be tested, but that declining the test will not affect the patient's health service access; encouragement of disclosure to sex partners; and, time to

ask questions of the provider (ibid.). Numerous studies, though, have shown that this amount of information is not provided as standard operating procedure for routine testing in Africa, including the testing of pregnant women (Evans and Ndirangu, 2011, p. 10; Hardon, et al., 2012, p. 6, Hensen, et al., 2012, pp. 64-65; von Lettow, et al., 2012, p. 15). Consequently, the risks or harms after testing for HIV can come as a surprise to some individuals who undergo routine testing even if they do not decline it. This was the case for some women who participated in the study conducted by Hardon, et al., who were chased out of the house, abandoned, or divorced by their partners after they disclosed their positive status to them (2012, pp. 10-11). These very unfortunate results of their disclosure of positive HIV status by women to their partners may have been because clinical practice at the time of their testing did not include discussion of the potential risks of disclosure, including discrimination, abandonment and/or violence. Or, the women may have misjudged the support they would receive from their partners after their disclosure. No matter what the preceding circumstances were for these individual women, their changed living situations after disclosure underscore how important it is for clinicians to provide comprehensive pre-test information, including the potential risks surrounding disclosure of HIV-positive test results.

2.11 PRE-TEST COUNSELLING AS A CRUCIAL STEP

Even though the WHO has abandoned its earlier focus on pre-test counselling in its routine testing guidelines, I believe pre-test counselling is an essential part of the routine counselling and testing services that should be provided. The reason why pre-test counselling is crucially related to HIV testing is that it is in the patient's best interest to receive in-depth counselling prior to the HIV test, rather than wait until the test result is known. I believe it is every human being's right to have access to information to

potentially save his or her life. Further, the right to receive health care information when it best can be accessed, that is, when a patient is not emotionally upset and thus the information is more likely to be used to personal health advantage afterward seems like it should be an essential aspect of fulfilling the right to health. While it is not possible to control when health-related information is received, regarding the right to health, the WHO states that:

> "The right to health includes access to timely, acceptable, and affordable health care of appropriate quality" and that the right to health "extends not only to timely and appropriate health care but also to the underlying determinants of health...and access to health-related education and information, including on sexual and reproductive health" (WHO, 2013e, pp. 1-2).

The WHO clearly recognises that timely access to health-related education and information is important. To limit the provision of crucial information and individual counselling surrounding HIV testing to the stage when most patients are upset—either in shock or in celebration after receiving an HIV test result—goes against the notion that patients should receive potentially life-saving information in a timely way when they are in a state to be able to consider the full import of it. To already be in a position to be able to understand the usefulness of the information patients have been given in pre-test counselling after receiving their test results and be able to act on the information and counselling they already received immediately, if need be, or at the next relevant time in the future can be a life-saving approach regarding HIV prevention. This step should not be minimised for 'public health' reasons, i.e., test as many people as possible and don't waste time in advance explaining all the testing-related details many people will not need to know. Yet the whole HIV testing process is crucial to its ethical implementation.

2.12 IMPLEMENTATION OF POST-TEST COUNSELLING

As mentioned earlier in this chapter, the WHO has recommended post-test counselling for every individual who is tested for HIV, whether the person tests positive or negative (2007, p. 39). The importance of post-test counselling for anyone tested for HIV, including individuals who test negative, has been emphasised by many others, as noted previously (Rujumba, et al., 2013, p. 8). The need for post-test counselling of individuals who test negative is to ensure they understand: the meaning of the test results; the limitations of rapid HIV testing if very recent exposure to HIV has occurred and the patient may be in the 'window period' when antibody test results are negative, but infection still may occur; the importance of practicing prevention behaviours for individuals at risk of infection; and, any possible referrals to support groups or for prevention counselling and/or commodities (Fethers, Andrews, McCoy, et al., 2008, pp. 94-95). But perhaps the most basic reason post-test counselling of individuals who test negative is needed is to ensure they understand that a negative test result is good, rather than bad as some have inferred when no post-test counselling has been provided. For example in Hardon et al.'s study of routine testing in four African countries, only 55% of the respondents said the meaning of the test result had been explained to them in pre-test counselling, again supporting the need for comprehensive information provision to foster good understanding (2012, p. 6).

Rujumba, et al.'s recent study in Uganda found that the post-test counselling given to HIV-negative women was so short that some of them did not believe they really had tested negative, and others had questions left unanswered during the post-test counselling (2013, p. 8). Few of the women who tested negative mentioned the benefit of knowing they were negative to the study interviewers, who saw the very limited post-test counselling provided

to them as a missed opportunity to promote HIV prevention behaviours (ibid., pp. 8-9). Moreover, some of these women were told by counsellors that if they remained faithful to their husbands, they would not test positive in the future (ibid., p. 11). This information is erroneous if the husband was already HIV-positive and the wife not yet infected, or if the husband was not faithful to the wife and became infected in the future (ibid., p. 11). Importantly, Rujumba, et al. also found that some of the women who tested positive who had tested negative previously doubted their positive test results, which could have a significant impact on their interest in access to care in the future (ibid., p. 8). Despite the availability of PMTCT services at the hospital where Rujumba, et al.'s study took place, the study participants "feared a positive test result as it was associated with the fear of death, living with HIV, and being blamed for bringing HIV infection to the family" (ibid., p. 9). These study findings showed that the women's fear of HIV testing was significant even though they believed the routine testing was compulsory, and their fear of stigma and discrimination by their partners and family members if they tested HIV-positive was very real. The findings also show that stigma and discrimination continue to be significant factors affecting HIV testing decisions by at least some African women.

That many clinics are not providing post-test counselling after routine testing to individuals who test negative rather than just telling the person the result is negative is a cause for concern. It is important for each person to know that it is possible s/he may test positive in the future if the person is in the 'window period' or becomes HIV-infected at a later date. There also is a concern about individuals who test negative practicing sexual disinhibition in the future, whereby they decide they must be immune to HIV based on any past risk-taking behavior and not testing positive and then continuing to practice risky behaviours thereafter (Shelton, 2008, p. 274; Hensen, Baggaley, Wong, et al., 2012, p. 68).

Thus post-test counselling for individuals who test negative can and should serve as an opportunity to provide guidance and support for practicing prevention behaviours in the future. Moreover, since pregnant women have a higher risk of acquiring HIV infection than non-pregnant women, it is essential that they receive post-test counselling if they test negative to inform them of their potential risk of future infection during their pregnancy (Turan, et al., 2011, p. 1). Rujumba, et al.'s recent study of pregnant women in Uganda stating they were given inadequate attention during post-test counselling shows what a serious oversight these women felt they had experienced from the very limited post-test counselling they received, leaving them with unanswered questions and doubts by some about their negative test results (2013, p. 10). It also is essential for individuals testing negative to ensure they have good understanding of how they can remain negative by discussing individual risk-reduction strategies with them, especially if this topic was not covered in pre-test counselling or if individual pre-test counselling was not provided. These topics within post-test counselling show why it is essential for ethical and human rights reasons for clinics to provide patients with comprehensive information for the present and for their use in the future. Routine testing should not be seen by providers as an end in itself, even if there are structural constraints in regard to counselling provision surrounding HIV testing due to low staffing levels at some clinics (ibid., p. 9). The use of lay counsellors for HIV counselling and testing has been the strategy taken in many African countries for more than a decade.

It is important to realise that post-test counselling can provide information that women need to know and can use as self-efficacy for the rest of their lives, whether they test negative or positive. Rujumba, et al.'s study showed that many women in Uganda were very concerned about the struggles of living with HIV, the future of their marriage, and

caring for themselves and their children "amidst poverty, stigma and marginalisation in the African setting" (ibid., p. 9). Further, the investigators of the four-country study of routine testing in Burkina Faso, Kenya, Malawi, and Uganda noted that one of the advantages of routine testing for pregnant women where PMTCT is available to those who test positive is that women from lower socio-economic groups who may not have been able to access VCT previously can test for HIV and access PMTCT services, if needed (Obermeyer, Neuman, Hardon, et al., 2013, p. 1). It seems crucial not to minimise any opportunity to provide women with key information and supportive counselling around HIV and their health. Counselling surrounding HIV testing may be the only opportunity that many women, especially women from the lowest socio-economic groups, have to receive individual counselling in their whole lives.

Heywood noted that the expansion of HIV testing through routine testing to the detriment of pre- and post-test counselling could have a negative impact on the ability of people to cope after receiving a positive result, which could lead to a lack of adherence to care and treatment where it is available and undermine their health and well-being in the future (2005, p. 17). Nurses generally are the health-care workers providing routine counselling and testing in many settings, especially in hospitals related to PMTCT provision. Evans and Ndirangu noticed based on statements by nurse participants in their study in Kenya how easily "counselling quality and the boundaries between voluntary informed consent and coercion can become rather blurred," and that nurses are "stressed by breaking bad news and handling ethical dilemmas" (2009, p. 723). Evans and Ndirangu were concerned by the quality of the implementation of the various components of routine testing the nurses were providing and recommended that the routine testing implementation process be strengthened (ibid.). Based on their study findings, Evans and Ndirangu recommended

the identification of best practices and key obstacles to routine testing implementation through research of nurse and patient experiences, greater nurse participation in policy development, and strengthening of nurse training and mentoring (ibid.). Their study findings and recommendations imply that having a routine testing policy on paper designed by the WHO or a national health service is one thing; and, implementing a policy adequately and ethically can be quite another.

2.13 HIV TESTING AND LINKAGES TO PREVENTION AND CARE

Importantly, a number of studies in the past few years have examined whether routine testing in sub-Saharan African clinical settings is actually resulting in linking more patients who test positive to care. This was the rationale used by the WHO to initiate routine testing, as was highlighted earlier in this chapter. However, a study by Dalal and colleagues in South Africa in 2011 found that while opt-out routine testing at a clinic versus VCT referrals increased HIV testing uptake, although not by much, after three months of routine testing only four of 106 patients (3.8%) who tested positive at the clinic had registered for the treatment available (Dalal, Lee, Farirai, et al., 2011 p. 1). The study investigators also noted the lack of motivation of the routine testing providers to test many patients, the need for strong leadership to train the providers in routine testing, and the need for additional interventions to link patients testing positive to HIV treatment centres (ibid.). Moreover, a recent study by Topp, et al. in seven clinics in Lusaka, Zambia, found that routine testing did not facilitate more timely HIV-positive diagnoses and referrals to care, but it acted as a "safety net" for individuals who had low CD4 counts who otherwise were unwilling or unable to test elsewhere (Topp, Li, Chipukuma, et al., 2012, p. 1). In fact, more eligible patients accessed treatment within a month after receiving VCT than individuals testing positive through routine testing in Topp, et al.'s study (ibid.). Neither

Dalal, et al.'s nor Topp, et al.'s study examined the ethics surrounding routine testing or the patient reactions to it. Nonetheless, the studies showed that routine testing in these settings was not meeting its mandate by linking many people who tested positive to treatment. Whether or not those who tested positive in the studies may have started practicing safe sex thereafter so that their infection was not passed on to others is unknown.

In 2011 Walensky and Bassett focused on how low the HIV testing rates still were in Africa despite the continent's huge HIV epidemics and emphasised that testing was seen as the gateway to care (p. 1). They remarked that "a poorly conceived and executed testing programme can backfire toward an infringement on human rights," which Lesotho was accused of by Human Rights Watch in 2008 (Human Rights Watch, p. 1). According to Human Rights Watch in reaction to site visits made by the organisation's staff members in 2007 to monitor Lesotho's "Know Your Status" nationwide HIV testing campaign,

> "Human rights protections should be an integral part of any testing campaign, not an optional element that can be added or left out depending on availability of resources. These campaigns need careful planning, sufficient funding, good training, ample coordination, proper oversight, and the involvement of civil society which can play a critical role in ensuring accountability and reporting potential human rights abuses" (Lohman, 2008, p. 3).

I believe these same requirements should be mandatory for implementing any HIV testing protocol, including routine testing, not only for national or local testing campaigns. Walensky and Bassett also focused their research and analysis on cost-effectiveness

studies of HIV testing that were conducted in resource-limited settings, including in Africa (2011, p. 2). They concluded that while HIV testing was deemed by the cost-effectiveness study investigators to be a worthy investment, a better investment would be to ensure at the later stage that the testing was linked to the cascade of care and treatment available (ibid., p. 2). Thus Walensky and Bassett noted that testing in and of itself is not the most efficacious or effective intervention unless it is linked to interventions promoting care and treatment of individuals testing positive (ibid., p. 2).

Linking HIV testing to treatment and other medical services that otherwise would not be available without knowledge of HIV status is the basic rationale behind routine testing by the WHO, which has been documented herein (WHO, 2010b, p. 20). I believe that all HIV testing protocols should be linked to care and treatment for individuals testing positive and prevention support for individuals testing negative. Yet the WHO itself noted in 2012, five years after releasing its routine testing guidelines, that linkages after HIV counselling and testing to treatment and prevention are generally weak, regardless of the testing approach used, including all the facility-based routine testing and community-based testing (2012, p. 48). Thus the organisation that recommended the routine testing policy for generalised HIV epidemics in Africa recognised the schism between the policy and its practice. Moreover, a year later study investigators in Uganda went so far as to write, "Delays and failures in initiation of ART among treatment eligible patients may compromise the effectiveness of HIV care in Africa," emphasising how widespread the inadequate care situation was (Geng, Bwana, Muyindike, et al., 2013, p. 1). When routine testing is not linked to treatment or individual risk-reduction counselling, which it currently is not in many locations in Africa, I do not believe that routine testing can be considered an ethical protocol. Unless there are benefits available to individuals who know their HIV status that

can be discussed with them before testing, convincing them to test for HIV is coercive. I suspect that if Human Rights Watch examined some of the clinics where routine testing is being implemented in Africa in 2015, they would find similar violations of human rights as they found seven years ago in Lesotho: poor training of providers; insufficient counselling, including a specific informed consent process; lack of confidentiality in some cases; and, limited or no linkages to prevention and care services for the individuals tested (Lohman, 2008, pp. 25-50).

As Human Rights Watch pointed out in 2008, "there is little point in knowing your status if you cannot do anything with that knowledge" (Lohman, p. 32). When people test positive through routine testing if they are not linked to any care and treatment services, they likely will suffer from internal stigma even if they do not share their positive status with anyone else. One recent study in the USA and Puerto Rico found that more than 65% of 1,766 individuals suffered from depression after testing positive (Eller, Rivero-Mendez, Voss, et al., 2013, p. 1). As mentioned previously, if women share their positive test results with their partners or husbands, they may suffer GBV, abandonment, or divorce (Hardon, et al., 2012, pp. 10-11). If other members of their community learn they are living with HIV, it is likely that many PLHIV will suffer stigma and discrimination from community members (Simbayi, et al., 2007, p. 1823). Wilcher and Cates focused on both the human rights and public health perspectives of women's sexual and reproductive health, especially women living with HIV. (2010, p. 833). They noted that infected women are more vulnerable to rights abuses than uninfected individuals, but that sexual and reproductive health and HIV linkages at the policy, programme, and service delivery levels are particularly important to ensure their sexual and reproductive needs are met (ibid., p. 839). Also emphasizing gender bias, de Bruyn and Paxton wrote that "some women who

test positive experience significantly more discrimination from their partners, families and community members than HIV-positive men do" (2005, p. 1). Consequently, at the same time individuals testing HIV-positive realise they are living with a life-threatening illness, they can be castigated by their partners, family, and community members because of the social stigma and discrimination their illness provokes. As mentioned above, it is hard to identify a lasting benefit from routine testing if no care or treatment is provided afterwards to people testing positive.

If PMTCT is not provided to pregnant women testing positive through routine testing or ART provided to these women after they give birth, they are faced with the knowledge that their baby may become infected with HIV. De Bruyn and Paxton and others also felt that it is unfair to test pregnant women solely or mainly to prevent mother-to-child transmission of HIV if there are no support services available to protect their rights and enable them to live as healthily as possible after giving birth (ibid., p. 1). Moreover, if no prevention services and commodities are provided to people testing negative through routine testing, they may or may not understand the reality that they may be negative today but they may become infected in the future, if they are unable to take prevention precautions. The inability of many African women to protect themselves from HIV infection by using condoms has been described by many as just one aspect of African women having less power than men in sexual relationships (Chersich and Rees, 2008, p. S34; UNDP, 2012, p. 67).

Many of the research study results cited in this chapter have shown the continuing intense stigma and discrimination surrounding the HIV epidemic, including the fear of HIV testing by many. Indeed, according to Adimora, Ramirez, Auerbach, et al. in 2013, "Societies

have made little headway in combating stigma, despite the longstanding recognition that stigma undermines HIV prevention efforts" (p. S171). Amidst intense stigma and discrimination surrounding HIV and their position of lesser power in intimate relationships, it is hard to attribute to many African women the agency they need to make an autonomous decision regarding informed consent for routine HIV testing if they suddenly are faced with it in a clinic. "Freedom from violence is perhaps the most fundamental expression of agency," according to Klugman (2013, p. 3). Yet according to the WHO in 2013, the proportion of African women who have reported intimate partner violence or non-partner sexual violence is 45.6%, the highest proportion of any region in the world (WHO, 2013b, p. 20). Indeed, Gruskin, Ahmed and Ferguson wrote that routine testing "may inadvertently exacerbate a women's risk of stigma from her partner, family and community" (2008, p. 31). Based on the risk of substantial negative impacts on women of routine testing, I continue to view it as an unethical HIV testing protocol if it is not implemented with the opportunity for a woman to give truly informed—and considered—consent, thus exercising her autonomy, with pre- and post-test counselling provided, and linked to prevention and/or treatment services after testing negative or positive.

CHAPTER 3: HIV TESTING AND JUSTICE

3.0 RECENT HISTORY OF HEALTH AND HUMAN RIGHTS

In 1996 Jonathan Mann wrote, "The world of health and human rights has moved away from earlier simplistic assumptions about a necessary conflict between public health goals and human rights norms" (Mann, 1996, p. 1). This physician and international programme leader of the HIV/AIDS pandemic response initially at the World Health Organization, who died tragically in a plane crash two years later, had realised in his work on HIV in Africa and later internationally that underlying societal issues "determine to the largest extent, who lives and who dies, when, and of what" (ibid., p. 1). Dr. Mann was a visionary in the field of health and human rights. Many working in this field, especially individuals focusing on HIV/AIDS, found him inspirational in his thinking and writing about health and human rights and social justice. In a commemoration speech in 2008, ten years after Dr. Mann died, UNAIDS Executive Director Dr. Peter Piot said, "If somebody else had been in charge of the [WHO] Global Programme on AIDS, they would have created it with other ideas, with old-fashioned public health ideas, such as quarantine and forced testing" (UNAIDS, 2008b, p. 2). Justice Michael Kirby of the High Court of Australia, who also spoke at the commemoration for Jonathan Mann in 2008, said that Dr. Mann told him the first time they met that "AIDS is a women's issue…a women's issue because of women's disempowerment" (UNAIDS, 2008b, p. 3). I believe that Dr. Mann's positioning of health and human rights based on his experience with the HIV/AIDS pandemic and its impact on women and his understanding of the harm that forced HIV testing could inflict on society and especially on women is what made him inspirational to so many people, including me. Jonathan Mann's views remain a bulwark for some of the views expressed in this thesis. He has had a long-lasting influence on my work on HIV/AIDS for more than 20 years and

indeed on my views on human rights related to HIV testing. Dr. Mann understood that we have to confront social inequality in our response to the spread of sexually transmitted diseases (STD), including HIV, and that linking human rights and public health is "both a return to the historical concerns of public health and the beginning of a new chapter in the relationship between health and society" (Mann, 1996, p. 1). My belief remains that in order to have the level of public health impact we need in our response to the HIV/AIDS pandemic, we must take a human rights-based approach. Otherwise, we are ignoring the people, indeed the individuals, most at risk of HIV infection and who make up the largest proportion of those who are infected with the virus—women in Africa, who make up 57% of PLHIV on the continent (UNAIDS, 2013, p. 78). Promoting social justice as a human right of these women in regard to HIV testing is one of the purposes of writing this thesis. In this chapter I will explore justice as both an issue and a human right related to HIV testing.

3.1 AUTONOMY AND JUSTICE

Drawing on broadly Kantian categories, autonomy may be thought of as what we owe to ourselves, our ability to make the best choice for oneself, to be able to weigh the various factors involved and make a decision that respects our own individual autonomy and self-legislation (Kant, 1996, p. xxiv). Immanuel Kant believed this is a God-given human right (ibid., p. 245). In fact, Kant viewed the duty to oneself also as a special ethical duty (ibid., p. 385). According to Slote, "it is considered irrational for people not to care about their own welfare," and, "it does seem implausible to deny the irrationality of acting against self-interest or of lacking concern for one's own well-being" (2007, p. 106). For this reason, the duty to oneself will be explored extensively in Chapter 5. The previous chapter in this thesis focused on the ethical aspects of autonomy related to HIV testing, including

the necessity of informed consent for testing and the potential benefits and harms that should be made known to individuals in advance regarding HIV testing, which they should take into account in their decision-making on whether to test for HIV or not. Justice, it seems to me, is what we owe to other people. Certainly, we should respect the autonomy of other individuals, which is a bioethical principle (Beauchamp and Childress, 2001, p. 12). Yet respecting the dignity of another person is a fundamental right that also is tied to justice by giving another person her just due. Kant also viewed the duty to oneself as corresponding to the duty to others (1996, p. 395). Of relevance is that Kant also believed that social inequalities between people are fundamentally unjust (ibid., p. xix). According to Kant, assessing the morality of one's actions toward others is as important as assessing the legality of one's actions toward others (ibid., p. 523). One might perceive that to Kant justice toward others functions on two levels: what we owe to others legally and what we owe to them morally. Aligned with these two levels of justice, one might think of HIV testing firstly as a policy that needs to be in accordance with overall justice in the legal realm, that is, nothing should be done to someone else, including HIV testing, which does not conform to law. At the same time, and aligned with Kantian thinking, is that nothing should be done to someone else that is immoral. The 'golden rule' comes to mind regarding this view of justice; to paraphrase the biblical version: 'do unto others as you would have them do unto you' (Matthew 7:12). Some modern philosophers, including Flew and Rawls, have considered the 'golden rule,' also sometimes called 'the ethic of reciprocity' to be the most fundamental principle of human rights as well as a concept found in many religions (Flew, 1979, p. 134; Rawls, 1999a, p. 424). This notion of treating others as how oneself would like to be treated is also fundamental to the concept of the equality of all human beings. The concepts of equality and justice are interwoven in an individual moral sense. While in the contemporary legal realm these concepts may not

play out as interwoven since the needs of society can overrule individual needs, these two concepts are fundamentally why laws exist.

3.2 RAWLS ON JUSTICE AS FAIRNESS

Philosopher John Rawls explored justice from the point of view of the "original position of equality," which he noted covers all rational persons (Rawls, 1999a, pp. 222-223). Yet Rawls also famously explored his own notion of "justice as fairness…to handle the contingencies of particular situations" (ibid., p. 243). Rawls equated the duty of respect to another human being not only because the person is a moral being, but is a "being with a sense of justice" (ibid., p. 297). Rawls directly linked autonomy with justice; however, in that example he did so more as respecting someone who has a sense of justice rather than oneself having a duty to act justly toward another person. The main idea of justice as fairness to Rawls was that the principles of justice would be agreed to by everyone in the position of equality, that is, all persons would agree on what justice entails (ibid., p. 384). Rawls also equated justice as fairness as relating to persons benefitting from opportunities offered by institutions (ibid., p. 301). I would argue that Rawls's notion of justice as fairness is relevant to HIV counselling and testing policy and the implementation of it, both of which are set and implemented by institutions, such as the WHO, a hospital, or a community-based organisation providing HIV testing services. Rawls also noted that justice as fairness relies on the importance of one's self-esteem and the ability to fulfill one's intentions, which provides one with enough confidence to not begrudge others the fulfillment of their intentions (ibid., pp. 386-387). The connection of these ideas of Rawls behind justice as fairness seems directly related to respecting the autonomy of an individual to decide for herself whether she wants to test for HIV at an institution implementing routine testing or seek counselling and testing in the community or even at

home or not be tested for HIV. Rawls's ideas certainly challenge the notion of coercive HIV testing as fair, and they position mandatory testing as wholly unfair and unjust.

3.2.1 Justice and Self-Esteem and HIV Testing

Also relevant to HIV testing and HIV/AIDS itself is Rawls's examination of the feeling of shame regarding his theory of justice. Again Rawls focused on the importance of self-respect and self-esteem; when an injury occurs to self-esteem, the resulting shame is both painful and encompasses the loss of a prized good, that is, one's own self-esteem (ibid., p. 388). There are several aspects of HIV testing potentially related to the loss of self-respect and self-esteem. The losses of self-esteem surrounding HIV testing include the lack of informed consent needed to promote an individual's ability to choose to test for HIV or not. Being forced to test, or coerced into HIV testing, or to undergo mandatory testing has been noted as a loss of self-respect by individuals, including by pregnant women in Kenya and Uganda in a study cited above in Chapter 2 (Hardon, et al., 2012, p. 9). More prominently, testing HIV-positive has resulted in a huge loss of self-esteem and immediately provoking a sense of shame, as well as bringing on depression in many individuals, also cited in the previous chapter (Simbayi, et al., 2007, p. 1823; Eller, et al., 2013, p. 1). Rawls noted self-esteem relates to "those on whom we depend to confirm the sense of our own worth" (ibid., p. 389). As noted earlier, patients seeking health care are in a position of lesser power regarding health-care providers, including HIV counselling and testing providers (Hamela, et al., 2013, p. 36). Patients are indeed dependent on them for their healthcare, and they are very vulnerable to disrespect from and poor interaction with healthcare providers, one of the most common examples of stigma and discrimination surrounding HIV/AIDS (Turan, et al., 2011, p. 2). Any patient seeking health-care provision is in a very vulnerable position to potential loss of self-esteem through what she

may feel is coerced HIV testing, particularly if she tests positive. In describing the feelings of moral shame and guilt, Rawls discussed the "diminishment" of the self based on one's anxiety about the loss of respect from others and indeed loss of one's own self-respect for not living up to one's ideals (ibid., p. 391). This potential sense of shame and loss of self-respect describes the fears of testing HIV-positive noted by many, based on community members' reactions to and treatment of PLHIV, as well as how some women have described feeling about themselves (Simbayi, et al., 2007, p. 1823; van Lettow, et al., 2012, p. 9).

3.2.2 Human Rights Jurisprudence and HIV

Rawls also discussed that in order to have a complaint against an institution, the injury to or unjust treatment of individuals by the institution must be shown (ibid., p. 385). A case related to justice as fairness and HIV testing was argued in Kenya in 2004 when a woman brought legal action against her former employer who had fired her based on her HIV status, which she claimed was a violation of her freedom from discrimination (Lawyers Collective and O'Neill Institute for National and Global Health Law, 2013, p. 1). She also claimed that the doctor and the hospital that had tested her for HIV had done so without her consent, a violation of her right to privacy, and also had disclosed her HIV status to her employer without her knowledge, violating her right to confidentiality (ibid.). The High Court at Nairobi found her complaint a reasonable cause of action for the redress and relief of the violation of her human rights based on "the nature of the case, the universality of the HIV/AIDS pandemic and the development of human rights jurisprudence" (ibid.). This case legally connects the ethical principles of autonomy and justice with human rights jurisprudence regarding HIV testing and the violations of her rights as just cause for redress. It also illustrates several examples of rights violations in one case related to HIV

testing, showing how pertinent the ethical implementation of aspects of HIV testing can be to individual human rights and justice. Moreover, one might perceive based on the court judgment that the judge of the High Court at Nairobi would agree with the statement by Rawls that "the highest moral motive is the desire to do what is right and just simply because it is right and just" (Rawls, 1999a, p. 418).

3.2.3 Rawls on Mill and Justice

Also relevant to HIV testing is Rawls's notion of reciprocity as reconciling "the points of view of the self and of others as equal moral persons" and that "neither concern for others nor for the self has priority" (ibid., p. 424). Based on these positions, Rawls likely would disagree with testing individuals for HIV against their will or in a coerced way via opt-out testing to promote the public health goal of decreasing new HIV infections because coercion undermines their equality and their individual autonomy. I believe he would consider such approaches to HIV testing as unjust policy of institutions, infringing on the just treatment of others. Rawls also expressed his notion of reciprocity regarding the views of philosopher John Stuart Mill, who famously wrote, "the only reason for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others" (Mill, 1999, p. 105). In regard to HIV testing, Mill's view seems most applicable for individuals who know they are infected with HIV and who willfully do not disclose their status to their sex partners to intentionally spread infection. There have been two recent court cases in Canada regarding failure of non-disclosure of positive HIV status as constituting fraud, since the court found that exposure to infection can risk significant bodily harm (HIV Justice Network, 2012, p. 1). Yet Rawls felt that Mill would agree with the notion of reciprocity expressed by the principles of justice because he believed that Mill's view was that "justice strikes a balance between altruism

and claims of the self" (Rawls, 1999a, p. 440). In fact according to philosopher Isaiah Berlin, Mill felt that "man has an indefeasible right to keep his private life to himself and to fight for this right" (Berlin, 1991, p. 159). Based on these views, HIV testing could be thought of as an act that should be balanced between the good of others and the good of oneself—not an act that should be surrendered to the good of others. Indeed, the violence that occurs against people living with HIV can be life-threatening, and it has ended the life of more than one woman in South Africa (Associated Press, 1998, p. 1; Carroll, 2003, p.1).

3.2.4 Rawls on Justice and Equality

Rawls did not contend that justice as fairness is the most stable conception of justice, and he felt he could not prove it to be so (Rawls, 1999a, p. 441). Yet he believed that moral persons are capable of having a sense of justice and have the desire to apply and act upon the principles of justice; and, that individuals with a lesser sense of justice should not be deprived from the full protection of justice (ibid., pp.442-443). Indeed, Rawls denied that basic rights and liberties should vary with individual capacity and that in the concept of justice as fairness any moral person is "owed all the guarantees of justice" (ibid., p. 443). This concept is also important regarding the HIV testing of women in Africa, women who may be illiterate and not endowed with a deep sense of self-efficacy and individual agency. Yet these women should be treated justly and fairly in regard to their decision to test for HIV or not. Justice obviously is relevant also to the HIV testing of minors, including adolescent girls who are under the age of consent in some countries. Like Kant, Rawls believed that equality is the first principle of justice and that it applies to all persons—irrespective of their position in society (ibid., p. 447). Consequently, even though most women generally are in a lesser socio-economic position than men in African

countries, their position should have no bearing on what is owed to them as moral human beings and their just treatment in regard to HIV testing.

Rawls felt that justice is the most important principle of society and that it has the ability "to transform our perspective on the social world and to reconcile us to…the conditions of human life" (ibid., p. 448). Yet he also equated justice as fairness with the Kantian view of persons acting autonomously, expressing their nature as free and equal human beings and reflecting their situation as individuals in the world, subject to the circumstances of justice (ibid, p. 452). What is notable is that expressing one's autonomy does not override being subject to the principle of justice. Indeed, Rawls believed that it is precisely our nature as free and rational human beings that makes us accountable for behaving justly (ibid., p. 455). Therefore we should respect the autonomy of each person and treat each individual justly. We are individually accountable for the just treatment of other rational human beings, even if we are working in a very busy clinic with a monthly HIV testing target, even if we have just learned that our spouse is infected with HIV, and even if we have just heard our neighbor is deathly ill with AIDS and lives in the house where our children have played every afternoon for months.

According to Rawls, "a well-ordered society affirms the autonomy of persons and encourages the objectivity of their considered judgments of justice" (ibid., p. 456). One could easily extrapolate this affirmation of autonomy and consideration of just judgments in regard to institutions supporting HIV testing and healthcare provision generally. For Rawls felt that "the collective activity of justice is the preeminent form of human flourishing" and that "the public realisation of justice is a value of community" (ibid., p. 463). Clearly, Rawls did not separate the need for individuals to practice justice from the

need for community members to be just to each other. In fact, Rawls felt that we are mutually bound by accepting the principles of justice (ibid., p. 500). Likewise, institutions and community-based organisations also are bound by accepting and practicing the principles of justice. Rawls believed that justice is our first priority, which should govern all our aims and actions (ibid., p. 503). He implied that putting justice at the centre gives meaning to the ideas of respect and human dignity as respect for other persons is shown by treating them justly (ibid., p. 513). Near the end of his book, *A Theory of Justice*, Rawls wrote:

> "Thus to respect persons is to recognize that they possess an inviolability founded on justice that even the welfare of society as a whole cannot override. It is to affirm that the loss of freedom for some is not made right by a greater welfare enjoyed by others" (ibid.).

In reading these statements, it is hard to imagine that Rawls would justify coercive or mandatory HIV testing. It is hard to imagine that he would support the neglect of securing truly informed consent for HIV testing. And, it is hard to imagine that he would consider HIV testing alone without supportive counselling and access to other services to be a just intervention to protect public health.

3.3 NELSON MANDELA, JUSTICE AND HIV

It is hard to imagine that Nelson Mandela would have supported the coercive HIV testing of women either. And, it is even harder to imagine that he would have supported the HIV testing of children without providing them with access to ART if they tested positive. As an internationally prominent HIV/AIDS prevention and care advocate, Nelson Mandela said on World AIDS Day during his presidency in 1994:

> "We need to ensure that we provide the supportive environment to afford people the capacity to protect themselves through increasing access to condoms, drugs for sexually transmitted diseases, access to health care and testing, and counselling facilities. At all times we must speak out against the stigma, blame, shame and denial that has thus far been associated with this epidemic" (2013, p. 19).

Clearly, Mandela's words support the need for just treatment of PLHIV in the same way he supported the just treatment of all people. It is important to note how well he understood the need for counselling in regard to HIV/AIDS, which was unusual for someone of his generation and background; counselling was not commonly accessible to someone who lived in the circumstances in which Nelson Mandela did for most of his life. Yet similar to Rawls and others, Mandela focused on the importance of self-confidence in realising and maintaining individual agency. He realised how the stigma of HIV/AIDS undermines self-confidence for which counselling can be very beneficial. Mandela noted at the opening of Zola Clinic in Soweto in 2002, "…stigma is sometimes more dangerous than the terminal disease itself. Because you can cure, you can fight and live as long as possible with the assistance of drugs, but a stigma, it destroys your self-confidence" (ibid., p. 21). Self-confidence is closely interlinked with self-knowledge and self-care. As a man who had spent 27 years in prison, Mandela understood how important self-confidence is to surviving, to healthy living, and not losing hope against tremendous odds. He felt the pain of PLHIV when he spoke of being with people with HIV/AIDS during his presidency, and he noticed how other people moved to the other side of the room from them and even from him out of fear of infection. He movingly said at Nolungile Clinic in Khayelitsha in 2002,

"We must love, encourage and inspire people who are HIV-positive. This is the greatest contribution we can make in the fight against AIDS" (ibid., p. 22).

Nelson Mandela focused on HIV/AIDS as an issue of justice and human rights. In 2003 at the famous 46664 concert held at Greenpoint Stadium in Cape Town, he stated, "AIDS is no longer just a disease: it is a human rights issue" (ibid., p. 23). And, at the opening of the first public-private HIV/AIDS treatment site in South Africa at GF Jooste Hospital in Cape Town that year, he said, "Health cannot be a question of income; it is a fundamental human right. We must give people hope that it is possible to lead a healthy, fulfilling life even with HIV/AIDS" (ibid.). Again Mandela focused on individual agency and justice, but also, importantly, the right to health. Yet he also realised that fundamentally HIV/AIDS is also a right to life issue. Mandela said in Switzerland late in 2003, "The most basic dignity, the right to live and to live healthily, is under threat from this destructive pandemic" (ibid.). When access to treatment for a terminal disease such as HIV/AIDS is unavailable as it was for about 20 years and remains unavailable to many in sub-Saharan Africa, as cited in Chapter 2, HIV/AIDS indeed is a right to life issue. Mandela understood this fact and articulated it clearly. Indeed, no one has been more eloquent than Nelson Mandela in speaking about HIV/AIDS and the impact it has on individuals and on society. What is also germane is that Mandela did not see a lack of resources as an excuse for the lack of a full-fledged response to the epidemic. In 2004, he said, "History will judge us harshly if we do not respond with all the energy and resources that we can bring to bear in the fight against HIV/AIDS" (ibid.).

