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Sexual and reproductive health and rights of women living with HIV
A long road to travel…

South African women living with HIV and AIDS's ability to exercise their sexual and reproductive rights and to achieve optimum sexual and reproductive health is one of contradictions.

Introduction

On the one hand, South Africa has an enabling legislative and policy framework that promotes gender equality, the right to health and enshrines women's sexual and reproductive health and rights. There are also numerous laws and policies in place, which protect people who are HIV positive and living with AIDS. However, at the same time, traditional gender norms and practices, which underpin and promote the unequal status of women, combined with the levels of poverty experienced by the majority of women in South Africa (particularly black women living in rural areas or in urban informal settlements), contribute to a situation whereby women bear the disproportionate burden of reproductive health problems; are seen to be primarily responsible for contraception and childcare; and have less power to negotiate when, with whom and why to have sex. Women bear the brunt of the HIV and AIDS pandemic, both in terms of levels of infection, as well as shouldering the burden of care of people living with AIDS. At the same time, indices of violence against women in South Africa are amongst the highest in the world, this combined with HIV and AIDS and poverty, contributes to women's poor sexual and reproductive health status, especially women living with HIV and AIDS.

Brief situational analysis of HIV and AIDS in South Africa

South Africa currently faces one of the worst HIV and AIDS pandemics in the world, whose mode of transmission is fundamentally heterosexual. Estimates range from 5,300,000 adults and children living with HIV and AIDS[1] to 6.29 million at the end of 2004[2]. It is estimated that 11% of the total population is HIV positive; of which 18.5% are between the ages of 15 – 49.[3]

Due to the fact that vulnerability to HIV infection and living with AIDS defining conditions is a result

Editorial…

> *Reproductive rights are central to human rights… they derive from the recognition of the basic right of all individuals and couples to make decisions about reproduction free of discrimination, coercion or violence. They include the right to the highest standard of health and the right to determine the number, timing and spacing of children. They comprise the right to safe childbearing, and the right of all individuals to protect themselves from HIV and other sexually transmitted infections*. [UNDPF, 2005]

While sexual and reproductive health and rights are recognised to be essential to the enjoyment of other fundamental rights and freedoms, the extent to which people are in the position to access, claim and enjoy sexual and reproductive health and rights is equally recognised to be indicative of the gendered nature of HIV and AIDS realities and challenges. Taking these recognised correlations into account would also mean that any response to HIV and AIDS has to have, at its core, not only the access to, but also the enjoyment of, sexual and reproductive health and rights.

In reality, however, the extent to which sexual and reproductive health rights are accessible and enjoyable remains to be largely defined by gendered inequalities, imbalances and injustices, as well as prevailing HIV related stigma and discrimination. Moreover, reality is characterised by prevailing beliefs and prejudices that people living with HIV should not engage in sex and/or have children. As a result, access to information and services is denied and sexual and reproductive health and rights are further limited.

It is within this framework that this edition of the ***ALQ*** focuses on sexual and reproductive health rights in the context of HIV and AIDS. The various articles in this issue examine a range of sexual and reproductive health rights and needs, as they relate to HIV and AIDS realities and challenges. The societal context in which especially women living with HIV and AIDS make choices about sexual and reproductive health and rights; the intersecting health and human rights crises of HIV and AIDS and gender violence; the inseparable link between sexual and reproductive health and HIV and AIDS; as well as human rights instruments as a potential tool to claim sexual and reproductive rights are some of the issues explored in this edition. This issue is also introducing experiences and challenges from Rwanda; '*making a point*' about the '*fear factor*' deterring men from accessing HIV testing services; and providing women's sector comments on the National Strategic Plan for HIV and AIDS.

In this edition, **Susan Holland-Muter** discusses sexual and reproductive health and rights concerns of women living with HIV. Examining the societal context in which women living with HIV and AIDS '*make*' decisions regarding sexual and reproductive health and rights, she argues that in order for sexual and reproductive rights to become a reality, the understanding of sexuality and the role it plays in people's lives has to be re-shaped and re-signified; the social meaning attached to being a woman has to be challenged; and sexuality has to be seen as an integral dimension of being a human being.

Recognising the AU Protocol on the Rights of Women as a tool to claim sexual and reproductive rights, **Caroline Murrithi** raises the question as to whether or not the Protocol adequately caters for all women, including women living with HIV and AIDS. Examining women's realities and challenges pertaining to their sexual and reproductive health, and looking at the opportunities within the Protocol to address these, she argues that the Protocol, despite its progressiveness fails to adequately address the needs and realities of women living with HIV and AIDS and thus, calls for further advocacy and lobbying so as to ensure that the sexual and reproductive health rights of all women are equally protected by the Protocol.

The intersecting and mutually reinforcing health and human rights crises of HIV and AIDS and gender-based violence are discussed by **Susana Fried**. Analysing some of the critical issues surrounding the intersection of gender-based violence and HIV and AIDS, and introducing some promising practices addressing these intersecting crises, she places gender equality at the centre of the debate and argues that only as and when responses are comprehensive, gender-sensitive and human rights-based, will they carry the potential to effectively address the intersection of HIV and AIDS and gender-based violence, and to create conditions for safe, healthy, consensual and diverse sexualities and life choices for all.

The extent to which the access to, and realisation

of inequalities in society, and at the same time deepens existing inequalities, the pandemic features distinctive racial, class, age and gender distributions.

...women have to take the decision about whether or not they should take the pregnancy to term in a context where motherhood is revered and where there is significant family and community pressure on women to have children...

Women make up 57% of the 5,100,000 adults between the ages of 15 – 49 who are HIV positive.[4] The prevalence rate is higher for women than men aged 15 – 34 years. It increases dramatically among young females and peaks at 33.3% for women aged 25 – 29 years. The increase is more progressive for men on the other hand, and peaks at a lower level than for women, 23.3% in age groups 30 – 34 and 35 – 39.[5] The Department of Health's 2005 National HIV and Syphilis Sero-Prevalence Survey of women attending public health antenatal clinics estimated that 30.2% of pregnant women were HIV positive. Women who were 20 – 34 years old were the worst affected, with prevalence rates of up to 40% for women aged 25 – 29 years.

Young people aged 15 – 24 years are especially at risk of HIV infection, accounting for 60% of all HIV infections. However, young women make up 77% of those living with HIV and AIDS in the 15 – 24 age group.[6]

Racial disparities are also revealed with 16% HIV prevalence for Africans, 6.8% for Coloureds, 5.6% for Whites and 2.7% for Indians between the ages of 15 – 49 years in 2004.[7]

It is estimated that about 525,000 people were living with AIDS defining conditions, and 44% of total deaths in South Africa can be attributed to AIDS related causes in 2004.[8] The 2nd Saving Mothers Report revealed that AIDS is the leading course of maternal deaths in South Africa, with estimates ranging from 17 – 27.6%.

What are the sexual and reproductive health and rights concerns of women living with HIV and AIDS?

South Africa is signatory to both international agreements and programmes of action, which outline the scope of issues, concerns and actions required to promote women's sexual and reproductive health and rights.

The 1994 International Conference on Population and Development Program of Action (ICPD POA) defined *reproductive rights* as the rights of couples and individuals to:

- Decide freely and responsibly on the number, spacing and timing of their children, and to have the information, education and means to do so;
- Attain the highest standard of sexual and reproductive health, and make decisions about reproduction free of discrimination, coercion and violence.

The women's rights perspective enshrined in the ICPD POA was consolidated in Beijing during the 1995 Fourth World Conference on Women (FWCW) Platform for Action. The Platform for Action defined sexual rights as

> *...the human rights of women include their right to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence.*[9]

However, the context in which women living with HIV and AIDS '*make*' decisions regarding their sexual health and rights, and reproductive health and rights is often characterised by a range of negative factors related to their unequal status as women in relation to men, lack of education and information, or in relation to the gender specific stigma and discrimination faced by women who are living with HIV and AIDS.

of, sexual and reproductive health and rights impacts on HIV and AIDS realities and challenges in Nigeria are introduced by **Busari Olusegun**. Exploring various realities of sexual and reproductive health and rights, including practices of female genital mutilation and child marriages, he argues that it is not only vital to develop policies and programmes addressing the inseparable link between sexual and reproductive health and HIV and AIDS, but also crucial to effectively implement these policies and programmes, since the failure to adequately implement policies and programmes is worse than the absence of such policies and programmes.

Some of the specific sexual and reproductive health rights issues of women living with HIV and AIDS are introduced by **Nomampondo Barnabas**. Exploring various challenges that contribute to the violation of sexual and reproductive rights and looking at the scope of sexual and reproductive health services, she argues that the absence of informed choices and adequate sexual and reproductive health services not only denies women living with HIV and AIDS their sexual and reproductive health and rights, but also increases their risk of morbidity and mortality.

HIV realties and challenges from Rwanda are introduced by **Emmanuel Habumuremyi**. Analysing various responses to HIV and AIDS within the Rwandan context, including the use of cell phones to enhance HIV and AIDS treatment, support and care, he argues that, despite many successes and utilisation of innovative measures leading to the decline in HIV infection rates, there are many remaining challenges, including ignorance, continuously threatening the adequate response to HIV and AIDS in Rwanda.

Kent Klindera, **Dumisani Rebombo** and **Andrew Levack** are '*making a point*' about the '*fear factor*' defining men's preparedness and willingness to be tested for HIV. Recognising the importance of men accessing HIV testing services and analysing the factors deterring men from utilising available HIV testing services, the article argues that a new form of masculinity is needed to maximise the impact of HIV and AIDS strategies and programmes, since gender roles not only limit men's involvement in HIV and AIDS efforts, but also limit the success of these efforts.

While the particular examined reality may vary, there seems to be a common underlying reality – one of gendered inequalities, imbalances and injustices, as well as stigma, discrimination and violation of rights based on sex, gender, sexuality, and/or HIV status – which ultimately defines the extent to which sexual and reproductive health rights are accessible and realisable. Thus, sexual and reproductive health and rights are as much limited, as choices are influenced, by the gendered societal context and existing HIV related stigma and discrimination.

If we are to agree that the right to make informed choices '*free of discrimination, coercion or violence*' is at the core of sexual and reproductive health and rights, then we are to equally agree that the prevailing societal context, not only perpetuating, but also justifying, the occurrence of '*discrimination, coercion or violence*' based on sex, gender, sexuality and/or HIV status, '*threatens*' the very core of sexual and reproductive health and rights. Similarly, if we are to agree that rights are only as accessible as the societal context in which choices are made '*allows*', then we are to agree that it is the very same societal context, which '*prescribes*' the continuous denial of sexual and reproductive health and rights. Thus, at the core of sexual and reproductive health and rights is the societal context in which choices are made.

So, if we are to create an environment that *'allows'* individuals to make informed choices and decisions '*free of discrimination, coercion or violence*', then we are to challenge and transform the societal context in which choices are made. Only as and when the existing societal context '*denying*' individuals to make free and informed choices, is transformed, will sexual and reproductive health and rights become a reality. Until then, the extent to which people are in the position to make sexual and reproductive choices will continue to be defined by a person's sex, gender, sexuality and/or HIV status; and will remain to be indicative of HIV and AIDS realities and challenges. Thus, until the societal context is transformed, there will be no '*freedom of choice*', and individuals who claim their right to make sexual and reproductive choices will continue to be stigmatised, discriminated against and/or violated…

Johanna Kehler

Women living with HIV and AIDS often face many obstacles to prevent unwanted pregnancies. These include lack of access to information concerning the most appropriate methods, particularly about how contraceptives may interact with ARVs and medications to treat opportunistic infections; and an inability to use condoms and contraception consistently, due to unequal power relations with men, and pregnancies which may result from rape.[10]

Women often only find out their HIV status once they are pregnant, leaving them facing the decision whether or not to disclose to their partners, often fearing rejection, violence and of being accused of having brought the disease into the home. In addition to this, women have to take the decision about whether or not they should take the pregnancy to term in a context where motherhood is revered and where there is significant family and community pressure on women to have children, seeing it as fulfilling a woman's role in life and/or as a means to demonstrate adulthood status. However, these decisions are taken in a context where there is insufficient access to measures to prevent mother to child transmission of HIV (PMTCT) and where there is insufficient access to (and acceptance of) termination of pregnancy services.[11]

On the other hand, women living with HIV and AIDS face stigmatisation and social censure, if they want to, and do, have children. Women are charged with being irresponsible, because, as the argument goes, they will die and leave their children orphans, or they will infect their children. In addition, women living with HIV and AIDS suffer discrimination, often at the hands of healthcare workers, when women are pressured to *'abort'* or undergo forced sterilisation, for example, by being threatened to only have access to ARV treatment, if she agrees to undergo sterilisation procedures.

At the same time, there are barriers at the level of health programme design and in service provision, which do not cater to the full range of health needs, and specifically the sexual and reproductive health needs of women living with HIV and AIDS. Women's limited and insufficient access to ARVs notwithstanding, there is also the problem of ARVs being offered in a programme and service that is separated from, and does not address, their sexual and reproductive health (SHR) needs. These SRH needs are also often offered with a narrow focus on maternal health, especially issues around the prevention of mother to child transmission of HIV. Sexual needs and desires and information/education needs around safe and protective methods of engaging in pleasurable sex are not high on the agenda. Instead it has been charged that women living with HIV and AIDS are often faced with judgmental attitudes from healthcare workers, which discourage them from exercising a healthy and positive sexuality.[12]

What needs to be done in the future to promote women living with HIV and AIDS' sexual and reproductive rights?

There are many socio-economic and cultural shifts which need to take place in order to effectively promote women living with HIV and AIDS' sexual and reproductive rights which have been adequately addressed elsewhere. I would like to address two issues, notably that of reframing how we think and talk about and exercise sexuality, and of addressing the role of the state and community in taking responsibility for childcare and children.

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A rights framework provides a basis to begin addressing the context in which HIV infection takes place, and the stigma and discrimination that surrounds people living with HIV and AIDS. Within this scenario, I will highlight sexual and reproductive rights specifically, although the rights framework goes beyond this (including economic, social, cultural

and human rights more broadly). Within the context of women and girls being the most vulnerable to HIV infection, we often speak of promoting the rights of women and girls to choose when, with whom, how and why to have sex. I would agree with this. However, in order for these rights to become a reality, and in order to begin promoting women and girls' sexual rights, one would have to place sexuality itself under the microscope, examine how it has been understood and framed in a post colonial South Africa and re-signify our understanding of sexuality and the role it plays in our lives.

