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Direct or Directive?

The principle of free and informed decision-making^A

What 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?

Introduction

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 with HIV. This paper focuses on coercive practices regarding sterilisation and abortion services. It examines measures required of public and private healthcare 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 sterilisation. 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 (ART).¹

The *Agenda* had been largely developed in response to early HIV and AIDS health programming, which too

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Editorial...

To modify the social and cultural patterns of conduct of men and women, with a view to achieving the elimination of prejudices and customary and all other practices, which are based on the idea of the inferiority or superiority of either of the sexes, or on stereotyped roles for men and women.

[Women's Convention, Article 5(a)]

It is within the context of recognising the need to alter the gendered and normative societal context, defining especially women's HIV risks and vulnerabilities, that this edition of the *ALQ* is focusing on of the controversial debates at the intersection of women's rights and HIV realities. The extent to which women, particularly women living with HIV, are in the position to make free and informed reproductive health decisions; the barriers to accessing, claiming and enjoying both sexual rights and reproductive rights, as experienced by women living with HIV; and the feasibility of 'new' and 'proven' HIV prevention tools for women are some of the topics explored in this edition.

This edition is also 'making a point' on women's HIV realities and challenges in farming and rural communities; and introducing the *Justice and Women* (JAW) project, an initiative designed to change both informal and formal structures perpetuating both gender inequality and women's greater vulnerabilities to HIV and AIDS, as well as the *Bridging the Gap* project and publications focusing on the contentious and neglected issues at the intersection of sexual and reproductive health and rights and HIV.

In this edition, **Nisha Anand**, **Joanna Erdman**, **Lisa Kelly** and **Cheryl Robinson** explore the principle

of free and informed decision-making. Examining the realities and challenges of free and informed decision-making in the context of reproductive healthcare, with specific reference to women living with HIV and their decisions regarding termination of pregnancy and sterilisation, the article acknowledges the tension between public health and human rights approaches in reproductive health decision making, and argues that the right to free and informed decision-making is central to both a human rights and a public health perspective.

Discussing the potential of medical male circumcision as an HIV prevention tool, **Denis Matwa** examines the socio-cultural context of male circumcision. Emphasising the need for male circumcision to become a subject for public debate and never to be separated from known and proven HIV prevention methods, such as condoms, he argues that for male circumcision to become a 'successful' HIV prevention tool, patriarchal power relations need to be challenged and the safety of women has to be made a priority.

Based on a prior discussion on the potential of the diaphragm as a HIV risk reduction tool, **Zena Stein** and **Ida Susser** re-examine its role in HIV prevention. Highlighting advantages and disadvantages of both the diaphragm and the condom (female and male), the article argues that male and female condoms, combined with education, is the only protection currently available, as the diaphragm is 'not the magic bullet' we hoped for.

Recognising HIV positive women's right to a healthy and happy sexual and reproductive life, the article by the **International Community of Women Living with HIV/AIDS** (ICW) explores the realities and common barriers for women in realising both their sexual rights and reproductive rights. Discussing

often regarded women in instrumentalist terms.² The programming was characterised by a focus on preventing HIV transmission from mothers to their infants, without looking to the prevention of HIV 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.

...too few HIV positive pregnant women are able to access the treatment and services they require...

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 staff-member 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, 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.⁵ 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.

...women’s human rights are violated by the failure to both ensure non-discriminatory access to health services and to protect women from non-consensual medical interventions...

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

barriers, such as social disapproval and inadequate health information and services, the article argues that without the full and equal recognition of *all* rights and freedoms, women living with HIV will continue to have their sexual and reproductive rights limited, violated and/or denied.

Examining the challenges experienced by women living with HIV, **Wendy Pekeur** and **Susan Holland-Muter** are '*making a point*' about HIV realities and challenges in the agricultural sector. Discussing the life experiences of two women, the article highlights the need to address the social determinants fuelling HIV risks, including the need to challenge and transform social norms and values undermining women's rights, and argues that without '*breaking the cycle*' of social inequality, responses to HIV and AIDS will fail.

While the specific rights and realities examined in these articles may vary – from the right to make free and informed decisions to the right to enjoy a happy and pleasurable sexual life and the right to HIV prevention that is both readily accessible and safe – the common argument seems to be that without addressing, challenging and transforming the societal context, determining HIV risks and vulnerabilities, people's rights and freedoms will continue to be limited, violated, and/or denied – even more so if a person is female and living with HIV. Moreover, common to all arguments seems to be the recognition that the combination of gendered inequalities, stigma, discrimination, and a lack of adequate access to information not only compounds especially women's risks and vulnerabilities, but also renders most HIV programmes and interventions ineffective.

If we are to recognise women's rights in the context of HIV and AIDS, then we are not only to acknowledge the many barriers women, and particularly women

living with HIV, face in accessing, realising and enjoying their rights, but also to rigorously challenge the norm and values maintaining and strengthening these barriers. Similarly, if we are to recognise the need to challenge and transform the '*social fabric*', then we are to be prepared – no matter how '*uncomfortable*' it may be – to challenge and transform the patriarchal paradigm, which lies at the very core of the societal context that continues to '*justify*' and '*condone*' as much the violation of women and women's rights, as women's greater HIV risks and vulnerabilities.

However, challenging society's norms and values would demand not only the consistent use of rights-based approaches and arguments, but also may require '*courage*' and the preparedness to be perceived as '*the odd one out*', and to potentially become '*a lonely voice*' amongst friends and family, amongst co-workers and community members – in spite of the '*rightfulness*' of the approach and argument, as well as the '*greater good*' that would be achieved for society's '*social fabric*', if all people, regardless of their sex, would have free and equal access to fundamental rights and freedoms.

And so, only as and when we are '*brave*' enough to challenge the '*patriarchal system*' and to '*tackle*' the very foundation of our '*social fabrics*', will there be '*hope*' for women's rights to become reality, and for AIDS programmes and interventions to indeed respond to women's risks and vulnerabilities – until then, the '*status quo*' prevails, and so will the violation of women, women's bodies and women's rights...

Johanna Kehler

and to protect women from non-consensual 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) medical interventions, including abortion and sterilisation, 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 healthcare 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

... 'motherhood', as a social concept in the HIV and AIDS context, thus, became associated with 'harm'...

The guarantee of women's human rights 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 recognised that:

*...[l]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' decision-making 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? [...]

Reproductive Health Decision-Making in Context

The 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 programmes. 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 programmes, 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 recognise women as individuals, equally entitled to consideration on this basis.

*...strong moral and public condemnation
of the practice of abortion and
sterilisation impede women’s access to
safe legal services...*

Mothers are also strongly implicated in the more than 15 million children orphaned or abandoned, due to HIV-related ill-health, 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 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 self-esteem 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 sterilisation 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.

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 sterilisation. 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.

...this requires that women seeking reproductive healthcare are treated as ends in themselves, rather than means to achieve other goals...

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

As recognised by the World Health Organisation (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 decision-making 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 decision-making 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

...the right of women to control the disclosure and use of their personal information...

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 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] non-consensual medical treatment.³²

The Special Rapporteur on Violence Against Women further expressly recognised 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 is a particularly important principle in the HIV and AIDS context given the significant risks of stigma, violence, and/or abandonment...

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 decision-making, 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 recognises the particular importance of the right to privacy for women in the reproductive health context.³⁷

...a woman has to, and should, be aware that she has the right to decide in a manner contrary to professional opinion...

Equality and Non-Discrimination

This principle recognises 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 recognises 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 sterilisation. 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 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

...the fact that a woman may be poor, illiterate, or HIV positive does not detract from her ability to make informed reproductive choices...

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 healthcare 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

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

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 sterilisation. That is, their own health needs and desire for treatment may make women vulnerable to a provider’s advice or counselling regarding abortion or sterilisation.

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 healthcare 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 sterilisation.

...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 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 of Termination of Pregnancy Act*, HIV positive women have been instructed that abortion would only be provided on the condition that they agreed to be sterilised.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.

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

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; blamed for bringing HIV into a relationship or family; being deemed irresponsible if they 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 marginalised 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

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

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, non-discriminatory healthcare services. In its *General Comment 14: 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 non-judgmental 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

In its *General Recommendation 21 on Equality in Marriage and Family Relations*, the Committee on the Elimination of All Forms of Discrimination against Women (CEDAW) recognised the value of familial consultation, where practicable, but nevertheless stressed the fundamental importance of reproductive self-determination 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 decision-making.⁶² [...]

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 partly due to prohibitive costs.⁶³ 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.*⁶⁴

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.

...to make an informed reproductive choice, women living with HIV must be advised of all reproductive options...

A 1999 Report by the Special Rapporteur on Violence against Women emphasised 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 sterilisation 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.⁶⁵

Particularly in resource-poor settings, the provision of financial, or material, incentives to HIV positive women to terminate a pregnancy, or to undergo sterilisation, 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.*⁶⁶

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 recognised,

*...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 purpose, nature, consequences, and risks of the treatment, as well as potential alternative treatments, including no treatment at all. In the case of sterilisation, 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. [...]

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 sterilised. 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.⁶⁹

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

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 sterilisation. 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 infection⁷⁰, or the effect of certain ARVs on prenatal development⁷¹ – women should be informed of current knowledge deficits.⁷²

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.⁷³ Where a pregnancy is wanted, material information and counselling should be provided

regarding the means to prevent vertical HIV transmission and maternal-foetal medication.⁷⁴ [...]

(II) COMPREHENSION – FORM AND LANGUAGE

Free and informed decision-making 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 patient*⁷⁵.

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.⁷⁶ 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*’.⁷⁷

...ensure that information is provided in an appropriate form and manner, taking into account ‘personality, expectation, fears, beliefs, values, and cultural background’...

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 limitations⁷⁸. As noted by FIGO, the difficulty in providing this information to a patient who has had little education, for example, does not negate the medical provider’s obligation to fulfil this criteria.⁷⁹

(III) TIMELY PROVISION

Information must also be provided at a reasonable time. Consent to treatment, for example, should not be obtained while the patient is in a reduced state of consciousness. The importance of timing in provision of information was recognised by the CEDAW Committee in *A.S. v. Hungary*, where medical counselling regarding sterilisation 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.⁸⁰

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FOOTNOTES:

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- A. This article is an excerpt from Anand, N., Erdman, J., Kelly, L. & Robinson, C. 2009. Developing a human rights framework to address coerced sterilization and abortion: Articulating the principles of free and informed decision-making. Policy Brief. ATHENA Network & AIDS Legal Network. This publication forms part of the Bridging the Gap initiative. The full document can be obtained from www.athenanetwork.com or www.aln.org.za.**

Denis Matwa

The safety of women should be made a priority...