Most touchingly, Nelson Mandela proclaimed at a press conference he held on 6 January 2005, "My son has died of AIDS" (ibid.). Tragically, Makgatho Mandela was his only

surviving son. His older son, Thembekile, died in a car accident while Mandela was in prison, and the prison authorities notoriously would not allow him to leave prison briefly to attend his son's funeral (Mandela, 1995, p. 531). What may have caused Mandela even more pain in 2005 was that it was Makgatho who had sent the telegram to Mandela in prison on Robben Island in July 1969 informing him that Thembekile, who was 25, had been killed in a car accident, leaving two small children (ibid.). At the press conference about his son's death, Mandela also said, "I hope that as time goes on we will realise that it is important for us to talk openly about people who die from AIDS" (2013, p. 23). It is clear from these and other statements made by Mandela that he saw himself as a powerful spokesperson on HIV/AIDS. To be a leader on this issue of social justice, he obviously realised he had to be a role model and lead by example. Moreover, the recognition of Mandela's leadership on issues of justice and HIV/AIDS and his style of leading by example were repeated over and over by his former Robben Island fellow prisoners, his African National Congress (ANC) colleagues, and his grandchildren from 6-15 December 2013 during many memorial services held for Nelson Mandela across South Africa (Associated Press, 2013, pp. 1-2).

For someone who himself was deeply affected by HIV/AIDS—through his outstanding advocacy work surrounding the epidemic, his interaction with South Africans living with HIV, and the profound impact of the death of his son from this disease—it is not surprising that Mandela also had a special understanding of the impact of HIV/AIDS on women. At a later 46664 concert held in George, South Africa, in 2005, Mandela said, "Give a voice to the women of Africa in the fight against HIV and AIDS. Let their voices be heard in the centres of power. Let their voices be heard in the home. Let their voices be heard in the farms and factories, in the towns and villages" (2013, p. 24). Mandela saw women as the

voiceless souls of this epidemic, and he cried out for greater recognition of their importance in the collective response to HIV/AIDS and the need to give them their just due. Surely, if he had been asked, he would have demanded the right of women to test for HIV voluntarily and not to be denied the dignity of their right to choose whether to test for HIV or not when seeking healthcare. In my view there is no better way to state the current situation of African women regarding HIV/AIDS than what Mandela said in 2006 upon receiving Amnesty International's Ambassador of Conscience Award at the Nelson Mandela Foundation:

> "We know that the AIDS pandemic affects us all, and that it is women who bear the most significant burden of HIV and AIDS. As daughters, mothers, sisters and grandmothers, every day they experience and live out the reality of this pandemic. They are the forgotten prisoners of today" (ibid., p. 24).

Yet far too few have the understanding of the plight of African women and HIV/AIDS that Nelson Mandela so profoundly described. As a former prisoner himself for 27 years, that he identified with African women as prisoners of HIV/AIDS shows his deep insight into the suffering and deprivation of their rights that millions of African women have experienced for decades.

Perhaps Mandela's insights into the plight of women surrounding HIV/AIDS were just one more manifestation of his own personal knowledge of sacrifice and the deprivation of human rights on which he was so sensitive toward others in similar circumstances. Within months of his release from prison in 1990, Mandela said, "The basic human rights of all our citizens have to be protected and guaranteed, to ensure the genuine liberty of every individual" (ibid., p. 116). And, "To deny people their human rights is to challenge their

very humanity. To impose on them a wretched life of hunger and deprivation is to dehumanise them" (ibid.). Mandela continued speaking on this theme, including 18 years later in 2008, "Where there is poverty and sickness, including AIDS, where human beings are being oppressed, there is more work to be done. Our work is for freedom for all" (ibid., p. 117). It is well recognised that Mandela dedicated his life to justice and freedom for all, including women, and including PLHIV. He said in 2005:

> "We live in a world where the AIDS pandemic threatens the very fabric of our lives. Yet we spend more money on weapons than ensuring treatment and support for the millions infected by HIV. It is a world of great promise and hope. It is also a world of despair, disease and hunger" (ibid., p. 24).

It is illuminating to think of Nelson Mandela and his views on freedom, justice, human rights and HIV/AIDS in contrast to the attitudes of some healthcare providers in Africa in having no guilt about coercing HIV testing, saying they felt it benefitted patients, which is an act of paternalism and is unethical (Evans and Ndirangu, 2011, p. 7). Based on his statements on the need for care and support of PLHIV, I believe Nelson Mandela would disagree strongly with the WHO continuing to justify routine counselling and testing as an approach by healthcare providers where no or inadequate treatment is available to individuals testing HIV-positive, including PMTCT for only about 60% of pregnant women testing positive, which the WHO recognised in 2012 is common across Africa (WHO, 2012, p. 48).

3.4 JUSTICE AND HEALTH RIGHTS

Regarding access to health rights, human rights law professor Katarina Tomasevski developed a number of legal arguments on health rights in 1995 that were published as a

chapter in the book, *Economic, Social and Cultural Rights*. While Tomasevski (1953-2006) did not live to see her arguments come to fruition through relevant policy, her points are no less relevant and perhaps more so now than they were 15 years ago. They continue to provide history and illumination to the ongoing struggle for human rights related to health care, which has been a prominent banner of thousands of individuals and groups fighting for the past 10-20 years for a more comprehensive global and national response to the HIV/AIDS pandemic based on human rights. The following are some excerpts from Tomasevski's chapter on health rights published in 1995 that are relevant to this paper:

> "The right to health creates entitlements for individuals and corresponding obligations for governments…access to health care as an individual rights does not enjoy global recognition. One reason for this is the reluctance of governments to translate into practice such an individual entitlement which necessitates a large investment" (1995, p. 125).

Tomasevski provided more reasons why global health remains a contentious issue among governments: pointing out that the factors that either enhance or jeopardise health have a scope far beyond the health sector itself and intersect at the societal level through how developed it is and at the individual level through access to employment or income opportunities, housing, water and sanitation, and adequate nutrition (ibid., pp. 125-126). She also described how the legal reason for human rights related to global health and indeed public health itself are still evolving historically, including in relation to health law because health is subject to "vast legal regulation," which generally is not guided by the standards of human rights (ibid., p. 126). And, because issues surrounding public health, such as the control of communicable diseases, preceded the recognition of human rights historically, public health law developed without reference to individual rights (ibid., p.

127). Tomasevski also noted the international situation on human rights related to health regarding the relevant legal and regulatory documents available in 1995, suggesting they were "fragmentary provisions scattered through a variety of international legal and declaratory instruments rather than a uniform, consistently developed body of law" despite the general acknowledgement that national governments hold the responsibility for the health of their populations (ibid., pp. 128-129). In the following passage, she also addressed the conjuncture of human rights and health related to medical ethics, and the intersection of medical ethics with human rights related specifically to AIDS:

> "Human rights standards in health are complemented by medical ethics…Public health has been affected by the principle that law and not medicine should regulate restrictions of fundamental rights and freedoms. As always in human rights, movements to reinforce the universality emerge in response to violations. Before AIDS, little attention had been paid to human rights violations targeting the ill or the disabled, or to the denial of access to health care" (ibid., pp. 135, 139).

In laying out her arguments on health rights, Tomasevski did not limit her legal arguments on the right to health care to women and girls, especially in sub-Saharan Africa. Yet she recognised that the HIV epidemic epitomises violations of the individual right to health care for which so many have fought and are still fighting in many countries, especially in Africa. In regard to HIV/AIDS, the human right to health care has been largely neglected or ignored by health authorities in favor of a determined focus in some countries to impinge the human rights of individuals in the name of protecting public health. However, just testing millions of people for HIV does not prevent the spread of the epidemic.

Ironically, as also presented herein, we have learned in the past few years based on research study results, which have received global recognition, that treating people for HIV and AIDS may prevent thousands, if not millions, of new infections through decreasing the infectiousness of people living with HIV (Cohen, et al., 2011, p. 493).

3.5 HEALTH RIGHTS AND HIV

For public health authorities to rely on long established health law to implement health policy that is misguided in its application to this particular infectious disease recognises neither its salience to the HIV epidemic, nor its salience to the contemporary recognition and enforcement of human rights. Ignoring or avoiding individual and collective human rights simply continues bad public health practice. I have chosen to focus specifically on the rights of women and girls in sub-Saharan Africa related to the epidemic and specifically to HIV testing because I believe these individuals, and collectively as a group, are the most vulnerable to human rights violations related to the HIV response and indeed to GBV, social disenfranchisement, community condemnation, and familial abandonment. They need protection from these prevalent consequences of testing positive for HIV and, through research study results that will be described in Chapter 5, from the frequent stigma and discrimination resulting simply from the HIV testing itself, whether they test positive or negative. What's more, it is important to protect human rights from the outset, that is, from being given the opportunity of counselling and testing for HIV and deciding whether or not to test, rather than focusing only on the point after testing HIV-positive when treatment should commence, or testing HIV-negative when a referral should be made to supportive services to help maintain one's negative status. All of these steps are necessary, and only invoking the need for a rights-based approach after an individual has tested HIV-positive is simply too late to respect, protect, and fulfil individual human rights.

I am concerned that in 2013-2015 there is growing international impetus to support the human rights related to HIV/AIDS of 'key populations' such as sex workers, gay men, people who inject drugs, transgender persons, and persons in detention and prison while, at the same time, there seems to be complacency about and even neglect of protecting the HIV/AIDS-related human rights of women and girls, who comprise 57% of the HIV infections in Africa (Beyrer, 2013, p. 1; UNAIDS, 2013, p. 78). This situation seems ironic when there is growing awareness of the impact of GBV on the HIV infection of women and girls (UNDP, 2012, p. 64). Certainly, the human rights—all human rights—of sex workers, gay men and women, people who inject drugs, transgender persons, including transgender women, and persons in detention and prison should be protected. But it should not have to take another Nelson Mandela to recognise that women in Africa are the prisoners of this epidemic. In December 2013 the President-Elect of the International AIDS Society, Chris Beyrer, wrote of excluding access to prevention and treatment services of the key populations named above, "These exclusions are violations of the right to health and to dignity and, because untreated HIV infection is fatal, of the right to life itself. This is morally unacceptable and scientifically indefensible" (Beyrer, 2013, p. 1). Beyrer is right in writing that denying these individuals their human rights, including their right to life itself, is morally indefensible. Mandela surely would agree with him, as do I. But it also is crucially important to realise that women continue to be denied their basic human rights, including their right to life itself, on a daily basis in many areas in Africa where treatment for HIV/AIDS remains unavailable (and unavailable to men also). The right to life is indeed the most fundamental right human beings have. Yet it can be overlooked or simply forgotten in regard to individuals who feel powerless in society, which is the common plight of African women and is an issue of social justice.

UNAIDS has recognised that "persistent gender inequality and human rights violations that put women and girls at greater risk of and vulnerability to HIV continue to hamper progress and threaten the gains that have been made in preventing HIV transmission and in increasing access to antiretroviral therapy" (2010, p. 1). However, this joint UN programmatic body also recognised that discrimination against and brutality and injustice toward women and girls means they are excluded from decision-making and crimes against them can be committed with impunity (ibid.). These statements acknowledge that women and girls continue to suffer indignities and that their human rights frequently are ignored, sometimes by societies at large in addition to their sex partners, family members, other members of their communities, and even health workers. Indeed, the Special Rapporteur of the United Nations Human Rights Council on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health noted in 2011, "Providing women and girls with knowledge and skills relating to their sexual and reproductive health, related education and information enhances their freedom in making informed health-related decisions, and promotes their equal participation in society" (Grover, 2011, p. 19). This statement centres on the right of women and girls to health, including the right to sexual and reproductive health information, which includes information about HIV/AIDS and sexually transmitted infection (STI) prevention, treatment, care, and HIV testing. What's more, the Special Rapporteur went on to write in 2011 that States have an obligation to fulfill the right to health, requiring the development of strategies to ensure that "comprehensive sexual and reproductive health education and information is provided to everyone, especially women and girls" (ibid.). Consequently, where such information is not available, which it is not in many clinics in Africa due to the lack of resources and/or lack of government will, individuals are being denied the

realisation of their right to health. The Special Rapporteur also noted in 2011 that women and girls are the most likely to be affected by the related gap in available health services because they have a higher risk of HIV and STI exposure, as well as maternal mortality, unsafe abortions, and unwanted or unplanned pregnancies (ibid., p.18). Finally, the Special Rapporteur highlighted that "women often have less power or control in their relationships, which makes them disproportionately vulnerable to coercion, abuse and exploitation," preventing them from enjoying the highest attainable standard of physical and mental health (ibid.).

There is clear recognition in some quarters that women and girls are not realising their right to health especially in regard to sexual and reproductive health, including HIV/AIDS, and there are some efforts to promote greater attention to this need. For example in 2013, the African Commission on Human and Peoples' Rights established two landmark resolutions, urging states to: (1) "protect and promote women's right to land and property" as many women have been pushed off their land and have lost their property when their spouses have died of AIDS, and, (2) "to put in place mechanisms to ensure that women living with HIV are not subjected to coercion, pressure or undue inducement by health care providers…in order to secure consent for sterilisation" (Ezer, 2013, p. 1). This statement by the African Commission acknowledges the same type of coercion some health care providers exert on women for HIV testing. The Open Society Institute (OSI) found these African Commission resolutions to be bringing African women "one step closer to justice," but the OSI noted that it is up to African states to ensure the critical human rights protections of women by respecting, protecting, and fulfilling their fundamental human rights (ibid.). Unfortunately, there has been no noticeable follow-up to date to these African Commission resolutions in African states. One can only hope progress will be

made in the future. Ironically, in April 2014 in South Africa, the Gauteng Department of Health made a settlement agreement to pay an HIV-positive woman nearly half a million rands for damages, including the pain and suffering she felt resulting from her coercive sterilisation in a public hospital (Skosana, 2014, p. 1). And, according to a spokeswoman for the NGO, Her Rights Initiative, the forced sterilisation of HIV-positive women has been reported in all the provinces in South Africa (ibid., p. 2).

According to Gruskin, Mills and Tarantola, "Integration of human rights in international health systems is increasingly driven by the recognition that the respect, protection, and fulfillment of human, civil, political, economic, social and cultural rights is necessary—not because they are the binding legal obligations of governments, but because they are essential for improvement of the health status of individuals and populations" (2007, p. 449). They also pointed out that it is important regarding human rights not only to focus on the outcomes of health interventions, but also on the way they are implemented (ibid., p. 453). This is one of the purposes of this thesis, that is, to examine how HIV counselling and testing protocols are implemented currently in Africa, and the impact of the implementation of these protocols especially on the rights, ethical treatment of, and just actions toward women and girls.

The following are some additional general points and specific examples from sub-Saharan Africa that support the importance of exposing these challenges to the bioethical and human rights of women and girls to help determine and generate preventative and supportive mitigation policies and mechanisms. The current implementation of some HIV testing protocols, especially routine testing, of women and girls in various locales in sub-

Saharan Africa challenges their rights as individuals and collectively as a group amidst an extremely stigmatised disease epidemic. According to Watts and Seeley:

> "The gender-related aspects of HIV stigma, including that violence and the fear of violence may act as important barriers to women accessing services, testing and disclosure, have long been documented" (2014, p, 1).

And, according to a recent study on interpersonal violence (IPV) and HIV in Uganda:

> "HIV positive status and disclosure might increase risk of interpersonal violence (IPV), and fear of violence can prevent women from learning and sharing their HIV status and from accessing treatment" (Wagman, Gray, Campbell, et al., 2014, p. 2).

In a paper Tomasevski wrote in 2005 on the human rights approach to HIV/AIDS, she noted that earlier in the epidemic, "HIV testing was dangerous because it could lead to the loss of livelihood or even life" (p. 1). However, I would posit that in many places HIV testing remains dangerous because individual rights related to HIV/AIDS remain unprotected, as many of the examples outlined earlier in this paper have documented. This situation is especially the case for women and adolescent girls. Further, while human rights related to HIV/AIDS nowadays may be more recognised in some locales than they were earlier in the epidemic, they still are not realised by many individuals and by women and girls as a group in sub-Saharan Africa. Their rights can be frequently and easily violated. The lack of truly informed consent related to HIV testing as well as the commonality of

coercion to test are just two examples, which are described via various examples in chapters herein.

In 1998, the Office of the United Nations High Commissioner for Human Rights and UNAIDS released the HIV/AIDS and Human Rights International Guidelines, which noted the following on the human rights of women:

> "Discrimination against women, de facto and de jure, renders them disproportionately vulnerable to HIV/AIDS. Women's subordination in the family and in public life is one of the root causes of the rapidly increasing rate of infection among women. Systematic discrimination based on gender also impairs women's ability to deal with the consequences of their own infection and/or infection in the family, in social, economic and personal terms" (1998, p. 41).

These international guidelines from the UN also explained:

> "HIV/AIDS demonstrates the indivisibility of human rights since the realization of economic, social and cultural rights, as well as civil and political rights, is essential to an effective response. Furthermore, a right-based approach to HIV/AIDS is grounded in concepts of human dignity and equality which can be found in all cultures and traditions" (ibid., p. 38).

If anything, the recognition of the need to respect the human dignity and equality of women and girls has become more important as time has gone on as shown by the statement, above, by UN agencies in 1998. Much of the philosophical background and more recent research study results enumerated in this paper identify the fundamentality of these principles and how women and girls still strive in Africa to reach the apex of the pyramid of human dignity and equality—on the same level as men and boys—rather than continuing to flounder at the bottom.

3.6 RECENT HIV AND RIGHTS CHALLENGES IN AFRICA

Also important to bear in mind is that by honoring and protecting the individual and collective rights related to HIV counselling and testing, there is a greater likelihood of reaching the public health goal of decreasing the number of new infections. One aspect of this is that maintaining the confidentiality of HIV testing itself and the results of each HIV test will help prevent girls and women from being exposed to unnecessary, unwarranted, and harmful stigma and discrimination. According to a recent study on adolescents living with HIV in Zambia, one 17-year-old girl described why she had not disclosed her HIV-positive status to any of her friends, “I will be segregated and they will only want to play with those who are not HIV positive” (Denison, Banda, Dennis, et al., 2015, p. 3). Protecting the lives of adolescents living with HIV is a very serious issue: between 2005 and 2012, HIV-related mortality among adolescents living with HIV increased globally by 50% (ibid., p. 1). Moreover, the majority of the 2.1 million adolescents living with HIV around the world reside in sub-Saharan Africa (ibid.). Most importantly, adolescent girls are at greater risk biologically and socio-culturally of HIV infection than adolescent boys, which is readily reflected in the different HIV prevalence rates between boys and young

men aged 15-24 years and girls and young women in the same age group in six Southern African countries, as noted below, in the Southern African Development Community (SADC)'s *2014 Contextual Scorecard and Factsheet on HIV* (Africa Coalition on Maternal, Newborn & Child Health, 2014), p. 1):

Table 1: HIV Prevalence in Females & Males Aged 15-24 in 6 Southern African Countries

Country	HIV Prevalence % Females Aged 15-24	HIV Prevalence % Males Aged 15-24
Botswana	6.0%	3.5%
Lesotho	10.5%	5.8%
Mozambique	6.1%	2.7%
Namibia	4.8%	2.7%
South Africa	13.1%	4.0%
Swaziland	12.4%	7.1%

Source: SADC/Africa Coalition on Maternal, Newborn & Child Health, 2014

As is illustrated above, in most of these countries, the HIV prevalence rate in girls and young women is twice the rate in boys and young men, although in South Africa the rate in girls and young women is three times higher than in boys and young men. These statistics show the extreme vulnerability of young females to HIV, most particularly in South Africa, where the largest number of people living with HIV in any country in the world reside, estimated at 6.8 million in 2015 of which about 56%, or an estimated 3.9 million, were women (UNAIDS, 2014b, pp. A27, A33; UNAIDS, 2015, p. 1). Surrounded by South Africa, Lesotho illustrates another country where young women are extremely vulnerable to HIV: in 2013 young women in Lesotho aged 20-24 had the highest HIV prevalence rate in the world in their age group at 24% (O'Grady, 2014, p. 6).

Whether the decision is to be made by a woman or a man or a boy or a girl, facilitating the freedom of choice about whether to test for HIV or not will prevent HIV testing from being the hurdle some see it as and thus do not access health care for fear of mandatory or

forced testing or the inability to receive any treatment and care for any illness without first testing for HIV. While this is a human rights issue related to the freedom of choice for every individual, it is most pertinent to women, especially women and adolescent girls, whose rights can be ignored or overridden through coerced HIV testing. An example from the analysis of recent research study results from HIV prevention intervention trials of women in several sub-Saharan African countries using antiretroviral therapy (ART) to prevent sexual transmission of HIV described how the need for "choice" for women regarding HIV prevention methods is only starting to be understood by researchers (even though most of the researchers who were involved in the studies are women themselves): "Although the importance of choice has been recognized and incorporated into contraceptive provision, it is an emerging idea in HIV prevention" (Mack, Evens, Tolley, et al., 2014, p. 2). One wonders how and why the concept of women having a choice of a product to use for such a crucial health-related issue as HIV prevention in sub-Saharan Africa would not have occurred as a key issue previously over the 30-year HIV epidemic? I believe these findings also highlight how little understanding remains of the socio-cultural predicament of women in sub-Saharan Africa related to the realisation of their human rights generally and specifically in regard to their health. The confluence of gender inequality, GBV, and the HIV epidemic can be a deadly equation for many, if not millions, of women and adolescent girls in sub-Saharan Africa. That this fact is only starting to be understood based on the failure of recent HIV prevention research trials seems rather astonishing. Yet this situation supports the need for more attention to the human and health rights of these women and girls related to the HIV epidemic and indeed to the starting point of HIV testing in order to be able finally to launch an effective response to this pandemic.

While it is important to recognise when, where, and how human rights regarding HIV/AIDS are infringed by health care providers, it also is important to reflect the profound views supporting the rights of patients expressed by some leading health care providers. Marcia Angell wrote in 1993, more than 20 years ago, "We should be loath to abandon or modify the patient-centered ethic, and we should be wary of ethical justifications for doing so" (p. 136). Moreover, Angell did not separate the duties of physicians toward their patients from those duties we all have toward other human beings: "Ethics should be based on fundamental moral principles governing our behavior toward one another" (ibid.). Also, Edmund D. Pellegrino, writing specifically about the treatment of AIDS patients, wrote in 1987, more than 25 years ago, "three things—the nature of illness, the non-proprietary character of medical knowledge, and the oath of fidelity to the patients' interests—generate strong moral obligations" (p. 131). Thus like Jonathan Mann, Nelson Mandela, and some others, it is hard to imagine Angell and Pellegrino agreeing to coercive HIV testing simply to test more patients for HIV and, where it is available, not providing treatment to patients who test HIV-positive and need it.

It also is important to realise the influence the HIV/AIDS epidemic has had on global health generally, including the increasing recognition of the right to health and access to social justice for individuals and groups with health issues of serious concern. Brandt wrote that the HIV/AIDS epidemic has had "powerful effects on research and science, clinical practices, and broader policy," and has "reshaped conventional wisdoms in public health, research practice, cultural attitudes, and social behaviours" (2013, p. 2149). While acknowledging the truth of Brandt's statement, it is important to focus on the implementation of HIV/AIDS policy as it plays out on the ground. There have been many changes in HIV/AIDS-related policies in many countries since the epidemic started.

Brandt noted that early reactions to the epidemic in some countries "reflected traditional approaches to public health and the "police powers" of the state, including mandatory testing, isolation, detention, and quarantine" (ibid., p. 2151). Such policies and practices have not changed everywhere over the last 20 years, however. Cuba remains an example where mandatory testing is still the policy for pregnant women, the sex partners over the last six months of individuals testing HIV-positive, and anyone diagnosed with an STI (Hoffman, 2004, pp. 208-209). Moreover, anyone testing positive in Cuba must go to a sanatorium for eight weeks of HIV/AIDS education and quarantine (and permanent quarantine, i.e., jail, if an individual is found to practice unsafe sex afterward); and, pregnant women are provided with PMTCT services, but must deliver by caesarean section to minimise HIV transmission to the baby (ibid.). One beneficial aspect of Cuba's HIV/AIDS policy and practices, though, is that the country has made its own generic HIV medications since 2001, which are administered to positive individuals by HIV specialists (ibid., p. 209). While Cuba has slowed the spread of HIV, the island nation has accomplished this by 'policing' its epidemic, especially through the use of its mandatory testing policy of pregnant women, and not by aligning its HIV/AIDS policies and practices with the principles of social justice.

Despite Cuba's ability to control its HIV epidemic through restrictive policies, many have noted the global epidemic is so large and spread so widely around the world, even supranational, that no individual country can adequately address its epidemic amidst globalisation and the extensive movement of people, international trade, and that infectious diseases know no borders (Brandt, p. 2152). Consequently, nations and sectors must work together to staunch the spread of HIV through shared endeavors, which was the rationale for the founding of UNAIDS in 1996, now comprised by 11 UN agency cosponsors with

financial support from many nations, and which takes the lead on human rights policy related to HIV/AIDS (UNAIDS, 2013). There also is growing international realisation that only by recognising and protecting human rights, including the rights to treatment and care, gender equality, and health information, will HIV interventions—directed both at the individual and population levels—be successful (Brandt, p. 2152). However, such acknowledgment of the need to work together still has not coalesced into delivering the range and volume of services needed to prevent, treat, and care for HIV infection anywhere in the world, with the greatest need continuing in sub-Saharan Africa. The provision of equity through social justice to PLHIV, and especially women in regard to HIV, remains elusive.

The efforts to scale up HIV counselling and testing continue despite some clinicians and public health officials trying to 'normalise' the epidemic by routine testing of as many people as possible in the face of largely undiminished stigma and discrimination and amidst the voices of human rights advocates who remain concerned about any lack of privacy, confidentiality, counselling, and consent surrounding HIV testing (Branson, Viall and Marum, 2013, p. S118). Some of the problems surrounding the implementation of routine testing in Africa have been explored in Chapter 2 herein. But it also is worth noting that in 2010 fewer than half of the hospitals in the US were planning to implement the CDC's routine testing policy initiated in 2006 (ibid.). This example of what is actually happening on the ground shows that efforts to contain the spread of HIV are still hindered by a lack of resources, both human and financial, even in the wealthiest countries in comparison to the resource-constrained countries in sub-Saharan Africa. Because of the problems emanating from the substantial stigma and discrimination surrounding HIV that continues in sub-Saharan Africa (and elsewhere) and the extensive lack of resources to

respond to the continuing epidemic, including for the scaling up of HIV testing, some are promoting home-based HIV testing. Home-based HIV testing has seen a high uptake in some of the limited studies done in Africa to date (ibid., p. S119). The key aspects of home-based testing are that it is voluntary and confidential. Whether counselling is made available surrounding home-based testing varies, but at least the testing has not been coerced as far as we know. That the testing is done at home and not at a public facility, where concerns about confidentiality, stigma, and discrimination remain common, means that it is more appealing than facility-based testing to many people, including Africans (ibid.). How the linkages to treatment and care will work for individuals testing HIV-positive at home, however, remain as outstanding issues, since these facilities still are not widespread in Africa, as noted earlier. Because PLHIV, and especially women living with HIV, feel excluded, unequal, and stigmatised, it is unclear whether home-based HIV testing could be one path toward helping to resolve the various needs for social justice currently embedded in the HIV epidemic. But it is important to provide more options regarding HIV testing that respect each individual's human rights and preserve the needs for informed consent, confidentiality, access to counselling, and access to prevention and care services for individuals who need them, whether they test negative or positive.

In regard to justice and health care, Beauchamp and Faden wrote 35 years ago, "It is hard to imagine that we are not obliged by a string of moral principles such as beneficence, non-maleficence and justice to provide a decent minimum of health care" (1979, p. 128). They argued that there is a social obligation to provide health care goods and services as an aspect of social justice; what they noted as problematic was the scope of what such health care goods and services should encompass (ibid.). While Beauchamp and Faden were not writing about the HIV epidemic in 1979, their argument is just as relevant today, if not

more so. Regarding the HIV epidemic and justice, it is salient to note that justice related to health care concerns the rights of everyone, not only those who can pay for their own health care. According to Plato, justice consists of rendering to each person her due, what she has a right to, and thus to do someone justice means to uphold or protect the person's rights (Gewirth, 2003, p. 220). Gewirth has noted that rights are important interests not only of individuals, but also of groups (ibid.). Using this paradigm for justice related to health care, then, each individual has a right to health care and, indeed, an individual as a member of a group diagnosed with HIV or AIDS has a right to health care. It is unjust that treatment for HIV is not available to many individuals diagnosed HIV-positive living in sub-Saharan African countries where treatment is available only to a limited extent. What's more, treatment is available in some areas only to those who can pay for it. Yet even where ART is free to individuals who have met the threshold for accessing treatment, only those who have the financial resources to be able to travel to a clinic once a month, which can be far from where they live, can avail themselves of ART monthly and adhere to the daily regimen. Even clinics located within walking distance can be very difficult for people who are ill to access (Kagee, Remien, Berkman, et al., 2011, p. 3). Moreover, the lack of financial resources has been a prominent reason for many women who have been provided with ART not adhering to the daily regimen due to the need to travel to access the medication on a regular basis (ibid., p. 5). According to Rachel Jewkes, "women's subordinate position in a highly patriarchal society has critically shaped their HIV risk" (2009, p. 27). Indeed, it also shapes their opportunities to adhere to HIV medication. Many women also face additional political and cultural barriers to adherence, such as child-care burdens in addition to economic dependence upon men amidst the general structural barriers of poverty and health illiteracy, so common in Africa and which many women in Africa confront regarding health care-seeking behaviours and especially adherence to a

daily treatment regimen (Kagee, et al., 2011, pp. 3, 5; Phillips, Thebus, Bekker, et al., 2014, p. 1).

The health system itself is unjust when it does not address the needs of the poor and marginalised. The broader socioeconomic context of women's HIV risk suggests that transforming gender roles to increase gender equity and promote women's health is vitally important, not only for women but to provide greater ballast to society in the future generally (Jewkes, 2009, p. 37). Since a patriarchal society offers women fewer opportunities than men and women do not share equally in positions of power, this has an impact on society beyond women as they make up 50% of society (Isaacs, 2002, p. 131). The economic subordination of women in addition to their lower social status not only has a profound impact on the health of women, but it also has an impact on their families, their communities, and the larger society. I again wonder about the rationale behind routine testing in relation to justice when accessing treatment is so difficult, if not impossible for many, and adhering to it daily especially for the poverty-stricken, most prominently women, can be a losing battle. Indeed, according to Boetsen regarding HIV risk and survival strategies, "The combination of poverty and gender inequality—with all its extremes of powerlessness, violence and abuse—trap many women in hopeless situations" (2009, p. 77). That some women recognise their socioeconomic subordination and systemic disadvantage, but feel powerless to address it is a social tragedy (Isaacs, 2002, p. 132). Yet this situation underscores the enormous health tragedy wrought by the HIV epidemic on society broadly and the further injustices of the epidemic as it plays out in the daily lives of individual women and gender collectively.

Jonathan Mann noted more than 15 years ago that modern human rights were developed entirely outside the health domain, and they seek to articulate the preconditions for human well-being in society rather than follow biomedical or public health traditions from the past (1997, p. 2). Thus Mann found human rights to be a more useful framework as well as a vocabulary and guide for analysing and responding to the societal determinants of health, which previous biomedical and public health conceptions largely ignored (ibid.). Mann came to this determination, which some agree with (including me), based on what he saw happening surrounding the HIV/AIDS epidemic on which he worked in Africa. He realised through his own observations that "human rights violations have health impacts, that is, adverse effects on physical, mental and social well-being" (ibid.). I believe what Mann wrote in 1997, the year before he was killed in a plane crash, remains just as true and relevant today as it was then—that the adverse effects of human rights violations on physical, mental and social well-being "still remain, in large part to be discovered and documented" (UNAIDS, 2008b, p. 2; Mann, 1997, p. 2). In fact, in late December 2013 a missive was sent from the Global Fund to Fight AIDS, Tuberculosis and Malaria calling for proposals to provide technical assistance on human rights, gender, and community systems strengthening, with the first step listed as a request to conduct a situational analysis to document the human rights barriers to accessing health services and gender equality in specific countries, including 25 countries in Africa (Global Fund, 2013, pp. 1, 4-6). This example is illustrative of the progress that still needs to be made in documenting barriers to health care and gender equality, particularly in Africa.

3.7 JUSTICE, HEALTH AND HUMAN RIGHTS

Interestingly, Mann also wrote in 1997, "human rights is a language most useful for guiding societal level analysis and work, while ethics is a language most useful for guiding

individual behavior" (Mann, 1997, p. 3). At the same time he made this distinction, Mann also wrote that individuals with specific roles and competencies, such as physicians and public health providers, need to mix human rights and ethical concepts and language in their work (ibid.). Thus Mann combined the need for professionals to protect the rights of individuals and the rights of groups. He also noted that the Universal Declaration of Human Rights, ratified by the United Nations in 1948, starts with "All human beings are born free and equal in dignity and rights," with the dignity of all at the forefront of the document, not distinguishing the rights of one person from the rights of another person as all are equal (ibid.; UN, 1948, p. 1). Mann explicitly was trying to build bridges "between medicine and public health, and between ethics and human rights," noting that the objective in doing so was to staunch competition and to secure justice in health care (Mann, 1997, p. 4). In writing about health and human rights, Mann, too, bound the concepts of individual human dignity together with justice for each and every person, and indeed justice for all, harkening back to John Rawls and Plato. As noted at the beginning of this chapter, Mann also felt that the evolving approach to women's health, involving greater understanding of the specific health needs of women and how to address them, was based on health professionals learning that promoting and protecting human rights may be essential for promoting and protecting health (Mann, 1996, p. 1). It is my hope that this learning curve about women's health, emphasised by Mann, and centrally the rights of women, is still evolving. And, that the arc of this moral universe, to paraphrase American civil rights leader Martin Luther King in 1965 and health and human rights leader Jonathan Mann in 1997, is indeed long, but will eventually bend toward justice (Mariam, 2009, p. 1).

In analysing the right to health care in regard to HIV/AIDS treatment and its relationship to HIV testing, it is important to position these issues within the larger context of the HIV epidemic and the attitudes of many that have significant impacts on the response to it, including the continuing marginalisation of the rights of women. According to women's non-governmental organisation leader and self-professed PLHIV Alice Welbourn,

> "…the way out of the HIV pandemic is not through medication alone but through nurturing respect, care, dignity, support, rights, happiness—and safety—for everyone affected by HIV, everywhere. I look forward—still—to the day when these women's rights initiatives also will be given the credit and recognition they deserve" (2013, pp. 2-3).

Welbourn poignantly pointed out that while treatment should be provided to individuals who need it, which many believe will help slow the spread of HIV infection, just relying on a biomedical fix to the epidemic will not end it. She, too, understands the role of human rights, and especially women's rights, in society's overall confrontation with the epidemic and the need to change attitudes toward those affected by it. In taking this understanding further, one realises that fighting for the rights of women essentially means that one is fighting for the rights of all individuals affected by the epidemic. And, placing the HIV epidemic in the larger framework of human rights, what American revolutionary leader Thomas Jefferson wrote in 1789 also is salient: "What is true of every member of society, individually, is true of all of them collectively; since the rights of the whole can be no more than the sum of the rights of the individuals" (Jefferson, 1789, p. 7). This statement is particularly apt for conjoining the health rights of individuals with the health rights of society collectively. If the rights of individuals are not protected and realised, then the collective rights of society also cannot be protected and realised.

