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Venerated or reviled – who's knowledge counts?

Women, HIV and the *Question of Evidence*: A global challenge¹

Alice Welbourn

Many in-depth years of living and working in East Africa, followed by the fortune in having a certain breadth of travels to other communities, have shaped the kind of work I have done for over 20 years. They have moved me away from the geographical specifics of anthropological research into a more generalist view of how societies function, including our own.

Those connections with so many women, men and young people in so many very different communities in very varied contexts – pastoralist, agricultural, with Islamic, Christian, or traditional belief systems – have enabled me to understand far more clearly than any text book ever did how limited our approach to supporting

communities can often be, when we divide the world up into health, agriculture, housing, education, finance and other sectors, rather than recognising that from an individual's or a community's perspective, all these sectors inevitably overlap and form a continuum of experience. We cannot just assume that our typological division of governmental departments is actually the best way for us to support others in their development.

I also need to state clearly that the focus of this contribution, which is specifically on women, HIV and motherhood, and the challenge that the drive for an 'evidence-base' for action raises in this respect, is very much based on personal experience, rather than on academic textbooks.

I was myself diagnosed with HIV in 1992, 18 years ago, when I was expecting a baby. I was full of excitement at the prospect of this new sibling for my older children, and my GP, knowing that I had lived and worked abroad, suggested that I might have an HIV test on top of all the routine ones. The

Mujeres Adelante

A NEWSLETTER ON WOMEN'S RIGHTS AND HIV

Editorial...

As part of our *Moving towards Vienna*, and our ongoing efforts to highlight especially women's realities and challenges impacting on HIV risks and related rights abuses; to advocate for adequate and rights-based responses to the intersection of women's rights and HIV realities and risks; and to contribute to and further the discourse on some of the contentious issues of women and women's rights in the context of HIV and AIDS, the AIDS Legal Network (ALN), in collaboration with the Athena Network, will produce a series of *Special ALQ/Mujeres Adelante Editions* focusing on women's rights and HIV.

The first issue of this series explores some of the realities impacting on the extent to which women's rights are accessible and realisable, as well as on the adequacy of responses to women's risks and vulnerabilities to both HIV infection and human rights abuses. The '*question of evidence*' as a global challenge in the response to women and HIV; engaging men and the role of men's organisations in the process of gender transformation; the need to engender the response to HIV in India; and the extent to which sexual and reproductive rights are realisable for women in polygamous relations are some of the issues discussed in this edition.

This issue also discusses the notion of '*choice*' for pregnant women in a rural context; shares '*musings*' on HIV testing and pregnancy; and introduces '*conversations*', a new feature, bringing forward the voices of women who have become an integral part of the response to women and women's rights in the context of HIV and AIDS.

Focussing specifically on women, HIV and motherhood, **Alice Welbourn** explores the '*question of evidence*' and the various challenges associated with the current call for '*evidence-based*' responses to women and HIV. The article discusses women's realities and challenges in the context of pregnancy, antenatal care, and motherhood, and elaborates on how existing challenges are further exacerbated by the introduction of laws criminalising HIV transmission. Raising questions as to '*whose knowledge counts*' and who has the '*power*' to gather '*formal evidence*', she argues that the '*question of evidence*' is a political one, and that the '*evidence base for action*' approach has thus far been deeply detrimental for ensuring the rights of positive women.

The extent to which confidentiality, consent and counselling – the three C's of HIV testing – are realisable for pregnant women in a rural context is discussed by **Amber Howard Cornelius**. Examining the interrelations between socio-cultural norms, rural women's lived realities, and the notion that the three 'C's' are based on the assumption that women have the freedom and autonomy to make choices in their lives, she raises the question of '*what are her real choices?*' and whether or not HIV testing during pregnancy is '*ethical*' from a poor rural woman's perspective.

In this issue

1. **Venerated or reviled - who's knowledge counts?**
Women, HIV and the Question of Evidence: A global challenge
Page 1
2. **Editorial**
Page 2
3. **What are her real choices...?**
Pregnancy and HIV testing in a rural context
Page 15
4. **Making gender truly relational...**
Engaging men in transforming gender inequalities, reducing violence and preventing HIV
Page 17
5. **For us to realise our common goal...**
Men's organisations and gender transformation
Page 25
6. **Choices tend to be limited for women...**
Sexual and reproductive rights of women in polygamous unions
Page 28
7. **The power to 'opt-out'...**
Musings on HIV testing of women
Page 33
8. **Pervasive societal attitudes must change...**
Engendering the response to HIV and AIDS in India
Page 36
9. **In conversation with Cebile Dlamini**
Page 47

Continued on page 4

Mujeres Adelante

other tests all came back fine, but the HIV one did not. My partner – now my husband – and I were devastated. He – apparently miraculously at the time – though I now know this to be quite common – remained and remains HIV negative. And he, ironically was himself working as a public health doctor in international development, and was focusing increasingly on HIV. Yet neither of us had remotely suspected that I might have HIV, fit and healthy as I was – and am. We were really fortunate. Our GP was a total rock, we were seen the very next day – a Saturday –

by the HIV specialist who is still my consultant in Oxford and I was very quickly receiving total care and support from the consultant obstetrician in Oxford also. In those early days, before there was any treatment at all for HIV, there was a substantial risk that being pregnant might either hasten my death or might result in the baby failing to thrive or dying – both of which would have been terrible for the older children as well. So we went through an agonising week before deciding to have a medical termination. I was extraordinarily fortunate in experiencing total care, respect and support from my partner, my GP, my HIV consultant, my obstetrician and all his staff. Yet I still felt totally devastated by both my HIV and by losing the baby. Both my partner and I imagined that I would likely be dead in six months, despite reassurances to

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the contrary from my HIV consultant. I did not dare tell my own siblings or parents for fear that I would not be able to cope with supporting their shock also. We just shared the knowledge with a very few very close friends. The sense of isolation and grief were completely overwhelming and it took me a full two years to begin to surface from this.