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Although South Africa was colonised by both the English and the Dutch, and there are a myriad of understandings and experiences of sexuality in local cultures, the hegemonic influence of an English Victorian Christian world view of sexuality in South Africa is clear for all to see. Within this worldview, sex is seen to be a dirty and shameful act; a private, taboo subject, and only seen to be good and Christian when it is exercised for purposes of reproduction, and within the context of a monogamous Christian marriage. In this case, it takes place between a man and a woman, during their reproductive life cycles, and in the '*missionary position*'. Over time, there has been a growing acceptance of other kinds of sexual acts between married partners, including oral sex and maybe a range of different penetrative positions, but apart from that, engaging in other sexual acts will lead to '*hell and damnation*'.

It is for this reason that HIV and AIDS is being signified as the result of '*sinful behaviour*' and as '*a punishment from God*'. It is within this context that there is the belief that people who are living with HIV and AIDS should not engage in sex, that they have been irresponsible and should now reap the rewards for their '*wanton and promiscuous behaviour*', by abstaining from sex for the rest of their lives.

This also is the context in which promoting the rights of people, specially women, to sexual pleasure is regarded as vaguely shameful, and definitely not as important and integral to somebody's dignity, health and well-being, as their right to housing, food, and work. In the context of gendered norms, where men are seen to be the active sexual subjects, sexual pleasure and sexual needs are seen to be a male prerogative. A woman's relationship to sex is seen to be an expression of love and affection for their (male) partner, preferably married (if not, at least monogamous partner), and to enable her to become what society has seen to be the main signifier of womanhood, a mother. In addition, a wife's sexuality (and women more generally) is seen to be in function of providing for their husband's and men's sexual pleasure.

So a necessary part of promoting women and girls' sexual rights, and particularly women who are living with HIV and AIDS's sexual rights, is to reshape and re-signify society's world view of sexuality, and the role that it plays in our lives. In this case, it would be to see sexuality as an integral dimension of being a human being, and an integral part of achieving emotional, spiritual and physical well-being. That is, that sex is normal and part of everyday life. Sex is something to be spoken about, taught openly to the young, and exercised within the context of rights and responsibilities.

Part of this would include reshaping the role that sexuality plays in the lives of both women and men. Sex needs to be seen as just as important and just as necessary and part of a person's identity for both women and men. This would also mean changing the social reactions to a woman who openly wants and desires sex for her own pleasure, and not just her partner. This would mean confronting and challenging the social

power that society ascribes to men in determining when, where, how and why to have sex. It would also mean men taking equal contraceptive responsibility, and not seeing this as only a woman's responsibility.

Related to this is the need to normalise and '*sexify*' safer sex. As soon as one writes '*safer sex*', then the association of '*good, hard and pleasurable sex*' might go out of one's head. However, part of '*sexifying*' and normalising safer sex is to reshape the meanings and practices associated with barrier methods, namely condoms (female and male), gloves, and dental dams. Promoting the idea that condoms do not mean infidelity, not loving somebody, and/or lack of pleasure would go a long way towards promoting their acceptance and use. If we could do this in a context where sex is normal, and is seen as a means to communicate and express oneself, then finding ways to put it on (and in) as part of the sexual itself, might go some way to addressing the resistance to condom use.

Motherhood, childcare and the role of the state and community

Firstly, I think it is important that society needs to be challenged to re-signify the social meaning attached to being a woman. In this case, it is necessary to promote the idea that women have value and meaning in life, because they exist as human beings, and not just because they bear children. In this sense, it is necessary to change the association that being a woman equals being a mother. In this context, choosing to have a child or not, is the outcome of individual choice and desire, and not as a precondition to have status, acceptance and power in a community.

Secondly, it is important to recognise that it is not just women who have children and who should bear the responsibility for their care and upbringing. Here, it is important to recognise that it is also the father who plays a role, firstly in making the baby and secondly, that it should also be his social responsibility to care for the child, both in terms of upbringing, as well as contributing to paying for their upkeep.

A related issue is what role should communities and the state play, and what responsibility should the state assume for childcare? Different cultures in South Africa have different social norms around who should be responsible for children, ranging from the extended family and community's responsibility to being only that of the individual mother (and at times, father). However, in the current context of breakdown in social relationships, notions of there being an extended family and community responsibility has increasingly disappeared, leaving individual women to carry the burden. This is not necessarily the biological mother, as in the context of children, who survive parents who have died from AIDS related diseases, many grandmothers, aunts, cousins and other (female) community members are taking on the responsibility of caring for orphaned children.

...the state has a responsibility to ensure that its citizens, in this case pregnant women who are HIV positive, have access to healthcare services that would allow women to have safe and healthy pregnancies, and healthy babies...

I would argue that women living with HIV and AIDS have the right to choose whether or not to have children. If women infected with HIV choose to have children, the state has a responsibility to ensure that its citizens, in this case pregnant women who are HIV positive, have access to healthcare services that would allow women to have safe and healthy pregnancies, and healthy babies. This would include general healthcare, antenatal care, and prevention of mother to child transmission of HIV.

In a similar vein, it is interesting for me the disparity of support provided by the state for childcare depending on one's relationship to the child. A foster parent receives about eight times the amount of money, than a biological parent, if one compares the Child

Care Grant and Foster Care Grant[13]. Are the costs not the same? This disparity reinforces the notion that having a child is a private responsibility and the state only steps in when the biological parents or family are unable to do so.

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I would argue that this should be revisited, and that minimally the grants should be the same. This is especially important considering that a person living with HIV and AIDS will suffer the ill effects of opportunistic infections and side effects from the ARVs, which will limit their abilities to work and/or create income. In this context then, strategies to support women's (and families') reproductive choices need to go beyond merely counteracting the discrimination and stigma associated with choosing to have a child, while living with an illness, but needs to consider the economic support that would be required from the state.

FOOTNOTES:

1. UNAIDS. 2004. Report on the Global HIV/AIDS Epidemic.
2. Statistics South Africa cited in Health System Trust. 2005. South African Health Review 2005.
3. ASSA 2002 model. Health System Trust. 2005. South African Health Review 2005.
4. UNAIDS. 2004. Report on the Global HIV/AIDS Epidemic.
5. Human Sciences Research Council. 2005. South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey 2005. Cape Town.
6. UNAIDS. 2002. Report on the Global HIV/AIDS Epidemic.
7. Statistics South Africa cited in Health System Trust. 2005. South African Health Review 2005.
8. ASSA 2002 model. Health System Trust. 2005. South African Health Review 2005.
9. FWCW Platform for Action, 96 as cited in Family Care International, 2000. Sexual and Reproductive Health Briefing Cards. Family Care International, New York.
10. de Bruyn, M. 2002. *Reproductive Choice and Women Living with HIV/AIDS*. IPAS.
11. Ibid.
12. Odhiambo, D. 2006. 'Do HIV and AIDS make us less human than others…? Fertility desires and sexual and reproductive health needs of people living with HIV'. In: *ALQ*, November 2006.
13. The Child Support Grant amount is R190 and the Foster Care Grant amount is R590.

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Caroline Murrithi

A tool for claiming sexual and reproductive rights…

The AU Protocol on the Rights of Women

The coming into force of the Protocol to the African Charter on Human and Peoples Rights on the Rights of Women (otherwise known as the Women's Protocol) on 25th November 2005 was a victory for the women of Africa. At last, women can celebrate the creation of a legal framework that solely addresses women's plight in Africa.

The Women's Protocol was drafted to compliment the already existing African Charter on Human and Peoples' Rights (herein the 'African Charter'). The African Charter (1981) was the first human rights instrument to include three generations of rights; namely, civil and political rights; the social, economic and cultural rights; as well as group rights. It was a breakthrough for Africa and marked for the first time the willingness and commitment by African States to adhere to international standards of human rights, while addressing the specific needs of Africans.

The African Charter in Article 2 enshrines the principle of non-discrimination on the grounds of race, ethnic group, colour, *sex*, language, religion, political or any other opinion, national and social origin, fortune, birth or *other status*. Despite its progressive nature, the African Charter was, however, criticised for failing to adequately provide for women. The African Charter has only one provision, Article 18(3), which calls on member states to

> *…eradicate all forms of discrimination against women and ensure the protection of women and children as stipulated in international declarations and conventions.*

The Women's Protocol was, therefore, drafted to supplement this provision and clearly lay out the rights for women.

The Women's Protocol was adopted in July 2003 and came into force on 25th November 2005, becoming the fastest human rights instrument to come into force in Africa. It should be noted that this was due to concerted efforts amongst activists, women rights organisations and individuals, who had actively participated in the drafting of the Women's Protocol and did not want the gains, made for women, to be lost.

The Women's Protocol is a special document as it specifically addresses the challenges that African women face daily, such as lack of access to land and other resources, harmful traditional practices, conflict, and exclusion from political participation. The Women's Protocol is the first international human rights instrument to call for a legal prohibition of female genital mutilation (FGM) and other harmful traditional practices; it protects women's rights to own land and property; protects the rights of women in marriage and upon dissolution of marriage; it provides protection for widows, elderly women, women with disabilities and women in distress, among other rights.

The Women's Protocol is also the first international human rights instrument to expressly frame women's reproductive rights as a human right's issue and guarantee a woman's right to control her fertility. This is a big step towards the recognition of women's reproductive rights and a cause for celebration. The Women's Protocol gives women in Africa a tool by which to claim their sexual and reproductive rights. The question, however, is whether or not the Protocol will cater for all women, including women living with HIV and AIDS.

What challenges do women living with HIV and AIDS face?

Women living with HIV and AIDS often face numerous challenges regarding their sexual and reproductive health. Generally, women's access to healthcare is often compounded with social, economic and political inequalities.[1] However, for women living with HIV and

AIDS this is more complicated, as they have to deal with the stigma and discrimination, because of their HIV positive status. Women in general tend to be marginalised in their community and have no access to economic resources, are uneducated and are economically dependant on their male relative or spouses. This makes women vulnerable to HIV and AIDS infection, as they have no decision-making capacity within the society.

...rights and freedoms are intertwined, and if women cannot enjoy their basic rights and freedoms to bodily integrity and dignity, they also cannot enjoy good health...

Furthermore, women fear going for HIV testing, because of the social implications and the blame that is often put upon women as the '*virus transmitters*'. A positive HIV test result can easily result in violence from spouse or partner; loss of her children; alienation from her family; as well as loss of property and livelihood. In addition, women and girls are the caregivers in the society, when a member of the family is unwell, the onus is on the woman to provide the care required. For women living with HIV and AIDS this often means that they have neither the time nor resources to seek the required medical attention, have no time to rest and eat well. This is further complicated by the fact that for most rural women hospitals and clinics are inaccessible and expensive and, therefore, a mere luxury they cannot afford. Women simply do not have the time or resources to address their own health issues and seek medical intervention.

Women, due to socio-economic realities, are often not in the position to negotiate safer sex, even when they are infected with HIV, and are at a constant risk of re-infection. Women living with HIV and AIDS are often discouraged by medical practitioners to have children and, in some instances, have been sterilised to prevent them from bearing children, due to the possibility of transmitting the HI virus to their child. The right to bodily integrity; right to family; the right to control their fertility; and the right to decide whether or not to have children are violated and women, who choose to have children, are often viewed by the society as irresponsible.

How then can these challenges be addressed to enable women to achieve the highest attainable standard of health and enjoy their rights and freedoms? Simply put, for women to enjoy their health and reproductive rights, women must first be empowered; be protected from discrimination and violence; and be in the position to enjoy the most basic rights and freedoms. According to HernÁndez-Truyo[2] the concept of women's reproductive health must be redefined beyond *'sick'* and '*medicalised*' to include matters of well-being, such as education, economic self-determination, political participation, environmental safety and personal security. She further states that the issue of reproductive freedoms highlights the critical importance of approaching rights as indivisible and reveals the normative weakness of the single-right approach. It is, therefore, important that, as we look at women's rights, we realise that these rights and freedoms are intertwined, and if women cannot enjoy their basic rights and freedoms to bodily integrity and dignity, they also cannot enjoy good health.

Opportunities within the Protocol

Looked at holistically, the Protocol provides various human rights protections that would ensure that all women, and in particular women living with HIV and AIDS, are protected. The Protocol, in its Preamble, reiterates the principle of non discrimination enshrined in Article 2 and 18(2) of the African Charter. This requires states to take measures that eliminate discrimination on the numerous grounds including gender and '*other status'*. Women living with HIV and AIDS can utilise these provisions to address discrimination, especially regarding access to adequate health services.

The Protocol provides for the right to dignity[3] and obliges state parties to adopt and implement appropriate measures to ensure the protection of this right and protection from all forms of violence, particularly

sexual and verbal violence. The right to dignity is an acknowledgment of the intrinsic worth of human beings, a right to be treated as worthy of respect and concern.[4] It further provides for the right to life, integrity and security of the person[5], and demands that state parties enact and enforce laws that prohibit violence against women, including unwanted or forced sex, whether in private or public.

This is a key development in the international human rights discourse. Traditional international human rights law and the UN system did not consider so called '*private acts'* or acts '*perpetrated by private actors'*, and acts that take place in a traditionally private sphere, such as the home, to be human rights violations.[6] This left the issue of violence against women out of the legal system and the human rights realm in general. The reality is that most women suffer violence within the domestic or private sphere; for example domestic violence and violence occurring within the family and the community. In addition, legal doctrines protecting the privacy of the home and family have been widely used to justify the failure of the State and society to intervene when violence and abuse is committed against women in the family and to take remedial actions.[7] State parties under the Protocol are, therefore, obligated to take action to protect women within the private sphere.

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Another key development is that the Protocol requires state parties to allocate budgetary and other resources for the implementation and monitoring of actions aimed at eradicating violence against women.[8] Therefore, state parties are precluded from using lack of resources as an excuse for not implementing measures to protect all women from violence against women.

...state parties are precluded from using lack of resources as an excuse for not implementing measures to protect all women from violence against women...

The Protocol in Article 14 explicitly provides for sexual and reproductive health rights of women. It states that women's sexual and reproductive health is to be both respected and promoted, which is predicated on women's right to control their fertility and by an obligation of states to provide *adequate*, *affordable* and *accessible* health services.[9] Article 14 of the Protocol provides for a number of health and reproductive rights for women, including the right to control fertility; the right to decide whether or not to have children and the number and spacing of children; the right to choose a method of contraception; the right to self protection and to be protected against sexually transmitted infections, including HIV and AIDS; the right to be informed of one's health status and the health status of one's partner, if infected with sexually transmitted infections, such as HIV and AIDS; and the right to have family planning education.