As Ashford has written, “Human rights claims are claims of basic justice” (2007, p. 185). Ashford also has argued that human rights claims can be made toward private individuals and social institutions (ibid.). Human rights impose corresponding duties, which require taking positive actions (ibid., pp. 184, 187). In relation to health care this means that health care providers have a positive duty to provide health care, as do health-care related social institutions, such as the WHO, in relation to its policies, or a hospital in relation to its mandate for health care provision. It also is incumbent on these institutions to promote human rights in regard to their policies toward and implementation of health care, including HIV testing protocols. According to Ashford, an individual agent or institution also is responsible for any violations of negative duties of justice when harm has occurred to an individual based on the action or non-action of the individual or institution acting as an agent (ibid., pp. 204-205). This stance on the negative duties of justice also relates to HIV testing. Where HIV-positive test results have been made known to other community members or a spouse who has inflicted related punishment on an individual, the lack of confidentiality has resulted in a specific harm caused by the individual or institution, violating the duty of justice. As seen in the case in Kenya discussed earlier in this chapter, the woman whose positive status was made known by a hospital to her employer resulting in the loss of her job also involved a legal claim, which the court agreed was a violation of her human rights. It is worth noting, however, that the violation of the human right to justice in regard to the disclosure of confidential HIV status is not based on a woman being beaten by her spouse or a member of the community, or losing her job, which is the result of the disclosure. Rather, the violation is based on the disclosure of her HIV status itself, as the health-care provider and the institution have a negative duty not to violate her right to confidentiality. In regard to positive and negative duties related to justice, Ashford has a

different view than that of Kant as he drew a distinction between positive and negative duties, whereby positive duties should be seen as duties of benevolence rather than as duties of justice (ibid., p. 213). Specifically in regard to HIV testing, I would argue that positive duties are duties of justice rather than benevolence, or beneficence (depending on the exact word used by different philosophers historically to convoke the same or a similar idea), the bioethical principle that will be explored to a greater extent in the following chapter.

Importantly, Ashford also has focused on the right to justice as existing independently of any institution and what its relevant policy may be, as institutions are supposed to be "minimally just" (ibid., p. 217). If institutions fail to guarantee the right to justice for every human being, "and such failure is reasonably avoidable, they are judged to be unjust," according to Ashford (ibid.). Ashford's view is aligned with Scanlon's view of justice, which is that an action is right if and only if it is not prohibited by a set of moral principles for the general regulation of behavior that no one could reasonably reject (ibid., p. 209; Scanlon, 1986, p. 151). In other words, it is accepted that others would agree someone has performed a right action if there could be no reasonable objection to it. How this relates to HIV testing is that individuals and institutions must abide by the principles of justice in their implementation of HIV testing protocols and in all their actions related to HIV testing, including both before and after testing individuals and groups. If any action occurs that could be felt by the majority to be unjust or which could be reasonably considered unjust, it would be a wrong action and against the principles of justice.

Prominent health ethicist Norman Daniels has focused on the social determinants of health in regard to justice, health. and healthcare, writing that promoting social justice is a crucial

step toward improving health because what is needed for social and political well-being is also needed for mental and physical health (2001, p. 6). Daniels acknowledged that social inequality is important at the individual level, but also, "the more unequal a society is in economic terms, the more unequal it is in health terms" (ibid., p. 7). What is especially germane to Africans is that Daniels feels that "health inequalities across demographic groups are unjust when they result from unjust distribution of the socially controllable factors affecting health" (Daniels, 2009, p. 36). Daniels also acknowledged that financial and geographical barriers to access health care impose different burdens on the health care needs of particular groups and that positive steps should be taken to ensure unmet needs are detected (Daniels, 1996, p. 199). If one considers the situation of most women in Africa, they are socially and socioeconomically inferior to men, as noted earlier, and many have lesser access to health care because of their more limited socioeconomic conditions and opportunities. Consequently, their health is at greater risk of potential harm because fundamentally the importance of their health is not equal to that of men as viewed by society. According to Daniels, health inequalities that derive from social determinants are unjust (Daniels, 2001, p. 8). Thus by applying the principle of justice related to health as explicated by Daniels, the inequality of the health of women in Africa can be seen as unjust, one of the themes of this thesis. If one accepts this premise, then it becomes necessary to determine whether there is a gender difference in regard to HIV testing in Africa resulting in potentially unequal approaches, unequal implementation, and unequal outcomes. I would posit that this unjust situation is certainly true in regard to routine testing in Africa because: (1) more women than men are tested for HIV through routine testing because women biologically have a greater need than men to access health care, which is where routine testing occurs; (2) women have a greater risk of coercive testing than men due to their inferior position of power in relation to health care providers,

especially during pregnancy, explored in Chapter 2 of this thesis; and, (3) women are less able to adhere to treatment for HIV after it has been provided than men based on their lower socioeconomic status and their role as the primary care provider in the family unit, which inhibit adherence and was cited earlier in this chapter.

Of significance is that Daniels also has examined the right to health care and distributive justice, whereby "justice requires that all societies meet health care needs fairly based on reasonable resource constraints" (ibid., p. 9). However, he has noted that there is no agreement on the principles of distributive justice that would guide the determination of how to set fair limits on health care provision (ibid.). Based on the extensive range of competing health care needs, there is moral disagreement about what constitutes the fair allocation of health care resources (ibid.). Nonetheless and importantly, Daniels has noted the need to "appeal to human rights protections against discrimination, to be more specific, as in decisions about HIV/AIDS treatment policy or coverage for services," illuminating the situation of inequality and injustice occurring in regard to access to HIV/AIDS treatment, particularly the problem African women have in accessing and adhering to HIV/AIDS treatment if they test HIV-positive (2009, p. 38). Moreover, Daniels has listed "preventive, curative, and rehabilitative personal medical services" as integral health care needs that individuals require in order "to maintain, restore or provide functional equivalents (where possible) to normal species functioning," which he claims supports each individual having a range of opportunity through which each one can lead a satisfying or happy life (Daniels, 1996, p. 185). Daniels felt that impairment of normal functioning through disease constitutes "a fundamental restriction on individual opportunity relative to the normal opportunity range" in that normal opportunity range is a crude measure of the importance of health care needs at the macro or societal level (ibid., p. 188). Daniels

claimed that “we ought to subsume health care under a principle of justice guaranteeing fair equality of opportunity” in describing his theory of distributive justice (ibid., p. 189).

Central to Daniels’ important focus on discrimination related to HIV/AIDS treatment policy is that discussion about the morality of providing ART to Africans who need it and the immorality of not providing it as a part of national resource allocation toward health care has been ongoing in regard to HIV/AIDS for years both in Africa and in external donor countries. For example, the Abuja Declaration, which emanated from the HIV/AIDS epidemic and was signed by some 50 African heads of state in 2001 pledging to allocate 15% of each country’s annual budget to the improvement of the health sector, was based on a number of factors in addition to the morality of the pledge (OAU, 2001, p. 5). The Declaration states:

> “We recognize that the epidemic of HIV/AIDS, Tuberculosis and Other Related Infectious Diseases constitute not only a major health crisis, but also an exceptional threat to Africa’s development, social cohesion, political stability, food security as well as the greatest global threat to the survival and life expectancy of African peoples” (ibid., p. 3).

Clearly, the African heads of state recognised the extreme impact the HIV/AIDS epidemic was having on their countries’ security, economies, and future stability, rather than taking the decision based on a moral imperative alone. Nonetheless, the Declaration also acknowledged the greater impact of the epidemic specifically on women, “We recognise that biologically, women and girls are particularly vulnerable to HIV infection. In addition, economic and social inequalities and traditionally accepted gender roles leave them in a subordinate position to men” (ibid., p. 2). The Declaration also prioritised mobilising

human, material, and financial resources to provide care and support and quality treatment to infected populations, and it called on donor countries to complement the resources allocated by African countries themselves to fight HIV/AIDS, TB and the related infectious diseases (ibid., pp. 5-6). In its various aspects, only a few of which are noted here, the Declaration focused on the principles of justice, the right to health care, and distributive justice via the request for contributions to health systems and treatment from countries with much greater financial resources than African countries. This request for financial resources from donor countries was essentially a request for the practice of cosmopolitanism by these countries (Pogge, 2002, p. 86). In recognising we are all one global community, a sense of responsibility was imposed on external donor countries by the Declaration to provide available aid where it is needed as a manifestation of justice. Cosmopolitanism essentially aims to balance a lack of equality and increase equity through wealthier countries recognising the equality of the citizens of impoverished countries and providing external aid. The globalisation of infectious disease, especially HIV, fits this paradigm centrally. Providing aid for treatment of African PLHIV and resources for the weak health systems in these countries is an aspect of practicing global justice to which the Abuja Declaration tipped its hat and for which a number of external donor countries should be commended for their support. Indeed, Daniels also pointed out the obligations to justice of each individual beyond that of nations, "all individuals have duties of justice to promote just institutions: this means professionals and their institutions," cementing this need within the healthcare system itself and those who profess to serve it (2009, p. 40). More specifically Daniels wrote, "I am inclined to apply that same approach to the relationship between social obligations to meet health needs and professional obligations of clinicians," bringing the obligation to practice justice by individual clinicians toward all the individuals they counsel, diagnose, and treat (ibid.).

According to Beauchamp and Childress, “justice is a group of norms for distributing benefits risks, and costs fairly” (2001, p. 12). In their examination of distributive justice and what it means, Beauchamp and Childress noted that egalitarian theories of justice related to health specify that persons should receive an equal distribution of health care, while not requiring an equal sharing of all possible resources (ibid., p. 233). Yet what an equal distribution of health care would consist of remains in question given the differences in health status and need for health care from person to person. Beauchamp and Childress also focused on justice through the operation of just procedures, such as fair play, rather than focusing on just outcomes through an equal distribution of resources (ibid., p. 232). This notion of justice also supports the just and fair implementation of HIV testing protocols so that everyone is treated equally, and no one is discriminated against through any action or treated unfairly in any way. Procedural justice also is linked to the need to respect each and every person’s autonomy to prevent unfair discrimination against particular persons based on a perceived lack of equality. Procedural justice also appropriately acknowledges that health care resources are limited, and it aims to use a just and fair process in establishing what the limits are—despite ongoing disagreements about what they should be.

In regard to justice, Michael Sandel has differentiated the “independent self” or “private identity” from the “public identity” of moral persons (2000, p. 323). He observed that the private identity of the independent self can change over time based on a person’s aims and attachments, yet in contrast, “our “public identity” is not affected by changes over time in our conceptions of the good” or what should constitute justice to other human beings (ibid.). In our public identity, according to Sandel, there should be no special aims,

attachments, loyalties, or allegiances; rather, the primacy of justice must prevail toward everyone (ibid.). Sandel has delineated what we owe to ourselves, or our friends or family members, as different from what we owe to each other as fellow human beings. One might view this contrast made by Sandel as similar to the difference between autonomy, what we owe to ourselves, and justice, what we owe to other human beings. Positioning his stance as "justice and community," Sandel posits that it is precisely because we cannot know each other or each person's ends or aims well enough "to govern by the common good alone" that we need justice (ibid., p. 324). In other words, because we are a community, we need justice as our guide. Yet Sandel does not call himself a communitarian. He argued that "principles of justice that derive their moral force from values commonly espoused or widely shared in a particular community or tradition" is the communitarian way of linking justice and the good, whereby the values of the community defines what it just or unjust (Sandel, 1998, p. x). However, Sandel holds that rather than rights resting on prevailing social values, which he sees as the communitarian view, "rights depend for their justification on the moral importance of the ends they serve" (ibid., p. xi). He believes both communitarians and liberals, such as Rawls, who believe that "certain individual rights are so important that even the general welfare cannot override them," avoid judging the "content of the ends that rights promote" (ibid., pp. x, xi). As his critique of those who criticise the priority of right, Sandel thinks that as individuals we can make sense of our moral and political obligations, that is, the ends we choose for ourselves and the ends we choose in regard to others, in wholly voluntarist terms (ibid., pp. 186-187). Moreover, to Sandel, the self is of primary importance: "As the self is prior to the aims it affirms, so a well-ordered society, defined by justice, is prior to the aims—communitarian or otherwise—its members may profess. This is the sense, both moral and epistemological, in which justice is the first virtue of social institutions" (ibid., p. 64).

To Sandel, it would seem, the paternal attitudes of health care providers deciding it is in the patient's best interest to test her for HIV whether she wants the test or not, or is even aware she has been tested specifically for HIV, do not promote or fulfill justice. And, as "justice is the first virtue of social institutions," according to Sandel, justice rather than paternalism is what social institutions should aim to practice (ibid.). Sandel's point of view that we do not know enough about each other and each other's aims to really know what the 'common good' is for each other is an interesting underlying premise that seems to support the essential need for the practice of human rights. Sandel also undermines the basic premise behind utilitarianism, that a morally good action is one that benefits or promotes the greatest good or happiness of the greatest number of people, when he writes that we do not really know what the common good is (ibid., p. 324; Merriam-Webster, 2013, p. 1). Moreover, Onora O'Neill in her book, *Bounds of Justice*, wrote that most contemporary utilitarians "argue energetically that paternalism and violations of rights do not maximise utility," supporting the increasing recognition and influence of human rights and the need to subvert paternalistic attitudes related to the provision of justice (2000, p. 33).

In considering distributive justice it is worth noting Robert Nozick's statement that "it is best to view some patterned principles of distributive justice as rough rules of thumb meant to approximate the general result of applying the principles of rectification of injustice" (1968, p. 231). Sandel also argued, "Where justice replaces injustice, other things being equal, the overall moral improvement is clear" (1998, p. 32). I believe there are a variety of problems inherent in making decisions about distributive justice, such as exactly what, to whom, who provides it, and who decides? Thus I find Nozick's

conception of it as “applying the principles of rectification of injustice” to be a more comfortable notion than some other descriptions of the aim of distributive justice (1968, p. 231). Nozick’s conception seems to be a recognition of the need to attempt to balance justice where injustice already is apparent or has occurred, rather than establishing some type of standard for justice when the whole system is unequal at the start regarding access to goods and services and indeed basic health. Distributive justice in health care is complicated by the inequalities in the health status of individuals and populations, the resource constraints of health care systems worldwide and especially in African countries, and that each and every human being has some health care needs. Thus it appears to be impossible to be objective about distributive justice related to health care.

In regard to HIV testing, if one goes back to the Beauchamp and Childress definition about the fair distribution of the benefits, risks, and costs, then there certainly are greater related risks and costs to individuals and groups who already are marginalised by society, which includes women and girls. The greatest benefit of HIV testing occurs, of course, to individuals who will have access to ART soon after testing HIV-positive and who will be able to adhere to the medication on a daily basis, which is questionable for many women. According to Onora O’Neill, “…we have no reason to think that principles of justice are relevant only to the action of individuals” (2000, p. 160). And, “We need in particular to be able to judge what specific institutions and action are needed if poor women in poor economies are to be accorded justice” (ibid., p. 159). O’Neill focused specifically on gender and justice when she wrote the following, which also resonates strongly in regard to the principle of informed consent as it relates to justice as well as autonomy:

> “Dissent becomes harder when capacities to act are less developed and more vulnerable, and when opportunities for independent action

> are restricted. Capacities to act are constrained both by lack of knowledge and abilities and by commitments to others. Institutional arrangements can disable agency both by limiting capacities to reason and act independently and by raising demands to meet the needs and satisfy the desires of others. Apparent 'consent' to such arrangements does not show they are just. Whenever 'consent' reflects ignorance, or lack of capacity or opportunity to do anything but 'consent', it does not legitimate. Thinking in this way about justice we can see that it demands more, not less, to be just to the vulnerable, who are easier to deceive and to victimize than the strong because their 'consent' is all too easily elicited. Yet both idealized and relativized accounts of justice tend to conceal the fact that justice to the weak demands more than justice to the strong. Idealized accounts of justice tend to ignore vulnerability and relativized accounts to legitimate it" (ibid., p. 163).

Taking into account the normality of the demands of others on women and their vulnerability to power structures, O'Neill has encapsulated in a beautifully articulated paragraph how intertwined are the needs and obligations of individuals and institutions for respecting autonomy, agency, and justice of women, especially in sub-Saharan African countries. When women are coerced or forced into routine testing for HIV, their rights clearly are overridden, and the obligations of individuals and institutions to respect their rights through the provision of services are ignored and maligned. Since the bioethical principles of beneficence and non-maleficence also arise surrounding this discussion of justice related to HIV testing, most prominently of women, these two principles will be examined in the following chapters.

CHAPTER 4: HIV TESTING AND BENEFICENCE

4.0 INTRODUCTION TO BENEFICENCE

> "…No qualities are more intitled to the general good-will and approbation of mankind than beneficence…nothing can bestow more merit on any human creature than the sentiment of benevolence in an eminent degree; and *that* a part, at least, of its merit arises from its tendency to promote the interests of our species, and bestow happiness on human society" (Hume, 1751, pp. 2, 4).

Eighteenth century philosopher David Hume considered 'beneficence,' which stems from the Latin, "bene," and "facere"—to do well—as a quality of human nature; and, he considered 'benevolence,' stemming from "bene" and "volens"—an intention to do well—as a principle of human nature (Norton, 1993, p. 179; *Encyclopedia of Bioethics*, p.1; *Stanford Encyclopedia of Philosophy*, 2014, p. 2). However, Hume did not believe that practicing benevolence should be impartial toward everyone in the way he felt justice requires (Penelhum, 2003, p. 250). Hume did not believe that beneficence is owed to mankind in general, but to one's family members, friends, or fellow citizens (ibid., p. 249). He believed that benevolence promotes the happiness of others and that acting from such a motive makes a person virtuous (Norton, 1993, pp. 161-162). Hume also felt that practicing a beneficent act expresses "the highest merit, which human nature is capable of attaining" (Hume, 1751, p. 1).

According to philosopher Onora O'Neill, many ethical traditions extol universal benevolence, including love for all mankind or a concern for all (1996, p. 195). Indeed, philosophers Cicero, Seneca and Kant conceived of beneficence as a duty, although

without a corresponding right (Frankena, 1982, p. 63). Roman philosopher Marcus Tullius Cicero wrote in his historically and ethically influential letter to his son, De Officiis ("On Duties" or "On Obligations"), in 44 B.C. in the last year of his life that "Beneficence needs to be trained by practice" (Cicero, 1887, p. 2). Cicero also wrote, "Duties of justice and benevolence to be preferred to those of prudence or wisdom," giving priority to the duties that focus more on actions toward others than on duties to the self (ibid., p. 3). However, many philosophers do not consider benevolence and beneficence as basic ethical principles or duties on par with justice as the basic structure of society and framework for social stability (Rawls, 1999a, p. 47; Rizzo, 2008, p. 883).

Beneficence is considered by many, including philosopher John Rawls, to be a supererogatory action, which O'Neill defines as "action that exceeds the demands of duty, yet is ethically admirable" (1996, p. 206; Rawls, 1999a, p. 94). She categorises beneficence as a social virtue that is practiced selectively and feasibly. As a social virtue, beneficence is not required to be practiced toward everyone in general or to a maximum amount, but to whom one wants to show "help, care, love, generosity, support or solidarity" (ibid., p. 195). Thus because beneficence is not required toward everyone, an act of beneficence is "unclaimable, unwaivable and unenforceable, and there will be no universal rights to others' virtuous action" (ibid.). O'Neill also noted that because social virtues such as beneficence arise due to special relationships to others and flourish within these relationships, they do not "replicate the structure or tasks of special duties of justice" (ibid., p. 196). Even dependent relationships that create special opportunities or special urgencies for specific forms of help, care, or concern remain imperfect obligations as opposed to justice, a perfect obligation with required action owed to all, claimed both O'Neill and Rawls (ibid., pp. 188, 196, 197; Rawls, 1999a, p. 301). O'Neill also noted,

however, that commitment to practicing the universal principles of justice is most effectively expressed by the specific institutions designed to limit risks of injury and "to secure and maintain basic capacities and capabilities for action for all" (l996, p. 191). Thus she further separated the practice of beneficence from the more fundamental need for all to practice justice.

4.1 HISTORY OF BENEFICENCE IN THE PROVISION OF MEDICAL CARE

Yet practicing beneficence is *expected* of medical providers rather than considering such actions they undertake as extraordinary or 'supererogatory'. The Hippocratic Oath (430 B.C.?), a compilation of ancient texts on the proper behavior of physicians and their relationship to their patients, includes the principle of beneficence: "Salus aegroti suprema lex," or "the well-being of the patient shall be the supreme law" (Martin, 2003, p. 182; Pappas, Kiriaze and Falagas, 2007, p. 347; Gaizler and Nyeky, 2011, p. 1). The Hippocratic Code (Corpus Hippocraticum), known more commonly as the 'Hippocratic Oath,' has guided the practice of Western Medicine for more than 2,000 years (Pappas, Kiriaze and Falagas, 2007, p. 348). According to bioethicists Beauchamp and Childress, health care providers' professional obligations and virtues have been seen as commitments to the practice of beneficence (2001, p. 176). Of interest is that the ancient thinking behind health care providers practicing the principle of beneficence may be appreciated more in the present day by Eastern European medical practitioners than by practitioners in many other countries. Beneficence is seen in Eastern European countries as the main principle of the Hippocratic Oath guiding the doctor-patient relationship as opposed to doing no harm to patients, the principle of non-maleficence, which shall be explicated in the following chapter (Gaizler and Nyeky, 2011, p. 1). While medical training in some countries may prioritise the primacy of the principle of non-maleficence over beneficence, O'Neill has

noted that many unknown health care workers live their lives "attentively devoted to caring for others across weary and difficult years" (1996, p. 207). Swiss physician Martin also tellingly noted that "salus should not be understood as only health, but also as safety (at worst, survival)" (2003, p. 182). Moreover, Beauchamp and Childress have pointed out that practicing beneficence means taking positive steps to help others, not merely refraining from harming them (2001, p. 165).

Beauchamp and Childress also discussed the bioethical conflict between a health care provider not interested in following a patient's wishes and wanting to make a contrary decision about a patient's care supposedly in the patient's best interest (ibid., p. 165). This example describes how respect for autonomy challenges paternalistic views by health care providers, which they may view as beneficence, about where the best interests of a patient may really lie. Beauchamp and Childress describe the conflict between respect for autonomy and 'professional beneficence' as a central problem in biomedical ethics (ibid., p. 176). I would argue that health care providers should keep in mind when making such decisions, however, Martin's salient point that health, safety, and survival must enter into the multi-layered equation for a health care provider as they naturally do in a patient's decision-making. This consideration is important even if the provider is not well acquainted with the patient's personal circumstances. Moreover, these three factors—health, safety, and survival—are at the center of individuals' routine-testing decisions. The context of such HIV testing and the patient's life and circumstances become central elements of the testing decision given the possible outcome of a diagnosis of a potentially deadly illness amidst a social environment dangerously rife with stigma and discrimination. The three elements also should be at the core of the understanding of

healthcare providers related to the decisions individuals make on whether to undergo routine testing for HIV or not.

Bioethicists Edmund Pellegrino and David Thomasma, rather than agreeing with Beauchamp and Childress that respect for patient autonomy and beneficence are in conflict with each other, noted that in some cases there can be a 'tension' between the values of patient welfare, or beneficence, and respect for persons, or patient autonomy (1987, p. 45). Yet they also focused on the importance of context:

> "There is also no way to define clearly what is absolutely best for the patient in medical terms alone. That definition is always related to the values the patient professes, those the institution and society assume, and those the culture holds to be important. Lacking any unequivocal definition of "benefit," the physician cannot presume to define the whole of the patient's good without essential input from the patient" (ibid., p. 38).

In fact Pellegrino and Thomasma proposed a model for medical decisions they called "beneficence in trust" (ibid.). One rationale for their model was that when a health care provider trains to be and then offers herself to another as a healer, implicit in this relationship is a sense of trust and a promise from the provider "to help and to act on behalf of the good of the patient" (ibid., p. 41). According to Pellegrino and Thomasma, "Medicine as a human activity is of necessity a form of beneficence" (ibid.). Moreover, they also focused on the unique situation of each patient—that each patient must be handled individually, not only for medical reasons but because of the moral implications of providing a healing service to fellow humans who are in a more vulnerable position than oneself and who potentially or really are suffering (ibid., pp. 41-42). Thus Pellegrino and

Thomasma clearly acknowledged the power differential between the health care provider and the patient. Noting that both autonomy and paternalism are superseded by a health care provider's obligation to act beneficently, Pellegrino and Thomasma also wrote that choosing between acting to foster autonomy or acting paternalistically should be based on what benefits the patient most, not on the provider's intellectual convictions or emotional impulses (ibid., p. 42). This sense of beneficence flies in the face of nurses who have coerced women to test for HIV 'because it's in their best interest'. When, according to Beauchamp and Childress and Pellegrino and Thomasma, "beneficence provides the primary goal and rationale of medicine and health," it seems impossible not to cite the importance of healthcare providers practicing beneficence in implementing routine HIV testing protocols by respecting a patient's autonomous decision on whether to test or not, abiding by the patient's decision, and not pretending that the test is mandatory or coercing the patient into testing because it supposedly is in her best interest (Beauchamp and Childress, 1994, p. 271; Pellegrino and Thomasma, 1987, pp. 41-42).

According to Kass and Gielen, beneficence requires the balancing of benefits and harms that may result from an action to determine whether or not, on balance, the action is beneficial (1998, p. 92). Health care providers generally do not know what all the individual harms may be to someone who tests HIV-positive. Yet they certainly know that HIV remains a highly stigmatised disease with possible negative repercussions directed toward individuals from spouses/partners, family members, colleagues, and community members. They also should realise that it may not be in the patient's best interest to test for HIV if no treatment for the disease is available if s/he tests positive, or possibly no treatment will be made available until the person has become very ill. It may be in the best interest of others if the patient tests HIV-positive and then refrains from having sex or uses

condoms every time she has sex so as not to transmit the virus. However, many African women are not in a position to refrain from having sex with their husbands or regular sex partners, nor can they negotiate condom use as this effort indicates they may be HIV-positive with potentially disastrous effects, including GBV, abandonment, or ejection from their homes (MacPherson, Richards, Namakhoma, et al., 2014, p. 6; Richardson, Collins, Kung, et al., 2014, p. 1). According to an editorial in *The Lancet* in 2006, "Moreover, most research indicates that testing alone has little or no effect on behavior. The crucial step is counselling and promotion of behavior change" (Lancet, 2006, p. 1118). Yet as discussed in previous chapters of this thesis, coercion by health care providers for patients to undergo routine testing for HIV remains a common practice in some clinical facilities in Africa, which is hardly a beneficent act.

According to Beauchamp and Childress, "rules of beneficence present positive requirements of action," rather than prohibitions of negative action, as will be explored later related to non-maleficence (1994, p. 262). They called this principle of beneficence 'positive beneficence' (Beauchamp and Childress, 2001, p. 175). They highlighted another principle of beneficence, which they called 'utility,' which "requires that agents balance benefits and drawbacks to produce the best overall results," more or less the same view as Kass and Gielen (1998, p. 92.). This approach of balancing benefits and drawbacks is the fundamental basis for the importance of respecting patient autonomy and for health care workers not assuming or patriarchally deciding that the community's best interest is paramount. Indeed, the concept of self-preservation will be investigated in the following chapter. Beauchamp and Childress also nodded to the concepts professed by Pellegrino and Thomasma in stating that "sometimes beneficence is viewed as incorporating the

patient's autonomous choices in the sense that the patient's preferences help to determine what counts as a medical benefit" (2001, p. 176).

Nonetheless, Beauchamp and Childress disagreed with their contemporaries Pellegrino and Thomasma and ancient medical ethicists on the real status of beneficence in medical practice, stating: "Neither the patient nor the physician has premier overriding authority, and no preeminent principle exists in biomedical ethics, not even the obligation to act in the patient's best interest" (ibid., p. 177). This seems to be a very broad statement to make even though Beauchamp and Childress say they believe it is consistent with beneficence being the primary goal and rationale of medicine and health care (ibid.). While, of course, there are limits to a health care provider being in the position to meet all the patient's best interests, I would argue that beneficence should be the primary goal of a health care provider—to help and to heal a patient, if needed, rather than simply not doing the patient any harm, which is the more common objective of the Hippocratic Oath in many countries nowadays. It almost seems that "salus aegroti suprema lex" simply has been forgotten in many countries, or at least in essence has been neglected. Or, perhaps the healing tradition described over the course of millennia by health care providers as their true calling has been overridden recently by other, more mundane vocational priorities—heightened professional and/or social status, long-term financial opportunities available through the practice of medicine, or disinterest in the time-consuming responsibilities involved in healing? Perhaps for many contemporary physicians, the calling to be "a healer" no longer exists. Some of these reasons likely were behind Pellegrino and Thomasma's bioethical undertaking of cementing beneficence as pre-eminent in the medical lexicon in the present day—as it indeed was in ancient times. They wrote,

> "Ultimately, the good of the patient depends as much on the

> physician's character as his capacity to make these judgments. Furthermore, it depends on the extent to which he can be trusted to keep the good of the patient as his primary aim" (1987, p. 4).

Moreover, Beauchamp and Childress went on to delimit the scope of beneficence in medical care, writing, "…the medical profession's role of beneficent care of patients is misconstrued if modeled primarily on philanthropy, altruism, and personal commitment" (1994, p. 270). This statement seems to belie the importance of any individual's calling to be a healer. Beauchamp and Childress further stated that instead of health care providers professing beliefs and personal endeavors of philanthropy, altruism, and commitment in medicine, their care of patients is rooted in reciprocity, that is, giving and receiving, which creates an obligation of beneficence to patients and to society—although what that specific obligation is was "difficult" for them to specify (ibid.). Nonetheless, they identified the obligation of beneficent treatment of a patient by a physician as due to the relationship of the patient and provider, also recognising that "the idea that beneficence expresses the primary obligation in health care is ancient" (ibid., pp. 270-271). Consequently, while Beauchamp and Childress show respect for the importance of beneficence in health care and a certain regard for its long-standing pre-eminence in the medical realm, they do not seem to give the same weight to beneficence as an integral and necessary character trait in health care providers as did Pellegrino and Thomasma. Rather, Beauchamp and Childress seem to focus on beneficence as a professional obligation to patients more aligned with being accountable as a service provider. Yet the sense of beneficence falling under the rubric of providing a service to their patients as a core bioethical principle of health care providers seems no different than an auto mechanic providing good service for a car due to the payment she will receive from the owner, which is also a professional obligation. Thus

this designation of beneficence by Beauchamp and Childress seems more akin to Rawls's focus on justice as a mutually agreed contractual obligation to other human beings rather than beneficence (Rawls, 1999a, pp. 46, 95). While Rawls saw beneficence as a supererogatory characteristic of individuals along with courage and mercy, he claimed that upholding justice was a positive natural duty (ibid., p. 94). He believed that the concept of benevolence was a "second-order notion" (ibid., p. 223). According to Rawls, the contract doctrine presupposes that all the parties to it are moral persons and rational individuals with "a capacity for a sense of justice," and that based on their equal dignity, "they are to be treated as the principles of justice require" (ibid., p. 289).

Philosopher Thomas Hobbes's *Leviathan* served as the classic source for what has developed into modern social contract theory, explicated by Rawls initially in 1958 and more recently by others (Hobbes, 2000, p. 63; Rawls, 1999a, pp. 306-308; Nagel, 2000, p. 296). Yet the approach used by Beauchamp and Childress in addressing beneficence as an obligation of health care providers to their patients is in essence what Hobbes called in 1651 "commutative justice," not beneficence (Hobbes, 2000, p. 72). Hobbes wrote that "commutative justice is the justice of a contractor—that is a performance of a covenant in buying and selling…exchanging…" (ibid.). In other words, to Hobbes commutative justice would be the appropriate term for health care providers giving their patients their due, that is, as service providers selling health services to the individuals who need these services. This reflection of Hobbes's notion of 'commutative justice' seems to be the forerunner of Beauchamp and Childress's description of beneficence as rooted in the reciprocal relationship of giving and receiving. However, I would argue that Beauchamp and Childress's denotation of beneficence as giving and receiving is a necessary, but insufficient condition for beneficence. It is difficult to determine from some of their

descriptions, aspects, or definitions of beneficence whether Beauchamp and Childress really endow the principle of beneficence with any real bioethical moral authority. While it can be difficult to separate moral principles from each other in a fully comprehensive and comprehensible way, I would argue that some of the explanations of beneficence related to health care by Beauchamp and Childress do not seem very satisfactory. As reviewed above, I would argue that one or more of their descriptions of beneficence veer into the realm of justice; thus I do not believe they have given beneficence its just due.

Historically, 40 years after Hobbes introduced the premise of a hypothetical contract among individuals across society as a means to respect and ensure the practice of justice, philosopher John Locke wrote in 1691 about what he called the "social compact" in *Two Treatises of Government* (1960, p. 108). Locke's social compact was "fair to everybody" and each person made the same sacrifices to have the same benefits through "consent"…"guaranteeing, defining and giving substance to everybody's freedom" (ibid.). Likewise, according to contemporary philosopher Thomas Nagel, Rawls's contract theory was based on "the fundamental attitude toward persons on which justice as fairness depends is a respect for their autonomy or freedom" (2000, p. 296). Thus it appears to me that the idea of contract theory or contract doctrine, which Hobbes, Locke, and Rawls used to conceptualise the requirement of justice or freedom for everyone in society has been extrapolated by Beauchamp and Childress to encompass the beneficent relationship between a health care provider and her patients. Although there is a similarity to the social contract in the provider-patient relationship, I would argue that this relationship loses the central core of what beneficence really is. Beneficence is not justice or freedom that is owed to everyone, or to all patients, it is care, and indeed the best care possible, which is owed to patients by health care providers. Thus to me beneficence falls into the realm of

what O'Neill and Rawls defined as a supererogatory obligation to all individuals in social relationships, that is, as a virtue but without a corresponding right held by all individuals (O'Neill, 1996, p. 137; Rawls, 1999a, pp. 94-95). For health care providers, however, beneficence in its fullest sense becomes a normative obligation owed to the individuals who are their patients. Importantly, Hippocrates wrote in *Of the Physician*, "A good physician avoids all measures that are not conducive to the welfare of the patient," (1846, p. 19). In other words, patients have a right to beneficent care from health care providers, not just the right to get care from health care providers, but the right to receive as good care as possible. This right also is aligned and consistent with the World Health Organization's Constitution adopted in 1946, which states, "The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social conditions," although WHO's Constitution relates more specifically to the obligations of nation states rather than individual healthcare providers (WHO, 1946, p. 1).

4.2 BENEFICENCE AND FEMINIST THEORY

Of relevance to beneficence and to an ethic of care is the recent emergence of feminists, such as psychologist Carol Gilligan and philosopher Virginia Held, who have emphasised, or over-emphasised in O'Neill's view, that women have a distinctive moral voice and vision and caring ethic that they believe encompasses the totality of morality (Gilligan, 1985, pp. 15, 17, 22, 26, 30, 34; O'Neill, 2000, p. 109; Held, 2006, pp. 88, 95). This is not a view for which I would argue as there would be no need for a special focus on the principle of beneficence in bioethics if care encompassed all moral principles. Moreover, that women have been historically and currently the main caregivers in the family and in society as a whole has been based at least partly on their biology—as the half of human

society capable of giving birth, feeding, and nurturing infants. The extension of women as the main caregivers in society across all age groups has not been because they are uniquely endowed with the moral characteristics integral to the ethic of care. The evolution of women's position in society is still ongoing via the thrust for equality due to their lower socio-economic status, especially in developing countries, and particularly in sub-Saharan Africa, where patriarchy continues to reign supreme in the social, economic, and most political spheres (MacPherson, Richards, Namakhoma, et al., 2014, pp. 5-6). Perhaps some might view a caregiver, a woman's traditional role, as the opposite of a warrior, a man's traditional role and desire to take advantage of women's traditional role as caregivers as the all-encompassing embodiment that subsumes all other roles, virtues, and moral planes? Yet as a woman I find women's subservient role in society as the group generally stuck with familial caregiving when elevated by some to the pre-eminence, or supreme law to use Hippocrates's phrase, of human morality to be ironic at best. This conception also is potentially exploitative in pigeon-holing women in their traditional box only as caregivers, rather than also as socially, economically, and politically productive human beings with equal status to men. What's more, every human being has the potential to care for other human beings and, when mature, to take good care of other human beings. To believe that only women possess such characteristics and capacities actually belies the equality of the sexes and the need for men to accept more responsibility as caregivers in many families and in society in general.