As a part of my recovery process, I was fortunate enough to be taken on as a trustee by the local AIDS support group in Oxford and began, with a nurse friend I met there, who is also HIV positive, a self-help positive women's group, which is still going strong. Once anti-retroviral drugs did arrive, it was like the Lazarus effect. We suddenly stopped going to one another's funerals, wondering whose would be next; and began once more to think about possible futures for ourselves and our families. One of the many things we discussed in the group was the lack of support from other senior health staff in the Oxford area for the idea of HIV positive women having children. So there were women from Oxford travelling to London for antenatal care, to have the children they so dearly wanted. Our group enabled us to share this and other similar information between us.

Another part of my recovery process was to be able to develop a training manual² on gender, HIV, communication and relationship skills, using those years in international

Engaging men in the process of transforming gender inequalities, reducing violence and preventing HIV is the focus of the article by **Gary Barker** and **Dean Peacock**. Examining how policies and programmes can effectively engage men towards achieving gender equality, the article provides an overview of key human rights and health challenges in the region, discusses issues of masculinities, violence and health, and calls for policies and programmes to move 'beyond gender binaries' and to 'making gender truly relational'. Highlighting the potential of 'working with men', the article argues that 'real social change' can only be achieved if both women and men are equally 'targeted' in gender equality and social justice policies and programmes.

Continuing the discussion on 'working with men', **Cherith Sanger** examines the role of men and men's organisations in the process of gender transformation from a woman's human rights defenders perspective. Acknowledging that many women support men's organisations working towards gender transformation, she reflects on issues of power and privilege, the risk of men being seen as 'fixing the problem', and the many challenges linked to funding and 'who' gets the funding for gender transformation. While the author cautions of 'marginalising' men's organisations, she argues that for 'common goals' to be realisable men's organisations must recognise that 'women have paved the path' for the work men do towards gender transformation.

In the context of women's rights and HIV risks, **Lydia Mavengere** discusses the

extent to which sexual and reproductive rights are a 'reality' for women in polygamous unions. Placing the concept of choice at the centre of the discussion, she explores various societal expectations and cultural pressures impacting on women's 'ability' in polygamous unions to make sexual and reproductive choices, and highlights women's implicit risks for HIV transmission and rights abuses. The article concludes that 'choices tend to be limited for women', and argues that women's risks are as 'multiplied' in polygamous relationships as in any other 'multiple concurrent relationship'.

The risks of rights abuses inherent to the expansion of provider-initiated HIV testing of pregnant women has been an integral part of the discourse on women's rights and HIV for a long time. Looking at the realities and presumptions of women's 'power', the 'musings' by **Promise Mthembu** raises questions as to the adequacy of programmes and interventions that seem to assume that women, and especially positive women, have the 'power to opt-out', the 'power to choose', and the 'power to challenge' healthcare providers. Sharing her thoughts and concerns, she argues that as long as programmes continue to be 'far removed from women's realities of power', women will remain 'powerless' to 'opt-out' and to decide for themselves.

Introducing gender dimensions and its impact on HIV risks and realities in India, **Tahmid Chowdhury, Lily Walkover, L. Ramakrishnan, Pawan Dhall, Manish Soosai, Tyler Crone, and Sai Subhasree Raghavan** provide an overview of the historic conception of

gender and women's vulnerabilities in India, and explore 'good practices' of mainstreaming gender into the HIV response. The article highlights the need for interventions that specifically address women's HIV risks and vulnerabilities, facilitate women's empowerment, and focus on women's rights. Discussing various approaches to women and HIV, the article argues that a truly 'engendered response to HIV' can only be achieved if the 'deep-rooted inequalities' leading to women's risks and vulnerabilities are 'tackled'.

Although the articles examine very diverse segments of women's realities in the context of HIV and AIDS, there is the common understanding that women's realities and lived experiences need to be at the core of a rights-based response to HIV and AIDS, and become the 'evidence' based on which programmes and interventions are designed and implemented. There also seems to be the common argument that as long as the 'question of women's power', real and/or presumed, is not adequately addressed in programme design and implementation, there is no assurance that women are indeed in the position to benefit from available programmes, interventions and services; that an 'evidence base for action' does not become another barrier for women and women's rights; and that efforts to address women's realities are based on a true reflection of women's HIV risks and vulnerabilities, and thus offer an effective response to women needs.

JOHANNA KEHLER

Mujeres Adelante

development training, to enable 'ordinary' community members, who cannot necessarily read or write, to discuss together safely the issues they face in their own communities; to analyse why we behave in the ways we do; and to work out for themselves realistic solutions to these issues in their own communities. This manual was developed first in a rural community in Uganda, but has now reached around most of the world and is in use in the Pacific, South and South East Asia, sub-Saharan Africa, Latin America, the Caribbean and even Russia, Kyrgyzstan and Estonia.

That, supported by the small NGO, encouraging me to develop this manual, was a hugely important part of my own recovery. They believed in me. It felt that I had something meaningful to offer from my own personal experiences of living with this bug in my body and gave me the opportunity and space to develop those experiences into a training manual to support others.

So I am trying to share how through these support systems – my partner, close friends, the fantastic health staff, the local AIDS group and the NGO, and their combined belief in the validity of my own personal experiences, despite all my sense of devastation and loss, I was able to put something back and share those personal experiences with others, in order to reduce – or at

least – temper their own sense of pain and loss. There are thousands of positive women like me around the world who, if they have had any resources available to them, have also started self-help groups, or have supported others to avoid going through what they have. Each of us has felt very isolated as we began, but just trusted our instincts to do what we thought best might help. It is only later,

as we have grown in confidence and connections, that we have realised how so many of us have been doing similar things, to keep ourselves sane and to do what we can to help those around us.

But as I became further involved in international development work at a global scale, rather than at a grassroots scale, and as I gradually became more open about my HIV positive status, from around 2003 onwards, I also realised increasingly how exceptionally fortunate I had been in my support and how rare such support is for the vast majority of positive women around the world – especially when it comes to having sex and having children.