The Protocol does not simply list the rights that women are entitled to, but also lays out the follow-up actions that states must take to ensure that the rights provided are realised. A fundamental challenge to women's sexual and reproductive health is access to health services and access to information pertaining to their health. The Protocol in this regard places an obligation on state members to ensure that women have access to adequate, affordable and accessible healthcare and that state parties must implement programmes to disseminate information on women's sexual and reproductive health. To ensure that states do not use

any excuse for non-implementation, the drafters of the Protocol incorporated Article 26 which requires that state parties

> *…undertake all necessary measures and in particular provide budgetary and other resources for the full and effective implementation of the rights herein.*

This precludes state parties from neglecting to set aside a budget for sexual and reproductive healthcare and information to all women, amongst other obligations, stated under the Protocol.

In this regard the Protocol provides a more detailed list of sexual and reproductive rights than other global human rights instruments. The Protocol drew inspiration from the Convention on the Elimination of all Forms of Discrimination Against Women (CEDAW), which calls on state members to '*eliminate discrimination against women in the field of health care'*[10] and guarantees women the '*right to access to health care services'*[11], and to '*decide freely and responsibly on the number and spacing of the children and have access to information, education and means to enable* [her] *to exercise this right'*[12]. The Protocol is the only treaty to specifically address women's rights in relation to HIV and AIDS and to identify protection from HIV and AIDS as a key component of women's sexual and reproductive rights.[13] The Protocol further requires States to provide information, education and communication programmes to women, especially to women in the rural areas.[14]

Shortcomings within the Protocol

Despite these progressive provisions, the Protocol has been criticised for failing to provide adequate protection for women living with HIV and AIDS. According to Delport[15] the Protocol approaches HIV and AIDS as a purely health issue, failing to link it with other human rights issues, such as principles of gender equality, right to dignity and bodily autonomy, freedom from gender-based violence, and freedom from discrimination. However, this omission is not fatal as the Protocol has numerous provisions, which, if read together with Article 14, would amount to sufficient protection for women living with HIV and AIDS.

Another shortcoming of the Protocol is that the same provision advocates for the right to be informed of one's health status and the health status of one's partners, if affected with a sexually transmittable infection, such as HIV and AIDS. Taking note that the intention of the Protocol is to protect individuals from HIV and AIDS infection, it fails to recognise the realities that women often face. Women, due to their reproductive role, often visit hospitals and clinics more often than men and are, therefore, more likely to undergo HIV testing during pre-natal visits. This provision takes away women's right to privacy and confidentiality and, thus, discourages women from seeking medical attention for fear that once their HIV status is discovered, their partners would be notified. This fear is justified considering the social outcomes of such a revelation. This provision would also discourage women from going for voluntary HIV testing and in effect prevent women from knowing their HIV status and living positively. This in totality affects women's right to access health services.

...the Protocol approaches HIV and AIDS as a purely health issue, failing to link it with other human rights issues, such as principles of gender equality, right to dignity and bodily autonomy, freedom from gender-based violence, and freedom from discrimination...

These provisions, therefore, require the most favourable interpretation in order that they serve all women. It is a call to further advocacy and lobbying by women and other non-state actors to ensure that women living with HIV and AIDS are not discriminated against within the healthcare system and that their right to dignity and integrity are respected.

The beauty of the Protocol, despite the evident challenges, is that it recognises that countries sometimes have more advanced laws and policies that provide for more rights other than those listed within the Protocol. As a result, the Protocol in Article 31 states that none of the provisions within the Protocol would affect more favourable provisions in national legislation or any other regional or international treaties. This, therefore, calls on states to always apply the most favourable human rights standards.

Summary

In conclusion, women in Africa have a very progressive instrument with which to claim their sexual and reproductive health. The Protocol is a new instrument that will require progressive interpretation to ensure that women's rights are adequately protected. To ensure that the gains made for women are not lost, we must ensure to incorporate the already existing guidelines and recommendations adopted by the various UN agencies and others working in sexual and reproductive health rights. Legal and policy framework that support women's sexual and reproductive rights must be strengthened to enable women to claim their rights, as well as to create national policies and laws that address gender norms, violence, stigma and discrimination as potential barriers to women's access to care and treatment. The Protocol gives women living with HIV and AIDS a chance to claim their sexual and reproductive rights and shape the thinking and discourse relating to their sexual and reproductive health rights.

...the Protocol is a new instrument that will require progressive interpretation to ensure that women's rights are adequately protected...

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Susana T. Fried[1]

Rights are too often overlooked…

HIV and AIDS and gender-based violence – Intersecting health and human rights crises

Two pandemics threaten the health, lives and rights of women throughout the world: one is HIV and AIDS and the other is gender-based violence against women and girls.

Introduction[2]

Violence against women and girls is a major contributor to death and illness amongst women, as well as to social isolation, restrictions on freedom of movement, and loss of personal autonomy. Research confirms that violence, and particularly intimate partner violence, also is a leading factor in the increasing '*feminisation*' of the global AIDS pandemic, resulting in disproportionately higher rates of HIV infection amongst women and girls. Simultaneously, evidence confirms HIV and AIDS as both a cause and a consequence of the gender-based violence, stigma and discrimination that women and girls face in their families and communities, in peace and in conflict settings, by state and non-state actors, and within and outside of intimate partnerships.

For more than two decades, international women's movements have fought for both international recognition of, and concrete action to promote, the human rights of all women. At the core of this are the principles that every woman has the human right to be free from violence, coercion, stigma and discrimination, and that every individual has the right to achieve the highest attainable standard of health, including sexual and reproductive health. Founded in these core values, the following essay is addressed to the intersecting health and human rights crises of HIV and AIDS and gender-based violence, with an emphasis on violence against women and girls. The essay seeks to define and identify some of the critical issues surrounding the intersection of gender-based violence and HIV and AIDS from an analytical perspective that sets gender equality and women's empowerment at the core of any effective initiative. It is anchored in the contention that inadequate attention has been paid to gender-based violence and HIV and AIDS as intersecting and mutually reinforcing crises. At the same time, there are promising practices being spearheaded by women's rights organisations that deserve greater support and attention, particularly as models to be replicated and/or scaled up.

The article first sets out the importance of understanding the intersection of HIV and AIDS and gender-based violence. It stresses that gender-based violence is rooted in gender inequality, and has a lethal dynamic by itself and in combination with HIV and AIDS. Next, it provides information about how differences in race, ethnicity, language, sexuality, age, and many other social factors have a significant and differential impact on the effect of both gender-based violence and HIV and AIDS on the lives of women and girls in various communities. Third, it highlights some of the key obstacles and challenges to comprehensively addressing the intersection of gender-based violence and HIV and AIDS, and the barrier this presents to effective prevention, services and advocacy. Fourth, it emphasises the importance of a comprehensive, gender and human rights sensitive-response to both HIV and AIDS and gender-based violence, providing some of the key elements of such an approach. The potential heightened risk of violence against women and girls engendered by strategies such as '*provider initiated*' testing practices that are not fully gender-sensitive and human rights-based underscores the urgency of '*globalising*' such a comprehensive approach. Finally, it concludes by offering examples of promising practices from colleagues in a variety of countries, communities and circumstances.

HIV and AIDS and gender-based violence: Intersecting health and human rights crises

As colleagues at the Center for Women's Global Leadership have stated succinctly,

> *…around the world, women are facing a catastrophic assault on their bodies, rights and health as a result of the prevalence of both HIV and the unrelenting omnipresence of violence against women*.[3]

Each constitutes a crisis on its own, and the combination produces a particularly potent poison. Increasingly, women are dealing with the way violence places them at greater risk of contracting HIV, while women who are living with HIV are more likely to be targets of violence, because of the additional layers of discrimination and stigma they face. Elements of the AIDS testing and treatment machinery may also bring risk, such as the danger of violence connected to disclosure of HIV serostatus or coercive testing in the guise of VCT (voluntary counselling and testing), or the insidious treatment of women as '*vectors of disease*', as in the case of PMTCT (prevention of mother-to-child transmission) programmes that fail to treat pregnant women who are living with HIV as patients or clients with rights, but rather only as, and nothing more than, child-bearers.

An increasing number of analysts and observers are noting that violence against women is a cause of HIV, as well as a consequence.[4] A recent article in *Clarin*, a national newspaper in Argentina, notes that

> *…*[s]*exual violence directly increases women's risk of HIV infection, be it through rape within or outside a relationship, trafficking of women, sexual exploitation and commerce or sexual violence committed in armed conflict. All of these, according to* [Mabel] *Bianco* [founder of FEIM, Fundacíon para Estudio y Investigacíon de la Mujer, Buenos Aires, Argentina], *are forms of violence that expose women to HIV transmission. Only 10 percent of sexual abuses and rapes are reported. Women who do not report sexual abuse or rape are also not accepting prophylactic treatment after possible exposure to HIV and this is how the probability of infection increases*.[5]

...increasingly, women are dealing with the way violence places them at greater risk of contracting HIV, while women who are living with HIV are more likely to be targets of violence, because of the additional layers of discrimination and stigma...

A report in the UN-sponsored IRIN/PLUSNEWS, makes this point painfully clear:

> *A Zambian nongovernmental organisation (NGO) revealed this week that it records eight cases of rape of young girls every week at its centre in the capital, Lusaka. The statistics were released by the Young Women's Christian Association (YWCA) of Zambia to mark the start of the global campaign, '16 Days of Activism Against Gender Violence', which runs from 25 November - International Day for the Elimination of Violence Against Women - until International Human Rights Day on 10 December. Katembu Kaumba, YWCA's executive director, said alongside the abuse of girls, the organisation's shelter in Lusaka also recorded 10 cases of rape of adult women every week... 'Nationally, the figure is much higher - about 12 every week', said Superintendent Presphord Kasale, who heads the Victims Support Unit of the Lusaka Division of the Zambia Police Service*.[6]

Noting the linkage between violence against women and HIV and AIDS, the UN Special Rapporteur's 2005 report to the UN Commission on Human Rights stressed that '[t]*he lack of respect for women's rights both fuels the epidemic and exacerbates its impact*'.[7] However, governments, donors, multilateral institutions, international organisations and many civil society actors have failed to fully integrate programming for

gender equality and women's empowerment into their HIV and AIDS, or indeed, their gender-based violence programming.

...the situation is exacerbated by the all-too-frequent lack of accountability and political will by governments and donors – only in rare instances have states fully committed to protecting and promoting women's human rights...

The situation is exacerbated by the all-too-frequent lack of accountability and political will by governments and donors – only in rare instances have states fully committed to protecting and promoting women's human rights in relation to violence or HIV prevention, including development of policies encouraging swift investigation of abuses and direct punishment for perpetrators. Government actors are generally unwilling to address abuses committed by soldiers, police and other agents of the state, as well as the sexual violence that takes place within the family, community and other traditionally '*private spheres*'.[8] This latter point is of particular concern to women, as much of the violence they face takes place within this *private* arena and is inflicted by non-state actors, like husbands and other family members. Among donors, the level of funding for efforts to address gender-based violence remains extremely small,[9] while the integration of violence against women programming in the much larger pot of funding for HIV and AIDS is scant and hard to find.[10]

The diversity of women and girls: Social factors and risks

A recent resolution on HIV and AIDS and human rights by the UN Human Rights Council notes with concern that

> *…an estimated 95 per cent of all people infected with HIV live in the developing world, mostly in conditions of poverty, underdevelopment, conflict and inadequate measures for the prevention, care and treatment of HIV infection, and that marginalized groups in these societies are even more vulnerable to HIV infection and the impact of AIDS….*[11]

However, such a multi-faceted analysis must go further and deeper. Gender inequality and violence against women often inhibits women's and girls' ability to take full advantage of crucial – even life-saving-services. First, women victims/survivors of violence have different experiences and different options available to them than girls who are victims/survivors. Age is a key factor in determining risk and vulnerability to both gender-based violence and to HIV and AIDS. A recent study by the WHO found that as many as 30% of women in some locations reported that their first sexual experience was coerced or forced.[12] The younger the women were at the time of sexual initiation, the higher the chance that it was violent.[13] Moreover, HIV and AIDS is fast becoming *a girls' epidemic*: The WHO notes that

> *…*[y]*oung people (aged 15-24) account for half of all new HIV infections, and of infected youths, two-thirds are female. In parts of sub-Saharan Africa, teen girls are six times more likely to be infected than male peers. The burden of care also falls on girls who may leave school to care for sick relatives*.[14]

...the younger the women were at the time of sexual initiation, the higher the chance that it was violent...

Furthermore, age-related risks do not only correspond to youth. Patterns of wife-inheritance in some communities have been noted to fuel the spread of HIV.[15] In some communities, older women, in particular, may be targeted for rape in connection to HIV and AIDS. For instance, during a recent trip, UN special envoy on HIV/AIDS in Africa, Stephen Lewis,

reported hearing disturbing statistics: '*Rapes of women and girls were escalating every month, and half the girls sexually assaulted were under 12*'.[16] Lewis noted that an even more startling pattern also emerged. He commented that

> *...a significant number of women aged 65 to 80 were also raped. The men who did it were confident they could have unprotected sex with them without getting AIDS.*[17]

...women who are infected with HIV face a range of real or potential human rights abuses – from non-consensual testing and disclosure of results, to stigmatisation, isolation and shunning by their families and communities, to threats of, or actual violence...

Other elements of social location also effect women's and girls' vulnerability to both violence and HIV and AIDS. Women who are infected with HIV face a range of real or potential human rights abuses – from non-consensual testing and disclosure of results, to stigmatisation, isolation and shunning by their families and communities, to threats of, or actual violence committed against them. Marginalised racial, ethnic or cultural status exacerbates the risk of contracting HIV and AIDS. In the United States, for example, the Kaiser Family Foundation reports that '[r]*acial and ethnic minorities have been disproportionately affected by HIV/AIDS since the beginning of the epidemic, and minority Americans now represent the majority of new AIDS cases (71%) and of those estimated to be living with AIDS (64%) in 2003*' with African-Americans and Latinos accounting for a disproportionate share of new AIDS diagnoses.[18] Moreover, women of colour are particularly hard hit with African American women accounting for 67% of estimated new AIDS diagnoses among women in 2003, while Latinas account for 16%.[19]

Discrimination and a hostile legal and political environment seriously circumscribe efforts to address the health and rights of marginalised communities. Cases such as HIV outreach workers being arrested on sodomy charges, or as sex workers (using evidence of carrying condoms as an indication of prostitution) are simply the tip of the iceberg.[20] Various forms of '*minority*' status also indicate risk. For example, the estimated HIV prevalence rate amongst self-identified gay men in South Africa may be as high as 30%, while the rates for transgender individuals may be even higher. Amongst sex workers, available data from 2000 shows that slightly over 50% of sex workers were HIV-positive.[21] In Nepal, an HIV prevalence rate amongst men who have sex with men of 3.9%[22], exists alongside a long-term and consistent pattern of serious violence and abuse of *metis* (transgender persons).[23] Moreover, while women who have sex with women are generally considered to be a '*low risk*' group, the calculation changes when lesbians are targeted for violence.[24] For example, due to the high incidence of rape, HIV and AIDS rates amongst black South African lesbians are reportedly as high as in the general population.[25] And even where HIV appears to be on the rise amongst lesbians, as in Thailand, prevention information is rarely addressed specifically to them.[26]

...a significant number of women aged 65 to 80 were also raped. The men who did it were confident they could have unprotected sex with them without getting AIDS...

