

Bridging the Gap: Developing a Human Rights Framework to Address Coerced Sterilization and Abortion

Articulating the Principle of Free and Informed Decision-Making

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I. BACKGROUND

number of challenging gender and human rights issues have emerged parallel to, and stemming from, the growing attention to, and demand for, the integration of reproductive and sexual health and rights and HIV-related policies, programmes, and interventions.

With support from the Packard Foundation, the ATHENA Network has launched a Reference Group to identify and address emerging trends and neglected issues at the intersection of sexual and reproductive health and rights (SRHR) and HIV, with a core focus on the priorities and perspectives of women living with, and affected by, HIV and AIDS. Current ATHENA Reference Group members include AIDS Legal Network, Center for Reproductive Rights, Health Systems Trust, ICW, ICW Southern Africa, Ipas, Namibia Women's Health Network, and the Salamander Trust.

As part of a multi-prong strategy, ATHENA, the Center for Reproductive Rights, and ICW collaborated with the Health Equity and Law Clinic of the International Reproductive and Sexual Health Law Programme at the University of Toronto to develop a human rights framework

to analyze the increasingly documented practice of coerced and forced sterilization and abortion among HIV positive women in Southern Africa and globally.

This paper is one piece of a broader initiative to advance the sexual and reproductive rights of women living with HIV, particularly the right to safe, healthy motherhood, and to true reproductive choices. The broader initiative includes a mapping of emerging trends and neglected issues at the intersection of sexual and reproductive rights and health and HIV; documentation by HIV positive women of their interface with the healthcare system around their sexual and reproductive rights and health; use of human rights mechanisms, including the Special Rapporteur; community mobilization; and the development of fact sheets and policy briefs on priority issues.

II. INTRODUCTION



are the duties of providers and ministries of health to ensure that women living with HIV are fully informed and have the capacity to freely decide whether or not to become pregnant, to carry a pregnancy to term, or to terminate a pregnancy?

This human rights analysis discusses the ethical, legal, and human rights principles of free and informed decision-making as applied to the reproductive health choices of women living HIV. This paper focuses on coercive practices regarding sterilization and abortion services. It examines measures required of public and private health care providers to eliminate discrimination against women living with HIV, and to ensure women's free and informed access to reproductive healthcare services, including abortion and sterilization. The Health Equity and Law Clinic is pleased to provide this human rights analysis as part of a larger documentation and advocacy initiative of the ATHENA Network and partners on the reproductive rights of women living with HIV in Southern Africa and globally.

In 2006, the UNAIDS Agenda for Action on Women and AIDS responded to the gendered impact of HIV and AIDS by calling on governments to ensure that AIDS health programmes 'work for women' – in particular, by

...expanding access
to health services that
women need, including,
comprehensive education,
sexual and reproductive
health services, antenatal
care, prevention of mother
to child transmission
(PMTCT) programs, and
equitable access to
antiretroviral therapy (ARV).¹

The Agenda had been largely

developed in response to early HIV and AIDS health programming, which too often regarded women in instrumentalist terms.2 The programming was characterized by a focus on preventing transmission from mothers to their infants, without looking to the prevention of transmission from parents to children. Other dominant encounters with 'mothers' included the 15 million children orphaned or abandoned due to HIV-related ill-health or death of their parents. The common understanding had been that it was mothers who infected, and who orphaned or abandoned, their children.

Reproductive healthcare in the HIV and AIDS context has, thus, been complicated by public health concerns respecting 'mother-to-child transmission', and the future care of children born to women living with HIV.3 As a result, HIV positive women have encountered, and continue to experience, both subtle and overt pressure from health providers, partners, families, communities, and the state to terminate existing, and to avoid future, pregnancies. In 1998, the South African Medical Journal published a letter from a hospital staffmember which stated:

...(i) The availability of antiretroviral treatment should be conditional on voluntary or enforced sterilisation after the present pregnancy; (ii) ... termination of pregnancy should be considered in HIV-infected pregnant women,

...disadvantaged treatment violates the right to equality and non-discrimination, as well as the right to the highest attainable standard of health...

either voluntarily or by law; (iii) an Act of Parliament should be considered to the effect that all HIV-infected women in their reproductive years should be sterilised.⁴

Although many health professionals may not openly voice such opinions, research studies and anecdotal reports indicate that such attitudes are widespread. The High Commissioner for Human Rights (OHCHR) and Joint United Nations Programme on AIDS (UNAIDS) have expressly addressed this problem of coercion. In a 1998 statement, it noted that programmes targeting pregnant women

...often emphasize coercive measures directed towards the risk of transmitting HIV to the foetus, such as mandatory testing followed by coerced abortion or sterilization.⁶

While attitudes have slightly shifted since the introduction and greater availability of anti-retroviral therapy, too few HIV positive pregnant women are able to access the treatment and services they require. In many cases, providers do not perceive

their advice as coercive, but instead as providing 'counselling and guidance' to women, who face many challenges in the bearing and raising of children as a consequence of their HIV positive status.