...millions of dollars go on being spent on programmes, which we know to be fundamentally flawed...

...if we cannot support women during motherhood where – or what – is our humanity...

WOMEN AND MOTHERHOOD

The position of women and motherhood globally, as we all well know, is one both venerated and reviled. On the one hand we have, in Christianity for example, the image of the Virgin Mary.³ The love of a mother for her child is considered to be the purest love imaginable for humans. On the other hand of course we also have the shameful history of how women were treated in relation to illegitimacy over the years.

Kate Adie's powerful book, *Nobody's Child*,⁴ describes with great poignancy the pain, suffering and loss of identity, which many have encountered as adopted children. The book charts the history of how badly both women and their children were treated by society over the centuries. We hear about the fate of the Magdalena Sisters in Ireland⁵, but here in England also, convents, the poor houses and psychiatric hospitals often beckoned for women who had given birth out of wedlock.

As Helena Kennedy has argued eloquently in her book, *Eve was framed*⁶, the inequality of women in relation to many aspects of life has been enshrined in our laws for many centuries, as they have been created by male academics and male parliamentarians who, by their very nature, could not, and did not, experience what it was like to be a woman in relation to the laws, which they created. When her book was first published it was considered very radical, but it is now a standard first year text book for law students. However, the law in England, Baroness Kennedy would argue, is still very male-oriented. Moreover, English law has shaped the laws in many other countries around the world, which used to appear pink on the map. It is sobering and perhaps not entirely coincidental that 66% of people with HIV and over 72% of women with HIV are Commonwealth citizens⁷. For instance, laws criminalising homosexuality, and therefore, outlawing good same-sex sex education, are especially common in Commonwealth countries, as the current Anti-Homosexuality Bill in Uganda, calling for the death sentence for gay people, highlights⁸.

Any discussion of women and motherhood – and, God

forbid – sexuality, was carefully censored and closely restricted. Women could have sex and give birth 'safely' within marriage – but any pre- or extra-marital sexual activity or pregnancy was deeply censored, even until very recently in the UK. Consider then the impact of HIV on women's lives.

Globally, all countries have connected HIV with sex, with death, with 'promiscuity', with homosexuality and 'immoral'

ways, with 'junkies', foreigners, and the 'dregs' of society – basically all the -isms, -phobias and taboos that are universals around the world have landed up in the HIV basket⁹. This may be a great way of distancing ourselves from the causes and consequences of HIV in our societies and making us feel powerful enough to avoid having anything to do with HIV ourselves. And the stigma

of HIV has been used as yet another whip which those of us with power often use to beat those whom we conveniently have banished to the margins of all our societies. And this seems to continue around the world, despite there being many examples which have shown repeatedly that this ostrich approach to HIV is *not* one which has protected any nation from HIV to date.

PREGNANCY AND ANTENATAL CARE

This has had a particularly pernicious effect on *women* with HIV in relation to *motherhood*. Unfortunately, in most parts of the world, the means by which HIV has been measured has been by recording the prevalence of HIV amongst women attending antenatal centres. This is because pregnancy is the one time when women are most likely to want to access western healthcare services, for the sake of their babies – and there is

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no equivalent time in men's lives¹⁰. So the consequence of this is that it is pregnant women who have been, and are, targeted by health services for HIV testing. When I asked at a recent

UN conference why it

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might not be possible for men in the police or armed forces to be mass tested anonymously – so as to preserve their confidentiality, but to give us some equivalent figures for men – I learnt that this is indeed being done,

but that the figures are not released, because countries consider them to be a state secret. Thus, pregnant women are the recipients of this news; pregnant women receive the brunt of negative public opinion, including from over-stretched and under-trained health staff. And pregnant women are verbally and physically abused¹¹ by these health staff, and by their partners, in-laws and neighbours, and are often being thrown out of the marital home and having to leave their older children behind.

When I was in Northern Kenya in May 2006, a UN doctor colleague told me that he had just visited a local health centre where the staff told him that a woman had come in that morning to tell them that they had told her a month previously that she was HIV positive. She told them that since then she had been beaten up and thrown out by her husband and had not been able to see her children. Her own natal family had also rejected her. She now said that she was bleeding and was returning to the health staff to ask them what she was now expected to do.

I have heard this story repeatedly from many different quarters of the world, including the UK, where a positive HIV diagnosis in pregnant women is met regularly with violence, ostracism and rejection¹².

Yet, HIV testing during pregnancy persists – because of the opportunity that an intervention at this stage offers to reduce or stop vertical HIV transmission from a woman to her child. And this is a very real opportunity. In fact, recent statistics¹³ here in the UK have shown that if a woman is properly treated during pregnancy then the chances of her passing HIV on to her baby are less than 1 in 1,000 – which is a very far cry from the 30% vertical transmission levels if no treatment is available. So an 'AIDS-free generation', as it is called, is a potential reality.

But what is missing in this equation is not just the fact that drugs are still not as widely available as they should be, but that the way in which a woman is treated by the health staff¹⁴ – and therefore by the rest of society – has not been taken into account. In fact, not only have women not been adequately cared for, they have in fact been criticised

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for getting pregnant at all. And agencies promoting child health have actually played a subtle but key part in promoting this image of 'irresponsible women going around having sex and producing babies'. Yet in most of the world, women a) have scant say over whether or not they have sex with their partners; b) have even less say in whether or not they use condoms; and c) still have the rights and desires for motherhood, regardless.

In South Africa, the situation which women face has become so dire that women are voting with their feet and *not* attending their local antenatal clinic when they become pregnant.¹⁵ This is because they know they will have to undergo an HIV test (which is supposed to be voluntary); they know that if they test positive for HIV that all their community will know about it (when the test and its result are also supposed to be entirely confidential); and they also have seen what has happened in their community to other women who have tested HIV positive. Thus, women are deciding instead to travel up to 60 kms outside their own neighbourhood to access antenatal services elsewhere. Yet we know that this long distance access is entirely unsustainable, because of the costs and time involved. However, when I and my other activist colleagues share these stories at meetings or in our writings, we are asked '*where is the evidence base for your assertions*'.

