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Sex and Sexuality
in the context of HIV and AIDS

South Africa has one of the most progressive constitutions in the world, yet the reality of life in South Africa often does not live up to these ideals. Examples of continuing inequality and discrimination are especially evident around issues of sex and sexuality in the context of HIV and AIDS.

DEFINING SEX AND SEXUALITY

Sex[1] in its simplest form is a physical act. In sub-Saharan Africa it is also the most common way that HIV is spread. Yet, how sex is defined beyond these facts leads into the realm of meanings and assumptions. Existing sex education materials indicate that sex is about vaginal, heterosexual, consensual sex between two people. Many religious teachings portray sex as a means of procreation. Women's magazines talk about sex in terms of pleasure and orgasm with a male partner. In addition, high prevalence of sexual assault in South Africa also indicates that for some, sex is not consensual and has more to do with power. While these are only a few examples of ideas and meanings about sex and the purpose of sex, it highlights the difficulty in defining sex.

Constitutionally guaranteed rights, such as the right to be treated equally and not to be discriminated against on grounds of gender, sex and sexual orientation (Constitution[2], Section 9); the right to freedom and security of the person, including the right to bodily and psychological integrity, the right to make reproductive choices, as well as the right to security in, and control over, one's body (Constitution, Section 12); and the right to inherent dignity (Constitution, Section 10) arguably indicate that everyone has the right to choose where, when, how and with whom they engage in sexual activity. Yet, Cornell, Reid and Walker [2003:22] argue that in the South African context

> *Sex is social – whom we have sex with, how and where we have sex, our views about sexual morality and even the objects of our sexual desire are not necessarily individual choices. The environment in which we live influences the extent to which we are able to control these choices.*

The societal context determining the choices about why, where, how and with whom to engage sexually, also defines the understanding and meaning of sexuality. A definition taken off a website specifically geared towards teenagers exploring questions around sex defines sexuality as:

> *…Referring to the interplay of physical, psychological, social, emotional, and spiritual makeup of an individual. It also encompasses gender, gender role, gender identity, sexual orientation, sexual preference, and social norms as they affect physical, emotional, and spiritual life.*[3]

This definition goes beyond common assumptions and limitations that sexuality merely refers to what some people call

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Editorial

> *The toll on women and girls...presents Africa and the world with a practical and moral challenge, which places gender at the centre of the human condition. The practice of ignoring gender analysis has turned out to be lethal.* (Stephen Lewis, 2002)

It is the very *'toll on women and girls'* that seems to be the persistent challenge in addressing and responding to HIV and AIDS realities. Infection rates remain to be on the rise, prevention messages seem to bypass the ones it is meant to *'protect',* stigma and discrimination experienced by people living with, and affected by, HIV and AIDS prevail, instead of subside – and it is women and girl children who remain, and are increasingly, the ones who are disproportionately impacted and affected by the pandemic.

It is within this context of the persistent feminisation of the HIV and AIDS pandemic that this double edition of the *ALQ* focuses on gender, sex and sexuality in the context of HIV and AIDS. The various articles in this issue examine a broad range of realities as to the extent to which the gendered societal context, including the meaning and understanding of *'appropriate'* and *'acceptable'* sex and sexuality, indeed addresses and/or perpetuates the feminisation of the HIV and AIDS pandemic. The ABC prevention message, virginity testing, the meaning and understanding of sex and sexuality, adherence to PEP following sexual assault, the role of HIV and AIDS communication, and ethical considerations in narrative research, as well as proposed changes to the sexual offences legislation as it impacts on the criminalisation of non-disclosed sexual exposure to HIV and AIDS, and on the LGBT community are some of the issues explored in this edition. This issue also continues with the integral features of the *ALQ,* introducing HIV and AIDS realities and challenges from Zimbabwe, experiences from Vulindlela, a village in KwaZulu Natal, and *'making a point'* about Christian responses to HIV and AIDS.

In this issue, **Emma Harvey** and **Johanna Kehler** explore the meaning and understanding of sex and sexuality, as well as various myths and realities of sex and sexuality in the context of HIV and AIDS. Recognising the moralisation and judgement of sex and sexuality, the article argues that as long as sex and sexuality is not de-moralised and free of judgement, sexual choices, including the choice to prevent HIV infection, will remain limited, whilst judgement leading to stigma and discrimination, as experienced by people living with, and affected by, HIV and AIDS, will continue.

The proposal of the Children's Bill to prohibit virginity testing of children has caused heated debates on the *'pros'* and *'cons'* of such practice with both sides invoking the violations of rights, as well as referencing the HIV pandemic. **Carol Bower** introduces a rights based position to virginity testing and raises the question as to why *'virginity'* is such a *'hot issue'*. She argues that virginity testing of children is not only a gross violation of children's rights, but also counter-productive in that virginity testing exacerbates children's vulnerability.

Acknowledging increasing HIV infection rates, especially amongst women, **Rachel Elfenbein**, examines the meaning, interpretation and impact of the ABC prevention message. She looks at the 'A', 'B' and 'C' of the prevention message raising questions as to its adequacy and argues that as long as gendered inequal ties and imbalances are not taken into account, the ABC prevention message will perpetuate the spread of HIV.

The potential of proposed sexual offences legislation to address the persistent discrimination of the LGBT community is discussed by **Evashnee Naidu**. Examining various proposed changes to the current legislation, she argues that while non-discriminatory legislation might soon be in place, it can possibly not impact on prevailing societal prejudices, and/or application and implementation of the law, which would, in reality, afford lesbians and gays equal protection by the law.

Sadiyya Haffejee introduces research findings from a study exploring factors that influence adherence to post exposure prophylaxis following sexual assault. She argues, that factors influencing adherence to PEP are complex and thus, adherence is as much dependent upon the skill, knowledge and attitude of health facility staff, as it is dependent upon the individual characteristics of the rape survivor and the support received.

The extent to which the criminalisation of non-disclosed exposure of HIV and AIDS, as proposed by the Sexual Offences Bill, could assist in the diffusion of HIV and AIDS, is examined by **Johanna van Rooij**. She explores various arguments for and against such criminalisation and argues that in light of HIV related stigma, the criminalisation of HIV-related behaviour might not only exacerbate stigma, but also would not serve the purpose intended with such a criminalisation.

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sexual identity, or sexual orientation, or identifying as lesbian, gay, bisexual or transgender (LGBT). It defines sexuality as encompassing the physical act itself, as well as perceptions, beliefs and behaviours towards the physical act.

The above highlights the extent to which the societal context largely determines the meaning of sex and sexuality. This very same societal context further describes *'appropriate'* sex and sexuality and, thus, limits individual choices accordingly. However, the one common factor amongst all the variety and diversity of understandings about sex and sexuality seems to be the paradigm of patriarchy. A paradigm that not only defines men as holding power in relationships, both on an interpersonal and societal level, but also determines different behavioural norms around sex for women and men and that defines sex as heterosexual, resulting, amongst other things, in a gender bias that is unfavourable to women. This patriarchal paradigm further contradicts the understanding of equality as enshrined in the Constitution that everybody is equal and therefore deserves equal treatment, irrespective of one's gender, sex and/or sexual orientation.

...still a challenge for many men that a wife has the right to refuse sex to her husband, it seems to be equally challenging for many wives to have the right to make her own decisions...

This unequal power between women and men is often expressed in sexual relationships and is further related to the societal context determining the extent to which individuals are in the position to make sexual choices, and to enjoy the right to choose when, where and with whom to engage in sexual activity. When gender roles are determined by patriarchy, then it is mostly men who determine the decisions about sex and sexuality. Thus, it is the patriarchal way of thinking that largely determines gender norms and, subsequently, defines the kind of sexual choices women and men can make.

MYTH VERSUS REALITY

In the context of manhood and its meaning, Cornell, Reid and Walker [2003:26] argue:

> *How do men prove their manhood? A number of case studies undertaken in Southern Africa identify dominant behaviour in men. These include … exercising control over women, coercive sex… Of course, not all men behave in this way.*

It could be argued that *'manhood'* is also largely defined by sexual promiscuity, to always be ready for, and say yes to, sex, while for the majority of girls and women what seems mostly valued is *'purity'* and *'virginity'*, and girls and women are encouraged to say *'no'* to sex as a way of remaining *'good girls'*. This seems to indicate that issues of sex and sexuality are largely *'taboo'* for women, while for men sex and sexuality define their manhood, which is further, as mentioned earlier, often based on dominating women both socially and sexually.

The practice of *'dry sex'*[4], where women often use herbs to ensure that there is no lubrication – a natural reaction to sexual stimulation – during sex, is, arguably another example of gendered definitions of sex and sexuality. This practice seems to indicate that women are not to show, or have, any pleasure from the sexual encounter. In addition, this also impacts on women's physiological vulnerability to HIV infection, since *'dry sex'* creates more friction, more tears in the thin skin lining the vaginal walls creating openings for seminal fluids, that might contain HIV, to enter a woman's bloodstream.

Another example is the notion that men have a *'right'* to their sexual pleasure, whenever and as often as deemed necessary. One implication of this is the myth that *'men just cannot control themselves'*, implying that *'it is not their fault'* if they *'force'* sex onto their partner. The unequal power during these encounters does, however, raise the question as to the ability to negotiate condom use. In other words, as long as beliefs, such as men have full rights over the bodies of *'their'* women, prevail, women's ability to negotiate safer sex remains limited. While it seems to be still a challenge for many men that a wife has the right to refuse sex to her husband, it seems to be equally challenging for many wives to have the right to make her own decisions about safer sex and reproduction. Or, as stated in the 2005 State of World Population Report [2005:45]: *'Studies show that married women would often rather risk infection than ask their husbands to use a condom'*.

Cornell, Reid and Walker [2003:22] argue that *'sex is also about power – who initiates sex, who makes the decisions… these decisions are contested because relationships between men and women are unequal'*. While this unequal power may play out in encounters of consensual sex it seems to be more often the case in non-consensual sex, since *'non-consensual sex is an abuse of power commonly rooted in gender norms – societal assumptions and expectations about what it means to be male or female'*[5].

In South Africa, statistics on rape vary from 52000 reported cases a year (police records for girls and women only) to 1.69 million (SA Law Reform Commission)[6]. The reality is also that the majority of survivors of these assaults are women, and

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The need for ethical considerations as the core of narrative research with women who are infected and affected by HIV and AIDS is discussed by **Sunnette Pienaar**. She argues that while the narrative approach to research facilitates a process for women, infected and affected by HIV and AIDS, to speak out and tell their stories, it also needs to facilitate a process of re-evaluating oneself, for the process to be ethical.

The role of HIV and AIDS communication as a means of addressing and/or perpetuating the feminisation of the pandemic is explored by **Lene Øverland**. Analysing mainstream media as to how HIV and AIDS is portrayed and as to who owns and who accesses mainstream media, she argues that a two-way communication, as provided by a few alternative media interventions, not only opens the dialogue between sender and receiver, but is also crucial to HIV and AIDS communication aiming to address HIV and AIDS realities and challenges.

Vulindlela, a rural community in KwaZulu Natal, is introduced by **Lilian Mboyi**, through sharing challenges experienced, both personal and professional. She explores various challenges of the rural community, discusses some of the core findings of research conducted in the area and argues that there is hope for the future, since HIV treatment is becoming a reality.

Miriam Madziwa introduces HIV and AIDS realities and challenges in Zimbabwe. Looking at the economic meltdown, Operation Murambatsvina, falling health care standards and raising medical costs, voluntary counselling and testing, sexual violence, and the role of the media, she argues that it is women and girl children who are disproportionately infected and affected by HIV and AIDS in Zimbabwe.

'Making a point' about Christianity, **Barbara Schmid** explores Christian responses to HIV prevention and caring for people infected and affected by HIV and AIDS. She raises questions as to the adequacy of the Christian response and argues that while a lot has been achieved, a lot more needs to be done, especially pertaining to prevention, to stigma hindering adequate prevention, and to orphans and vulnerable children.

Looking into and exploring various gendered realities, it seems, once again, confirmed that without taking into account the persistent gendered inequalities and imbalances, the *'toll on women and girls'* will persist, HIV prevention messages will continue to fail the ones most vulnerable and at risk, and thus, the feminisation of the pandemic will continue. The recurring argument seems to be that the feminisation of the pandemic manifests itself in all realities; that the feminisation of HIV and AIDS is as much prescribed by gendered behaviours, attitudes and practices, as it is institutionalised; that the moralisation of sexual behaviour and subsequent prescription of *'appropriate'* sexual behaviour is not only further marginalising the already marginalised, but also seemingly justifying the *'exclusion'* of the ones who portray *'inappropriate'* sexual behaviour; and that the feminisation of the pandemic is not due to a lack of a constitutional and legislative framework, but rather due to the resistance and/or failure to challenge the gendered societal context.

If we are to agree that gender is *'at the centre of human condition',* then '*gender'* cannot be addressed in isolation or in a vacuum ignoring, and constantly failing to take into account, realities marked by gendered inequalities, imbalances and injustices leading to, and justifying, the very same feminisation of the HIV and AIDS pandemic. Recognising the need to challenge the gendered context of society, the status quo, thus, implies that the very *'centre of human condition'* has to be challenged and transformed in order to be in the position to begin the reversal of the *'lethal'* outcome of the gendered nature of society. Meaning, understanding and interpretations of *'gender'* and its reflection in core beliefs of what is *'appropriate'* and *'good'* behaviour, including sexual behaviour, seems to be the *'human condition'* in need of re-evaluating, addressing and challenging.

Thus, if we are to address the *'toll on women and girls',* the feminisation of the HIV and AIDS pandemic, the societal gendered prescription of behaviour and core beliefs, limiting not only individual choices, but also the access and realisation of fundamental rights and freedoms accordingly, needs to be challenged and transformed into a concept based on equality and human dignity, irrespective of one's sex, gender, sexuality and/or choice.

If we fail to challenge the status quo, the very same gendered context of society will continue to prescribe who, how, when, where and why people are vulnerable to, and at risk of, HIV infection – and thus, prescribe women and girls to be the ones who are most vulnerable to, and at risk of, HIV infection, the ones who are disproportionately impacted and affected by HIV and AIDS realities, the ones for whom fundamental rights and freedoms have little or no impact in their lives – the feminisation of the HIV and AIDS pandemic continues...

JOHANNA KEHLER

the majority of the perpetrators are men. Sexual assault clearly violates a person's right to be equal, their physical and psychological integrity, their right to control what happens to their body, and their inherent dignity, as much as it negates the possibility of negotiating safer sex and, thus, plays a significant role in the spread of HIV.

The spread of HIV through sexual encounters, both consensual and non-consensual, is further aggravated by gender-based power imbalances. Gender roles limiting women's ability to make sexual choices also determine that girls and women are often more impacted by HIV and AIDS infections. The 2005 State of World Population Report estimates that 57% of people living with HIV in sub-Saharan Africa are women. In South Africa, the HIV prevalence rates are 23.5% amongst women, as compared to 18.1% amongst men[7]. In addition, patriarchal defined gender roles also place women in the position of primary caregivers and, thus, girls and women are more affected by the spread of the virus. In other words, the societal context determining the extent to which women are in the position to take control over, and make, sexual choices also defines women as the ones bearing the brunt of the impact of the lack of choices and, thus, the brunt of the HIV and AIDS pandemic.

...the majority of women, who contract HIV, contract the virus within a marriage or long-term relationship, where women have not engaged in extra-marital sexual activity.

Most of the beliefs and examples above seem to relate to sex as heterosexual vaginal sex, an understanding further strengthened in sexual education material, meant to assist in preventing the spread of HIV. Prevention messages, such as ABC (**A**bstain, **B**e Faithful, **C**ondomise) are, subsequently, largely based on this narrow definition of sex, and often emphasise the 'A' and 'B', creating the idea that sex is only safe within marriage. Educational materials, based on such a definition of sex, not only fails to take into account unequal gender relationships and gender violence, but also, arguably, discriminates against people, who engage in sexual activities other than the one described as *'norm'*. Such narrow understanding of sex seemingly also fails to take into account that marriages are not necessarily monogamous, especially in a societal context in which multiple wives and/or sex partners are culturally and religiously sanctioned[8]. In addition, commonly available educational material aimed at preventing the spread of HIV through safer sex messages are based on the assumption that the sexual encounter will be one of vaginal penetration. Once again, this discriminates against people, who choose to engage in sexual activities other than heterosexual sex and/or vaginal penetrative sex.

The above clearly indicates that the societal context determining sexual choices is the same societal context prescribing the *'norm'* of what sex is *'supposed'* to be and the why, how, when and with whom to engage sexually. Thus, individual sexual choices are, arguably, limited to the choice of whether or not to *'conform'* to the *'norm'* and to be treated and *'judged'* accordingly.

In other words, the societal context defining sex and sexuality also seems to define the *'norm'* of sex and sexuality. Further, the *'norm'* seems to be not only based within a moral context of *'good'* and *'bad'* and, thus, often leads to the perpetuation of ideas that sex is *'dirty'*, *'no good'* and *'shouldn't be enjoyed'*, and that sex is *'wrong'*, *'a sin'* and *'punishable'*. Again, these ideas also contribute to the taboo, secrecy and shame around sex and sexuality. The moralisation and judgement of sex and sexuality also create ideas about what is *'good'* and *'okay'* sex, and/or what is *'bad'* and *'wrong'* sex. These ideas of *'good'* and *'bad'* often differ between women and men and are least favourable to people *'outside'* the patriarchal paradigm, such as women, unmarried sexually active people and/or people who identify as LGBT, resulting, amongst other things, in discrimination, marginalisation and a lack of freedom to make informed choices.

The moralisation and judgement of sex and sexuality impact greatly on people who are living with HIV and AIDS. Since the most common form of HIV transmission is through sex, and sex is seen as *'shameful'*, the perception created is that HIV is a *'shameful disease'*. This perception reinforces not only the idea of sex as *'bad'*, when engaging in sex could be life-threatening, but also the idea that sexually active people, especially the ones sexually engaging outside the *'norm'*, in some ways *'deserve'* to contract a life-threatening disease. In the context of HIV and AIDS, added to the idea of *'good'* and *'bad'* sex, is the idea of *'safe'* and *'unsafe'* sex. Often, the two are collapsed, *'good'* sex is *'safe'* sex, or no sex at all, and *'bad'* sex is *'unsafe'* sex, or sex outside the *'norm'*.

As a result, the most common assumption seems to be that a person must have contracted HIV through *'bad'* sexual behaviour, furthering the discrimination and stigma that is all too prevalent for people living with HIV and AIDS. And this assumption prevails, despite the fact that numerous research findings indicate that the majority of women, who contract HIV, contracting the virus within a marriage or long-term relationship, where women have not engaged in extra-marital sexual activity.[9] Yet, the stigma and discrimination remain.

Stigma and discrimination might not be mere judgements. Judgements can often lead to action, and have potentially life-threatening consequences. Mkhize[10]

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discussed the various ways in which access to appropriate health care is influenced by sexuality and being identified as LGBT. Judgements about who has the right to have sex with who, can also lead to violation, not only of the right to be free from discrimination, but also the right to physical and psychological integrity. Incidences of black women who are raped and assaulted, because they identify as lesbians; and a boy punishing his girlfriend for alleged infidelity by organising an *'istimela'* or gang rape are only two of the examples highlighting consequences of judgements pertaining to sex and sexuality.[11]

CONCLUSION

The underlying factor highlighted is the extent to which the moralisation of sex and sexuality violates fundamental human rights, such as the right to equality and non-discrimination and the right to human dignity. By judging what is *'right'* and *'wrong'* sexual behaviour, the right mostly violated is, arguably, the right to be respected and to be treated equally, irrespective of one's choices.

The fundamental issue seems to be the prevailing gendered inequalities and imbalances, as well as discrimination on the basis of one's sex, gender, HIV status and/or sexual orientation, limiting one's space to realise rights around sex and sexuality. Social norms and the gendered societal context determining women's ability to make their own choices, need to be challenged, since, as argued in the 2005 State of World Population Report [2005:7], *'the ability to make free and informed choices in reproductive life...underpins self-determination in all other areas of women's lives'*.

In addition, it is the prevailing moralisation and judgement of sex and sexuality, as well as assumptions about what is *'good'* and *'bad'* sex and sexuality within the patriarchal paradigm that need to be challenged. Challenging the moralisation and common assumptions about *'good'* and *'bad'* sex, may also lead to changing the models and framework of sex education, encouraging people to make fully informed choices about sexual activities and safer sex, in an environment free from judgement and discrimination.