A human rights approach to free and informed reproductive health decision-making is guided by the principle that all women have a right to reproductive autonomy, including the right to bear children, regardless of their HIV status. The Convention on the Elimination of Discrimination against Women,7 for example, provides that women's human rights are violated by the failure to both ensure non-discriminatory access to health services and to protect women from nonconsensual medical interventions. Rather, women are entitled by right to acceptable healthcare services, defined as

> ...those which are delivered in a way that ensures that a woman gives her fully informed consent, respects her dignity, guarantees her confidentiality and is sensitive to her needs and perspectives.⁸

Coercive (or non-consensual)

...counselling programmes must, therefore, be assessed according to whether or not HIV positive women are treated with equal concern, dignity, and respect...

medical interventions, including abortion and sterilization, constitute grave violations of women's human rights, as guaranteed not only in the Women's Convention, but also the International Covenant on Civil and Political Rights (the Political Covenant),9 and the International Covenant on Economic, Social and Cultural Rights (the Economic Covenant). 10 The violation of women's human rights to acceptable reproductive health care also undermines broader public health goals by dissuading women from seeking care and services. 11 Women may be deterred

> ...from accessing care, because of the negative associations of HIV, or because they anticipate or experience prejudicial behaviour from healthcare providers.¹²

The guarantee of women's human right to free and informed reproductive healthcare decision-making is, thus, essential from both a human rights and a public health perspective. While a woman's HIV positive status may influence her healthcare decision-making, it should not result in her

discriminatory treatment at the hands of health providers or the health system. Prevention and other health programmes should provide information and access to services in a manner that respects the dignity of women by facilitating their free and informed reproductive decision-making. In the 1998 Guidelines on HIV/AIDS and Human Rights, UNAIDS and the Office of the United Nations High Commissioner for Human Rights expressly recognized that:

...[I]aws should...be
enacted to ensure women's
reproductive and sexual
rights, including the right
of independent access to
reproductive and STD health
information and services
and means of contraception,
including safe and legal
abortion and the freedom
to choose among these, the
right to determine number
and spacing of children.¹³

The tension between public health and human rights approaches in reproductive health decision-making, to the extent that there is one, usually arises not from a difference in objectives, but a difference

in chosen means to achieve legitimate public health objectives. Rather than viewing public health and human rights approaches in starkly opposing terms, it is more useful and more accurate to consider how existing tensions in implementation can be overcome. What does the legal standard of 'free and informed' decisionmaking require in practice? What information is material to informed decision-making? What constitutes a free or voluntary decision? What constraints on reproductive decision-making are impermissible?

This paper explores these and other questions in the following three sections:

- Part III examines social, cultural and economic factors that influence reproductive decision-making, and in particular, conceptions of motherhood, pregnancy, abortion, and sterilization in the HIV and AIDS context.
- Part IV identifies legal, ethical, and human rights principles underlying the two main precepts of free and informed healthcare decision-making with particular reference to

women living with HIV and their decisions regarding abortion and sterilization. These two precepts are: (1) decision-making must be voluntary, free of coercion, and without threat or improper inducement; and (2) decision-making must be based on the timely provision of material information.

 Part V applies the human rights framework developed through the paper to representative scenarios and emerging trends.

III. REPRODUCTIVE HEALTH DECISION-MAKING IN CONTEXT

he gendered impact of the HIV and AIDS pandemics is well-acknowledged. As expressed by then United Nations Secretary Kofi Annan: 'In Africa, AIDS has a woman's face'.14 The focus on women. and in particular pregnant women, in the HIV and AIDS epidemics has been both positive and negative in effect. HIV prevention and treatment programmes have been modified to account for the distinctive needs and circumstances of women in an effort to ensure

effective prevention and equitable treatment programs. However, women also became identified as 'vectors' of disease transmission, and in particular, mother-to-child transmission, through delivery and breastfeeding. Efforts have been focused on prevention of transmission rather than the health and well-being of mothers themselves. In 2003, for example, the Constitutional Court of South Africa ordered the South African government to develop programmes for providing Nevirapine to HIV positive women to reduce risk of perinatal transmission.15 Although this decision represents a significant advancement for women's equitable access to PMTCT programs, the Court did not address the ongoing and unmet health needs of women themselves.¹⁶ The failure in many countries to continue to provide antiretroviral medicines to women post-delivery, demonstrates a failure to recognize women as individuals, equally entitled to consideration on this basis.

Mothers are also strongly implicated in the more than 15 million children orphaned or

abandoned, due to HIV-related illhealth, or death of their parents. A 2005 Human Rights Watch Report, for example, noted that in Russia 10 to 20 percent of all children born to HIV positive mothers are abandoned to the care of the state.17 'Motherhood', as a social concept in the HIV and AIDS context, thus became associated with 'harm' - harm of both infection and abandonment. In Botswana, for example, pregnant HIV positive women have been referred to as 'suicide bombers'.