Coercive sterilisation

In Namibia, South Africa, Papua New Guinea and Chile, to name but four countries, attitudes towards positive women wanting children have gone even further. Coerced sterilisations¹⁶ have been undertaken by senior health professionals, who have requested women, whilst in labour, to sign forms agreeing to this. The women only learnt what had been done when they returned to the health centres for contraceptive care after the babies were born. When our colleagues in Namibia have questioned the doctors concerned, they have happily replied, explaining that of course this is a good thing, since '*these women are HIV*

positive and they already have too many children'. Yet when our colleagues decided to take the Namibian Ministry of Health to court with a few test cases last autumn, they were told that the cases were inadmissible since they had taken place over 12 months ago.

CRIMINALISATION OF HIV TRANSMISSION

Then on top of all this, over the past three years there has been a growing move to pass laws that criminalise HIV transmission in many parts of the world. And this too has an especially negative effect on women – which is ironic because, to be fair, various states have introduced criminalisation of HIV transmission in the misguided hope that it might curb men from transmitting HIV to their partners.

The criminalisation agenda has been fuelled by a US-backed initiative under the Bush regime, based on punitive US domestic policy, where the numbers of people with HIV are enormous. As Helena Kennedy has said, a certain '*hysteria*' and fear of the '*other*' has encouraged governments to '*reach for the law*' in a vain attempt to '*control*' the spread of HIV, along similar lines to their '*war on terror*'¹⁷. Launched first in West Africa, this so-called '*Model AIDS Law*' has been promoted and adopted now in varying forms in several countries across Africa. However, despite the good intentions of this initiative, laws are well known to turn round and bite those whom they are supposed to be protecting, and states often realise that *they* have bitten off more than they can chew when

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it is too late. It is far harder to amend or rescind laws, than it is to introduce them. Thus, in Sierra Leone¹⁸, for example, if a woman transmits HIV to her child, she can be fined or jailed up to seven years or both¹⁹.

Let us examine this more closely:

- Where is the guarantee for a woman of access to condoms for prevention, of access to negotiation skills to use a condom with her partner, of access to microbicides if they want children, or the guarantee of treatment access for a positive woman and her child?
- Where is the guarantee against negative judgmental attitudes from the front line female health workers (many of whom, by the way, are themselves struggling with violent relationships and potential HIV in their own lives)?
- Where is the guarantee of that love, care and support from partner, family and friends, which we know makes adherence to medication so much higher, when it is available?

If all these criteria were very firmly in place, maybe then and *only* then might one begin to even *remotely* consider criminal proceedings – but what about the effect of criminal proceedings not only on a woman's life, but on her existing children?

Let us not forget that all this antenatal HIV testing initiative has been driven from the outset by a well-intentioned, but ill-conceived – and I use that word advisedly – determination to create that 'AIDS-free'

generation. I would have thought that sticking a child's mother in prison and branding her as a criminal was a pretty sure-fire way of ensuring that this child is going to be more vulnerable than ever to not just having HIV, but dying pretty fast of AIDS, without their mother around to look out for them any more. And just as 'illegitimate' and 'foundling' children were blamed for their mothers' supposed wrong-doings in England in the past, so children of women in prison are also branded.

This drive towards criminalisation²⁰ is also likely to have a negative effect on HIV testing. The spread of criminalisation legislation means that many years of careful, committed and compassionate HIV prevention work in many countries are collapsing through people's fears that testing positive will mean that they could then be branded as 'disease vectors' and as 'criminals'. Men figure – quite sensibly – that if they remain ignorant of their HIV status, they can claim ignorance in a court of law. Women realise that they can avoid partner violence against themselves, and their children, if they do not have their HIV positive status known or disclosed²¹. This fear of knowing one's status, exacerbated by these consequences, is a disaster

for prevention, especially since most HIV transmission takes place amongst those who are unaware of their status.

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OTHER 'SCIENTIFIC FACTS' AND UK REALITIES

The gulf even here in the UK, between the scientific facts and popular scare-mongering, based on deeply rooted prejudices²², shock and amaze many of our African colleagues. Just last February, I saw a report in *The*

Daily Mail, which was full of utter factual rubbish about HIV contagion²³. We did get *The Daily Mail* to issue a rather lame correction to this article. But the damage was no doubt done for some, and *The Daily Mail* is mild compared with some other media activities²⁴.

Some positive women in the UK are being told by their doctors that they should not start new relationships, in case they might be criminally convicted²⁵. Last summer some GPs in London told a colleague of mine, who was trying to run an HIV session with them, that they knew all about HIV – and that the normal rate of HIV transmission from women to their children is 50%...!

Many in the UK, including doctors, also believe that women should never have sex – or children – if they are HIV positive. Positive women, here too in the UK are experiencing physical and other forms of violence from partners on learning that they are positive. One recently had ‘AIDS’ daubed on her car with indelible paint by her neighbours. Others have their children’s HIV status exposed at school.

What makes this all the more ironic is that a Swiss study

two years back found that if we are stable on treatment, have an undetectable viral load, and no other STIs are present, we have negligible chance of transmitting HIV to others, even without a condom²⁶.

We also know

that treatment can be rolled out – now 3 million, out of the 9 million of us who need treatment, are getting it and taking it as responsibly as we can, despite assumptions that we probably could not – but that is still 6 million too short – and many women continue to face many logistic, as well as psychological problems with accessing medication.²⁷ These include having to seek permission and funds from male partners to access services, having their drugs taken from them for use by their partners as soon as they reach home – and sometimes being beaten at home even for showing their face at the treatment centre.²⁸

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WHERE IS THE EVIDENCE?