Unless the notions of sex and sexuality as *'taboo'* and *'shameful'* are challenged, the realisation and enjoyment of the right to like, enjoy and explore sex and sexuality, the principles outlined in South Africa's Sexual Rights Charter[12], will remain limited accordingly.

Lastly, challenging the discrimination, marginalisation and inequalities, as well as the lack of respect for choices pertaining to sex and sexuality will also help to diminish the stigma of people living with HIV and AIDS and contribute to the realisation of the right to equality for everyone, irrespective of one's choices.

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FOOTNOTES:

[1] It must be noted that sex in this article refers to sexual activity and not sex as in biological attributes that determine whether a person is a woman or a man.

[2] The Constitution of South Africa, Act 108 of 1996.

[3] http://www.coolnurse.com/sex_glossary/glossary_s.htm

[4] van der Poll, L. 2003. *'Formulating an appropriate legal response to dry sex and virginity testing within the discourse on sexuality and human rights in Africa'*. Paper presented at the Sex and Secrecy Conference. 20 – 25 June 2003. South Africa.

[5] *'Youth lens: Gender norms underlie sexual coercion'*. (http://fhi.org/en/RH/Pubs/Network/v23_4/index.htm)

[6] Smith, C. 2005. *Keeping it in their Pants: Politicians, men and sexual assault in South Africa.* Harold Wolpe Memorial Lecture, 17 March 2005, University of KwaZulu-Natal.

[7] 2005 State of World Population Report.

[8] 2005 State of World Population Report.

[9] Hamblin, J. & Reid, E. 1999. *Women, the HIV Epidemic and Human Rights: A Tragic Imperative.* UNDP HIV and Development Programme, Issues Paper No. 8.

[10] Mkhize, N. 2005. 'Homophobia is supposed to have no place'. In ALQ, June 2005.

[11] Cornell, M., Reid, G. & Walker, L. 2003. *Waiting to Happen.* Cape Town: Double Storey. p 28.

[12] *South Africa's Sexual Rights Charter*. Women's Health Project.

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Carol Bower

Virginity Testing: In whose interest?

The Children's Bill[1], read for the second time in Parliament on 22nd June 2005 and approved by the National Assembly on that date, contains one short clause that has caused a furore. Section 12(4) states that *'Virginity testing of children is prohibited'*.

The ones for and against the practice have engaged in heated exchanges on the issue, and the range of arguments made on both sides of the debate is broad. Both invoke the violation of rights in support of their views and both reference the HIV pandemic. However, neither side pays more than passing attention to the issue of *WHY* virginity is such a *'hot issue'*. Yet, it is this very issue – the why of it – that is central to RAPCAN's position with regard to virginity testing.

It must also be noted that the ones who claim that *'virginity testing has been banned'* are incorrect – the Children's Bill is relevant only for children, which it defines as human beings under the age of 18. And it is the Children's Bill which has banned virginity testing of children.

THE RIGHT AND PROPER 'PLACE' FOR CHILDREN

South Africa, through the ratification of a number of international treaties and conventions, is obliged to recognise and protect the rights of children, and promote their realisation. Principally, these are the United Nations Convention on the Rights of the Child (CRC), ratified by South Africa in June 1995 and the African Union Charter on the Rights and Welfare of the Child (the Charter), ratified in 2000. The rights to survival, development, protection and participation, and the *'best interest'* principle, are considered to be fundamental to the CRC, and there are many areas of congruence between it and the Charter.

The Constitution of South Africa[2] guarantees the rights of all South Africans (including children), and Section 28 concerns the special rights of children. Numerous pieces of domestic legislation also focus on the rights of children, at least in sections. These include the South African Schools Act (No 84 of 1996), the Domestic Violence Act (No 116 of 1998), the Choice on Termination of Pregnancy Act (No 92 of 1996), the Children's Bill (2003), the Criminal Amendment (Sexual Offences) Bill (2003) and the Child Justice Bill (2002). In addition, a number of policies intended to give effect to the rights of children have been developed.

Despite these various pieces of legislation and policy, the reality remains that the rights of children in South Africa are in general protected, neither in the homes nor in the communities in which they live, and, it is our experience at RAPCAN, that there is a poor understanding of the inalienable nature of children's rights in society at large. A common comment that we hear is *'the problem with children today is that we have given them too many rights'*. Such a comment is arguably based on the failure to understand that children are bearers of rights in their own right, which also lies at the heart of the virginity testing debate (and others, such as that around corporal punishment in the home). Notions of children as owned by their parents and of their virginity status as representing the *'honour'* of their families, lie behind the insistence of knowing whether or not the hymen is intact.

It remains true in South Africa that women's status is largely determined by their relationship to men – father, husband, brother or son. For this system to work, it is absolutely necessary to know to whom each child born *'belongs'* – i.e. who is that child's father? And the only way to be sure of that, throughout most of human history, has been to be sure of who has had the opportunity to impregnate the mother. Which means she must remain a certifiable virgin until her husband claims her. Which is why her virginity needs to be *'tested'*.

THE RIGHTS POSITION

Supporters of the practice of virginity testing (mainly traditional leaders in the Eastern Cape and KwaZulu Natal) have interpreted the ban contained in the Children's Bill as a violation of the right to practice one's culture (Constitution, Section 31). The ones against define virginity testing as a violation of the right to protection (Constitution, Section 28(1)(d)), the right to privacy (Constitution, Section 14), the right to dignity (Constitution, Section 10), the right to bodily integrity (Constitution, Section 12) and the right to equality (Constitution, Section 9). Both sides have invoked the rights position.

The rights of all South Africans, including South African children, are protected by the Constitution of South Africa. In general, the rights outlined in the Constitution are not absolute, and provision is made for the limitation of rights, in Section 36, which provides criteria for the limitation of rights and guidance on decision-making in this regard[3]. Clearly, the rights of children and others to practice their cultural traditions and participate in the cultural life of their communities need to be balanced against the right to protection, to privacy, to bodily integrity and to equality. However, at RAPCAN, we are of the opinion that these decisions need also to be informed by an understanding of WHY it seems so important that women are virgins until they marry, and the underlying ownership, power and control issues that are relevant here.

RAPCAN believes that a number of rights are violated by the practice of virginity testing.

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The right to equality [Section 9]

Given the underlying reasons for virginity testing (related to a degree of certainty about the paternity of a woman's children), it is not surprising to find that it generally applies only to women. Advocate Tseliso Thipanyane quotes a newspaper report which claims that there is a virginity test for boys[4], and that the virginity of both young men and young women is prized[5]. However, the test for boys is entirely non-invasive, unlike that for girls. Sanctions against men who engaged in pre-marital sex are focussed more on whether or not the woman/girl was a virgin at the time of the seduction, rather than on the virginity status of the man/boy. For an unmarried man, an active sex life is confirmation of his masculinity[6]; for the woman, it reduces her 'bride-price'. It can also, and often has, threatened her life.

This clearly indicates that the practice of virginity testing violates the right to equality.

The right to dignity [Section 10]

Virginity testing involves an investigation of whether or not the hymen is intact. However, the presence or absence of the hymen does not necessarily relate to whether or not one has engaged in penetrative sex. The hymen can and does break because of tampon use, or physical activity; some women are born without one[7]. Thus, the presence or absence of the hymen is not a fool-proof indicator of *'virginity'*. To be identified as a non-virgin, is to be exposed to stigmatisation and ridicule, both during the ceremony and afterwards.

Both the public invasion of privacy necessitated by the virginity test itself, and the public humiliation which is often the consequence of it's *'findings'* constitute a violation of the right to dignity.

The right to bodily integrity [Section 12]

The ones who support the practice of virginity testing claim that girls who are inspected have consented to be tested. Considering the expectation that girls must *'willingly'* allow virginity testing, and if they do not, they have something to hide, clearly indicates that this is not really informed and willing consent.

The common understanding is that a refusal is construed as evidence of being sexually active, while families are seen as being *'honoured'* by the virgin status of the unmarried women and girls within their household. The social pressure to undergo the test mitigates any choice in the matter for the girl or woman concerned.

Under these circumstances, the right to security in and control over one's body is violated.

The right to privacy [Section 14]

Both the testing of virginity and the communication of the results of the test are very public events. Considering the significant negative consequences of being identified as a non-virgin, such public disclosure can place the girl or woman at considerable physical and emotional risk. It really is a *'Catch-22 situation'* – if she refuses the test, she is suspected of *'improper'* conduct, if she takes it and fails, she is guilty of *'improper'* conduct.

To be identified as a non-virgin, is to be exposed to stigmatisation and ridicule, both during the ceremony and afterwards.

Either way, she is publicly humiliated, devalued, and placed at physical and emotional risk.

This public exposure violates the right to privacy, with frequently devastating consequences.

The right to protection [Section 28(1)(d)]

The rate of rape in South Africa is alarmingly high and rising. The rape of young children is a particular problem[8]. Government has committed itself to combating the sexual abuse of children, and NGOs also play a vital role in this regard. Much of the work being done to raise awareness of abuse among children as a prevention strategy focuses on recognising, rejecting and reporting touching of their genitals, even when the person doing the touching is stronger and more powerful than the child.

> **In a society with high levels of gang-related activities, where the rape, and even murder, of a virgin forms part of the initiation of gang members, public identification of virgins could become a death sentence.**

Virginity testing undermines this strategy and the contradiction of the instructions to children for their protection can and will confuse children. It, undoubtedly, also renders children more vulnerable to sexual abuse.

Children, identified as non-virgins, are exposed to physical and emotional danger, as has already been shown. Additionally, children who have been sexually abused and who are identified as non-virgins face increased risks of abandonment, rejection and violence[9].

Children identified as virgins are also at risk. Given the premium that most societies place on virginity, their *'value'* in terms of potential exploitation and possible trafficking is linked to their virgin status. In a society with high levels of gang-related activities, where the rape, and even murder, of a virgin forms part of the initiation of gang members, public identification of virgins could become a death sentence.

Children and young girls who are at risk of not passing a virginity test have been known to take steps which endanger their health to convince the testers that they are virgins. These measures include the insertion of meat and other foreign objects into the vagina[10]. There is also evidence that girls resort to anal sex in order to preserve the hymen[11]. Many virginity testers neither use gloves nor wash their hands between 'testing' – with the related risk of transferring infections between the ones being tested.

Hence, it is argued that the practice of virginity testing not only exacerbates vulnerability, but also violates the child's right to protection.

CONCLUSION

It is RAPCAN's position that virginity testing violates a number of rights, and places girls at risk of physical, emotional, and sexual abuse. These risks outweigh the considerations related to the right for communities and individuals to participate in and practice their culture. RAPCAN, thus, supports the ban on virginity testing for people under the age of 18.

However, it is also RAPCAN's position that the underlying issues related to the importance given to virginity in our society should be confronted. In addition to the prohibition on virginity testing, awareness raising and education which confronts the notions of ownership, power and control implicit in the value placed on virginity should form part of a strategy aimed at reducing the vulnerability of women and girls to violence of many kinds.

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Rachel Elfenbein

'ABC': A gendered look at HIV prevention

The Human Immunodeficiency Virus (HIV) is preventable. Even though it is preventable, the number of people who are infected with the virus is growing. In Sub-Saharan Africa, the number of women infected with HIV is greater, than the number of men. Almost 60% of people infected with HIV in Sub-Saharan Africa are female.[1]

In addition, young women (aged 15-24 years) are more than three times more likely to be infected with HIV, than young men.[2] The increasing numbers of people infected with HIV, and women in particular, seem to indicate that the success of HIV prevention strategies is questionable. Looking at the gender imbalances in these statistics, it could be argued that HIV prevention programmes are limited and problematic in whom they actually target and whom they reach.

This article will examine the popular ABC (**A**bstain, **B**e Faithful, **C**ondomise) HIV prevention strategy and its underlying assumptions from a gender perspective. Such analysis will explore the human rights violations and challenges that the ABC message seems to ignore and that fuel the spread of the HIV pandemic. As Delport [2005] states:

> *It is only if the rights to equality and non-discrimination are violated that the virus can take advantage of the social, political, and economic vulnerability this creates to flourish unabated among women. Far from being merely a health issue, the pandemic is now recognised as a human rights and development crisis. Gender inequality is at the root of this crisis.*

THE ORIGINS OF ABC

The Abstain, Be Faithful, and Condomise HIV prevention strategy originated in Uganda in the early 1990's. At the time, Uganda had a 30% HIV prevalence rate, the highest in the world. Through multiple approaches to preventing and treating HIV and AIDS, the prevalence rate in the country decreased to a current 6%.[3] Uganda has been heralded as a HIV prevention *'success story'*, with its ABC programme often interpreted to be the key to such *'success'*. The ABC prevention strategy has, subsequently, been exported to many countries as a proven way to prevent the spread of the HIV pandemic.

A closer analysis of the ABC prevention strategy in Uganda, however, reveals fundamental flaws in its *'success'*. Of the estimated one million Ugandans currently living with HIV, 56% are female.[4] While 97% of married women have abstained from sex until marriage and remained faithful to their husbands, 32% of women are married to men, who have multiple wives.[5] This indicates that many Ugandan women who have heeded the ABC prevention strategy and, especially the first two focal points of the strategy, therefore, are the ones who contracted HIV. These statistics, arguably, raise as much questions as to the efficacy of the ABC prevention strategy in Uganda, as to the adequacy of replicating this prevention strategy in other countries, especially in Sub-Saharan Africa and in South Africa in particular.

ABC AND THE SOCIETAL CONTEXT OF THE HIV PANDEMIC

The spread of the HIV and AIDS pandemic occurs within a broader societal context in which women and men are not treated equally and in which women often experience multiple forms of discrimination. Prevailing gendered inequalities place women in a position in which they are more vulnerable to HIV infection. Or, as Piot [2005] states: *'the link between gender inequality and death has never been so direct as with AIDS'*.

Even though, the ABC prevention strategy seemingly fails to take into account the prevailing gendered inequalities and imbalances, this approach continues to be the primary prevention strategy in Sub-Saharan Africa. Furthermore, as argued by Hamblin & Reid [1991]

> *...these prevention measures are drawn from men's physique and lifestyle and should be directed at men. As means by which women can protect themselves from HIV, they are hopelessly inadequate.*

These measures also fail to respond to the fact that women are, biologically, more susceptible to HIV infection, due to their genital areas tearing more easily and, thus, become more exposed to the virus during sexual intercourse.[6] Moreover, the ABC prevention strategy seems to be inadequate, since it ignores the gendered societal context, defining women's realities. Or as Hamblin and Reid [1991] argue:

> *…the social and cultural determinants of HIV infection in women are very different from those for men because they relate to the role of women within relationships, families, and communities which, in turn, determines the nature and patterns of sexual activity that place women at risk for infection.*

Since persistent patriarchal systems and male dominance define women largely as 'inferior', in both the public and private spheres, women often depend on men economically for their survival and are, therefore, left with little or no space to negotiate the terms of their sexual relationships and to protect themselves from HIV infection. And this is the same patriarchal system and male dominance in all spheres of society that determines the extent to which women are in the position to claim and enjoy fundamental rights and freedoms, such as the right to freedom and security of the person (Constitution[7], Section 12), specifically the right to be free from all forms of violence (Constitution, Section 12(1)(c)) and the right to security in, and control over, their bodies (Constitution, Section 12(2)(b)). It is in this context that

> *…abstinence is meaningless to women coerced into sex, faithfulness offers little protection to wives whose husbands have several sex partners, and condoms require the cooperation of men.* [Bryjak, 2005]

Thus, it is arguably men's sexual and gendered behaviour that, to a large extent, places women at risk of HIV infection, since, as argued by Bryjak [2005], *'while men are driving the AIDS epidemic in large degree, women become the victims'*.

ENGENDERING THE 'A' IN ABC

Following the ABC prevention strategy, people are first and foremost supposed to abstain from sex. The underlying assumption seems to be that people are supposed to abstain from sex until marriage. This prescription of abstinence is problematic for several reasons.

Firstly, the meaning/principle of abstinence is not clearly defined and, thus, leaves 'room' for individual interpretations. Abstinence, as in not engaging in sex at all or until a specified time; abstinence, as in not engaging in vaginal sex or any type of sexual activities; and/or interpretations as to who is to abstain from sex and when are only a few examples. However, any individual interpretation of abstinence can, arguably, not be removed from the gendered societal context in which this interpretation is made. It is within this gendered societal context that *'sex is usually considered a marital obligation, so wives are at higher risk for HIV than their single counterparts who can choose to abstain'* [Feuer, 2004] and that, due to women's economic dependency, *'sexual intercourse is not a question of choice but rather a question of survival'* [Hamblin & Reid, 1991]. This seems to also indicate that while

> *…abstinence-until-marriage programs erroneously assume that marriage is a protective factor against HIV... evidence increasingly demonstrates that because women have few rights within marriage, marriage may be a key risk factor for HIV.* [Sexuality Information and Education Council, 2004]

Furthermore, women's realities, have to, arguably, taken into account, since for many women, the *'choice'* to abstain from sex and, thus, not to expose themselves to HIV infection is often characterised by poverty. High rates of poverty lead to a situation in which many women engage in transactional sex in order to survive and in order to support both themselves and their families.

> *For these women, sex work is not an occupation or even a chosen lifestyle, but a pragmatic measure to overcome transitory economic hardship. The risk of HIV transmission to which they are exposed has to be tragically balanced by them against need.* [Hamblin & Reid, 1991]

ENGENDERING THE 'B' IN ABC: MARRIAGE AS A RISK FACTOR FOR HIV INFECTION

The ABC approach to prevention is most commonly interpreted in such a way that in order to prevent HIV infection, people must abstain from sex before marriage and be faithful to their partners once they marry. Once again, this interpretation raises questions, since the *'instruction'* for married partners to be faithful to one another occurs in a societal context in which polygamy is not only culturally and religiously sanctioned, but also to a large extent socially *'acceptable'*. Subsequently, it seems to be largely *'acceptable'* for men to have multiple sexual partners before and while married, yet the same behaviour is *'unacceptable'* for women.

> *Social constructs dictate that married women have little or no power to negotiate the basis upon which their relationships with their husbands take place. Once married, women are usually expected to remain faithful to their husbands but are unable to compel fidelity in return... The tendency for men to have sexual relationships outside their marriage is reinforced by male migration and mobility when men leave the village to obtain work elsewhere.* [Hamblin & Reid, 1991]

It is further argued that even if men do remain faithful once they are married, women remain at higher risk for HIV infection, because men often do not abstain from sex before marriage. Once again, reality and common social practices do not seem to

...since the *'instruction'* for married partners to be faithful to one another occurs in a societal context in which polygamy is not only culturally and religiously sanctioned, but also to a large extent socially *'acceptable'*.

coincide with the principles of the ABC prevention strategy. Furthermore, while communities often accept and expect young women to have relationships with, and marry, older men, it is these very relationships that place women at risk of HIV infection. One of the reasons, argued by Delport [2005], is that

> *...marriage to an older man creates significant imbalances between husband and wife in terms of experience, authority, and economic autonomy... Early marriage often goes hand in hand with violence against women.*

The above seems to indicate that abstinence and fidelity have neither prevented the spread of HIV nor the disproportional infection of women, since men seem to have not heeded them.

> *As a prevention strategy, reducing the number of one's sexual partners is of no help to the many women who have sexual intercourse only with their husband or regular partner. Having only one sexual partner has been a tragic failure as a means of HIV protection against HIV for wives.* [Hamblin & Reid, 1991]

Thus, marriage, the very institution that the ABC prevention strategy holds to be sacred and safe, becomes the one that places women most at risk of HIV infection. Latest research findings and statistics indicate that the

> *…majority of newly HIV-positive women are contracting the virus within marriage from their husbands.. These women complied with the prevention messages they were given, and yet doing so fails to protect them. Promoting abstinence or faithfulness will leave millions of people without the ability to protect themselves from infection.* [Sindig, 2005:38]

Indeed, as the pandemic spreads, the proportion of wives to all infected women is increasing.[8]

ENGENDERING THE 'C' IN ABC: WHO CONTROLS CONTRACEPTION USE?