This construction of motherhood, filtering into reproductive healthcare provision, results in a bias against women becoming pregnant, or choosing to continue their pregnancies to term. This is evident, for example, in the exclusive focus of many health programmes on barrier methods of protection, such as condoms.

The construction of motherhood as 'harmful', and thus, 'undesirable' is opposed by the high social valuing of pregnancy, motherhood, and reproduction by women

...ministerial or professional guidelines may be required to ensure that health providers recognize and acknowledge the aggravating health effects of HIV on pregnancy...

...counselling programmes must, therefore, be assessed according to whether or not HIV positive women are treated with equal concern, dignity, and respect...

themselves, as well as by partners, families, communities, and the broader normative structures, including the many cultural and religious stereotypes. As noted by Sofia Gruskin, many of the social factors that influence women's vulnerability to HIV infection are closely connected to women's reproductive health and capacity, because of the high value placed on pregnancy.18 For many women worldwide, pregnancy and child-bearing is central to a woman's selfesteem and sense of personal satisfaction. Demonstrated fertility may also affect a woman's status in her community and family, and may be central to her economic existence.19 Regardless of individual desires to become a mother, many women, therefore, may not forgo reproductive opportunities where the condition of maintaining marital, de facto, or transactional sexual, unions is seen essential to women's economic and physical security. Such pressures often render it difficult for women to employ contraceptive measures, or to safely terminate pregnancies. In addition, strong moral and public condemnation of the practice of abortion and sterilization impede

women's access to safe legal services. Strong cultural and religious stereotypes respecting women as mothers also impact on decision-making regarding pregnancy, contraception, and abortion.

IV. PRINCIPLES OF FREE AND INFORMED DECISION-MAKING

The following Part identifies legal, ethical, and human rights principles underlying the two main precepts of free and informed healthcare decision-making with particular reference to women living with HIV, and their decisions regarding abortion and sterilization. These two precepts are: (1) Decision-making must be voluntary, free of coercion, and without threat or improper inducement; and (2) decisionmaking must be based on the timely provision of material information.

A. The underlying principles of free and informed decision-making

As recognized by the World Health Organization (WHO),

...the informed consent

of the patient is a prerequisite for any medical intervention.²⁰

Free and informed decision-making is guided by the principle that all women have a right to freedom and information to make decisions about their reproductive healthcare. ²¹ The following ethical, legal, and human rights principles underlie this guarantee:

Dignity

Free and informed decisionmaking rests on respect for the inherent dignity of every person.²² This requires that women seeking reproductive healthcare are treated as ends in themselves, rather than means to achieve other goals.23 This principle also requires that each woman is treated as an individual with unique needs, capacities and desires, rather than according to her gender, race, or health status. The Royal College of Obstetricians and Gynaecologists requires that 'patients should be treated with courtesy and respect', allowing 'their dignity to be maintained at all times'.24 This requires that women are both respected and supported in the decision-making process. The component of

'acceptability' under the right to health expressly acknowledges the importance of ensuring that healthcare services are delivered in a manner respectful of human dignity.²⁵

Autonomy and Self-Determination

Free and informed decisionmaking is premised on an understanding that individuals are 'independent moral agents with the 'right' to choose how to live their own lives'.²⁶ This includes independence

> ...from controlling interferences by others and from personal limitation that prevent meaningful choice, such as inadequate knowledge.²⁷

Women are entitled to make decisions on the basis of their personal values, beliefs, and views. ²⁸ Principles of autonomy and self-determination are captured in the right 'to decide freely and responsibly on the number and spacing of their children' ²⁹ and the right 'to found a family'. ³⁰ The right to health further encompasses 'the right to control one's health and body, including sexual and reproductive freedom'. ³¹

Bodily or Physical Integrity/ Inviolability of the Person

This principle relates to the right of individuals to be free from violence to the body or person. In the healthcare context, it is associated with the right to be free from coercive or otherwise non-consensual medical intervention. It also concerns the

...providers have a legal duty to present, or disclose, information that is material to the decision-making of a patient, in a form that the patient can understand and recall...

infliction of unnecessary pain or suffering in the delivery of care. This principle is reflected in a number of human rights protected under international law, in particular, the right to life, the right to liberty and security of the person, the right to be free from torture or other cruel, inhuman or degrading treatment. For example, the right to health also includes 'the right to be free from interference, such as the right to be free from torture, [and] nonconsensual medical treatment'.32 The Special Rapporteur on Violence Against Women further expressly recognized that:

> ...[f]orced abortions, forced contraception, coerced pregnancy and unsafe abortions each constitute violations of a woman's physical integrity and security of person.³³