And so we circle back to the question of evidence and an ‘evidence base for action’. An ‘evidence base for action’ is what medical bodies, such as the Centers for Disease Control in Atlanta (CDC), or the National Institute of Health (NIH), or the Food and Drug Administration (FDA); government, such as the US government; and international aid donors, such as USAID and others, want to rely on when they support something or fund something. In certain respects, it is really important to rely on an evidence base – for instance, under the Bush Regime, PEPFAR (the President’s Emergency Plan for AIDS Relief) played havoc with years of good international

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HIV prevention work in many African countries, when it refused to fund condoms and insisted on programmes only promoting abstinence and fidelity. So, in this case it was critical to draw on the 'evidence base', and to be able to say that comprehensive, non-judgemental sex education and promotion of, and access to, condoms was essential in order to challenge the Bush regime's approach to HIV prevention. but in many other respects, an 'evidence base for action' has been deeply detrimental to ensuring the rights of positive

women, since if the formal research to produce evidence for something *has not* been done, it is officially not acceptable to do it.

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WHO HIV Department reports state that more women than men are accessing ARVs from public health centres, without any explanation as to why²⁹. But this quantitatively higher figure for women

is because of this specific public health policy which targets pregnant women. The reports give no indication of the serious *qualitative* issues – the emotional and physical costs – and the sexual and reproductive health costs – experienced by these women through these ante-natal 'prevention of mother to child transmission' programmes.

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If we challenge certain UN organisations or others on this, they reply '*where is your evidence*' for the human rights abuses that I have been describing here. And so the cycle continues.

And why don't we have '*evidence*'? Well, there are two points I would like to tease out here. One is the fact that a '*formal evidence base*' too often means a quantitative study, which requires formal academic skills in questionnaires and statistics. A '*formal evidence base*' also requires considerable

funding. Neither these academic skills nor funding are in great abundance for very poor women – or even less poor – living with HIV around the world.

Donors or policy-makers rarely ask '*whose knowledge counts?*'. It is normally assumed that it is the role of academics to create and hold knowledge, to define the questions that need to be asked, and to design and operate the processes that will answer them. But what if the questions that are being asked are not the questions that those of us who do not have access to academic skills or financial resources want to have asked? What if the questions which are being asked are not eliciting the inherent knowledge that we have, based on our personal and collective experiences? What if the questions we would want to have asked, or would ourselves ask, are too complicated, because they cross boundaries of knowledge between different academic or professional sectors, or because they are too political? What if we push the boat out in challenging others' judgments about who we are or why we have HIV? These questions rarely get asked by academics.

Therefore, the very question of a 'knowledge base' becomes a political one, a question of power, in relation to who is said to *have* knowledge³⁰ and who is said *not* to have it. Yet, donors increasingly will only fund interventions, which have a formal evidence base. And thus, in my view, innovation and experimentation have been undermined, and the opportunity for new learning to take place, bridging different disciplines, and creating new *real* knowledge through daring to take risks and learn from our mistakes, has just been firmly repressed. Meanwhile, millions of dollars go on being spent on programmes, which we know to be

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fundamentally flawed,
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diversity of positive
women's lives beyond
the clinic door, and
have only focused on a
bio-medical techno-fix,
which does not begin

to address the multi-faceted challenges being faced by these women in their lives.

The other point I would like to raise about the question of an 'evidence base' is a more philosophical one – but one which is, I think, equally relevant and important. This is the question of 'them' and 'us', the 'emic' and 'etic' in anthropological terms, the insider/outsider issue and the constant requirement for the researcher to be able to prove that he – or she – has done all they can to produce independent 'knowledge' – as if any knowledge to do with psycho-social issues can somehow be entirely objective. This approach to scientific knowledge is grounded in

our Cartesian view of the world. As I touched upon earlier, no one sector can overcome HIV. HIV *is not* just a health issue. It is *not* just about education. It is *not* just about religious beliefs. It is *not* just something you can stick a law on. It *is* about all of *us* and about all these *sectors* reaching out and working together, across professional and national boundaries to root out our 'us and them' mentalities, which fuel and fan this virus. We in the West have very much fallen into this Cartesian philosophical trap of focusing on 'I'-*identity*, this 'I think, therefore I am' of Descartes. We have, I think very much to our loss, forgotten about our essential *inter-connectedness*, our humanity, our 'we'-*identity*.³¹ Satish Kumar³², philosopher and ecologist, offers a traditional rhyme at the start of one of his books:

*From you I receive,
To you I give,
Together we share,
By this we live.*

I have also learnt that life and HIV are about all of *us* – we in the world, together – how we interact with one another, learn from one another, remembering that scientists and academics, doctors and nurses, politicians and lawyers too have HIV – though sadly, they still rarely dare to admit it, for fear of losing their jobs and their status amongst their peers. I actually personally know quite a few of them, but of course I respect their confidentiality. So HIV is about whether or not in the face of adversity, we batten down the hatches, and lob grenades out of our bunker at anyone whom we have banished to the margins. Or whether or not we open up, share what we can, seek to reach out to enquire, to learn from and to understand one another better.

So I think as we look again at the *Question of Evidence*,

Mujeres Adelante

we need to remind ourselves that pain and suffering, love and respect, hope and trust all exist in the world and are real, despite the fact that we do not, to my knowledge at least, yet have a formal knowledge base to 'prove' that they exist. I believe strongly that the root causes of HIV in *all* societies, wherever we live in the world – and how we respond to our diagnosis – are related to imbalances of power: between men and women, old and young, rich and poor,

higher and lower castes or classes; between those who feel loved, cared for and respected and those who do not; and between those who wield political power – and therefore *own* 'knowledge' – and those who do not.