The ABC prevention strategy *'dictates'* that people should first and foremost abstain from sex, until marriage, and be faithful to their partners once they are married. The 'C', as in condomise, only seems to become part of prevention as and when people cannot abstain from sex or are not faithful in their relationships. Thus, condom use, as a form of prevention, seems to become marginalised, due to the promotion of abstinence and being faithful. Furthermore, the ABC prevention strategy often limits the prescription of condom use to groups of people perceived to be at *'high risk'* of HIV infection, such as sex workers and truck drivers.[9] The isolation of *'high risk'* groups not only misrepresents and displaces the level of risk, as the current statistics outlined above show that the largest group of people at risk for HIV infection are married women, but also perpetuates the stigmatisation of people belonging to *'high risk'* groups.

In addition, many married women are not in the position to exercise their rights to make decisions about their sexual relationships and/or reproduction. *'The autonomy needed by a woman in order to negotiate safer sex depends on the realisation of her right to equality in many different areas of life'* [Delport, 2005]. Gendered inequalities and imbalances largely determine that women are not in the position to negotiate and practice safer sex and, thus, prevent HIV infection.

> *Power imbalances and inequalities between men and women render many women unable to negotiate safer sexual practices with their partners... In unequal relationships, women demanding safer sex may risk impoverishment or assault. Social norms dictate that women should be passive and compliant in sexual relations. The right to decide how and when sex takes place is regarded as a male prerogative.* [Delport, 2005]

It also has to be acknowledged that male condoms are much more widely available, but female condoms – a protection method that women control themselves and that, therefore, offers women a way to take control over their own bodies – are not as widely available.

WHAT ABOUT GBV (GENDER-BASED VIOLENCE)?

While the most common, and seemingly societal 'accepted', interpretation of the ABC prevention strategy reduces HIV prevention to three seemingly easy steps, in reality, preventing HIV transmission is not as easy, especially as and when women live in abusive relationships and/or in situations in which women are sexually violated.

The 'ABC' arguably fails to take into account prevailing gendered inequalities and imbalances, including high rates of abuse and/or sexual violence and, thus, fails to address and respond to women's needs. On the contrary, this prevention strategy seems to be based on the assumption that everyone is treated equally and, therefore, can equally negotiate and agree upon faithfulness and regular condom use within marriage and/or sexual relationships. However, this is not reality. The reality is that

...as long as the ABC prevention strategy does not address fundamental human rights... it arguably perpetuates not only the spread of HIV, but also the gendered nature of the HIV pandemic.

> *...married, monogamous women are highly vulnerable to HIV infection due to their lack of rights within marriage, difficulties negotiating safer sex, extended partner abuse and domestic violence.* [Sindig, 2005:38]

Reality also shows, as argued by Auerbach [2004:A31] that

> *…a significant risk factor for HIV infection is violence, to which all women are more susceptible. One South African study found that women who were beaten or dominated by their partners were 48% more likely to become infected than women who lived in non-violent households.*

In other words, violence and/or threats of violence severely limit women's ability to negotiate safer sexual behaviour, including condom use, with their male partners.[10]

The apparent link between sexual violence and HIV transmission also directly impacts on especially women's risk of contracting HIV, through sexual abuse and violence is not eliminated[11], even if women do follow the 'ABC', since

> *...transmission of HIV and other sexually transmitted infections will persist – despite common STI/HIV prevention approaches emphasizing ABC – as long as non-consensual sex remains widespread.'* [Family Health International, 2005:4]

FROM ABC TO A HUMAN RIGHTS-BASED APPROACH TO HIV PREVENTION

The above clearly indicates that the most common interpretation of the ABC prevention strategy simplifies HIV prevention, since it fails to take into account the gendered context of society. Or, as argued by Hamblin and Reid [1991]:

> *Knowing what has to be done in order to protect oneself from HIV is meaningless if one has no power to control the circumstances that give rise to the risk or in which prevention must occur.*

Thus, as long as the ABC prevention strategy does not address fundamental human rights of equality and non-discrimination, as well as underlying factors of gender-based violence, it arguably perpetuates not only the spread of HIV, but also the gendered nature of the HIV pandemic. It is the very same interaction between HIV infection, prevailing value and belief systems and the realities and needs of women that need to be recognised in order to attain the fundamental changes required to stem the pandemic.

In reality, the number of women infected with HIV relative to men infected with HIV increases every year and women more and more become the face of HIV and AIDS, due to gendered inequalities. HIV prevention strategies, therefore, need to address and promote everyone's right to equality and non-discrimination, the right to be free from all forms of violence, as well as the right to make sexual and reproductive decisions and the right to security in, and control over, one's body, if the spread of the pandemic is to be halted. Or as argued by Hamblin and Reid [1991], *'prevention strategies will only ever be effective in protecting women from the effects of HIV if they embrace a recognition and active promotion of the human rights of women'*. Human rights must be used proactively in the prevention of HIV.

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Evashnee Naidu

Sexual Offences Bill:
Impact on the lesbian, gay, bisexual and transgender community?

South Africa's Constitution[1], one of the most progressive in the world, expressly includes, as the first country, *sexual orientation* as one of the grounds of *non-discrimination* [2].

However, despite the progressive constitutional provisions, there are still old laws, such as the Sexual Offences Act (No 23 of 1957), and social prejudices that discriminate both directly and indirectly against lesbians and gays.

Previously, the common law crime of sodomy prohibited consensual sex between men. The law was silent on the issue of consensual sex between women.

In 1997, the National Coalition for Gay and Lesbian Equality (NCGLE) and the South African Human Rights Commission (SAHRC) challenged the common law crime of sodomy as unconstitutional and the Constitutional Court[3] ruled it to be no longer a crime for men to have sex with men.

> *The discriminatory prohibitions on sex between men reinforces already existing societal prejudices and severely increases the negative aspects of such prejudices on their lives. … But such provisions also impinge peripherally on other harmful ways on gay men which go beyond the immediate impact on their dignity and self-esteem. Their consequences 'legitimate or encourage blackmail police entrapment, violence ('queer-bashing') and peripheral discrimination, such as refusal of facilities, accommodation and opportunities'…*[4]

AGE OF CONSENT

The current Sexual Offences Act (No 23 of 1957) has a different age of consent for heterosexual people and for homosexual people. Heterosexual people may have sex with each other at the age of 16, while lesbian and gay people can only consent to sex at the age of 19.

This means that it is still illegal for young lesbians or gay men to have sex. Technically, same-sex couples consenting to sex below the age of 19 could be prosecuted and sent to jail. This clearly indicates that current sexual offences legislation discriminates against same-sex relationships and, thus, should be declared unconstitutional.

The unequal age of consent also increases the risk of HIV infection amongst same-sex couples, as it adds to the prejudice faced by lesbians and gays in South Africa and further hinders adequate access to sexuality education, information and treatment for sexually transmitted diseases.

17 year old Simon[5] shares his story…

> *Being gay while still at school is not one of the easiest things in the world. I have always felt 'different' from the other guys. I was never really interested in the types of activities that guys my age were interested in, such as sports or girls. I never had any male friends. And as a result I felt alienated and alone.*
>
> *The older boys used to beat me up and tease me with names like 'sissie' or 'faggot'! I was constantly humiliated in front of all the other kids. I had no friends. I couldn't tell anyone about my feelings as I feared they would not understand. I was also afraid that my family would no longer love me, and that they would punish me for being 'different'. I was afraid of not being accepted and of being humiliated. I didn't want to be labelled 'abnormal'.*
>
> *I was so confused and frightened. I thought that there was something wrong with me. I thought I was the only guy in the world who was attracted to other guys. I felt guilty about my feelings and thoughts. No one was there to tell me that these feelings and thoughts were both natural and normal and that homosexuals could lead very healthy and fulfilling lives.*
>
> *I kept waiting to hear something about homosexuality – but I got nothing. I kept thinking this may be a phase, but it wasn't. I used to fear that gays were sinners and had absolutely no rights at all. I wish there was someone I could have talked to or at least something I could have read that could have helped.*

Since then, the South African Law Reform Commission (SALC) has held numerous discussions throughout South Africa on a new draft Sexual Offences Bill (SOB). The SALC has also recommended that the age of consent should be 16 years for both heterosexual and homosexual people.

Thus, the proposed change to the sexual offences legislation will remove the discrimination based on sexual orientation pertaining to the age of consent, which is currently defined differently according to sexual orientation. In addition, it could be argued, that this recommendation carries the potential to assist the lesbian and gay community accessing material about sexual education, accessing preventative measures, accessing treatment, but most of all assist in addressing the stigma and discrimination associated with being lesbian or gay.

Heterosexual people may have sex with each other at the age of 16, while lesbian and gay people can only consent to sex at the age of 19.

COMMON LAW DEFINITION OF RAPE

The current common law definition of rape consists of a *man* who has *unlawful sexual intercourse* with a *woman without* her *consent*. This offence can only be committed by a man against a woman, by the penetration of the penis into the vagina. This offence excludes anal penetration, oral penetration or penetration by foreign objects.

The definition is not only gender-biased, but also fails to provide for rape against a person of the same sex.

> *18 year old Johan[6] was at a party with friends. They were all drinking. Sadly, some of Johan's friends took this opportunity to 'gang-rape' him. When he went to the nearest police station to report the matter, he was chased out of the police station because he was drunk. He thereafter went to the local hospital to be examined. After many hours he was finally attended to and given a starter pack of PEP[7]. When he went back to the hospital two days later to receive the rest of his treatment, a nurse laughed at him and said to him that men could not be raped, so he could not get access to treatment.*

Technically, the nurse in the above example was correct, since under the current definition of rape, Johan could not have been raped. The ones who *'raped'* him would, under current legislation, have been liable to prosecution on charges of indecent assault, irrespective of the fact that Johan was *'raped'* and the violation, as well as the emotional and physical trauma, experienced by Johan, is no less than the one experienced by a woman who has been raped.

The charge of indecent assault in existing sexual offences legislation is used for sexual offences, which are of a lesser degree than that of rape. Classing Johan's experience as an act of indecent assault derogates from the seriousness of the offence.

The proposed changes to the sexual offences legislation broaden the offence of rape, especially with regard to the aspect of gender 'neutrality'. This offence addresses the unlawful and intentional penetration of a *person* by the genital organs of one person into the *anus* or *genital organs of another person*. This clearly allows for the recognition of the fact that both women and men can be victims and/or perpetrators of the crime of rape.

This proposed change would also greatly impact on the gay community, in that it allows for gay males who have been *'raped'*, and have experienced the same kind of violation and physical and emotional harm that women experience, to have the right to equal protection and benefit of the law[8].

Two further recommendations pertaining to sexual violation and sexual penetration[9], is also very progressive, especially in recognising the reality in which many of the gay community are sexually assaulted by members of the *'straight'* public, inserting foreign objects into their anuses. These

The ones who *'raped'* him would, under current legislation, have been liable to prosecution on charges of indecent assault, ... in existing sexual offences legislation is used for sexual offences, which are of a lesser degree than that of rape.

offences respectively provide for the unlawful and intentional use of an *object* to penetrate a *person's anus or genital organs*, and the penetration of a person's *mouth* by a person or animal's genital organs.

In areas in the Eastern Cape and Northern Kwa-Zulu Natal, people suspected to be lesbian or gay are considered to be practicing witchcraft and are attacked by their local communities.

While these proposed legislative amendments are definitely more in line with the Constitution, it cannot possibly impact on prevailing societal prejudices, and/or affect the application and implementation of laws.

SOCIETAL CONTEXT

In reality, and despite constitutional and proposed legislative provisions, lesbians and gays still experience a lot of prejudice in their families, communities, workplaces, schools, religious institutions, as well as in public services.[10]

In 1990, the United States Department of Health and Human Services published a report on Youth Suicide. The report found that *'gay youth are 2 to 3 times more likely to attempt suicide than other young people'*[11]. Up to 30% of completed youth suicides annually involved gay youth.

The report[12] concluded that

> *The root of the problem of gay youth suicide is a society that discriminates against and stigmatizes homosexuals while failing to recognize that a substantial number of its youth has a gay or lesbian orientation.*

In South Africa, in 1994, a 16-year old lesbian contacted the Centre for Applied Legal Studies for assistance. She regularly faced harassment at school. At home, her divorced mother and mother's boyfriend physically assaulted her on a daily basis because she was a lesbian. Her father and stepmother also harassed and threatened her about her sexual orientation.

The Social Services were asked to remove her from her mother's custody. They delayed. Two weeks later, she stabbed her mother's boyfriend with a knife when he assaulted her again.[13]

Lesbian youth are raped in their townships every day in an attempt to change their sexual preference.[14] In areas in the Eastern Cape and Northern Kwa-Zulu Natal, people suspected to be lesbian or gay are considered to be practicing witchcraft and are attacked by their local communities.[15] These examples, arguably, also highlight the lack of understanding around lesbian and gay issues.

CONCLUSION

It is well and good for South Africa to have constitutional provisions and progressive pieces of existing and proposed legislation providing for equal protection and benefit of the law, irrespective of one's sexual orientation. The above, however, are only a few examples of the reality experienced by young lesbians and gays indicating that the challenge remains to be the extent to which, especially lesbian and gay youth, are equally protected and are equally in the position to access justice.

FOOTNOTES:

1. The Constitution of South Africa, Act 108 of 1996.
2. Section 9(3) of the Constitution.
3. National Coalition for Gay and Lesbian Equality and the South African Human Rights Commission v Minister of Justice and the Attorney-General of the Witwatersrand, 1998.
4. National Coalition for Gay and Lesbian Equality v Minister of Justice 1999 (1) SA 6 (CC), paras 20-1,25.
5. Simon (not his real name) is a former client of the Durban Community Centre.
6. Johan (not his real name) is a former client of the Durban Community Centre.
7. Post-exposure prophylaxis (PEP).
8. Section 9(1) of the Constitution.
9. Criminal Law (Sexual Offences) Amendment Bill (2003).
10. See also Mkhize, N. 2005. 'Homophobia is supposed to have no place'. In *ALQ*, June 2005.
11. As quoted in ALP/ALN. 2001. *HIV/AIDS and the Law Manual.* Cape Town. p. 232.
12. US Department of Health and Human Services. 1990. *Report on Youth Suicide.*
13. As quoted in ALP/ALN. 2001. *HIV/AIDS and the Law Manual.* Cape Town. p. 232.
14. See also Isaack, W. 2005. 'Crimes of hate and prejudice against black lesbians'. In *ALQ*, November 2004.
15. See also Mkhize, N. 2005. 'Homophobia is supposed to have no place'. In *ALQ*, June 2005.

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Sadiyya Haffejee

Post exposure prophylaxis following sexual assault

Statistics from the Gauteng Department of Health (GDoH) reveal that less then 27% of patients who take post exposure prophylaxis (PEP) after a sexual assault complete the full 28 day course of treatment.

This non-adherence in the face of the high rates of sexual violence and the nature of the HIV pandemic in South Africa is cause for concern, yet very few research studies have investigated this.

The Centre for the Study of Violence and Reconciliation (CSVR), on behalf of the GDoH, addressed this issue in a study conducted in 2004. The study was carried out at various PEP facilities in Gauteng Province and looked specifically at factors influencing adherence to PEP following sexual assault. This paper presents a summary of the most salient findings from the study. [1]

LITERATURE REVIEW

A review of the literature on post exposure prophylaxis found unpleasant side effects, associated with the use of PEP, to be the most common explanation for low adherence. Other factors posited as influencing adherence included patients' perception of their risk of HIV infection; the (non)availability of counselling and support to the survivor; the nature and quality of relationships between health care staff and patients; patient knowledge and understanding of the drug regimen and the necessity of taking it; and the stigma attached to both sexual assault and HIV.[2] Kistner (2003)[3] identified additional factors that appear to affect adherence, such as the extent of patients' access to reliable primary medical care, as well as their ability to keep appointments for follow up consultations; and finally, how able patients are to fit the medication into their daily routine and to take it in front of others.

METHODOLOGY

To adequately investigate factors influencing patient's adherence to PEP, various methods of data collection that relied on both quantitative and qualitative methods were employed. Primary sources of data collection included observations at seven PEP facilities in Gauteng, interviews with 37 health workers across these sites, interviews with 67 sexual assault survivors and data collection schedules tracking rape survivors' adherence to PEP. A secondary source of data was GDoH's monthly reports. Employing multiple sources of data allowed for triangulation of data.

Research sites

The seven sites included in the study presented a mixture of urban and peri-urban sites in Gauteng Province and varied with regards to patient load, with some of these sites being amongst the busiest in the province and others less busy.

FINDINGS

In the following sections, findings from interviews conducted at PEP facilities with health care workers (HCW) at the seven sites and with sexual assault survivors are presented.

Findings from facility observations and interviews with health care workers

Findings from the study revealed disparate levels of training and knowledge amongst health care workers responsible for providing PEP. Of the 37 HCWs interviewed, approximately 6 nurses and 1 doctor had been trained on the medico-legal examination and 21 were unaware of the treatment protocol. Training sessions varied from half a day to three weeks. Interviews also suggested that most health workers have a limited understanding of the side effects of the medication, as well as how to treat it.

It appeared that the best trained and most committed staff were on duty during the day, while less effective service appeared more likely at night and over weekends, when casualty staff were responsible for providing services. Given that the majority of rapes are reported at night and over weekends, this is likely to result in many rape survivors who will have their first contact with less-trained and less-knowledgeable health workers.

Staff shortages and limited resources also appeared to be a constraint to providing an effective service at some sites. In addition to inadequate equipment for conducting a thorough medico-legal examination, staff across 4 of the 7 sites reported running out of PEP drugs. Staff shortages at some of the facilities meant that despite certain health workers' ability and motivation, they were unable to spend as much time with patients as was necessary. Thus, at least some patients would have left the facility not fully understanding the importance of the medication or how to take it. This situation was exacerbated by the fact that these facilities appeared to have little or no information materials on the drug regimen for patients to take home and read later.

Of the 37 HCWs interviewed, approximately 6 nurses and 1 doctor had been trained on the medico-legal examination and 21 were unaware of the treatment protocol.

Furthermore, some health care workers appeared to lack the necessary training and the much needed skill to counsel survivors. Social workers and lay counsellors were not available on a 24 hour basis at all facilities and, where available, appeared to have disparate levels of trauma training. Furthermore, judgmental attitudes towards sexual assault patients were reported at some sites. Once again, the situation was aggravated by the fact that interagency referrals appeared to be largely non-existent at some sites; four of the seven sites had no referral links to rape trauma counselling services.

Findings from rape survivor interviews

A total of 67 interviews were conducted with rape survivors. Of these interviews, 15 were in-depth and 52 were shorter structured questionnaires administered when patients returned for repeats.

Findings from the study show that patients failed to adhere to the drug regimen, due to side effects, forgetting to take their medication and not taking their medication properly.

Almost all rape survivors reported side effects, some of which were debilitating and did not improve. Ineffective treatment of side-effects was a key finding from this study, emerging from the rape survivor interviews, the health worker interviews and reinforced by our observations. While all health workers knew that the drugs caused side effects, the interviews found that few knew how to treat such side effects adequately. The study also found that in the majority of cases, patients were not telling nurses about the side effects they experienced, and nurses in turn were not asking. The limited interaction that health workers had with rape survivors collecting their repeat medication was not sufficient to enquire about patients' well-being.

Another key finding affecting adherence was rape survivors' lack of understanding of the drug regimen. Three reasons for this lack of understanding are suggested by the study. Firstly, some health workers are unfamiliar with the drugs so it is possible that they provide patients with either inaccurate or insufficient information. Secondly, while other staff may be sufficiently knowledgeable, by their own admission, they do not spend sufficient time explaining PEP to patients. Finally, some patients are in no condition to absorb all this information in the immediate aftermath of the rape.

Fear of contracting HIV emerged as a motivating factor in encouraging patients interviewed to complete PEP. Interviews also suggested that the support of others was crucial to helping many women persevere with treatment. Because their motivation sometimes fluctuated and they did not always remember their medication, adherence was helped by supportive others (such as family, friends and workmates) assisting patients to take PEP.

Ineffective treatment of side-effects was a key finding from this study, emerging from the rape survivor interviews...

The practice of supplying weekly dosages of the PEP treatment also appeared to assist patients in continuing treatment. The reduced number of pills received at each visit appeared to be less overwhelming and the weekly contact with HCWs appeared to motivate patients. However, it was noted, that this arrangement was not suited to all patients, since the ones who work or attend school appeared to find it difficult to return on a weekly basis.