Privacy/Confidentiality

This principle refers to the right of women to control the disclosure and use of their personal information, and the corresponding obligation of providers, and others, who receive information in confidence, to respect this right.³⁴ Privacy is integral to the decision-making

process. Without its guarantee, women may be deterred from seeking advice and treatment, or may not disclose relevant information. Informed decisionmaking, however, requires the accurate and full exchange of information.35 Privacy is a particularly important principle in the HIV and AIDS context given the significant risks of stigma, violence, and/or abandonment that some women face upon disclosure of their HIV positive status.36 International human rights law recognizes the particular importance of the right to privacy for women in the reproductive health context.37

Equality and Non-Discrimination

This principle recognizes that free and informed decision-making is a right of all persons without discrimination. Thus, women should not be deprived of the right to decide reproductive healthcare matters, because of their sex or gender. Other prohibited grounds, include for example, poverty, age, sex, race, ethnicity, disability, health, or marital status, and geography. The right to health, as protected under the Economic Covenant, imposes immediate obligations to ensure access to healthcare, without discrimination

of any kind.³⁸ This does, however, not require identical treatment. Instead, the principle of equality and non-discrimination recognizes important differences between women and men, as well as among women themselves, that may require a difference in treatment in order to ensure free and informed decision-making.

The following sections of the paper consider these principles under the two main precepts of free and informed decision-making with particular reference to women living with HIV, and their decisions regarding abortion and sterilization. These two precepts are:

- Decision-making must be voluntary, free of coercion, and without threat or improper inducement; and
- Decision-making must be based on the timely provision of material information.

B. Free and voluntary reproductive decision-making

Decision-making is considered coerced, in other words *not* free and voluntary, as and when:

...any action, or threat of action...compels the patient to behave in a manner inconsistent with [her] own wishes. The compelling aspect can be direct physical or chemical restraint, or it can be indirect threatened recriminations or indirect 'force of authority' which convinces the patient that

...health providers are prohibited from performing invasive non-therapeutic procedures to which the patients did not freely consent...

no other legal or medical alternative is available to [her].³⁹

(i) Coercion in the Clinical Care Context: The Medical Provider

Free decision-making includes 'freedom from any bias introduced, consciously or unconsciously' by health providers. 40 Providers may introduce bias into the decision-making process through a number of means, including: directive counselling, inducement, and conscientious objection.

Directive Counselling

Counselling is defined as the ...process of enhancing a subject's ability to assess and understand the situation, evaluate options, and make an informed choice or decision.⁴¹

The intention is to facilitate, but not dictate, the decision-making process. Freedom from coercion is, thus, not incompatible with a health provider giving reasons to favour one option over another.⁴²
Counselling should consist of the provision of information, including medical recommendations, in a

non-directive and non-judgmental manner.⁴³ Where a method of advice or recommendation overwhelms the decision-making process, the line between 'acceptable' and 'directive' counselling has been crossed.⁴⁴ A woman has to, and should, be aware that she has the right to decide in a manner contrary to professional opinion.⁴⁵

This is particularly true in the case of reproductive choices and decisions. As Cook, Dickens and Fathalla (2003) note:

While in other fields of medicine, patients are required to give their informed consent to the treatment proposed by the health care provider, freely and without undue pressure or inducement, in the case of reproductive health care, clients have to make informed choices and decisions. 46

For this reason, the term 'counselling' is especially relevant in the sexual and reproductive health care context where the participation of the 'patient' in health decisions is central.

The determination of whether or not counselling is directive is undertaken from the perspective of the patient. Thus, the question is whether or not counselling is

> ...perceived that way, especially by women who are accustomed to relying on health workers' expertise and by women who are not accustomed to challenging persons in positions of authority.⁴⁷

Providers should understand, and be aware of, the power imbalances in the patient-provider relationship, which may impede the exercise of free decision-making. Providers should also 'question whether their ethical judgments reinforce gender, class, or racial inequality', particularly with respect to advice beyond strictly health-related issues.⁴⁸

Concerns about power imbalances are especially pronounced in the HIV and AIDS context, where women's sexual and reproductive choices may be intricately linked to their own health status. Because HIV positive women require information, care, and treatment for their own health needs, they may be reluctant to challenge a healthcare provider's advice to terminate a pregnancy, or to undergo sterilization. That is, their own health needs and desire for treatment may make women vulnerable to a provider's advice or counselling regarding abortion or sterilization.

In high HIV-prevalence areas,

the risk of directive or coercive counselling is amplified by the fact that women and girls with the greatest risk of HIV-infection are often poor, under-educated, and subject to intersecting forms of discrimination. This may make it less likely for them to effectively challenge or question 'advice' from persons in authority, including healthcare providers.

It is essential that providers of reproductive health care services respect all women and their decisions. The fact that a woman may be poor, illiterate, or HIV positive does not detract from her ability to make informed reproductive choices regarding pregnancy, abortion, or sterilization.