The former UN Special Rapporteur on violence against women, Radhika Coomaraswamy, documented the combined impact of gender and race in her extensive report on international, regional and national developments in the area of violence against women: 1994-2003, covering her years as Special Rapporteur. For example, in the case of violence against women in

Costa Rica, the Special Rapporteur found that

> …[d]*omestic violence against black women is more widespread, especially between couples made of a white man and a black woman. Black women tend to be more reluctant in filing complaints. It is a clear case of intersection of gender and race which multiplies the impact of domestic violence against women*.[27]

Other institutional issues, such as profiling of particular groups (including in, but not limited to, situations related to the war on terrorism), historic and persistent discriminatory practices against racial and ethnic minorities by the police and other state actors, amongst other circumstances, can lead to perpetrators of violence against women in racially diverse communities acting with virtual impunity. Agents of the state often are protected against appropriate investigation and punishment. Thus they, along with other perpetrators of abuse, are able to act with impunity. The result is not only unrelenting gender-based violence, but the exacerbation of HIV and AIDS.

...due to the high incidence of rape, HIV and AIDS rates amongst black South African lesbians are reportedly as high as in the general population...

Obstacles and strategies

The lack of adequate human and financial resources cannot be underscored enough as both cause and effect of the compartmentalisation of violence against women and HIV and AIDS.[28] This resource issue cuts through almost all of these critical challenges and serves as an example of how they are interlinked. Without adequate funding, research and campaigning may fail to reach potential impact, adequately document their experiences in a way that facilitates replication, and are unable to be scaled up. However, while more funding is crucial, it will only mitigate, but not arrest, either HIV and AIDS or violence against women, nor will it achieve gender equality, without a clear understanding and analysis of the impact of policy, programming and funding.

...HIV and AIDS funding ... fails to interrogate its gender bias, and therefore, often fails to reduce HIV infections amongst women, or mitigate its more general impact on women and girls...

The current framework for HIV and AIDS funding (inclusive of the acronyms of VCT [voluntary counselling and testing], ABC [abstain, be faithful, use condoms], PMTCT [prevention of mother-to-child transmission] amongst others) fails to interrogate its gender bias, and therefore, often fails to reduce HIV infections amongst women, or mitigate its more general impact on women and girls. This includes, for example, PMTCT programmes that treat women only in the context of childbearing, VCT programmes that fail to understand that '*voluntary*' can become coercion in a context of gender inequality and a pervasive threat of violence, or that ABC initiatives generally ignore the fact that many women and girls are not in a position to negotiate the conditions of a sexual encounter. The current axiom of universal access to prevention, treatment, support and care will not reach its goals nor halt the feminisation of the pandemic without a gender-sensitive realignment fully anchored in human rights norms and standards. Nor will a '*results-based*' focus that emphasises quantity over quality necessarily protect the rights of women.

The need for comprehensive, gender-sensitive and human rights-based responses

A gender- and human rights sensitive approach to HIV and AIDS and gender-based violence are essential to finding innovative and effective solutions.

Addressing the human rights implications of HIV and AIDS and violence against women requires grappling with gender inequality and other forms of discrimination at all levels – from policy reform to community education. Moreover, the links between human rights, HIV and AIDS and violence against women must be made in practical ways that have immediate impact on women's lives. Women benefit most when '*rights-based approaches*', including principles of non-discrimination, accountability, transparency, and participation are used in provision of services, as well as in advocacy efforts.[29]

...the links between human rights, HIV and AIDS and violence against women must be made in practical ways that have immediate impact on women's lives...

Take, for example, initiatives focusing on the prevention of mother-to-child transmission (PMTCT). The availability of medications that can block the transmission of HIV during pregnancy, childbirth and the postnatal period has created new opportunities to slow the spread of HIV and AIDS. Governments have begun establishing programmes to facilitate access to these medications for pregnant women. These initiatives enable pregnant women to reduce significantly the chances that their infants will be born with HIV. While the benefits of PMTCT programmes are immense – for individual women, their children, and societies alike – it is crucial that governments implement these programmes with a keen awareness of the experiences of all women living with HIV and AIDS and with respect for their human rights. PMTCT programmes are primarily conceived as prevention programmes for infants. This focus on prevention leaves the concerns of women living with HIV and AIDS largely invisible. In many contexts, the women are forgotten after they deliver healthy infants. In addition, in any healthcare setting in which women are under the care of providers, however, women receiving treatment have rights as patients. These rights are too often overlooked. These encompass their right to privacy and to physical integrity, including their right **not** to be tested for HIV without their informed choice or consent, or to have their HIV status disclosed without their permission.

Promising practices: Lessons from women's rights and HIV and AIDS organisations

The progress of discerning and distilling promising practices is a lynchpin of an effective response. Governments, multilateral institutions and donors must engage in a dialogue with civil society in order to draw important lessons that will allow for governments and donors to provide the resources for scaling up effective gender and human rights-based strategies, and to support the social movements within which these new, innovative and/or effective strategies are grown. A number of these innovative programmes have been featured in *Strengthening Resistance: Confronting Violence Against Women and HIV/AIDS*, a 2006 publication of the Center for Women's Global Leadership.

From street theatre to telenovelas/soap operas to traditional lobbying, activists in both gender-based violence and HIV and AIDS communities are beginning to focus attention to ways both crises interact in a negative spiral.[30] The use of media has, in several cases, provided promising results. Soul City in South Africa is one of the most well-known '*infotainment*' outlets addressing HIV and AIDS and, with some frequency, gender-based violence. Another is Puntos de Encuentro in Managua, Nicaragua. Their concern with exhibiting an integrated approach formed the basis for a *Sexto Sentido*, one of Nicaragua's most popular soap operas. One storyline involves Gabriel, a young, popular character who discovers he is infected with HIV as a result of his having had unprotected sex with Martha, an equally treasured soon-to-be divorced woman who has unknowingly contracted HIV from a philandering husband, who refuses to wear a condom.

...PMTCT programmes are primarily conceived as prevention programmes for infants. This focus ... leaves the concerns of women living with HIV and AIDS largely invisible...

Cultural stereotypes involving sex workers and other sexually active women, and myths involving condom use and the virtues of machismo, are systematically undermined – and reframed – as the story progresses. And opportunities to revisit the issues presented are provided to people who view a special edition of the soap opera story, now being packaged for use with youth and other audiences around the country and abroad.[31]

Another promising practice involves the pairing of HIV and AIDS and gender-based violence initiatives. One such endeavour involves the Institute for Social Development Studies (ISDS) and the Center for Studies and Applied Sciences in Gender-Family-Women and Adolescents (CSAGA), both based in Hanoi, Viet Nam, conducted with the support of the Program on International Health and Human Rights at the Harvard University School of Public Health in the United States. ISDS and their violence against women services-focused partner, CSAGA, determined how they could best share resources to collect and analyse relevant data, as well as train counsellors to use that information to inform their everyday work with clients. As Nguyen of ISDS says:

> *Our objective became to see the linkages between HIV and violence and use those findings to provide training for counsellors, and then, later on, conduct advocacy with the public through mass media channels*[32].

Since the inauguration of their hotline services in 1997, CSAGA had been keeping track of anonymous data on the types of calls its counsellors had received. These hotlines have been quite active: on average, 3,000 calls per year have involved violence against women alone. Six notebooks containing summaries of counsellors' conversations with callers over the years also provided rich sources of data for research on both violence and HIV and AIDS. Interestingly, despite the rich amounts of data, and while overall findings have yet to be reported, the groups found few connections between the issues were made by counsellors or callers. In fact, says Nguyen:

> *Very, very few of the summaries are about HIV and violence…In the counsellor's minds…there's no linkage of the issues, so they don't have a related question to ask – they just follow the complaint of the customer.*

The information ISDS gleaned from both investigations is currently being used to help structure a focus group session with several long time CSAGA counsellors and a training session for their colleagues. An evaluation will be conducted at the end of this year.[33]

...governments and donors must fully grapple with the fact that the category of 'women and girls' encompasses a vast array of different groups of women and girls...

A third example involves paying attention to the experiences of women living with HIV and AIDS when designing responses and services. One such organisation is Creatíon Positiva, a member of the International Community of Women Living with HIV/AIDS based in Barcelona, Spain. Creación Positiva delivers a wide variety of HIV-related services to women and men, including individual and group support, research, and community-wide workshops on a broad range of topics. '*In a typical year, we might work individually with about 35 men and 100 women*', says programme coordinator Montse Pineda. She adds:

> *...We connect with people by putting our flyers in hospitals, through our website, and by word of mouth. We have workshops on prevention and on sexuality – not safe sex, but comprehensive workshops on sexuality ...In 2005, the organisation*

> *conducted six of these* [romantic love] *workshops on November 25, the International Day Against Violence Against Women.*[34]

Creación Positiva has been attentive to the connection between violence against women and HIV and AIDS since early on. Pineda says:

> *Because we have worked with women for many years, we saw that there was an important link between violence against women and HIV and AIDS ... Many of the women we work with have lived with violence and we saw we had to make the issue explicit.*

Today, as a result of their participation in the global 16 Days of Activism Against Gender Violence campaign and other activities, Creación Positiva's influence now extends beyond the regional level in several respects. The organisation, for example, has also published two research studies,

> *...including the biggest study done so far in Spain on the needs of women who are HIV positive. The study included 258 women, and includes data on violence and HIV positive women. It was the only such study carried out for 2004 and 2005.*

Other national work includes playing both advisory and research roles on a nationwide study of stigmatisation. As Pineda puts it, '*We are a reference point in Spain*'.[35]

Recommendations

The following recommendations build on the collective knowledge, experience and analysis of partners in the '*Women Won't Wait. End HIV and Violence Against Women and Girls. Now.*' campaign and their colleagues from many regions.

- In devising services and distributing resources, governments and donors must fully grapple with the fact that the category of *'women and girls'* encompasses a vast array of different groups of women and girls, whether identified by age, race, language, sexuality, indigenous or refugee status, etc. And this diversity also reflects specific and varying needs with regard to prevention of, protection from, and response to both HIV and AIDS and gender-based violence.

...health policies or practices can create risks in women's and girls' lives, whether as a result of mandatory or forced testing, or breaches of confidentiality and rights to privacy...

- Governments, donors and service providers must pay attention to the need to ensure women's informed choice and consent, and of the persistent threats of violence women face in their everyday lives. Critical to this sensitivity is an understanding of how access to services and other interventions varies according to a woman's race, sexuality, class, rural or urban location, age, status as indigenous, etc. Without careful attention to the importance of such differences, health policies or practices can create risks in women's and girls' lives, whether as a result of mandatory or forced testing, or breaches of confidentiality and rights to privacy, especially in relation to disclosure of HIV status and partner notification policies.
- Governments, donors, multilateral institutions, international organisations and national civil society actors must support and facilitate greater communication amongst sectors, organisations and social movements. Such diverse participation in policy dialogues will enrich the possibility of devising and implementing the strongest responses to gender-based violence, HIV and AIDS and their intersection.
- Governments, with the support of donors, need to increase the level of resources for training legal and social service providers. For example, healthcare providers must be well-acquainted with human rights approaches to service delivery and health policy development, while judges, lawyers, policy and prosecutors must fully understand the

importance of gender- and human rights sensitive responses to gender-based violence and HIV and AIDS.

...governments must create or change legislation to promote ... programmes that are equipped to address violence and HIV and AIDS in straightforward, meaningful ways...

- Governments must create or change legislation to promote non-discrimination, and also must commit to funding initiatives and programmes that are equipped to address violence and HIV and AIDS in straightforward, meaningful ways, including, for example, the provision of post-exposure prophylaxis (PEP) to survivors of sexual assault; medically accurate, evidence-informed information without restriction or censorship; and comprehensive sexuality education and detailed information about HIV prevention, treatment care and support. This includes a focus on the rights of women in their own individual right as citizens.
- Governments must commit themselves to working toward changing discriminatory attitudes and address '*taboo topics*', including sexuality, sex work, drug use, and the rights of women to control their own bodies, sexuality and decision-making about families and parenting, in line with their international human rights obligations.
- Governments must uphold fundamental human rights standards in creating prevention, protection and actions to address gender-based violence and HIV and AIDS. These standards include requirements of informed consent, confidentiality and choice, provider-patient confidentiality, appropriate and accessible health, social and legal services without discrimination.
- Governments, with the support of donors, multilateral institutions, international organisations and a diverse range of civil society groups, must support community-wide education and information initiatives in order to combat the fear, silence and myths surrounding HIV and AIDS and gender-based violence.

Ultimately, in devising interventions, governments, with the support of donors, multilateral agencies, and international organisations must draw on the experiences of women's rights and women and HIV and AIDS organisations and build their participation into the policymaking, implementation, monitoring and evaluation processes. This includes a policy process centred on advancing and protecting women's human rights. They must, for instance, promote women's status in both the home and the public sphere at the same time that they ensure, for example, that government clinics promote and protect women's rights and provide protection for women living with HIV and AIDS, who might suffer abuse.

...support community-wide education and information initiatives in order to combat the fear, silence and myths surrounding HIV and AIDS and gender-based violence...

In the end, it is crucial to assert that addressing violence against women and girls must be a central principle of all human rights, health, humanitarian and development programming. Moreover, gender-sensitive efforts require striving toward a greater goal – achieving gender equality, women's empowerment and creating the conditions for safe, healthy, consensual and diverse sexualities and life choices for all, including safe and pleasurable sexuality for all people, including people who are living with HIV and those who are not.