The in-depth interviews in particular suggested that some patients took pride in their sense of responsibility and would not have welcomed calls from health workers. For one patient, such a call would have been an unwelcome reminder of the rape, while for others such calls suggested that they could not be relied upon or trusted to take their medication. However, because these patients completed their PEP, they are the exception rather than the rule and may well be a group for whom being reliable is more important than it might be to others.

The interviews also highlighted other factors potentially influencing adherence, such as transport difficulties, the belief that PEP gives people HIV, health facilities' reputation for (not) caring and curing, not feeling ill (meaning that medication was no longer required), and finally, fear, as a result of the trauma suffered, which may prevent some patients from going anywhere at all.

DISCUSSION AND RECOMMENDATIONS

Findings from the study suggest that factors influencing adherence are dependent upon the skill, knowledge and attitudes of health facility staff, individual characteristics of the rape survivor, and the nature of support they receive in their immediate environment. To enhance the effectiveness of the service, the following recommendations were made.

Increase understanding amongst survivors of how to take the drugs

Findings suggest that patients taking PEP often do not understand how to take the drugs, how the drugs work or how to treat the side effects. This failure often results in patients defaulting or taking the drugs incorrectly and, thereby, negating its effectiveness.

The first step in ensuring that survivors understand how to take the treatment, is to ensure that all health care workers implementing the PEP service are fully congruent with the drug regimen and are able to communicate this information in an empathic manner. To this end, the study recommended that all staff providing PEP services have a minimum level of knowledge and skills to deal with rape survivors. Following the training, staff should be assessed on their understanding of the training material and on their suitability to work with sexual assault patients.

Additionally, the study recommends that patients be provided with easy to read information that they can take home and read when they are less traumatised. Information should include a simple background on the treatment and its purpose, instructions on how to take the treatment and its duration. Information on side effects should also be included, along with a reminder to patients that side effects must be reported to health care staff. This insert should further tell patients about available over-the-counter remedies for some of the side effects. Written, as well as visual, information should be made available in all the relevant languages.

Furthermore, the study recommended that after each visit health workers should enquire how the patient is doing. This would provide an important opportunity to clarify misinformation and provide treatment to ameliorate side effects.

Strengthen health workers' support of rape survivors

At most sites it appeared as though health workers' primary focus was on providing the drugs, with less thought and time spent on the emotional needs of the survivor. It was observed that health workers were not always equipped with the necessary skills and attitude to counsel rape survivors or to facilitate support groups. Support for PEP facility staff, some of whom appeared de-motivated, was lacking. Lastly, PEP facilities also seemed to be functioning in isolation, with relations between health, the police and NGOs relatively undeveloped.

> **...the study recommends that patients be provided with easy to read information that they can take home and read when they are less traumatised.**

The study, therefore, recommends that health care services for rape survivors should not only be limited to the provision of PEP. The emotional and psychological impact of the trauma suffered should be acknowledged and counselling expanded to include trauma counselling as well. In addition to ensuring that health care staff are equipped with the necessary information on the PEP regimen,

Health care workers should be closely evaluated for their suitability; screening of all potential counsellors should be undertaken by trained professionals and supervision of the ones providing the counselling service set in place.

efforts should be undertaken to ensure that the quality, attitude and approach of staff are suited to patients' needs. Health care workers should be closely evaluated for their suitability; screening of all potential counsellors should be undertaken by trained professionals and supervision of the ones providing the counselling service set in place. To ensure that staff providing the service do not suffer secondary trauma, regular de-briefing sessions with trained professionals is suggested. Health care staff should be encouraged to make trauma counselling referrals to specialist rape crisis organisations in the area. Whilst counselling forms an essential component of the treatment of survivors, it should be delivered by skilled counsellors.

Furthermore, the feasibility of follow-up calls should be investigated. Counselling appointments and repeat visits need to be co-ordinated for the same day wherever possible to prevent patients having to make two trips in one week to the hospital, thus reducing financial costs.

Support from family and friends appeared to be integral in assisting rape survivors and if patients require such support, it should be allowed and encouraged. It is recommended that materials also be developed for family members around being a *'treatment helper'*.

Further recommendations suggested include:

- The practice of providing weekly packs be continued as it appeared to motivate some rape survivors– although flexibility should be exercised to accommodate the ones who cannot get to the facility on a weekly basis.
- The location of facilities should be investigated, as evidence suggests that the casualty department is unsuited to rape survivors.
- The possibility of dispensing a less complicated drug regimen, like Combivir should be investigated.

CONCLUSION

From the research it was apparent that the factors influencing adherence are complex, with no one factor emerging as the primary course of non-adherence. Based on the findings, a number of recommendations have been suggested, many of which are cost effective and relatively simple to institute. In addition, recommendations are not specific to the facilities investigated; they are instead extensive enough to be instituted at all facilities offering PEP.

In conclusion, it is important to note that although the study identified problems in the administration of PEP at the facilities investigated, there are many motivated and highly skilled health care workers at some of the facilities who are doing all they can to provide a good service. These efforts should be commended and supported.

FOOTNOTES:

1. Vetten, L. & Haffejee, S. 2004. *Factors affecting adherence to Post-Exposure Prophylaxis in the aftermath of Sexual Assault: Key findings from seven sites in Gauteng Province.* The full report can be obtained from the Centre for the Study of Violence and Reconciliation.
2. Kachienga, M. 2004. *Factors promoting or limiting adherence to post exposure prophylaxis (PEP) regimes internationally and nationally.* Johannesburg: Centre for the Study of Violence and Reconciliation.
3. Kistner, U. 2003. *Rape and post-exposure prophylaxis in South Africa.* Johannesburg: CADRE/Department of Health.

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Microbicides:
A new weapon in the war against HIV

Introduction

Microba-what? This is the general reaction from people when asked, whether or not they have heard of microbicides. Perhaps our ignorance relates to the fact that information regarding the topic has not been widely distributed. However, the question still looms, *‘what do microbicides have to do with us?’.* The answer lies in the HIV and AIDS pandemic.

Around the world, women’s health and lives are at risk every day, because there are too few options in STD protection. Scientists are presently conducting research with the objective of developing microbicides, which, if proven effective, would give women the power to protect themselves from contracting sexually transmitted diseases (STD’s) and HIV.

Presently, 55% of women in Africa have HIV and AIDS. In fact, 15,000 new infections occur everyday. AIDS is ranked among the world’s most devastating infectious diseases, which creates a greater need for new and effective preventative measures. This is where MICROBICIDES come in.

A microbicide is a chemical substance, which **may** prevent the transmission of HIV and other sexually transmitted diseases, when used properly. It can take the form of a gel, cream, foam, suppository or film, and is applied intravaginally before sexual intercourse.

A rampant issue South Africa is facing, is empowering partners to discuss each other’s sexual history in an open, honest and comfortable dialogue. Although, the microbicide shouldn’t necessarily be a substitute for open discussion about such issues, microbicide can be used without the knowledge of one’s partner.

There are three phases in testing the efficiency of microbicides. Phase 1 and Phase 2 aim to test their safety. Phase 3 tests whether or not the product works to prevent HIV. Although not yet available, five products have entered phase 3 testing in South Africa.

Microbicides would work in one of the following ways:

- Killing the HIV and STD pathogens;
- Creating a barrier against infections and thus enhancing the bodies’ natural defences;
- Preventing replication of the virus;
- Preventing infection from spreading.

Currently, prevention strategies that emphasise mutual monogamy, e.g. the male condom, require co-operation by the woman’s partner. Women may influence, but cannot control a man’s sexual behaviour. Additionally, violence, coercion, and economic dependency can make it difficult for women to *‘negotiate’* condom use or to leave a partnership that places women at risk.

History

Microbicide research has been taking place for the last ten years. Since 1990, a number of government research agencies, private organisations and multi-national bodies, like the World Health Organization (WHO), have recognised the great potential of microbicides. Scientists and advocates quickly recognised the importance of coordinating the work globally, and in 1994, the International Working Group on Microbicides was born. Intensive lobbying in the US and Europe has raised the awareness of microbicides, and, subsequently, more funding has become available[1]. However, despite enormous scientific and public health potential, microbicide research has been under-funded and politically marginalised.

The South African government has been silent on the issue of microbicides to the extent that it has failed to even mention microbicides in their HIV/AIDS and STD Strategic Plan 2000 – 2005. Although, the government does acknowledge that microbicide research is taking place, it does not provide any funding for such research. Thus, advocacy campaigns in South Africa are currently aimed at government providing funding for research and subsidising microbicide availability.

Accessibility, availability and demand

Women have expressed a positive attitude toward the use of microbicidal products. Accessibility studies in India, South Africa, USA and Brazil have confirmed the urgent need, women feel, for a preventative method that they can control. Although, scientists are now in Phase 3 of the trials, microbicides will only, with sufficient investment, be available within 5 years.

Barriers to microbicides development

So, given all the potential advantages, why have microbicides not taken centre-stage in HIV research? The answer may lie in society's approach to the disease. When the virus was first discovered, people assumed that an effective vaccine will soon be available, and in the meantime safer-sex campaigns will hold the virus at bay.

In reality, how soon microbicides materialise, will depend on how successful we are in tackling not only the scientific challenges, but also the societal issues especially the level of funding for microbicide development, which needs to be greatly increased.

Would a microbicide eliminate the need for condoms?

Condoms would remain the option of choice, because, when used consistently and correctly, they are more likely to provide better protection than a microbicide. But for people, who cannot or will not use a condom, and particularly for women, whose partners refuse to use condoms, microbicides will provide an important *'fallback'* that can save lives and have a substantial impact on the epidemic.

Microbicides have the added advantage in that they are within women's control. Though, microbicides may not have a 100% efficacy rate, they could prevent up to 3.7 million infections in three years.

Conclusion

The ultimate objective is to provide women with a tool to empower themselves. A microbicide would, thus, serve a dual purpose, in that it does not only provide women with an additional preventative measure against HIV and AIDS and other STDs, but it would also give women a sense of control over their sexual relationships.

Microbicides alone will not solve the immense problem of HIV and AIDS, but together with condoms, and eventually AIDS vaccines, they will give people a wider choice of protective measures.

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FOOTNOTE:

[1] New Scientists. 2003. *HIV Focus Protect & Survive.* p 43.

Johanna van Rooij[1]

Criminal liability for non-disclosed sexual exposure to HIV and AIDS

Since medical science today lacks the technology to cure or to stop the spread of HIV, many are demanding that the law be employed for protection. There are a broad variety of legal measures one could think of in the fight against the diffusion of HIV and AIDS. In South Africa, the debate focuses on one of the possible legal measures, the criminalisation of non-disclosed exposure to HIV or AIDS. The present debate appears to be in response to the Criminal Law Sexual Offences Amendment Bill (2003), where such criminalisation has been suggested.

Criminalisation can be regarded as an efficient method, in that society clearly shows its position regarding intentional non-disclosed exposure to HIV or AIDS. It could also play the role of reparation to the victim. However, criminalisation is a drastic measure, since it is a direct tool of state power. It could, therefore, be argued that criminalisation should only be used with great caution.

Besides general arguments against criminalisation per se, one could also question such legislation in the special context of HIV and AIDS, since the criminalisation of non-disclosed exposure to HIV could only constitute one of several ways to address the spread of HIV. But one also has to question if criminalisation can truly lead to its goal, namely to prevent the further spread of HIV and AIDS. Many representatives from civil society have suggested that this would not be the case. Furthermore, some seem to believe that such criminalisation would even be counter-productive and, thus, help to diffuse the HIV virus. Before such legislation is enacted, it seems logical to take the voice of civil society into account.

CRIMINALISATION AND ITS GENERAL DIFFICULTIES

Criminalisation means that a punishment is prescribed for a certain conduct. Behind the criminalisation lies a political statement that the conduct in question is so repugnant that it deserves to be sanctioned with a penalty. Criminalisation fulfils a normative and an informative purpose. Through the legislation, the state creates norms to be followed and at the same time informs the citizens of the existence of these norms. Besides that, criminalisation constitutes a base for law enforcement agents and the judiciary to, within the frames of their authority, make sure a penalty and a sentence are delivered to the person guilty of the criminalised conduct.

There is, arguably, a general agreement in most democratic societies that criminalisation, as a method to prevent violations of public norms, should be used with precaution. Criminalisation is normally not the only, nor always the most efficient means, to obstruct non-desirable conduct in a society. Besides, it is a fairly costly method. It could, therefore, be argued that a society's resources should only be used for conduct that causes considerable damage to the society and only in circumstances where there is no other way to regulate such activity.

To criminalise a certain conduct does not automatically lead to a punishment of the perpetrator, since there are a variety of factors that need to be fulfilled, if criminalisation is to function in practice. Firstly, the criminal conduct needs to come to the authority's knowledge. Secondly, the state has to have enough resources to investigate the crime and to identify the perpetrator. Thirdly, it must be possible to prove the crime before a court. And finally, the state has to have resources to carry out the sentence. Thus, there are a number of factors to take into consideration, when criminalising special conduct in a society. [2]

SPECIAL DIFFICULTIES IN THE CONTEXT OF HIV AND AIDS

To criminalise intentional non-disclosure of HIV and AIDS raises a number of specific difficulties. Objectively, to be able to judge whether or not such a criminal conduct took place, one would have to prove that the defendant had HIV or AIDS at the time of the commission of the crime. In addition, one would further have to be able to prove, beyond reasonable doubt, that the victim acquired the infection from the act of the perpetrator. In other words, one would have to be able to prove causality between the criminal act and the damageable effect. Even though, there are scientific possibilities to prove such causality (DNA tests can test if the structure of the antibodies in the victim resemble the ones of the defendant), this is a fairly costly method.

There are also subjective difficulties in proving criminalised non-disclosure of HIV or AIDS. The prosecutor must be able to show that the defendant was fully informed of the risks and the consequences of unprotected sexual intercourse whilst infected with HIV or AIDS. The conduct would only constitute a crime, if the defendant knew the risks, or reasonably must have been aware, and still engaged in unprotected sexual intercourse. It must, thus, have been the intention to cause the damageable effect.

Finally, criminalising such non-disclosure of HIV also causes difficulties when it comes to sentencing. Since the defendants in such cases would themselves be victims of their own disease, it could be argued that a punishment would be rather meaningless. One would also have to take the availability of health care services in prison into account and the extent to which such a sanction would affect the defendant's health condition. In this context, it has to be noted, that a defendant's HIV infection has, until now, often been regarded as a mitigating factor in South African case law.

> **...one would further have to be able to prove, beyond reasonable doubt, that the victim acquired the infection from the act of the perpetrator**

CRIMINALISATION THROUGH COMMON LAW

The fact that the South African government is planning to criminalise intentional non-disclosed exposure to HIV or AIDS, does not mean that this conduct has not been regarded as criminal before. Possible prosecutions for deliberate conduct, which cause an exposure to, or a transmission of HIV, include murder, attempted murder, assault, assault with the intent to do grievous bodily harm, indecent assault, fraud and *crimen injuria*.[3] The recent case *State v. Nyalungu*[4] shows that it is indeed possible, to successfully prosecute HIV-related behaviour under the existing common law, without a specific statutory law. The defendant in this case was found guilty of rape and attempted murder. The latter charge was based on the fact that the defendant was HIV positive at the time of the crime and that he therefore intentionally had exposed the victim to the risk of transmission of the virus through the rape. It was uncertain at the time of the trial whether or not the victim had become infected with HIV.

> **Since the defendants in such cases would themselves be victims of their own disease, it could be argued that a punishment would be rather meaningless.**

CRIMINALISATION THROUGH STATUTORY LAW

The current draft of the Sexual Offences Bill (2003)[5] has created a separate offence called *Criminal non-disclosure of HIV or AIDS*. The definition states that *'a person (A) who engages in intimate contact with another person (B) and who intentionally does not disclose to B that he or she has HIV or AIDS'* is guilty of the offence. *'Intimate contact'* is defined as *'contact of a sexual nature that exposes the body of one person to a bodily fluid of another person'*. It is further recommended that if the other party was aware of the fact that her or his sexual partner was infected with HIV or AIDS and still consented to sexual penetration; it should be regarded as a defence to the charge. It is also suggested that prosecution of this offence could only be instituted with a written authorisation from the National Director of Public Prosecutions, and only if instituting the prosecution would be in the interests of justice, with due regard to the circumstances surrounding the offence and the personal circumstances of both parties.[6]

It is unclear at the moment whether or not the proposed changes to the sexual offences legislation will be passed by the Parliament. However, if these changes pass, there are a number of legal issues that need to be addressed. Firstly, the question arises whether or not this intentional crime should be interpreted to include *dolus eventualis*. Should *'intentionally'* only cover *dolus directus* (aim and object to infect) and *dolus indirectus* (foresight of substantial certainty) or also include *dolus eventualis* (foresees the possibility that the prohibited consequence might occur, in substantially the same manner as that in

> **In South Africa, the HIV positive status is highly stigmatised and, thus, criminalisation of HIV-related behaviour might exacerbate this stigma...**

which it actually does occur, or the prohibited circumstance might exist and accepts this possibility into the bargain)? An inclusion of *dolus eventualis* could, however, imply imposing a duty on people to undergo HIV testing.[7] Secondly, the question arises whether or not the common law crimes used to date for HIV-related behaviour, such as attempted murder, are still to be used for this conduct. Since the legislation does not say anything explicitly about an eventual annulment, the problem of a future collision between the common law and the statutory law seems to be imminent.

POSSIBLE SOCIAL OUTCOMES OF CRIMINALISATION THROUGH STATUTORY LAW

Criminalisation of intentional non-disclosed exposure to HIV or AIDS through statutory law could, besides legal difficulties, also give rise to practical difficulties, and more seriously to non-desirable effects.

Firstly, one would have to investigate the possibility of the courts administering and adequately implementing this new offence. Taking cognisance of the high numbers of HIV infected people in South Africa, the risk of an overburdened criminal justice system would, arguably, have to be considered. If the resources of the judicial system are lacking, the criminal penalties could be regarded as empty threats. Another practical issue, against special legislation, is the lack of flexibility that this method brings. To legislate is complicated and time-demanding. If, for example, anti-retroviral drugs become more available, or a cure for the disease is found, there would be a need to adapt the statutory law. These changes could instantly be taken into account through the common law system, which has an inherent higher flexibility.

> **...such legislation could lead to a situation in which fewer people would choose to be tested to avoid being prosecuted for intentional criminal conduct.**

More importantly, the criminalisation of intentional non-disclosed exposure to HIV or AIDS would possibly not fulfil its purpose, but instead risk being counter-productive. In South Africa, the HIV positive status is highly stigmatised and, thus, criminalisation of HIV-related behaviour might exacerbate this stigma, since all people tested, or perceived to be HIV positive would risk being regarded as potential perpetrators. Furthermore, such legislation could lead to a situation in which fewer people would choose to be tested to avoid being prosecuted for intentional criminal conduct. Subsequently, people infected with HIV, who do not know their status, would also risk alienating themselves from medical care. In the long run, criminalisation could, thus, challenge the extent to which society is in the position to control and manage the pandemic and to treat its citizens suffering from the disease. Criminalisation through statutory law could, therefore, potentially aggravate an already critical situation.

Finally, the high number of NGOs, who are against this criminalisation, should be taken into consideration. The *National Civil Society Coalition on the Sexual Offences Bill*[8] has formulated a fact sheet about the suggested offence of *Criminal non-disclosure of HIV or AIDS*. According to their views, such criminalisation could have a disproportionately negative impact on women, who are often less likely to disclose their HIV status for fear of violent recrimination, economic hardship or social abandonment. The fact sheet also points to the fact that most HIV transmissions occur in circumstances where neither party knows their HIV status. Criminalisation could, therefore, be considered meaningless.

Taking all these factors into consideration, it could, therefore, be argued, that under current South African circumstances, the criminalisation of intentional non-disclosure of HIV or AIDS would not serve the purpose intended.