Women, literate or illiterate, rich or poor, given the information and the right to choose and decide, will make the right decisions for themselves and their families, and for the community at large.⁴⁹

Ministries of Health have a

...the conditions under which consent is sought, may also negate any consent obtained...

duty to challenge paternalistic stereotypes of women as incapable of making sound health choices.⁵⁰

Inducement/Incentives

The use of incentives to achieve an outcome that accords with the health provider's wishes is also an unacceptable example of coercion. In South Africa, the use of incentives has been reported in relation to pregnancy termination. Although abortion is ensured under South Africa's Choice on Termination of Pregnancy Act, HIV positive women have been instructed that abortion would only be provided on the condition that they agreed to be sterilized.51 Women are denied access to a healthcare procedure, unless they undergo a medical intervention, which they do not desire. Such conduct violates two principles of free decision-making: autonomy and bodily integrity.

Non-Medical Judgment or Objection

Respect for patient autonomy requires that healthcare professionals are non-judgmental and non-discriminatory in their provision of health services.

However, most women living with HIV face significant stigma and discrimination, ⁵² including by healthcare providers. Forms of such stigma include:

...perceptions that women living with HIV are promiscuous; blame for bringing HIV into a relationship or family; being deemed irresponsible if they

...attention must, thus, be paid to the particular circumstances of the patient to ensure that information is provided in an appropriate form and manner...

desire to have children; and being considered as vectors of HIV transmission to their children.⁵³

Sex workers and women who use injection drugs are further marginalized through negative moral judgments about their 'lifestyles', or work. In addition, some healthcare providers are reluctant to provide abortion, or delivery services, to women living with HIV, due to HIV transmission concerns.⁵⁴

Where a medical provider refuses to treat a woman because she is HIV positive, this constitutes a clear violation of human rights law. Healthcare providers are prohibited from discriminating against persons seeking services on such grounds as religion, marital status, sexual orientation, and/ or HIV positive status.55 In addition, the intersecting forms of moral judgment, stigma, and discrimination experienced by women living with HIV are violations of states' obligations to provide accessible, nondiscriminatory healthcare services. In its General Comment 14 to The Right to the Highest

Attainable Standard of Health (Article 12), the Committee on Economic, Social, and Cultural Rights outlined four interrelated and essential elements of the right to health. ⁵⁶ These include available, accessible, acceptable, and quality health services. A crucial condition of accessible care is 'non-discrimination', namely that

...health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination...⁵⁷

States have an obligation to ensure that medical and nursing training includes instruction on the importance of nonjudgmental care. It is essential that national and hospital health policies challenge negative stereotypes and judgments about women's reproductive choices, regardless of their HIV-status. Peer counsellors, and other support groups for women living with HIV, can provide useful fora for challenging stigma and assisting women in coping with discrimination.58

(ii) Coercion in the Family:

Parents, Partners and Husbands
The obligation of providers to
counteract or overcome the
influence of third parties is
limited:

...Providers are under no general legal duty to isolate or protect patients from the normal influences that affect their lives.⁵⁹

However, providers are responsible:

...if they impose treatments on patients when it is obvious that recipients' resistance is being overborne by the insistence of third parties, such as partners, parents, or parents-in-law. Providers may be equally liable, for instance for negligence, for denying care that patients prefer because of knowledge of third parties' opposition. 60

The Committee on the
Elimination of All Forms of
Discrimination against Women
(CEDAW) recognized, in its *General*Recommendation 21 on Equality
in Marriage and Family Relations,
the value of familial consultation,

where practicable, but nevertheless stressed the fundamental importance of reproductive selfdetermination for women:

Decisions to have children or not, while preferably made in consultation with spouse or partner, must not nevertheless be limited by spouse, parent, partner or Government.⁶¹

The influence that partners, husbands and families may exert over a woman's reproductive decision-making can be particularly pronounced where religious or customary practices undermine her autonomy. Unequal gender relations may also prove particularly problematic in ensuring women's free reproductive health decisionmaking.62 Spousal veto laws and fee requirements for health services can operate directly and indirectly to violate women's right to free and informed decisionmaking. Legal requirements of spousal authorization for sterilization or abortion services are recognized violations of women's human rights.63

Fee requirements, even though permitted for the operation of health systems, can lead to rights violations, especially where they prevent access to health services, or lead to breaches of medical confidentiality. In a Zimbabwean study, researchers found that HIV positive women who wanted to end childbearing were often unable to do so, because of an inability to access abortion services, which was

...the right to receive and impart information is, thus, fundamental to a woman's ability to informed decision-making...

partly due to prohibitive costs.⁶⁴
Because women frequently rely
on their spouse, partner, and/or
family to pay for health services,
they are vulnerable to breaches
of confidentiality when they do
access care. Where third party
payment is required,

...disclosure is the responsibility of the proposed patient, not the healthcare provider, although providers may generalize information by reference, for instance, to gynaecological care, and not be specific.⁶⁵

Ensuring confidentiality is particularly important in the HIV and AIDS context, given the significant stigma and discrimination that women often experience upon disclosure.