FOOTNOTES:

1. Susana T. Fried is the author of *'Show Us the Money: Is violence against women on the HIV&AIDS donor agenda?'* produced as part of the campaign Women Won't Wait: End HIV and violence against women and girls. Now. For more information about the campaign go to www.womenwontwait.org. The submission and this adaptation was produced with the support of Actionaid International.
2. This piece is adapted from a submission made to the UN Secretary-General's report on HIV and Human Rights in December 2006. The submission was made by The Center for Women's Global Leadership (US), in collaboration with Action Aid International, Action Canada for Population and Development/ ACPD (Canada), Center for Health and Gender Equity/CHANGE (US), Center for Reproductive Rights (US), Fundación para Estudio e Investigación de la Mujer /FEIM (Argentina), Gestos- Soropositividade, Comunicação e Gênero (Brazil), International AIDS Women's Caucus, International Women's Health Coalition/IWHC (US), Latin American and Caribbean Women´s Health Network/LACWHN, in reference to *Resolution 2005/84* (adopted by consensus on 21 April 2005) calling for the UN Secretary General to prepare a report on steps taken to promote and implement programs to address the urgent HIV-related human rights of women, children and vulnerable groups in the context of prevention, care and access to treatment as described in the Guidelines on HIV/ AIDS and Human Rights for the Human Rights Council. Neelanjana Mukhia (Actionaid International), Laura Katzive (Center for Reproductive Rights) and Cynthia Rothschild (Center for Women's Global Leadership) made invaluable contributions to the submission. However, the content and opinions remain the responsibility of the author.
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Busari Olusegun

One thing leads to another…
Sexual and Reproductive Health Rights in Nigeria

Nigeria is unarguably the most populous African and Black nation on earth. For the first time since political independence from British colonialism in 1960 democracy has managed to survive for up to seven years at a stretch.

Introduction

The current democratic dispensation is not only fragile, but also bedevilled by flagrant disregard for the rule of law. The issue of rights generally does not exist in a typical military dictatorship, the kind of which Nigerians experienced for more than three decades. The polity is gradually becoming conducive for the citizenry to appreciate and to demand their rights.

There is a link between political climate and leadership of a nation and the sexual and reproductive health rights of its people. They are all interrelated. One thing leads to another and nothing occurs in isolation in life, whether good or bad. This article will discuss the extent to which sexual and reproductive health rights are accessible and realisable in Nigeria and how this links to existing challenges and realities of the HIV and AIDS epidemics. Sexual and reproductive health issues take a centre stage in the HIV and AIDS realities in Nigeria, since sexual and reproductive health is inseparable from HIV and AIDS. They are like a double edged sword, representing both causes and consequences. Sexual and reproductive health rights problems constitute the hydrocarbon fuel, while HIV and AIDS is the wild fire. The resultant ashes represent the lives of millions infected and affected by HIV and AIDS.

Adolescent health

Adolescence marks the developmental transition from childhood to adulthood, and a time when many important social, economic, biological and demographic events set the stage for adult life. The World Health Organisation (WHO) defines adolescents as individuals in the 10-19 year age group.

This stage is crucial to the future health of young people. Mismanagement of this period impacts negatively on the physical, mental and social well-being of young people. No doubt, there is a strong link between adolescence and HIV and AIDS. And this is due, at least in part, to the virtual non-existence of adolescent health rights and services.

One of the basic rights of adolescents is the right to correct and timely sex and reproductive health education. Although this problem is multifactorial, family institution and culture play a vital role. Healthy sex education is a taboo in most Nigerian cultures and traditional homes. The parents '*abhor it*', the school teachers '*frown at it*', the clergies call it '*a sin*', and the government '*neglects it*'.

The prevailing socio-economic climate does not offer adolescents the opportunities to develop their human and social capital through qualitative schooling and work-related training. In primary and secondary schools, sexual harassment of female students by male teachers seems to have become part of the curriculum. Over 1000 female students in Nigerian primary and secondary schools once protested to the Federal Minister of Education over the increasing incidence of sexual harassment in their schools. This situation poses great danger and exposes young people to HIV and AIDS. A sexual advance to a child, or an adolescent, by her male teacher is not only criminal, but also a sign of moral bankruptcy and abuse of responsibility. This is sexual harassment, an offence that should be punishable by law, even if it is only to serve as a deterrent to others. These

are teachers that should educate their students with life skills and constructive sex education to enable young people to achieve optimal, safe psychosexual growth and development. The adolescent girl is much more affected, as a result of restrictive gender definition. The lives of these girls are characterised by limited education, lack of economic and social opportunities, early marriage and childbearing, as well as limited influence on decisions affecting their lives. Adolescent girls typically make the transition to adulthood amidst constraints in life options that are highly gender defined, with few social assets, and with limited control over economic resources.

...sexual and reproductive health rights problems constitute the hydrocarbon fuel, while HIV and AIDS is the wild fire. The resultant ashes represent the lives of millions infected and affected by HIV and AIDS...

All of these factors place adolescent girls at increased risk of HIV and AIDS and other STIs. There is a need for the development of adolescent friendly health services, as a way to encourage earlier and safer health seeking behaviour amongst adolescents. Some of the basic principles of adolescent friendly health services are: confidentiality and privacy; acceptability to local community; involvement of adolescents in the planning and monitoring of services; and accessibility.

Condom Use

The condom remains an effective tool to reduce sexual transmission of HIV and other sexually transmitted infections (STIs), even for people living with HIV and AIDS, who are sexually active. It is also an effective barrier contraceptive device. But there are so many obstacles. The fact is that condoms are still not widely used in Nigeria. As and when condoms are used, the problems of inconsistent and incorrect use are recurring decimals. The non-availability factor is very prominent. Sexually active people in the rural areas do not know where to turn to to get condoms – and even if they were to turn everywhere, condoms are no where to be found. Furthermore, the quality of condoms in the market is also a big problem. In a place, where regulatory agencies have failed woefully to ensure circulation of good quality condoms, and where profit-making is exalted above the value of life, it may seem more reasonable to avoid using condoms, than to have a false sense of security.

The ban imposed by religious institutions on condoms, describing the condom as a '*satanic instrument*' is still in effect. A condom is called '*an agent of sin*', and anyone who uses a condom is '*a sinner and hell bound*'.

Overall, there seems to be little or no change in risky behaviours, unprotected sex is '*a natural thing*' and to have STIs as a man is a matter of pride and an emblem of sexual and physical maturity. With all these problems with condoms, there seems to be no end in sight to the decimation of lives by HIV and AIDS, while the transmission of HIV continues as the hand of a clock ticks away.

Legality or otherwise of 'abortion': The plague of unsafe procedures

Although, the controversial issue of legality or otherwise of '*abortion*' is not a subject for discussion here, it remains a critical factor in the context of sexual and reproductive health. According to the Nigerian Constitution, '*abortion*' is illegal, except for therapeutic purposes. But unprotected sex and its consequences, unwanted pregnancies, continue unabated. The sad reality is that unwanted pregnancies are relieved under-cover, as pregnant girls and women secretly visit '*under-the-bridge quack clinics*' and '*nursing homes*'. Some non-medical personnel use medical equipments to perform '*abortions*'.

Stigma, societal ridicule and rejection, and fear of the law have driven '*abortion practices*' into secrecy, where little or no emphasis is laid on aseptic procedures. Unsterilised and sub-standard instruments are used in unhygienic environments, with no safety or antiseptic precautions. Unsafe '*abortions*' continue to contribute substantially to reproductive morbidity and mortality

worldwide, especially amongst poor women in developing countries. Every year 70,000 – 100,000 women die from unsafe abortions, 99% of them in developing countries.

...unprotected sex is 'a natural thing' and to have STIs as a man is a matter of pride and an emblem of sexual and physical maturity...

If HIV infected women are pregnant and do not want the pregnancy, because there is no access to prevention of mother to child transmission of HIV programmes (PMTCT), can therapeutic abortion be performed? This is one of the so many questions that are begging for answers. As far as I am concerned, there is a form of abortion, I call '*coercive abortion*'. I am living with HIV and have the desire to have a child. I am a poor woman with a wage not enough to buy antiretroviral drugs. There is no PMTCT service within my reach and I am already pregnant. Though I want a child, I still dread the possibility of having an HIV infected baby. So, I decide to have a secret abortion. Where? Of course, in a tiny dirty clinic in a slum somewhere, because it is illegal! That is what I call a '*coercive abortion*', in that I have been coerced by forces beyond my human control to take that step. So, '*coercive abortions*' are common in resource-poor settings of the world, where abortion is illegal.

The majority of unsafe abortions amongst adolescents take place, because the pregnancy is unwanted and unplanned. This also shows that the use of contraceptives is poor amongst young people. The provision of adequate knowledge on contraceptive services, as well as ensuring the availability of, and access to, emergency contraceptives are vitally important in this context.[1]

Gender-based inequalities and violence

Gender inequalities have been recognised as a major structural factor that facilitates HIV transmission. There is interplay between gender norms and violence and sexual reproductive health and HIV outcomes. Gender-based violence has important implications for sexual and reproductive health and sexual behaviour. The power imbalances are expressed in sexual relationships and seem to confer on men the ability to determine women's sexual and reproductive health choices, including the use of a condom.[2]

It is, however, sad to note that, despite what the public is being made to believe about government's unwavering commitment to address HIV and AIDS, there are no definite policies to either challenge patriarchal gender norms or to address gender-based violence. Although, gender-based violence has been internationally recognised as a violation of women's human rights, as well as women's sexual and reproductive health rights, there is no part of the constitution that accommodates this issue. There are virtually no sexual and reproductive health services to provide care and support for victims of gender-based violence.

Addressing biased gender norms and masculinities in sexual and reproductive health policy and programme context will, arguably, contribute to the improvement of the health and rights of women and children, as well as of men.[3] Additionally, women need assistance in acquiring skills to become economically productive, including economic literacy, access to savings and formal sector employment.

Antenatal, labour and postnatal health services

About 70-80% of deliveries still take place at homes.[4] These deliveries occur an under unhygienic ambience, placing the lives of both the child and the mother in grave danger. Quality antenatal services are not available for the majority of Nigerian pregnant women. The traditional birth attendants sometime add salt to injury promoting more complications, in that their blades or scissors are often not well sterilised and, thus, these instruments can be a potential medium for transmission of blood-borne infections, such as Hepatitis C and B, and HIV.

Pregnant women infected with HIV are particularly at risk, since there is no access to specialised antenatal, labour and postnatal services that reduce the risk of mother to child transmission of HIV. Some women hide their pregnancy and prefer to deliver at home, because of intimidating stigma and rejection by the society, including some healthcare workers.[5]

Treatment of sexually transmitted infections

Non-HIV sexually transmitted infections (STIs) are the major cause of disease burden, after maternity related causes, in young adult women in developing countries. Untreated STIs are thought to account for 15% of foetal wastage and 30-50% of antenatal infections. STIs are also associated with about 3-5 times increased risk of HIV transmission.[6]

Stigma associated with STIs has further impacted on patients' rights to come out and seek adequate treatment, as and when it is available. In some places, it is not only the lack of adequate services, but also the lack of qualified health professionals to make appropriate diagnosis and institute effective treatment. Another perennial problem is the issue of fake and substandard antimicrobial drugs that are in circulation. Currently, I am not aware of any programme addressing herpes simplex virus (HSV), which is becoming increasingly common.

All these problems additively deny clients their rights to good quality sexual and reproductive health and also expose people to an increased risk of HIV infection. There is an urgent need for affordable, rapid, point of care screening tests for STIs in all public health infrastructures, including antenatal care settings.

Female genital mutilation/cutting

Female genital mutilation (FGM) is one of the cultural realities that are fuelling HIV and AIDS in Africa. This traditional practice affects an estimated 130 million girls and women, mainly in Africa. It is a harmful practice that violates international standards for girls' and women's rights and often leads to serious health problems. It is one of the practices that has brought untold pains to women for a very long time. No doubt, this unsafe procedure has contributed to the feminisation of HIV and AIDS in Africa. FGM, which often involves the partial, total excision, and sometimes sewing up, of the female genitalia or other deliberate injury to the female genital organ for mostly cultural reason, is a practical source of HIV transmission and its perpetuation in Africa.[7]

...adolescent girls typically make the transition to adulthood amidst constraints in life options that are highly gender defined, with few social assets, and with limited control over economic resources...

According to the WHO, there are an estimated 100 million circumcised women in the world. The majority of these women are in Africa where the practice is mostly carried out on girls under the age of 10 years. FGM is a practice that is rooted in ignorance, myths and traditional mores. Young women are coerced, and in some instances charmed, into doing it. In some societies, parents who refuse to circumcise their female children are stigmatised, discriminated against, or may even be sent away from a local village. For a young woman to be identified as uncircumcised is to be seen as sexually promiscuous and ridiculed.[8]

Traditional doctors, community elders and local experts, who often claim to be the custodians of culture and traditions, carry out this '*heinous act*' in the most unhygienic places. In most instances, unsterilised sharp instruments are used to perform this procedure with multiple usage and high risk of transmission of infections, such as HIV and hepatitis B and C. Many young girls have been infected with HIV in Africa, especially in countries where the practice is rampant, through this harmful act. Other repercussions of FGM/C include heavy blood loss, psychological trauma, difficulties during childbirth, gynaecological problems and at times even death.

Female genital mutilation and cutting is a very serious issue and needs to be addressed with all seriousness, if the response to HIV and AIDS, and child/girl child abuse, in Africa is to be successful. There is, as of yet, no coordinated approach to end this practice in Nigeria.

Child marriages

Child marriage violates girls' human rights and adversely

affects their health and well-being. In northern Nigeria, child marriage is the norm, where 45% of girls are married by age 15 and 73 % are married by age 18. Poverty plays a major role in the decision to marry off girls early.

...female genital mutilation (FGM) is one of the cultural realities that are fuelling HIV and AIDS in Africa. This traditional practice affects an estimated 130 million girls and women, mainly in Africa...