Some feminists have separated the ethics of care from care as it is conceptualised in virtue ethics. In virtue ethics, care is characterised by virtue ethicist Michael Slote as the primary virtue in a morality based on a motive of caring, which "can offer a general account of right and wrong action and political justice" (Held, 2006, p. 19). Yet some feminists claim

that virtue ethics focuses on the states of character of an individual, while the ethics of care is concerned with caring relations (ibid.). For example, feminist Virgina Held suggests that "Care is not the same as benevolence, in my view, since it is more the characterization of a social relation than the description of an individual disposition, and social relations are not reducible to individual states" (ibid., p. 42). Both of these accounts seem to elevate "care" to a position that sounds more god-like or saintly, or perhaps 'supererogatory', than someone simply undertaking a caring or beneficent act. Perhaps what is meant is an attitude, which would then encompass both the 'motive,' which is important to virtue ethics, and the relationship, which is important to the feminist ethics of care. Held goes on to state that "care involves moral considerations at least as important as those of justice" (ibid.). Yet she also thinks that she trumps Slote's concept of care because her definition requires the disposition to care, the ability to engage in care, and the exercise of care (ibid., p. 51). Thus perhaps Held was leading up to the steps involved in a caring act? However, Slote has "argued that the individual trait or virtue of (empathetic) caring is ethically more fundamental than caring relationships" (2007, p. 86). In this statement Slote has agreed with liberal feminist philosopher Martha Nussbaum, who wrote, "the flourishing of human beings taken one by one is both analytically and normatively prior to the flourishing of the state, or the nation or the religious group" (Nussbaum, 1999, p. 62). While Slote has recognised the differences some feminists have with his views on care, prioritising caring relationships over his motive, attitude, or virtue of care, he believes it is not necessary to decide between the two approaches to care (Slote, 2007, p. 118).

Thus what some feminist philosophers have added to the philosophical dialogue is the importance of taking into account groups and the positions of groups in the ethical equation. Feminist philosopher Susan Sherwin articulates this point of view as follows:

> "The types of questions feminists add to the moral agenda cannot be captured from within the moral and political resources of liberal individualism; they require a different type of moral and political framework…The questions that feminists raise involve more than violations of individual autonomy or failures of distributive justice among individuals in isolation…Feminists ask how different social groups are likely to be affected…We can only begin to explore strategies for eliminating the injustice represented by these group-based harms and benefits if we understand the fact that they are essentially group-based in their construction. Thus we need a moral and political ontology that recognizes the possibility of group-based harms and benefits even if we remain committed to the view that all harms ultimately attach to individuals" (2002, pp. 283, 285).

Feminist Held also interpolated this difference between individual and group rights, writing, "When justice is the guiding value, it requires that individual rights be respected. But when we are concerned with the relatedness that constitutes a social group and is needed to hold it together, we should look, I think, to care" (Held, 2004, p. 68).

4.3 BENEFICENT PRACTICE TOWARD INDIVIDUALS

In contrast to Held's views, I would agree more readily with Slote's stance regarding individuals and groups that "morality—both in the form of moral virtue and in the form of moral obligation or duty—centers around the empathetically caring concern to promote the welfare of other individuals or groups of individuals" (2007, p. 118). However, I would argue that in the social realm justice is more basic than care as an obligation to every individual human being and as the more fundamental conceptualisation of morality. It is

possible for individuals to be just to everyone, but not to provide individual care to everyone as this depends on individual circumstances and available resources. Thus I agree with Rawls that there is a "natural duty of justice," and that it is a "fundamental requirement for individuals" (Rawls, 1999a, p. 296). Slote insightfully wrote, "Our ordinary thought about the morality of individual action divides, by and large, into two main categories: moral issues about beneficence or helping others, and moral issues about deontology" (2007, p. 36). Since deontology is "the theory or study of duty or moral obligation: the ethics of duty," according to Webster's Dictionary, or "duty-based ethics", I would classify justice as a duty, both to individuals and to groups (*Webster's New International Dictionary*, 1966, p. 603; Kay, 2014, p. 2). But I would argue that care or beneficence is a choice one makes as to whether to give it to other individual human beings—except in the case of health care practitioners when beneficence toward patients is a duty. Moreover, according to Moodley, "all doctors have a responsibility to provide beneficial treatment" (2011, p. 57). This thinking also is consistent with rights-based theory. According to philosopher Ronald Dworkin,

> "Right-based and duty-based theories…place the individual at the center, and take his decision or conduct as of fundamental importance. Right-based theories are…concerned with the independence rather than the conformity of individual action. They presuppose and protect the value of individual thought and choice" (1977, p. 172).

As well as valuing the choice of individuals, Dworkin also emphasised the importance of concern and respect, which I would argue are aligned with care but are not encompassed or superseded by care. Dworkin also wrote,

> "…justice as fairness rests on the assumption of a natural right of

> all men and women to equality of concern and respect, a right they possess not by virtue of birth or characteristic or merit or excellence but simply as human beings with the capacity to make plans and give justice" (ibid., p. 182).

What Dworkin is famous for, though, is his notion of individual rights as trumps:

> "Individual rights are political trumps held by individuals. Individuals have rights when, for some reason, a collective goal is not a sufficient justification for denying them what they wish, as individuals, to have or to do, or not a sufficient justification for imposing some loss or injury upon them" (ibid., p. xi).

This important contemporary philosophical and human rights paradigm by Dworkin prioritising individual rights reflects the stance for which I am arguing in this thesis related to the routine HIV testing of women and girls in sub-Saharan Africa. But, I would argue, it also encompasses the routine HIV testing of anyone anywhere. The collective goal of testing people for HIV supposedly to stem the epidemic does not justify routine testing as beneficent treatment of individuals. The procedure does not in many cases provide them with an opportunity for real choice. And, as mentioned earlier, just testing people for HIV will not have an impact on new infections and the epidemic as a whole without treatment provision for individuals who test positive. Treating the individuals who test positive and providing them with access to ART soon after they test HIV-positive would be beneficent treatment (Kavanagh, Cohn, Mabote, et al., 2015, p. 1). It also would help prevent further spread of HIV. But I also believe it is a duty of justice to make ART available to individuals testing HIV-positive if routine testing is the testing protocol implemented. I believe routine testing should not be implemented where there is no linkage to the

provision of ART, including not "offering" routine testing where only single-dose nevirapine is available to help prevent mother-to-child transmission of HIV. For example, the prevention of HIV transmission from mothers to their infants is of limited value if the mothers die while the children are very young, leaving them without anyone to care for them (Alcorn, 2014, p. 1). Moreover, maternal mortality based on HIV infection can predict child mortality (ibid.). Also, the threat of drug resistance is growing. A recent study in South Africa showed a high prevalence of resistance to ARVs among infants newly diagnosed with HIV, with 57% of the infants who had undergone PMTCT resistant to the category of drugs that includes nevirapine, non-nucleoside reverse transcriptase inhibitors (NNRTIs), which is still the most commonly used drug for PMTCT in sub-Saharan Africa (Carter, 2014, p. 1). Drug-resistance means that microorganisms causing infection have become resistant to the medication(s) used to treat the infection, rendering the drug(s) ineffective. Thus the use of these drugs does no good, and the use of them also can spread drug-resistant virus in the case of HIV. Even so despite these issues, it remains up to each individual to decide whether she wants to access ART if testing HIV-positive and indeed decides she wants to get tested in the first place if routine testing is offered, whether or not she is pregnant. The issues surrounding self-preservation will be explored in the following chapter in relation to the principle of non-maleficence.

Philosopher Anthony Price argues that choice is the same as practical judgement and identifies the origin of such intended reasoning with Aristotle's *Nicomachean Ethics*, writing that "we make a choice to take or avoid something, but form an opinion about what it is, or in what way it is beneficial; choice is commended for having the right object" (2005, p. 265). Thus a beneficent action, whether it will be beneficial to ourselves or to another person, involves reasoning and choosing whether to take a certain action. Price

describes his view of beneficent choice in conjunction with philosopher Sarah Broadie's explanation of Aristotle's stance on the practical judgement of health care practitioners: "all ultimately aim to produce or preserve what everyone values and refers to as 'health', but the end which figures in the premises of medical deliberation differs with experts of different caliber or different training" (ibid., pp. 264, 267). What is in contention here is what Aristotle called "what is best" for the patient; and, Broadie noted that different practitioners can have different visions and goals for 'what is best' for the patient, depending on the practitioner's background, training, and experience (ibid., p. 267).

Philosophers Keld Thorgaard and Uffe Juul Jensen also have noted the importance of each individual patient to Aristotle in his *Nicomachean Ethics*; that each patient deserves special treatment or what can be called beneficent treatment, "the physician treats the patients 'one by one' and his responsibility is to the health of the individual patient" (2011, p. 5). This statement is consistent with the rights of the individual and that each patient has specific traits and particular circumstances that need to be taken into account in making beneficent choices (ibid., pp. 3, 5). Thorgaard and Jensen also stressed the important claim by clinician and medical ethicist Alvan Feinstein in 1994 not only of the importance of patient autonomy, but the inclusion in decision-making of the patient's judgment on what she feels is the end goal of beneficent treatment (ibid., p. 3). According to Feinstein, they noted, patients "are the only persons who can suitably observe, evaluate, and rate their own quality of life and the important features of their own health status" yet, "patients have seldom been asked or allowed to indicate their own values and beliefs" (ibid.). Thorgaard and Jensen also saluted the importance of clinician and ethicist Henrik R. Wulff and medical researcher Peter C. Gotzsche's emphasis in clinical decision-making on uniting

humanistic and ethical components, “from an understanding of the patient as a fellow human being” (ibid., p. 2).

The thinking outlined above by Thorgaard and Jensen, Feinstein, Wulff and Gotzsche supports health care providers including an analysis of the individual patient’s needs; a knowledge and understanding of the context; and, a recognition of the patient’s equality with oneself not only in decision-making about treatment, but in discussing any health-related decision. I would posit that the patient’s medical and social history also must be considered as part of the patient’s needs and context, which could have an impact on the patient’s HIV and health status. All of these elements feed into—or should feed into—decision-making on routine testing. Health care providers should realise and not neglect the importance of these factors in decision-making. Without such understanding of the various influential factors, it seems unlikely, if not impossible, that anyone could grasp what a beneficent decision would be regarding another person, including a patient. Moreover, as noted by Feinstein and Thorgaard and Jensen, the patient should have confidence in the health care provider’s choices regarding the patient, or in the comprehensive laying out of the choices to the patient, with the underlying assumption of receiving beneficent care (ibid., p. 3). Having such confidence goes hand-in-hand with the notion that the patient believes she will be receiving beneficent care; that the health care provider will be looking out for her best interests; that the provider will consult with her when a choice needs to be made; and, if appropriate, that the health care provider may make a recommendation about the best possible choice to make. However, the choice should be the patient’s decision when the patient is competent, rather than coerced, or potentially be considered an example of a decision actually made by the provider in a paternalistic way. As, according to Feinstein, only individuals themselves “can suitably

observe, evaluate and rate their own health status," meaning patients are in the best position to judge what is best for themselves in health care (ibid., p. 8). The focus here, obviously, on what is best for the patient rather than what may seem to be best for the community.

In Hume's conception of virtue, he considered the two qualities most useful in other people as benevolence and justice, yet he considered the qualities most useful to ourselves to be different (Russell, 2013, p. 99). The qualities Hume considered most useful to ourselves will be explored in the next chapter. Bioethicist Justin Oakley believes that "Medical beneficence qualifies as a virtue because it focuses doctors on their patients' interests and blocks inclinations towards the unnecessary interventions of defensive medicine" (2013, p. 205). Unnecessary testing is one aspect of "defensive medicine", or the anxiety about possible malpractice lawsuits, which can be practiced by physicians or other health care providers. I would argue that routine HIV testing of everyone presenting for healthcare, the HIV testing protocol used in some countries nowadays as mentioned earlier, can be considered as defensive medicine or perhaps more appropriately as defensive public health. Where and when HIV testing is not warranted, it is not beneficent unless it is done expressly at the patient's wishes or is initiated by the patient in the case of a request for voluntary testing. Oakley also noted that virtue ethicists have done little work on various questions of justice in healthcare, including the ethical concerns that have been raised surrounding infectious diseases and emerging pandemics, which is one of the bioethical principles this thesis is attempting to address along with beneficence and the other ethical principles (ibid., p. 215).

4.4 BENEFICENCE AS A VIRTUE

Philosopher and theologian Thomas Aquinas called the virtue of doing good "beneficentia" (MacIntyre, 1999, p. 121). And virtue ethicist Alasdair MacIntyre discussed how Aquinas described how a single action of doing good, a beneficent action, may also encompass other virtues, such as the virtue of charity, the virtue of taking pity, or the virtue of justice (ibid.). However, Aquinas separated the virtue of justice into different parts, stating that giving someone what is owed to them is strict justice, not a manifestation of the virtue of justice (ibid.). To Aquinas the beneficent individual gives more than what justice requires or is owed to another human being; beneficence can even be a case of how helping to relieve another's distress relieves one's own distress (ibid.). Thus, beneficent actions can serve more than one purpose. Surely many healthcare providers practice beneficence in this way, in which relieving a patient's ills relieves the provider's distress. Also, vice versa, a provider may be distressed by her inability to relieve a patient's illness. MacIntyre suggested, following Aquinas, that one action can be just, generous, beneficent, and indeed stem from pity all at the same time; however, individuals need to be educated to form this understanding of beneficence in its various manifestations (ibid.). One wonders whether many healthcare providers in countries where medical education does not priortise "salus aegroti suprema lex" are trained in the provision of any form of beneficence, much less how a beneficent action they may perform toward a patient can also be a virtuous action encompassing other virtues?

MacIntyre also described how distributions of power can play out through acts of beneficence, that is, on the parts of both the giver and the receiver as, he noted, was recognised by many other thinkers, including Foucault, Augustine, Hobbes, and Marx (ibid., p. 102). He highlighted how "institutionalised networks of giving and receiving" can both mask and protect positions of power in which "victimisation and exploitation"

can be part and parcel of participation in such networks (ibid.). MacIntyre also advised that "in our lives we have to learn how to live both with and against realities of power" (ibid.). This advice is germane for all healthcare providers and is especially resonant regarding routine HIV testing where positions of power can undermine justice, beneficence, and other virtues. Respecting autonomy through the implementation of the informed consent process, rendering justice, and providing beneficent treatment through using complete protocols for HIV testing and making referrals for treatment or follow-up care and support is aligned with MacIntyre's view that the best is "when a distribution of power has been achieved which allows power to serve the ends to which rules of giving and receiving are directed" (ibid., p. 103).

In discussing beneficence and benevolence ethicist Simon Robinson has pointed out that "empathy is closely connected to the virtue of benevolence" (2008, p. 116). Empathy with one's patient seems essential to providing good healthcare, the ability to identify what the patient is undergoing, enduring, or suffering from, to walk in the shoes of the patient. I would argue that empathy is also needed as a part of the process of benevolent decision-making. Robinson describes empathy as "the capacity to hear and understand underlying feelings" (ibid., pp. 116-117). Empathy is a quality essential to the counselling process and, according to psychologist and HIV/AIDS counsellor Alta van Dyk, "empathy should be used in all phases of the counselling process" (2008, p. 235). Empathy should be involved in any discussions between patient and provider related to HIV testing if the patient has not volunteered for HIV testing and wants to discuss her particular situation and potential fears of the test or the test result. In HIV testing it also is essential to notify the patient in advance of the benefits and potential harms of such testing, including its clinical benefits and risks such as discrimination or abandonment, according to the

guidelines of the WHO (2010c, p. 10). Moreover, according to the WHO's protocol for routine testing, the client or patient must be given an opportunity to ask questions in the pre-test information session that is required to be provided by the healthcare practitioner or counsellor (ibid.). Robinson also has noted how practicing empathy enables healthcare providers to be aware of and accept their own limitations as a professional and as a person and also to be conscious of not taking a paternalistic attitude toward the patient by imposing their own needs on the relationship (2008, p. 117). As mentioned earlier, urging patients to test for HIV to reach testing quotas obviously would be paternalistic and defy the practice of empathy. Also noted by Robinson is that while empathy is essential to the caring and counselling professions, it is not unique to these professions, thus supporting empathy and beneficence as what he calls a 'transferable' virtue (ibid.).

Robinson also noted that empathy is "a foundation of spiritual awareness," which recalls the Hippocratic focus on the healer having spiritual powers (ibid.). For, according to Hippocrates, the healer "dare not ascribe to his art unqualified power, when he reflects on its frequent failures; even when success attends, it is to Heaven alone he owes it" (Hippocrates, 1846, p. 6). This quote is included not to imply that all healing is God's work, but that there is a spiritual side to healing, which may be diminishing in importance among contemporary health care providers. For example, Robinson has identified the key importance of virtues in the practice of care, as follows:

> "Virtues are necessary for the delivery of professional care, including spiritual care and the capacity to respond ethically. On the other hand, virtues also involve the spiritual needs of the carer. Carers need a sense of unconditional acceptance, a work context that they can put their faith in and which gives

> the space to work through their life meaning, the development of hope and so on….The generation of hope thus demands that the truth be arrived at through empathy, with all its ambiguities and limitations" (2008, pp. 125, 145).

This passage suggests how important it is to carers to practice beneficence to maintain the spiritual side of their profession involved in healing, that not being true to patients also means not being true to oneself. To pretend to patients that HIV testing is standard operating procedure without any caring attached to it, and without acknowledging the needs for beneficence in its implementation, prevents the healthcare provider from delivering this health service in the way it is supposed to be done, which also is a manifestation of taking the first step toward the power to heal.

In considering the beneficent treatment of women in healthcare, it is essential to realise that women as individuals and as a group need consideration, as described earlier. They individually and as a group may be subject to neglect, coercion, and/or abuse, which may play out in healthcare situations. Pregnant women may be considered as the most vulnerable of women, both individually and as a group. Not realising the contextual needs of women, including individual pregnant women, who are asked to undergo routine testing is negligent. Talking them into testing for HIV when they would prefer not to is indeed coercive. And, lying to them that routine testing is actually mandatory for pregnant women—or for any woman—is abusive of their inferior position of power in the healthcare realm. Yet in medical ethics, beneficence means "the active promotion of goodness, kindness and charity" (Moodley, 2011, p. 57). And, in Roman law, beneficence meant a "right," which is resonant with its importance in healthcare to Hippocrates and implies more than just a contractual relationship (ibid., p. 203). What's more, the World

Health Organization has focused on the Universal Declaration of Human Rights in regard to HIV testing, stating, "…governments are also responsible for ensuring that HIV testing, like all other essential health services, is not offered, recommended or provided in a way that discriminates against any person or group of people" (2010c, p. 10). And, according to the WHO, "Governments must do all they can to prevent such human rights violations, both for the protection of the individual and the effectiveness of the national response to HIV" (ibid.). Thus the WHO supports pro-active beneficent action by governments to prevent human rights violations related to HIV testing—not simply that governments must prosecute human rights violations after they are committed. Indeed, the WHO supports prevention of human rights violations toward individuals occurring from HIV testing as well as toward groups, recognising that HIV policies and programmes must be rights-based to succeed. And, I would argue, HIV testing programmes should prioritise the practice of beneficence in the implementation of the testing protocols, especially toward women and girls, who are the most vulnerable in the power structure embedded in the provider-patient relationship. The following chapter will develop this need further, focusing on the principle of non-maleficence.

CHAPTER 5: HIV TESTING AND NON-MALEFICENCE

5.0 THE EMEGENCE OF NON-MALEFICENCE

> "The physician must be able to tell the antecedents, know the present, and foretell the future--must mediate these things, and have two special objects in view with regard to disease, namely, to do good or to do no harm" (Hippocrates, 1868, pp. 8-9).

The quote, above, from *Of the Epidemics* written by Hippocrates circa 400 B.C. is what some believe to be the source for physicians of the admonition, "Primum non nocere" or "First do no harm," which is the bioethical principle of non-maleficence (*McGraw-Hill Concise Dictionary of Modern Medicine*, 2002). "First do no harm" is commonly attributed to text included in "The Oath" of Hippocrates, although some say this is an erroneous attribution as the quote actually originated in his treatise on epidemic diseases (1868, pp. 8-9). The Hippocratic Oath does state, however, that "…for the benefit of the sick…I will keep them from harm and injustice," or according to the von Staden translation, "But from (what is) to their harm or injustice I will keep (them)" (Miles, 2004, p. ii). For more than 2,000 years through history, physicians and health care practitioners have designated their basic duty in the practicing of their profession as to do no harm to the patient. Perhaps not coincidentally, about 20 years before Hippocrates wrote *Of the Epidemics*, Plato wrote in 380 B.C. in a dialogue in the *Republic*, through which he had Socrates explaining his treatise on justice, "We have shown that it is never just to harm anyone" (2000, p. 25). It is plausible that years later Hippocrates may have been consciously adapting Plato's focus on not doing anyone harm as a principle of justice to his own principle on the just practice health care practitioners should direct toward their patients.

5.0.1 Mill and the Harm Principle

Yet what is known as the 'harm principle' in philosophy and bioethics is commonly attributed to philosopher John Stuart Mill based on his statement in his book, *On Liberty*, originally published in 1859, "…the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others" (1999, p.6). Thus the 'harm principle' is a principle that originated in antiquity regarding medical care, yet it is used more widely today as a principle related to individual freedom and justice far more broadly. What is especially germane to both one's own health care and the health care of others and even to making one's own decision about HIV testing is that Mill went on to write in *On Liberty*,

> "The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute. Over himself, over his own body and mind, the individual is sovereign" (ibid.).

Mill did not write that decisions about our bodies and minds should depend on what may affect others. He focused his statement on the central premise that one's body is one's own property, and we are not to base our decisions about what to do or not to do with our bodies on the feelings or priorities—or even the health—of others. This is the central premise of a woman's right to her own reproductive health decisions, even though this right is hotly debated today in many cultures, religions, and countries. It also is the premise behind self-efficacy and health-seeking behavior, which is of central importance to both individual and public health. Mill went on to say in the same essay,

> "Each is the proper guardian of his own health, whether bodily,

> or mental or spiritual. Mankind are greater gainers by suffering each other to live as seems good to themselves, than by compelling each to live as seems good to the rest" (ibid., p. 8).

In this statement, Mill not only points out how important it is for the individual to maintain control over his or her body, but that mankind as a whole benefits from each person being the "proper guardian" of their own health. He also centers decision-making about health matters in the individual, rather than taking a 'public health approach' that many today consider to be the overriding focus.

Yet, ironically, Mill seems to have been especially prescient regarding the circumstances of present society when he wrote in the same treatise,

> "…There is also in the world at large an increasing inclination to stretch unduly the powers of society over the individual, both by the force of opinion and even by that of legislation: and as the tendency of all the changes taking place in the world is to strengthen society, and diminish the power of the individual, this encroachment is not one of the evils which tend spontaneously to disappear, but, on the contrary, to grow more and more formidable" (ibid.).

Mill might have been writing specifically about the argument between public health versus individual health and the right of society trumping the right of the individual. Yet he was not. He was really writing about the liberty of the individual and individual thought and decisions in a more profound way beyond just focusing on health. Mill made the reader realise he was identifying and describing a broader paradigm when he wrote at the end of his "Chapter 1, Introductory" chapter in *On Liberty*, "Those grounds, when rightly

understood, are of a much wider application than to only one division of the subject…" (ibid., p. 9). Thus he understood that some might find his writing narrowly focused on one subject or another, while he was really taking an all-encompassing stance on individual liberty and the rights of individuals.

Mill went on to write in Chapter 4 of *On Liberty*, "…with respect to his own feelings and circumstances, the most ordinary man or woman has means of knowledge immeasurably surpassing those that can be possessed by any one [sic] else" (ibid., p. 2). In his understanding of individuals and his support for their right to their own decision-making about themselves, Mill also may have been alluding to their right to informed consent in such decision-making. Or, one would think that he certainly would agree with the right to informed consent of individuals regarding their health care. But what Mill is substantially known for regarding individuals and health care is indeed the "harm principle," which supports the right of individuals to make their own health-care decisions if they will not harm anyone else. And, he also supports the need for health care providers not to harm individuals. I posit that Mill also meant that health care practitioners should not harm any individuals in the name of 'public health,' because that would deny them the freedom of choice and thus their liberty, as well as inflict potential harm on them.

Importantly Mill also noted in *On Liberty*, the duty one has to oneself:

> "The term duty to oneself, when it means anything more than prudence, means self-respect or self-development; and for none of these is any one accountable to his fellow-creatures, because for none of them is it for the good of mankind that he be held accountable to them" (ibid., p. 4).

Mill was writing not only on the importance of individual freedom, but also on the importance of individuals to exercise that freedom. Concurrent with supporting each individual to demand respect from others, Mill, in emphasising self-respect, also called on individuals to care for themselves and to develop themselves. He set the locus of accountability for doing so on oneself. Thus Mill saw self-development and self-care as a personal responsibility. However, Mill did not see self-development as benefiting only the self; he acknowledged that others can benefit from individuals' self-development. In Chapter 3 of *On Liberty*, he wrote, "In proportion to the development of his individuality, each person becomes more valuable to himself, and is therefore capable of being more valuable to others" (ibid., p. 7). Consequently, in stating his views on individual freedom, Mill was not neglecting the needs of society, but noting that what benefits individuals also can benefit the larger society. This recognition of the overall social value emanating from protecting individuals is similar to that of Warren and Brandeis, who both subsequently became justices in the United States Supreme Court, in writing in the *Harvard Law Review* in the U.S., some thirty years later than Mill in 1890, that "…the protection of society must come mainly through a recognition of the rights of the individual" (1890, p**.** 11). While Warren and Brandeis were writing primarily about the right to privacy, their stance is essentially the same as that of Mill in his writing about individual freedom; that is, the individual has a right to freedom and the freedom to protect or maintain her or his individual privacy. Such a right to privacy also relates to the right to confidentiality regarding one's own health information.

5.0.2 Non-Maleficence and Individual Freedom

The importance of individual freedom and the individual freedom and privacy to make one's own decisions, including private decisions, is also entwined with philosopher

Immanuel Kant's notion of autonomy. According to Mary Gregor's translation of Kant's *Groundwork of the Metaphysics of Morals*, which he wrote in 1785, Kant's conception of individuals is that we are self-governing and, because of this, we are autonomous moral beings (Gregor, 1998, p. xxix). Gregor also noted that respecting a person as a rational being, which is central to Kant's philosophy, means that we must respect her right to make her own decisions about her own life and her own actions (ibid., p. xvii). Of course, this perspective also encompasses respecting her right to decide whether to be tested for HIV—or not. What Kant also is known for in his *Groundwork*, however, is "the concept of necessary duty to oneself" (Kant, 1964, p. 91). Perhaps his most well-known statement in the *Groundwork* is the following:

> "Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end" (ibid.).

In this passage, Kant is not only supporting the primacy of the self, but also the need to respect other persons as one respects oneself, and to see them as autonomous beings who are not to be used simply as a means to further one's own goals or treated as objects to which one acts for or against. Kant's approach to the treatment of other human beings also can be stretched to embrace HIV testing: individuals should not be tested for HIV simply because health care providers wish to know if they are infected with the virus just to try to prevent others from being infected, but only if each individual will benefit from the test result herself—after deciding if she wants to be tested for HIV—through the provision of same-day antiretroviral therapy (ART), if needed and available, or through a referral for it, and through access to the available means of prevention of HIV transmission. This stance and upshot seems to be aligned with Kant's thinking in the following passage from the *Groundwork*:

> "For the man whom I seek to use for my own purposes by such promise cannot possibly agree with my way of behaving to him, and so cannot himself share the end of the action" (ibid., p. 92).

And,

> "For then it is manifest that a violator of the rights of man intends to use the person of others merely as a means without taking into consideration that, as rational beings, they ought always at the same time to be rated as ends—that is, only as beings who must themselves be able to share in the end of the very same action" (ibid.).

That Kant would have difficulty agreeing with the focus of public health workers on testing as many people for HIV as possible, and not necessarily through an informed consent process, with the hope to subvert new infections without making treatment available to all who test HIV-positive seems undeniable based on his writing. Kant went on in the *Groundwork* to further explicate the duty one has to oneself: "…in regard to contingent (meritorious) duty to oneself, it is not enough that an action should refrain from conflicting with humanity in our own person as an end in itself: it must also *harmonise* with this end" (ibid.). Thus Kant was explaining that individuals have a positive duty to respect themselves and to behave and act with their own self-respect highest in their mind—at the same time they do not behave or act in such a way as to disrespect others. Consequently, like Mill in the century that followed, Kant believed that the duty to respect the self precedes the duty to respect others, yet it should not preclude respecting others. Kant seems to be describing the need that each one of us has, or should have, to balance our own needs with the needs of others in developing ourselves and in 'living a good life.' Yet this is no more a need of every individual than it is also a need of each and every

health care provider. This brings us back to the importance of autonomy to Kant, who wrote in the *Groundwork,* "Autonomy is therefore the ground of the dignity of human nature and of every rational nature" (ibid., p. 97). He also wrote in the *Groundwork* relevant to this argument, "the above principle of autonomy is the sole principle of ethics" that is, respecting oneself and respecting others is the fundamental approach we should take to our own behavior and our behavior toward others (ibid., p. 102). That Kant's expectation is as relevant for health care providers as it is for others underlies this argument related to Kant's principle of respect for autonomy in that human beings are an end in themselves and not a means for testing anyone for HIV, whether we are deciding to test ourselves or whether we are involved in testing others. Moreover, South Africa's "Patient's Rights Charter," which underscores patients' right to dignity, guarantees each person "the right to participate in decision-making on matters affecting one's health" (Department of Health (DOH), 1996, p. 3). The Charter also pertains to HIV testing as it states, "A person may refuse treatment and such refusal shall be verbal or in writing provided that such refusal does not endanger the health of others" (ibid., p. 11). And, the Charter also supports a focus on care of the self: the first responsibility of every patient or client is "to take care of his or her health" (ibid., p. 16). Thus the South African Patients' Rights Charter is aligned with Kant's dictum of respecting oneself and others and the duty of caring for oneself as fundamental ethical principles. In the laying out of the rights and responsibilities related to individuals and health care, the Charter also is aligned with Mill's 'harm principle' and the bioethical principle of non-maleficence—to do no harm.

5.1 NON-MALEFICENCE AND SELF-PRESERVATION

Writing in the 1700s, Philosopher Jean-Jacques Rousseau also focused on the moral development of the individual, through what he called "*amour de soi*," or love of the self

(Grimsley, 1973, pp. 54-55). Rousseau claimed that man's *amour de soi* was his most primordial characteristic (ibid., p. 55). To Rousseau, the fundamental urge of man is the basic impulse of self-preservation, the will to survive (ibid., p. 33). He also called *amour de soi* the only passion that is natural to man (ibid., p. 46). Hence to Rousseau, in his pedagogical treatise and novel entitled *Emile*, in which he described his views on the human condition, self-preservation is the first and foremost instinct that any of us have; it is basic to human nature and natural law that our fundamental desire is to continue our existence (O'Hagan 2003, pp. 22, 59; Grimsley, 1973, p. 44). Moreover, Rousseau considered self-preservation, or *amour de soi*, to be one of the four basic elements of human nature, along with freedom, compassion, and perfectibility (O'Hagan, 2003, p. 22). Rousseau's special focus on self-preservation is a basic feeling with which it is likely every person can identify—that our most fundamental urge is the will to survive. It is the stuff of which military medals are made; that is, medals are bestowed on those who endanger their existence, who test their survival, who risk their lives. It is the highest stake anyone can bet, and we honor individuals who have jeopardised their own lives to save the lives of others or to help save their countries. While Rousseau considered our will to survive as part of our animal nature, he separated human beings from animals in that humans also make decisions on a higher plane than mere survival (Clarke, 2003, p. 120). Human beings reflect on what is likely to be beneficial or harmful to them, according to Rousseau, and make decisions based on the aspects they see in any situation or action (ibid.). Again, we see in Rousseau the principle of harm and the potential for harm to the self as the field of engagement for decision-making.

In recognising that humans have more sophisticated mind/body characteristics than other animals, Rousseau also noted that the will to survive has no inherent moral quality

(Grimsley, 1973, p. 55). It is when encountering other human beings, according to Rousseau, that morality comes into play (ibid.). However, some contemporary philosophers (and this author) believe morality also concerns human beings' treatment of animals, not only how we treat each other, as well as the necessary conservation of natural resources, which in contrast with Rousseau's philosophy is presently considered to be interlinked to the survivability of human beings and animals (and plants).

What in bioethics is now called empathy, or the identification with another, commonly referred to as 'walking in the shoes' of another, is what Rousseau termed to be the 'pity' we feel in identifying with a 'suffering creature' (ibid., p. 57). While Rousseau saw pity as characteristic of "an expansive soul," he stated that there are other elements in the self beyond pity, which form the basis of morality (ibid.). Rousseau went on in *Emile* to describe the importance of conscience and reason to guide human action and endeavor and that these two human characteristics support each other (ibid., p. 67). Yet, Rousseau, too, like a number of other philosophers discussed in this paper, emphasised the importance of the "freedom to choose" in pursuit of the good, beyond survival, and that our bodies and senses play a key role in such pursuits (ibid.).

In the development of his theory on *amour de soi,* Rousseau explicated that in its highest form, it is no longer just an impulse toward survival in human beings, but that it embraces various other aspects of our existence (ibid., p. 68). In fact, Rousseau equated *amour de soi* in its highest form as the 'love of the soul' (ibid., pp. 68-69). He stated in *Emile:*

> "But when the force of an expansive soul makes me identify
> myself with my neighbor, and I feel my own self, so to speak,
> in him, then it is in order not to suffer myself that I want him

> not to suffer. I am interested in him out of love for myself, and the reason for the precept is in nature itself which inspires in me the desire for my own well-being in whatever place I feel myself to exist. From this I conclude that it is not true that the precepts of natural law are founded on reason alone. They have a base more solid and sure. Love of men derived from love of self is the principle of human justice" (Rousseau, 1762, IV. 523. Fn /235. Fn, O'Hagan, 2003, p. 129).

I wonder if anyone could possibly disagree with this passage as a description fundamental to morality, if not a description of every aspect of morality. As, according to Rousseau, when we see ourselves mirrored in other human beings, we understand and practice justice toward them as we do (or should do) to ourselves.

Likewise, I would posit that it is so common for women to see their calling as caring for others rather than themselves that it is important for women to be raised to care for themselves as a being of primary importance. I also believe that African society traditionally views African women as second-class citizens (as I have explicated earlier in this paper), which is still playing out in 2015 in the inequitable and sometimes forced HIV testing of women, and particularly pregnant women, in sub-Saharan African countries. I do not believe that Rousseau would view this practice as just, fair, or equitably human, and surely not as the practice of *amour de soi* in its highest form. The coercion practiced by some health care providers to get women to test for HIV is certainly not 'love for the soul.' In my view, it leans more toward love for the self in its lowest form when the objective is to raise HIV testing rates simply for health care professionals to ostensibly show higher rates of personal or institutional productivity as I argued earlier.

English philosopher Thomas Hobbes, writing in the 1600s, also focused on self-preservation. But, unlike Rousseau, according to Tuck, Hobbes felt that self-preservation is a moral principle and a natural right (Tuck, 1989, p. 51). Hobbes felt that this natural right is balanced by a fundamental duty or 'natural law' to abstain from harming others, except when one's "own preservation is at stake" (ibid.). In 1640 in his treatise, *Elements of Law*, Hobbes wrote, "It is therefore a *right of nature*: that every man may preserve his own life and limbs, with all the power he hath" (ibid., p. 60). According to Hobbes's 'general theory of action,' which he outlined in *Leviathan* in 1651 and which was his most original contribution to the theory of the state, human beings act in such a way as to secure what we believe to be good for us, and the right to preserve ourselves is a special case of this general right (ibid.; Skinner, 1999, p. 7). In fact, to Hobbes the right to self-preservation is the only natural right we have (Tuck, 1989, p. 60). While Hobbes recognised that a person might have wants that have nothing to do with surviving, he felt that such wants were irrelevant to the natural right of survival (Hobbes, 1991, p. xvii). Similar to his contemporary, Hugo Grotius, who was a Dutch philosopher, jurist, and theologian, Hobbes felt that whatever else people may believe, they will always want to preserve themselves; and, that all men will agree with this right (Tuck, 1989, p. 61). In *Leviathan*, Hobbes again asserted man's right to self-preservation and wrote that this right "is the Liberty each man hath to use his own power as he will himselfe [sic], for the preservation of his own nature" (ibid., p. 63). Hobbes was pointing out that what he called "Liberty" was actually man's right, rather than a duty related to other people, and it is up to each person to decide how to protect oneself in exercising that right. Hobbes went on to write in the *Leviathan*, "…for no man is obliged (when the protection of the law faileth,) not to protect himself, by the best means he can" (Hobbes, 1991, p. 208). Thus Hobbes was citing the primacy of the

right to self-preservation even when what should be legal protection for one's life is not evident or has fallen by the wayside. He reiterated his stance on this principle when he wrote, "…no Law can oblige a man to abandon his own preservation" (ibid.).