(iii) Coercion by the State

The actions of healthcare providers can be directly influenced by governmental social and health policies. This can occur in the context of State population growth schemes, designed to either lower or raise fertility rates. Too often, these schemes involve socio-economic incentives or disincentives to achieve their goals, strongly influencing individual decisions

about childbearing and family size, especially among members of lower socio-economic classes or ethnic minority groups.

A 1999 Report by the Special Rapporteur on Violence against Women emphasized that coercive population practices constitute violence against women, through denial of the right to reproductive self-determination. Practices may deny 'a woman's right to bear children or may punish her for exercising that right'.

Such incentive or disincentive schemes to limit population growth, including among persons living with HIV, undermine women's free decision-making regarding pregnancy and abortion or sterilization services. The perception that financial incentives have 'more to do with coercion than with choice' in developing countries, and that for the 'desperately poor, there is no such thing as free choice' reflects concern that the impoverished will have their decision, as to whether or not to have more children foreclosed by the threat of monetary loss, or the offer of monetary gain.66

Particularly in resource-

poor settings, the provision of financial, or material, incentives to HIV positive women to terminate a pregnancy, or to undergo sterilization, will often be tantamount to coercion. For these reasons, the ICPD discourages the use of incentives and disincentives, stating that

...governments are
encouraged to focus most
of their efforts towards
meeting their population
and development objectives
through education and
voluntary measures
rather than schemes
involving incentives and
disincentives.⁶⁷

The provision of cogent and non-biased information regarding the implications of pregnancy and future pregnancies among women living with HIV should serve as the foundation for patient/client counselling and government health policy.

C. Informed decision-making

In order for a woman's right to reproductive autonomy to be fully recognized,

...reproductive health care must provide complete and impartial information regarding the full range of contraceptive methods and reproductive health issues generally.⁶⁸

The right to receive and impart information is, thus, fundamental to a woman's ability to informed decision-making.

(i) Material Information

Material information should be comprehensive, describing the

...particularly in resource-poor settings, the provision of financial, or material, incentives to HIV positive women to terminate a pregnancy, or to undergo sterilization, will often be tantamount to coercion...

purpose, nature, consequences, and risks of the treatment, as well as potential alternative treatments, including no treatment at all. In the case of sterilization, as advised by FIGO, comprehensive information would include available alternatives. such as long-term reversible forms of contraception, or no treatment at all, as well as details about the procedure itself, what it entails in terms of pain and recovery times, and intended benefits as contrasted with serious or frequently occurring risks.69 In the case of decisions about whether or not to terminate a pregnancy, because of feared transmission, women should be informed about interventions, which can significantly reduce the risk of perinatal transmission.

Even where abortion is legally available, for instance through a health exception, women may be unaware of this option and may not access abortion services, or post-abortion care, due to a lack of information, prohibitive costs, or negative attitudes on the part of abortion providers.⁷⁰

In order to make an informed reproductive choice, women living

with HIV must be advised of all reproductive options, including continuing with a pregnancy, undergoing an induced abortion, or being sterilized. Some of the most pressing questions for an HIV positive woman in the reproductive context include her own health status, the presence of any other interfering diseases, the potential consequences of HIV for her child, and the HIV-status of any of her previous children.⁷¹

Women living with HIV must also be informed of all the risks and consequences of continuing, or terminating, a pregnancy, as well as of subsequent sterilization. Women further need to be informed of the relevant risks and benefits of current or proposed medications, for both herself and the foetus. Where scientific knowledge is limited in certain areas - for instance, the interaction between pregnancy and HIV-infection⁷², or the effect of certain ARVs on prenatal development73 - women should be informed of current knowledge deficits.74

Practitioners have a professional duty to abide by scientifically and professionally

determined definitions of reproductive health services and to exercise care and integrity not to misrepresent or mischaracterise them on the basis of personal beliefs. The Where a pregnancy is wanted, material information and counselling should be provided regarding the means to prevent vertical HIV transmission and maternal-foetal medication.

Because sterilization is a surgical procedure that is intended to be permanent, it is crucial that a women's decision is free and informed.⁷⁷ UNFPA and WHO Guidelines regarding sterilization emphasize that 'particular attention is needed for young women or women with mental health problems, including depressive conditions'. This means that

...all women, irrespective of HIV status, must understand the permanence of sterilization and be informed of alternative contraceptive methods.⁷⁸

(ii) Comprehension – Form and Language

Free and informed decisionmaking requires more than the provision of information. Rather, information must be comprehensible. This requires, according to FIGO,

...appropriate disclosure to the patient of adequate and understandable information in a form and language understood by the patient⁷⁹. Comprehension will be based on many factors, including age and maturity, educational and cultural background, native language, even state of consciousness and willingness or opportunity to ask questions. 80 Attention must, thus, be paid to the particular circumstances of the patient to ensure that information is provided in an appropriate form and manner, taking into account 'personality, expectation, fears, beliefs, values, and cultural background'. 81

It is also essential that the information is provided in a language that is understandable to the individual patient, providing for any linguistic or cognitive limitations⁸². As noted by FIGO, the difficulty in providing this information to a patient who has had little education, for example, does not