A critical look at medical male circumcision as a HIV prevention tool

Male circumcision has been performed largely for religious, ethnical and cultural reasons. In certain parts of South Africa, more particularly in the Eastern Cape, Western Cape, and Mpumalanga provinces, circumcision has been practised largely for traditional and cultural reasons, depending on the particular ethnic groups that live in a particular area. Recently, it has been suggested that male circumcision can play a very important role in containing the spread of HIV and AIDS, if it is performed correctly and used in combination with other prevention tools.

Since medical male circumcision is said to be one of the methods preventing HIV infection from females to males, the purpose of this paper is to briefly look at the historical significance of this institution, so as to understand how it can actually help in mitigating the spread of HIV and AIDS. This paper will argue that male circumcision cannot solely be used as an HIV prevention tool.

It is wise to understand the context of male circumcision in certain African communities if it is going to have the desired effects. For male circumcision to be effective as an HIV prevention tool, it need to be used in combination with the other known prevention measures such as condoms, female condoms and the development of an effective microbicide.

Male circumcision as a prevention tool

It must be noted that there is a difference between traditional male circumcision and medical male circumcision. The advantages of traditional male

circumcision include the fact that one receives advice as to how to behave as a man. This advice includes, among other things, that (a) a man must be responsible in his family and the community at large; (b) violence, both physical and psychological, is not something to be used to resolve disagreements; and (c) men must always respect their female partners. It encourages initiates to become good members of the community once they are men. It is during this period that the importance of taking responsibility for one's actions is emphasised. It must be pointed out that the advice that is given to initiates at the traditional male circumcision schools is contradictory, in that although it professes to encourage respect for women, it also places emphasis on the fallacy that males are the 'heads' of the family, as is demonstrated below.

It must be pointed out that traditional male circumcision has disadvantages as well. Firstly, traditional male circumcision reinforces the patriarchal power relations that perpetuate the oppression of women in society. It is at these initiation schools that young initiates develop and maintain the false mentality that they are 'superior' to women. It is during this period that the false notion of males as 'heads' of the household or family is emphasised. This notion of males as 'heads' of the family or household, also implies that women must be the 'subordinates'. Linked to this, is the view that young initiates, when coming out of the circumcision school, must 'cleanse' themselves of 'bad omen' by engaging in sex with young women when they go back to the community – thus, portraying a total disrespect for women.

Secondly, the implements that are, most of the time, used

at circumcision schools are not washed with any disinfectant, exposing the initiate to infection of the wound itself as a result. Stinson [2008] also raises this point of hygiene in her study on male circumcision in South Africa, noting that

...the sterility and reuse of surgical instruments, traditionally an assegai is used; implements may be blunt or reused. This practice has been implicated in the spread of blood-borne infections, such as tetanus, hepatitis B and STDs, including HIV/AIDS. As yet, no study of HIV/AIDS in relation to ritual circumcision has been carried out, as youths presenting at hospitals are not routinely tested¹.

It must further be pointed out that in all the processes that are taking place at the traditional male circumcision schools, condom use is not promoted, also impacting on women's higher risk of acquiring sexually transmitted infections, including HIV.

Because of these shortcomings, this form of male circumcision cannot be used effectively as an HIV prevention tool.

...traditional male circumcision reinforces the patriarchal power relations that perpetuate the oppression of women in society...

On the contrary, medical male circumcision is usually very safe, as this type of male circumcision is usually performed by a trained person who knows exactly what they are doing. For this kind of male circumcision (medical) to be acceptable in the communities, it is important to explain thoroughly to communities that, in the time of AIDS, it is important to do things in a very professional way. However, the disadvantage of medical male circumcision is that, the advice that is present at the traditional form of male circumcision is absent here.

It is necessary to mention here the importance of the clinical trials conducted in Uganda, Kenya and South Africa on medical male circumcision as a prevention tool. As stated by Sawires et al [2007]:

On December 13, 2006, the National Institutes of Health (NIH) announced the early termination of two randomised controlled trials of male circumcision-in Kenya and Uganda- on the basis of interim evidence that male circumcision provided a protective benefit against HIV infection of 53% among the 2784 Kenyan men and 51% among the 4996 Ugandan men enrolled in the respective studies. The Kenya and Uganda trials replicated the landmark findings of the South African Orange Farm study, the first randomised controlled trial to report a greater than 50% protective benefit of male circumcision.²

However, the results from these trials were not without some challenges. For instance, more particularly in the Uganda studies, some participants got infected with HIV, because they engaged in unsafe sex while their wounds did not heal well. Weiss et al [2008] also mention some challenges of the trials conducted in Kenya and in South Africa, mainly attributed to the handling of the wounds themselves. They note that

...comparing the adverse event rates in the trials is complex, as different definitions and criteria were used. In the Kenya trial, adverse events possibly, probably or definitely related to circumcision occurred in 23 of 1334 circumcised participants (1.7%). All adverse events were mild or moderate and resolved with treatment within hours or days. In the South African trial, the adverse event rate was 54 per 1495 (3.6%) in HIV negative men.³

These studies clearly show that medical male circumcision is not without challenges. From the

information available from these trials, it is abundantly clear that medical male circumcision must not be praised as the ‘*second coming of the Messiah*’. On the contrary, medical male circumcision should be used in combination with the other known HIV prevention tools. Male circumcision may have some advantages to both males and females as well, as available data suggest that fewer men are in a position to acquire HIV as a result of male circumcision. Moreover, male circumcision reduces the rates of genital ulcer disease and sexually transmitted infections in males.

*... the greatest advantage
to both male and female
is the consistent use of condoms...*

It is a known fact that men are very reluctant to use the public health facilities, unlike their women partners. Women who have circumcised male sexual partners are often at a lesser risk of acquiring sexually transmitted infections. However, this must not be interpreted as if circumcised males cannot transmit HIV to their partners. Moreover, as stated by WHO [2009]

...people need to understand that male circumcision only decreases the risk of HIV infection and does not give complete protection against the virus. Circumcised men can become HIV infected, and, if HIV-positive, can infect their sexual partners. Incorrect perceptions of protection may lead to an increase in risk behaviours, including a reduction in condom use. Men may use their circumcision status as a reason for not using condoms, while women may be less inclined to insist on condom use if their male partners are circumcised.⁴

It is, therefore, important not to divorce male circumcision from other known and proven HIV prevention strategies, such as the development of effective

microbicides, making female condoms accessible to all women and, most importantly, put more focus on the research and development of pre-exposure prophylaxis (PrEP) for the explicit purpose of protecting women against HIV infection. It is often argued that women with circumcised male partners have lower rates of genital ulceration and trichomonas infections. While this might be the case, it must be emphasised that the greatest advantage to both male and female is the consistent use of condoms.

The historical injustice

As an institution on its own, male circumcision without doubt, has been used as an instrument of patriarchal power and domination in South Africa. Male circumcision has been practised solely as a rite of passage to manhood, especially among the Nguni speaking people who practice it. Amongst this group of people, the prospective person to undergo this practice, one needed to prove himself by working very hard to acquire resources so that he can go to the circumcision school. This is important in that it created a culture of responsibility on the part of the person intending to become a man. It was foreign among the Nguni speaking people for a male to go to a medical practitioner for the purposes of circumcision. A male who ‘*dared*’ to take such a route was, and is still, regarded in many communities, as *inkomo edla yodwa* (pariah). It must not be forgotten that what is happening at the male circumcision school is very secret. It is only the circumcised men who know what is happening there. Beyond that, no one must ever know about what is actually taking place there, especially women, including the mother of the person who is undergoing circumcision.

The need for this secrecy is, arguably, just a social construct designed to perpetuate women’s oppression. It is against the original concept of an initiation school. As argued by Stinson [2008]

...a profound aspect of the initiation school is the acquisition of cultural knowledge. It is where young men receive instruction in courtship and marriage practices. Cultural expectations regarding social responsibilities and their conduct as men in the community are transmitted and following initiation; men are afforded numerous privileges associated with their status. Men who've been through initiation are distinguishable by their social behaviour and a particular vocabulary they learn during their time in the bush.⁵

It is not in the scope of this paper to discuss traditional male circumcision thoroughly. However, it is important to give a clear picture of what it is, as this institution has been interpreted and used by different people to serve certain counter-productive tendencies. The fact of being circumcised, and therefore being 'man', has caused males to wield immense (imagined) power, not only over women, but also over men who are uncircumcised or men who opted for the 'other route'. Uncircumcised men have been, and still are, referred to as 'boys' in these communities.

It is important to note that amongst the Nguni speakers there are those communities who do not practice male circumcision for religious or cultural reasons. However, this is totally disregarded by the majority of the circumcising communities. Furthermore, if, in these circumcising communities one's circumcision has been performed by a medical doctor, that person is not regarded a 'complete' man, he is a *pinini* (half-man). He becomes a social outcast in the community. Once a person has gone to the circumcision school successfully, he is now a 'real man' and he can be in a position to marry and start his own family.

There are many things that can be said around the interpretation of male circumcision in our communities, but for the purpose of this paper, just a glimpse of how male circumcision is treated in certain communities can be provided. Mafalapitsa [2008] states that

...MC (male circumcision) is not a new practice in his native South Africa. Culturally, it can be seen as a rite of manhood; the practice of MC, particularly with the loss of blood, can be considered sacred. It is a practice to enforcing masculinity. It can also be a very dangerous one.⁶

...the introduction of medical male circumcision as an HIV preventative tool is going to face extreme resistance in these communities...

This is very dangerous indeed! It can be dangerous in the sense that those who have been to the traditional male circumcision school tend to undermine those who have not been. Ultimately, this reinforces the already unequal power relations in the communities. As a result of this canard, many families and friendships have been broken.

The introduction of medical male circumcision as an HIV preventative tool is going to face extreme resistance in these communities, unless mass education and communication on its advantages is articulated very well. Sawires et al [2007] clearly point out that

...the benefit from male circumcision is relative, not absolute, and the challenge will be to devise communication strategies to reinforce this point clearly. The recent developments in male circumcision present an opportunity to develop new and innovative prevention messaging and especially to reinforce the need for combination prevention that encourages people to use all of the prevention tools available to them.⁷

It must also be emphasised that without the participation of traditional circumcisers in interventions promoting medical male circumcision as a prevention tool against HIV transmission, this strategy is not going to succeed.

...if male circumcision is to be used successfully as an HIV prevention tool, it will require women to be included in the entire process...