Child marriage is a gory example of cross generational sexual practice as the husbands of the child brides are considerably older than their wives; the average age difference between husband and wife is 12 years and is often increased to 18 years in polygamous marriages. Child marriages mostly occur in a part of the country where polygamous marriage is a religious and cultural practice, and where women are confined to '*purdah*' and men expected to express their masculinity at '*sexual prowess*' outside the boundaries of home. The man comes home infected with HIV in a setting, where religion forbids condom use and men make most household and family decisions, not only concerning major issues, but also about mundane matters, such as purchases for daily needs and composition of meals. Negotiation for condom use is an affront on the man's superiority and morality, and often degenerates into violence and economic sanctions on the woman, or she may even be sent away. Thus, child marriage is a breeding ground for HIV transmission in northern Nigeria.[9]

Prevention of mother to child transmission (PMTCT)

Mother to child transmission (MTCT) of HIV is responsible for 90% of HIV infections in children worldwide. Therefore, PMTCT is a programme of hope for both the HIV infected mothers and their unborn children. I consider access to PMTCT services as a fundamental human right of both the mother and the unborn child. Procreation is a natural and biological right for everyone, irrespective of a person's HIV status. Thus, the presence of HIV in a woman of child bearing age should never be an obstacle to her desire to have a child, or even children, if there is a free and accessible effective PMTCT programme in place.[10]

In Nigeria, however, PMTCT is a good programme on policy papers, but not in reality. In Nigerian reality, PMTCT programmes and services are characterised by weak grassroots presence; by health workers who lack the basic capacity; and a policy/programme framework that is too fragile to administer and implement the programme effectively, which, as argued, is worse than the complete absence of PMTCT programmes and services.

FOOTNOTES:

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Nomampondo Barnabas

In the absence of informed choice…

Sexual and reproductive health rights in the context of HIV and AIDS

Women have the right

- To decide with who, when, how or not to have sex
- To decide whether or not to terminate a pregnancy. Termination of pregnancy is performed based on only the woman's informed consent.
- To make a decision whether or not to terminate their pregnancy, because of their HIV seropositive status, without coercion
- To be assisted and supported to make an informed decision/choice

Introduction

Globally, women are the face of the AIDS epidemic, constituting about 60% of people infected in sub-Saharan Africa alone. Most of the women are not aware of their HIV status until they are tested during ante-natal visits. Many women living with HIV and AIDS face a major challenge of accessing and receiving adequate sexual and reproductive health services. This is often complicated by stigma and discrimination, which in most cases result in denial, infringement and violation of their rights. Women's sexual and reproductive rights have always been a subject for discussion and contestation. Women have the right of a satisfying and safe sex life; have the capacity to reproduce; and the freedom to decide when and how often to do so. Although all women have the same rights and similar needs for sexual and reproductive healthcare, women living with HIV and AIDS require additional care and counselling during their reproductive cycle. Research suggests that most women who are HIV positive do not receive information, support, referrals and related services necessary to meet their specific sexual and reproductive health rights and needs. This article is going to explore some of the specific sexual and reproductive health rights issues of women living with HIV and AIDS.

Understanding realities of women living with HIV and AIDS

Despite the growing recognition of sexual and reproductive health rights for women living with HIV and AIDS, there are still factors that make such rights only a dream for most women.

> *For many women, an HIV diagnosis brings about significant changes in the way they enact their sexuality and how they feel about sexual relationships.*[1]

It is commonly believed that HIV seropositive women should not get pregnant. If they are pregnant, they are either frowned at or advised or pressurised to terminate their pregnancies. Some women have been denied contraceptives. When women living with HIV are pregnant, the emphasis is often on saving the unborn child's life, neglecting the health of the women.

Infection with HIV can affect woman's sexual health in different ways, including decreased sexual desire or satisfaction; feeling guilty or ashamed; resentment towards a sexual partner; and sometimes infertility. In societies where women are expected to have children, women living with HIV, who opt not to have children, must contend with both social disapproval of being childless and the suspicions and prejudices surrounding their HIV positive status. Most women have to seek

consent from their partners regarding their sexual and reproductive health. Choices about fertility and family size are in most cases not taken by women, but instead by their partners.[2]

> *...the primary right that has been violated for everyone is the right to accurate and detailed information ... from a human rights perspective also we should see people as intelligent human beings who are much more likely to make rational decisions if they are given the facts rather than hiding the facts for fear that they will do something risky.*[3]

Challenges

Women living with HIV and AIDS face many challenges to exercise their rights. One of the major challenges that contribute to the violation of sexual and reproductive health rights for women infected with HIV is that men/partners often lack knowledge and skills to support women living with HIV and AIDS. There is also a lack of exploration on alternatives to biological parenting, such as foster care or adoption.

...women need to obtain consent from in-laws to seek services, or may even be inherited by the spouse's relative after death of their spouse...

Other challenges include lack of information, as well as structural barriers:

Lack of information – There is generally limited knowledge about the availability of facilities offering sexual and reproductive healthcare services to women and specifically to women who are seropositive for HIV. Moreover, in the instances where this knowledge is available, access to these facilities is restricted by inadequate infrastructure, such as inaccessibility, due to long distances and the costs of transport. Sexual and reproductive health information, care and counselling to assist women living with HIV and AIDS to make decisions about their sexual and reproductive healthcare, are very limited.

Structural barriers to improving the sexual and reproductive health of women living with HIV and AIDS

- High illiteracy rates and lack of decision making power – Rural women or illiterate women experience difficulty to access information and services. Poverty and long distances to services further limit the access to services and information.
- Role of culture and inequity in relationships – Cultural norms and women's status affect women's ability to access services. For instance, women need to obtain consent from in-laws to seek services, or may even be inherited by the spouse's relative after death of their spouse.

  > *Our culture is a problem sometimes because there is a belief that a man's word is final – so this gives women less opportunity to decide on sexual and reproductive issues. If a woman is married and lobola has been paid, even the in-laws believe they have something to say.*[4]
- Power in sexual relationships – In most cases, male partners dominate the actual act of sex. Women also encounter enormous difficulties with partners in monogamous relationships to use barrier methods, such as condoms.

  > *He does not force me to have sex with him, but he does emotionally because if I refuse then I don't get money, he might leave me for another woman or won't talk to me. This spoils the mood of the house, so I feel obliged.*[5]
- High prevalence of domestic violence – Many women experience and fear violence in their relationships. Some do not seek treatment for sexual and reproductive health problems for fear of violence or abandonment or being blamed by their partners for bringing the infection into the relationship. Domestic violence is viewed as a

private family matter and is often sanctioned by other family members (in-laws).

> *Women believe they can accept abuse from men because they are financially dependent on them. Men have to decide about sexual activities.*[6]

...domestic violence is viewed as a private family matter and is often sanctioned by other family members (in-laws)...

- Perceived societal roles versus individual rights – Women often experience pressure to have children, due to cultural norms prescribing that a woman's role is to bear children. Women living with HIV and AIDS face discrimination when they decide or choose not to have children. In addition, their ability to make their own decisions regarding sterilisation is often limited.

Irrespective of all these challenges, it is imperative that the decision of women whether or not to have sex, or to have a child, has to be an open and free negotiation process, irrespective of her HIV status.

Recommendations

The following are some of the measures to address the above challenges and to ensure women's access to quality sexual and reproductive health.

- Increase education and awareness on sexual and reproductive health needs for women living with HIV and AIDS.
- Provision of effective sexual and reproductive healthcare for women living with HIV and AIDS should be guided first and foremost by a rights-based approach. Policies and programmes should identify and address gaps through advocacy, strategic planning and collaborative commitments to bridge the reality of existing services and women's desires and rights to fulfil their sexual and reproductive health needs.
- Greater involvement of women living with HIV and AIDS – The complexities of the lives and circumstances of women living with HIV and AIDS require their involvement in policy-making and programme designing in order to effectively address issues that concern their lives.
- Build support for sexual and reproductive health rights of women living with HIV and AIDS – Leadership and participation of women living with HIV and AIDS is crucial in designing, planning and implementing the support. Promote sexual and reproductive health of women living with HIV and AIDS in everyday life and policy formulation.
- Ensure that the health sector can meet the needs of women living with HIV and AIDS by various means, including ongoing education and training, and adequate resource allocation. Develop a comprehensive sexual and reproductive health and HIV and AIDS curriculum for all training institutions.
- Implement programmes that will meet the sexual and reproductive health needs for women living with HIV and AIDS within the health systems and ensure that these programmes are understood and supported at the highest political level.

Scope of sexual and reproductive health services

Widening the scope of sexual and reproductive health services also means offering a greater range of actual services than currently provided. Currently, there is unevenness of health providers' understanding of sexual and reproductive health of women living with HIV and ability to respond to the needs of women living with HIV.

In order to provide adequate and effective sexual and reproductive health services for women living with HIV and AIDS, various factors need to be taken into account, including:[7]

- Promoting sexual health – Some of the specific actions that are needed to promote sexual and reproductive health needs of women living with

HIV and AIDS include addressing the particular sexual and reproductive health needs of women living with HIV and AIDS, as well as ensuring the availability of relevant and appropriate information and counselling.

...women living with HIV should not be discouraged, instead be given accurate information during counselling, including the reassurance that it is allright to have children...

- Family planning counselling – Access to family planning counselling for women living with HIV should be a priority in sexual and reproductive health services. This service can assist women living with HIV and AIDS to consider their choices and make informed decisions about pregnancy and contraceptive use that will suit their needs and lifestyle. This should be integrated into all phases of HIV care and treatment. Barrier contraceptives should be particularly promoted for women who are not planning to become pregnant. Actually, '*dual protection*' should be highly recommended. In addition, the potential effects of a pregnancy on HIV progression and the implications for family planning; and the risk of transmitting HIV to the unborn child are information that should be part of family planning counselling.
- Counselling for women infected with HIV who are planning a pregnancy – Women living with HIV should not be discouraged, instead be given accurate information during counselling, including the reassurance that it is allright to have children. However, women living with HIV need special counselling, support and guidance throughout the process in areas, such as the timing of conception, so that conception occurs as and when their medical status has been optimised. They also need to be advised on precautions to take to reduce the risk of mother to child transmission of HIV during pregnancy, labour and delivery. Prior to that, women living with HIV and AIDS should also be informed about different options of parenting without having to go through pregnancy, such as adoption and fostering.
- Counselling during pregnancy, childbirth and post delivery – Many women in abusive relationships are at increased risk of experiencing domestic violence during pregnancy with consequences both for her and the baby, such as spontaneous miscarriage and pre-term labour. Throughout pregnancy, delivery and post delivery periods, emphasis of counselling should be placed on promoting healthy practices for the wellness of the mother and the baby. This should involve interventions to reduce the risk of mother to child transmission of HIV and to avoid re-infections during pregnancy. Care should be provided in a sensitive and confidential manner, considering the stigma and discrimination that is associated with HIV.
- Termination of pregnancy – Even where contraceptive services are available, unintended pregnancies still occur for various reasons or under certain circumstances, such as the partner may be opposed to contraceptives or condom use; and the woman may be coerced or forced to have sex. There is also a need to ensure that safe termination of pregnancy is available and accessible to women living with HIV and AIDS. Termination of pregnancy counselling should be provided by a trained person and is to be non-directive, non-judgmental and confidential. If the healthcare worker suspects coercion, the woman should be referred for additional counselling in an endeavour to ensure fully informed and free decision making. Being pressurised or coerced to undergo a termination of pregnancy is a violation of human rights. All women, who, regardless of their HIV status, choose a termination of pregnancy are to be treated with respect, non-judgmental attitudes and have access to appropriate care and referral.

Sexual and reproductive health of women receiving antiretroviral treatment

There are a number of factors that need to be considered so

as to ensure the sexual and reproductive health of women receiving antiretroviral treatment. These include that:

- For equity, humanitarian and moral reasons, women must have access to antiretroviral therapy when needed. Antiretroviral therapy for women is an essential component of initiatives to reduce maternal morbidity and mortality, prevent mother to child transmission of HIV and secure the health and sexual well-being of a woman living with HIV and AIDS.
- Although women living with HIV and AIDS may differ in the presentation and response to treatment, standard treatment protocols are effective for women receiving antiretroviral treatment (ART). In addition, the possibility of unplanned or unintended pregnancy must be considered when selecting an ART regimen for women.

...in the absence of informed choices and adequate sexual and reproductive health services, women living with HIV and AIDS are even at a greater risk of morbidity and mortality...

- ART programmes need to be sensitive to women needs, especially in relation to their sexual and reproductive health.
- Special efforts to support adherence may be needed during pregnancy, delivery and post delivery.
- Making ART widely available to include partners and children will also ensure that women are not tempted to share their treatment with other family members, which may not be an appropriate regimen for these other groups.

Conclusion

Every woman has the right to have sex and the right to decide whether or not to have children. This is a universally recognised fundamental human right for a woman. However, women living with HIV and AIDS are being systematically discouraged to practice this right. Sexual and reproductive health services for women living with HIV and AIDS have to incorporate all standard reproductive healthcare offered to every woman. Moreover, this care should be curtailed to meet the specific needs of women living with HIV and AIDS, irrespective of their sexual activity.

Through lack of information, stigma and discrimination, women who are infected with HIV are often denied their sexual and reproductive health rights. In the absence of informed choices and adequate sexual and reproductive health services, women living with HIV and AIDS are even at a greater risk of morbidity and mortality.

> *...I think the services should be more humane. They should see women as complete people and not only as reproducers or HIV positive. Women are still devalued...*[8]

> ...[HIV positive women] *need services... I don't differ form other women who are not positive. Well, there is the virus in my blood... I have the same rights...*[9]

FOOTNOTES:

1. Bell, E. & Orza, L. 2006.'Understanding positive women's realities'. In: *Exchange on HIV/AIDS, Sexuality and Gender*, 2006(3):1-4.
2. The State of the World Population Report. 2005. Chapter Four.
3. EngenderHealth/Harvard University/ICW/Ipas/UNFPA. 2006. *Sexual and reproductive health of HIV positive women and adolescent girls: A dialogue on rights, policies and services*. p.9.
4. Policy Project. 2005. *Meeting the reproductive health needs of HIV positive women in Swaziland*. Policy Project.
5. Ibid.
6. Ibid.
7. See also World Health Organisation. 2006. *Sexual and reproductive health of women living with HIV/AIDS: Guidelines on care, treatment and support for women living with HIV/AIDS and their children*. WHO.
8. EngenderHealth/UNFPA. 2006. *Sexual and reproductive health needs of women and adolescent girls living with HIV*. p.17.
9. EngenderHealth/UNFPA. 2006. *Sexual and reproductive health needs of women and adolescent girls living with HIV*. p.45.

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Civil Society Women's Sector Declaration of Commitment[1] to the HIV & AIDS and STIs National Strategic Plan 2007 – 2011

We, a group of representatives from women in civil society having met on 8 – 9 March 2007, at Liban Conference Centre in Johannesburg, have drafted this declaration, on the proviso that the key concerns raised by this group are integrated into the National Strategic Plan (NSP).

Preamble

We, the women's sector of civil society, salute the government of South Africa for developing the NSP and engaging civil society in the process. We acknowledge that government has recognised the challenges facing the sector and responded through the NSP.