(iii) Timely Provision

Information must also be provided at a reasonable time. Consent to treatment, for

negate the medical provider's obligation to fulfil this criteria.83

...for the 'desperately poor, there is no such thing as free choice'... example, should not be obtained while the patient is in a reduced state of consciousness. The importance of timing in provision of information was recognized by the CEDAW Committee in A.S. v. Hungary, where medical counselling regarding sterilization was deemed inadequate to ensure free and informed consent. In this case, not only was the counselling provided during an emergency caesarean section, but the information provided was not comprehended by the petitioner. This was clearly evident in her subsequent questions regarding further childbearing.84

V. CASE STUDIES

art V applies
the rights-based framework
developed in Part IV to a series of
representative fact situations in
an effort to identify coercive, or
otherwise objectionable, conduct
in concrete circumstances.
Applicable ethical standards,
laws, and regulations, as well
as human rights guarantees are
summarized.

Conditioning of Access to
 Publicly-Funded Treatment or
 Prenatal Care on Consent to
 Sterilization or Abortion
 Reports indicate that some

...states have an obligation to ensure that medical and nursing training includes instruction on the importance of non-judgmental care...

anti-retroviral treatment programmes may require women to use provider-defined contraceptive methods, or undergo sterilization, in order to be eligible for treatment.⁸⁵ The International Federation of Gynaecology and Obstetrics (FIGO) Committee for the Ethical Aspects of Human Reproduction and Women's Health states that

...no incentives should be given or coercion applied to promote or discourage any particular decision regarding sterilization. In particular, withholding other medical care by linking it to sterilization is unacceptable.⁸⁶

Women are forced to either undergo sterilization, or forgo necessary medical treatment. Ministries of Health, or their agents, may be statutorily barred from enacting policies that condition care on sterilization/abortion insofar as they subvert the intended purpose of statutory duties (to provide necessary health services without charge), or

may be viewed as against public policy, since health providers are prohibited from performing invasive non-therapeutic procedures to which the patients did not freely consent.

Involuntary Sterilization

- **During Caesarean Section Deliveries** Emergency sterilization is permissible only in a lifethreatening situation, during an operative procedure, in which the physician determines that prior consent is not possible. The physician must certify that the patient was in imminent danger of loss of life and the required consent could not be obtained with prejudicing the health or life of the patient. Even if sterilization becomes medically advised during an operative procedure, sterilization without consent is not warranted. Principles of informed consent may require, for example, that proper prior warning is provided to all patients, or that accountability mechanisms are implemented to ensure
- that any sterilization was in fact required as an emergency measure. The conditions under which consent is sought, may also negate any consent obtained. In Szijjarto v. Hungary (CEDAW Communication), for example, prior to undergoing a caesarean section, but while on the operating table, the patient was asked to sign a form consenting to sterilization and a handwritten note requesting sterilization. The Latin term for sterilization, a term unfamiliar to the patient, was used. Medical records also indicate that, at the time consent was sought, the patient was reportedly in poor health.
- consent to Abortion Based on Health Provider's Failure to Inform of Options to Reduce Risk of Vertical Transmission of HIV Providers have a legal duty to present, or disclose, information that is material to the decision-making of a patient, in a form that the patient can understand and recall. Decisions both to

accept recommended care and to decline other forms of care must be adequately informed. For example, options to reduce risk of vertical transmission of HIV, and the effectiveness of such options, should be explained and offered to allow a woman to make an informed choice.

Lack of Access (on the Basis of Financial or Other Barriers) to Measures that Prevent, or Reduce, the Risk of Vertical Transmission of HIV Despite the availability of effective interventions for the prevention of vertical transmission, access is often restricted in settings with limited resources. An HIV positive woman's entitlement to anti-retroviral medication is protected by the Women's Convention, which requires the provision of

> ...appropriate services in connection with pregnancy, confinement and the postnatal period, granting free services where necessary (Article 12(2)).

The right of the woman to appropriate services is reinforced by the child's right to appropriate care. The Children's Convention requires states to ensure the provision of appropriate prenatal and post-natal health care for women (Article 24(2)).

HIV and the Therapeutic

...health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination...