FOOTNOTES:

1. In April 2005, I was awarded a scholarship from the *Swedish International Development Cooperation Agency* to, within my law studies, carry out a Minor Field Study in South Africa investigating the issue of criminal liability in the context of HIV and AIDS. This article is based on literature review, as well as discussions with various NGOs and professors of law and political science at the University of Cape Town.
2. Swedish Government Bill, 1994/95:23, p. 52 ff.
3. Burchell, J. & Milton, J. 2005. *Principles of Criminal Law.* 3d Edition. Juta. p. 724.
4. State v Nyalungu 2005 JOL 13254 (T). Case number CC 94/04. Judgment date 15/03/2004.
5. Criminal Law (Sexual Offences) Amendment Bill, Section 5.
6. Criminal Law (Sexual Offences) Amendment Bill, Section 5(4).
7. Burchell, J. & Milton, J. 2005. *Principles of Criminal Law*. 3d Edition. Juta. pp 467 & 725.
8. The working group member organisations include: AIDS Law Project; Childline SA; Centre for Applied Legal Studies; Centre for the Study of Violence and Reconciliation; Concerned People Against Abuse; Lawyers for Human Rights; Ngata Safety and Health Promotion; NISAA Institute for Women's Development; People Opposing Woman Abuse; Port Elizabeth Rape Crisis Centre; Rape Crisis Cape Town Trust; Resources Aimed at the Prevention of Child Abuse and Neglect; Save the Children Sweden; Sex Workers Education and Advocacy Taskforce; Thohoyandou Victim Empowerment Project; Tshwaranang Legal Advocacy Centre; Western Cape Network on Violence against Women.

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Sunette Pienaar

The untold stories of women and AIDS

Ethical considerations in a feminist narrative research experience

Black women in previously disadvantaged communities in South Africa carry the burden of triple oppression: (a) the social engineering policies synonymous with apartheid have marginalised women economically and socially; (b) patriarchy, embedded in cultural and religious discourses, has rendered women voiceless and powerless; and (c) HIV and AIDS is targeting the most vulnerable, namely women and children. Not only are women carrying the brunt of HIV infections, but they also carry the extra burden of caring for the sick and the dying.

Ethical considerations should, therefore, be at the core of doing research with women in previously disadvantaged communities, infected and/or affected by HIV and AIDS, about care and/or the lack of care. The methodology chosen should be accountable to these ethical considerations. As a contextual liberation and feminist theologian, the writer argues a narrative approach to doing research with marginalised women. The article concludes with a reflection on the implementation of some of the ethical principles in the research.

> *You and I are close, we intertwine; you may stand on the other side of the hill once in a while, but you may also be me, while remaining what you are and what I am not.* [Trinh, 1989a:90]

‘DEAR GOD, FILL ME WITH YOUR HOLY SPIRIT FOR I AM ONLY A WOMAN’

Ever since I could remember, I wanted to be a *‘dominee’*. A strange calling, it seemed, given the fact the Dutch Reformed Church did not allow women to practice theology then.

In retrospect, my mother contributed considerably towards my calling by challenging power discourses in society. She reminded me constantly that we are all human beings created equally by God. Neither money, status nor gender made one person more important than another. I, therefore, believed that I could challenge viewpoints different from my own, no matter who speaks them. I was continuously reprimanded for not being submissive to my *‘meerderes’*.

These beliefs brought me into conflict with the *‘powerful’* in my community since an early age. I challenged the principal in primary school for the disrespectful way he addressed pupils and I refused corporal punishment. I confronted the *‘dominee’* for expecting me to learn the Ten Commandments by heart, as a prerequisite to be accepted as a member of the congregation, and I challenged school rules fabricated to strengthen patriarchal discourse. The *‘powerful’* assured my mother that I was going through a phase of teenage immaturity.

Before enrolling for a BA (admission) at the Rand Afrikaans University, I visited my *‘dominee’* to share the excitement of my decision to study theology. He tried to convince me to change my study direction, ‘*…as this is no job for a woman*’. The theology class of 1992 consisted of three female students and seventy-eight male students. The top achievers throughout my student career were all women.

With its emphasis no longer on dogma, which focuses on the rules and regulations of the church, but on the ethical implications of such rules and regulations on the lives of human beings, ***post-modern theology*** suited my beliefs well and I could reassure myself of my sanity.

The ethical considerations of post-modern theology impressed itself on my heart. Russouw [1993:903] uses the phrase *‘from being right to doing right’*, to describe this ethical aspect of post-modern theology. A Christian understanding of the world can never be anti-human. Christians of all denominations should, therefore, not only be sensitive to suffering in general, but should be especially sensitive to the practical consequences of theological perspectives and practises based on belief. Dogmas have tended to marginalise and disempower many people, which also means that these people’s voices have been silenced.

Dogmas have tended to marginalise and disempower many people, which also means that these people’s voices have been silenced.

Russouw [1993:902,903] writes:

> *Theology has a long and rich tradition from which it can draw in its response to the challenge to care for the marginalized in society. Liberation theology and the most recent research on the historical Jesus are only two of the recent developments which have again focused on the special concern displayed in Scripture for the marginalized … God therefore reveals and illustrates through the story of his people and the story of Jesus a special concern for those whose human value and dignity is denied by society – those in danger of dropping out of the care of society, or who has been excommunicated from society.*

Ethical considerations function very strongly in post-modern theology. At this point, I want to mention Foucault[1], because he is a post-structuralist, who concentrates on ethical issues and relational power. Parker [1989:61] writes about Foucault’s idea of relational power:

> *What is spoken, and who may speak, are issues of power. As well as organizing and excluding forms of knowledge, discourse relates and helps organize social relations as power relations.*

In a post-modern worldview, I think it is important to ask the question raised by Parker [1989:61]: ‘*What is spoken and who may speak?*’ I raise the question in order to ask about the ethical implications of an action or discourse. Ethical considerations involve a focus on power relations. Parker [1989:67] says: ‘*Not only are social relations stressed, and social relations as they are embodied in discourse, but we may view these relations as power relations.*’ Foucault, as quote in McHoul and Grace [1993:39], argues:

> *Power is everywhere, not because it embraces everything but because it comes from everywhere … Power comes from below; that is there is no binary and all-encompassing opposition between ruler and ruled at the root of power relations, and serving as a general matrix – no such duality extending from the top down and reacting on more and more limited groups to the very depths of the social body. One must suppose rather that the manifold relations of force that take shape and come into play in the machinery of production, in families, limited groups and institutions, are the basis for wide-ranging effects of cleavage that run through the social body as a whole.*

If power is everywhere, then women and children have power to resist, although, they have been silenced by discourses embedded in patriarchy, sexuality, gender, culture & ethnicity and race. Post-modern culture insists that people with so-called expert knowledge are not the only ones to whom one should listen when decisions are made. The ones who are affected by such decisions also have a valuable and indispensable contribution to make – even if they are considered non-experts or non-literates in terms of modern rationality. Expertise must be enriched and informed by the experience of the ones on the receiving side of expert opinion. This post-modern emphasis becomes especially clear in the concern for the ones, who have been marginalised in modern culture – the ones, who have been socially rejected by modern society and the ones, who are not fit to compete in modern society.[2]

Post-modern theology is concerned with the ethics of our day-to-day life, and not with the dogma of ‘*being right*’.

Post-modern theology is concerned with the ethics of our day-to-day life, and not with the dogma of ‘*being right*’. Patriarchal discourse has involved, for many years, a misapplication of dogma, resulting in a negative influence on many people and a marginalisation of many voices. Post-modern theology leaves a door open to de-construct discourses embedded in patriarchy, sexuality gender, culture & ethnicity and race, because of its relational power and ethical considerations, to ‘*do right*’ instead of ‘*being right*’. Post-modern theology has influenced my thoughts about dogma and ethics, and opened my mind to listen to people's lived experiences, instead of the theories and dogmas that I was taught, were the only way.

The *'socio-economic pattern of contextualisation'* described by Bosch [1991:421] as *'evolutionary or revolutionary'*, converted me to *'doing'* theology. Contextual theology claims to be an epistemological break from traditional theologies designed to serve the interest of the West. It is affirming justice against oppression, shifting from the general to the local; co-constructing a variety of *'local theologies'* [3]; and opposing a Western theology claiming universal validity. This necessitates self-other actions that go beyond the luxury of merely *thinking* commitments, to *doing* commitments. It is committed to the poor and the marginalised, it has the notion that theology can only be done *with* the ones, who suffer. It emphasises *doing* theology, since doing is more important than knowing or speaking (hermeneutic of the deed)[4].

Dr Beyers Naudé addressed the theological students in my final study year for obtaining the BD degree. It was only then that I realised that as a white person, I grew up in a different South Africa from the one he described. He told us about the atrocities of the 'apartheid' government against the black people. He also shared his own story of marginalisation in the church, as a result of his beliefs and his stand against apartheid. I was disillusioned by the role the Dutch Reformed Church played in the institutionalisation of 'apartheid.' Churchgoing became a tedious activity of the scrutinising of sermons and voices of church leaders, measuring them against the same scriptures used to condone apartheid.

Liberation theology took on a new meaning for me, as I read the life stories of Nelson Mandela and his comrades.

> *Liberation is a process in which oppressive groups acknowledges their responsibility for structures of domination and name the forces that lead to repentance and conversion* [Welch, 1990:157].

Feminist theology was introduced to me in the form of a single assignment in my final year. It was only after two years, as a youth pastor in the church, that I started to comprehend the necessity for a feminist theology [5] that exposes the harmful effects of a hierarchical model in religions, while enhancing an egalitarian model.

I came to understand that my sexuality could hinder and even shame my ministry. The church council even reprimanded a female colleague of mine for wearing trousers. The *'tannies'* in my congregation warned me to be careful in my conduct with boys, as I am a woman. My husband, also a minister and youth pastor before me, was never reprimanded in this way for dealing with the young girls in the congregation.

Gender stereotyping also caused friction with my colleagues (all male) and their wives. My male colleagues would greet each other with the hand and would wave an informal 'hello' to my side at meetings. During tea breaks at meetings, all eyes turned to me for pouring tea. Needless to say, I refused to do 'domestic tasks' at the church or greet anyone who didn't greet me properly. This stereotyped me as someone who deemed herself better than the wives of the other ministers. They are God's servants, who would continue with the demeaning tasks I refused to do.

Not only are women carrying the brunt of HIV infections, but they also carry the extra burden of caring for the sick and the dying.

I was asked to do a sermon on women's day at our church one year and never again. A few *'tannies'* confronted me after my sermon for preaching a heresy as the Bible stipulated that women have to be submissive to their husbands. A female elder prayed before one sermon: *'Dear God, this is only a woman. Fulfil her with the Holy Spirit to preach your word'*. Some others would walk out, as soon as I mount the pulpit. I was in desperate need of feminist practices that seek *'justice, peace, healing and wholeness for all in partnership'* [Ackermann, 1991:96]. Feminist theology represents *'a radical critique of patriarchal religious and theological thinking'* [Isherwood & McEwan, 1991:61]. It is within the community of feminist theologians where I found food for my soul. Feminist theology also takes into account ethical considerations. Griffen (1989)[6] states, that post-modern theology is supportive of feminist or post-patriarchal theology.

Contextual liberation and feminist theology motivated me to found an organisation that would aim at alleviating the suffering of the most vulnerable members of society being women and children, by facilitating change in communities. I longed for women to have a

Cultural practices embedded in religious beliefs and hierarchical systems render African women voiceless and powerless.

platform to voice their stories and to be given the chance to create their own alternative stories. Heartbeat, Centre for Community Development, has become my vehicle for *'doing'* theology.

I set foot in a township for the first time in 1999 as part of my endeavours of initiating the activities of Heartbeat. I was twenty-nine years old and this would be my first encounter with the township community socially engineered by the apartheid government.

Women in this community were exposed to triple discrimination: (a) the social engineering policies synonymous with apartheid have marginalised women economically and socially; (b) patriarchy, embedded in cultural and religious discourses, has rendered women voiceless and powerless and (c) HIV and AIDS is targeting the most vulnerable: women and children. Not only are women carrying the brunt of HIV infections, but they also carry the extra burden of caring for the sick and the dying.

Although a new peaceful democracy has dawned on South Africa in 1994, a handful of women ministers were appointed in parliament, and although, a constitution that enshrines women's rights were adopted, the lot of most black women stayed unchanged and unchallenged in their communities. Cultural practices embedded in religious beliefs and hierarchical systems render African women voiceless and powerless. This is exacerbated by their poor economic status. AIDS adds an extra burden of care on their worn-down shoulders.

I was committed to research that would

> *...not only contribute to the transformation of our society through care with the marginalised and disadvantaged, but also address cultural discourses and societal practices that promote injustices* [Kotzé & Kotzé, 2001:viii].

I wanted to render women in previously disadvantaged communities, infected and/or affected by HIV and AIDS, the opportunity to share their stories of care and/or the lack of care. I aimed to ensure that I apply a research methodology true to the ethical principles of post-modern-, contextual liberation- and feminist theology.

LISTENING TO THE STORIES OF WOMEN: ETHICAL CONSIDERATIONS IN THE CHOICE OF A METHODOLOGY

Qualitative research

I strongly identify with the ethical principles inherent to qualitative research, because qualitative research is a form of participatory research, which challenges the traditional notion of the researcher as the expert and blurs the boundaries between *'researcher'* and *'researched'*[7].

Attempts are made to acknowledge and reduce the distance between the researcher and the researched and so control the effects of subjectivity.[8] In qualitative research, the researcher and participant are interdependent in the process.[9] My research became *'co-research'*[10], or, as Dixon [1999:45] prefers, *'co-search'* in the real sense of the word, as my beliefs, my preconceived ideas and my personal feelings were challenged. I realised that

> *...hiding the 'I' is a pretence, a fraud that forces me to hide my passion, to deny who I am, and to pretend that my words are separate from me. Acknowledging the 'I' allows me to reveal myself and my feelings* [Dudley-Marling, 1996:36].

...for a long time minority and disempowered groups became research populations in projects, which advantaged academics, while the ones being studied enjoyed no benefits at all.

One implication of qualitative research for the power-sharing between researcher and researched or participant is that the participant benefits from the research project at the time that it is taking place. Furthermore, the participant in the project is, from start to finish, an owner and co-creator of knowledge.

This has several implications for the ethics of research in that it addresses issues such as accountability, deceit and informed consent. Most importantly, it corrects the injustice that for a long time minority and disempowered groups became research populations in projects, which advantaged academics, while the ones being studied enjoyed no benefits at all.

I am concerned with how the voices of the women are to be heard, with what authority and in what form. This concern was a central issue to my research. Some quantitative research has dismissed, marginalised or maintained control over the voices of others by an insistence on the imposition of researcher-determined positivist and neo-positivist evaluatory criteria, internal and external validity, reliability and objectivity.[11]

...talk about the intimate daily struggles of women infected/affected by HIV and AIDS and their experiences of care or the lack of care, without blaming or rejecting women for what the problem has caused in their lives.

Together with other feminist researchers, I am highly conscious of the absence of women's voices, distortions, and the charge that preparing an account in the usual social science modes only replicates hierarchical conditions found in the parent disciplines, where women are outside the account.[12]

In Africa we do things together through stories

I chose a narrative approach to research encompassing the ethics embedded in post-modern- contextual liberation- and feminist theology.

The narrative world view proposes that human beings are interpreting beings and that we are active in interpreting our experiences as we live our lives.[13] According to White [1995b:14], a narrative perspective proposes that we live according to the stories that we have about our lives, that these stories actually shape our lives, constitute our lives and that they *'embrace'* our lives.

Freedman and Combs [1996:31] suggest that, when therapists (in this case *'researchers'*) listen to people's stories in order to *'make an assessment'* or *'take a history of the illness'* or *'offer an interpretation'*, they are approaching people's stories from a modernist, *'structuralist'* point of view. However, within a post-modern social constructionist world view, it is important to attend to cultural and contextual stories, as well as to individual people's stories. I agree with McLean [1997:17] that an individual's stories have been influenced by the social, cultural, political and economic environments in which the individual has lived. Freedman and Combs [1996:32] quote Mair in this regard:

> *Stories inform life. They hold us together and keep us apart. We inhabit the great stories of our culture. We live through stories. We are lived by the stories of our race and place.*

The narrative approach is a comfortable way to be true to post-modern social-constructionism in the following way described by Müller, Van Deventer and Human [2001]:

> *For us, the aim of the research is not to bring about change, but to listen to the stories and to be drawn into those stories. While the structuralist researcher has objectivity in mind by trying to be an observer from outside, and by trying to bring about change from the outside, the narrative researcher has subjective integrity in mind and strives for participatory observation.*

All the research companions travel together in the scientific vehicle of social constructionism, which Manaka [2001:5] summarises well by explaining *'in Africa we do things together through stories'*.

The narrative approach is derived from a post-modern social construction discourse. This has implications not only for the way in which narrative researchers think about truth, but also for the way in which we try to be truthful in doing research.

> *The 'crisis' of post modernity is not simply one of believing, but of revolutions in patterns of work and leisure, use of technology, the exercise of civic power, participation and citizenship, access to resources, relationships to the environment, and the use and abuse of scientific innovations.* [Graham, 2000:107]

Narrative researchers, such as Müller, Van Deventer and Human [2001:76-96], add to the above the *use and abuse of research* and the importance to deconstruct the sometimes abusiveness of research projects. Therefore, these narrative researchers choose not to use language such as *'research objects'* or *'research population'*, but rather refer to *'research participants'* or *'co-researchers'*.

White, following on from Foucault[14], writes that power is knowledge and knowledge is power. This implies that the ones, who have power, also have knowledge and vice versa. Power and power relations can be seen in everyday interactions, techniques and practises, such as the hierarchising of individuals in relation to one another.[15]

Patriarchal, gender, sexuality, and culture & ethnicity and race discourses, have all rendered power to men in our society, while women and children have been subjugated by this power. These discourses have become dominant narratives which have been internalised by all people who were marginalised by it, because they thought that this is the way things should be. By deconstructing this power or discourses, space can be opened up for alternative understandings or insights, and the speaking out of the ones, who have been marginalised.

Accountability requires researchers to confront the ethical responsibilities involved in the work they are doing with regard to the people they are working with.

A narrative approach offers useful ideas to facilitate a process in which women infected and/or affected by HIV and AIDS, from disadvantaged communities can speak out about their experiences of care and/or the lack of care. White [1998:1] indicates that the primary focus of a narrative approach is people's expressions of their experiences of life. Winslade and Monk [1992:2,3] say about a narrative approach:

> *We live our lives according to the stories we tell ourselves and the stories that others tell about us. Narrative counselling is a deceptively simple therapy. It is based on the idea that we all generate stories to make sense of ourselves and of the circumstances of our lives. However, we are not the sole authors of our stories. Many of the dominant stories that govern our lives were generated in our early experiences of childhood at home, at school, at church, in the neighbourhood.*

These stories constitute our dominant way of interpreting and experiencing our lives. These stories also include experiences that do not fit into people's day to day lives. These experiences are sometimes told, as if they are part of someone's life. People experience themselves as the problem, but, according to White [1988/9:6], *'the problem is the problem, the person is not the problem'*. Externalising the problem opens up fresh ways to talk about the intimate daily struggles of women infected/affected by HIV and AIDS and their experiences of care or the lack of care, without blaming or rejecting women for what the problem has caused in their lives. Furthermore, it gives women a chance to share the stories and experiences that constitute their lives.

A narrative approach emphasises transparency, reflexive conversations and accountability. Multiple reflexive conversations used in post-modern discourse act as ways of deconstructing the power/knowledge relation.[16] In this way, the number of interpretations are expanded and *'subjects'* are made *'participants'*, co-producing research, training and therapy [Kotzé & Kotzé, 1997:37]. Through transparency, the therapy is deconstructed, in such a way that the participants can reflect on the process of communication. It contributes to a context in which people are more able to decide for themselves how they might take the therapist's responses[17]. Thus, transparency involves a deconstruction of the power of the therapist, entering the therapy or research equal to the clients or participants.

Accountability is about addressing power differences. Accountability requires researchers to confront the ethical responsibilities involved in the work they are doing with regard to the people they are working with.

LIVING WITH HIV AND AIDS: A DAY IN THE LIFE OF THE UBISI FAMILY [18]

Nkele greets Mpeki and myself friendly. Her two-year old daughter's face lights up with a smile. The twenty-one year old Nkele is a beautiful girl with stunning features. Her dream is to enrol with the Western College of Engineering later this year (2003). In tears, she once told me that it was very difficult caring for her terminally ill sister all the time. Rose calls on her day and night: to feed her, to give her medicine, to turn her, and to change the towels that she so often soils. *'It is too much'*, she said.