We pledge our commitment and support to ensure the integrated implementation of the NSP through partnership. We recognise the centrality of addressing women's position in society as fundamental to address HIV and AIDS in South Africa. Only a gender transformatory response built on active partnership between government and civil society, will address the vulnerability of women.

We believe

- That the Constitution of South Africa which guarantees our right to equality, freedom and dignity provides a strong basis for centering women's rights, particularly sexual and reproductive rights, in the response to HIV and AIDS.
- That South Africa's commitments to international conventions, instruments and treaties further consolidate government's obligations to women's rights.
- That patriarchy continues to reinforce the oppression and marginalisation of women and girls in this country.
- That women have the right and the ability to participate meaningfully and lead in all decision making processes at policy, legislative and programme level.
- That adequate resource allocation is critical for efficient and effective implementation of the NSP.

We recognise

- The gains that have been made in terms of advancing a women's rights agenda.
- That, despite these gains, women and girls are the most vulnerable and affected by both HIV and AIDS, because of their biological and socio-economic status.
- That South Africa has extremely high levels of violence against women and children, including rape, sexual assault and domestic violence.
- Maternal mortality and morbidity remains unacceptably high.
- Women are diverse in terms of their daily lived

realities and identities including 'race', class, sexual orientation, disability, pregnancy status, HIV status, age and nationality.

- That for successful implementation, the women's sector of civil society must be in full partnership, be meaningfully involved, lead and be adequately resourced.

- The need to strengthen the women's civil society sector.

We therefore commit to

- Play our role in the implementation of the NSP through active partnership around critical areas, such as policy formulation, support and coordination, capacity building, research and strengthening the capacity of the sector to play its part.

- Build the capacity of the sector to be sustainable, unified, networked and accountable.

- Fulfil our responsibility to work in partnership to ensure the effective implementation of the NSP.

- Hold government accountable for the NSP and other relevant, existing policies that affect women and girls, through monitoring and advocacy.

And urge government to

- Recognise that women's rights are fundamental in addressing HIV and AIDS in the effective implementation of the NSP and show leadership in the areas of gender consciousness and sexuality.

- Fully acknowledge, support and strengthen the contributions made by women in civil society and communities.

- Recognise that the implementation of the NSP will only be achieved with full partnership with women in civil society.

- Accelerate efforts to address violence against women and children to ensure that access to prevention, protection and empowerment services for all women, including women living with HIV, girls and young women, pregnant women, sex workers, lesbian, bisexual, transsexual and intersex women and refugees is adequately resourced.

- Commit adequate resources through long-term commitments to women in civil society.

- Review macro-economic policy to ensure that poverty and unemployment are addressed and privatisation of health services, which further deepens women's and girls' vulnerability, are addressed.

- Address human resource challenges to ensure the optimal implementation of the NSP so that there will be no exploitation of women's labour at a community level.

- Establish functional mechanisms that will facilitate an integrated, comprehensive and rights based approach within government and between government and civil society.

Let us move forward in a spirit of solidarity, as a people committed to implementing the NSP, in ways that fundamentally transforms the inequality between women and men and entrenches women's autonomy over their own health, bodies and lives.

FOOTNOTES:

1. This Declaration is a draft prepared and agreed in principle on 09 March 2007 at the Civil Society Women's Sector Meeting. This meeting took place before the final version of the National Strategic Plan (NSP) was launched. For more information and updates on this Declaration go to www.womensnet.org.za

ALQ | March 2007

Emmanuel Habumuremyi[1]

HIV and AIDS on the decline due to innovative measures…

Experiences from Rwanda

A multisectorial, multidisciplinary, decentralised and community-based approach is reducing HIV and AIDS infection rates in Rwanda. This has been achieved through a system involving adequate policies, fast field information collection, sensitisation and follow-up by stakeholders in HIV prevention. This system impacts on stigma reduction, voluntary HIV testing, home-based care promotion, and the adherence to HIV associations so as to respond to the challenges of the pandemic disease.

Country situational analysis

Rwanda is a very youthful country, with nearly 50% of the population under the age of 17. The country is amongst the ten countries in Africa most severely affected by HIV and AIDS. Rwanda is facing a generalised epidemic. National estimates indicate that in 2005, the adult prevalence rate is in the range of 4% to 11% amongst women attending antenatal care services and 3% amongst the general population. An estimated 250 000 adults and children were living with HIV and AIDS at the end of 2003. Prevalence rates have been documented to be higher in urban areas, than in rural areas. In 2003, the HIV prevalence in Kigali, the Rwandan capital, amongst women attending antenatal clinics was 13.2%. Outside major urban areas, the median prevalence amongst pregnant women tested for HIV was 3.1%. Prevalence rates appear to have stabilised in urban areas, but continue to rise slightly in rural areas. An estimated 160 000 children younger than 17 years had lost one or more parent to the disease at the end of 2003. The burden of HIV and tuberculosis (TB) co-infection is high (estimated to be between 40% and 60%).[2]

Factors contributing to the rapid spread of the disease include the low levels of awareness about HIV and AIDS, high incidences of multiple sex partners, low rates of condom use, early onset of sexual activity, and the overall civil crisis of the 1990s, especially during the 1994 genocide.

Solution to address HIV and AIDS expansion

Currently, Rwanda has developed national policies on HIV testing and treatment. In 2002, the Treatment and Research AIDS Center was established to expand access to HIV testing and counselling, prevention of mother-to-child transmission, and clinical care and support for people living with HIV and AIDS, including antiretroviral therapy. Guidelines for antiretroviral therapy, voluntary counselling and testing for HIV, treatment of opportunistic infections and prevention of mother-to-child transmission have been developed and recently revised, so as to adhere to international standards. Guidelines for antiretroviral therapy for children are being developed. With support from the Global Fund to Fight AIDS, Tuberculosis and Malaria, Rwanda plans to establish a national network on voluntary counselling and testing for HIV, with the objective of expanding the number of sites at the provincial level.

Multiple coordinating bodies have been created in the past three years at national and decentralised levels:

Government structures:

- In 2000, the National AIDS Control Commission was created, under the Office of the President to coordinate a multisectoral programme;
- In 2001, the Treatment and Research AIDS

Centre was created, to coordinate monitoring and evaluation of care, treatment and drug stocks and reports to the Commission. Minister of State for major epidemics was appointed in 2002, within the Ministry of Health. In 2006, there was the decentralisation of the Commission (within government administrative restructures) for representation in 30 District Committees for the Fight against AIDS; and

Non-governmental structures:

- Coordinating umbrella organisations that represent people living with HIV, youth, faith-based organisations, women, private sector, media and cluster of HIV (Government of Rwanda and Development partners) is in place and it is very active.

To better monitor the effectiveness of these structures, measures to operationalise and harmonise standard operating procedures have been put in place, such as a mapping of activities of all implementing agencies, who now sign memoranda of understanding with the National AIDS Control Commission.

Field information collection

According to the Ambassador Mark Dybul, U.S. Global AIDS Coordinator,

> *People living with HIV in the developing world deserve high-quality treatment and care, and this innovative partnership will ensure that health workers and program managers get the timely, relevant information they need – even when they serve patients in the most remote areas.*

Today, Rwanda is using a system that uses cell phones to bolster HIV and AIDS care and the system's impact in Rwanda. The system, which was created by a USA-based company Voxiva[3], allows health workers to send reports using a cell phone directly from the field to a central database. The system was launched in Rwanda two years ago to identify people living with HIV and AIDS. It now connects 75% of the country's 340 clinics and covers 32,000 people. Each time a person living with HIV is entered into the system, the information is sent to a central database in Kigali. Weekly reports are also created to cover data, including clinics' stocks of antiretroviral drugs, and monthly reports cover the number of people with access to antiretrovirals.

In addition, clinics receive messages with information about laboratory tests and drug recall alerts sent by the Ministry of Health. According to the Rwandan HIV/AIDS Minister, Dr Innocent Nyaruhirira, by identifying individual patients in a central database, the Ministry of Health can follow-up on individual patients, even when they change clinics, since mobile phones are almost everywhere in Rwanda.

Under the initiative called *'Phones-for-Health',* health workers in the field can access software loaded on a standard Motorola cell phone to enter HIV and AIDS and health information into a central database in real time.

> *Health workers will also be able to use the system to order medicine, send alerts, download treatment guidelines, training materials and access other appropriate information…Managers at the regional and national level can access information in real-time via a web based database.* [Paul Meyer, Chairman of Voxiva][4]

Rwandan authorities in charge of HIV and AIDS prevention see that with TRACnet, Rwanda has a powerful tool to manage the HIV and AIDS programme and deliver care to Rwanda's patients affected by HIV and AIDS. Healthcare workers use something as simple as a cell phone – even where there is no electricity – to report on the number of patients on treatment, drug stock levels and other key data needed. According to the CNLS Executive Secretary, Dr Binagwaho,

> *...Rwanda is the first country in Africa with a national-scale, real-time information system to manage its HIV and AIDS programme.*

Mechanisms taken to hinder AIDS progress

Home-based care

Delivering care at home has been a means to support people living with AIDS in Rwanda since the beginning of the epidemic. The formal concept of

home-based care in Rwanda began with a small set of programmes in 2001. In 2003, a more structured set of home-based care (HBC) programmes were launched, and within six months, HBC in Rwanda expanded tremendously.[5]

Although the current set of HBC programmes is relatively new and small in scale, an unofficial estimate suggests that there are up to 30 HBC programmes. Current HBC programmes are primarily financed by international donors, including the U.S. Agency for International Development (USAID), and are established by non-governmental organisations, such as *Médecins Sans Frontieres*, World Vision, Africare, Family Health International (FHI), and CARE International.

Food security and nutritional support tend to be central in responding to the needs of households coping with HIV. In response, USAID, through the Food for Peace Programme and Emergency Food Programme, and the U.N. World Food Programme (WFP) donate supplemental food rations for individuals living with HIV and AIDS and their families. Given the increase in HBC programmes in Rwanda, the government of Rwanda has developed guidelines for home-based care. Guidelines tend to focus on technical concepts of HIV infection and steps for health professionals in assisting people living with HIV and AIDS, including paediatric HIV and AIDS and palliative care. While current guidelines do not extend to discussions of antiretroviral therapy at home and issues of drug resistance, a few programmes have extended to include counselling to discuss ARV treatment adherence, to ensure ARV regimen compliance, and to avoid drug resistance.[6]

The role of Protection and Care for Families against HIV/AIDS (PACFA)

The Protection and Care for Families against HIV/AIDS (PACFA), which has recently marked its five year anniversary, is also playing a big role in HIV and AIDS reduction in Rwanda.

> *PACFA's efforts in the last five years are aimed at ensuring that there are no new HIV infections, poverty reduction and, the development of a highly skilled and educated population.*[7]

An initiative of the First Lady, Mrs Jeannette Kagame, PACFA was created following a summit of First Ladies of Sub-Saharan Africa on children and HIV and AIDS prevention, held in May 2001 in Kigali. The First Ladies at the conference signed '*The Kigali Declaration*', formally committing to mobilise resources to improve the lives and lessen the suffering of vulnerable populations.

HIV and AIDS associations

In Rwanda, people living with HIV and AIDS are creating associations to sensitise the population on how to avoid HIV. These associations are urged to come together and form cooperatives, so as to reap from the advantages that accrue thereto. There is, however, a problem of low income for some of the associations, which would require them to work with the associations that have sufficient funds.

The National Commission against HIV/AIDS (CNLS) has a deliberate policy of helping out the associations, as long as they amalgamate into bigger bodies through which they can access different forms of assistance. Some measures have been taken by the CNLS, in collaboration with the Rwanda Network of People Living with HIV/AIDS (RRP+), after realising that many a time the funds meant for the grassroots AIDS associations do not reach these associations, as they are often used up by their leaders. The decision was taken to create fairness, because different donors give support at different times, which in most cases benefits associations with better access to the donor community, often at the expense of the very remote that may be severely affected by HIV and AIDS.

This system will, therefore, help distributing the resources to all beneficiaries equally. CNLS being responsible for policies on AIDS, will act as a central conduit through which all aid will be coordinated.

Conclusion

A lot has been done to prevent the progress of HIV and AIDS in Rwanda. However, there remains much ignorance about HIV and AIDS, requiring a huge

effort to promote public awareness. Moreover, the ongoing initiatives to put HIV and AIDS at the centre of the world's development agenda, have enormous potential for mobilising the vastly increased political and financial resources required to bring the epidemic under control and to care for affected individuals and communities.

In conclusion, some of the key challenges threatening the adequate response to HIV and AIDS in Rwanda include the following:

- Prevention and behavioural change: Behavioural change remains a barrier and communication messages are conflicting for the youth. Further efforts need to be made for predictable and sustainable financing of the national plan to facilitate universal access. The current national plan proposes to address this issue.
- There is need to enhance access to health services and to promote contraceptive use with a particular emphasis on the dual protection function of barrier methods. The rate of condom use is still very low, (only 2.4 % of the population use condoms);
- The small number and low uptake of voluntary counselling and testing (VCT) for HIV services;
- Urgent need to promote prevention of mother to child transmission (PMTCT), through capacity building;
- Care for people living with HIV and AIDS: Although a national association of people living with HIV and AIDS was recently created, there is little coordination amongst the associations and little external support; and
- Hiring and training health district workers and improving the HIV and AIDS drug distribution mechanism.

FOOTNOTES:

1. Andrew Ward from the *'phone-for-health'* programme, working in partnership with the GSM Association's Development Fund, the US President's Emergency Plan for AIDS Relief (PEPFAR), Accenture Development Partnership, Motorola, MTN and Voxiva, provided invaluable information and comments to the article.
2. See also Kayirangwa, E., Hanson, J., Munyakazi, L. & Kabeja, A. 'Current trends in Rwanda's HIV/AIDS epidemic,' *Sexually Transmitted Infections,* [http://sti.bmj.com/cgi/content/full/82/suppl_1/i27]; Office of the United States Global AIDS Coordinator. 2006. *HIV/AIDS Situation in Rwanda*; WHO. 2005. *Rwanda: Summery country profile for HIV/AIDS treatment scale-up.*
3. For more information go to www.voxiva.net.
4. This system by Voxiva is called TRACnet.
5. See also Chandler, R., Decker C., & Nziyige, B. 2004. *Estimating the cost of providing home-based care for HIV/AIDS in Rwanda.* Partners for Health Reform*plus,* June 2004.
6. See also Ministry of Health. 2006. National guidelines for food and nutrition support and care for people living with HIV/AIDS in Rwanda, Kigali.
7. 'PACFA Marks Anniversary'. In: *The New Times*, February 10, 2007: [www.newtimes.co.rw]

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Kent Klindera, Dumisani Rebombo, Andrew Levack

Fear Factor
Voluntary Counselling and Testing for HIV and Masculinity in South Africa

Clarence's male cousin recently died from HIV. Clarence had never really thought of his own status, because HIV had never really hit so close to home. It was a disease of 'them' not 'us.' In his days, Clarence certainly had numerous partners. Even today, although he has a girlfriend, he also occasionally has sex with other women. He knows he is safe, because his girlfriend was recently tested for HIV and told him she was HIV negative. As long as she continues to test negative for HIV, Clarence is not afraid.