The important role of women in male circumcision

As has been pointed out above, male circumcision has gone hand in hand with male domination for a very long time. It can no longer be denied that women are the ones who carry the burden of HIV and AIDS more than any other groups in society. If male circumcision is to be used successfully as an HIV prevention tool, it will require women to be included in the entire process. It cannot be denied that most circumcised males, after learning that male circumcision may reduce the transmission of HIV from female to male, will no longer see the need to use condoms. If circumcised men get infected as a result of not wanting to use condoms, they will simply blame their female partners. Recognising the risks of medical male circumcision Mukhia [2008] further states that

...the positioning of male circumcision as reducing HIV transmission from women to men may perpetuate or reinforce perceptions of women as 'vectors' or transmitters of disease, and may in turn, lead to increased gender-based discrimination.⁸

Similarly, Bass [2008] emphasises that

...another major concern is around stigma: will male circumcision be viewed as a 'badge' of HIV negative status, and so increase the blame, stigma and abuse directed at HIV positive women, who are blamed for bringing HIV into the relationship?⁹

The behaviour of men in relation to their perception of women need to be changed entirely. Men should

be encouraged to use condoms consistently and, most importantly, reduce the number of their sexual partners. Coupled with this is the importance of promoting gender equality. As the joint WHO and UNAIDS recommendations [2007] state:

...policy makers and programme developers should adopt approaches to the scale up of male circumcision services that include the goals of changing gender norms and roles and promoting gender equality; programme managers should monitor and minimize potential negative gender-related impacts of male circumcision programmes.¹⁰

For male circumcision to be effective as an HIV prevention tool, it is important that it be used in combination with other known prevention methods. This means that HIV prevention and treatment methods must be seen to be working for women as well. It is not going to help improve the overall situation, if limited available resources are to be diverted to male circumcision, as if it is the sole HIV prevention tool available. Male circumcision must be part of a comprehensive approach to prevent HIV transmission. Male circumcision, as it appears for now, seems not to come up with any conclusive or logical evidence that women will benefit. In the current situation, the feminisation of the HIV epidemic is starkly demonstrated at all levels of society and thus, it is important to ensure that 'new' interventions will not perpetuate, but instead alleviate women's greater vulnerabilities to HIV.

The important role of communication and mass media

There is a strong need to clarify the role of medical male circumcision in the prevention of HIV infection. It must be stated categorically and clearly that male circumcision, on its own, does not protect against HIV infection. It is important to convey this message in the mass media, such

as bill boards, print and electronic media. This view is further emphasised by Pendry et al [2008], when citing the importance of good messaging.

...it is critically important that we- as advocates, researchers, community members, and individuals affected by HIV- explore both the interpretation of male circumcision as an intervention and an HIV prevention tool at the community level and how this is communicated through the media. Most headline news is that male circumcision reduces the rate of transmission. There is no mention of the fact that it reduces it in the instance of female to male transmission only, nor that there continues to be the need to use condoms, with male circumcision as an additional preventative technology, not the elusive 'silver bullet' that could mean that men no longer need to use a condom.¹¹

Community newspapers and community radio stations can play a very important role in disseminating information around male circumcision as an HIV prevention tool. Going hand in hand with good communication and mass media is the importance of convening mass community meetings or *izimbizos*. These meetings should be inclusive of both men and women, and government should take the initiative of funding such community engagements. The WHO and UNAIDS recommendations [2007] also mention the importance of communities, stating that

...communities, and particularly men opting for the procedure and their partners, require careful and balanced information and education materials that underline that male circumcision is not a 'magic bullet' for HIV prevention but is complementary to other ways of reducing risk of HIV infection.¹²

In addition, public debates on the subject of male circumcision should be encouraged, so that all people can have a clear understanding of its implications and importance. This will assist in clarifying some of the

misconceptions that males, if circumcised, cannot get infected with HIV. Moreover, as argued by Bass [2008],

...successful introduction of any new HIV prevention strategy requires carefully-developed, context-specific messaging that addresses the concerns, questions and roles of all community members in implementing, accessing or understanding the new strategy. (This goes for old strategies, too, like female condoms, which are still, sadly, inaccessible and under-utilised world-wide).¹³

...the behaviour of men in relation to their perception of women needs to be changed entirely...

The need for the state and programme managers to be pro-active

It is crucial that the state institutions and the programme managers involved in the implementation of medical male circumcision play a very active part in ensuring the safety and efficacy of medical male circumcision. The state should closely monitor the safety of all medical male circumcision interventions – which would also protect from ‘charlatans’ who are going to see male circumcision as a business opportunity. Sawires at al [2007] highlight

...the need to ensure that there are sufficient qualified personnel available to do circumcisions is critical. Whether the procedure needs to be done by a physician, or whether nurses or others can do it, should be immediately addressed and these discussions should include local authorities and community members. Basic competency levels must be established together with mechanisms for certifying that personnel are able to meet these standards. This type of model is already happening in South Africa where traditional surgeons

*are certified to do male circumcision safely and, from anecdotal information, many more are eager to work with physicians and nurses.*¹⁴

Moreover, the state and programme managers need to state clearly in the communities that the introduction of medical male circumcision is not intended to undermine 'the institution' of male circumcision. It must be made known that medical male circumcision is purely an intervention designed to reduce the impact of HIV and AIDS in communities. There is also the need for all stakeholders to give clear and concise messages about the advantages and disadvantages of medical male circumcision as a prevention tool against HIV infection. As the UNAIDS/AIDS Law Project [2007] paper cautions:

*...although the results of these trials are highly significant, it is essential to emphasise that male circumcision does not provide complete protection against HIV. Furthermore, HIV-infected circumcised men can still transmit HIV to female and male sexual partners. There is no strong evidence that male circumcision reduces the risk of HIV transmission to a female partner, or that male circumcision reduces the risk of HIV transmission during anal sex to the receptive partner, whether male or female.*¹⁵

...male circumcision, on its own, does not protect against HIV infection...

Conclusion

The existing patriarchal power relations need to be challenged, if medical male circumcision is to become a 'successful' HIV prevention tool. Moreover, any medical male circumcision information and messaging must clearly state that male circumcision on its own is not the remedy

against HIV infection. Male circumcision should be used in combination with other HIV prevention measures, such as consistent condom use, making female condoms accessible to every woman, reduction of multiple sexual partners, and the development of an effective microbicide. If there is a real need for medical male circumcision programmes to be rolled out, the safety of women should be made a priority in all such interventions.

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Zena Stein and Ida Susser

No Magic Bullet...

Thoughts on going back to the female and male condom

Even today, only the male or female condom gives adequate protection against both reproduction and infection. A hormonal method, or an IUD, may be more convenient, but they do not protect against AIDS or the other sexually transmitted diseases. The male and female condom protect from infection, as well as prevent pregnancy.

This unpopular message must be appreciated by those who give advice to women and to men: and by the women and men themselves. For societies and families, the numbers of offspring desired have varied greatly, over time and place, as have the methods available to regulate family size. At this time, hormonal methods, whether by injection or orally, are the most efficient, with the IUD closely behind.

However, neither hormones nor the IUD protect against sexually transmitted infections. This is unfortunate, because both do permit a woman to make reproductive decisions and implement them on her own. However, where sexually transmitted infections might be present in a partner (a possibility that can be eliminated, but only with testing) then the most effective alternatives against conception and infection is the use of physical barriers, the male or female condom.

These barriers, unlike the hormonal methods and the IUD, have to be used around the time of coitus: although there is some flexibility for the female condom, which the woman can put into place some hours before coition, this is not true for the male condom. In either case, the partner is involved in their use.

If the barrier breaks, or is omitted on a particular occasion, the *'morning after pill'* is available. If necessary, easy access to abortion, if pregnancy is diagnosed soon enough, can help to improve the contraception achievable with these barrier methods. Thus, barrier methods are generally effective in preventing conception.

Current scientific opinion is that these physical barriers, if used correctly and absolutely always, will protect against the full range of sexually transmitted infections, and are the nearest thing we have to *'a magic bullet'*. Both the services and the education of the women, who use them, will be needed, and these are certainly not widely in place at this time. It is clear that they require a major input into the services, in their staffing, and in the training of caregivers, and into a much greater understanding by women, and now for men too, of what will achieve *'appreciation'* on their parts, to do what is needed.

We had hoped that the vaginal diaphragm might be a way at least of reducing risk both for conception and infection. Low priced, it usually needs one fitting by a provider,

after which a single product can be used for years. It also has the unique advantage that it can be used ‘*discretely*’, meaning that the partner is often unaware of its use. As a contraceptive, it used to be rated as good – or as bad – as the condom, but of course these ratings could never be sure that the device had actually been used on each encounter. Adding a spermicide gel with the diaphragm did apparently improve its contraceptive effectiveness. But, unfortunately, and contrary to our recent claim in this journal, after careful testing on a larger series of women, it failed to protect adequately against sexually transmitted infections, including HIV.

*...the male and female condoms
plus education are the only current
protections available...*

Moreover, the theory, on which the testing was based, was that the majority of infections took place in the cervix, the entrance to the uterus. It may be that the diaphragm does not adequately and securely protect the cervix, or that infection can also take place in the vaginal epithelium, or of course, that the test failed, because women did not really use the device. Whatever the reasons, we cannot regard the diaphragm as dual protection, even to the extent of reducing risk.

As we all know, for the future ‘*battle against AIDS*’ we can, at least, hope for a vaccine, or a microbicide – usually in the form of a gel which the woman places in her vagina at the time of sex, or with one kind of gel under test before

or after, or on a ring that stays on the cervix and exudes the needed chemical, or with a pill which she inserts and which melts in the vagina. We may be on the verge of finding one of these, which has some anti-HIV effect, but will not be contraceptive, nor will it act against the other sexually transmitted diseases. Another approach against AIDS, also under test, is for a pill to be taken orally, before or after sex, or even every day. There is also the important relevance of the now widespread treatment of HIV, which will reduce transmission, and also circumcision of men, which will reduce their risk of acquiring infection of HIV, and in time the risks for women too. All these and other possibilities are presently under study, but none give a woman today ‘*the magic bullet*’ for which we hope.

In conclusion, the take-home message is that the male and female condoms plus education are the only current protections available, which address both contraception and infection. Knowledge of our bodies and anatomy, which is required for the effective use of condoms, should also make the next steps easier as other protections become available.

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International Community of Women Living with HIV/AIDS (ICW)

Making rights work for us...

Sexual and reproductive rights for women living with HIV

I dream of HIV positive women in Swaziland having the liberty to choose whether or not to conceive. Of having the freedom to engage in sexual relationships if we want to, without fear or criticism from others [ICW member Swaziland]¹

ICW and sexual and reproductive rights (SRR)

In 1999 ICW, the only international network of HIV positive women, initiated research and capacity building workshops in Zimbabwe, West Africa, Thailand and Latin America to explore HIV positive women's experiences of living with HIV. What we learnt confirmed what we were already hearing from HIV positive women: the freedom to make choices regarding their sex lives and to have and rear children were their priority concerns, alongside issues, such as poverty and nutrition.

Our members'² testimonies led to the decision by ICW to hire a global advocacy officer, in 2001, specifically dedicated to advocating for HIV positive women's sexual and reproductive rights in order to add a focus on the sexual and reproductive health and rights (SRHR) of HIV positive women, including HIV positive young women, in all our work (research, capacity building, developing advocacy strategies and advocacy itself) and to complement our existing focus on the greater involvement of people living with HIV (GIPA), access to care, treatment and support (ACTS), and violence against women (VAW). More recently, other networks, NGOs and

even the UN have realised the importance of addressing the sexual and reproductive health (SRH) and, to some extent, the 'SR rights' of HIV positive women and men in ensuring an effective response to the pandemic.