On this warm February morning, she looks like any other twenty-one year old in Atteridgeville, a township on the west side of Pretoria, dressed in a t-shirt and denim skirt. She smiles at my interpreter's (Mpeki) trendy, blue sunglasses. I comment that Mpeki has a different pair of sunglasses for every outfit. We all laugh.

I have brought Rose her favourite chocolate and a fruit juice. By now, I am familiar with the smell of the bacterial infections that accompany AIDS. It used to scare me off and rush my visits to Rose. Rose says she missed me. I realised that I missed her too.

The rash that covers her body is red and swollen. She scratches herself without stopping. The *'special'* vaseline that the (ZCC) Zionist Christian Church gave her doesn't help like it used to. Her father pays more than one thousand rand quarterly for the medicines from the church: a mixture of teas and coffees, an aloe vera drink and the special vaseline. I start scratching intuitively. She says she likes Mpeki's sunglasses. Mpeki breaks off a piece of chocolate and hands it to Rose. She closes her eyes as she slowly savours the taste.

Rose's mother, MaRose, enters into the room. She welcomes me as a family member. *'You are one of the Radebe's now'*, she says. MaRose walks from the informal settlement everyday to come and wash her daughter. The informal settlement is five kilometres away from the house where Rose is staying. She is also taking care of Rose's six year old daughter. I recall how desperate she was the first day I met her. At the time she was emotionally drained of taking care of Rose and she longed for Rose to admit herself to Kalafong Hospital, two kilometres from where Rose stays, but Rose was afraid of going there, she wanted to die at home, not in a strange hospital *'where nurses treat you badly'*.

Mpeki told me that Rose was experiencing some family problems and I asked Rose if she would like to share with me. Rose did not share this story with me on her own account, but she did share it with Mpeki. (During a later incident Rose told Mpeki in front of me that she needed money for food and if she could borrow money from Mpeki. Her choice was to share this story with Mpeki and not with me). The story that Rose narrated is one of bewitchment and stigma. The house where Rose is staying belonged to her grandfather. Her grandfather disowned her uncle because of his relationship with a girlfriend. This girlfriend was bewitching the uncle and he was given the choice either to leave her or to move with her to Mashengu, the informal settlement in Atteridgeville. There, the grandfather said, they could start their own family.

I thought of the way that enemies of a nation were paraded naked through the streets, so that everyone could shout and spit at them. Our situation bore some similarities.

After the grandfather died, the uncle and the girlfriend moved into the house where Rose and her sister stay. The uncle tore up the title deed and Rose's mother did not know who the house belonged to.

The girlfriend now shouts to passers by: *'Stop AIDS, stop AIDS!'* She also sings songs about AIDS, so that every one in the street can hear. She stands outside Rose's window saying that no one cares for Rose. At night, the girlfriend switches off the main power switch. This way Rose cannot see and when she turns she falls off the bed. She is only flesh and bone and the pain with the falling is excruciating. Because she is so weak, she cannot get onto the bed again. Rose says the attitude of the girlfriend used to hurt her, but now she doesn't care anymore.

The uncle doesn't want to take Rose to the offices to access the child support grant for her six-year old daughter, who lives with her grandmother. He doesn't allow AIDS in his car, he says. MaRose has to fetch a wheelchair from the community hall and Rose has to be pushed up the gravel road to the grant offices two kilometres away.

Rose called on Nkele. She said she wanted to talk to her. She told Nkele that she wished Nkele would sometimes just talk and laugh with her. She rushes in and out, because she is always busy. Nkele said that it is true, that she is always busy. The two sisters agreed on a ten minute talk every day. An alternative preferred story has developed in the relationship between Rose and Nkele today.

Today is the day of accessing the grant and Rose asks if I would take her to the grant office. Rose first had to be dressed by her mom, before we could take her. Nkele placed a towel on the back seat of my car. Rose's mother and uncle carried her to the car. She seemed heavy despite her slight frame. I turned the radio and air conditioning on. A market was operating from across the grant offices and many people were hanging out at the market place. Everyone seemed to be eating something.

I stopped in front of the gate where a heavily armed guard was standing. He told me that I could park outside the gate and then push Rose in a wheelchair to the offices. I thought of the humiliation of lifting Rose in front of all these people into a wheelchair and parading her through the crowd. Her legs were covered with open sores and she was very frail. A man appeared with a wheelchair and lifted her roughly and without much ado into the wheelchair.

I walked with Rose and Nkele. It felt as if eyes were piercing right through us. I thought of the way that enemies of a nation were paraded naked through the streets, so that everyone could shout and spit at them. Our situation bore some similarities.

The guys at the payout point explained that the people at the Welfare office had a backlog and, therefore, Rose's fingerprint have not yet been cleared so that her sister can access the grant on her behalf. She will have to come back again next month. I see the disappointment on Rose's face and feel discouraged myself. The staff at the payout point doesn't look at Rose. They smile friendly at Nkele. I catch a glimpse of someone staring at Rose and when I caught his eye, he looked away. We journeyed back again through the staring crowds to the car parked in front of the market place. Someone tried to sell refuse bags to me and I scolded him.

When I opened the back door, I noticed that the towel had spots of blood and pus on it. The man who helped us in the first place again appeared. He seemed in a hurry and grabbed Rose under the arms. The next moment she was screaming. Everyone stopped whatever they were doing and stared at us. I rushed to the other door to open it as she was halfway in and halfway out of the car. I realised she must be in intense pain. The guy managed to get her legs into the car and she curled into a foetus position. There were tears on her cheeks and her big eyes were opened wide with pain. Tears of humiliation, anger and frustration burnt my eyes. Nkele didn't blink an eye when her sister screamed.

I asked Rose if she was OK and she managed a nod. On my way back home, I asked her what hurt so badly and she explained that it was the steel of the wheelchair against her bones. I realised that she had little flesh covering her bones and that she must have experienced intense pain.

As soon as we have carried Rose to the bed, I told the family that I had to leave for a meeting. I had only one wish, to wash the dirt from my body.

CRITICAL REFLECTION

The fact that Rose chose to share certain stories with Mpeki and not with me, probed me to critically reflect on the reasons for her choices. There is a definite difference in the position between the teller, being Rose, and the listener, being myself, as well as between telling the tale and hearing it. I am a white, middle class woman and Rose is a marginalised poverty-stricken woman of colour. She is telling her story in a post-apartheid South Africa, where history will take its course in creating new meaning from the discourses synonymous with 'apartheid.' It is imperative to pay attention to how our multiple identities are construed and played out at any one time in any one context.

> **I am asking a woman of colour to tell her stories, while I am doing the writing up of it? I assumed that because she is a marginalised woman, she wants to tell her unheard story? What about her right to silence?**

Why did I want to listen to the story of Rose? Was it a matter of entertainment, as *'that voices of difference likely to bring us what we can't have and to divert us from the monotony of sameness?'* [Trinh, 1989a:88], I am asking a woman of colour to tell her stories, while I am doing the writing up of it? I assumed that because she is a marginalised woman, she wants to tell her unheard story? What about her right to silence? *'Silence as a will not to say or a will to unsay and as a language of its own has barely been explored'* [Trinh, 1989a:373].

I believe that *'…alliances might then be possible between white, heterosexual, able-bodied and middle- class women and women on the margins'* [Spivak, 1990:47] when we, as researchers, are more secure in our respective commitments to probing beneath the surface of what we know, to how we know.

When I started my research, I honestly couldn't claim that I was acting only, or even primarily, in my co-researcher's interests. I wanted to do this research to a) obtain credibility for myself and my organisation in the HIV and AIDS care field and b) obtain a doctorate degree. My own self-interest, rather than the client's best interests, controlled the initial care towards the research participant. However, my interest has changed to such an extent that my relationship with Rose has become more important than my thesis. I realised what started off as a selfish endeavour with a stranger, ended up as a journey with a friend. An alternative research story has developed.

Explaining the aim, methodology and notion of multiple narrative meaning to educated people in their own language already poses a challenge...

In this research project, there was only partial sharing of power, because I identified the research problem and I determined the research questions and aims. However, the co-researcher determined the outcome of the questions and aims. Although, there was only partial sharing of power between the co-researcher and myself, I endeavoured to share power through transparency, frequent reflection and accountability. My aim in power-sharing was to ensure that the co-researcher benefited from the research project at the time when it was taking place.

Before even engaging with my co-researcher in conversation, the relational power discourses already existed by the mere fact that I am a white, middle-class, well-educated woman doing research with a black, impoverished woman without any tertiary education. I knew from my experience with my work in black communities the past four years (1999 – 2003), that the expectation already existed that I would bring some resources into the Ubisi family, as I am white. In South Africa, white people, as the beneficiaries of 'apartheid', are still perceived as *'resourceful'* and black people as *'resource-less'* even though, there is a rising class of black professionals.

Although, I realised the importance to account Rose's story in her own language, I was constraint by the fact that I could not speak SeSotho. Rose had the opportunity to convey her story in her own language, but the fact that I couldn't understand SeSotho, hindered me from capturing her story in her own words. To this extent, I was incapable of allowing marginalised women's voices to be heard, as they tell their stories. I tried to be as accountable as possible by reflecting on previous discussions before engaging in new discussions and documenting the words of the translator. But this was not my co-researcher's own words, it was already an interpretation. I apologise in this study for the *'distortion'* of my co-researcher's voice.

Is informed consent really possible in doing cross-cultural narrative research with poorly literate people, who are marginalised by society? Explaining the aim, methodology and notion of multiple narrative meaning to educated people in their own language already poses a challenge, as they are unfamiliar with the social research jargon. I realised that my translator also didn't have a clear understanding of the aim of my research and she had to translate it into another language to a poorly educated co-researcher. I am however, not prepared to silence Rose's voice by excluding her from the project on the notion that she doesn't grasp the meaning of multiple narratives, as Gottlieb and Lasser (2001)[19] suggest. As a feminist and contextual liberation theologian, my ethical responsibility lies with creating the opportunity for the voiceless to tell their stories. As an alternative to once off informed consent, I acquired continuous consent from my co-researcher as the narrative process unfolded, as power discourses were deconstructed and as Rose shared more and more of her story.

I sensed unease with my co-researcher, when I initially interviewed her through loosely structured interview questions. The many questions stemmed her uneasy and seemed abusive to me. I later adopted a purely conversational style and started to participate in the daily activities of the family, as illustrated in the narrative above. It was through this activity that power was deconstructed to such an extent that Rose and her family started sharing family problems and stories of stigma and abuse, as illustrated in the story of the girlfriend, who turns off the main switch at night. I agree with Oakley [1986:41] that

> *...the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship.*

I became an honoured member of the family through announcement. This brought new ethical matters to the forefront. My opinion was asked on family and community matters. I gave it only when asked and assured the family time and again that this was only my opinion and not necessarily the right one. In close family matters, as is the case with the relationship between Rose and her sister, Nkele, I took on the role of facilitating the outcome of an alternative story of care.

A poorly educated woman, according to westernised standards, who was terminally ill and whose life story was influenced by cultural discourses totally different from my own cultural background, who could not even speak my language, advised me on my life.

The discourse of the medicines posed, what I thought at first, an ethical dilemma. Rose was not using the Western medicines prescribed by the clinic, except for the *Stopitch*, but she was using the traditional medicine of her church. I felt at first that this was adding to the deterioration of her health and I tried to persuade her to abandon the traditional medicines for the Western medicines that I believed were effective. It was only after I experienced that the *Stopitch* proved ineffective for her itching, that an alternative story developed in my mind about the use of alternative, '*spiritual'* medicines.

I could not hide the *'I'* in the circumstances that I was working. The smell of the bacterial infections affected me to such an extent that after my first encounter, I got nauseas at food that smelled strongly, for the first time in my life. When Rose wanted me to look at her bedsores, I changed the subject, because I could not face it. There was a time that the family was so depressed because of Rose's illness, that I prayed that she would rather die. I was repulsed by the open sores on Rose's legs that oozed blood and pus. I went through a phase of denial when I couldn't *'fix'* Rose's condition with Western medicines. I got angry with the way she was exposed to the community and the rough manner in which she was handled by volunteers at the community hall. I scolded the vendor, who sold black plastic bags, while I was trying to cope with the difficulties that Rose faced.

Rose also asked me about my family and I shared many stories with her about happenings in my life. She gave advice, which I followed and which had a positive outcome. A poorly educated woman, according to westernised standards, who was terminally ill and whose life story was influenced by cultural discourses totally different from my own cultural background, who could not even speak my language, advised me on my life. The discourse on the expert possessing the knowledge in my culture was challenged radically. A new alternative story on expert knowledge formed in my mind.

I could see the research participant benefiting from the research. I reacted on Rose's definition of care. Care, according to her, was to laugh and talk with her and to give her to eat what she likes and not what other people decide on her behalf. She wanted chocolate and fruit juice and I brought her chocolate and fruit juice. She conveyed to Mpeki that she misses me. She got upset when I skipped a visit.

Through caring for my co-researcher, I deconstructed the discourse of race and culture and I was accepted, as one of the family. My friendship with the Ubisi family has become part of my life and is no longer a research project only. It is not only unethical, but also impossible for me to break of ties with the Ubisi family. I am committed to this family and this is true to a hermeneutic off deed as described by Bosch[20]. I am indeed *'doing'* theology.

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FOOTNOTES:

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[16] Kvale, S. 1992. *Psychology and postmodernism.* London: Sage. See also Steier, F. 1991. *Research and reflexivity.* London: Sage.
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[18] The names are fictional.
[19] Gottlieb, M.C. & Lasser, J. 2001. Competing values: a respectful critique of narrative research, p 31-36. In *Ethics and Behavior,* 10508422, Vol 11, Issue 2. p 32.
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Lene Øverland

The Role of HIV and AIDS communication

The feminisation of the HIV and AIDS epidemic

All forms of communication are important in shaping the social environment in which HIV and AIDS exist. This article explores the role of mainstream media versus alternative media productions. It argues that both can play an important role in addressing the feminisation of the HIV and AIDS epidemic. However, the potential of media messages in addressing the feminisation of the HIV and AIDS epidemic depends on how they are produced, by whom they are produced and on how they are communicated. This article focuses on how the involvement of HIV positive people in the production of media and in the facilitation of media messages can contribute to effective HIV and AIDS communication.

HIV AND AIDS COMMUNICATION

In South Africa, large amounts of resources have been dedicated to HIV and AIDS information and communication campaigns. The content of these have primarily focused on prevention messages – *'on how to prevent the spread of HIV touninfected people'*. The content have further largely focused on the medical aspects of the disease and singled out high-risk groups, such as sex workers and injecting drug users, for specific attention.

This discourse has brought about a moralistic response to HIV and AIDS, whereby *'others'* are blamed for the spread of the virus through *'risk'* behaviour. This has marginalised vulnerable communities, and hampered the implementation of effective prevention strategies.

Women are especially vulnerable to HIV infection for biological and socio-cultural reasons. Gendered imbalances and realities, such as women's limited ability to negotiate safer sex practices and women's social status mostly described as subservient to men have to a large extent defined women's greater vulnerability to HIV. Information and communication campaigns often communicate statistics also proving the extreme high levels of violence against women, including sexual violence. However, the fact that violence places women at greater risk of HIV infection is seldom addressed in ways that empower women. Furthermore, accurate and relevant information that would allow women to move away from *'victim-hood'* and become *'agents of change'* are seldom communicated.

Prevention messages and campaigns, including the internationally well known ABC (**A**bstain, **B**e Faithful, **C**ondomise) prevention message, have failed to take into account how existing gender imbalances are impacting on individual behaviours and choices and, hence, vulnerability to HIV infection. The ABC prevention message gives no answers to questions such as *'Should a woman who is faithful to her husband condomise?'*, *'How can a woman negotiate condom use with a man who is hesitating to putting his penis into a 'plastic bag'?'* This message does not even answer the most common everyday challenges and has done little else than failing women and girls.

MAINSTREAM MEDIA PORTRAYAL

The South Africa mainstream media reports on the HIV and AIDS epidemic in a highly politicised way[1]. Further mainstream media carries dramatic reports that often compromise the right to privacy and dignity of people living with HIV and AIDS.

Most of the mainstream reports on HIV and AIDS lack educational content and gender awareness. Apart from sex workers, who are often depicted as *'vectors of disease'*, women are invariably depicted as *'HIV-positive mothers'* or as pregnant women who are of concern only insofar as they may infect their babies or leave their children as orphans.[2]

The mainstream media contains little, if any, information targeted specifically at people living with HIV and AIDS. Further, the voices of people infected with HIV are few and far between. When people living with HIV and AIDS are portrayed, it is often as *'patients'* in need of care and compassion.[3] The mainstream media have also tended to feature high profile people, rather than ordinary people.

The mainstream media has to a large extent made HIV and AIDS a woman's issue by both blaming women for the spread of the disease and by giving women the responsibility to *'fix'* the problem, which they, according to the most common messages, can do by *'behaving correctly'*.

The content of HIV and AIDS mainstream media portrayal can broadly and crudely be described as sensationalist, and the media thus, arguably, contributed to the feminisation of HIV and AIDS. One example is how the media portray sex workers as *'vectors of HIV transmission'* or more crudely as *'bad women'*. Another example of how the media portray women is as *'victims'* of HIV and AIDS. Finally, by *'avoiding'* to provide access to information that will make the consumers think for themselves and make informed decisions about their own lives, the

> **The ABC prevention message gives no answers to questions such as *'Should a woman who is faithful to her husband condomise?', 'How can a woman negotiate condom use with a man who is hesitating to putting his penis into a 'plastic bag'?'***

mainstream media has contributed to the feminisation of HIV and AIDS.

WHO OWNS THE MAINSTREAM MEDIA?

Ownership, editorship and production methodology are crucial agents in mainstream message production. In South Africa, the mainstream media is mainly owned and managed by white males, several of them with limited intellectual investment in South Africa. Very few of these males have taken the effort to develop and/or implement gender policies in their newsrooms, which could potentially encourage gendered analysis of HIV and AIDS. Further, most of the mainstream media is produced by journalists who, I dare say, write about HIV and AIDS without, or at least not admitting to, any personal experiences of HIV and AIDS, other than when in contact with their interview subject. Neither ownership nor management nor production methodology encourages reporting that addresses the gendered nature of HIV and AIDS.

ACCESSING THE MAISTREAM MEDIA

Gaining access to information through the mainstream media is challenging. Many South Africans, and especially women, cannot afford buying a newspaper, a TV, a radio or access the Internet. Further, many South Africans, and again mostly women, are not able to consume media in the preferred broadcast or print language. Finally, many people, and again especially women, do not have the time or the energy to critically engage with the mainstream media as a woman's day is filled with all sorts of domestic and other work related activities. As a result, the media reaches the elite and the few others who can afford gaining access.

FILM A TOOL FOR DEVELOPMENT

Access to alternative media, such as community media and media produced by developmental organisations, is in many instances as challenging as accessing mainstream media. However, there are a few exceptions to the *'rule'*.

Day Zero, a film production company based in Cape Town, launched the 'Steps for the future' (STEPS) project a few years back, and produced 38 documentaries and short films, as part of a media advocacy campaign intended to promote debate and discussion around HIV and AIDS related topics. These films portray unconventional stories that celebrate the strength of the people represented, and individual characters reflect on, and share, their experiences of HIV and AIDS. The characters of the films challenge fears with stories of hope and dismantle discrimination and ignorance through cultivating tolerance.

The characters of the STEPS films empower individuals and communities through facilitating discussions following the screenings of their films, and as such they provide access to education and information and promote the belief that *'actually life is a beautiful thing'*.

The most compelling success of the film series is the impact at a grassroots level across Southern Africa. Films are screened regularly using mobile cinemas in Lesotho, Zimbabwe, Zambia, Mozambique and South Africa, as well as in communities and schools across the region. Through these screenings it becomes possible to engage the audience in dialogue.

The STEPS films achieve their optimum potential when shown to groups and followed by facilitated discussions. This participatory approach encourages people to think for themselves, and it contributes to learning and working together to solve challenges at local, national and regional level.