Hobbes's clearly articulated views were fundamental in laying the groundwork for the right of the individual that has evolved in liberal philosophy (Mansfield, 2011, p. 112). That we have the right to preserve ourselves and to be able to individually determine how we can preserve ourselves is directly related to: deciding whether or not to test for HIV, whether or not to take ARVs if one tests HIV-positive and they are available, and whether or not to tell a sex partner, spouse, friend, neighbor, or family member that we are living with HIV if doing so potentially will jeopardise our 'life and limb,' or make our own self-preservation extremely difficult. To Hobbes, the right to refuse an HIV test would be a basic decision open to each individual. Of relevance to voluntary HIV testing is what Hobbes wrote about man's transfer of his own right to benefit someone else, "For it is a voluntary act: and of the voluntary acts of every man, the object is some *Good to himself*" (Hobbes, 1991, p. 93). Consequently, one would not expect Hobbes to agree with the revocation of one's right to voluntary testing for HIV if it would not be of benefit to the person to be tested for the disease, especially if it could invoke harm through stigma or discrimination or harm to the self via internal stigma.

In contrast to Hobbes's focus on the laws of nature as maxims of prudence towards our own self-preservation, according to Nicholas Jolley, English philosopher John Locke identified the law of nature as strictly emanating from God in his *Second Treatise on Government* (Jolley, 1999, p. 203). Because human beings are God's property, according to Locke, we have a duty under natural law not to destroy other human beings as to do so

would be to destroy his property (ibid., pp. 197, 203). In his *Second Treatise on Government*, written in 1689-90, Locke expounded this theory:

> "The state of nature has a law of nature to govern it, which obliges every one; and reason, which is that law, teaches all mankind who will consult it that, being all equal and independent, no one ought to harm another in his life, health, liberty or possessions…" (2000, p. 75).

In this passage, Locke identified several fundamental philosophical principles: namely, that we are all equal human beings, that we are all independent of each other, and that we have no right to harm another human being by taking away his life, injuring his health, or robbing him of his possessions. It is germane to highlight the importance Locke denotes on the right of another to his health and to harm another's health is to go against natural law, which we have no right to do to another human being. In the same treatise, Locke expanded his argument and included the right to self-preservation:

> "Every one, as he is bound to preserve himself and not to quit his station willfully, so by the like reason, when his own preservation comes not in competition, ought he, as much as he can, to preserve, the rest of mankind, and may not, unless it be to do justice to an offender, take away or impair the life, or what tends to the preservation of the life, the liberty, the health, limb, or goods of another" (ibid.).

Thus Locke recognised the right to self-preservation as a fundamental right of natural law and also used it as the ground for human beings having no right to harm another human being. The central core of Locke's philosophy is his theory of personal identity, which has formed the basis for modern conceptions and discussions of personal identity, although his

focus on natural law goes at least as far back as Stoic philosophy (Jolley, 1999, pp. 101, 197). Many scholars also believe that Locke's focus on life, liberty, etc., was the origin of U.S. President Thomas Jefferson's phrase, "life, liberty and the pursuit of happiness," as "inalienable Rights" and the protection of these rights as national objectives that he inserted into the American Declaration of Independence, which he drafted in June 1776 (Jefferson, 1776; Jolley, 1999, p. 203). Importantly, in Locke's passage, above, Locke again included health as a noteworthy right that cannot be transgressed by another, unless that person has committed an offense against justice, i.e., has broken the law. In considering health and the right not to transgress it, I would argue that this notion also includes transgressions against another's mental health, and that to test someone for HIV and not enable them to have access to ART if they test positive and want access to treatment is to harm them mentally. I believe that not only is it a human rights violation, but it is personally abusive to test someone for HIV unless the testing is voluntary because of the commonality of stigma and discrimination and because testing itself does not prevent the spread of HIV. An example of the potential impact of testing positive for HIV and not having access to treatment for the disease was summarised by a pregnant woman living in Uganda,

> "What is the use of testing when you know you cannot access medicine from your nearest health centre, and you can't travel to reach where the medicine is given? This can worsen your health with stress and probably kill you, so it is better when you don't confirm your HIV status" (UNAIDS, 2014a, p. 10).

In the view of French philosopher René Descartes (1596-1650) individuals have value as free and rational human beings; thus we should treat others with the respect they deserve

(Marshall, 1998, pp. 152-157). Descartes's view about our necessary treatment of other human beings goes hand-in-hand with his view on how we should treat ourselves: to value oneself as a free and rational human being is to have self-esteem, and it is the freedom of the will in exercising one's rationality that is an individual human being's real worth (Marshall, 1998, p. 151). He also believed that freedom of the will is a necessary condition to be able to value oneself; and, that self-satisfaction is the product of a personal commitment to one's individual freedom (ibid.).

According to his *Passions of the Soul*, written in 1649, the year before he died, Descartes believed one has perfect duties to oneself to act in a certain way or to refrain from acting in a certain way (ibid., p. 158). One perfect duty to oneself, according to Descartes, is to maintain one's physical well-being, which also allows the pursuit of the personal endeavors of one's choice (ibid., p. 162). He also believed that we have duties to others, including the perfect duty of practicing justice toward others and also the imperfect duty of practicing charity or benevolence toward others (ibid.). According to "Cartesian" philosophy, that is, the philosophy of Descartes, one should not commit an unjust act toward others; thus harm of another can never be justified (ibid., p. 163). To Descartes, ideal persons "esteem nothing more highly than doing good to others and disregarding their own self-interest" (ibid., pp. 165-166). Consequently, one's self-preservation is a perfect duty to Descartes. Yet in practicing benevolence toward others, one's own well-being should not be threatened, as this would go against the proper use of one's reason or rationality, which also is a perfect duty (ibid., p. 166). This view of Descartes is concurrent with the "Primum non nocere" principle, albeit Descartes did not limit its necessary practice to physicians or healers. Rather, felt Descartes, it is a philosophical principle all human beings should practice toward each other.

5.2 NON-MALEFICENE AND HUMAN RIGHTS

Moreover, Descartes went further than some other philosophers did in his stance on defending an individual's right to pursue one's self interest. To wit, by recognising and defending others' rights to their own self-interests, one legitimises one's own right to enjoy one's self-interest (Blom, 1978, p. 16). Since Descartes held a deep respect for human reason, he believed that each of us has an obligation to exercise our human reason (ibid., p. 18). And, exercising one's human reason is one's right by virtue of being human (ibid.). In this belief, Descartes was a forerunner of contemporary human rights theory, which rests fundamentally on the premise of human beings having the utmost value simply because they are human (Tasioulas, 2007, p. 76). Contemporary human rights theorists thus merely echo Descartes's belief that "all men are of equal inherent dignity," rather than developed a new principle they can claim as their own *sine qua non* (Blom, 1998, p. 18). A prominent example of such echoing is the start of the Preamble of the Universal Declaration of Human Rights (UDHR), ratified by the United Nations in 1948:

> "Whereas recognition of the inherent dignity and of the equal
> and inalienable rights of all members of the human family is
> the foundation of freedom, justice and peace in the world…"
> (UN, 1948, p. 1).

John Tasioulas recently has examined human interests related to human rights: "Properly registering the moral significance of human interests involves seeing them as the interests of persons who merit equal respect in virtue of that status" [of their being human] (Tasioulas, 2008, p. 38). Nonetheless, Tasioulas differentiates human rights from human interests in that rights are capable of generating duties and that "human rights are indeed *rights* and not simply a special class of interests" (ibid., p. 30). One posits, then, that

humans not only have an interest in survival, but indeed the right to survival, to which there is a corresponding duty, which at least some recognise, that is, to help other human beings to survive. It is the survival of other human beings on which this paper partly rests and the related arguments to help others to maintain their survival in addition to justifying their right to survive as a right that has been authenticated by a number of philosophers throughout history. However, Tasioulas cogently pointed out that it is not possible to comprehensively specify the duties that a particular right generates once and for all, as such duties can vary corresponding to the changes in the nature of the agents, in the institutions that are formed to fulfill the relevant rights, and the social contexts surrounding human behaviours and practices (2007, p. 94). Yet Tasioulas defended the universal moral right and the human right against physical abuse, both of which are grounded as universal human interests (ibid., p. 97). In carrying this principle further, Tasioulas clearly would support the right to survive as both a universal moral right and a human right. Importantly, Tasioulas states his rights-focused argument in a nutshell statement: "The underlying issue is not about enforceability or claimability; instead, it implicates one's deepest moral-philosophical commitments" (ibid., p. 99).

Following the moral commitment premise of Tasioulas, in the case of nurses, for example, who may claim they are only following institutional or national practice in testing a pregnant woman for HIV whether or not she has exercised truly informed consent and agreed to such testing, in other words, the implementation of coerced testing, the nurses or other health care providers cannot reasonably ethically justify such an act based on an institutional or even a national norm. Further, nurses have a professional responsibility to help others to survive by nature of their chosen vocation. Moreover, nurses have an individual moral duty to help others to survive by virtue of their being human, using

Tasioulas's reasoning, and especially in their chosen position of caring for other human beings. It seems to me that those in the 'caring professions' have the deepest and most profound duty to assist the survival of others. For what other reason could they possibly have chosen their profession than the ultimate need to help others to survive—assuming that this is the rationale for their vocational choice rather than purely for financial gain or other opportunism?

5.3 NON-MALEFICENCE RELATED TO HIV

That pregnant women living with HIV are in potential physical danger from their spouse or partner based on their status after disclosure of it to the spouse or partner has been described earlier in this paper a number of times. However, as time goes on an increasing amount of published research results underscore how important individual choice is to ethical decisions about HIV testing, especially for women and, most especially for pregnant women. The commonality of GBV, particularly in Africa, has received international attention for some ten years. For instance, in a study published by South Africa's Medical Research Council in 2003, the researchers found through interviews with 1,395 women in Soweto, outside Johannesburg, that intimate partner violence was prevalent (Dunkle, Jewkes, Brown, et al., 2003, p. 1). As examples, 13.7% of these women had experienced financial abuse; 67.5% of them had experienced emotional abuse; 50.4% had experienced physical abuse; and, 20.1% of them had experienced sexual abuse (ibid.). Moreover, 55.5% of the women reported that they had been physically or sexually assaulted by a male at some point previously in their lives (ibid.). The authors of the study concluded that "intimate partner violence seems to be associated with an increased risk that the abusive male partner has HIV," which highlights the real possibility that a pregnant woman living with HV may have been infected by her current partner (ibid., p.

3). Consequently, some pregnant women run serious risk of intimate partner violence if they test for HIV and disclose their positive status to their spouse or partner if he may become abusive as a result.

A recent study of nearly 2,000 women in Zimbabwe found that 33% of them reported intimate partner violence (IPV); and, their HIV status was associated with the intimate partner violence and with negative reactions immediately following disclosure (Shamu, Zarowsky, Shefer, et al., 2014, p. 1). What also is noteworthy about this study is that it showed that simply testing for HIV by these women precipitated IPV, whether they tested positive or negative, and that IPV was experienced by some of the women who had tested HIV-negative (ibid., pp.1, 4). The study's coauthors emphasised the gendered nature of HIV testing and that the testing and disclosure by women to their partners can have unintended consequences, including suffering IPV during pregnancy, particularly if a woman had suffered previous IPV in the relationship (ibid., p. 1). This study clearly documents that the fear of HIV testing many African women have described can be very well founded, especially if they have been abused in any way by their sex partner. Also, the commonality of abuse that such a high percentage of the women underwent highlights the real threat that violence poses for many women in sub-Saharan Africa based on the pervasive gender inequality and occurrence of violence in society. It also is important to note that this study was the first to systematically measure IPV after HIV disclosure, which several authors have noted over the past ten years as a potential consequence of HIV testing for women (ibid., pp. 2-3). Moreover, the study's authors noted two key points that relate to women's reproductive rights and choices in this social context:

1. "Control of women's reproductive and sexual health decision making was found to be associated with IPV experiences during

pregnancy in this study and elsewhere" (ibid., p. 4).

And,

2. "The high rates [of violence] may simply suggest a high level of IPV in more patriarchal relationships where men adhere to more hegemonic masculine roles such as controlling practices and believing they have a right to women's bodies" (ibid.).

One might question whether the IPV the women suffered was even related to their testing for HIV or perhaps was an ongoing relationship-centred activity which they periodically had to endure for reasons totally unrelated to testing. To counter this potential view, Shamu et al., noted that their study findings showed that a significant proportion of the women who had never experienced abuse before they were pregnant first experienced the abuse after disclosing their HIV status—whether they tested positive or negative—and a significant proportion of these women who underwent abuse after disclosure had tested HIV-positive (ibid.). Consequently, the results of this study show concrete evidence that HIV testing for many women in sub-Saharan Africa and their decisions about whether or not to disclose that they have tested for HIV to their partner, no matter what their HIV status is, matter a great deal to the future of their relationships and potentially to their own future physical and mental health.

For health care providers to pretend that testing everyone for HIV, or more specifically testing all pregnant women for HIV, is done only with their best interest in mind not only is misguided, but may be in many cases a maleficent act. The thinking of the health care providers in doing so, obviously, is a consequentialist approach, using the premise that these individuals are better off knowing their status, whether they test positive or negative. But, in reality, some of them may be worse off knowing their status, whether they test

positive or negative, if they share it with a previously or potentially abusive partner, or share it in a social context or a locale where simply testing for HIV is in and of itself considered to be an act commonly stigmatised, or when it is shared with others by a health professional without their knowledge. Health care providers in sub-Saharan Africa who do not recognise the real danger in which they may be putting some individuals, especially women, by insisting they test for HIV are acting either unconscious of or against Kant's maxim that the end does not justify the means in their stance that their testing of another person for HIV is always the right thing to do either for the person's good or for the good of public health—whether or not that person wants to be tested. According to Kant: "The duty of respect for my neighbor is contained in the maxim not to degrade any other to a mere means to my ends" (1996, p. 569). What's more, Kant believed that acting in respect of other human beings is a human duty no matter what one's relationship is with that person based on the following:

> "In accordance with the ethical law of perfection "love your neighbor as yourself," the maxim of benevolence (practical love of human beings) is a duty of all human beings toward one another, whether or not one finds them worthy of love" (ibid., p. 570).

5.4 NON-MALEFICENCE AS A HUMAN DUTY

Kant saw the need to respect other human beings as a primary duty of all of us—"…showing respect for a human being as a moral being (holding his duty in highest esteem) is also a duty that others have towards him and a right to which he cannot renounce his claim" (Gregor, 1998, p. 580). Thus to Kant we have to respect our own rights and indeed the rights of others, which they should not forego and cannot give away.

It is hard to infer that Kant would agree with the public health priority in disease outbreaks to usurp the rights of others supposedly in the name of public health when there is no reason to assume that individuals may be infectious to others. This is the case when nurses or doctors decide to test everyone for HIV whether or not they may be infected with the virus and whether or not ART is immediately available as lifelong treatment to individuals who test positive. What's more, the *HIV/AIDS and Human Rights International Guidelines* published by the United Nations in 1998 specify the essential linkage of human rights and public health:

> "In general, human rights and public health share the common objective to protect the rights and well-being of all individuals. From the human rights perspective, this can best be accomplished by promoting and protecting the rights and dignity of everyone, with special emphasis on those who are discriminated against or whose rights are otherwise interfered with. Similarly, public health objectives can best be accomplished by promoting health for all. With special emphasis on those who are vulnerable to threats to their physical, mental or social well-being. Thus health and human rights complement and mutually reinforce each other in any context. They also complement and mutually reinforce each other in the context of HIV/AIDS"
> (Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), 1998, p. 37).

It is interesting as well as ironic that the U.S. Centers for Disease Control and Prevention (CDC) in 2006 and the WHO in 2007 subsequently put in place guidance on provider-

initiated HIV testing and counseling (PITC) or "routine testing"—reversing the order of what was previously called 'HIV counselling and testing'—without acknowledging that this directive was a potential infringement of the right to test for HIV voluntarily if fully informed consent was not observed in implementing the new HIV testing recommendations.

In considering the total context of the HIV epidemic in sub-Saharan Africa where stigma toward and discrimination against people living with HIV is still the norm rather than an isolated incident, demanding or coercing patients in one's power to test for HIV defeats the fundamental health care principle and duty of "*primum non nocere.*" In his treatise, *Practical Philosophy,* based on Gregor's translation, Kant felt that it is up to human beings to stand up for their rights, indeed to demand their rights: "Be no man's lackey. – Do not let others tread with impunity on your rights" (Kant, 1996, p. 558). Further, Kant also focused on the importance of self-preservation to each and every person in the same tome, "…a human being is still bound to preserve his life simply by virtue of his quality as a person and whether he must acknowledge in this a duty (and indeed a strict duty) to himself" (ibid., p. 547). Thus Kant saw the duty of self-preservation to be a duty of each human being and that to deny one's need to preserve oneself is a "violation of duty to oneself" (ibid.). To Kant, and to some other philosophers as explored previously herein, the duty of self-preservation is the ultimate duty.

It also is worth noting at this stage that the health of a pregnant woman is not only essential for her own self-preservation and indeed for her own well-being, but also for the well-being of her foetus. When a pregnant woman undergoes interpersonal violence, not only is her health affected, but IPV is also associated with adverse health outcomes for her

foetus (Meuleners, Lee, Janssen, et al., 2011, p. 1). Based on research conducted in Australia, the adverse maternal outcomes from IPV can include potential miscarriage (< 20 weeks), placental separation from the wall of the uterus prior to birth, low placenta, preterm labour, premature membrane rupture, and postpartum haemorhaging (ibid., p. 2). As reported by the WHO, other research conducted in two cities in the USA found that consequences of IPV perpetrated on pregnant women also can result in low maternal weight gain, infections, and anaemia (WHO, 1997, p. 5). The adverse outcomes for the foetus or infant can include foetal distress, preterm birth, low birth weight (less than 2,500 grams), foetal death, and infant death (Meulners, et al., pp. 1-2). Obviously, the consequences of IPV on pregnant women and their foetuses can be very serious, life-threatening, and even result in death. Thus health care providers treating pregnant women and testing them for HIV should be cognisant of the range of potential negative impacts of HIV testing on these women, including possible IPV from spouses or partners after they test if they disclose having done so. Discussions about IPV by health workers with women in sub-Saharan Africa, and especially pregnant women, are needed as part of the HIV testing process. They should be deemed essential.

In the WHO's report on *Violence Against Women: A Priority Health Issue*, published in 1997, the WHO identified what health workers can do both to prevent and respond to cases of violence against women, issues that are as salient now as they were more than 15 years ago:

- "First, "do no harm." Unsympathetic or victim-blaming attitudes can reinforce isolation and self-blame, undermine women's self-confidence, and make it less likely that women will reach out for help.

- Be attentive to possible symptoms and signs of abuse and follow up on them.
- Where feasible, routinely ask clients about their experiences of abuse as part of normal history taking.
- Provide appropriate medical care and document in the client's medical records instances of abuse, including details of the perpetrator.
- Refer patients to available community resources.
- Maintain the privacy and confidentiality of client information and records" (1997, p. 6).

In addition to its focus on the role and responsibility of health workers to help prevent and respond to cases of violence against women, the WHO report listed 11 global declarations, covenants, resolutions, and special commission reports published to date that addressed the issue as of 1997 (ibid., pp. 7-8). The first global document mentioned in the WHO report was the Universal Declaration of Human Rights (UDHR) (UN, 1948). Article 3 of the UDHR states that everyone has the right to life, liberty and security of the person; Article 5 states that no one shall be subjected to torture or to cruel, inhuman, or degrading treatment or punishment (ibid., p. 7). Clearly, violence against women violates both Articles 3 and 5 of the Universal Declaration of Human Rights.

I would argue that in its PITC/routine HIV testing implementation guidance, issued in 2007, the WHO does not recognise how serious and widespread violence against women, especially in sub-Saharan Africa, is. The guidelines do not include the six bullet points laying out specific actions that health workers "at a minimum" can do to prevent or follow up on such violence, which the WHO published ten years earlier (1997, p. 6). The WHO

guidelines issued in 2007 do include discussing the risk of violence or suicide with patients who test HIV-positive, especially women (WHO, 2007, p. 11). Yet they do not recognise that simply testing for HIV can provoke violence, including verbal abuse, from others, including community members, as well as physical assault from spouses or partners, family members, or community members. Thus the WHO's 2007 guidelines are too limited in the scope of their HIV testing implementation guidance to health care workers related to the commonality of violence against women. Again, the WHO's obvious priority is testing for HIV; it is not counselling clients or patients who undergo HIV testing on the full range of topics important to discuss with them surrounding HIV testing and HIV itself.

The WHO PITC/routine testing guidelines for counselling pregnant women who test HIV-positive state that the discussion should include: "Use of antiretroviral drugs for the patient's own health, when indicated and available, and to prevent mother-to-child transmission" (ibid.). This statement does not say a health care provider should always discuss antiretroviral drugs with the patient related to the patient's health whether the drugs are available or not. Consequently, I would argue that this guidance violates the patient's "right to know" what her options really are if she tests HIV-positive, even if access to ART would not necessarily be made available to her. Further, every client or patient testing for HIV should know that ART exists, whether the individual tests positive or negative at present, as the person may test HIV-positive in the future. In particular, women and men in sub-Saharan Africa should be made aware of ART as part of the counselling process surrounding HIV testing because the disease is so prevalent in the region. In fact, its commonality is the primary rationale for the WHO recommending routine testing for HIV as an intervention for all individuals seeking medical care in sub-Saharan Africa, as described earlier in this paper.

The WHO PITC/routine testing guidance for counselling individuals testing HIV positive states: “Discuss possible disclosure of the result, when and how this may happen and to who” (ibid., p. 11). The guidance does not appear to acknowledge that disclosure may be a bad idea depending on the living and/or working conditions of the person testing HIV-positive—with women and girls as the most vulnerable members of this group. In sum, the guidelines seem to be negligent in their limited acknowledgment of IPV as well as violence in general, especially toward females in sub-Saharan Africa. I contend that the 2007 WHO PITC/routine testing guidance runs the risk of maleficence in its lack of comprehensiveness about the potential for violence against women and girls who test for HIV, whether they test negative or positive for the virus. This slant of the routine testing guidance seems odd as in 2006, the year before the PITC/routine testing guidance was published by the WHO, an article published in *The Lancet*, based on the WHO Multi-country Study on Women’s Health and Domestic Violence, reported the lifetime prevalence of physical and/or sexual partner violence ranged from 15% to 71% (Garcia-Moreno C, Jansen HA, Ellsberg M, et al., 2006, p. 1266). Moreover, the *Lancet* article started by stating:

> “Violence against women is now widely recognized as a serious human rights abuse, and increasingly as an important public health problem with substantial consequences for women’s physical, mental, sexual, and reproductive health” (ibid., p. 1260).

Based on the findings of the WHO study published before the WHO recommendations on PITC/routine testing for HIV were published, the lack of cognisance of the need for more sensitive and explicit guidance on the potential negative repercussions of HIV testing on women, especially for those testing positive, seems like more than a mere oversight. It

appears that the needs of individual women were not adequately recognised either in the HIV pre-test process or in the post-test process guidelines for health care workers in 2007. While the guidelines mention the possibility of violence if a woman tests positive for HIV, they do not appear to take into account that this is a public health problem; it is not only a problem for individual women. It is a problem for families, communities, and the public health system as a whole. Both the 1998 UN report on violence against women and the *Lancet* article published in 2006 show much greater awareness of the size of the problem of violence against women than the WHO PITC/routine testing guidelines. Again, I would argue that the principal emphasis of the WHO's 2007 PITC/routine testing guidelines is on testing and the reasons why, according to the WHO, it is so important to test people for HIV, rather than what the potential negative implications can be for individuals surrounding HIV testing. In short, the risks of HIV testing are not adequately addressed by the guidelines.

I believe that the potential maleficence of inadequately assessing the risks of HIV testing rather than focusing mainly on the possible beneficial outcomes of HIV testing, which in no way are guaranteed, should be addressed by the WHO and by national programmes and institutions that continue to push HIV testing as the main intervention priority. Instead, the intervention priority should be on ART enrolment as soon as possible of anyone testing HIV-positive and referrals to prevention support opportunities for anyone testing HIV-negative, as well as discussion of the prevention of onward transmission of anyone testing positive. As mentioned earlier, just testing people for HIV does no one any good without good accompanying counselling, whether they test positive or negative. Based on all the possible negative repercussions of HIV testing outlined herein, coerced HIV testing certainly can be a maleficent act, albeit an unintended result, if violence or suicide is the

outcome of an HIV test. I would posit that either no or inadequate discussion of the potential for violence occurring after HIV testing is also a potentially maleficent act. And, it should not be an HIV counselling and testing discussion topic reserved only for women.

It cannot be over emphasised that abused women are at an increased risk of anxiety, depression, post-traumatic stress disorder, suicide, and drug and alcohol abuse (Hegarty, Gunn, O'Doherty, et al., 2010, p. 2). The most common physical health problems resulting from IPV include injuries, chronic pain, gynecological, cardiovascular, neurological and gastrointestinal effects (ibid.). Adolescent girls and young women under age 25 are at even greater risk of violence, with pregnant women and girls at greatest risk, according to a study in Western Australia that took place from 2002-2008 (Meuleners, et al., 2011, p. 3). For adolescent girls, pregnancy is an especially risky time as they face the stress of making the transition to becoming a parent when they may not be emotionally, mentally, or physically ready to be a mother (UNICEF, 2014a, p. 50). If these pregnant adolescents live in sub-Saharan Africa, it is likely that they will be asked to test for HIV or possibly even coerced into testing for HIV. With sub-Saharan Africa's high rate of IPV, some of these young women will run a high risk of IPV resulting from having had an HIV test, particularly if they test HIV-positive and disclose this to a partner who does not support their HIV testing action. Violence suffered by pregnant adolescent girls can be extremely damaging to both the mother and her child, resulting in miscarriage, stillbirth, premature labour or delivery, low birth weight, or even maternal mortality (ibid.).

Indeed, violence against young women is a serious problem in sub-Saharan Africa. For example, according to UNICEF, in Eastern and Southern Africa, at least 12% of girls aged 15-19 reported incidents of physical violence in the previous 12 months, which documents

a high level of violence undergone by girls in this age group (ibid., p. 49). Moreover, in the Democratic Republic of Congo (DRC) 42% of girls in this age group reported incidents of physical violence in the previous year (ibid.). Physical violence toward young women and girls itself can be described as an epidemic out of control in some areas, with a dangerous conjunction where the HIV epidemic also is out of control, such as in Southern Africa. According to UNICEF survey results, 64% of women aged 18 to 24 in Zimbabwe reported incidents of physical violence prior to age 18 (ibid.). The adult HIV prevalence rate in Zimbabwe in 2013 was 15%, showing the confluence of these two epidemics with serious implications for adolescent girls and young women related to potential HIV infection (UNAIDS, 2014b, p. A9).

Based on reviewing the context of HIV testing in sub-Saharan Africa, it is hard to understand why the WHO PITC/routine testing guidelines included such a limited focus on the potential negative outcomes of HIV testing. The WHO was a co-sponsor of the first randomised, controlled trial (RCT) of voluntary HIV counselling and testing, a three-country study conducted in Kenya, Tanzania, and Trinidad from 1995 to 1998 (The Voluntary HIV-1 Counseling and Testing Efficacy Study Group, 2000, p. 111). This study's coauthors reported on "negative life consequences such as physical beatings and break-up of relationships" resulting from women testing HIV-positive, especially if the partner tested HIV-negative, results which were reported in *The Lancet* in 2000 (ibid., p. 110). Moreover, the same *Lancet* article also noted in another study "common signs of depression in women who found out that they were HIV-1 infected" (ibid.). Consequently, it hardly can be surmised that the WHO simply was not aware of interpersonal violence or depression as possible outcomes of HIV testing, especially in sub-Saharan Africa, and particularly as experienced by women. The seriousness of these potential outcomes from

HIV testing seem to have been ignored or overridden by WHO's focus on testing as many people as possible, even where no ART is available, or only to a very limited extent and to a very limited few, supposedly under the guise of a public health emergency or, at least, strategy.

Based on the discussion above, I do not believe that WHO's focus and guidelines on PITC/routine testing essentially are non-maleficent. I believe routine testing can be non-maleficent if testing is truly voluntary, not coerced, involving informed consent, counselling is provided, including post-test counselling to everyone who tests for HIV, whether their results are positive or negative, and referrals are given for people who test negative or positive and, most importantly, ART is made available to anyone testing HIV-positive. If ART is not available to anyone testing positive, I would argue that PITC/routine testing is maleficent—unless it is fully informed and voluntary with enough time allowed after the suggestion is made by the health care provider for the patient to make a considered decision to opt in—and the patient is told that ART will not be made available if the individual tests HIV-positive.

Many articles have noted that there is a real risk of depression and/or IPV after testing HIV-positive for many women in sub-Saharan Africa, especially if they do not have access to ART and other support systems. The same *Lancet* article published in 2000, quoted above, also stated:

> "Women need communication and negotiation skills to enable them to discuss sexual and other issues with their partners" (ibid.).

And,

> "…VCT strategies cannot be offered without giving the social, physical, and financial support needed to ensure that people who discover that they are HIV-1 infected have the protection and resources they need to cope with their diagnosis, especially women" (ibid.).

We are still years, if not decades, away from meeting this goal. However, the closest we can come to it is by providing ART to all individuals testing HIV-positive and through the provision of other health and psychosocial support mechanisms or at least referrals for them. That all of these services remain extremely sparse or simply unavailable in rural areas in sub-Saharan Africa again calls into question the non-maleficence of PITC/routine testing. According to a Commentary in late 2014 in the *Journal of the International AIDS Society*,

> "Gender inequality and violence against women remain important drivers of the HIV epidemic, particularly in sub-Saharan Africa, where women and girls represent 57% of people living with HIV. It has long been recognized that gender inequality is a core issue that underpins women's vulnerability to HIV in the region, with a combination of social, economic and cultural factors contributing to the higher levels of HIV infection occurring among women" (Watts and Seeley, 2014, p. 1).

Regarding pregnant women, single-dose nevirapine is still the most common method used to prevent mother-to-child transmission (PMTCT) of HIV in sub-Saharan Africa, even though the WHO 2013 treatment guidelines recommend making lifelong ART available to

pregnant women who are HIV-positive (WHO, 2013a, p. 92). What is also worrying is that in five sub-Saharan African countries, Kenya, Lesotho, Nigeria, South Africa, and Swaziland, there was a decline in PMTCT coverage in 2012 (UNICEF, 2014b, p. 8). Moreover, in four countries, Angola, Chad, DRC, and Nigeria, the national coverage of PMTCT in 2012 was less than 20% (ibid.). It seems very questionable to recommend that all pregnant women be routinely tested for HIV where ART, and only single-dose nevirapine in many cases, which can cause drug resistance to ART use by HIV-infected individuals later on, is not available to 80% of the pregnant women who would undergo HIV testing. Further, it seems negligent in 2015 to still use single-dose nevirapine as the primary PMTCT protocol when this will not protect the mother's health and there is strong, growing evidence of the real risk of survival of a baby or a young child after the death of the mother, and even before her death when she is too ill to provide appropriate care for her child (Clark, Kahn, Houle, et al., 2013, p. 1). Clark et al.'s study in South Africa in 2013 showed that the survival of young children is put at substantial risk when the mother becomes very ill, with a period of very high risk of child death in the two months prior to the mother's death and in the two months following her death (2013, p. 8). The study's coauthors documented that this effect is 1.5 times greater when the mother has HIV/AIDS or TB, although the overall pattern is the same for other serious illnesses a mother can suffer (ibid.). According to Clark et al., "Severe maternal illness coupled with declining ability to feed infants and children is a certain indicator of impending catastrophe" (ibid.). The following statement points out how crucial providing ART to the mother really is, not only to save her life, but also to save the life of her child: "The increasing rollout of antiretroviral therapy to mothers with HIV should lead to improved child survival, and there is evidence for this in other southern African countries" (ibid.).

Expanding on a topic noted earlier herein, it is salient to HIV testing and important to point out how common depression is in women generally. According to a recent editorial in *The New York Times*, "Depression is the most important thief of productive life for women around the world" (Rosenberg, 2014, p. 1). Testing positive for HIV, especially if there is no access to ART or access is extremely difficult, can provoke depression. A study conducted in KwaZulu-Natal province in South Africa found that suicide ideation rates were high among pregnant women with an unplanned or unwanted pregnancy and even higher among pregnant women who had tested HIV-positive (Rochat, Bland, Tomlinson, et al., 2013, p. 650). According to Rochat, et al.:

> "The link between antenatal depression and suicide ideation is important since in many Southern African settings the burden of antenatal depression is between 30% - 47% and risks are compounded by multiple factors including: HIV, with up to 43% of pregnant women in worst affected areas testing HIV-positive, high rates of unplanned pregnancies and intimate partner violence" (ibid., p. 651).

An interview with one of the women in the study in KwaZulu Natal is telling regarding the centrality of her HIV test to her depression and suicide ideation:

> "The cause of all these worries I have is that I am HIV-positive, my life really changed that day, I haven't told anybody, I am scared, where to start…all of these really bad feelings started when I got my results, when I learnt that I was positive" (ibid., p. 655).

It also is important to bear in mind the impact of GBV on women, resulting in depression. The KZN study's coauthors also noted that intimate partner violence as well as partner

conflict are strongly associated with antenatal depression in southern Africa; however, recent research in Europe has shown that accessing HIV treatment may lower suicide in HIV-infected individuals (ibid., p. 657). Nonetheless, the coauthors suggested that "it is probable that depression itself may inhibit a women's engagement with health services during pregnancy," which supports the serious consideration that needs to be given to the whole notion of routine testing of pregnant women for HIV even where ART is available to them (ibid., p. 658).

What's more, there is still too little recognition of the potential consequences of HIV testing on individual mental health and indeed why HIV testing is so scary to so many, especially women, including pregnant women. The authors of an article on a recent study of suicide ideation, depression and HIV among pregnant women in rural South Africa concluded:

> "In HIV epidemic settings, routine HIV testing in PMTCT programmes means that many women learn their HIV-positive status for the first time during pregnancy. It is well accepted that learning one's HIV-positive diagnosis is a negative life event, shown to be associated with onset of depression among non-pregnant women in South Africa and internationally" (ibid.).

Moreover, the same authors of the study noted a key point related to universal testing, which is the same thing as routine testing of pregnant women or anyone seeking care in a healthcare setting:

> "Since universal screening is seldom cost-effective in the absence

> of access to treatment, significant policy and public health investments are required to make suicide prevention and intervention feasible for pregnant women in these settings" (ibid.).