For many decades now the women's movement have pushed for SRHR to be enshrined in international human rights agreements and it is only over the last few years that HIV positive women's voices have entered and enriched these debates. Currently, HIV positive women have some protection under international human rights agreements. However, existing protocols do not address the specific services and conditions needed to ensure that HIV positive women can secure and protect their SHR. Moreover, the stigma and discrimination surrounding HIV has led to laws and policies, such as mandatory HIV testing, criminalisation of HIV transmission and coerced sterilisation of HIV positive women, which fly in the face of a rights-based agenda.

However, given that human rights are universal, examining current sexual and reproductive rights under international human rights law is a good place to start if we want to get leverage in demanding SRHR for HIV positive women.

What exactly are sexual and reproductive rights?

Like all women, HIV positive women have the right to a healthy and happy sexual and reproductive life. The rights associated with HIV positive women's sexual and reproductive lives are protected by several key international treaties that are legally binding and oblige the government to respect, protect, and fulfil these rights for HIV positive women. These treaties include the International Covenant on Economic, Social, and Cultural Rights (ICESCR); the International Covenant on Civil and Political Rights (ICCPR); the Convention on the Elimination of Discrimination Against Women (CEDAW); and the Convention Against Torture (CAT). These rights include

Sexual and Reproductive Health and Rights Found in Legally Binding Treaties

Support for a woman's right to accessible and appropriate reproductive healthcare is also supported by documents adopted at international conferences, which interpret and guide the realisation of legally binding treaties. These include the 1994 International Conference on Population and Development Programme of Action (ICPD) and the 1995 Fourth World Conference on Women. Specific to HIV/AIDS is the United Nations General Assembly Special Session on HIV/AIDS through which member states '*pledge to eliminate gender inequalities, gender-based abuse*'. The United Nations Declaration of Commitment on HIV/AIDS (2001) commits governments to strengthen policy and

Treaty	Some of the SRHR Impacting Positive Women's Lives
CEDAW	Non-discrimination with specific regard to health, right to services associated with pregnancy and maternal health, right to information, right to privacy
CAT	Right to be free from cruel, inhuman, or degrading treatment or punishment
ICCPR	Non-discrimination, liberty, security of person, right to be free from cruel, inhuman, or degrading treatment or punishment, right to privacy, right to dignity, right to found a family
ICESCR	Right to health, non-discrimination, right to found a family

programme linkages between HIV and AIDS and sexual and reproductive health, and pledge that women are able to exercise control over, and decide freely and responsibly on matters related to their sexuality. The International Guidelines on HIV/AIDS and Human Rights (1998) articulates that countries should enact laws that ensure women's reproductive and sexual rights,

the right to information, the right to health, the right to bodily integrity, the right to non-discrimination, the right to equality, the right to live free from inhuman and degrading treatment, the right to non-interference in one's privacy, the right to health, and the right to reproductive self-determination.

which include legal protection from sexual violence, access to information and services, and access to safe and legal abortion. Finally, the World Health Organisation (2002) offers several definitions, including sexual rights as the rights of all persons to receive sexuality education; bodily

integrity; decide to be sexually active or not; decide whether or not, and when, to have children; and pursue a satisfying, safe, and pleasurable sexual life.

*...laws and policies...fly in the face
of a rights-based agenda...*

**Excerpt from the Amsterdam Statement on
Sexual and Reproductive Health and Rights
for People Living with HIV**

Our Sexual and Reproductive Health and Rights:

- People living with HIV have the freedom of choice regarding consensual and pleasurable sexual expression.
- People living with HIV have the freedom of choice regarding reproduction, marriage and family planning.
- People living with HIV have the fundamental rights to access sexual health information and comprehensive sexual health services (1).

(1) Comprehensive sexual and reproductive health services include access to commodities including male and female condoms, water-based lubricants, gloves, antiretroviral therapy, sterile injection equipment, opioid substitution therapy, infertility treatment including assisted reproduction, semen washing, emergency contraception, sexual PEP, and support services after sexual assault regardless of gender, age, sexuality, cultural background, ethnicity, religion, income, educational level, environment, situation and context³.

***Making rights work for HIV positive people -
A global movement of HIV positive people
calling for SRHR***

ICW's work on the SRHR of HIV positive women and that of other organisations, such as the International Planned Parenthood Federation (IPPF), Ipas, Engenderhealth, and the United Nations (UN) has now taken on a global momentum. On 05 to 07 December 2007, the first international consultation led by people living with HIV to address their sexual and reproductive health (SRH) was held in Amsterdam, the Netherlands. At the consultation sixty five HIV positive women, men and transgenders from around the world articulated a vision statement to guide advocacy, policy, legal, programmatic and funding priorities that respect sexual and reproductive health and rights, and to underscore the need for health systems to do the same.

*...women are able to exercise control
over, and decide freely and responsibly on
matters related to their sexuality...*

***What does this practically mean for
HIV positive women?***

Realising sexual rights

HIV positive women and men face disapproval in general for continuing to have sexual relationships and this impacts on their ability to enjoy sexual fulfilment. Gender inequalities lead to an extra layer of stigma and discrimination for HIV positive women seeking to realise their sexual rights. Violations of women's wider rights, such as widow inheritance, lack of access to property inheritance and unequal employment opportunities, violence and the fear of

violence and stereotypical notions of female purity can mean that, when two people who engage in a sexual relationship have differing ideas of what constitutes sexual pleasure and consent, it is the woman who is not in a position to negotiate. This is not made any easier by the lack of commitment to develop female-controlled barrier methods, accessible to all women and that work for HIV positive women. Many of us can not conceive a world where our wishes about sex can be expressed and are taken seriously. And, if we are not able to have a good sex life, it is not the justice system that we would turn to, in order to seek redress. It is, generally, only when women experience physical violence or coercion that they turn to the institutions of the justice system (the police and judiciary) for protection – where, too often, these institutions let them down. So who protects women's right to a healthy, satisfying and pleasurable sex life?

At the time of my diagnosis, I was in a good relationship with someone else and although we had always had protected sex I could no longer have sex with him. I felt dirty, disgusting, used and as far from sexy as humanly possible. The relationship ended and I spent the next four years celibate. [ICW member, Zimbabwe]⁴

Moreover, many HIV positive women and men in consensual sexual relationships are not in the position, due to discriminatory or ill-equipped and under-informed health services, to access the services and information that would allow them to engage in sexual relationships free from fear of transmitting HIV and STIs or of conceiving. Sadly, in many societies discussions around consensual, pleasurable sex are met with double standards, hypocrisy, ridicule and/or are dismissed as unimportant or immoral. In our advocacy we often have to portray HIV positive women as either

victims of male sexual aggression or duplicity, or potential or actual mothers, rather than as sexual agents in their own right, in order to get SRHR issues onto the agenda. This can lead to the mis-targeting of sexual health programmes and advocacy on SRHR.

What do you do about fulfilling your sexual needs and desires when you keep getting gynaecological infections as I do? What makes things worse is that these infections are constantly referred to as sexually transmitted infections (STIs). It makes you feel totally undesirable. With treatment you have fewer episodes and things eventually become normal. You can have healthy, pleasurable, non-violent sexual activity, which is what we all desire. [ICW member, Nigeria]⁵

**... it is the woman who is not
in a position to negotiate...**

To have a good and healthy sex life also depends on being able to maintain one's sexual health. We know that many women lack access to treatments for STI's, reproductive tract infections, and regular sexual health screening, including pap smears and barrier methods, like female condoms⁶. HIV positive women's increased susceptibility to STIs, including HPV, calls for greater access to services; training for and understanding on the part of service providers; as well as openness about sexual health issues with partners. Yet, how do we raise these 'embarrassing' issues with our partners and with health providers? What if our partners don't want to talk about it or won't let us go to the health centre or we fear raising it with them? This is the kind of situation that our members raise

with us. They also report being treated badly by healthcare providers, who feel they should not be engaging in sex, or blame them for not engaging in safer sex. How are HIV positive women supposed to maintain their sexual health and health in general, if their sexual health issues are treated as their 'fault' and their rights to non-discriminatory treatment are not respected?

...in many societies discussions around consensual, pleasurable sex are met with double standards, hypocrisy, ridicule and/or are dismissed as unimportant or immoral...

*A few of us have been infected with STIs, but it has been hard to go for treatment. Our husbands have refused to let us go to hospital because the service providers will ask us to call our husbands in, as they might have the infection too. Our husbands sometimes go to treat themselves secretly but they refuse to provide us money to go for treatment. [ICW member, Tanzania]*⁷

*There is a chemical applied to warts that should not touch uninfected parts and they say 'do it yourself'. [ICW member, Swaziland]*⁸

Realising reproductive rights

*This is my first pregnancy. I would really love to have a child. [ICW Member, Zimbabwe]*⁹

Despite the fact that HIV positive women have the right

to make informed voluntary decisions about whether or not to have children and the right to healthy motherhood, in practice it is hard to achieve reproductive rights and ensure full reproductive health.

...in practice it is hard to achieve reproductive rights and ensure full reproductive health...

Testimonies shared by ICW members, all of whom are HIV positive women from around the world, show that those who choose not to have (more) children struggle to access appropriate contraceptives and related services. Negotiating family planning with sexual partners can also be difficult. If both partners have the right to make decisions about family planning then what happens if they disagree? Mutually supportive and shared decision-making is what many of us aspire to. However, as a women's rights organisation, ICW supports a woman's right to decide what happens to her body and that includes the number and spacing of her children. Therefore, any programme that advocates for the involvement of a woman's partner in family planning decisions, has to consider the context in which a woman gives her consent to their involvement.

I became pregnant again because my husband did not use condoms consistently. I was not aware of my pregnancy until the third month. I went to a private hospital and paid for an abortion. I did not tell my husband for fear of getting beaten up. When he asked why I was so weak, I lied to him saying 'Ohhh...I was lifting some heavy things and I started bleeding. I think

it is not there anymore.'The fourth time I was pregnant we went to the hospital but they refused to conduct the delivery. Again I delivered at home but the baby was stillborn. I do not think I can bear this anymore and I want a sterilisation. [HIV positive woman, India]¹⁰

...emphasis on HIV testing in antenatal clinics serves to reinforce the belief that women bring the virus into the family...

A decision not to have children is influenced by negative social reactions to HIV positive women having children and/or fear of passing on the virus to the baby. In fact, when HIV positive women do want to get pregnant or find that they are pregnant, they often face a lack of services and information about how to safely conceive, have a healthy pregnancy and look after a baby. This situation is exacerbated by severe discrimination by healthcare workers, communities, the media, politicians, and even HIV activists, against HIV positive women who wish to have children or who are pregnant. One of the most serious manifestations of this discrimination is coerced sterilisation of HIV positive women by health workers, as documented by ICW in Namibia¹¹.