The films have also proven to have a life after the screenings. STEPS has found that messages from facilitated screenings are being shared in the communities where the films are shown. This means that on average, each screening would impact upon at least ten times the amount of people watching a given screening.[4]

MEANINGFUL INVOLVEMENT OF PEOPLE LIVING WITH HIV AND AIDS

Sesotho Media & Development is a non-governmental organisation based in Maseru, Lesotho. The organisation works in partnership with

> **In South Africa, the mainstream media is mainly owned and managed by white males, several of them with limited intellectual investment in South Africa.**

> **...a two-way communication process whereby the audience ... are offered a safe place to ask intimate and difficult questions, and be given information relevant to their needs – not according to the needs identified by HIV and AIDS *'experts'* or health reporters.**

STEPS and operates a mobile video unit. Sesotho Media & Development combines the use of film and facilitators, who are living with HIV and AIDS, guide discussions.

Thabo, Thabiso, and Malousi, who are all facilitators at Sesotho Media & Development, are also the central characters in Dumasani Phakati's documentary film *'Ho Ea Rona'* and in Theboho Edkin's documentary film *'Ask me I am Positive'*. These films are popular among audiences in Lesotho for its depiction of men dealing with their HIV status in an environment that is familiar to the audiences.

The most striking aspect of screening *'Ho Ea Rona'* and *'Ask Me I am Positive'* in Lesotho is that the energetic characters in films facilitate the discussions. For audiences, the reality of HIV and AIDS is brought to life through the documentary viewing, and reinforced through discussions with the characters. While this kind of synergy is not always possible, it is important to note that in the Lesotho context, the common response from audience members is that *'seeing is believing'*. The films are important because they make people believe.

SO WHAT DISTINGUISHES THESE FILMS FROM WHAT WE SEE ON TV EVERY DAY?

One crucial aspect that distinguishes the STEPS films from other film series is the active and meaningful involvement of people living with HIV and AIDS through the production and outreach process as a priority element of the communication strategy. In other words, the process offers an opportunity for a two-way communication process whereby the audience of the films are offered a safe place to ask intimate and difficult questions, and be given information relevant to their needs – not according to the needs identified by HIV and AIDS *'experts'* or health reporters.

The underlying philosophy of STEPS is that confronting the indifference, irresponsibility and stigma that surround HIV and AIDS is the first step towards taking responsibility for ourselves and for one another. STEPS has documented that viewers throughout the region empathise with the characters in the STEPS film collection. The films give people a chance to look inside themselves and then to look at one another in a new light.

These STEPS film screenings are not directed specifically at women or men. The films do not provide all the answers to our questions – they rather raise more questions and heat our emotions. Their messages reach us, as human beings, and make many, both women and men, realise and take responsibility for our own and other people's lives.

BRINGING IT ALL TOGETHER

Information about HIV and AIDS is crucial in our lives. However, the potential of HIV and AIDS communication to make a change in our lives depends on how we receive information and the extent to which we are able to interact with the information we receive. One-way communication, as provided by the mainstream media, does not allow the receivers of messages to ask questions and receive answers. However, two-way communication, as provided by a few alternative media interventions, opens up for dialogue between sender and receiver.

In my view, three key words are crucial to HIV and AIDS communication

- A production methodology that both involves and takes the target audience seriously;
- A distribution strategy that involves people infected and affected by HIV and AIDS; and
- An intervention based on dialogue rather than *'instruction'* and a moralistic approach.

At stake in this article is the feminisation of HIV and AIDS. Before producing new messages, we need to ask ourselves how we can best address this issue: Do we need to produce information specifically targeted at men to reverse the HIV and AIDS epidemic? Has time come to address HIV and AIDS as an issue that affects us all no matter what our identities are? Do we need to focus our energies on mobilising women and men collectively to develop capacity to improve our abilities to change our own lives?

FOOTNOTES:

1. Øverland, L. 2004. Managing the Message. *A baseline snapshot of HIV and AIDS media coverage in Mozambique, Namibia, South Africa and Zimbabwe in the context of governance.*
2. Ibid
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4. STEPS, Impact Study, 2003.

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Campaign on **access to social grants**

Approximately 60% (11 million) of children in South Africa live in dire poverty, on less than R200 a month. Approximately 30% of the country's population experience food shortage. For many children, this means starvation. Recently, at a children's workshop, a 15-year old child said: *'for my side the biggest problem is food. Sometimes we end up not getting any food at home and don't know what to do'*. As of March 2004, over 4.3 million children were receiving the Child Support Grant (CSG). However, an estimated 56% of children below the age of 18 years still live on less that R215 a month and receive no form of social assistance from the government. Although, there is an improvement, more needs to be done.

These are some of the problems faced by children today, despite the South African Constitution[1] providing in Section 27(1)(c) that if a parent is unable to provide for a child's basic needs, then the State must do so. Section 28(1)(c) of the Constitution further guarantees children the right to basic nutrition, shelter, basic health care services and social services.

Social assistance is non-contributory money given by the State to help persons provide for their needs, intending to alleviate poverty. According to the Social Assistance Act (No 13 of 2004), children are entitled to Child Support Grants, Foster Care Grants and Care Dependency Grants. The Child Support Grant is available to a primary caregiver of a child under the age of 11, who qualifies in terms of the means test. A primary caregiver is a person who is above the age of 18 years. The maximum amount payable for the grant is R170 per child.

The Foster Care Grant is payable to a foster parent provided that the child has been legally placed in their custody by a court. The maximum amount payable is R530 per child. Children who have been orphaned by the death of their biological parents are automatically considered to be in need of care and, thus, eligible for foster placement and the grant.

The Care-Dependency Grant is available for children living with disability, under the age of 18 years, who require permanent home-based care. Once the child's health improves, s/he no longer qualifies for this type of grant.

There is a definite need for social grants for HIV infected children, since such a grant could be used to provide children with adequate nutrition and medication that will strengthen their immune system. Currently, a child will qualify for the Child Dependency Grant when HIV-related illnesses render the child severely ill and in need of permanent home-based care.

People experience numerous challenges when attempting to access these grants. Firstly, many applicants do not possess the required documents and the costs of travelling to the offices of the Social Welfare departments, to apply for grants and/or to obtain photographs, identity documents and birth certificates are excessive. The existing administration is under-resourced and welfare officers do not communicate accurately and effectively with applicants. There are also cases of abuse and misuse of authority amongst administrative officers. The application-processing period is lengthy and the means test is inadequate. Many children in need do not qualify in terms of the current means test threshold. The maximum earning rates allowed are R800 per month in urban areas and R1100 per month in informal dwellings or rural areas.

As of April 2005, the Child Support Grant is available for children up to the age of 14 years. There is, however, also an increasing occurrence of households run by minors below 18 years of age. These children are in need of the grants available, but are unable to access them due to their age.

Finally, most people do not have access to the grants, due to the lack of knowledge of their right to access the grants.

In light of the above challenges, some of the possible solutions include:

- Provide efficient administration to shorten the application-processing period;
- Monitor the administration in order to prevent an abuse and misuse of authority;
- Increase the amount allocated in the means test, which would result in a greater number of children in need eligible for the grant;
- Increase the age limit of the grant to 18 years; and
- Create public awareness by providing workshops and distributing pamphlets.

The role taken by non-governmental organisations such as ACESS (Alliance for Children's Entitlement to Social Security) and Black Sash is to assist the caregiver in trying to obtain the documentation they require in order to access these grants. We, at the Campus Law Clinic, are developing a media campaign to create awareness around the issue, aiming to target and enlighten members of the public of their right of access to these grants.

For any further information please contact the Campus Law Clinic on +27 31 260 2446 or at bernardr@ukzn.ac.za.

FOOTNOTE:

[1] The Constitution of South Africa, Act 108 of 1996.

My two years in rural KwaZulu Natal

Facing the realities of poverty, navigating the complexities of HIV and AIDS stigma and discrimination and embracing the dawn of HIV treatment[1]

Lilian Benita Mboyi

Background of area

Vulindlela is a rural community situated about 150 km west of Durban. There are seven Primary Health Care (PHC) clinics that are nurse-managed public sector health centres, providing comprehensive primary care. The clinics provide family planning (FP) services, including male condoms, syndromic treatment of STIs, antenatal care, early childhood services, treatment of opportunistic infections and voluntary testing and counselling services. The PHC clinics are linked by ambulance to the regional referral hospitals, namely Grey's Hospital (about 30 minutes away), and Edendale Hospital (about 20 minutes away).

There are approximately 60 organisations in the area, representing a variety of civic interests, such as youth, women, religion, politics, and housing. Several non-governmental organisations are currently providing HIV prevention and home-based care services to the community. In contrast to other rural areas in KwaZulu-Natal, employment opportunities exist within Vulindlela through extensive forestry projects. In addition, men seek employment in Pietermaritzburg and Howick. These men usually commute daily or live in Pietermaritzburg during the week and return home over the weekend. Women are also employed by the forestry projects and engage in communal income-generating activities, such as gardening and sewing.

Inroads into the community

I joined the CAPRISA research station in Vulindlela at the end of January 2004 with brimming excitement of being away from the 'hum-drum' of urban corporate life and to enter the gentle pace of a rural setting. It took a few weeks to adjust to communicating in Zulu on a daily basis, as opposed to English, and managing eight field workers. There was a lot to learn about research and also about the people I was going to be working with. I had to get used to the culture of politeness, being captious and generally tapping onto my long forgotten humble nature.

In the first field visit, I felt beaten, shocked by the poverty. I had read about it, but nothing had prepared me for the lived reality. At one home in particular, we found an old woman with two grandchildren in a dusty and bare hut. I could smell and touch the poverty. The children were eating what seemed to be left over from the night before and did not seem appropriate for breakfast. It was a very cold day and the two children were barely dressed. There was not even a warm fire in the huge round hut, but a few dying cinders, probably from the night before. The woman explained that the parents of the children were away looking for work and not often home. The old woman seemed like she had nothing to her name, let alone enough to feed the children, and because the children have no birth certificates, she had no access to the Child Support Grant. Her meagre income came from working on a contract, clearing the roadside.

This was a picture of what life was like in this village. I realised, life was hard in this place.

Every morning on the way to work, I was greeted by sights of women carrying heavy logs on their heads to use as fire wood. The women always seemed to have walked long distances, machetes in hands, into the commercial forest to chop the wood. The forest provides casual employment for a lucky few. Others are domestic workers in Howick, some work in industry. This is few and far between. Most women, and some men, are at home. Children do attend school, and, fortunately, the attendance is high. But it seems – school is something children do, but with not much promise of a bright future. The education is mediocre with not many facilities to prepare children for the future. Prioritising at home draws children away from school work, with no option for extra lessons. With the parents barely educated, there are hardly any educational resources at home.

In some of the households, there are so many young children under the age of six, one could be forgiven for thinking it is a crèche. This is also related to childhood pregnancies and orphans. There are some child-headed households as well. Income is in the form of Child Care Grants, Foster Care Grants and there are some pensioners. In some households, nobody works, and this was quite familiar. Even though opportunities exist for many people to apply for grants, these are very difficult to access, since many people do not have birth certificates.

Death is a feature of this landscape, as evidenced by the graves, fresh and old, in almost every homestead. There is so much death – every weekend there is a tent for burial. By the end of the week, there are always a few tents pitched around the village. The deaths could be attributed to HIV, but not necessarily.

Administering the study

This cross-sectional study was conducted from February 2004 to July 2004. The household questionnaire recorded data on the number of occupants at the selected household; demographic characteristics of the occupants, including more detailed information on children under 18 years of age; the type of dwelling; source of water; latrine facilities; number and types of appliances in the household; religious and social affiliations; general health status of occupants; and mortality rates and cause of mortality in the past year.

The respondent survey also utilised a structured questionnaire that included closed and open-ended questions. The questionnaire included items on socio-demographic characteristics of the respondent, mental health, willingness to participate in HIV prevention research, faith-based organisations and their response to the HIV and AIDS epidemic, attitudes to people living with HIV and AIDS, virginity testing and gender.

Between November 2004 and January 2005, after analysing the results of the stigma and discrimination section of the quantitative study, we supplemented our findings with focus group discussions held with different groups in the community. Some of the discussions highlighted the difficulties people have with HIV testing and the actual barriers that lay in seeking treatment early.

Some results worth noting

Although, at the beginning of this specific research two years ago, we were already offering VCT, there was no treatment offered at the time. It was, therefore, of note that even at that stage, 28% of the respondents have had an HIV test in the past. Of those who had not had an HIV test in the past (n=429), the majority (63%, n=272) indicated that they would like to have an HIV test, and 36% (n=156) would not want to have an HIV test.

There are issues that came up in the survey and were backed up in the focus group discussions indicating that there were problems associated with testing. The feedback from the field workers during the debriefing sessions indicated that respondents were divided in their responses to the stigma and discrimination questions. At one level, respondents seemed understanding and accepting of the people infected and affected, and, at another level, respondents seemed to harbour fears of being stigmatised and discriminated against, were they to be found to be infected with HIV. Some of these fears stemmed from witnessing instances where a family member who had AIDS was isolated when they were sick or were not allowed to live in the household. Factors influencing disclosure included perception of limited knowledge of HIV test and/or disease among family members and community, as well as fear emanating from the understanding that HIV and AIDS is fatal. Most felt comfortable about disclosing their HIV status to family, but had concerns about disclosure outside of the family.

Other factors impacting disclosure of HIV status included concerns about adding to the emotional burden of the family, particularly where a death had already taken place previously. There was also the issue of embarrassment stemming from fear and shame.

Accessing treatment

The CAPRISA research facility started offering treatment to people infected with HIV and with a CD4 count of less than 200, in July 2004. Uptake was very slow and reluctant at the beginning. In the early days, we saw mostly people who were close to dying and who were not strong enough to start on the treatment regiments and largely needed to be referred to Greys Hospital or Edendale Hospital for other critical care. Several died in the clinic next door, either while waiting for an ambulance or had just arrived too late. This was emotionally a heavy time for the staff, because generally people were beginning to feel the burden of the AIDS epidemic translated into real time deaths on the door steps of medical care.

However, by the end of the year, there were beautiful stories emerging in the form of people, who had come to us with very low CD4 counts, blossoming back into the people that they used to be, before AIDS had struck them down. When they first came here, some of these people had to be carried into the consulting rooms to be attended to. This was definitely a good sign to send out hope to the whole community. Although, there were only ten such patients by the beginning of 2005, positive messages were reaching the community.

Hope for the future

As part of the CAPRISA AIDS Treatment (CAT) programme, we have tested, between October 2004 and September 2005, a total of 2469 people. Of these, 2172 were female and 297 were males. Of all tested, a total number of 1265 (1011 females and 254 males) have been registered on the CAT programme. Between October 2004 and September 2005, we have placed a total of 353 people (261 females and 92 males) on ARVs. It is encouraging to see these numbers increasing by the day, as we strive to initiate as many eligible people on treatment as possible.

It, indeed, seems a long way from when I started working in this community and people were still fairly reluctant to talk about HIV and AIDS. Even though the deaths are still occurring, more and more people are getting up to seek help while it is still early. This is a very encouraging signal for the future of this place, and many others where AIDS treatment is becoming a reality.

FOOTNOTE:

1. The articles is on personal reflections and field notes, as well as data from the CAPRISA AIDS Treatment programme (Oct 2004 to Sept 2005), from the Demographic Health Survey conducted Vulindlela, in the Inadi area (Jan 2004 to July 2004), from the Respondent Survey conducted in Vulindlela, in the Inadi area (Jan 2004 to July 2004), and from the focus groups discussions on HIV and AIDS Stigma and Discrimination held in the Inadi area of Vulindlela (Nov 2004 to Jan 2005).

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Miriam Madziwa

HIV and AIDS realities:
The Zimbabwean context

Zimbabwe's continued economic meltdown spells doom for people living with HIV and AIDS in the country, especially women and children. The economic crisis characterised by shortages of basic foodstuffs, fuel and foreign currency, coupled with raising inflation is making survival a challenge for most Zimbabweans. The challenges are even greater for women infected and affected by the HIV and AIDS pandemic.

ECONOMIC MELTDOWN

Inflation, which at the beginning of October 2005 stood at 360 percent and is projected, to have risen to 400 percent by year-end, is making it difficult for women to buy food and other basic commodities. In instances where the woman is infected, her ability to have a balanced diet, as recommended by health workers, has been eroded by inflation. Consequently, women and children are forced to survive on one-meal a day comprising mainly of sadza (thick mealie-meal porridge and boiled spinach.) And, unless the country imports more grain urgently, by the end of the year, putting this single meal on the table will be almost impossible for most families.

In instances when commodities, such as sugar, salt and cooking oil, are available, consumers have to queue for long hours and there is often the threat of harassment by police officers when anxious buyers turn rowdy in the queues.

Women living with the virus, or taking care of ill partners and children, cannot spend the day queuing thus their diets are further compromised. The alternative is to buy the goods on the 'black market', where prices are triple or even five times more than the gazetted prices.

Most companies producing basic items, such as soap and disinfectants, have closed down. The result is that such products, essential in home-based care, are in short supply and expensive when available. Without these products, women who carry the major burden of home-based care find it difficult to take good care of themselves and the ones in their care.

In rural areas, care givers report that they often cut down on the recommended doses, thus, exposing themselves to HIV infection. The net effect of the economic crisis is that women's capacity and ability to take care of themselves and their families has been severely compromised. In desperation, some women are turning to prostitution to look after their families and, thus, exposing themselves to HIV infection and re-infection.

Strategies required would be political intervention and commitment to a macro-economic turn around. At a household level, women and children could be encouraged and assisted to start gardening projects. The produce would help families have balanced diets without spending too much money. In arid areas, especially in the southern region, some AIDS service organisations have started such projects and are giving drip kits that maximise water usage for the plants to participants.

A 'stopgap' measure is to resume food handouts, especially for families and people living with HIV and AIDS.

OPERATION MURAMBATSVINA

In June 2005, the government conducted a clean-up exercise, code named Operation Murambatsvina (Drive Out Filth). According to a United Nations report, the operation left 700 000 people homeless and/or without a source of livelihood.

With respect to HIV and AIDS, the operation erased the numerous gains that AIDS service organisations had recorded during the past few years. The displacement and forced relocation of individuals from urban to rural settings disrupted access to medical care. Women and children, who were on public antiretroviral drugs (ARVs) programme, were relocated to rural areas where there are no clinics and access to ARVs is impossible. In such instances, the women and children have been forced to stop taking the drugs to the detriment of their health.

Additionally, support groups that had taken years to establish, crumbled as members were scattered all over the country. Some of the victims succumbed to opportunistic infections, such as pneumonia, from spending long winter nights in the open without warm clothing. Others contracted tuberculosis from sleeping in crowded church halls and holding camps alongside sputum positive patients, who were no longer on treatment. The opportunistic infections have gone untreated, leading to an increase in the number of deaths.

Reversing the adverse effects of Operation Murambatsvina will require AIDS service organisations to remobilise communities and to resuscitate support groups. The same organisations would also need to trace people living with HIV and AIDS who are on ARVs and help them continue taking their medication with the possibility of putting some of them on second regime treatment, which is not readily and cheaply available in the country. In Bulawayo, churches, working with MSF (Doctors without Borders), have started offering limited medical care to some of the victims.

FALLING HEALTH CARE STANDARDS VERSUS RAISING MEDICAL COSTS

The economic crisis, alluded to earlier, is causing havoc on Zimbabwe's health delivery system. Health care standards are dropping while costs continue to rise, due to the economic turmoil. Health workers, doctors and nurses are leaving the country for neighbouring South Africa, Australia and United Kingdom, where remuneration and working conditions are better. The remaining personnel are failing to cope with the number of people requiring treatment. In most hospitals, an average of 75 percent of admitted patients are suffering from HIV- related illnesses. Besides human resources, Zimbabwe's health institutions lack adequate and affordable drugs and equipment.

The drug shortage is a result of foreign currency shortages. The country has several pharmaceutical firms that are failing to produce badly needed medicines, because they do not have the requisite imported materials.

People living with HIV and AIDS taking locally produced ARVs could soon be forced to change combinations, because the local manufacturer, Varichem, has stopped production, citing foreign currency shortages. A month's dosage bought from public hospitals cost $50 000. Comparatively, imported generic ARVs are being sold for $1 500 000 for a month's supply. A number of people, who were getting their ARVS through private suppliers, are turning to public institutions for survival. There is, therefore, stiff competition for the drugs and, consequently, women are the worst affected.