Enabling full access to health education and information about HIV prevention and treatment on the community level and in primary and secondary schools will help women and girls protect themselves from the virus and provide the impetus for understanding and acknowledging potential HIV infection and seeking treatment and care, if needed. Moreover, this opportunity should be provided to everyone, especially in high HIV-prevalence settings, including through special educational campaigns. This educational need is urgent based on the impact of the HIV/AIDS epidemic in sub-Saharan Africa, particularly on women and girls. It may seem superfluous to reiterate how important the effects of the HIV epidemic have been on the economic development and health achievements in sub-Saharan Africa. However, it is worth noting that a systematic analysis of the Global Burden of Disease (GBD) Study 2013 showed that "HIV/AIDS has had a large enough effect to negate progress made in other causes contributing to decreases in life expectancy, particularly in southern sub-Saharan Africa" (GBD 2013 Mortality and Causes of Death Collaborators, 2015, p. 152). What's more, AIDS-related deaths in 2013 numbered 220,000 in South Africa, and 240,000 in Nigeria, showing that these two sub-Saharan African countries have HIV epidemics clearly remaining out of control (UNAIDS, 2014b, p. A57). In addition, two sub-Saharan African countries show that the PMTCT of HIV also remains a moving target related to education about, local awareness of, and access to PMTCT: in 2013 only 3% of the pregnant women in Madagascar who needed it were able to access PMTCT medication; and, in Nigeria only 31% of HIV-positive

pregnant women were able to do so (ibid.). These statistics are stunning, especially related to Nigeria, where nearly a quarter of a million people died from AIDS-related causes in 2013 (ibid., p. A63). Finally, regarding the 2013 statistics from UNAIDS related to HIV/AIDS, seven sub-Saharan African countries highlight how less than 50% of the people living with HIV who should be receiving ART, according to their national guidelines, were accessing it in 2013: only 1% in Madagascar; 23% in Nigeria; 24% in the Democratic Republic of Congo (DRC); 31% in both Lesotho and Mozambique; and, 43% in South Africa, the country with the highest number of HIV-infected people in the world (ibid., pp. A67-A68). These statistics document how great the continuing need is for education on HIV/AIDS, including on prevention and treatment, across sub-Saharan Africa, as well as the limited access to ART that is available, and the prevailingly high degree of stigma and discrimination that prevent many from seeking or continuing treatment, particularly women.

Providing ART to all women and girls who test HIV-positive will open the door to greater numbers of these individuals seeking HIV testing when they learn treatment definitely will be available if they test positive and will remain accessible to them. On the other hand, knowing that there will be a lack of treatment access if one tests HIV-positive has been and continues to be a serious deterrent to HIV testing where there is no treatment available, or treatment only available to those who are very ill, when it may be too late to really help. This has been a common observation across countries in sub-Saharan Africa. It is particularly relevant to women, who are more vulnerable to and suffer more commonly from HIV-related stigma and discrimination in this region. According to the authors of a recent study on the initiation of antiretroviral therapy (ART) and viral suppression in South Africa and Uganda,

> "The most important outcome metrics for HIV testing programmes are the proportions of participants tested and linked to HIV care, and viral suppression among those who initiate antiretroviral therapy" (Barnabas, van Rooyen, Tumwesigye, et al. 2014, p. e74).

Protecting pregnant women who test for HIV and particularly pregnant women who test HIV-positive from potential stigma and discrimination through counselling about whether they should share information about their test, including their test results, and with whom, and the inclusion of personal risk-reduction counselling about HIV and potential future GBV is an urgent need in all countries in sub-Saharan Africa, especially southern African countries with South Africa as a priority. Based on recent research conducted in sub-Saharan Africa, Watts and Seeley determined that:

> "Even with a highly effective prevention technology, such as PMTCT medication, violence and the fear of violence pose an important barrier to the elimination of vertical HIV transmission, and to ensuring that broader maternal and child health goals are met" (2014, p. 2).

All women and girls who test for HIV should receive personalised counselling about the possibility of GBV, how to prevent it, how to protect themselves as much as possible if it occurs, and where to access care and support and post-exposure prophylaxis (PEP) for potential HIV infection—whether the violence they have suffered relates specifically to HIV testing or not. Based on their study of the effectiveness of an intimate partner violence (IPV) and HIV prevention interventions in Uganda in 2014, Wagman and

colleagues had an important finding and recommendation for the future related to HIV counselling and testing for women:

> "HIV counselling and testing provides an opportunity to screen for and address IPV and counsellors could mitigate important contextual risk factors for HIV transmission that are associated with experiences of violence. We also recommend that HIV counselling and testing services consider the needs of violence survivors and offer risk reduction counselling and disclosure support in the context of women's risk of abuse" (Wagman, Gray, Campbell, et al., 2014, p. 9).

Understanding that many women in sub-Saharan Africa have very limited, if any, access to health care due to their socio-economic inequality with men, extensive poverty that limits their access to transportation to clinics, and a common lack of knowledge about health care as well as HIV prevention, care, and treatment options is still an unacknowledged political priority in most countries—as it is a general problem for most of the population because of extensive poverty. These ongoing conditions have an impact on the future economic development of these countries and indeed future generations. This is an even more serious issue related to women and girls living with HIV because of their compromised immune systems, which means they are more prone to other opportunistic infections, including pneumonia, tuberculosis, etc., as well as malaria, and mental health issues. In 2014, Kendall, et al. consulted with 30 international researchers and policymakers and reviewed the literature on HIV-related maternal mortality in sub-Saharan Africa and compiled several important findings, including:

> "Ensuring that people living with HIV are screened for tuberculosis and given prophylactic treatment is a core activity for HIV treatment and tuberculosis control programmes. Pregnant women living with HIV have an elevated risk of developing tuberculosis disease and of maternal death… Pregnancy and HIV both increase women's susceptibility to acquiring malaria and to developing active tuberculosis disease. Coinfection with either malaria or tuberculosis are also associated with increased risk of maternal death compared with women who have tuberculosis or malaria but are not living with HIV" (Kendall, Danel, Cooper, et al., 2014, pp. S251-252).

The lack of HIV treatment also exacerbates HIV disease progression, including the potential for developing AIDS-related cancers. A number of studies have taken place or are currently being conducted to learn more about how HIV relates to cancers among women in sub-Saharan Africa. However, this is not a newly discovered concern or new topic for research as the following shows:

> "HIV has always been associated with certain unusual cancers, especially Kaposi's sarcoma and non-Hodgkin lymphomas, as well as cervical cancer…in the low income HIV-endemic regions of sub-Saharan Africa, malignancies related to HIV have long been

> recognized as a major public health problem" (Cubasch, Joffe, Hanisch, et al., 2013, pp. 177-178).

While research is ongoing about the impact of HIV on breast cancer among women in sub-Saharan Africa, women living with HIV are at increased risk of cervical cancer, which has been known in South Africa for a number of years. Women who start to have sex at a young age, as a girl or in adolescence, are at increased risk of human papillomavirus (HPV) infection and developing cervical cancer even if they have sex with only one partner; their risk increases if they have sex with many sex partners (Africa Coalition on Maternal, Newborn & Child Health, 2014, p. 1). In fact, "cervical cancer is the leading cause of cancer death in women in southern Africa" (Richter and Dreyer, 2013, p. 291). A recent study among women attending public health clinics in one area of South Africa's Gauteng Province documented the highest rate of high-risk human papillomavirus (hrHPV) ever recorded in an unselected screening population (ibid.). It is also worth noting that Nigeria and South Africa are the two countries with the highest numbers of women with cervical cancer in Africa, which happen to be the same two countries with the largest numbers of people living with HIV, as mentioned earlier in this chapter (Africa Coalition on Maternal, Newborn & Child Health, 2014, p. 3; UNAIDS, 2014b, p. A57). This is important related to HIV testing because the high rates of cervical cancer and tuberculosis among women in Africa, with an estimated 380,000 TB cases overall in South Africa in 2013 as one example and 510,000 sub-Saharan African women dying of TB in 2013 as another, highlight the important opportunity for women who go to a clinic for screening for cervical cancer or TB to also test for HIV at the same time (WHO, 2014, p. 16). Yet if women feel they may be forced to test for HIV via routine testing if they go to a clinic for any sign or symptom of any illness, they may forego a clinic visit out of fear of HIV testing, a visit that could save their lives or at least prolong their lives if they have TB or

cervical cancer—whether or not they are infected with HIV. Indeed, HIV infection significantly raises the risk of persistent HPV infections in women, which can lead to cervical cancer (Africa Coalition on Maternal, Newborn & Child Health, 2014, p. 4). Consequently, the vulnerability of sub-Saharan African women to these diseases is yet another reason why HIV testing using ethical protocols is important, even urgent, for women in sub-Saharan Africa. What is needed to change the contextual hurdles of HIV testing is to decrease HIV-related stigma and discrimination with community prevention interventions against GBV and enforcement of laws protecting human rights; to increase greater accessibility for impoverished women who want to test for HIV; to strengthen the communication and media dissemination of health-specific messages re: HIV prevention and treatment to help more women understand the importance of testing for HIV; and, to make ART readily and regularly available to them and their family members if they or their partners or children test HIV-positive. Without these pieces being put into place, the routine testing of women remains unethical in my view.

Widespread understanding of the extensive health vulnerability of women living with HIV, especially pregnant women, still does not exist in any country in Africa. This situation remains largely unrecognised and unappreciated as a national and regional health crisis. A report released in 2015 by the Salamander Trust in the UK in conjunction with the WHO summarised the findings from a global survey of women living with HIV, which may be the first such survey (conducted in seven languages) ever undertaken. The report highlighted many issues that have received too little, if any, attention in the past, including the prevalence of mental health issues among women living with HIV:

> "HIV diagnosis is, in itself, a flashpoint for immediate and on-going

> mental health problems, especially depression, feelings of rejection, shame, self-blame, anxiety, insomnia, loneliness, and body image anxieties. Respondents' extremely high figures of HIV and mental health co-morbidity, which exceed previously quoted figures, may be provoked by, or have their roots in, a wide range of factors, including GBV—especially sexual violence, stigma (either HIV-related or related to gender identify and sexual orientation—often worsened by punitive legal and policy environments), poverty or financial stress, and homelessness" (Orza, Welbourn, Bewley, et al., 2015, p. 31).

As the caregivers in families as well as having a lower socioeconomic position in society, women and girls are plagued with more responsibilities in the home and support for family members while they themselves are more vulnerable to health issues related to reproduction and their greater biological vulnerability to HIV infection. The United Nations Special Rapporteur on Extreme Poverty and Human Rights reported in 2013 how women's unpaid care work affects them, including how the HIV/AIDS epidemic takes a heavy toll on women and girls:

> "Across the world, women and girls commit substantially more time than men to unpaid care work…the unequal distribution, intensity and lack of recognition of unpaid care work undermines the dignity of

> women caregivers, obstructs their enjoyment of several human rights on an equal basis with men, undermines progress towards gender equality and entrenches their disproportionate vulnerability to poverty across their lifetime…The HIV/AIDS pandemic has severely disrupted and/or increased unpaid care work in many countries. Women are affected by the virus in greater numbers than men…studies show that HIV/AIDS caregivers experience a negative impact on physical and mental health…Eighty per cent of family caregivers in South Africa have reported reduced income levels" (Sepulveda Carmona, 2013, pp. 4, 12, 16).

In addition, women are frequently blamed for bringing HIV into the family when the testing of anyone for HIV in many families occurs only because of a woman's pregnancy, a health event making these women more vulnerable to GBV, including psychological and emotional abuse. According to Watts and Seeley and the researchers who conducted a study on HIV and intimate partner violence in pregnancy in Johannesburg, South Africa, the study respondents described:

> "…how HIV diagnosis during pregnancy, and subsequent partner disclosure, are common triggers for violence within their relationships, with their disclosure of infection causing conflict, usually related to perceived infidelity and the notion that women are "bringing" the

> disease into the relationship" (2014, p. 2).

Moreover, the *HIV/AIDS and Human Rights International Guidelines* of the UN published in 1998 recognised the common attribution of the cause of HIV infection specifically to women as follows,

> "HIV/AIDS prevention and care for women are often undermined by pervasive misconceptions about HIV transmission and epidemiology. There is a tendency to stigmatize women as "vectors of disease," irrespective of the source of infection. As a consequence, women who are or are perceived to be HIV-positive face violence and discrimination in both public and private life" (Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS), 1998, p. 42).

Also, the authors of a recent analytic study of HIV-related maternal mortality in sub-Saharan Africa summarised precisely why gender stigma and discrimination and GBV are so destructive to women related to HIV, especially to pregnant women:

> "Gender discrimination and HIV-related stigma violate human rights and contribute to poor health outcomes, in part by creating barriers to women's utilization of essential maternity and HIV services. Anticipation or experience of disrespect and abuse in

> maternity care and HIV-related stigma and discrimination, including internalized stigma, have been associated with avoidance of skilled delivery, refusal of antenatal HIV testing, and for women living with HIV, not enrolling in HIV services, and reduced adherence to ART for prevention of vertical HIV transmission. One of the most egregious forms of gender discrimination, Intimate Partner Violence, is associated with increased likelihood of acquiring and living with HIV and with poor reproductive health outcomes among all women" (Kendall, Danel, Cooper, et al., 2014, p. S255).

In a relevant case in the European Court of Human Rights in 2003 between an applicant and France, the expert legal comments from the Center for Reproductive Rights centered on the human rights of the pregnant woman when she has been injured resulting in the involuntary termination of a wanted pregnancy:

> "Recognizing the injury caused to the pregnant woman when a wanted pregnancy is lost is consistent with human rights standards relating to women's health and physical integrity. When addressing issues of violence against pregnant women, international human rights bodies have recognized such violence as an infringement of the rights of the pregnant woman…" (Katzive and Zampas, 2003, pp. 9-10).

There are just so many issues women who test positive for HIV face in southern Africa related to the predominance of poverty, the commonality of interpersonal violence, and possible depression resulting for their situations in general, especially if they are pregnant and exacerbated by testing HIV-positive, that it seems impossible to justify the rather cavalier attitude that everyone should be routinely tested for HIV, most particularly pregnant women. To think that PITC/routine testing is non-maleficent based on the evidence cited herein is ignorant, if not maleficent itself.

The following final chapter will tie the various threads together explored herein on the bioethical and human rights implications surrounding the HIV testing of women and girls in sub-Saharan Africa. The chapter will reach some conclusions as well as provide some recommendations for HIV testing and counselling interventions that promise some success in respecting and abiding by the individual and collective rights of these groups, while also addressing effective strategies to prevent further HIV infections.

CHAPTER 6: CONCLUSION AND SOME RECOMMENDATIONS FOR THE FUTURE

6.0 BIOETHICAL CHALLENGES FOR HIV TESTING OF WOMEN IN AFRICA

In the preceding chapters, a number of points have been made about the bioethics and human rights challenges related to the HIV testing of women in sub-Saharan Africa. Included in these arguments have been many examples of how these challenges play out for women and girls in various sub-Saharan African countries and settings. The related philosophical principles also have been discussed in previous chapters. Some further explication will support and show why these principles and practices are important to address to strengthen both individual and global health toward better outcomes for women and girls in sub-Saharan Africa.

As discussed several times earlier in this paper, HIV is a greater biological, socioeconomic, and human rights threat to women than it is to men. This threat initially can be manifested through insensitive and even ignorant approaches to and conditions within which women and girls are tested for HIV, some against their knowledge of the testing, some coerced into the testing to be able to receive whatever care they have come to a clinic for, some informed that the testing is mandatory as a means of coercion, and some tested without any attempt by health professionals to implement informed consent of the testing process or to communicate the potential testing outcomes and what they mean, as well as future prevention, treatment, and care options, if any. Yet informed consent for HIV testing as an aspect of access to health-related information and services is a core bioethical and human right as the following describe:

1. "Because every health intervention (be it examination or treatment) constitutes interference with the individual, it is subject to the requirement of free and informed consent…" (Tomasevski, 1995, p. 136).

2. "Consent is defined as the agreement, expressed either verbally or in writing, to a proposed action or situation. For purposes of medical intervention or research, consent given by a subject for a procedure, course of treatment, or any other health intervention to be performed, must be informed. The subject should receive information about the intervention and must indicate that they understand the possible risks and/or benefits of participation; and, if consent is given, that it has been done so voluntarily without any feeling of coercion" (Fox, Ferguson, Ajose, et al., 2013, p. 3).

3. "Informed consent has historically been a cornerstone to ensuring autonomy during HIV testing…As the new guidance on HIV testing is implemented in different settings, it is critical to monitor women's testing experiences to ensure that a woman's right to make an informed, voluntary choice is not violated. Furthermore, models of testing that allow us to meet broader public health goals while simultaneously respecting women's autonomy are needed" (Groves, Maman, Msomi, et al., 2010, p. 1).

I would argue that the statement cited in 3, above, by women's health and research professionals about South Africa's new HIV testing protocol on routine testing in 2010 is no less important for women today in 2015 than it was then. Indeed, as recently as two years ago in 2013, South Africa's HIV epidemic was described by two South African physicians as "a poorly controlled human immunodeficiency virus (HIV) epidemic with high HIV prevalence, late diagnosis and incomplete access to timely treatment," implying that the public health interventions regarding HIV were not working (Richter & Dreyer, 2013, p. 2920). This was despite the country's routine testing policy having been put in place three years earlier. Informed consent remains a critical piece of the routine testing process, whether routine testing is suggested by health professionals in South Africa or in any other country.

6.1 BIOETHICAL CHALLENGES OF HIV TESTING OF ADOLESCENTS

Informed consent and indeed *consent* is a critical issue related to HIV testing particularly pertinent in the case of adolescents, as consent for HIV testing by adolescents varies from country to country related to the age of consent and whether a parent or guardian also needs to give consent for the testing of the adolescent; and, adolescents account for more than 41% of new HIV infections in the 15-49 age group worldwide (Fox, et al., 2013, pp. 3-4). The issues surrounding HIV testing, informed consent, and consent itself are of special concern to adolescent girls and young women in sub-Saharan Africa, where they account for 71% of the 3.8 million HIV infections in their age group across the region, which is also 76% of the global total of HIV infections among adolescents and young people (ibid., p. 1). Thus HIV testing, access to it if desired, the freedom to test or not, coercion related to it, and the potential lack of being able to test without parental

permission are all important issues surrounding the testing of adolescents, especially girls, in sub-Saharan Africa. These issues are at the core of HIV testing for adolescent girls in the region because of their heightened biological vulnerability to HIV infection as well as the greater risk they face because of the commonality of GBV, including gang rape, for which they need access to PEP within 72 hours afterward to minimise their HIV infection risk (ibid., p. 2).

It is critically important to protect the rights of women and girls related to HIV from the outset, that is, by providing access to information and HIV prevention methods and by helping to protect them from infection and maltreatment through HIV counselling and testing using a bioethical and human rights-based approach. According to the Report of the UN Special Rapporteur on Extreme Poverty and Human Rights in 2013, with an intentional focus on women as a vulnerable and marginalised group:

> "As part of their core obligations States must ensure the right of access to health facilities, goods, information and services—including in the area of sexual and reproductive health—on a non-discriminatory basis, especially for vulnerable or marginalized groups" (Sepúlveda Carmona, 2013, p. 12).

Eight years earlier in 2005 human rights lawyer Katarina Tomasevski addressed the "multiple human rights implications of HIV testing" as follows:

> "UNAIDS [has] advocated routine HIV testing in the context of sexually transmitted infections, pregnancy and 'where HIV

> is prevalent and antiretroviral treatment is available. Whether individuals can opt out of such routine testing depends on their knowledge of this choice and their capacity to exercise it…The conditions that make it possible for people to choose or refuse testing, or to refuse risky behavior whereby they might become infected, require examination of broader legal rules, not only those related to testing…Denials of women's rights impede the ability to self-protect" (2005, p. 4).

In the passage above, Tomsaevski focused her concern about HIV testing on the importance of having the choice to test or not. Related to choice is whether individuals facing routine testing for HIV are really autonomous and see themselves in a position to be able to make their own choice about testing—if they are given the opportunity—and believe they will not suffer any deleterious consequences from healthcare providers if they choose not to test for HIV. That having access to health services is crucial for anyone anywhere, and especially individuals in Africa where health services can be far less available than they are in industrialised countries, or of poor quality where they are available, is a caveat related to any disease and access to potential treatment or related services, including HIV and AIDS, and indeed HIV testing.

6.2 RECENT HIV RESEARCH RESULTS RELATED TO CHALLENGES WOMEN FACE IN SUB-SAHARAN AFRICA

A recent framework for the right of girls to education included in the ongoing Global Study on Women, Peace and Security by the United Nations focuses on the need for: availability; accessibility; acceptability; and, adaptability of education (Office of the High Commissioner on Human Rights, 2015, p. 8). I would argue that this same framework is an excellent one to apply to health services, including HIV testing. One size does not fit all related to education, health, or HIV testing. That many of the women participants in the recent Vaginal and Oral interventions to Control the Epidemic (VOICE) (MTN 003) HIV prevention trial conducted in South Africa, Uganda, and Zimbabwe from 2009 to 2012 who had agreed to take ART daily or use a vaginal microbicide to prevent sexual transmission of HIV neglected or decided not to take or use the prevention product, yet lied about not doing so for months so they could have access to monthly health services, shows how important such health service access really is, particularly to women in sub-Saharan Africa (Mastro, Sista and Abdool-Karim, 2014, p. 4). Yet the disappointing study results also documented how large an issue the stigma and discrimination surrounding HIV is in their communities, where women feared repercussions if they were seen as having any relationship to the possibility of present or future HIV infection, a level of stigma that was documented also by men in the communities (Saag, 2014, p. 565). It does not seem hard to imagine in this context fraught with stigma and discrimination related to HIV that the routine testing of individuals, particularly women, could backfire regarding the "acceptability" of this type of health service as a gateway to care for any health problem. It's a shame that apparently more than $90 million was spent and several years in the lives of the many women, health researchers, and physicians who were involved in this major study, whose disappointing results underscore the need to better understand the plight and behaviours of individual women and women as a group encountering the HIV epidemic in sub-Saharan Africa (ibid.). There remains an urgent need to systematically start to

politically, programmatically, and legally address the gender inequalities that foment the HIV epidemic, as well as the prevalent stigma and discrimination that continue to fuel the epidemic spread, particularly among women.

The VOICE study also recorded extraordinarily high annual HIV incidence rates of 4 to 9% in the women participating in the prevention trial in the three countries, rates that were significantly higher than expected by the study's designers (Mastro, Sista and Abdool-Karim, 2014, p. 1). Despite these depressing research study results, the need for more individuals to test for HIV to be able to get access to ART remains paramount. Because of this ongoing need, I propose that the prioritisation of routine testing as the HIV testing approach in South Africa and other sub-Saharan African countries should be reviewed as a truly ethically viable and acceptable and indeed successful 'routine' HIV testing strategy for everyone seeking health care for any condition in this region, including pregnant women, adolescent girls, all women, and members of any minority groups.

The VOICE trial, I believe, also documents the ultimate goal of the study participants as self-preservation, which I discussed at length in Chapter 5 related to the historic philosophical underpinning of this right—the ultimate human right—by Descartes, Hobbes, Kant, Locke, Mill, and Rousseau, among others. The concern of many of the women participants in VOICE with the opportunity to have access to monthly health care, many not wanting to take or use an unproven HIV prevention product on a regular basis so as not to possibly jeopardise their own health, and the potential physical, emotional, and psychological impact of the stigma and discrimination they could suffer if they were known to be affiliated with HIV through their own behaviours, activities, or via rumors in

the community supports their overall priority of self-preservation, the preservation of their positions in their families, socially in their communities, and even their reproductive future. I would argue that they should not be faulted for their need to protect and realise their own right to self-preservation. Rather, there needs to be more community mobilisation, planning, and acceptance, including methods to address gender disparities, implemented in advance of where such trials are funded to take place related to HIV in sub-Saharan Africa. In addition to what I suggest was self-preservation as the real priority of these women, their need for individual choice also surfaced as a secondary priority. Having a choice is important. It generally is a priority for human beings.

I also would posit that social justice and justice itself reared its head in the VOICE study results: it is not just to expect women to suffer potential serious stigma and discrimination on an individual basis for participating in a trial of any new product, even if the lives of many possibly could be extended if the study proves to be successful. Likewise, it is not just to expect women to immediately agree to routine testing for HIV supposedly to prevent HIV infections from occurring in other individuals when they may suffer serious stigma and discrimination from testing HIV-positive, or even for testing for HIV at all. Moreover, I don't believe routine HIV testing can be seen as a beneficent act unless anyone who tests HIV-positive has immediate access or a referral for access to ART if indeed they decide to go ahead with the test. And, I believe that in order to be ethical, routine testing must include pre-test counselling, fully informed consent, time to deliberate on one's individual testing decision, post-test counselling, and referrals to other available services. Where there is no more or less immediate ART access, or access to any other services, and where only single-dose nevirapine is available for PMTCT, I do not believe that routine testing is a beneficent or ethical HIV testing protocol. Further, as mentioned in

Chapter 5, routine testing for HIV, as practiced in some or perhaps even many health facilities in sub-Saharan Africa, is maleficent in that it can indeed harm an individual, especially someone who has not considered HIV testing previously, or someone who knows that merely testing for HIV may commence stigma and discrimination through a lack of confidentiality at health facilities that can spread across communities. These situations have been documented, and examples have been provided in previous chapters of this paper. For women who potentially face GBV because of testing for HIV, including testing HIV-positive, their health will suffer, psychologically even if not physically, and the impact may be long lasting or life threatening. What's more, they may be thrown out of their homes and even ostracised by their communities, or shunned by their family members and neighbors if they are allowed to remain living in the same place. They may lose their jobs—if they are lucky enough to have one—and they suddenly may have to figure out how their child or children or other family members can possibly be supported in the future. These are real issues of survival. These issues revolve around HIV testing here and now in 2015.

I believe all the issues surrounding HIV testing and indeed routine testing, or provider-initiated HIV testing, of women in sub-Saharan Africa have not been comprehensively examined before such policies have been put into place and routine testing has started to be implemented routinely. This stance was the genesis of this paper. I hope that some of the issues discussed herein have further illuminated how serious and important the reconsideration of HIV testing related to the contextual situation of gender-power relations of women and girls in sub-Saharan Africa really is. There is no time to waste by continuing to use HIV prevention and/or care approaches that do not work or that do not work for women. According to Geary and Bukusi,

> "Reducing HIV transmission among women in sub-Saharan Africa is key to ending the global AIDS epidemic, where over 70% of all new infections occur each year. Out of the over 16 million women living with HIV globally, over 12 million are in sub-Saharan Africa" (2014, p. 1).

To prevent further HIV infections among women, women have to be able to have access to HIV prevention methods and they have to be willing and want to use them. We are still lost amidst the framework of 'availability, accessibility, acceptability, and adaptability' related to overall health services, as well as HIV-related services, including testing. The need for women to make their own HIV testing decisions, whether it is to access voluntary counselling and testing, community- or home-based HIV testing, agree to diagnostic HIV testing if they are ill and seek care, or even access ethically promoted and implemented routine testing, whether they are healthy, ill, or pregnant, is each and every woman and girl's human right. No one has the right to take this human right away from any of them.

6.3 CONCLUSION ON THE BIOETHICAL AND HUMAN RIGHTS CHALLENGES OF THE HIV TESTING OF WOMEN IN SUB-SAHARAN AFRICA

Where HIV testing is practiced in sub-Saharan African countries, and anywhere for that matter, without alignment with the bioethical principles of respect for autonomy, justice, beneficence, and non-maleficence, and without protecting the human rights of individuals testing for HIV, including the provision of pre- and post-test counselling, implementing the informed consent process, maintaining the confidentiality of test results, and making

referrals to other services available to all individuals who test negative or positive as well as making antiretroviral therapy (ART) available to anyone who tests HIV-positive, such testing is unethical. Thus I posit that the routine testing for HIV of all individuals presenting to a clinic for healthcare—and the routine testing of all pregnant women for HIV—amidst the highly stigmatised HIV epidemic in sub-Saharan Africa is unethical.

6.4 RECOMMENDATIONS FOR PROGRAMMATIC AND POLICY CONSIDERATIONS RELATED TO HIV TESTING

The following are recommendations for either policy or programmatic considerations related to HIV testing:

- Where routine or provider-initiated testing can be promoted and implemented in an ethical manner, including pre-test counselling, fully informed consent, enough time to deliberate whether to test or not, post-test counselling including individual risk-reduction counselling for anyone testing HIV-positive so they do not get re-infected and to minimise the risk of onward transmission, or negative so they can prevent infection in the future, and post-test referrals, I suggest making this testing method an ‘opt-in’ option, rather than continue to use an ‘opt-out’ testing approach.
- Increase the availability and accessibility of HIV testing by expanding the range of HIV testing options offered in communities and at facilities, including door-to-door home-based testing by trained providers; community-based voluntary counselling and testing using trained lay counsellors; expanded hours for voluntary counselling and testing at health facilities, which also could be staffed by trained lay counsellors; and, sale of HIV testing kits with 24/7 phone lines available staffed by trained HIV/GBV counsellors to provide counselling support.

- Restrict routine testing to where ART is directly available to anyone testing HIV-positive and include adherence counselling, as well as follow-up care or make referrals to local follow-up: including prevention, treatment, care, and support services.
- Add HIV counselling and testing to all physician and nursing curricula in medical and nursing schools in sub-Saharan Africa and include bioethics and human rights training as part of this curriculum, as well as expand the training of community-based counsellors to include human and sexual and reproductive rights.
- Lower the age of HIV testing to 12 without the need for parental or guardian consent in the countries and/or locations where currently the age of consent is older than 12 or parental consent also is needed.
- Make sexual and reproductive health education with a central focus on healthy behaviours and gender equality a mandatory curriculum for boys and girls in all schools starting at age 8 and implement teacher and principal training on this topic where needed.
- Expand the availability of PEP for females and males—adults, adolescents, and children—in health facilities in sub-Saharan African countries with generalised HIV epidemics and include training for the police to ensure immediate care before a police report, where needed, is filed, and make PEP available for anyone who wants it based on potential HIV exposure, not just related to GBV or potential nosocomial exposure.
- Enforce the laws on the prevention and occurrence of GBV for both girls and boys and women and men and advocate for and enact laws, where needed, on this widespread crime in sub-Saharan African countries, especially the high-prevalence countries in southern Africa; and, review and reform any discriminatory laws based

on HIV transmission criminalisation in sub-Saharan African countries with a special focus on women and minority groups.

REFERENCES

Adimora AA, Ramirez C, Auerbach JD, et al. 2013. Preventing HIV Infection in Women. *Journal of Acquired Immune Deficiency Syndrome*. 63(Supplement 2): S168-S173. http://pdfs.journals.lww.com/jaids/2013/07012/Preventing_HIV_Infection_In_Women.11.pdf [Accessed 04.07.2013].

Africa Coalition on Maternal, Newborn & Child Health. 2014. *2014 Integrated Africa Cancer Factsheet Focusing on Cervical Cancer + Girls & Women Health/Sexual & Reproductive Health, HIV & Maternal Health*. Lagos: Afri-Dev.Info. http://www.who.int/pmnch/media/events/2014/Africa-cancer-factsheet.pdf [Accessed 02.02.2015].

Africa Coalition on Maternal, Newborn & Child Health. 2014. *Southern Africa/SADC 2014 Contextual Scorecard & Factsheet on: HIV; Sexual & Reproductive Health & Rights; and Universal Health Coverage*. http://www.afri-dev.info/sites/default/files/Southern%20Africa%2ORSHR%20%26%2OUHC%20scorecard%20%282024%20yrs-Fin.prf [Accessed 16.01.2015].

Agaba J. 2013. Activists Oppose Mandatory HIV Testing Plan. Uganda: *New Vision*. 12.09. Sent via email from RECTALMICRO@lists.critpath.org [Accessed 13.09.2013].

Alcorn K. 2014. Maternal Deaths Due to HIV Not Declining Despite PMTCT Successes in South Africa. *AIDSmap News*. 06.03. London: NAM. http://www.aidsmap.com/page/283384/?utm_source=NAM-E-mail-Promotion&utm_medium=aidsmap-news&utm_campaign=aidsmap-news [Accessed 26.03.2014].

Angell M. 1993. The Doctor as Double Agent. *Kennedy Institute of Ethics Journal*. 3: 279-286. Introduction to Bioethics course hand-out. University of the Witwatersrand, School of Clinical Medicine, 2006.

Angotti N, Dionne KY & Gaydosh L. 2010. An Offer You Can't Refuse? Provider-Initiated HIV Testing in Antenatal Clinics in Rural Malawi. *Health Policy and Planning*. 25(Advance Online): 1-9. http://heapol.oxfordjournals.org/content/early/2010/11/02/heapol.czq066.full.pdf+html. [Accessed 30.08.2013].

April M. 2010. Rethinking HIV Exceptionalism: The Ethics of Opt-out HIV Testing in Sub-Saharan Africa. *Bulletin of the World Health Organization*. 88: 703-708. http://www.who.int/bulletin/volumes/88/9/09-073049/en/ [Accessed 13.11.2013].

Armstrong R. 2008. Mandatory HIV Testing in Pregnancy: Is There Ever a Time? *Developing World Bioethics*. 8(1): 1-10. http://www.ncbi.nlm.nih.gov/pubmed/18315721 [Accessed 21.06.2009]

Ashford E. 2007. The Duties Imposed by the Human Right to Basic Necessities. In: Pogge T, ed. *Freedom from Poverty as a Human Right.* Oxford: Oxford University Press.

Associated Press. 1998. HIV Positive SAfrica Woman Murdered. Johannesburg: Associated Press. 03.12. http://www.aegis.com/news/ap/1998/AP981219.html [Accessed 25.11.2007].

Associated Press. 2013. *Go Well Madiba – Mandela Funeral Quotes*. News 24.12. http://www.news24.com/print/Article.aspx?iframe&aid=42337c61-e00e-4d3c-8b2c-8b09b... [Accessed 17.12.2013].

Baggaley R, Henson B, Ajose O, et al. 2012. From Caution to Urgency: The Evolution of HIV Testing and Counselling in Africa. *Bulletin of the World Health Organization.* 90: 652-658. http://www.who.int/bulletin/volumes/90/9/11-100818/en/ [Accessed 06.11.2013].

Barnabas RV, van Rooyen H, Tumwesigye E, et al. 2014. Initiation of Antiretroviral Therapy and Viral Suppression after Home Testing and HIV Counselling in KwaZulu-Natal, South Africa, and Mbarara District, Uganda: A Prospective, Observational Intervention Study. *Lancet HIV*. http://download.thelancet.com/pdfs/journals/lanhiv/PIIS2352301814700244.pdf?id=caaeM0fWHRX0rhqFkom0u [Accessed 02.12.2014].

Bartlett JG. 2009. Universal Voluntary HIV Testing with Immediate ART. *Medscape Infectious Diseases.* 2009a. http://www.medscape.com/viewarticle/589536 [Accessed 02.04.2009].

Barton A. 2014. Uganda's HIV Criminalization, Mandatory Testing Bill Signed into Law against Local and International Cautions of Harms to Health, Human Rights. *Science Speaks: HIV & TB News*. 20.08. http://sciencespeaksblog.org/2014/.../ugandas-hiv-criminalization-mandatory-testing-bill-signed-into-law-against-local-international-cautions-of-resulting-harms/ [Accessed 02.03.2015].

Bassett IV & Walensky RP. 2010. Integrating HIV Screening into Routine Health Care in Resource-Limited Settings. *Clinical Infectious Diseases.* 50(Supplement 3): S77-S84. http://sciencespeaks.files.wordpress.com/2010/05/integrating-hiv-screening-into-routine-health-care.pdf [Accessed 29.09.2010].

Beauchamp TL. 1990. Promise of the Beneficence Model for Medical Ethics. *Journal of Contemporary Health Law and Policy*. 6(1): 145-155. http://scholarship.lae.edu/cgi/viewcontent.cgi?article=1592&context=jchlp [Accessed 21.05.2014].

Beauchamp TL & Childress JF. 1994. *Principles of Biomedical Ethics*, 4th edition. New York: Oxford University Press. 560 p.

Beauchamp TL & Childress JF. 2001. *Principles of Biomedical Ethics*, 5th edition. New York: Oxford University Press. 455 p.

Beauchamp TL & Faden RR. 1979. The Right to Health and the Right to Health Care. *The Journal of Medicine and Philosophy*. 4(2): 118-130. [Sent via email by Thomas Pogge 01.08.2009].

Becker J, Tsague L, Sahabo R, et al. 2009. Provider Initiated Testing and Counseling (PITC) for HIV in Resource-limited Clinical Settings: Important Questions Unanswered. *PanAfrican Medical Journal*. 3(4): 1-8. http://www.panafrican-med-journal.com/content/editorial/3/4/pdf/4.pdf [Accessed 26.10.09].

Bekker LG, Venter F, Cohen K, et al. 2014. Provision of Antiretroviral Therapy in South Africa: The Nuts and Bolts. *Antiviral Therapy*. 19(Supplement 3): 105-116. http://www.intmedpress.com/serveFile.cfm?sUID=eb5d9fc6-3267-4737-ac8c-7d11b0694164. [Accessed 27.02.2015].