I only agreed [to tubal ligation] because I had no choice¹² but I was thinking, what if they find a medication one day – the possibility of having a child one day? This was going on in my mind. From that time I went through a lot of emotional confusion. Now I am

on treatment for a psychiatric problem. I get treatment every month. When I stop I start headache and I can not sleep. [ICW member, Namibia]¹³

Stigma and discrimination against HIV positive women are significant problems within and outside of health services, which directly violates women's rights to comprehensive reproductive health services, including safe abortion, family planning, and comprehensive maternal and child healthcare. This in turn compounds the lack of choice HIV positive women face regarding their sexual and reproductive lives, and adds to a woman's sense of demoralisation and lack of self-worth. Experiences of discriminatory treatment in the hands of health personnel and refusal of, or insistence that they access, services such as abortion, sterilisation and family planning, can lead to reluctance on the part of HIV positive women to access services or to disclose their status when seeking services. The subsequent lack of specialised care can result in severe complications, for example, incomplete abortions¹⁴.

My main concern is how the hospital will treat me because I refused sterilisation. They know I am HIV positive and I am afraid now. I want to plan a child if I have another and not because condom burst. [ICW member, Namibia]¹⁵

...the lack of choice... adds to a woman's sense of demoralisation and lack of self-worth...

Whether denied services because of their status or forced to access certain services, what HIV positive women

often lack in regards to their reproductive lives, is choice. HIV positive women can find themselves caught between pressure to have children, because of social expectations regarding married women and motherhood; the pressure from those that believe that HIV positive women should not have children; and inadequately resourced and informed health services.

We encourage HIV positive women not to get pregnant again. Actually we do not chase them when they become pregnant again...usually when they come back, they feel embarrassed so when I see such clients, I ask my colleague to attend to her...others simply do not come back. [Service Provider, Busia]¹⁶

...a decision not to have children is influenced by negative social reactions...

The manifestation of societal beliefs and attitudes towards HIV positive women's reproductive rights is reflected in the lack of access to, or information regarding, a full range of contraceptive choices. ICW members have reported being denied access to ARVs, unless they agree to have their fertility controlled by use of specified doctor-controlled contraceptive methods (intra-uterine devices, IUDs, or hormonal injections), which neither protect them from further STIs or HIV re-infection, nor potential HIV-negative partners from HIV infection¹⁷. Others have reported an assumption that as positive women, they will be using condoms as their 'chosen' form of contraception, despite absolutely no contraceptive counselling having taken place with health workers¹⁸. Yet, others have experienced a denial of information or access to contraceptive devices at all, on

the grounds that as an HIV positive woman, contraceptives would no longer be necessary¹⁹ – the implication being that positive women should not have sex.

The emphasis on HIV testing in antenatal clinics serves to reinforce the belief that women bring the virus into the family, at a time when they are struggling with the trauma of their HIV status and the impact on both their unborn and their older children. Testing services fail to consider that, the discrimination and gender inequalities HIV positive women face on disclosure of their HIV positive status, may result in many women not disclosing. Not disclosing, or the stigma and discrimination if they do, then prevents women from accessing appropriate care, treatment and support, or testing services, for themselves and their children. Badly-designed services, indiscreet health workers not protecting confidentiality, and ill-conceived policies, such as those criminalising HIV transmission, not only place HIV positive women's reproductive rights at risk, but also endanger their rights to the benefits of scientific progress, health, liberty and life.

...stigma and discrimination against HIV positive women are significant problems within and outside of health services...

Making our own rights agenda

Despite governments having committed to protecting sexual and reproductive health and rights, many positive women face ongoing rights violations including forced

sterilisation, inability to access abortion services, stigma and discrimination in healthcare settings and lack of access to medicine necessary for survival. Lack of support for HIV positive women's rights also creates the conditions within which it is almost impossible for us to exert our sexual and reproductive rights in sexual relationships. Although it may be impossible or undesirable to take our partners to court for being selfish in bed (in the absence of force), we can advocate for an environment that will enable us to make our own (and shared) choices regarding our sexual and reproductive lives and, given the right support, we can also hold health services and governments to account for failing to uphold our rights.

*...badly-designed services,
indiscreet health workers
not protecting confidentiality,
and ill-conceived policies...
place HIV positive women's
reproductive rights at risk...*

Therefore, in order to realise our **sexual rights** we want...

- a recognition that our rights are inter-dependant and that, in order to fulfil our SRHR, requires a recognition of *all* our rights
- recognition that it is okay for positive women to desire a safe, healthy, consensual, and pleasurable sex life
- open dialogue about sex, sexual pleasure, consent and sexual rights
- services (accessible, confidential, comprehensive and

non-judgmental) that can help us enjoy sex, without worrying about either the transmission of HIV and STIs or unwanted conception

- services (accessible, confidential, comprehensive and non-judgmental) for diagnosing and treating STIs and helping with unwanted pregnancies
- legal training and support for HIV positive women's networks seeking redress for SRR violations
- a commitment to accelerated research on microbicides and other women-controlled barrier methods
- full and meaningful involvement of HIV positive women in developing policies and programmes in order to ensure they reflect and address our realities
- de-criminalisation of sexual diversity
- legal protection and full access to sexual and reproductive health care for sex workers

Openness about my HIV status has changed many people's perception that HIV is a result of promiscuity, and punishment from God. It has helped other HIV-positive people come to terms with their status. They now look at me as a whole person. They now accept that I can have sex as an HIV-positive person, the same as eating, drinking, going to work.²⁰

*...what HIV positive women often lack
in regards to their reproductive lives,
is choice...*

In order for us to realise our **reproductive rights** we want...

- non-judgemental, confidential support, services and advice on family planning, abortion, conception,

child bearing and rearing, that will enable us to make informed decisions about whether or not to have children and how to rear them

- employment rights, for example, maternity leave and job protection, on becoming pregnant
- further research and funding into the effects of acute and chronic maternal and child morbidity, and uptake of peri-natal services of ante-natal testing policies and practices
- a reversal of harmful legislation, which effectively criminalises transmission of HIV both in general and in relation to pregnancy, childbirth and breastfeeding
- the meaningful involvement of HIV positive women in the design of policies and programmes in order to ensure they are relevant to our lives

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19. Paxton, et al. 2004. 'Oh, this one is infected'. ICW report on Women, HIV and human rights in the Asia Pacific region. ICW.
20. Narrated by Tarisai to Sunanda Ray of SAfAIDS.

Jennifer Bell and Amber Howard Cornelius

We must be the change we want to see in the world...¹

The Justice and Women (JAW) Project

JAW background and history

In 1998, a number of non-governmental organisations came together in Pietermaritzburg, KwaZulu Natal, to address the difficulties that women faced accessing their family law rights through the local Magistrates Court. An event was held where women were encouraged to speak of their experiences to court and other criminal justice personnel. Listening to the women, it was felt that there was a need for a service based at court, which would support women's access to their rights and which would monitor the court's delivery of services to women. This project came to be called *Justice and Women* (JAW), and for a period of four years was managed as a partnership between Family and Marriage Society of South Africa (FAMSA), Pietermaritzburg, and the Black Sash Midlands.

From the outset JAW grappled with the tension between the internal needs of the organisation and staff members, and the external needs of the community. JAW was staffed by women who themselves were in, or moving out, of abusive relationships, and the work in the organisation gave them skills and income to help facilitate the transition into a new place in the world. Because of their personal histories, the JAW staff provided a caring and supportive environment for other women experiencing violent and abusive relationships. We also spent a lot of time taking care of the psycho-social needs of the staff members, which sometimes negatively impacted on the amount of work we were able to do with

women outside of JAW. The other difficulty was the fact that staff had little formal skills and training, so it was a struggle to deepen the work and to begin addressing more systemic problems around gender inequality.

These tensions eventually led to the closure of JAW in 2004. When JAW reopened in 2005, it did so with the expressed intention of being a development organisation working on gender issues, rather than a direct service/welfare organisation. Direct legal support services addressing women's '*conditional*' issues remain an important part of JAW's work, but we try to balance that with work on women's '*positional*' issues related to gender and power. Nevertheless, the tensions experienced in the '*Old*' JAW continue in the '*New*' JAW – as you will come to read further on. So JAW is still in the process of emerging and finding an appropriate organisational structure and balance between the internal and external needs of the organisation.

Intentions

This project was designed with the intention of changing both the informal and formal structures, which perpetuate gender inequality and increase women's vulnerability to HIV and AIDS. JAW's work on gender is informed by the analytical framework developed by David Kelleher and Aruna Rao. The Kelleher/Rao framework explains how changes in gender-power relationships happen, and demonstrates how changes in formal structures (like legal systems) require changes in the informal structures (like the attitudes and

beliefs of judges and traditional leaders) to be effective. In our gender and HIV and AIDS work, we seek to build the capacity of the community to identify and evaluate both the formal and informal practices that give rise to inequitable power relationships between men and women, which in turn fuel the spread of HIV and AIDS.

To give an example of how we work, JAW facilitated a series of workshops or conversations with traditional council members in Yanguye (a traditional community near Melmoth in Zululand), as well as with a group of 30 community change agents to map prevailing customary practice, and to critically reflect on the linkages to women's vulnerability to HIV and AIDS and gender violence. Through this process, we have begun to help some members of the community to begin challenging practices that increase women's vulnerability to HIV and AIDS, and also to think about gender and power differently in their own relationships and families.

Methodologies and approaches

Using a Transformational Approach

The gender and AIDS activist and scholar Geeta Rao Gupta has identified several approaches for effectively addressing the intersection between HIV and AIDS, gender and sexuality. Among these are transformative approaches that seek to foster constructive roles for men in sexual and reproductive health. Transformative approaches also seek to facilitate an examination of gender and sexuality and its impact on male and female sexual health and work to redefine gender norms and encourage healthy sexuality.

The JAW project uses a transformative approach, as it includes men and diverse age groups in all aspects of the project design and implementation. The project's goal is not to undermine customary practices, but to help communities assess the impact custom has on sexual health, and to

envision how customary practices could be modified to reduce the risk of HIV infection within the community. Because older community members may have a different understanding and experience of customary practices, their input is important to help communities begin to see the dynamic nature of cultural practices and the role the community can play in shaping and transforming customs to fit new contexts – in particular HIV and AIDS and also a *'human rights'*/constitutional framework that is often seen to be at odds with customary practices.