Health workers are finding it difficult to adequately monitor people living with HIV and AIDS. Doctors report they are unable to do CD4 counts, because the necessary reagents are not available. Complimentary tests, such as viral load, are hardly done at public hospitals. As a result, doctors are putting patients on ARVs, based on symptoms presented, as staged by the World Health Organisation.

The majority of women on the public ARVs programmes are unemployed widows, who are struggling to raise $50 000 for their monthly dosage. Most of these women were involved in low-income projects, such as peanut butter, soap and candle making and vegetable vending. These income-generating activities have been outlawed, since Operation Murambatsvina started. Medicines for opportunistic infections are also in short supply, and when available, are unaffordable for many people living with HIV and AIDS. On the other hand, men are better off, because the greater majority are employed. They can afford medical aid schemes that help to buy the life-prolonging drugs while some companies have started buying ARVs for their employees. Companies are being encouraged to include spouses and children as beneficiaries of their ARV programmes.

From the above scenario, it is evident Zimbabwe will miss its 3 by 5 goals of having 100 000 people on ARVs the end of the year. Health and Child Welfare officials have since revised the figure downwards to 40 000.

It is hoped that the recently approved Global Fund disbursement of funds to Zimbabwe will be used to buyARVs and materials needed in combating the pandemic. An additional strategy would be to establish more donor funded ARV distribution points, such as The Centre in Harare, throughout the country.

VOLUNTARY COUNSELLING AND TESTING

Voluntary counselling and testing is slowly gaining acceptance, as Zimbabweans overcome fears of discrimination. Youths and adults are visiting centres to determine their status for a variety of reasons. Unfortunately for many expecting mothers, HIV testing is still not voluntary. Testing is routine for all pregnant women. Most of Zimbabwe's statistics on prevalence are based on results of pregnant women. Because the testing is not informed, when most of the HIV infected women get to know their status, they do not tell their partners, for fear of rejection. As a result, the objective of testing is lost.

An added problem for women is the increase in discordance among couples. There have been reports in the media of women, who have tested positive and been able to convince their partners to test and the spouses' results come back negative. In most such instances, the males have abandoned the women.

Affected women complain of inadequate counselling and knowledge on why and how discordance occurs to enable them to explain to their partners. Few women know and understand how the physiological differences between the sexes have a bearing on HIV infection. Being HIV positive is still considered a punishment for promiscuity and, if a woman is tested positive and the spouse tested negative, the woman is labelled *'loose'*.

Women taking care of infected children have the added burden of getting treatment for the children. Medication for children is equally difficult to come by and with regards to ARVs there are no suspensions available for children. Instead, mothers have to break the adult tablets and coax their children to drink the pills. Not an easy task.

To reduce suffering among women, more work has to be done to encourage VCT workers to fully counsel clients, especially expecting mothers. This would entail hiring more counsellors. Organisations, focusing on HIV and AIDS as it affects women and children, must detail and disseminate information on infection as new research findings are published. Such information needs to be translated into local languages, for the majority of English illiterate women to be informed.

Additionally, organisations, such as Padare Men's Forum, Africare and John Snow International, are running programmes to try and get men and youths involved in care and support of people living with HIV and AIDS to lessen the burden on women.

SEXUAL VIOLENCE

Sexual violence continues unabated in Zimbabwe. Women and girls are raped and abused by spouses, relatives, guardians and strangers, without much effort being made to bring the perpetrators to book. Marital rape, although legally recognised, is not socially accepted. As a result, married women continue to be exposed to HIV infection from promiscuous husbands, who openly have mistresses commonly known as 'small houses' and yet, refuse to use condoms.

Mistresses who are financially dependent on rich male partners also have little say in how and when to have sex. Any suggestions could spell the end of the relationship with dire consequences for the impoverished women. The economic hardships are forcing many women to remain in violent relationships that often expose them to infection and re-infection to HIV.

Young girls are equally at risk from parents, guardians and teachers. This year, the talking point among gender activists is the sexual abuse and rape of over 50 schoolgirls by a gardener and a teacher at a primary school in Macheke. The frightening incident revealed how vulnerable the girl child is to abuse, even in schools. What is also equally disheartening is the light sentences that perpetrators of sexual violence continue to receive from the courts.

One way of breaking the cycle of abuse is to help women to be economically empowered, so that they can look after themselves without depending on men. Women's organisations need to revive campaigns that emphasise personal respect and pride, so that women are not easily tempted to resort to prostitution as a way of earning a living.

The country also needs to come up with more safe houses that abused women and girls can turn to while they pick up the pieces. Too often, women and girls continue to live under the same roof with their abusers, because they have nowhere else to go. Gender activists need to step up campaigns to encourage women to use existing legislation that criminalises sexual violence.

THE ROLE OF THE MEDIA

In these strategies, the media, both electronic and print, has a role to play. Essentially, in HIV and AIDS campaigns, the role of the media should evolve to one of helping, reduce stigma surrounding the pandemic, through easy to understand and informative articles.

Sadly, the media in Zimbabwe has not done much in this regard. Most media articles on HIV and AIDS revolve around statistics of deaths and prevalence alongside pronouncements by government officials about policy issues. Some media have started running advice columns on positive living. These are, however, too technical for the understanding of the average readership. A further stereotype that has emerged in the coverage of HIV and AIDS is that this is a disease of the poor. Undeniably, there is a link between the two.

Most articles are based on what health officials and activists say. There is little interrogation of what is happening on the ground. Additionally, the reporting is not engendered. An example is the issue of condom supply. There are media reports that condoms are in short supply and government health officials are quoted as saying this is incorrect. The reports do not state that they are talking of free condoms, because in shops a variety of condoms are available. But women are essentially excluded in such stories, because few reporters care to explore the availability of the female condom. To most journalists, issues of condoms refer exclusively to the male condom. This effectively takes away women's only tool to negotiate for safer sex.

Women and children are given voices mainly as the *'victims'* of the pandemic. This runs contrary to awareness campaigns that highlight the fact that anyone can get infected. This feminisation of the pandemic has allowed men to take a back seat in all aspects of care work and support required by the ones infected and affected. Women form the core of home-based care and support groups. It is women, who are involved in taking care of orphans and vulnerable children. In the few instances that men are involved, they usually do not participate actively and instead, are often the secretaries and treasurers of the organisations. Most of the work the women do is unpaid and undervalued.

Journalists in Zimbabwe still tend to rely on single sources for their information so that readers rarely get to hear all sides of an issue. For example, there is a Moringa craze sweeping across the country. A few activists have pronounced that the leaves, roots and seeds of the plant that grows abundantly in the Zambezi valley are good for people living with HIV and AIDS. And, that is the line that most reporters have been taking without bothering to talk to pharmacists or scientists to verify whether or not such findings are indeed true. In the stories, no mention is made of possible side effects.

Frequently, one still reads and hears of *'AIDS sufferers'* in media reports, a worrying indication that not enough training is being done for media practitioners to effectively report on the pandemic. There is also the added stigma for journalists, who decide to actively cover HIV and AIDS issues. Such reporters are often stigmatised as being infected, thus, the keen interest in covering the subject. AIDS service organisations are trying to correct the current setup by offering HIV and AIDS training sessions to journalists, as well as annual competitions to honour those journalists that try to break existing stereotypes in their reporting. The stereotyping and lack of intimate knowledge about HIV and AIDS goes right up to the editors, who still believe health issues are not front page material. There is still the archaic belief that only politics sells, yet, HIV and AIDS is a topic that is close to the hearts and minds of the majority of readers and listeners, as most are infected or affected by the disease.

AIDS service organisations and media training institutions need to team up and come up with comprehensive training programmes on reporting HIV and AIDS. The training should include medical professionals with detailed knowledge of the disease and not just activist, so journalists have the basics of the HIV and AIDS. Such training would also help reporters to explore issues beyond prevalence rates and policy announcements to include ordinary people's voices and experiences in fighting the pandemic. Media practitioners must be encouraged to go for testing, so that when they write they are writing from an informed position. A journalist, who knows her or his HIV status, is likely to write a more informed piece, than a colleague, who still holds the belief that the disease is only among readers and listeners out there.

The picture that emerges when one looks at gender, sex and sexuality in the context of HIV and AIDS in Zimbabwe is one that is biased against women. Women form the majority of the ones infected and affected and yet, they are in the minority, when it comes to making decisions and giving input into how best the pandemic can be tackled.

Culture, stereotyping and stigmatisation have combined forces to ensure that Zimbabwean women and children remain hidden from public views, when talking about HIV and AIDS, while they stoically carry the burden of living with the virus. A starting point is campaigns that make the pandemic everybody's concern.

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making a point

Barbara Schmid

Christianity: Addressing or perpetuating the spread of HIV and AIDS?[1]

INTRODUCTION

The HIV and AIDS pandemic gives rise to three subsequent, but related waves, each of which rises slowly at first, then faster, until it eventually reaches a maximum, before it begins to subside. The first wave is that of HIV infections. It is followed, some years later, by the wave of deaths from AIDS-related causes. The last wave following on this is the wave of orphaning.

Each of these waves requires a specific response. I want to structure my discussion of the way in which the Christian community is addressing the pandemic in terms of these 3 waves.

A few general comments first:

- Churches were slow to take up the HIV challenge. With the exception of the Catholic Church and the Salvation Army, 15 years or more into the pandemic there were few institutional responses.
- Most responses were driven by passionate individuals, rather than the denominational leadership. (There are exceptions to this, such as the Anglican Archbishop.)
- In the last five to six years, there has been a huge shift. Many new initiatives were started and HIV and AIDS has been firmly established as a central concern for churches, drawing growing commitment of church resources.
- Even now, the response is still quite fragmented, with groups/ denominations preferring to do their own thing. Attempts to collaborate (or at least to ensure that they avoid duplications), with one another and government are slow in coming about.

RESPONDING TO THE WAVE OF INFECTIONS: PREVENTION

HIV Awareness

Prevention is one of the most common ways in which churches have taken on HIV, with churches most comfortable in promoting *Abstinence* until marriage, and *Faithfulness* within marriage. Since the focus is on youth, most programmes aim at *‘abstinence only’.* There is little acknowledgement of the fact that faithful married women in Africa are a risk group for HIV infection and no attempts are made to empower them!

There are, however, growing numbers of Christian groups, who do promote and provide condom use as one option; believing that it is up to individuals to choose which of the prevention approaches works for them. Often, these are NGOs, who have grown out of congregational projects, but have become independent, to be less constrained by denominational dogmatics.

Jenny Trinitapoli has done a (as yet unpublished) study in Malawi on *how* churches promote HIV prevention. Her finding is that most churches do preach on HIV-related issues, however, most messages from churches would be considered *‘conservative’.* She warns against imposing our norms on what is appropriate for given communities. Surely, she says, the question is, *‘does it work for **them**?’.*

I have to accept that this is the crucial question, yet, add a rider to it. Surely, *‘them’* is not a homogenous group. We have to ask: Who gets to decide and impose the norm? And what about those who fall outside it?

Most importantly, the question is to what extent, what is said translates into behaviour change. And here, it seems, the success of churches has been limited.

Counselling and testing

Some groups do promote and provide voluntary counselling and testing (VCT). A controversial issue here is the insistence in some contexts that couples get tested before the clergy will marry them.

Problems with Prevention – mostly related to stigma

- Churches, through the initial responses of a few Christian leaders to the emergence of AIDS as *‘god’s punishment for sin’,* have been the source of much stigma surrounding AIDS. While most Christians now aim for *‘compassion, not judgment’* very often the language and responses are still stigmatising. I am convinced that this is due to the fact that people living with HIV and AIDS are not involved!
- It is difficult to acknowledge that we are at risk, that members of our congregation are affected and infected by HIV. Churches here have eagerly followed the medico-moral discourse that identified risk groups – and assumed themselves not be at risk: *‘we are not gay, promiscuous, Black ….’* Many still hold to the notion that HIV infects *‘others’*.
- Churches find it difficult to address sexuality and the taboos around it. Opening this area for debate seems to imply an admission that the own ethical standards, upheld and ignored for centuries, are not adhered to. The unfortunate debate around the ABC prevention methods belongs here.
- There is a need to develop a new *‘Theology of Sexuality’*. Some new trends are emerging, but this is a slow process; and filtering through to those who need to hear – and live – it is even slower.
- Gender & Patriarchy: The structure of churches is patriarchal, and while changes are happening, ultimately men have the say. Even in HIV responses, which are driven to 90% or more by women, men are in leadership positions, taking decisions.
- Men are generally not addressed in interventions (and this is true for our public health system as well, not only for Christian responses). This is untenable when it is evident that it is men who are driving the pandemic.
- Few groups seem willing to take on prevention in *‘tainted’* groups: sex workers,

prisoners, men. Few seem aware how stigmatising the choice of churches to work overwhelmingly with *'the most innocent'* is.

RESPONDING TO THE WAVE OF AIDS RELATED SICKNESS AND DEATH

Once people start becoming seriously ill and dying of AIDS-related causes, churches responded to this need. They had always cared for the sick and dying. And they do so for those dying of AIDS.

Caring for people living with HIV and AIDS

Home-based care (HBC) is one of the most common responses to the AIDS pandemic amongst churches. HBC provides basic health care, emotional support, as well as material needs to those sent home from hospitals, because *'there is nothing more we can do for you'.*

An extensive network of HBC groups exists, many of them linked to faith-based organisations (FBOs) or congregations/ denominations. Unlike many other religious responses, these groups are usually well-integrated with each other and with the public health system.

Spiritual needs of people living with HIV and AIDS

Some specific questions arise for those dying of AIDS for which they need spiritual care. This includes preparing for death, dealing with guilt of becoming infected or having infected a partner or child.

ARVs

Only recently, some churches have ventured into the provision of ARVs. There are a few Catholic projects and one of the Moravian churches in the Eastern Cape. As this is an expensive intervention, requiring highly trained staff, not many churches take it on. And as the roll-out of ARVs in the public health system reaches further, it is not clear what role these projects will continue to have.

This is also seen as a crucial intervention into orphaning. The best thing to do for children is to keep their parents alive, so they do not become orphans.

Challenges regarding AIDS care

- We need to offer care and support to those involved in care giving, whether HBC, medical staff, or clergy suffering from funeral fatigue. Not enough support is available.
- All these responses suffer from lack of resources. They often rely on volunteers, many of whom are desperately poor themselves, and not adequately trained for the challenges they have to take on.

RESPONDING TO THE WAVE OF ORPHANING

Traditional institutional responses

A number of these existing orphanages and shelters for street children have shifted their emphasis, as increasing numbers of the children needing their care are de facto orphans, largely due to AIDS. Nazareth House and Beautiful Gates are well-known examples of homes caring for children orphaned by AIDS or living with HIV. They receive all sorts of support from the community and from many churches.

Some programmes focus on finding foster or adoptive parents for orphans. It is clear that with the enormous scale of orphans, such homes are not sufficient.

Community-based responses

Foster[2] did a study of orphans and vulnerable children responses in six African countries (Kenya, Malawi, Mozambique, Namibia, Swaziland and Uganda). There are currently around 5.8m orphans in these countries, with close to half orphaned due to AIDS.

Faith-based responses to orphans and vulnerable children are widespread throughout Africa. (It has to be noted that this study included all FBOs, not only Christian ones.) FBOs are coping with the epidemic by adapting traditional approaches and developing new ones. Many of the FBO projects are small scale, caring for a few orphans. Yet a total of 322 FBOs (out of 505 surveyed) supported about 140 000 orphans and vulnerable children. Most FBOs do so by relying on volunteers.

Most common was the provision of material support and school assistance, and most groups offer children religious teaching and spiritual support.

Challenges around orphans and vulnerable children responses:

- Huge numbers of children are being orphaned. Responses reach relatively small numbers of these. The scale of the pandemic is overwhelming, but we have to see the bigger picture.
- It seems easier to take on the care of babies and small children. A concerted effort is needed to reach out to teenaged orphans – they are an extremely vulnerable group and will impact seriously on society, if the only *'home'* they find is on the street and in gangs.
- Targeting AIDS orphans with responses is often counter-productive. Due to stigma, many who are eligible for the service do not come forward. And those, who do, may be resented by non-AIDS orphans. The trend is to offer services for orphans, irrespective of the reason for the death of their parents.
- The emphasis needs to be on strengthening extended families and communities caring for orphans, as well as orphans themselves who live in child-headed households, so they can provide the care that is needed.

FOOTNOTES:

[1] An earlier version of this article was presented at the AIDS Legal Network (ALN) Public Debate on 19 October 2005. See also Parry, S. 2005. *Responses of the Churches to HIV and AIDS in South Africa.* Geneva: World Council of Churches. & Schmid, B. 2002. *The churches' response to the HIV/AIDS pandemic: A case study of Christian agencies in the Cape Town area.* MSocSci Thesis, UCT.

[2] Foster, G. 2004. *'Study of the Response by Faith-Based Organizations to Orphans and Vulnerable Children: Preliminary Summary Report'.* Paper presented at the World Conference of Religions for Peace & United Nations Children Fund – UNICEF, 2004. See also UNAIDS, UNICEF & USAID. 2004. *Children on the Brink 2004: A joint report of new orphan estimates and a framework for action.* USAID.

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The fruits of democracy: Challenges for everyone

Sipho Fakude

It is the dawn of yet another decade of democracy in South Africa, since the first democratic election in 1994. The democratic government was then, and still is, faced with a critical challenge of mending a fragile society into a new South Africa, based on values of *human dignity, the achievement of equality and the advancement of human rights and freedoms* (Constitution[1], Section 1(a)). South Africa made history when adopting its new Constitution in 1996, a constitution which is based on the will of the people and guarantees everyone the right to equality and non-discrimination (Constitution, Section 9). Many injustices of the past dividing the nation, have been addressed by the Constitution. However, to make constitutional provisions a reality seems to pose very serious challenges for everyone.

Government, in an attempt to create an enabling environment for everyone, provided for a legislative and policy framework aimed at protecting everyone against any form of humiliation, degradation and other forms of violence. Even though, the legislation is in place, communities are faced with numerous challenges in accessing and enjoying their rights. One of the biggest challenges, however, seems to be the paradigm shift and/or changing of mind sets required. This shift is not going to happen overnight, it will be a long process.

The apparent gap between rights and lived realities raises questions as to how to ensure that the rights and freedoms enshrined in the Constitution become lived realities in communities and how to begin sensitising and capacitating community members with the knowledge and understanding of their rights and freedoms.

Acknowledging the prevailing injustices, inequalities and discriminatory attitudes and practices in the communities, also raises questions as to when are we going to treat people with dignity and respect. While Section 10 of the Constitution guarantees *everyone the right to have their dignity respected and protected,* the extent to which people are respected often differs due to their age, sex and/or HIV status. An all too common example is a child who stays with the grandmother due to the fact that the parent passed away. As and when it becomes known that the parent died of HIV-related illnesses, the treatment will change and be totally different. In some cases, the family will even insist that the child be tested, bringing to the fore *'excuses'* that it is in the best interest of the child. Subsequently, the child will suffer and be treated differently, because the parent died of HIV-related illnesses. This, arguably, is one of the reasons why people do not disclose their status, because immediately after they do, the child is suspected to also be infected with HIV and treated accordingly.

Children have the right to be treated like all human beings, as they are indeed human beings. And this includes that children have the right to have their dignity respected and protected. It is saddening to see that an 8 year old child is not going to school, because the child has a *'rash'*. A *'rash'* has deprived a child of her/his right to attend school, because teachers say 'it' (*'the rash'*) will be carried over to other learners. Where is justice and the right to equal treatment?

With the Apartheid government, one thing that divided the nation was race; today the nation still seems to be divided – by a disease. Is this just?

All in all, the challenges seem to be changing/shifting our mindsets from the concept of different treatment for different people to the concept of equal treatment for everyone. Lets all treat one another in a manner as I, myself, would like to be treated. Personally, I am looking forward to a time where all people will equally enjoy the benefits of democracy.

And we are moving forward. President Mbeki (15 April 2003) describes the journey:

> *The road we have travelled and the advances we have made convey the firm message that we are moving towards the accomplishment of the objectives we set ourselves. They tell us that, in the end, however long the road we still have to travel, we will win.*

FOOTNOTE:

1. The Constitution of South Africa, Act 108 of 1996.

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