Someone reminded me the other day that the word 'radical' is connected to the Latin word for 'root'. Perhaps we should all proclaim ourselves to be radicals, since somehow all of us need to better understand how HIV breeds and flourishes, on these root inequities and injustices in our lives, and the collective reluctance of those who *do* have power to look at, or challenge, the validity of their monopoly of the knowledge base. The stories I hear from other positive women in the UK continue to leave me shocked by how ignorant I myself am about

...HIV presents to us the epitome of the challenges we all face when we ask ourselves what health and healthcare mean to humanity...

what has happened to positive asylum seekers and positive drug users, here in Britain, in what we call a civilised democracy. So *we need to find the courage to right these injustices* and, in doing so, also halt the spread of HIV.

Around the world, parliaments, interior ministries, judges, police, the media, health workers, teachers, social workers – and the public at large – we all urgently need to educate ourselves about what HIV is, and what it is not.

And until *we* firmly address the mess, crisis

and heart break we have for the thousands of positive women – and men – here in the UK, we cannot legitimately criticise other states for what is happening within *their* jurisdictions. We all have an obligation to uphold the human rights of people with HIV. We all have an obligation to understand the critical fact that good treatment access means good prevention – since transmission risk with an undetectable viral load is negligible. We all need to uphold the rights of *all* women – whatever their HIV status – to a life of peace, free from physical, sexual and psychological violence, and to a life of sexual and reproductive choices.

Anand Grover, Human Rights Lawyer and UN Special Rapporteur on the Right to Health stated³³:

Are positive people there as tokens or are they effectively making decisions? Are affected persons involved from A to Z? Democratic and inclusive processes are essential to achieving human rights, and are at the core of better governance and better health outcomes.

In a sense, HIV presents to us the epitome of the challenges we all face when we ask ourselves what health and healthcare

mean to humanity. It questions our attitudes to human rights, our values, our attitudes to morality, our religious beliefs.

The environmental lobby has adopted the precautionary principle when it comes to deciding what can or cannot be built in our countryside. In fact, stringent laws are in place now in the UK to place the burden on industry to do no harm to the environment. Why is it still that such a precautionary, or a 'do no harm' principle still eludes us when it comes to how we treat pregnant women around the world? I continue to ask myself, if we cannot support women during motherhood where – or what – is our humanity.

As Einstein said, what is measurable is not necessarily important, and what is important is not necessarily measurable. To me, questioning what we mean by 'evidence', if we are ever to overcome HIV effectively, is our global challenge.

FOOTNOTES:

1. With thanks to Professor Anthony Pinching and his colleagues at the Peninsula College of Medicine and Dentistry, Universities of Exeter and Devon, England, for inviting me to make this presentation at the Knowledge Spa, Truro, Cornwall, in January 2010. With thanks also to Dr Johanna Kehler of the AIDS Legal Network, South Africa, for publishing this presentation.
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11. See Odetoynbo, M., Stephens, D. & Welbourn, A. 2009. 'Greater involvement of people living with HIV in health care'. In: *JIAS*. Available at [www.jiasociety.org/content/12/1/4] for various references on this.
12. See also Welbourn, A. 2010. 'WECARE+: Moving forward the Positive Women's Agenda, linking across Europe and Central Asia'. In: *ALQ/Mujeres Adelante*, Special Edition March 2010. pp40-45; and about issues facing women across Europe [www.salamandertrust.net/resources/WECARE+.pdf]
13. See i-Base report of CROI statistics, available at [http://i-base.info/htb/1865]
14. For a very interesting and insightful anthropological analysis of medical education, see Sinclair, S. 1997. *Making Doctors: An institutional apprenticeship*. Berg.
15. In South Africa women are travelling up to 60 kms from their homes to seek antenatal care away from their neighbourhoods, for fear that they will be tested for HIV before receiving care; that the HIV test will be positive; and that if this information was known in their communities that they would experience violence. Dr Johanna Kehler, AIDS Legal Network, personal communication. Oct 2008.
16. See, for instance, AIDS Legal Network reference, available at [www.stratshope.org/d-audio-maura.htm]
17. See [www.sophiaforum.net/index.php/Events/Legal_rights_and_social_wrongs] for an audio file of Helena Kennedy's speech.
18. NB: We have just (4th March 2010) received word from Sierra Leone that this particular part of the law is to be withdrawn.
19. [www.icw.org/node/354]
20. See also IPPF. 2008. *Verdict on a Virus*. Available at [www.ippf.org]
21. For a very interesting and insightful anthropological analysis of medical education, see Sinclair, S. 1997. *Making Doctors: An institutional apprenticeship*. Berg.
22. See, for example, [www.poz-fem-uk.org/resources.html] and [www.sophiaforum.net/index.php/page/News]
23. [www.dailymail.co.uk/news/article-1152437/Foster-carers-told-babies-HIV-positive-protect-childrens-human-rights.html]
24. See Reynolds, R. 2008. at [www.aids2008.org/Pag/PSession.aspx?s=475]
25. See also [www.poz-fem-uk.org/resources.html]
26. [www.saez.ch/pdf_f/2008/2008-05/2008-05-089.PDF]
27. [www.amnesty.org/en/library/asset/AFR53/001/2008/en/ebc94db1-f123-11dc-b3df-0fe44bc152bc/af530012008eng.pdf]
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What are her real choices...?

Pregnancy and HIV testing in a rural context

Some AIDS evangelists refuse to listen to the experiences of women living with HIV who face more violence and are having difficulty in challenging and seeking redress for violence, because of their HIV positive status. There are also a lot of unspoken assumptions about women as mothers implicit in the HIV testing of pregnant women – that, of course, women would want to know their HIV status and prevent the transmission of HIV to their unborn child. While this may be true for most women, it is also a lot more complicated in the context of poor, rural women's lives.

Amber Howard Cornelius

The three C's of HIV testing – confidentiality, consent and counselling – are also loaded with assumptions, most of which are at odds with rural women's lived experiences. Let's start with the notion of confidentiality: an idea which conjures images of a clinical setting in which the clinician and the patient are anonymous strangers unlikely to ever meet outside the healthcare setting. In rural communities, no one is anonymous. The people conducting HIV tests in local clinics are often powerful members of the community, as they have formal employment and access to financial resources and information, unlike the majority of women being tested at antenatal clinics, who are unemployed and who have little or no opportunity to learn about HIV and pregnancy in the privacy of their own homes, or in other safe, supportive, non-hierarchical spaces.