*...formal and informal practices
that give rise to inequitable power
relationships...which in turn fuel
the spread of HIV and AIDS...*

Train the trainer model, using family law rights as a point of entry into rural communities

This was the starting point for the work we did in Melmoth where we recruited and trained a group of 14 community members, some of whom are still with us, as family law educators (FLEs). Over a period of nine months the FLEs received gender consciousness training, read the Constitution, and worked through different pieces of family legislation, including the Recognition of Customary Marriages Act, the Domestic Violence Act, and the Maintenance Act.

Once trained, the FLEs were helped to design community workshops for both the Amakhosi and community members with the aim of not only informing them about their rights, but also to surface issues about women's ability to access support from the community, or other institutions, for family matters. These issues were documented and brought back to the Amakhosi to consider and to plan the next step

in the process. In these discussions the Amakhosi identified the need to focus on the interface between customary law and constitutional law and to understand the paradoxes rural communities face living between these two worlds.

Let the work and the issues emerge from the community's needs and concerns

We try to work in an organic process-driven way, letting the community come to things when they are ready. The issues of HIV and AIDS only came up two years into our work in the community. If we would have just come in and 'hit people over the head' with HIV and AIDS, our work would have been very different. The way that things evolved has allowed people to feel more comfortable and more open. It took time to create trust in that community. Now people are asking to talk about sexuality, and parenting, and disclosing their HIV status.

...the role the community can play in shaping and transforming customs to fit new contexts...

Creating spaces to talk and listen

We do not bring in experts, unless the community asks for specific training on an issue. Someone could come in with expertise and educate people about HIV and AIDS, but often people actually know the basics about HIV transmission. The real questions are about how we can live in a different way to reduce the risks, how can we engage with fear about knowing our HIV status, how we talk about sex with our partners and children. People have to talk a lot and feel listened to and think about things, before they are in a space where they can begin making changes that might seem scary or overwhelming. We have tried to work with the FLEs - who are community members themselves -

to create a container where people can have an experience of something different and have that to take back to their communities. If you work with someone from outside, you cannot plant seeds in the same way.

Our Mantra

We try to think about our work as creating a 'new normal' that is creating a new way for communities to experience relationships with themselves and with others – of having 'power with', rather than 'power over'. We are particularly mindful that to do the work in the community, the change has to start internally. So we believe that if we want to change people's experience of power, to challenge inequalities – that arise from one's gender, one's class, one's race etc. – we have to make sure that we are reflecting a new set of values in our personal lives, in the organisational structure, and in our policies.

So our mantra these days is that 'We must be the change we want to see in the world'. We believe that a lack of coherence undermines the organisation's integrity and ability to provide a new kind of leadership that speaks and acts consistently, which is unfortunately something that is lacking at a national level in government. When words and actions do not match up, one's ability to be effective is completely undermined.

Some of the JAW principals/assumptions are:

- Know thy self. You cannot be an effective facilitator and support people in making changes in their lives, to critically reflect on their own experience if you lack self-awareness and insight.
- Take responsibility – not in a clichéd understanding of the word, but in a deeply reflective way that also examines what stops us from taking responsibility for

ourselves and our choices and trying to think of new ways of overcoming these blockages.

- Be flexible, use humour, act with love and intentionality.

...we try to think about our work as creating a 'new normal'...

Highlights

Creation of Home-Based Care Network

Through our HIV and AIDS work, JAW has helped facilitate the creation of a network of 20 home-based care (HBC) organisations and is using this intervention to begin raising awareness about the gendered nature of community care work and about how it places an unfair economic burden on women.

We feel that, as the HIV and AIDS crisis continues to disproportionately impact on women and girls and increases their economic marginalisation, this is a crucial area for advocacy work. We also hope that through this intervention the quality of home-based care will improve, as community care workers receive the payment, training, and materials that they need, to work effectively.

Combating Stigma and Discrimination

A JAW staff member started a support group for HIV positive people in her rural community, after she struggled with treatment issues and questions. She has become an activist in her community, and facilitates a support group with 30+ members and provides support and information to countless others who see her as a place to get confidential, caring and advice. She chose to disclose her HIV status to the community in a meeting where the traditional leaders and other community leaders were present. Inkosi Biyela,

the community leader, was very moved by her courage and told those present that HIV was not a curse from God and that HIV positive people were still their children. He went on to tell the community that stigma and discrimination would not be allowed in his community and that all people should have the courage to know their status and get tested.

This moment marked a shift in people's willingness to disclose their HIV status and start talking more openly about the effects of HIV and AIDS in the community.

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FOOTNOTE:

1. Based on quote of Mahatma Gandhi (1869 – 1948).

Wendy Pekeur and Susan Holland-Muter

'Break the cycle' of social inequality... HIV realities in the agricultural sector

In South Africa, there are approximately 60 000 commercial farmers, who employ around 600 000 full-time workers and more than 300 000 part-time (casual or seasonal) workers. This means that approximately one million workers are employed in the agricultural sector, with a further 6 million livelihoods estimated to be directly and indirectly dependent on the sector¹.

Western Cape farm workers make up 9% of the economically active population in the province, and the province employs almost 18% of the labour force, and pays more than 23% of the total wage bill for agriculture in the country².

Historically, farm worker families work for the same farmer family for many generations and are 'passed on' from father to son³. The last decade has seen farmers changing their employment patterns, with an increase in the use of labour contractors. This has resulted in less job security, as well as a more mobile farm worker community⁴.

In March 2005, Agri-AIDS, an HIV/AIDS awareness project that brings HIV and AIDS treatment to rural areas, estimated that between 30 – 45% of South African farm workers are living with HIV⁵.

The low status of women, poverty, low levels of education, poor health status, violence, alcohol abuse, and migrancy all contribute to the high prevalence of HIV and AIDS amongst farm workers in South Africa. Research has shown that farm workers are among the

*...most vulnerable of all social strata with regard to income, health status, nutrition security and education.*⁶

Sikhula Sonke and the AIDS Legal Network (ALN) spoke to two women who work with Sikhula Sonke to gain a better understanding of the challenges experienced by women living with HIV on farms and in rural areas. Through the life experiences of two women – Sarah and Evelyn – some of the key issues which need to be dealt with in preventing and managing HIV and AIDS in rural communities, are raised.

Sarah's Story

Sarah is a former farm worker and is living with HIV. She was born in Rawsonville on a farm, and lived with her mother and grand parents who were all farm workers. For Sarah, these were very difficult years, with a mother who was in prison most of her childhood. A symptom of the breakdown in family structures and relationships, violence was something that Sarah experienced from a young age, at the hands of her mother, her sister, her aunt, and the family where she eventually worked and lived from the age of eight.

I and my sister had to sleep outside many nights and I ran away from home when I was eight, leaving with Muslim people who offered me a job as a child minder in Athlone... My employers mistreated me as I grew older, often beating me. I ran away after a few years and ended up in a place of safety in Wynberg. Then I went to the Parow

cloister and after the place closed down I was sent to Brackenfell cloister. I got into my first fight a day before the school holiday and was called into the office to be punished. I was afraid of the punishment and so decided to run away.

...a woman's position on a farm is usually determined by her relationship to a male farm worker...

Sarah returns to Rawsonville when she was 17. It was harvest time.

When I got to the farm where we used to stay, my family was no longer there. They had moved to another farm. When I found my family, my sister who opened the door did not recognise me and asked me who I was. She cried when I told her it's me. My mother was in prison again, and I told my sister that I'm sorry for coming back, because it was the same situation as before. I decided to leave school and started to work in the vineyards. I could not live with my aunt, since the owner of the farm did not want other people there.

I had to find a man to be able to get a place to live. I got married, but my husband was killed. I found another man and decided not to marry again and had a child with him. My second partner died of tuberculosis. I could not live with my family, because they used to abuse me and so I found another man when my child was one year and six months old.

Tenure security has historically been tied to permanent farm labour contracts, which in turn have

historically been given to men. This means that a woman's position on a farm is usually determined by her relationship to a male farm worker. Women are mostly hired as the wife or girlfriend of their male partner; in this way, becoming a literal extension of the male farm worker⁷.

Women are often employed as seasonal or casual workers, and generally earn substantially less than men. If the male worker loses his job, or passes away, his whole family gets evicted, regardless of whether or not the woman is also employed on the farm.

My new partner was using small brown pills and I could not understand why he was using it. I was afraid to ask him about them. He asked me to fetch his medicine when he was no longer able to do so. When I got to the hospital, I asked the sisters what was wrong with him. They told me I should speak to my partner, since they could not tell me. On 19 December 2002 the foreman told me I should wash my husband in order to take him to the doctor. When he came back in the evening, I asked him what was wrong. Only after the second time that I asked him did he tell me that he had AIDS. I cried and asked him why he kept it away from me. He responded that he was afraid I would leave him. I asked him if that was the reason why he abused me, he told me he wants to kill me first, and then he will die.

Ignorance of one's HIV status, denial to oneself of one's HIV positive status; hiding one's status from one's partner, due to the fear of being left, as well as fear of discrimination, more generally all undermine HIV and AIDS efforts. The aggressive and angry response of Sarah's partner to her request for an explanation as to why he abused her illustrates his anger and his need to

take his anger out on someone over whom he has power and control, his female partner. His own fear of death is ameliorated by him wanting to kill Sarah first – either by beating her or by engaging in unprotected sex with her in spite of him knowing his HIV positive status. Sarah was surrounded by men who knew about her partner's status – her partner, the foreman, the owner – all of whom were taking decisions about her partner's healthcare, which directly affected her, without involving her in any way.

...surrounded by men...all of whom were taking decisions about her partner's healthcare, which directly affected her, without involving her in any way...

Unequal power relations between women and men; the silence around sexuality; the need for safer sex in relationships; and the limited ability women have to negotiate condom use are all factors which contribute to women's vulnerability to being infected with HIV. Studies have highlighted that women who have experienced physical or sexual violence, or who have a controlling sexual partner, are one and a half times more likely to be HIV positive, than women who have never been abused⁸. This dependence and oppression is exacerbated in the context of a farm, where a woman's home and livelihood is dependent on her continued relationship with her male partner.

I went for a blood test the next day and had to wait for my results. My partner passed away on 1 January 2003. I received the results that I'm HIV positive the same month. I received medication

and went for counselling. I then attended a course on HIV which was organised by the Rawsonville Advice office. I asked a lot of questions to help myself. I was no longer well to work and started to work for the labour broker on the farm. I then applied for a disability grant.

The farmer did not want me to stay on the farm anymore. He applied for an eviction notice and the eviction was granted by the Magistrate in 2005. I tried to argue with the farmer, but the farmer told me that I must go. He knew about me, because the doctor had phoned him and told him my results. He pushed me and told me that I'm going to infect him with AIDS. I was evicted and had to leave the farm. My partner had savings, but the farmer refused to give it to me. My partner's family also came and took all of our things, and so I was left with nothing, not even a spoon. I had nowhere else to go and so went to live in the toilets in the Rawsonville sports field.