Michelle had been dating Sipho for over three years – never being tested for HIV. They had been trying to get pregnant for many months and finally it happened. Upon Michelle's first anti-natal visit, she was informed that she tested positive for HIV and should consider enrolling iton a PMTCT programme. When she arrived home in deep despair to inform Sipho of her HIV status, Sipho would not believe her story and accused her of infidelity. He subsequently moved out of the house and claims the child can not be his, since Michelle has HIV. Sipho is now refusing to test himself for HIV.

The above scenarios are common in South Africa. Clarence's case is known as '*proxy testing*', whereby one partner (typically male) send their sexual partners (typically female) to be tested for HIV. In Michelle's case, men are abandoning responsibility, because of female partners' HIV status. Why are these scenarios happening? What causes men to not seek voluntary counselling and testing (VCT) services? This article will explore various factors involved in men's lack of utilisation of VCT services, and explore strategies to get more men to take responsibility, get tested for HIV, and seek additional HIV and AIDS-related services when appropriate.

Men and VCT

Examining most data on voluntary counselling and testing (VCT) in South Africa, men are much less likely to be testing for HIV. With an adult HIV-prevalence rate of over 20 percent[1], South Africa's AIDS epidemic is one of the most severe in the world. In 2002, it was estimated that there were 6.5 million people in South Africa living with HIV and AIDS.[2] It is clear that men play a key role in fuelling South Africa's high rates of HIV infection. Over the past several years, numerous governmental and non-governmental organisations in South Africa have adopted large-scale national programmes that target men for HIV prevention. Although efforts to reach men with prevention messages have been established, men's participation in voluntary counselling and testing (VCT) services continues to be extremely low. Recent national studies in South Africa found that only one in five South Africans who are aware of VCT have been tested for HIV[3], and that men accounted for only 21% of all clients receiving VCT[4].

Men's utilisation of HIV testing is of great importance. Research conducted in developed and developing countries has shown that VCT can reduce high risk sexual practices, decrease rates of sexually transmitted infections, and reduce HIV transmission.[5,6] Men's participation in VCT has also been associated with increased support and involvement in prevention of mother-to-child transmission (PMTCT) programmes. A study in Nairobi found that HIV-infected women, whose partners came to the antenatal clinic for VCT, were more likely to receive nevirapine during follow-up, avoid breastfeeding their infant, and report condom use.[7] Men's utilisation of VCT also has implications

for uptake of antiretroviral treatment. A study in Johannesburg conducted between April and June of 2004 reported that women accessing antiretroviral medication outnumbered men by a ratio of 2 to 1.[8] The same study reported that women's CD4 count at initiation of treatment was significantly higher than men's, which suggests that men's reluctance to know their HIV status often leads men to seek treatment only when they become ill.

There have been several studies in South Africa and the region that looked at factors associated with VCT utilisation. A study in a township in Cape Town found that compared to people who had been tested for HIV, individuals who were not tested for HIV demonstrated significantly greater AIDS related stigma.[9] Such stigma included negative beliefs about people living with HIV and AIDS, shamefulness of the behaviour of people with HIV and AIDS, and the endorsement of social sanctions against people with HIV and AIDS.[10] A study of mineworkers in South Africa found that the major identified barriers to VCT were fear of testing HIV positive and potential consequences, such as stigmatisation, disease and death.[11] The same study also found that only 14% of men would be more likely to access VCT, if antiretroviral therapy became available. Focus groups with factory workers in Zimbabwe found reasons for not wanting to test for HIV included confidentiality concerns, fear of death, and stigmatisation. Men who wanted to know their HIV test results cited concern over past risk, desiring peace of mind, and wanting to plan their family's future.[12]

EngenderHealth Men and VCT Study[13]

In 2005, EngenderHealth conducted a study in Soweto, South Africa, to determine causes of the imbalance between men's and women's utilisation of VCT. Five focus groups were carried out with same-sex groups of men and women living in Soweto. Male focus group participants also completed a short survey to determine their HIV testing history and preference for HIV service delivery. Six individual interviews were carried out with men living in Soweto, who had previously tested for HIV. Seven individual interviews were also carried out with women who have participated in PMTCT programmes.

Results from this study, citing the reasons for men not testing for HIV, fell into three realms: individual factors, societal factors and institutional factors. In terms of *individual* factors, the data indicated that fear of one's HIV status was a leading factor inhibiting men to seek VCT. Additional *individual* factors included assuming that a partner's HIV status is one's own, no value seen in knowing one's HIV status, and no sense of vulnerability to HIV. *Societal* factors that contributed to men not utilising VCT included stigma and men's gender socialisation. *Institutional* factors included poor treatment by nurses and confidentiality concerns.

Examining the lead individual factor of ***fear of one's HIV test results,*** which is related to the societal factor of stigma, highlighted various issues linked heavily to issues of gender. These fears included fear of the stigma associated with HIV and AIDS, fear of death, as well as the fear of being seen as weak. Indeed, traditional gender roles portray men as strong and risk takers. Men and boys are told not to cry; not to share their emotions; and not to show that they are in pain. Thus, if a man is suffering from an illness, he is perceived to be less of a man and more like a weak woman. Thus, testing for HIV would be a sign of weakness, especially if a man is to be open about his HIV positive status. As is quite common, men who are living with HIV and AIDS often wait too long to seek treatment (often too late), as they fear being emasculated. During this waiting period, or should it be called a '*hiding period*', most men hide their fears. These men pretend to be strong and come up with various excuses to not seek care, such as the clinics and hospitals are not '*male-friendly*'. In fact, it is often argued that the clinics are not '*human friendly*', yet, women continue to utilise these services.

EngenderHealth/Men as Partners (MAP) Response

Clearly, a new form of masculinity is needed. As mentioned above, traditional gender roles limit men's involvement in HIV and AIDS efforts. However; clearly men are needed to be involved. To address these discrepancies, EngenderHealth implements the Men as Partners (MAP) programme. MAP is a global initiative designed to work with men on HIV and AIDS and reproductive health issues within a gender framework.

MAP is based on the realisation that current gender roles give men the power to influence women's reproductive health; that these roles put men at risk by associating risky health practices with manhood; and that men have women's vulnerability to HIV and AIDS and placing the burden of care and support for people living with AIDS squarely on women's shoulders. In the service of promoting gender equality and protecting women from HIV and AIDS, MAP draws the connections between sexism and racism and other forms of oppression, and strives to get men to see the ways in which gender equality is a fundamental human right of comparable importance to those fought for during the anti-apartheid years. This approach connects gender equality to South Africa's rich tradition of social justice activism and situates it squarely within human rights discourses and traditions embraced by most South African men. Many MAP educators come from activist backgrounds and apply their expertise to devising strategies that get men to take a proactive stand for gender equality and against women's oppression.

a positive role to play in improving their own health and the health of their families. It also addresses factors that inhibit men's health themselves.

MAP began in South Africa in 1998 through a collaboration between EngenderHealth and the Planned Parenthood Association of South Africa (PPASA). The programme involves running workshops with men, training male '*transformation agents*' (e.g. peer educators), raising community awareness related to gender and sexual and reproductive health (SRH), mobilising community to take action, and working to modify and establish just policies that work to support MAP goals.

MAP uses a human rights framework to enable men to recognise the ways in which contemporary gender roles mirror the oppressive relations of power characteristic of Apartheid. This oppression has devastating health consequences for women, placing them at risk of violence, limiting women's ability to negotiate the terms and conditions of sex and severely compromising their sexual and reproductive health, including increasing

Specifically related to HIV and AIDS, MAP recognises that contemporary gender roles can compromise men's sexual and reproductive health by encouraging men to equate a range of risky behaviours – the use of violence, alcohol and substance use, the pursuit of multiple sexual partners, the domination of women – with being manly, while simultaneously encouraging men to view health-seeking behaviours as a sign of weakness. A number of studies demonstrate clearly that such gender roles leave

men especially vulnerable to HIV infection, decrease the likelihood that they will seek HIV testing, and increase the likelihood of contributing to actions and situations that could spread the HI virus. Noar and Morokoff (2001) have documented the effects of '*masculinity ideology*' on condom usage and sexual and reproductive health in general and indicate that traditional men's gender roles lead to '*more negative condom attitudes and less consistent condom use*' and promote '*beliefs that sexual relationships are adversarial*'.[14]

Similarly, a recent study of antiretroviral treatment in Johannesburg[15], conducted between April and June of 2004, reported that women accessing ARVs '*outnumbered men by a ration of 2 to 1*'. This same study reported that women's CD4 count at initiation of treatment was also significantly higher than men's (100 cells/µl in women and 85 cells/µl in men) and concluded by saying:

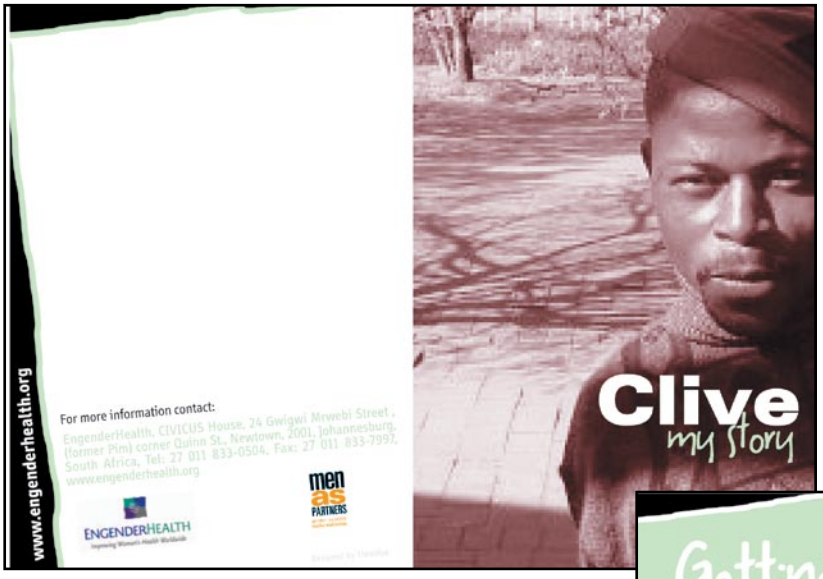
> *The observation that two thirds of patients were female, with 23% of women referred from prevention of mother to child transmission programmes, underscore the need for programmes that target HIV-infected men.*[16]

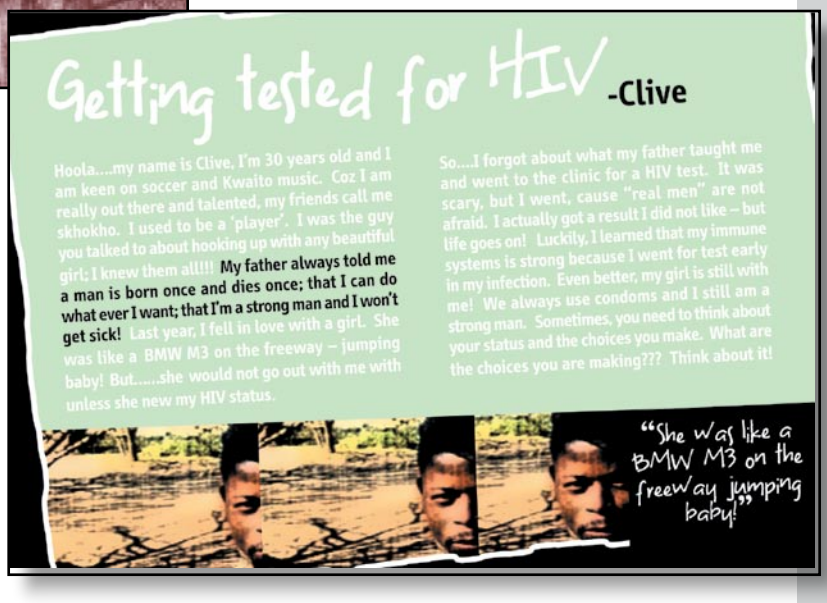
These findings were similar to those reported on in a study of VCT uptake in the Khayelitsha clinic outside Cape Town, South Africa, where 70% were women.[17]

Behaviour Change Community Strategies/ Picture Story Cards

MAP integrated behaviour change communication strategies into its efforts to assist men in redefining masculinity. A key aspect of behaviour change is motivation. Thus, MAP focuses on methods to motivate men to take action for change. Specifically related to VCT, EngenderHealth is focusing on the '*fear factor*' to convince men to not be afraid – and overcome the fear factor. Thus, one campaign MAP has utilised is the concept of '*strength*', with the tag line of '*My Strength is not for Hurting*'. Working in partnership with the Western Cape Office of the Premier and a US-based NGO Men can Stop Rape, EngenderHealth/MAP has a poster campaign encouraging men to show their strength by getting tested for HIV.

Similarly, EngenderHealth/MAP, in partnership with the United Nations Development Fund, is employing an additional strategy utilising '*picture story cards*'. These cards detail personal stories of men and women dealing with issues of HIV and AIDS and gender-based violence. The cards are based on true stories, and work to motivate men to be more responsible. They are based on the reality that men are supposed to be brave and strong – thus, men should be able to face their fears and get tested for HIV; or stop harassing women. The cards work to motivate men





(and women) to take action related to HIV and AIDS, including VCT, and gender-based violence. Based on the MAP methodology, the cards utilise social learning theory to motivate men to redefine masculinity – with emphasis placed on achieving gender equality. The cards, amongst other things, address issues of confronting fears related to getting tested for HIV; sharing housework with partners; reducing sexual harassment and child sexual abuse; and accepting gay and lesbian people.

EngenderHealth and its MAP programme partners will continue to address the ***fear factor*** related to men and VCT. For too long, men have left themselves behind in the gender movement. It is time that men take more action to limit the spread and impact of HIV and AIDS and gender-based violence. One way to act is to get tested for HIV and to take responsibility.

Hopefully, men like Clarence and Sipho mentioned above have read this article and are reconsidering their actions. Please help us in spreading the message.

FOOTNOTES:

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