Cultural norms are also part of the unexamined notion of confidentiality – as a largely Western concept of personhood and autonomy is superimposed over traditional African communities and value systems. As Western cultures value privacy, and live mainly in nuclear family settings, traditional communities value the collective and view all members of the community as an extended family of mothers and fathers, grandmothers and grandfathers, and children. Rural women are tested for HIV not by an anonymous nurse, who is a non-judgmental, unemotional clinician. Many women (young, unmarried women in particular)

feel judged by their older 'mothers' about the fact that they have been sexually active and have shamed their families by their pregnancy. A whole set of judgments about women's sexuality are implicit in the pregnancy and are simply compounded by a positive HIV test result.

Consent, like confidentiality, assumes that women have freedom and autonomy to make choices in their lives, yet many pregnant women have had few opportunities to make choices about their lives and their reproductive health. Most women do not have choices about whether or not condoms are used during sex, or whether or not other forms of contraception can be used. Many women have little or no knowledge about their bodies or about pregnancy and reproduction. Women do, however, learn from an early age not to question authority, to do as they are told and to defer to people in positions of power – husbands, in-laws, politicians, healthcare providers and all the others who have a higher position on the power hierarchy.

Much feminist writing has been done about consent and what it means for women. For example, when does a woman consent to have sex? When she doesn't kick and scream? What if she has sex, because of a tacit threat of violence? What if she has sex, because she is hungry and her partner buys her food? What if she has sex, because she needs a place for her and her children to live? Is that consent?

In the same way, rural women are particularly vulnerable, because if they refuse the HIV test, they are confronted with the expressed or tacit threat that care will be withheld. There is not

another clinic or another hospital close by to go to. What are her choices really? Even if she had a choice, would the power-laden context of the clinic or hospital be a place where a rural woman or any woman really, could exercise choice freely and face the disapproval and rejection of the clinic staff and doctors? Wouldn't refusing the test mean she was a terrible mother?

Finally we come to the third C – counselling. What kind of pre-test counselling should women receive? If a woman learns she is HIV positive, will she be told how to disclose her status to her partner and where to go if her in-laws throw her out of the family dwelling, when they discover she is positive? It is unlikely, because there are no shelters for rural women to turn to and no support services in place to help a woman negotiate with her family when she discloses her status. One supposes that a woman might also need to know that she will likely be blamed for bringing the infection into the family, because she is the first one to get tested. In fact, women are

...men hardly ever get tested for HIV, and pregnant women almost always do...

still largely blamed for transmitting HIV, because men hardly ever get tested for HIV, and pregnant women almost always do.

It would also only seem appropriate for women to be counselled about the fact that they can still transmit HIV to their babies after their birth, through mixed formula and breastfeeding. Of course, if a rural woman does not breastfeed her child, it is tantamount

...reconsider the three C's from a poor rural woman's perspective for a moment...

to public disclosure of her HIV positive status. Even if she decides to face the stares and formula feed only, she will have to deal with the cost of the formula and the fact that clinics often run out of supplies. So even if she wants to exclusively formula feed, she may have to choose between letting her baby starve when the clinic is out of supplies or breastfeed her infant and expose her to HIV infection. These do not seem like meaningful choices.

The fact that few women who test positive for HIV during pregnancy ever return for treatment, or ever bring their babies back for follow-up testing, does not seem to deter the blind determination of the healthcare establishment from continuing with provider-initiated HIV testing of pregnant women. Maybe they could reconsider the three C's from a poor rural woman's perspective for a moment – and decide whether or not this practice is ethical, and whether or not it will, in the end, help reduce the spread of HIV amongst the most vulnerable. More work needs to be done in many areas to encourage universal access to HIV testing, and to address the stigma, shame and denial around HIV, so that people – and marginalised women in particular – can start making meaningful choices about their health.

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Making gender truly relational...

Engaging men in transforming gender inequalities, reducing violence and preventing HIV

Gary Barker and Dean Peacock¹

In Africa, as throughout the world, we know that gender inequality continues to undermine democracy, impede development and compromise people's lives. Across the region, rigid gender norms, and harmful perceptions of what it means to be a man or a woman, encourage men to engage in high risk behaviours, condone violence against women, grant men the power to initiate and dictate the terms of sex, and make it difficult for women to protect themselves from either HIV or violence. Indeed, a growing body of research shows that these gender roles contribute to gender-based violence, alcohol, and drug abuse, and exacerbate the spread and impact of HIV and AIDS.

These data and these affirmations are not new. From global conferences, international agreements, national level policies and programmes assisting women in developing countries, lots has been tried to improve the situation of the world's women. Some of these efforts have worked. Girls are completing primary school worldwide, and in Africa at rates nearly equal to boys. They are entering the workforce (outside the home) in unprecedented numbers and benefiting from economic empowerment policies and maternal health initiatives. Most countries in Africa, and the rest of the world, now have laws that make domestic and sexual violence a crime.

We have advanced significantly in the last 20 years to make gender and gender inequalities visible in terms of the lives of women and girls. We have, however, too often neglected how gender plays out in the lives of men and boys – to the detriment of women, and to the detriment of men and boys.

All too often the quest for gender equality is still characterised as a zero sum game in which women's gains are presented as requiring significant, but inevitable, losses for men. We continue to fall too easily into a view of the world of men as perpetrators, or careless, self-centred or potentially violent and women as victims and disempowered.

We seek to call attention to the relational nature of gender – that is constructed in the power relations between women and men, and within groups of men and groups of women. In other words, we posit that gender is about women and men, and girls and boys, and argue that it is intertwined with the structural factors of poverty and inequality that frame their lives at the individual level of their relationships and daily realities.