Between 1994 and 2004, one million people were evicted from farms. 77% of the evictees were women and children, as their tenure was linked to the employment of a male household member. Evictions of farm workers and dwellers have increased since 1994. The increase in evictions could be attributed to farmers' responses to the labour legislation introduced after 1994 to regulate fair labour practices, such as the Labour Relations Act, the Labour Tenants Act, the Basic Conditions of Employment Act, the Extension of Security of Tenure Act, and the Sectoral Determination for Agriculture. There are few support structures available to people who are evicted, and the majority of people do not know where to go for help⁹.

With her eviction, Sarah's constitutional right to access to land in her own right was violated, as well as her right to access to adequate alternative accommodation, leaving her little option but to resort to the toilets on the Rawsonville sports field. At the same time, her child's right to shelter was violated, when her small child was evicted with her mother.

...dependence and oppression is exacerbated in the context of a farm...

High rates of mortality in South Africa have left many women widowed. Apart from having to deal with the death of their partners, widowers on the farms have to deal with losing their homes and livelihoods through evictions, as well as the common practice of being stripped of their assets by their husband's family.

As another example of the paternalism that exists on the farms, it is a common practice for the owner to mediate the relationship between the worker and the healthcare professional. In this way, it is quite common for the doctor to phone the farm owner and inform him of the HIV status of workers or any other important information related to the worker's health. This infantilising treatment of workers violates their right to privacy and undermines the workers' right to quality healthcare. A recent study has demonstrated that access to housing, health, education, transport and other amenities is frequently mediated by the owner¹⁰.

I went to the Municipality to ask if there is no home for me, since I was on a waiting list for housing from the 1990's. Other families had also been evicted illegally and were living under a bridge, which included a pregnant woman who gave birth

to her child three weeks after the eviction. I had to catch the baby [help deliver the baby]. The social worker asked me how I can catch the baby with my bare hands. This made me feel very bad, because I thought I was doing something good, but she shouted at me.

Sarah helping the women to give birth to the baby, without gloves, illustrates how people do not have the information (the need to protect oneself and others in situations where there are large amounts of blood like a birth), or the means (gloves) to live safely with HIV. Poor communities do not have access to healthcare, leaving their family members and those closest to them having to do what they can with the resources at hand. In these situations, social workers and other professionals should provide support and information, rather than reprimands.

Apart from poor treatment at the hands of public functionaries, Sarah also suffers daily insults, abuse and discrimination at the hands of community members – women and men. She says:

I am afraid to sit outside my door. People insult me, call me names and swear at me everyday... They say I am already dying. My daughter and sister want to fight on my behalf... I asked the Lord what did I do and ask Him to shut their mouths.

But Sarah does not let the taunts get her down. She feels the pain, but says that people who call her names are very afraid for themselves. On the way back to her house, Sarah looks so proud when she shows us the young girl child that she had helped deliver in the toilets in 2005. In spite of the hardships and problems in her life, Sarah is a 'fighter'. She is an active member of Sikhula Sonke and the Rawsonville branch treasurer. She is a cadre and assists farm workers and dwellers on a daily basis with

advice, taking statements and accompanying them to the police station to lay charges of human rights violations and assaults. She assists people with their injuries on duty, evictions and the violence that they suffer. She is an inspirational woman.

Speaking of her hopes and dreams for the future, she says:

I know I'm going to die, but I want to continue with life. I talk to God and ask Him to give me a chance to share my experience with others to prevent them from making the same mistakes.

Evelyn's Story

Evelyn is a 28 year old woman who lives in a farm near Wellington. She works in a wine cellar close to her home. She lives in a small house with her mother, stepfather and her two children. Violence has been an almost daily experience in Evelyn's life, where she has experienced it at the hands of community and family members and partners.

At 11, I was raped. My ma did nothing. I was a virgin, and was held down at knife point. He hit me and raped me. My mother did not take me to the doctor, nor did she report it to the police. The man who raped me paid my mother money.

The father of my children...was a very jealous man. He nearly killed me once, he has hit me in the face and all over, I have had cuts, blue eyes, I have scars... Whenever I went to my mother, my mother would put me out of the house.

After separating from the father of her children, due to his drug abuse, Evelyn shares her experience of being raped by him.

Then one day I took my kids over to his mother's place, they were having a party or something.

And then he asked to talk to me. He said we must speak at the house. I did not feel safe when I was going there... When we got there, he ripped off my clothes, he hit me and then he raped me.

**...violence against girl children
and women is rife on the farms...
exacerbated by alcohol
and drug abuse...**

Evelyn laid a charge at the police station and went to court. However, intimidation and lack of support from home led her to eventually drop the charges.

Then we were at the court, and we were discussing his case. His whole family was there, his mother, his sister and everybody, and not one member of my family was there. I eventually dropped the charges, I did not have a choice...they were all shouting at me to drop the case. ...they came to my home and intimidated me.... My mother and family were not worried. My mother said that I should drop the case. She really liked him...she wants me to go back to him... I dropped the case.

As we saw with Sarah's life story, violence against girl children and women is rife on the farms, as elsewhere in South Africa. This violence is often exacerbated by alcohol and drug abuse. The majority of alcohol abusers on farms are men. A survey in the Western Cape in 2006 found that 56% of adults were currently drinkers, 76% of whom were men and 34% women. Alcoholism on the farms can partly be attributed to the 'dop system', where workers used to be paid some of their wages with alcohol. Although this system has largely been abolished, the problem of entrenched alcohol abuse has not died

out. Hard drinking forms a large part of men's social activities, and can be seen as a culture of masculinity which frequently leads to violence, particularly against women¹¹.

Women often stay in violent relationships, because violence is such a routine and a daily part of their lives that it becomes 'normalised'. Another important factor is that women's access to land, housing and employment all depends on their relationship to this man. This severely limits women's options, as one would not just be leaving a violent partner, but would also be losing one's livelihood. This puts women at great risk – physically, emotionally and economically.

Poverty, and the lack of public policies to effectively deal with violence against women, contributes to mothers accepting payment from the rapist for their daughter's rape. Some family members perpetuate the cycle of violence against women by telling a woman to return to her abusive husband, because they feel it is an embarrassment for the daughter to return to the family home, thereby showing the rest of the community that the marriage did not work. There are also social beliefs that violence is something that should be resolved in the home where it happens and not made public for the whole community to talk about; that violence is 'a women's lot' and that the daughter needs to deal with it, as the mother has had to deal with it in her lifetime. From an economic point of view, if the daughter returns home (with any children she might have), she represents 'more mouths to feed' in an already overstretched family budget.

All of these beliefs and practices speak to how social, cultural and economic factors contribute to the mother, and other family members, playing a vital role in perpetuating violence against women. Family and community members (women and men) support rapists,

wife beaters and abusers, with the arguments that deflect from the responsibility that the man needs to assume for his actions.

Evelyn has also had a relationship with a woman. However, this relationship was not free from the same problems of infidelities and violence, which she had experienced with men.

One night we were arguing and she stabbed me with a screw driver, but then I stabbed her with a knife... She carried on coming here, but then I left her because she was being unfaithful. And I said to myself 'kan ni seer kry van 'n man, ni van a vrou ook'...

...violence is such a routine and a daily part of their lives that it becomes 'normalised'...

Speaking of her relationship with the man that she thinks infected her with HIV, Evelyn says:

I met another guy... He is a driver here. He is a married man. I didn't know that at the time. I fell in love with him. The women and men around here gossiped and said that he was married, but I didn't worry, because I loved him... Once I called his wife and I asked her if she was married to him. And she said yes, they had been married for ten years. But I said no, this was my man and I loved him. He was really nice to me; he bought me gold bracelets, gave me money and was really nice... We had such a good time...I had always asked him if he was married, and he said no, that she was just his girlfriend...he had children with her. Then I was getting so thin. Even my ma got

worried...she was asking, what is wrong with you? Other people were all saying I was looking so sick... Ma said she was worried and that I should go to the clinic and have a test...then one day I looked at the mirror and even I was scared looking at myself, I was so thin...I went to the clinic...I went back a week later for the results...and they told I was HIV positive ... I screamed, and I cried...and when I went out...I had to wipe my tears and try and look normal, like nothing had happened.

*...stigmatisation feeds on,
and perpetuates,
ideologies of 'othering'...*

More than half (53%) of the farm workers interviewed in a study, which aimed to identify best practice models of workplace programmes in selected rural areas in the Western Cape, revealed that they would not disclose their HIV status, due to a fear of rejection and ill treatment, especially from fellow workers¹². Some workers explained that they did not want to tell fellow farm workers because *'if I tell them it will become a story of gossip and they will not eat with me or sit next to me'*. Another worker said *'they will treat me differently; they will think that I will infect them'*¹³. When questioned on whether or not HIV is a problem on the farm, 86% of workers stated that they believed that it was not a problem, with more than half (55% of the 94% who completed the individual HIV risk rating) stating that they believed they were personally not at risk at all.

Stigmatisation feeds on, and perpetuates, ideologies of 'othering'. Usually based on fear, a false sense of security is developed when a person, or a group,

believes that it can only happen to others (from another group). Blame and stigmatisation make people feel safe, because they have done nothing to 'deserve' it, unlike the victim¹⁴.

Stigma is one of the most important things we need to address in the response to HIV and AIDS. Stigma prevents people from finding out their HIV status and contributes to them putting off testing. Fear of discrimination, rejection and isolation also contribute to people not disclosing their HIV positive status.

Stigma is further fuelled by discourses which focus on HIV and AIDS and death. Evelyn explained people's reactions to her when they found out her HIV status through gossip.

People would be watching me...if I was hanging clothes up on the line and my jeans would fall down because I was so thin, people would say, 'Ag shame'... Everybody was going around and telling me what they wanted of mine when I died...they would say, 'I really like that top, can I have it when you die?' Or they would say 'Oh, you are going to be such a good memory'.

When Evelyn disclosed her HIV status to her partner, he initially denied his role, arguing that it must have been her children's father who had infected her. Only after he got so sick he was bedridden did he call her and ask for her help. He apologised to her for infecting her and asked for their relationship to continue. She agreed and cared for him, accompanied him to the hospital to get tested and get treatment.

And so we carried on...and I would wash him and look after him...I would leave my children and go with him to the doctor to get his pills.

After a vast improvement in his health, he buys a car and continues his life as before. Evelyn describes one

night when she realises that he has moved on and is, in fact, with another woman.

He was having a birthday party here... He brings his girlfriend here to this farm...and when I tried to touch him, he said no, don't touch me...and then I realised that he was with this other woman...and so I went out to the car and damaged it...and the neighbours were saying to him, 'she is not your wife, call the police'...and so he called the police... and they came to the house ...and asked me if I had damaged his car and did I have a reason?... and so I said, I am not a jealous woman, this man gave me AIDS...tomorrow he can buy another car, but I can't buy another life.