Exception under Criminal **Abortion Laws**

In South Africa, a pregnancy may be terminated upon request of a woman during the first 12 weeks of pregnancy. From the 13th to 20th week of pregnancy, abortion is permitted if the continued pregnancy poses a risk of injury to the woman's physical or mental health; the pregnancy resulted from rape or incest; there exists substantial risk that the foetus would suffer from a severe physical or mental abnormality; or the continued pregnancy would significantly affect the social or economic circumstances of the woman.87

HIV positive women in South Africa have been dissuaded from accessing abortion services and maltreated while receiving services. Reports of abuse include being handed a foetus for disposal, and being 'granted' a termination of pregnancy only after agreeing to be sterilized.88 An HIV positive woman's rights to life and survival, under the Political Covenant and

to the highest attainable standard under the Economic Covenant, which include her physical, mental, and social well-being, reinforce her legal rights to terminate a pregnancy, where abortion is permitted for reasons of preservation of health or for reasons of HIV status. The WHO advises that:

> ...[w]here termination of pregnancy is both legal and acceptable, the HIV positive woman can be offered this option...the woman, or preferably the couple, should be provided with the information to make an informed decision without undue influence from health care workers and counselors.89

In order to operationalize the therapeutic exception, ministerial or professional guidelines may be required to ensure that health providers recognize and acknowledge the aggravating health effects of HIV on pregnancy. In Guyana, the law specifically provides that the health indication covers AIDS and HIV-positivity.90 There remains

some disagreement as to whether or not it is preferable to explicitly identify HIV status in statutory language. 91 The preferred strategy may be context-specific.

Coercive Sterilization/
 Abortion on Basis of Health
 Status and Race/Ethnicity

The concluding observations of the Committee on Elimination of Racial Discrimination (CERD) recognizes targeting of mandatory HIV testing, or sex work social cleansing programmes, on the basis of national origin or race as a form of discrimination. In 2006, for example, CERD praised the Mexican government's criminalization of forced sterilization, but reiterated its concern regarding the forced sterilization of indigenous women in Chiapas, Guerrero, and Oaxaca. The government was encouraged to investigate and punish the perpetrators of such practices and to provide compensation for victims.

Content of Counselling Programmes

Counselling programmes should be provided by a trained person and be non-directive, non-judgmental, and confidential. Counselling programs may differ depending on a woman's HIV-status. In one reported clinic, for example, HIV-negative patients are offered

...respect for patient autonomy requires that healthcare professionals are non-judgmental and non-discriminatory in their provision of health services...

a range of family planning methods immediately after delivery, as well as standard services at the family planning clinic thereafter. HIV positive women, by contrast, are offered the option of sterilization immediately after an elective caesarean section. Different counselling programs may be appropriate for HIV positive and HIVnegative women. Difference alone is not objectionable, especially where the program responds to the differing needs and circumstances of HIV positive women, as identified by the women themselves (CEDAW principle of substantive equality). Difference in the programs may, however, be based on discriminatory views of HIV positive persons. Counselling programmes must, therefore, be assessed according to whether or not HIV positive women are treated with equal concern, dignity, and respect.

 Disclosure of Pregnancy and HIV Status

> Test results are sometimes provided to partners, husbands or

other family members of pregnant women, based on the assumption that partners will make decisions about whether or not to continue the pregnancy. Medical providers owe a duty of confidentiality to their patients. The right to self-determination captures interference in decisionmaking by both state and private actors, including husbands and parents. CEDAW, for example, advises that governments

...should not restrict women's access to health services... on the ground that women do not have the authorization of husbands, partners, parents or health authorities.

Denied Access to Quality
 Prenatal and Obstetric Care
 on the Basis of HIV Status,
 Mistreatment/Abuse within
 Health Care Setting

Reports are cited of hospital discharge, refused admission, or forced home delivery on the basis of HIV status. Women living with HIV that are denied skilled birth attendance are placed at greater risk of maternal mortality and morbidity. Women may also receive substandard care, as a consequence of disproving attitudes of health providers. It is unnecessary, for example, for women living with HIV to be isolated, or separated from, other women during childbirth. Pregnant sex workers and women who use injection drugs may face additional stigma. Disadvantaged treatment violates the right to equality and non-discrimination, as well as the right to the highest attainable standard of health.

CONCLUSION

he above human rights analysis of ethical, legal and human rights principles of free and informed decision-making in the context of reproductive health choices of positive women, clearly highlights that HIV positive women's realities of accessing reproductive healthcare is primarily defined by coercive practises, especially regarding sterilisation and abortion services. Thus, positive women's experiences continue to be marked by human rights abuses and violation, despite existing

human rights principles and provisions affording reproductive health choices based on free and informed decision-making. So, while women's right to autonomy, including women's right to reproductive autonomy, is an integral part of the fundamental human rights framework, the extent to which women, and especially HIV positive women, are in the position to access and realise this right, remains severely limited.

Recognising the principles of free and voluntary decisionmaking regarding reproductive choices, as well as the fact that decision-making processes are to be based on timely provision of material information, it seems equally essential to acknowledge the gendered and unequal societal context in which reproductive healthcare is accessed, and reproductive choices are made - greatly impacting on both reproductive decision-making and women's greater risk to human rights abuses in the context

of reproductive healthcare. It

...Ministries of Health have a duty to challenge paternalistic stereotypes of women as incapable of making sound health choices...

is, thus, argued that the right to reproductive autonomy, including free and voluntary decision-making in the context of sterilisation and abortion services, will only become truly accessible to HIV positive women as and when the societal context, in which rights are accessed and decisions are made, equally affords women the right to make informed decisions about reproductive choices.

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