Bello FA, Ogunbode OO, Adesina OA, et al. 2011. Acceptability of Counselling and Testing for HIV Infection in Women in Labour at the University College Hospital, Ibadan, Nigeria. *African Health Sciences*. 11(1): 30-35. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3092324/pdf/AFHS1101-0030.pdf [Accessed 08.11.2013].

Berlin I. 1991. John Stuart Mill and the Ends of Life. In: Gray J & Smith GW, eds. *On Liberty: in Focus*. London: Routledge. pp. 131-161.

Bernard EJ & Cameron S. 2013. *Advancing HIV Justice: A Program Report on Achievements and Challenges in Global Advocacy against HIV Criminalisation*. Amsterdam/London: Global Network of People Living with HIV and HIV Justice Network. http://www.hivjustice.net/wp-content/uploads/2013/05/Advancing-HIV-Justice-June-2013.pdf [Accessed 05.11.2013].

Beyrer C. 2013. HIV Now: Why Human Rights Matter More than Ever. *Journal of the International AIDS Society*. 15: 1-2. http://www.jiasociety.org/index.php./jias/article/view18968 [Accessed 12.12.2013].

Blom JJ. 1978. *Descartes: His Moral Philosophy and Psychology*. Hassocks, Sussex: The Harvester Press. 309 p.

Boetsen J. 2009. Transactable Sex and Unsafe Practices: Gender and Sex when Living with HIV in Tanzania. In: Boetsen J & Poku NK, eds. *Gender and HIV/AIDS: Critical Perspectives from the Developing World*. Surrey: Ashgate e-Book.

Botswana Network on Ethics, Law and HIV/AIDS (BONELA). 2013. *Botswana's Draconian Public Health Bill Approved by Parliament. BONELA Will Challenge It as Unconstitutional Once President Signs in Law* (Update 3). 05.04. Gaborone: Botswana Network on Ethics, Law and HIV/AIDS (BONELA). http://www.hivjustice.net/news/botswana-public-health-bill-hiv-related-provisions-counter-productive-discriminatory-unconstitutional-and-barbaric [Accessed 27.02.2014].

Brandt AM. 2013. How AIDS Invented Global Health. *The New England Journal of Medicine*. 368(23): 2149-2152. http://www.nejm.org/doi/pdf/10.1056/NEJMp1305297 [Accessed 29.11.2013].

Branson BM, Handsfield HH, Lampe MA, et al. 2006. Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings. *Morbidity*

and Mortality Weekly Recommendations and Reports. 55: 1-17. http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5514a1.htm [Accessed 23.09.2006].

Branson BM, Viall A, & Marum E. 2013. Expanding HIV Testing: Back to the Future. *Journal of Acquired Immune Deficiency Syndrome*. 63(Supplement 2): S117-S121. http://pdfs.journals.lww.com/jaids/2013/07012/Expanding_HIV_Testing_Back_to_the_Future.2.pdf [Accessed 14.11.2013].

Burnett M. 2014. *Dispatches: Another Step Back for Uganda's HIV Fight*. New York: Human Rights Watch. http://www.hrw.org/print/news/2014/09/09/dispatches-another-step-back-uganda-s-hiv-fight [Accessed 02.03.2015].

Buse K, Eba P, Sigurdson J, et al. 2013. Leveraging HIV-Related Human Rights Achievements through a Framework Convention on Global Health. *Health and Human Rights*. 15(1): 96-110 http://worpress.sph.harvard.edu/hhrjournal/wp-content/uploads/sites/13/2013/06/Buse-Final.pdf [Accessed 02.09.2013].

Cairns G. 2009. 'Treatment as Prevention' Must Not Violate Human Rights, Conference Told. *Aidsmap News.* 21.07. http://www.aidsmap.com/en/news/C35EF8E0-2F47-4F7B-909C-6D30FB600972.asp... [Accessed 23.02.2010].

Cameron E. 2005. *Witness to AIDS*. Cape Town: Tafelberg. 238 p.

Cameron E. 2010. Stigma, Human Rights, Testing and Treatment–Time for Action. *The Southern African Journal of HIV Medicine*. 37: 6-18.

Campbell C & Gibbes A. 2009. Stigma, Gender and HIV: Case Studies of Inter-Sectionality. In: Boetsen J & Poku NK, eds. *Gender and HIV/AIDS: Critical Perspectives from the Developing World.* Surrey: Ashgate e-Book. pp. 29-46.

Carroll R. 2003. AIDS Activist Murdered in Gang Rape. *The Guardian*. 22.12. http://www.guardian.co.uk/southafrica/story/0,13262,1111505,00.html [Accessed 25.11.2007].

Carter M. 2014. High Rates of Drug Resistance among HIV-Positive Infants in South Africa. *HIV & AIDS Information*. 13.07. pp.1-2. London: NAM. http://www.aidsmap.com/print/High-rates-of-drug-resistance-among-HIV-positive-infants-in-south-Africa/page/2890445/ [Accessed 17.07.2014].

Centers for Disease Control and Prevention (CDC). 2004. Introduction of Routine HIV Testing in Prenatal Care—Botswana, 2004. *Morbidity and Mortality Weekly*. 53(46): 1083-1086. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5346a2.htm [Accessed 13.11.2013].

Centers for Disease Control and Prevention. 2011. *Implementation of Routine HIV Testing in Health Care Settings: Issue for Community Health Centers*. Atlanta: National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention.

http://www.cdc.gov/HIV/topics/testing/resources/guidelines/pdf/routineHIVtesting.pdf [Accessed 06.11.2013].

Centers for Disease Control and Prevention. 2013. *Pregnancy Complications-Reproductive Health.* Atlanta: Centers for Disease Control and Prevention. Division of Reproductive Health. http://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregcomplications.htm [Accessed 07.11.2013].

Chersich MF & Rees HV. 2008. Vulnerability of Women in Southern Africa to Infection with HIV: Biological Determinants and Priority Health Sector Interventions. *AIDS*. 22(Supplement 4): S27-S40.

Christman J & Anderson J. 2005. Introduction. In: Christmas J & Anderson J, eds. *Autonomy and the Challenges to Liberalism*. Cambridge: Cambridge University Press. 383 p.

Cicero MT. 1887. *Ethical Writings of Cicero: Book I.* Peabody AP, trans. Boston: Little, Brown, and Company. 542 p. http://Oll.Libertyfund.org/titles/cicero-rthical-writings-on-moral-duties-on-old-age-on-friendship-scipios-dream [Accessed 16.05.2014].

Clark SJ, Kahn K, Houle B, et al. 2013. Young Children's Probability of Dying Before and After Their Mother's Death: A Rural South Africa Population-Based Surveillance Survey. *PLOS Medicine.* 10(3): 1-10. http://www.plosmedicine.org/article/fetchObject.action?uri-info:doi/10.1371/journal.pmed.1001409&representation=PDF [Accessed 22.03.2105].

Clarke D. 2003. *Descartes's Theory of Mind*. Oxford: Clarendon Press. 267 p.

Cohen MS, Chen YQ, McCauley M, et al. 2011. Prevention of HIV-1 Infection with Early Antiretroviral Therapy. *The New England Journal of Medicine*. 365(6): 493-505. http://www.nejm.org/doi/.pdf/10.1056/NEJMoa1105243 [Accessed 14.03.2015].

Conway-Smith E. 2010. South Africa Launches World's Biggest Anti-AIDS Drive. *GlobalPost*. 20.05. http://globalpost.com/print/5552848 [Accessed 29.05.2010].

Cubasch H, Joffe M, Hanisch R, et al. 2013. Breast Cancer Characteristics and HIV among 1,092 Women in Soweto, South Africa. *Breast Cancer Research and Treatment*. 140: 177-186. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3706733/pdf/10549_2013_Article_2606.pdf [Accessed 02.02.2015].

Dalal S, Lee CW, Farirai T, et al. 2011. Provider-Initiated HIV Testing and Counseling: Increased Uptake in Two Public Community Health Centers in South Africa and Implications for Scale-Up. *PLoS One*. 6(11): 1-8. http://www.ncbi.nlm.nih.gov/pubmed/22114668 [Accessed 17.11.2013].

Daniels, N. 1981. Health-Care Needs and Distributive Justice. In: Cohen M, Nagel T & Scanlon T, eds. *Medicine and Moral Philosophy*. Princeton: Princeton University Press. [Sent via email by Thomas Pogge 01.08.2009].

Daniels N. 1996. *Justice and Justification: Reflective Equilibrium in Theory and Practice*. Cambridge: Cambridge University Press. 365 p.

Daniels N. 2001. Justice, Health and Health Care. *American Journal of Bioethics.* 1(2): 2-16. http://www.hsph.harvard.edu/benchmark/ndaniels/pdf/justice_health.pdf [Accessed 08.06.2010].

Daniels N. 2009. Just Health: Replies and Further Thoughts. *Journal of Medical Ethics*. 35: 36-41. http://jme.bmj.com/content/35/1/36.full.pdf [Accessed 13.11.2011].

Das-Douglas M, Chu P, Santos G-M, et al. 2010. Decreases in Community Viral Load Are Associated with a Reduction in New HIV Diagnoses in San Francisco; Abstract 33. San Francisco: 17th Conference on Retroviruses and Opportunistic Infections; 16-19.02. http://www.hiv@natap.org [Accessed 14.05.2010].

De Bruyn M & Paxton S. 2005. HIV Testing of Pregnant Women—What is Needed to Protect Positive Women's Needs and Rights? *Sexual Health.* 2(3): 143-151. http://www.ncbi.nlm.nih.gov/pubmed/16335542 [Accessed 20.06.2013].

De Grazia D, Mappes TA & Brand-Ballard J. 2011. *Biomedical Ethics*. New York: McGraw Hill. 752 p.

De Zulueta P & Boulton M. 2007. Routine Antenatal HIV Testing: The Responses and Perceptions of Pregnant Women and the Viability of Informed Consent: A Qualitative Study. *Journal of Medical Ethics*. 33: 329-336. http://jme.bmj.com/cgi/content/abstract/33/6/329 [Accessed 06.04.2009].

Denison JA, Banda H, Dennis AC, et al. 2015. "The Sky Is the Limit": Adhering to Antiretroviral Therapy and HIV Self-Management from the Perspectives of Adolescents Living with HIV and their Adult Caregivers. *Journal of the International AIDS Society.* 18: 1-5. http://www.jiasociety.org/index.php/jias/article/view/19358 [Accessed 27.01.2015].

Department of Health. Republic of South Africa. 1996. *The Patients' Rights Charter*. Pretoria: Department of Health. http://www.doh.gov.za/docs/legislation/patientsrights/chartere.html [Accessed 21.03.2015].

Department of Health. Republic of South Africa. 2014. *National Consolidated Guidelines for the Prevention of Mother-to-Child Transmission of HIV (PMTCT) and the Management of HIV in Children, Adolescents and Adults*. Pretoria: Department of Health. http://www.health.gov.za/docs/hivAids/HIVguidelinesJan2015final.pdf. [Accessed 27.02.2015].

Doherty T, Tabana H, Jackson D, et al. 2013. Effect of Home Based HIV Counselling and Testing Intervention in Rural South Africa: Cluster Randomised Trial. *BMJ*. 346: 1-11. http://www.bmj.com/bmj/346/bmj.f3481.full.pdf. [Accessed 12.03.2015].

Dunkle K, Jewkes R, Brown H, et al. 2003. *Gender-Based Violence and HIV Infection among Pregnant Women in Soweto: A Technical Report to the Australian Agency for*

International Development. Canberra: Australian Agency for International Development (AusAID). 57 p. http://www.mrc.ac.za/gender/women.pdf [Accessed 26.11.2014].

Dworkin R. 1977. *Taking Rights Seriously*. London: Duckworth. 293 p.

Elander G & Hermeren G. 2013. Autonomy and Paternalistic Behaviour in Care. *Scandinavian Journal of Caring Sciences*. 3(4): 1-2. http://www.readcube.com/articles/10.1111%2Fj.1471-6712.1989.tb00286.x [Accessed 04.03.2015].

Eller LS, Rivero-Mendez M, Voss J, et al. 2013. Depressive Symptoms, Self-Esteem, HIV Symptom Management Self-Efficacy and Self-Compassion in People Living with HIV. *AIDS Care*. 26(7): 795-803. http://www.nbci.nlm.nih.gov/pubmed/24093715?goback=%2Egde_3414723_member_58... [Accessed 01.11.2013].

Encyclopedia of Bioethics. 2014. Beneficence. http://www.encyclopedia.com/article-1G2-3402500068/beneficence.html [Accessed 13.05.2014].

Evans C & Ndirangu E. 2011. Implementing Routine Provider Initiated HIV Testing in Public Healthcare Facilities in Kenya: A Qualitative Descriptive Study of Nurses' Experiences. *AIDS Care*. 23(10): 1291-1297. http://peer.ccsd.cnrs.fr/docs/00/71/09/15/PDF/PEER_stage2_10.1080%252FO9540121.2011.555751.pdf [Accessed 20.08.2013].

Ezer T. 2013. *How Improving Women's Rights Helps Stop AIDS in Africa*. 16.12. New York: Open Society Foundations. http://www.opensocietyoundations.org/voices/how-improving-womens-rights-helps-stop... [Accessed 17.12.2013].

Fallon A. 2014. *No Hope for AIDS-Free Generation in Uganda as Controversial HIV Bill is Signed into Law*. Kampala: Inter Press Service 21.08. http://www.ipsnews.net/2014/08/no-hope-for-aids-free-generation-in-uganda-as-controversial-hiv-bill-is-signed-into-law/ [Accessed 04.03.2015].

Fethers K, Andrews P, McCoy R, et al. 2008. Talking about Testing: Pre-Test and Post-Test Discussion. In: Australian Society for HIV Medicine. *HIV, Viral Hepatitis and STUIs: A Guide for Primary Care*. Surry Hills, NSW: Australian Society for HIV Medicine. http://www.ashm.org.au/images/publications/monographs/HIV_viral_hepatitis_and_STIs_a_guide_for_primary_care/hiv_viral_hep_chapter_9.pdf [Accessed 21.11.2013].

Flew A, ed. 1979. Golden Rule. *A Dictionary of Philosophy*. London: Pan Books in association with MacMillan Press. http://en.wikipedia.org/wiki/Golden_Rule [Accessed 04.12.2013].

Forsyth BWC, Barringer SR, Wall TA, et al. 2004. Rapid Testing of Women in Labor: Too Long a Delay. *Journal of Acquired Immune Deficiency Syndrome*. 35(2): 151-154. http://journals.lww.com/jaids/fulltext/2004/02010/rapid_hiv_testing_of_women_in_labor__too_long_a.8.aspx. [Accessed 04.03.2015].

Fox K, Ferguson J, Ajose W, et al. 2013. *Adolescent Consent to HIV Testing: A Review of Current Policies and Issues in Sub-Saharan Africa*. Geneva: World Health Organization. 100 p. http://www.ncbi.nlm.nih.gov/books/NBK217962/pdf/TOC.pdf [Accessed 31.03.2015].

Frankena WK. 1982. Beneficence in an Ethics of Virtue. *Philosophy and Medicine.* 11: 63-81. http://link.springer.com/chapter/10.1007%2F978-94-009-7769-3_3#page-1 [Accessed 16.05.2014].

Friedman M. 2005. Autonomy and Male Dominance. In: Christmas J & Anderson J, eds. *Autonomy and the Challenges to Liberalism*. Cambridge: Cambridge University Press. pp. 150-169.

Gaillard P, Melis R, Mwanyumba F, et al. 2002. Vulnerability of Women in an African Setting: Lessons for Mother-to-Child HIV Transmission Prevention Programmes. *AIDS*. 16(6): 937-939. http://0-gateway.ut.ovid.com.innopac.wits.ac.za/gw1/ovidweb.cgi [Accessed 01.08.2007].

Gaizler G & Nyeky K. 2011. Hippocratic Medical Ethics. *Bioethics.* http://www.tankonyvtar.hu/en/tartalom/tamop425/0006_Bioetika_es_kornyezeti_etika/ch01s02.html [Accessed 13.05.2014].

Garcia-Moreno C, Jansen HAFM, Ellsberg M, et al. 2006. Prevalence of Intimate Partner Violence: Findings from the WHO Multi-Country Study on Women's Health and Domestic Violence. *The Lancet*. 368: 1260-1269. http://www.who.int/gender/violence/who_multi-country_study/media_corner/Prevalence_intimatepartner_WHOstudy.pdf [Accessed 04.12.2014].

Garcia-Moreno C, Pallitto C, DeVries K, et al. 2013. *Global and Regional Estimates of Violence against Women: Prevalence and Health Effects of Intimate Partner Violence and Non-Partner Sexual Violence.* Geneva: World Health Organization/London School of Hygiene & Tropical Medicine/South African Medical Research Council. http://apps.who.int/iris/bitstream/10665/85239/1/9789241564625_eng.pdf [Accessed 21.06.2013].

Gari S, Malungo JRS, Martin-Hilber A, et al. 2013. HIV Testing and Tolerance to Gender Based Violence: A Cross-Sectional Study in Zambia. *PLOS One*. 8(8): 109. http://www.plosone.org/article/fetchobject,action?uri=info%3Adoi%2F10.1371%2Fjournal.pone.0071922&representation=PDF [Accessed 29.09.2013].

Geary CW & Bukusi EA. 2014. Women and ARV-Based HIV Prevention—Challenges and Opportunities. *Journal of the International AIDS Society*. 17(Supplement 2): 1-4. http://jiasociety.org/index.php/jias/article/view/19356 [Accessed 05.02.2015].

Geng EH, Bwana MB, Muyindike W, et al. 2013. Failure to Initiate Antiretroviral Therapy, Loss to Follow-Up and Mortality among HIV-Infected Patients during the Pre-ART Period in Uganda. *Journal of Acquired Immune Deficiency Syndrome.* 63(2): e64-e71. http://www.ncbi.nlm.nih.gov/pubmed/23429504 [Accessed 15.11.2013].

Gewirth A. 2007. Duties to Fulfill the Human Rights of the Poor. In: Pogge T, ed. *Freedom from Poverty as a Human Right*. Oxford: Oxford University Press, pp. 219-236.

Gilligan C. 1985. In a Different Voice: Women's Conceptions of Self and of Morality. In: Eisenstein H & Jardine A, eds. *The Future of Difference*. New Brunswick, NJ: Rutgers University Press. pp. 274-317. http://sfonline.barnard.edu/sfxxx/douments/gilligan.pdf [Accessed 18.07.2014].

Global Burden of Disease 2013 Mortality and Causes of Death Collaborators. 2015. Global, Regional, and National Age-Sex Specific All-Cause and Cause-Specific Mortality for 240 Causes of Death, 1990-2013: A Systematic Analysis for the Global Burden of Disease Study 2013. *The Lancet*. 385: 117-161. http://www.thelancet.com/pdfs/journals/lancet/PIISO140-6736(14)61682-2.pdf [Accessed 15.01.2015].

Global Fund. 2013. *Request for Proposal RFP No. TGF-13-065: Technical Assistance on Human Rights, Gender, Community Systems Strengthening and Key Population Engagement in the Global Fund New Funding Model January – June 2014*. Geneva: The Global Fund to Fight AIDS, Tuberculosis and Malaria. 19.12. [Received via email from the Global Fund on 24.12.2013].

Gonzalez C, Dana J, Koshino H, et al. 2004. The Framing Effect and Risky Decisions: Examining Cognitive Functions with fMRI. *Journal of Economic Psychology*. 26: 1-20. http://www.cobi.cmu.edu/reprints/Gonzalez/JOEP2005_decision-making.pdf [Accessed 20.11.2009].

Granich RM, Gilks CF, Dye C, et al. 2009. Universal Voluntary HIV Testing with Immediate Antiretroviral Therapy as a Strategy for Elimination of HIV Transmission: A Mathematical Model. *The Lancet*. 373(9697): 48-57. http://www.lancet.com/journals/lancet/article/PIIS0140-6736(08)61697-9/abstract [Accessed 15.07.2009].

Gregor M. 1998. Introduction. *Groundwork of the Metaphysics of Morals*. Gregor M, trans. Cambridge: Cambridge University Press. 76 p.

Grimsley R. 1973. The *Philosophy of Rousseau*. London: Oxford University Press. 182 p.

Groves AK, Maman S, Msomi S, et al. 2010. The Complexity of Consent: Women's Experiences Testing for HIV at an Antenatal Clinic in Durban, South Africa. *AIDS Care.* 22(5): 538-544. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2992088/pdf/nihms228009.pdf [Accessed 02.11.2013].

Gruskin S, Ahmed S, Ferguson L. 2008. Provider-initiated HIV Testing and Counseling in Health Facilities — What Does this Mean for the Health and Human Rights of Pregnant Women? *Developing World Bioethics*. 8(1): 23-32. http://www.ncbi.nlm.nih.gov/pubmed/18315722 [Accessed 04.12.2011].

Gruskin S, Mills EJ & Tarantola D. 2007. History, Principles, and Practice of Health and Human Rights. *The Lancet.* 370: 449-455. http://www.hospicecare.com/uploads/2011/8/history_principles_practice_health_human_rights_the_lancet.pdf [Accessed 18.12.2013].

Gupta S, Granich R, Suthar AB, et al. 2013. Global Policy Review of Antiretroviral Therapy Eligibility Criteria for Treatment and Prevention of HIV and Tuberculosis in Adults, Pregnant Women, and Serodiscordant Couples. *Journal of Acquired Immune Deficiency Syndrome*. 62(3): e87-97. http://www.ncbi.nlm.nih.gov/pubmed/23187942 [Accessed 15.11.2013].

Hamela G, Tembo T, Rosenberg NE, et al. 2013. Womens Experiences of HIV Testing and Counselling in the Labour Ward: A Case of Bwaila Hospital. *Malawi Medical Journal*. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3784934/pdf/MMJ2502-0036.pdf [Accessed 08.11.2013].

Hardon A, Vernooj E, Bongololo-Mbera G, et al. 2012. Women's Views on Consent, Counseling and Confidentiality in PMTCT: A Mixed-Methods Study in Four African Countries. *BMC Public Health.* 12(26): 1-15. http://www.biomedcentral.com/content/pdf/1471-2458-12-26.pdf [Accessed 18.11.2013].

Hegarty KL, Gunn JM, O'Doherty LJ, et al. 2010. Women's Evaluation of Abuse and Violence Care in General Practice: A Cluster Randomised Controlled trial (WEAVE). *BMC Public Health*. 10(2): 1-11. http://www.biomedcentral.com/content/pdf/1471-2458-10-2.pdf [Accessed 27.11.2014].

Held V. 2004. Taking Care: Care as Practice and Value. In: Calhoun C, ed. *Setting the Moral Compass: Essays by Women Philosophers*. Oxford: Oxford University Press. pp. 59-71.

Held V. 2006. *The Ethics of Care: Personal, Political and Global*. Oxford: Oxford University Press. 224 p.

Hensen B, Baggaley R, Wong VJ, et al. 2012. Universal Voluntary HIV Testing in Antenatal Care Settings: A Review of the Contribution of Provider-Initiated Testing & Counselling. *Tropical Medicine and International Health*. 17(1): 59-70. http://onlinelibrary.wiley.com/doi/10.1111/j.1365-3156.2011.02893.x/pdf [Accessed 13.11.2013].

Heywood MJ. 2005. The Routine Offer of HIV Counseling and Testing: A Human Right. *Health and Human Rights*. 8(2): 13-19.

Hippocrates. 1846. *The Writings of Hippocrates and Galen*. Coxe JR, trans. Philadelphia: Lindsay and Blakiston. http://oll.libertyfund.org/titles/hippocrates-the-writings-of-hippocrates-and-galen [Accessed 22.05.2014].

Hippocrates. 1849. *The Oath*. Adams F, trans. London: Sydenham Society. http://classics.mit.edu/Hippocrates/hippooath.html [Accessed 02.01.2008].

Hippocrates. 1868. *Of the Epidemics*. Adams F, trans. New York: Dover. 56 p.

HIV Justice Network. 2012. *Canada: Supreme Court Makes Bad Law Worse.* 05.10. http://www.hivjustice.net/news/canada-supreme-court-makes-bad-law-worse/ [Accessed 05.12.2013].

Hobbes T. 1991. *Leviathan*. Tuck R, ed. Cambridge: Cambridge University Press. 618 p.

Hobbes T. 2000. The State of Nature and the Laws of Nature. In: Solomon RC, Murphy MC, eds. *What Is Justice? Classic and Contemporary Readings*. New York: Oxford University Press. pp. 63-73.

Hoffman SZ. 2004. HIV/AIDS in Cuba: A Model for Care or an Ethical Dilemma? *African Health Sciences.* 4(3): 208-209. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2688320/pdf/AFHS0403-0208.pdf [Accessed 20.12.2013].

Horwood C, Butler LM, Haskins L, et al. 2013. HIV-Infected Adolescent Mothers and Their Infants: Low Coverage of HIV Services and High Risk pf HIV Transmission in KwaZulu-Natal, South Africa. *PLOS One*. 8(9): 1-8. http://www.plosone.org/article/fetchObject.action?uri=info%3Adoi%2F10.1371%2Fjournal.pone.0074568&representation=PDF [Accessed 29.09.2013].

Hsieh Y-H & de Arazoza H. 2009. Correspondence. *The Lancet.* 373: 1079. http://www.who.int/hiv/events/artprevention/epstein.pdf [Accessed 08.04.2010].

Hume D. 1751. Section II. Of Benevolence. Part I. *An Enquiry into the Principles of Morals.* pp. 1-6. http://ebooks.adelaide.edu.au/h/hume/david/h92pm/chapter2.html [Accessed 10.04.2014].

Hume D. 1978. *Treatise of Human Nature, Book III.* Selby-Bigge AL, ed., Nidditch PH, rev. Oxford: Clarendon Press.

IRIN PlusNews. 2010. South Africa: National HIV Testing Campaign Disappoints. *IRIN Plus News*. 07.09. http:///www.plusnews.org/Report.aspx?ReportID=90410 [Accessed 04.12.2011].

Isaacs T. 2002. Feminism and Agency. In: Brennan S, ed. *Feminist Moral Philosophy*. Calgary: University of Calgary Press. pp. 129-154.

Jefferson T. 1776. *The Charters of Freedom: A New World Is at Hand. Declaration of Independence*. Washington: The U.S. National Archives & Records Administration. http://www.archives.gov/charters/print_friendly.html?page=declaration_transcript_content.html&title=NARA%20%7C%20the%20Declaration%20of%20Indepdendence%3A%20A%20Transcription [Accessed 27.10.2014].

Jefferson T. 1789. Letter to James Madison. *Thomas Jefferson on Politics & Government.* Inalienable Rights: The Nature of Our Rights. ME7: 455, Papers 15: 393. http://etext.virginia.edu/jefferson/quotations.jeff0100.htm [Accessed 09.09.2008].

Jewkes R. 2009. HIV and Women. In: Rohleder P, Swatz L, Kalichman SC, et al, eds. *HIV/AIDS in South Africa: 25 Years On*. New York: Springer. pp. 27-40.

Jewkes R, Dunkle K, Nduna M, et al. 2010. Intimate Partner Violence, Relationship Power Inequity, and Incidence of HIV Infection in Young Women in South Africa: A Cohort Study. *The Lancet*. 376(9734): 41-48. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2810%296048-X/fulltext [Accessed 02.09.2013].

Jolley N. 1999. *Locke: His Philosophical Thought*. Oxford: Oxford University Press. 244 p.

Jonsen AR. 1975. Do No Harm: Axiom of Medical Ethics. In: Spicker SF, Englhardt HT Jr., eds. P*hilosophical Medical Ethics: Its Nature and Significance*. Dordrecht: D. Reidel Publishing Company. 264 p.

Jürgens R, Cohen J, Tarantola D, et al. 2009. Correspondence. *The Lancet*. 373: 1079. http://www.who.int/hiv/events/artprevention/epstein.pdf [Accessed 08.04.2010].

Kagee A, Remien RH, Berkman A, et al. 2011. Structural Barriers to ART Adherence in Southern Africa: Challenges and potential Ways Forward. *Global Public Health*. 6(1): 83-97. http://necbi.nlm.nih/gov/pmc/articles/PMC3056922/pdf/nihms247245.pdf [Accessed 23.12.20130.

Kant I. 1964. *Groundwork of the Metaphysic of Morals*. Paton HJ, trans. New York: Harper Collins 148 p.

Kant I. 1991. *The Moral Law: Groundwork of the Metaphysic of Morals*. Paton HJ, trans. London: Routledge. 143 p.

Kant I. 1996. *Practical Philosophy*. Gregor MJ, trans. & ed. New York: Cambridge University Press, 1996. 668 p.

Kass NE & Gielen AC. 1998. The Ethics of Contact Tracing Programs and their Implications for Women. *Duke Journal of Gender Law & Policy*. 5: 89-102. http://www.law.duke.edu/shell/cite.pl?+Duke+J.+Gender+L.+&+Pol'y+89 [Accessed 17.10.2007].

Katzive L & Zampas C. 2003. *In the European Court of Human Rights (Case No. 53924/00) Between VO Applicant and France Respondent: Written Comments by Center for Reproductive Rights.* New York: Center for Reproductive Rights. http://www.law/georgetown.edu/rossrights/docs/cases/vocomm.pdf [Accessed 27.11.2014].

Kavanagh MM, Cohn J, Mabote, et al. 2015. Evolving Human Rights and the Science of Antiretroviral Medicine. *Health and Human Rights*. 17: 1-20.

http://www.hhrjournal.org/2015/06/04/evolving-human-rights-and-the-science-of-antiretroviral-medicine/ [Accessed 31.08.2015].

Kay C. 1997. *Notes on Deontology*. pp. 1-2. http://sites.wofford.edu/kaycd/deontology/ [Accessed 18.07.2014].

Kendall T, Danel I, Cooper D, et al. 2014. Eliminating Preventable HIV-Related Maternal Mortality in Sub-Saharan Africa: What Do We Need to Know*? Journal of Acquired Immune Deficiency Syndrome*. 67(Supplement 4): S25-S256. http://journals.lww.com/jaids/Fulltext/2014/12011/Eliminating_Preventable_HIV_Related_Maternal.12.aspx [Accessed 18.12.2014].

Kenyon K. 2005. Routine HIV Testing: A View from Botswana. *Health and Human Rights*. 8(2): 21-23. http://www.hhrjournal.org/wp-content/uploads/sites/13/2013/07/5-Kenyon.pdf. [Accessed 03.03.2015].

King ML. 2013. "We shall overcome because the arc of a moral universe is long, but it bends toward justice." *Oxford Dictionary of Quotations.* Oxford: Oxford University Press. http://global.oup.com/booksites/content/9780199237173/whoquoted/ [Accessed 24.12.2013].

Klugman J. 2013. *Why Development Must Tackle Gender-Based Violence.* 13.10. London: Thomson-Reuters Foundation. http://trust.org/item/20132013183644-bikt2?mkt_tok=3RkMMJVVWFF9wsRonvanOce%2FhmjTEU5z16ews [Accessed 14.10.2013].

Knight R, Shoveller J, Greyson D, et al. 2013. Advancing Population and Public Health Ethics Regarding HIV Testing: A Scoping Review. *Critical Public Health*. 24(3): 283-295. http://www,tandfonline.com/doi/pdf/10.1080/09581596.2013.800188 [Accessed 30.08.2013].

Lancet Editorial. 2006. HIV: Compulsory Testing and Falling Incidence? *The Lancet.* 367: 1118. http://download.thelancet.com/pdfs/journals/lancet/PIIS0140673606684857.pdf [Accessed 04.12.2011].

Lawyers Collective and O'Neill Institute for National and Global Health Law. 2013. *J.A.O. v. Homepark Caterers LTD & 2 Ors., (2004) eKLR (Kenya).* http://www.globalhealthrights.org/africa/j-a-o-v-homepark-caterers-ltd-2-ors/ [Accessed 05.12.2013].

Le Clerc-Madlala S, Simbayi LC & Cloete A. 2009. The Sociocultural Aspects of HIV/AIDS in South Africa. In: Rohleder P, Swartz L & Kalichman S, eds. *HIV/AIDS in South Africa 25 Years On: Psychosocial Perspectives*. pp. 13 – 26. New York: Springer.

Locke J. 1960. *Two Treatises of Government.* Laslett P, ed. Cambridge: Cambridge University Press. 520 p.

Locke J. 2000. John Locke, "The State of Nature and the Social Contract" from Second Treatise of Government (1690). In: Solomon RC & Murphy MC, eds. *What Is Justice:*

Classic and Contemporary Readings, 2nd edition. New York: Oxford University Press. pp. 74-80.

Logan A, Plank R, Bogart L, et al. 2013. Acceptability of Early Initiation of Antiretrovirals for Treatment as Prevention among HIV-Infected Persons in Mochudi, Botswana. Abstract MOAC0204. 7th IAS Conference on HIV Pathogenesis, Treatment and Prevention, 30.6-03.07, Kuala Lumpur. http://pag.ias2013.org/Abstracts.aspx?AID=2369. [Accessed 29.08.2013].

Lohman D. 2008. *A Testing Challenge*. Windhoek and New York: AIDS & Rights Alliance for Southern Africa and Human Rights Watch. 65 p. http://www.hrw.org/print/reports/2008/11/17/testing-challenge [Accessed 22.11.2013].

Loutfy MR, Sherr L, Sonnenberg-Schwan U, et al. 2013. Caring for Women Living with HIV: Gaps in the Evidence. *Journal of the International AIDS Society*. 16: 1-10. http://www.jiasociety.org/index.php/jias/article/view/18509 [Accessed 02.10.2013].

MacIntyre A. 1999. *Dependent Rational Animals: Why Human Beings Need Virtues*. Chicago: Open Court. 102 p.

Mack N, Evens EM, Tolley EE, et al. 2014. The Importance of Choice in the Rollout of ARV-Based Prevention to User Groups in Kenya and South Africa: A Qualitative Study. *Journal of the International AIDS Society.* 17(supplement 2): 1-6. http://www.jiasociety.org/index.php/jias/article/view/19157/3976 [Accessed 05.02.2015].

MacPherson EE, Richards E, Namakhoma I, et al. 2014. Gender Equity and Sexual and Reproductive Health in Eastern and Southern Africa: A Critical Overview of the Literature. *Global Health Action*. 7: 1-9. http://www.globalhealthaction.net/index.php/gha/article/view/23717. [Accessed 01.07.2014].

Maman S & King E. 2008. Changes in HIV Testing Policies and the Implications for Women. *Journal of Midwifery & Women's Health*. 53(3): 195-201. http://www.medscape.com/viewarticle/573983 [Accessed 05.09.2008].

Mandela N. 1995. *Long Walk to Freedom: The Autobiography of Nelson Mandela*. London: Abacus. 768 p.

Mandela NR. 2013. *Nelson Mandela By Himself: The Authorised Book of Quotations.* Hatang S and Venter S, eds. Johannesburg: Pan Macmillan South Africa. 252 p.

Mann JM. 1996. Health and Human Rights. *British Medical Journal*. 312: 924-925. http://www.bmj.com/content/312/7036/924.short [Accessed 20.04.2010].

Mann JM. 1997. Medicine and Public Health, Ethics and Human Rights. Hastings, NY: *The Hastings Center Report*. 27(3): 6-13. http://findarticles.com/p/article/mi_go2103/is_n3_v27/ai_n28688564/pg_8/?tag=content;col1 [Accessed 04.12.2011].

Mansfield HC. 2011. *Tocqueville: A Very Short Introduction*. New York: Oxford University Press. 135 p.

Manson NC & O'Neill O. 2007. *Rethinking Informed Consent in Bioethics*. New York: Cambridge University Press. 228 p.

Mariam AG. 2009. *The Arc of Justice*. Ethiomedia. 20.04. http://www.ethiomedia.com/adroit/2172.html [Accessed 26.12.2013].

Marshall J. 1998. *Descartes's Moral Theory*. Ithaca: Cornell University Press. 192 p.

Martin JF. 2003. The Physician/Care Provider and Politics. *European Journal of Public Health.* 13: 182-184. http://eurpub.oxfordjournals/Org/content/13/2/182.full.pdf [Accessed 16.05.2014].