She goes on to explain how she found out that this woman was just one amongst many of his sexual relationships. He had girlfriends located in different points of his truck routes. She heard that he got some pregnant, but that their babies had died. When she told some of these women about her experience with him, they did not believe her. Some common responses to her were *'but he does not look like he has AIDS'*, and *'but I love him'*. She was eventually told by her family members to stop making trouble for him.

Then she says:

...then I thought, maybe he knew that he was sick beforehand, but just didn't tell me...

Evelyn's story is not unique. Her story speaks to the ways in which gender relations and the different norms and practices for women and men in sexuality have been constructed in society. Her story speaks to how gender and sexuality intertwine in such a way that places women at greater risk of HIV infection. Prevailing norms encourage men to be the sexual initiators and to have multiple partners, whilst women are taught to be

accepting of this, to equate sex with love, to feel fulfilled merely by being a wife or girlfriend of a man. Just like many other women, Evelyn nursed her partner back to health, yet, was abandoned as soon as he was feeling well and able to continue with his life. It illustrates the way in which women will continue to care and support the men that they love, and also of the male entitlement that expects this to happen.

...gender relations and the different norms and practices for women and men in sexuality have been constructed in society...

What is clear is that her story illustrates that HIV prevention programmes need to go beyond promoting 'ABC' and need to promote open discussion of why and how we have sexual relationships and to explore the context of power within which these take place; to discuss how we love, trust, respect and care for each other or not; who has rights and how we exercise them; what are our responsibilities; why do women accept and collude with men, when they have multiple partners evidently without protection, why do men (and women) have multiple partners without transparency; what does it mean to protect yourself and to have safer sex?

Evelyn's story also is a call for us to look at the issue of violence in our daily lives and of how it accompanies us from before we are born to the day we die.

What to do?

It is important to bear in mind that preventing HIV and the development and implementation of HIV and AIDS workplace policies, take place in a total institution

where people are living and mostly working in the same place. They take place in an environment where farm owners and managers have a very top down approach to workers, where there is almost a feudal-like relationship between owners and workers. Workers are poorly paid and are subject to many abuses. They do not always know their rights, are poorly organised and are not always able to exercise their rights. Patriarchy is alive and well on the farms, in that ownership is mostly in the hands of men, and the existence of a sexual division of labour which sees men working in more skilled and better paid jobs, and where women's access to lesser paid work and a home is mediated through her relationship to a man. The violence and exploitation is something which characterises all relationships on the farm: owner – worker (men and women); within sexual and emotional relationships (marriages, parents and children).

There needs to be land transformation, both in terms of ensuring that farm workers have access to land in their own right, as well as particular attention being paid to women getting access to and ownership of land and housing.

Government needs to prosecute illegal evictions and stem the tide of farm workers being expelled from the land. Women and men need to be paid a just wage for the work that they do. This means that government has to revisit its sectoral determination for farm workers and increase the minimum wages. Apart from the right to earn a living wage, the relationship between poverty and HIV and AIDS has been well documented.

On the whole, HIV and AIDS workplace policies are not in place in farms. Even where they do exist, there is little or no knowledge of their existence and/or content¹⁵. Government has to enforce the legal obligation for farm owners to have HIV and AIDS work place policies.

Considering that fewer farm workers are staying on farms, and the increased mobility amongst farm workers; there is a stronger need for HIV and AIDS work place policies and programmes to be present for the impact to be felt.

*...women's access to lesser paid work
and a home is mediated through her
relationship to a man...*

Farm workers' vulnerability to HIV is worsened by the low levels of education and high levels of illiteracy. Studies¹⁶ have demonstrated that

...higher levels of education are directly related to increased awareness and knowledge of HIV/AIDS, greater knowledge of testing facilities, higher rates of condom use and better communication between partners about HIV prevention.

Access to education for farm workers and rural areas, generally, is a priority.

Both private and public healthcare needs to ensure that they deal with workers as people, as adults, and not use the farm owner as a mediator. Healthcare institutions and systems in the rural areas need to be strengthened. HIV prevention messages need to take into account the particular information needs of women and men in the context of a farm, condoms need to be available and accessible on farms, as well as HIV care and treatment services.

As one worker pointed out,¹⁷

HIV is an important issue that concerns all workers. They hear about it daily, but they do not understand the depth and the seriousness of it. But if we can get people to talk about HIV more regularly, then

I think the people will know much more about it... and then the people will also not shy away from working with people who have HIV.

There needs to be a concerted effort to talk about HIV, sexuality and gender relations. Key to these discussions is the need to challenge and transform social norms and values that undermine women's rights more generally, and particularly in the context of sexuality.

Moreover, there is a need for more social organisation around HIV and AIDS. This includes the establishment of support groups for people living with HIV, the establishment of networks of human rights NGOs, feminist organisations, trade unions, and development organisations focussing on HIV and AIDS and farm workers, as well as the growth of political organisations of people living with HIV. Sikhula Sonke has begun such kind of organising along with some human rights and development NGOs working in the Western Cape.

...there needs to be a concerted effort to talk about HIV, sexuality and gender relations...

The response to HIV needs to be multi-faceted and multi-pronged. It needs to tackle cultural, economic, social and political factors. All efforts need to break the cycle of the silence surrounding gender inequalities, and to break the cycle of social inequality. Without addressing the social determinants which underlie HIV transmission, all attempts to address HIV and AIDS will fall short of their mark.

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FOOTNOTES:

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4. CRLS & Van Zyl, M. 2006. *Straight Talk: HIV/AIDS on farms in the Western Cape*. Centre for Rural Legal Studies, Stellenbosch.
5. *Ibid.*
6. Lemke, 2005:847, as cited in CRLS & Kehler, J. 2008. *Everyone will be informed: HIV workplace policies and programmes on farms*. Centre for Rural Legal Studies, Stellenbosch.
7. Shabodien, F. 2006. *Livelihoods Struggles of Women Farm Workers in South Africa*. [www.wfp.org.za/pdf/livelihood_struggles_of_sa_women_farm_workers_2006.pdf]
8. Dunkle, K. et al. 2003. *Gender based violence and HIV infection among pregnant women in Soweto*. Medical Research Council, Johannesburg.
9. CRLS & Van Zyl, M. 2006. *Straight Talk: HIV/AIDS on farms in the Western Cape*. Centre for Rural Legal Studies, Stellenbosch.
10. *Ibid.*
11. *Ibid.*
12. CRLS & Kehler, J. 2008. *Everyone will be informed: HIV Workplace policies and programmes on farms*. Centre for Rural Legal Studies, Stellenbosch.
13. *Ibid*, p33.
14. CRLS & Van Zyl, M. 2006. *Straight Talk: HIV/AIDS on farms in the Western Cape*. Centre for Rural Legal Studies, Stellenbosch. p17.
15. CRLS & Kehler, J. 2008. *Everyone will be informed: HIV Workplace policies and programmes on farms*. Centre for Rural Legal Studies, Stellenbosch.
16. UNAIDS. 2004. *Facing the Future Together*. Report of the Secretary General's Task Force on Women, Girls and HIV/AIDS in Southern Africa. UNAIDS, Pretoria..
17. CRLS & Kehler, J. 2008. *Everyone will be informed: HIV Workplace policies and programmes on farms*. Centre for Rural Legal Studies, Stellenbosch. p43.

Bridging the Gap

Based on the premise that a 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 sexual and reproductive health and rights (SRHR) and HIV-related policies, programmes, and interventions, the *Bridging the Gap* initiative has been launched by the ATHENA Network, a global network for the advancement of gender equity and human rights in the global response to HIV and AIDS.

Examining current debates, discourse, policy and programme developments, ATHENA found an absence of a critical gender or human rights analysis – and a continuing gap between the reproductive and sexual health, gender, human rights, and HIV communities in numerous recent policy debates and legislative trends; as well as an absence of consistent attention to, or sustained engagement with, the experiences and expertise of women living with HIV, which addresses sexual and reproductive health and rights in a comprehensive, coherent manner. As part of the ongoing work of the ATHENA Network to bridge these gaps, emerging trends and neglected issues that need greater attention have been identified, some of which include:

- *Disturbing trends in legislation*, such as legislation criminalising HIV transmission from a pregnant woman to her foetus; and laws mandating HIV testing for pregnant women and/or their babies after delivery and that mandate disclosure of a woman's serostatus
- *Gaps in realising women's reproductive choices and rights in the context of HIV*, such as the absence of robust attention to the needs and desires of women living with HIV; an increasing body of evidence documenting coerced and/or forced sterilisation of women living with HIV; and the inadequate access to prevention services for HIV positive pregnant women, who are then blamed for infecting their unborn child and treated as 'vectors of disease'
- *Failure to place HIV prevention, treatment, and care strategies in an SRHR framework*, including the need for increased access to vaccinations (e.g.,

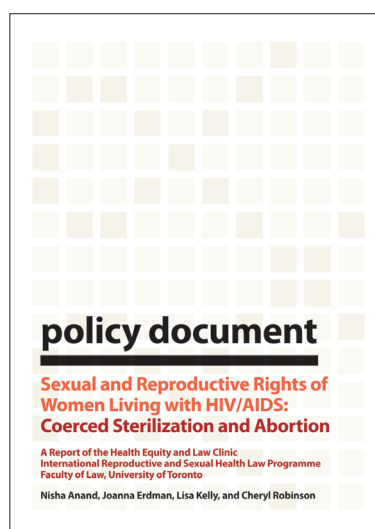
for HPV), screening and treatment for reproductive tract infections (e.g., genital herpes) and cancers, particularly breast and cervical cancer among HIV positive women; the unmet need for female condoms, and clarity on other forms of contraception that would be best suited for positive women; and the absence of a critical gender analysis of medical male circumcision as an HIV prevention strategy

- *Inadequate responses to the intersection of gender-based violence and HIV*, including the need for greater availability of, and access to, services for survivors of sexual violence, such as post-exposure prophylaxis (PEP), emergency contraception, and safe, legal abortion, as well as psychological and legal support
- *Lack of consistent attention to the sexual and reproductive rights and health of adolescents in the context of HIV*, including the need to comprehensively address the sexuality and reproductive desires of positive youth

- *Gaps between the sexual and reproductive health, gender, human rights, and HIV communities*, including women's rights advocates failing to partner fully with networks of women living with HIV

An integral part of the *Bridging the Gap* initiative is the development of policy briefs, documentations and fact sheets on neglected issues at the intersection of sexual and reproductive health and rights and HIV. The first set of publications, launched at the 2009 South African AIDS Conference, include a **Policy Brief** on the principle of free and informed decision making in the context of reproductive healthcare; a **Fact Sheet** on HPV, cervical cancer and HIV; as well as a **Case Study** documenting human rights abuses in reproductive healthcare settings in Namibia.

For more information and/or to obtain a copy of the publications please go to www.athenanetwork.com or to www.aln.org.za.



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