Mastro TD, Sista N & Abdool-Karim Q. 2014. ARV-Based HIV Prevention for Women—Where We Are in 2014. *Journal of the International AIDS Society.* 17(Supplement 2): 1-6. http://www.jiasociety.org/index.php/jias/articles/view/19154/3958 [Accessed 05.02.2015].

Matthew. 80-90 AD. King James Version: Matthew Chapter 7. New Testament, *The Bible*. http://www.sacred-texta.com/bib/kjv/mat007.htm [Accessed 04.12.2013].

Mbanje P. 2013. Zimbabwe: Outrage over Proposed Mandatory HIV-Testing. *The Standard.* 20.08. http://allafrica.com/stories/201308260322.html [Accessed 29.08.2013].

McGraw-Hill Concise Dictionary of Modern Medicine. 2002. Primum Non Nocere. New York: The McGraw-Hill Companies. http://medical-dictionary.thefreedictionary.com/Primum+Non+Nocere [Accessed 31.03.2015].

Medical Dictionary. 2014. Primum Non Nocere. http://medical-dictionary.thefreedictionary.com/First%2c+do+no+harm [Accessed 11.07.2014].

Medley A, Garcia-Moreno C, McGill S, et al. 2004. Rates, Barriers and Outcomes of HIV Serostatus Disclosure among Women in Developing Countries: Implications for Prevention of Mother-to-Child Transmission Programmes. *Bulletin of the World Health Organization*. 82(4): 299-307. http://www.ncbi.nlm.nih.gov/pubmed/15259260 [Accessed 20.06.2013].

Merriam-Webster Dictionary. 2013. Springfield, MA: Merriam-Webster. Utilitarianism. http://www.merriam-webster.com/dictionary/utilitarianism [Accessed 28.12.2013].

Metz T. 2005. The Ethics of Routine HIV Testing: A Respect-Based Analysis. *South African Journal on Human Rights*. 21: 370-405.

Meuleners LB, Lee AH, Janssen PA, et al. 2011. Maternal and Foetal Outcomes among Pregnant Women Hospitalised due to Interpersonal Violence: A Population Based Study in Western Australia, 2002-2008. *BMC Pregnancy and Childbirth*. 11(70): 1-7. http://www.biomedcentral.com/content/ pdf/1471-2393-11-70.pdf [Accessed 27.11.2014].

Miles SH. 2004. *The Hippocratic Oath and the Ethics of Medicine*. Oxford: Oxford University Press. 232 p.

Mill JS. 1999. *On Liberty*. Peterborough, CA: Broadview Press. http://etext.library.adelaide.edu.au/m/mill/john_stuart/m645o/chapter3.html http://etext.liberty.adelaide.edu/au/m/mill/john_stuart/m645o/chapter4.html http://www.utilitarianism.com/ol/one/html [Accessed 30.06.2008].

Moodley K. 2011. Beneficence. In: Moodley K, ed. *Medical Ethics, Law and Human Rights*. Pretoria: Van Schaik Publishers. 377 p.

Nagel T. 2000. Internal Difficulties with Justice as Fairness. In: Solomon RC, Murphy MC, eds. *What Is Justice? Classic and Contemporary Readings*. New York: Oxford University Press, 2nd edition. pp. 295-300.

National Department of Health. Republic of South Africa. 2009. *Policy Guidelines for HIV Counselling and Testing (HCT).* Pretoria: National Department of Health. http://www.justice.gov.za/vg/hiv/docs/2009_FinalDraft-HCT-Policy-PIC-22Oct.pdf [Accessed 07.11.2013].

National Department of Health. Republic of South Africa. 2010. *Clinical Guidelines for the Management of HIV & AIDS in Adults and Adolescents.* Pretoria: National Department of Health. http://www.mediaaids.org/content/page/art_in-south_africa [Accessed 15.11.2013].

National Institutes of Health. 2013. *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*. Bethesda: National Institutes of Health. 262 p. http://aidsinfo.nih.gov/contentfiles/lvguidelines/adultandadolescentgl.pdf [Accessed 29.03.2015].

News Botswana. 2013. *Public Health Bill Signed into Law*. 23.09. http://mybroadband.co.za/vb/showthread.php/561807-public-health-bill-in-Botswana [Accessed 04.03.2015].

Niccolai LM, King E, d'Entremont D, et al. 2006. Disclosure of HIV Serostatus to Sex Partners: A New Approach to Measurement. *Sexually Transmitted Diseases*. 33(2): 102-105. http://journals.lww.com/stdjournal/Fulltext/2006/02000/Disclosure_of_HIV Serostatus_to_Sex_Partners_A.7.aspx [Accessed 20.09.2007].

Norton DF. 1993. Hume, Human Nature, and the Foundations of Morality. In: Norton DF, ed. *The Cambridge Companion Guide to Hume*. Cambridge: Cambridge University Press. 400 p.

Nozick R. 1968. *Anarchy, State, and Utopia*. New York: Basic Books. 334 p.

Nussbaum MC. 1999. *Sex and Social Justice*. New York: Oxford University Press. 488 p.

Oakley J. 2013. Virtue Ethics and Bioethics. In: Russell DC, ed. *The Cambridge Companion to Virtue Ethics*. Cambridge: Cambridge University Press. pp. 197-220.

Obermeyer CM, Neuman M, Hardon A, et al. 2013. Socio-economic Determinants of HIV Testing and Counselling: A Comparative Study in Four African Countries. *Tropical*

Medicine & International Health. 18(9): 1110-1118. http://www.ncbi.nlm.nih.gov/pubmed/23937702?goback=%2Egde_3381406_member_58... [Accessed 17.11.2013].

Office of the High Commissioner on Human Rights. 2015. *Background Paper on Attacks Against Girls Seeking to Access Education*. Geneva: Office of the High Commissioner on Human Rights. http://www.ohchr.org/Documents/HRBodies/CEDAW/Report_attacks_on_girls_Feb2015.pdf [Accessed 10.02.2015].

Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS). 1998. *HIV/AIDS and Human Rights: International Guidelines*. New York and Geneva: United Nations.

O'Grady M. 2005. *Community-Based VCT (CBVCT) Project: VCT Training Workshops Final Report.* Pretoria: Academy for Educational Development. 36 p.

O'Grady M, Sadaphal S, Mandjo J-L, et al. 2013. *Evaluation of the Integrated Health Project in the Democratic Republic of Congo*. Vienna, VA: International Business & Technical Consultants, Inc. 55 p.

O'Grady M. 2014. *The Situation of Adolescents and HIV in Lesotho*. Maseru: UNICEF. 16 p.

O'Hagan T. 2003. *Rousseau*. London: Routledge. 320 p.

O'Neill O. 1996. *Towards Justice and Virtue.* Cambridge: Cambridge University Press. 230 p.

O'Neill O. 2000. *Bounds of Justice*. Cambridge: Cambridge University Press. 219 p.

O'Neill O. 2002. *Autonomy and Trust in Bioethics*. Cambridge: Cambridge University Press. 228 p.

Organisation of African Unity. 2001. *Abuja Declaration on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases*. African Summit on HIV/AIDS, Tuberculosis and Other Infectious Diseases, Abuja, Nigeria, 24-27.04. pp. 1-8. http://www.un.org/ga/aids/pdf/abuja_declaration.pdf [Accessed 27.12.2013].

Orza L, Welbourn A, Bewley S, et al. 2015. *Building a Safe House on Firm Ground.* London and Geneva: Salamander Trust and World Health Organization. [Sent via email by Alice Welbourn 22.01.2015].

Oshana M. 2006. *Personal Autonomy in Society*. Aldershot: Ashgate Publishing Limited. 190 p.

Pappas G, Kiriaze IJ & Falagas ME. 2008. Insights into Infectious Disease in the Era of Hippocrates. *International Journal of Infectious Diseases*. 12(4): 347-350. http://www.ncbi.nlm.nih.gov/pubmed/18178502 [Accessed 12.12.2008].

Pellegrino ED. 1975. Moral Agency and Professional Ethics. In: Spicker SF, Engelhardt HT, Jr., eds. *Philosophical Medical Ethics: Its Nature and Significance*. Dordrecht: D. Reidel Publishing Company, pp. 130-131.

Pellegrino ED. 1987. Altruism, Self-Interest, and Medical Ethics. *Journal of the American Medical Association*. 258: 130-136. Introduction to Bioethics course reader. University of the Witwatersrand, School of Clinical Medicine, 2006.

Pellegrino ED & Thomasma DC. 1987. The Conflict between Autonomy and Beneficence in Medical Ethics: Proposal for a Resolution. *Journal of Contemporary Health Law and Policy*. 3(1): 23-46. http://scholarship.law.edu/cgi/viewcontent.cgi?article=16897content=jchlp [Accessed21.05.2014].

Penelhum T. 2003. *Themes in Hume: The Self, the Will, Religion*. Oxford: Clarendon Press. 294 p.

Phillips T, Thebus E, Bekker L-G, et al. 2014. Disengagement of HIV-positive Pregnant Women from Antiretroviral Therapy Services: A Cohort Study. *Journal of the International AIDS Society*. http://www.jiasociety.org/index.php/jias/article/view/19242 [Accessed 31.08.2015].

Piot P. 2008. *New Generation of Health and Human Rights Advocates Inspired by Dr. Jonathan Mann*. Geneva: UNAIDS. http://www.unaids.org/en/resources/presscentre/featurestories/2008/december/20081210j... [Accessed 04.12.2013].

Piot P, Kazatchkine M, Dybul M, et al. 2009. Lessons and Myths in the HIV/AIDS Response (Authors' reply.) *The Lancet*. 374(9702): 1675-1676. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(09)61988-7/fulltext [Accessed 18.11.2013].

Plato. 2000. Justice in the State and in the Soul from the Republic (ca. 380 B.C.). In: Solomon RC & Murphy MC, eds. *What Is Justice? Classic and Contemporary Readings*, 2nd edition. New York: Oxford University Press. pp. 21-34.

Pogge T. 2002. Cosmopolitanism: A Defence. *Critical Review of International Social and Political Philosophy*. 5(3): 86-91. [Sent via email by the author 01.08.2009].

Pogge T. 2008. Growth and Inequality: Understanding Recent Trends and Political Choices. *Dissent.* 55(1): 66-75. http://www.dissentmagazine.org/article/?article=990 [Accessed 07.08.2009].

Price AW. 2005. Aristotelian Virtue and Practical Judgement. In: Gill C, ed. *Virtue, Norms, and Objectivity: Issue in Ancient and Modern Ethics*. Oxford: Clarendon Press. pp. 257-278.

Rawls J. 1999a. *A Theory of Justice*, Revised edition. Oxford: Oxford University Press, 560 p.

Rawls. J. 1999b. *The Law of Peoples*. Cambridge, Mass: Harvard University Press, 208 p.

Rawls J. 2000. John Rawls, "Justice as Fairness as a Political Conception of Justice," from "Justice as Fairness: Political not Metaphysics". In: Solomon RC & Murphy MC, eds. *What Is Justice? Classic and Contemporary Readings*. New York: Oxford University Press. pp. 339-345.

Rennie S & Behets F. 2006. Desperately Seeking Targets: The Ethics of Routine HIV Testing in Low-Income Countries. *Bulletin of the World Health Organization.* 84: 52-57. http://www.scielosp.org/scielo.php?pid=SOO42_96862006.000100014&script_sci_arttest [Accessed 02.02.2008].

Republic of South Africa. 1996. *Constitution of the Republic of South Africa.* Pretoria: Government of South Africa. http://www.gov/za/documents/constitution/constitution-republic-south-africa-1996-1. [Accessed 16.01.2015].

Richardson ET, Collins SE, Kung T, et al. 2014. Gender Inequality and HIV Transmission: A Global Analysis. *Journal of the International AIDS Society*. 17: 1-5. http://www.jiasociety.org/index.php/jias/article/view/19035. [Accessed 16.07.2014].

Richter K & Dreyer G. 2013. Paradigm Shift Needed for Cervical Cancer: HPV Infection is the Real Epidemic. *South African Medical Journal*. 103(5): 2920-292. http://www.samj.org.za/index.php/samj/article/view/6936/5068 [Accessed 02.02.2015].

Rizzo MJ. 2008. Justice Versus Benevolence: A Modern Humean View. *Minnesota Journal of Law, Science & Technology*. 9(2): 883-898. http://www.mjlst.umn.edu/prod/groups/ahc/@pub/@ahc/@mjlst/documents/asset/ahc_asset_366132.pdf

Robinson S. 2008. *Spirituality, Ethics and Care*. London: Jessica Kingsley Publishers. 208 p.

Rochat TJ, Bland RM, Tomlinson M, et al. 2013. Suicide Indeation, Depression and HIV among Pregnant Women in Rural South Africa. *Health*. 5(3A): 650-661. http://www.scirp.org/journal/Paperinformation.aspc?PaperID=-29610#:VlrART-htzg [Accessed 12.12.2014].

Rosen S & Fox M. 2011. Retention in HICV Care between Testing and Treatment in Sub-Saharan Africa: A Systematic Review. *PLoS Medicine*. 8(7): 1-15. http://www.plosmedicine.org/articles/info%3Adoi%2F10.1371%3Fjournal.pmed.1001056 [Accessed 15.11.2013].

Rosenberg T. 2014. A Depression-Fighting Strategy That Could Go Viral. *International New York Times.* 04.12. http://opinionator.blogs.nytimes.com [Accessed 06.12.2014].

Ruark A, Shelton JD, Halperin DT, et al. 2009. Correspondence. *The Lancet.* 373: 1078. http://www.who.int/hiv/events/artprevention/epstein.pdf [Accessed 08.04.2010].

Rujumba J, Neema S, Tumwine JK, et al. 2013. Pregnant Women's Experiences of Routine Counselling and Testing for HIV in Eastern Uganda: A Qualitative Study. *BMC*

Health Services Research. 13(189): 1-13. http://download.springer.com/static/pdf/471/art%253A10.1186%252F1472-6963-13-189.pdf [Accessed 21.11.2013].

Russell P. 2013. Hume's Anatomy of Virtue. In: Russell DC, ed. *The Cambridge Companion to Virtue Ethics*. Cambridge: Cambridge University Press. pp. 92-123.

Saag M. 2015. Preventing HIV in Women—Still Trying to Find Their VOICE. *The New England Journal of Medicine*. 372(6): 564-566. http://www.nejm.org/doi/full/10.1056/NEJMe1415750 [Accessed 23.03.2015].

Sandel M. 2000. Justice and Community. In: Solomon RC, Murphy MC, eds. *What Is Justice: Classic and Contemporary Readings.* New York: Oxford University Press, 2nd edition. pp. 315-324.

Sandel M. 1998. *Liberalism and the Limits of Justice.* Cambridge: Cambridge University Press, Second edition. 252 p.

Scanlon TM. 1986. *The Significance of Choice.* Oxford, The Tanner Lectures on Human Values Delivered at Brasenose College, Oxford University, May (series). http://www.tannerlectures.utah.edu/lectures/documents/scanlon88.pdf [Accessed 28.09.2010].

Selgelid MJ. 2008. Improving Global Health: Counting Reasons Why. *Developing World Bioethics*. 8(2): 115-125. http://0-www.swetwise.com.innopac.wits.ac.za/FullTextProxy/suproxy?url=http%3A%2F%2FWWW3.interscience.wiley.com%2 [Accessed 12.04.2010].

Sepulveda-Carmona M. 2013. *Extreme Poverty and Human Rights*. New York: United Nations General Assembly. http://papers.ssm.com/sol3/papers.cfm?abstract_id=2437791 [Accessed 23.03.2015].

Shamu S, Zarowsky C, Shefer T, et al. 2014. Intimate Partner Violence after Disclosure of HIV Test Results among Pregnant Women in Harare, Zimbabwe. *PLOS One*. 9(10): 1-8. http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0109447 [Accessed 26.11.2014].

Shelton JD. 2008. Counselling and Testing for HIV Prevention. *The Lancet*. 372: 273-275. http://0-proquest.umi.com.innopac.wits.ac.za/pdqlink?index=0&did=1525285601&SrchMode=1&sid=1&Fmt=6%VInst=PROD%VType=PQD&RQT=309&VName=PQD&TS=1263213462&ClientId=58117 [Accessed 11.01.2010].

Sherwin S. 2002. The Importance of Ontology for Feminist Policy-Making. In: Brennan S, ed. *Feminist Moral Philosophy*. Calgary: University of Calgary Press. pp. 273-295.

Shue H. 1996. *Basic Rights: Subsistence, Affluence and U.S. Foreign Policy*, 2nd edition. Princeton: Princeton University Press. 256 p.

Simbayi LC, Kalichman SC, Strebel A, et al. 2007. Disclosure of HIV Status to Sex Partners and Sexual Risk Behaviours among HIV-positive Men and Women, Cape Town, South Africa. *Sexually Transmitted Infections.* 83(1): 29-34. http://0-gateway.tx.ovid.com.innopac.wits.ac.za/gw2/ovidweb.cgi [Accessed 16.09.2007].

Simoni JM & Pantalone DW. 2004. Secrets and Safety in the Age of AIDS: Does HIV Disclosure Lead to Safer Sex? *Topics in HIV Medicine*. 12(4): 109-118. http://www.aisusa.org/pub/topics/2004/issue4/109.pdf [Accessed 11.09.2007].

Skinner Q. 1999. Hobbes and the Purely Artificial Person of the State. *The Journal of Political Philosophy*. 7(1): 1-29. http://www.sussex.ac.uk/Users/sefd0/tx/Skinner1999.pdf [Accessed 04.09.2014].

Skosana I. 2014. Gauteng Pays after Forced Sterilisation of HIV-Positive Woman. *Mail & Guardian* 11.04. 1-3. http://mg.co.za/article/2014-04-11-gauteng-pays-after-forced-steilisation-for-hiv-positive-woman [Accessed 22.04.2014].

Slote M. 2007. *The Ethics of Care and Empathy.* London: Routledge. 133 p.

Smith RJ, Okano JT, Kahn JS, et al. 2010. Evolutionary Dynamics of Complex Networks of HIV Drug-Resistant Strains: The Case of San Francisco. *Sciencexpress*, 14.01. http://www.sciencexpress.org/14_January_2010/Page_1/10.1126/science.118056 [Accessed 21.03.2010].

Sokol DK. 2010. How to Think Like an Ethicist. *British Medical Journal.* 340: c3256. http://www.bmj.com/cgi/content/extract/340/jun23_2/c3256papetoc? [Accessed 30.06.2010].

Southern Africa Litigation Centre. 2013. *African Commission Condemns Coerced Sterilisation of Women Living with HIV.* Johannesburg: Southern Africa Litigation Centre. Sent via email: PamelaT@salc.org.za. [Accessed 07.11.2013].

Stanford Encyclopedia of Philosophy. 2014. The Principle of Beneficence in Applied Ethics. Stanford: Stanford Encyclopedia of Philosophy. http://plato.stanford.edu/entries/principle-beneficence/ [Accessed 13.05.2014].

Staveteig S, Wang S, Head SK, et al. 2013. Demographic Patterns of HIV Testing Uptake in Sub-Saharan Africa. *DHS Comparative Reports No. 30*. Calverton, MD: ICF International. https://dhsprogram.com/pubs/pdf/CR30/CR30.pdf [Accessed 27.02.2014].

Sullivan K. 2005. Male Self-Disclosure of HIV-Positive Serostatus to Sex Partners: A Review of the Literature. *Journal of the Association of Nurses in AIDS Care.* 16(6): 33-47. http://sti.bmj.com/cgi/content/full/83/1/29 [Accessed 20.09.2007].

Tasioulas J. 2007. The Moral Reality of Human Rights. In: Pogge T, ed. *Freedom from Poverty as a Human Right*. Oxford: Oxford University Press, pp. 75-101.

Tasioulas J. 2008. *Taking Rights out of Human Rights*. [unpublished manuscript]. 23 p.

The Internet Encyclopedia of Philosophy. 2014. Beneficence in an Ethics of Virtue. Martin: University of Tennessee. http://www.iep.utm.edu/bioethic/#SH2a [Accessed 16.05.2014].

The Voluntary HIV-1 Counseling and Testing Efficacy Study Group. 2000. Efficacy of Voluntary HIV-1 Counselling and Testing in Individuals and Couples in Kenya, Tanzania, and Trinidad: A Randomised Trial. *The Lancet*. 356: 103-112. http://www.sciencedirect.com/science/article/pii/SO140673600024466 [Accessed 09.12.2014].

Thom R. 2009. Common Mental Disorders in People Living with HIV/AIDS. *The Southern African Journal of HIV Medicine*. 35: 8-13.

Thorgaard K & Jensen UJ. 2011. Evidence and the End of Medicine. *Medicine, Health Care and Philosophy*. 14(3): 273-280. http://www.mk-skadborg.dk/evidence.pdf [Accessed 28.05.2014].

Tomasevski K. 1995. Health Rights. In: Eide A, Krause C & Rosas A, eds. *Economic, Social and Cultural Rights*. Dordrecht: Martinus Nijhoff Publishers. pp. 125-142.

Tomasevski K. 2005. Why a Human Rights Approach to HIV/AIDS Makes all the Difference. *Rights in Action: Human Rights and Poverty Reduction*. London: Overseas Development Institute. http://www.odi.org/sites/odi.org.uk/files/odi-assets/publications-opinion-files/4357.pdf [Accessed 26.01.2015].

Topp S, Chipukuma JM, Chiko MM, et al. 2011. Opt-Out Provider-Initiated HIV Testing and Counselling in Primary Care Outpatient Clinics in Zambia. *Bulletin of the World Health Organization*. 89: 328-335A. http://www.who.int/bulletin/volumes/89/5/10-084442/en [Accessed 06.11.2013].

Topp SM, Li MS, Chipukuma, et al. 2012. Does Provider-Initiated Counselling and Testing (PITC) Strengthen Early Diagnosis and Treatment Initiation? Results from an Analysis of an Urban Cohort of HIV-Positive Patients in Lusaka, Zambia. *Journal of Acquired Immune Deficiency Syndrome.* 15(2): 1-9. http://www.ncbi.nlm.nih.gov/pubmed/23010377 [Accessed 17.11.2013].

Tuck R. 1989. *Hobbes.* Oxford: Oxford University Press. 127 p.

Turan JM, Bukusi EA, Onono M, et al. 2011. HIV/AIDS Stigma and Refusal of HIV Testing among Pregnant Women in Rural Kenya: Results from the MAMAS Study. *AIDS and Behavior*. 15(6): 1111-1120. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3127002/ [Accessed 20.06.2013].

UNAIDS. 2008a. *Fast Facts about HIV Testing and Counselling*. Geneva: UNAIDS. http://data.unaids.org/pub/Factsheet/2008/20080627_fastfacts_testing_en.pdf [Accessed 31.01.2010].

UNAIDS. 2008b. *New Generation of Health and Human Rights Advocates Inspired by Dr Jonathan Mann*. Geneva: UNAIDS.

http://www.unaids.org/en/resources/presscentre/featurestories/2008/december/20081210j... [Accessed 04.12.2013].

UNAIDS. 2010. *Agenda for Accelerated Country Action for Women, Girls, Gender Equality and HIV*. Geneva: UNAIDS. 34 p. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/20100226_jc1794_agenda_for_Accelerated_country... [Accessed 29.08.2013].

UNAIDS. 2012. *Regional Fact Sheet 2012: Sub-Saharan Africa*. Geneva: UNAIDS. http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/document/epidemiology/2012/gr2012/2012_FS_regional_SSA_en.pdf [Accessed 29.03.2015].

UNAIDS. 2013. *Access to Antiretroviral Therapy in Africa: Status Report on Progress towards the 2015 Targets*. Geneva: UNAIDS. http://www.unaids.org/sites/default/files/media_asset/20131219_AccessARTAfrica_StatusReportProgresstoward2015Targets_en_0.pdf [Accessed 27.02.2015].

UNAIDS. 2014a. *Gender Matters: Overcoming Gender-Related Barriers to Prevent New HIV Infections among Children and Keep their Mothers Alive*. Geneva: UANIDS. http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2014/JC2647 [Accessed 22.10.2014].

UNAIDS. 2014b. *UNAIDS Report on the Global AIDS Epidemic 2013*. Geneva: UNAIDS. http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf [Accessed 28.09.2013].

UNAIDS. 2015. South Africa. Geneva: UNAIDS. http://www.unaids.org/en/regionscountries/countries/southafrica. [Accessed 31.08.2015].

UNAIDS Global Reference Group on HIV/AIDS and Human Rights. 2004. *UNAIDS/WHO Policy Statement on HIV Testing*. Geneva: UNAIDS/World Health Organization (WHO). 3 p. http://www.who/int/hiv/pub/vct/en/hivtestingpolicy04.pdf [Accessed 14.12.2014].

UNESCO. 2005. *HIV and AIDS in the Caucasus Region: A Socio-Cultural Approach.* Paris: UNESCO. http://unesdoc.unesco.org/images/0014/001414/141152e.pdf [Accessed 20.05.2010].

United Nations (UN). 1948. *Universal Declaration of Human Rights*. New York: United Nations. http://www.un.org/en/documents/udhr/ [Accessed 27.02.2014].

United Nations Children's Fund (UNICEF). 2014a. *Hidden in Plain Sight: A Statistical Analysis of Violence Against Children*. New York: UNICEF. 206 p. http://files.unicef.org/publications/files/Hidden_in_plain_sight_statistical_analysis__EN_3_Sept_2014.pdf [Accessed 27.11.2014].

United Nations Children's Fund (UNICEF). 2014b. *Towards an AIDS-Free Generation: Children and AIDS Sixth Stocktaking Report, 2013*. New York: UNICEF. http://www.unicef.org/publications/files/children_and_AIDS_Sixth_Stocktaking_Report_EN.pdf [Accessed 22.03.2015].

United Nations Development Programme (UNDP). 2012. *Global Commission on HIV and the Law: Risks, Rights & Health*. New York: United Nations Development Programme. http://www.hivlawcommission.org/resources/report/FinalReport-Risks,Rights&Health-EN.pdf [Accessed 02.10.2013].

Van Dyk A. 2008. *HIVAIDS Care & Counselling: A Multidisciplinary Approach*, 4th edition. Cape Town: Pearson Education South Africa. 512 p.

Van Lettow M, Kapito-Tembo A, Kaunda-Khangamwa B, et al. 2012. *Increasing the Uptake of the HIV Testing in Maternal Health in Malawi.* Discussion Paper Series No. 5. Johannesburg/Waterloo, Ont: Centre for International Governance and Innovation (CIGI) and South Africa Institute of International Affairs (SAIIA). 17 p. http://www.africaportal.org/sites/default/files/Africa%20Initiative%20Discussion%20Paper%20No.%205.pdf [Accessed 07.11.2013].

Wagman JA, Gray RH, Campbell JC, et al. 2014. Effectiveness of an Integrated Intimate Partner Violence and HIV Prevention Intervention in Rakai, Uganda: Analysis of an Intervention in an Existing Cluster Randomised Cohort. *The Lancet Global Health*. 3(1): e23-e33. http://download.thelancet.com/pdfs/journals/langlo/PIIS221409X14703444.pdf?id=iaayhoxTdPa-159kf030u [Accessed 11.12.2014].

Walensky RP & Bassett IV. 2011. HIV Self-Testing and the Missing Linkage. *PLoS Medicine*. 8(10): 1-2. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3186809/pdf/pmed.1001101.pdf [Accessed 15.11.2013].

Walensky RP, Paltiel AD, Losina E, et al. 2010. Test and Treat DC: Forecasting the Impact of a Comprehensive HIV Strategy in Washington, DC. *Clinical Infectious Diseases.* 51(4): 1-9. http://cid.oxfordjournals.org/content/51/4/392.long [Accessed 29.09.2010].

Wandel S, Egger M, Rangsin R, et al. 2008. Duration from Seroconversion to Eligibility for Antiretroviral Therapy and from ART Eligibility to Death in Adult HIV-Infected Patients from Low and Middle-Income Countries: A Collaborative Analysis of Prospective Studies. *Sexually Transmitted Infections*. 84(Supplement 1): i31-i36. http://www.ncbi.nlm.nih.gov/pubmed/18647863 [Accessed 15.11.2013].

Warren SD & Brandeis LD. 1890. The Right to Privacy. *Harvard Law Review*. IV: 1-11. http://www-swiss.ai.mit.edu/6805/articles/privacy/Privacy_brand_warr2.html [Accessed 09.07.2008].

Watts C & Seeley J. 2014. Addressing Gender Inequality and Intimate Partner Violence as Critical Barriers to an Effective HIV Response in Sub-Saharan Africa. *Journal of the International AIDS Society*. 17: 1-3. http://www.jiasociety.org/index.php/jias/article/view19849 [Accessed 11.12.2014].

Webster's Third New International Dictionary. 1966. Deontology. Chicago: G.&C. Merriam Co.

Weiser SD, Heisler M, Leiter K, et al. 2006. Routine HIV Testing in Botswana: A Population-Based Study on Attitudes, Practices, and Human Rights Concerns. *PLOS Medicine*. 3: 1013-1022. http://www.plosmedicine.org/article/info:doi/10.1371/journal.pmed.0030 [Accessed 26.09.2007].

Welbourn A. 2013. *An End to AIDS?: Not Through Medication Alone*. London: Salamander Trust. 01.12. http://www.opendemocracy.net/5050/alice-welbourn/end-to-aids-not-through-medication-alone [Accessed 24.12.2013].

Wilcher R & Cates W. 2009. Reproductive Choice for Women with HIV. *Bulletin of the World Health Organization*. 87: 833-839. http://www.who.int/bulletin/volumes/87/11/08-059360/en [Accessed 14.10.2013].

Wong LH, Van Rooyen H, Modiba P, et al. 2009. Test and Tell: Correlates and Consequences of Testing and Disclosure of HIV Status in South Africa (HPTN 043 Project Accept). *Journal of Acquired Immune Deficiency Syndrome.* 50: 215-222. http://0-ovidsp.tx.ovid.com.innopac.wits.ac.za/spb/ovidweb.cgi [Accessed 16.03.2009].

World Health Organization (WHO). 1946. *Constitution of the World Health Organization*. http://www.who.int/governance/eb/who_constitution_en.pdf [Accessed 26.05.2014].

World Health Organization (WHO). 1997. *Violence Against Women: A Priority Health Issue*. Geneva: World Health Organization, Family and Reproductive Health. 13 p. http://www.who.int/violence_injury_prevention/media/en/154.pdf [Accessed 27.11.2014].

World Health Organization (WHO). 2006. An Interview with Peter Selwyn, MD, MPH. *World Health Organization Pain & Palliative Care Communications Program.* 19(4): 1. http://www.whocacerpain.wisc.edu/?q-node/78 [Accessed 20.11.2013].

World Health Organization (WHO). 2007. *Guidance on Provider-Initiated HIV Testing and Counselling in Heath Facilities*. Geneva: World Health Organization. 68 p. http://www.who.int/hiv/pub/guidelines/9789241595568_en.pdf [Accessed 23.03.2015].

World Health Organization (WHO). 2008. Towards Universal Access: Scaling Up Priority HIV/AIDS Interventions in the Health Sector Progress Report, June 2008. 9 p. http://www.unicef.org/media/files/UA_Media_Summary.pdf [Accessed 31.08.2015].

World Health Organization (WHO). 2009. *Rapid Advice: Use of Antiretroviral Drugs for Treating Pregnant Women and Prevention HIV Infection in Infants*. Geneva: World Health Organization. http://www.who.int/hiv/pub/mtct/rapid_advice_mtct.pdf [Accessed 29.03.2010].

World Health Organization (WHO). 2010a. *New Guidance on Prevention of Mother-to-Child Transmission of HIV and Infant Feeding in the Context of HIV*. Geneva: World Health Organization. Mhtml:file://D:\WHO_PMTCT_New_guidance_July2010.mht [Accessed 05.11.2013].

World Health Organization (WHO). 2010b. *Priority Interventions HIV/AIDS Prevention, Treatment and Care in the Health Sector*. Geneva: World Health Organization. http://www.who.int/hiv/pub/guidelines/9789241500234_eng.pdf [Accessed 15.11.2013].

World Health Organization (WHO). 2010c. *Scaling Up HIV Testing and Counseling in the WHO European Region as an Essential Component of Efforts to Achieve Universal Access to HIV Prevention, Treatment, Care and Support*. Copenhagen: World Health Organization. http://www.euro.who.int/_data/asstes/pdf_file/0007/85489/E93715.pdf [Accessed 31.04.2014].

World Health Organization (WHO). 2011. *Provider-Initiated HIV Testing and Counselling: One-Day Training Programme.* Geneva: World Health Organization http://whqlibdoc.who.int/publications/2011/9789241501293_eng.pdf [Accessed 21.11.2013].

World Health Organization (WHO). 2012. *Service Delivery Approaches to HIV Testing and Counselling (HTC): A Strategic HTC Programme Framework*. Geneva: World Health Organization. http://apps.who.int/iris/bitstream/10665/75206/1/9789241593877_eng.pdf [Accessed 13.11.2013].

World Health Organization (WHO). 2013. *Consolidated Guidelines on the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection: Recommendations for a Public Health Approach.* Geneva: World Health Organization. 272 p. http://www.ncbi.nlm.nih.gov/books/NBK195400/pdf/TOC.pdf [Accessed 12.03.2015].

World Health Organization (WHO). 2013b. *Global and Regional Estimates of Violence against Women: Prevalence and Health Effects of Intimate Partner Violence and Non-Partner Sexual Violence*. Geneva: World Health Organization. http://apps.who.int/iris/bistream/10665/85239/1/9789241564625_eng.pdf [Accessed 04.11.2013].

World Health Organization (WHO). 2013c. *HIV and Adolescents: Guidance for HIV Testing and Counselling and Care for Adolescents Living with HIV*. Geneva: World Health Organization. http://apps.who.int/iris/bitstream/10665/95147/1/WHO_HIV_2013.141_eng.psf [Accessed 04.02.2015].

World Health Organization (WHO). 2013. *HIV/AIDS Fact Sheet No 360*. Geneva: World Health Organization. http://www.who.int/mediacentre/factsheets/fs360/en/ [Accessed 04.11.2013].

World Health Organization (WHO). 2013. *The Right to Health Fact Sheet No 323*. Geneva: World Health Organization. http://www.who.int/mediacentre/factsheets/fs323/en/ [Accessed 22.11.2013].

World Health Organization (WHO). 2014. Drug Resistance. *Antimicrobial Resistance: Global Report on Surveillance 2014.* Geneva: World Health Organization. http://who.int/topics/drug_resistance/en/ [Accessed 18.07.2014].

World Health Organization (WHO). 2014. *Global Tuberculosis Report.* http://www.who.int/tb/publications/global_report/gtbr14_executive_summary.pdf?ua=1 [Accessed 02.02.2015].

World Health Organization (WHO)/UNAIDS. 2007. *Guidance on Provider-Initiated HIV Testing and Counselling in Health Facilities.* Geneva: World Health Organization/UNAIDS. http://www.who.int/hiv/pub/vct/pitc2007/en [Accessed 27.04.2008].

World Health Organization (WHO)/UNAIDS/Deutsch Gesellschaft für Technische Zusammenarbeit (GTZ)/International HIV/AIDS Alliance. 2004. *Scaling-Up HIV Testing and Counselling Services: A Toolkit for Programme Managers*. Geneva: World Health Organization. http://www.who.int/hiv/pub/vct/counsellingtestingtoolkit.pdf [Accessed 13.11.2013].

World Medical Association (WMA). 2005. Chapter Two – Physicians and Patients. *World Medical Association Medical Ethics Manual.* Geneva: World Medical Association. http://www.wma.net/en/30publications/30ethicsmanual/pdf/chap_2_en.pdf [Accessed 04.03.2015].

Wynia MK. 2006. Routine Screening: Informed Consent, Stigma and the Waning of HIV Exceptionalism. *The American Journal of Bioethics.* 6(4): 5-6. http://www.informaworld.com/smpp/content~content=a756628459~db=all [Accessed 04.06.2009].

Young SD, Hlavka Z, Modiba P, et al. 2010. HIV-Related Stigma, Social Norms, and HIV Testing in Soweto and Vulindlela, South Africa: National Institutes of Mental Health Project Accept (HPTN 043). *Journal of Acquired Immune Deficiency Syndrome*. 55(5): 620-624. http://globalhealth.med.ucla.edu/publications/young.jaids.pdf [Accessed 02.09.2013].