'Gender' as a concept calls our attention to how these power inequalities play out in the daily lives of men and women, boys and girls, and how women, girls, boys and men are too often socialised to live inside rigid constraints about what women and men are supposed to do and be.

We have too often neglected or ignored that men and boys are also enmeshed in gendered relations, norms and structures. These norms and relations mean that some groups of men and boys have more power than others, and that men and boys too often feel they have to live up to violent and inequitable versions of manhood.

As we look at research from Africa on the state of women, we can focus on the negative – and there is no shortage of it. Many men continue to use violence, or remain indifferent to the needs and vulnerabilities of women and girls, while others use their economic, social and physical power to exploit women and girls. But – and this part we too often miss – there are also stories of change. There are changes happening for the better throughout Africa, in how women and men live together, at the country level, at the cultural level, at the community level, and

at the individual level. And there is a common element to nearly all of these stories of change: cooperation and flexibility. In other words, men and women living together and transforming what it means to be men and women to find something closer to equality. This is what we mean by gender as relational.

If our goal is to achieve gender equality and to build just and democratic societies that reflect and reinforce healthy and respectful relationships, then, we argue, we will accomplish this faster and more effectively, if we recognise that both women and men have an investment in transforming gender relations. It is in our interests to move beyond gender binaries and to act on the evidence that shows that men and boys can be mobilised to support gender transformation – in solidarity with women, but also based on their own desire for healthier and happier lives.

BACKGROUND

Before we examine how policies and programmes can effectively engage men in transforming gender inequalities, it is useful to provide some background on the region – on key health and human rights issues.

The HIV and AIDS Epidemic

Sub-Saharan Africa remains the epicentre of the AIDS pandemic. While the region has just over 10% of the world's population, it is home to more than 60% of all people living with HIV – 25.8 million².

The AIDS pandemic disproportionately affects women, both in terms of rates of infection and the burden of care and support they carry for those with AIDS-related illnesses. Many studies have revealed that young women in sub-Saharan Africa are much more likely to be infected than men. Women are made

particularly vulnerable to HIV by conditions of poverty, limited empowerment and entrenched gender inequalities. Women continue to bear subordinate status across much of Africa, and gender norms condoning men's violence against women, grant men the power to initiate and dictate the terms of sex, and make it extremely difficult for women to protect themselves from

either HIV or violence. In some settings, notions of masculinity are associated with an ideal of unprotected sex, often with multiple partners.

While knowledge about HIV and AIDS has increased in most parts of Africa in the past ten years, knowledge alone is not enough to create safer sex behaviour. In Kenya, for example, young men reported experiencing conflicting pressures between their knowledge about HIV and AIDS and safer sex behaviour and their actions: in other

words, between what they knew they should do and what they actually did.³

The unequal balance of power between young men and women, combined with the patterns of risk behaviours among young men often associated with traditional gender roles, suggest that '*young men play a key role in shaping the future of the epidemic*'⁴ in Africa. Indeed, if we take into account that Africa is the world's youngest continent, with the largest proportion of its population under the age of 24 years than any other part of the world, this cohort of African young men represent a tremendous opportunity to transform gender

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requires understanding
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...be relational;
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norms, to view their sexuality not as predatory or dominating, but based on negotiation, mutual respect, rights and safety.

Gender-based violence

Like HIV and AIDS, Africa has some of the world's highest recorded or researched rates of domestic and sexual violence. Research conducted by the Medical Research Council in 2004 shows that in South Africa, a woman is killed by her intimate

partner every six hours.

This is the highest rate recorded anywhere in the world. A more recent study reports that 27% of men acknowledge to have raped a woman, many

of them more than once. In South Africa, because women have so little faith in the criminal justice system, only one in nine rape victims actually report rapes to the police; and fewer than 10% of reported rapes lead to conviction. Inadequate recording of statistics makes it impossible to determine conviction rates for domestic violence, but a recent study of domestic violence homicides in South Africa showed conviction rates no higher than 37.3%.⁵ Put another way, over 90% of rapists and nearly two thirds of men who kill their intimate partner go unpunished in South Africa. This sends a clear message to perpetrators that they are unlikely to be apprehended or convicted, and gives women little reason to believe that they can safely leave abusive relationships – even if they suspect their partner is putting them at risk of HIV transmission.

Similarly, in Namibia, 36% of women interviewed reported physical violence and 20% reported experiencing physical or sexual violence during the past 12 months.⁶ A study by Physicians for Human Rights found that in Botswana, 30% of women reported that their partner alone made the decision

whether or not to have sex. In Swaziland, 34% of women, compared to 4% of men, reported not being permitted to use a condom by a sexual partner at least once in the past year.⁷ The problem is not limited to the SADC region: In Ethiopia, 18% of women interviewed reported that their first sexual experience was forced, while 70% reported experiencing intimate partner violence, either physical or sexual.⁸

Although there are few reliable or official statistics on the extent of violence against women and girls in countries in West Africa, a number of studies indicate a pervasive problem in that part of the region as well.⁹ But there is still a culture of silence around violence against women; and Ghana and Sierra Leone are the exceptions in the region to have (only very recently) passed Domestic Violence Acts prohibiting domestic violence.¹⁰ In Nigeria, where intimate partner violence is one of the most common forms of gender-based violence, in some parts of the country a husband is permitted to cane his wife in order to 'correct' her.¹¹ The

practice of female genital mutilation (FGM) is still prevalent: in Nigeria, 19% of young women undergo FGM¹², while in Sierra Leone 90%

of women are circumcised. Sexual violence in schools is also a widespread problem, with very few countries having set up protective or preventative measures for pupils.¹³

These levels of violence are not just a public health problem; they also represent a serious threat to the continent's new and emerging democracies and undermine the ability of citizens to claim and exercise their rights. In South Africa, the new Constitution – widely recognised as a model not only for Africa but around the world – makes clear that:

Everyone has the right to bodily and psychological

...to effect real social

change, we must target both

men and women...

...they equate manhood

with aggression, dominance

over women, and sexual

conquest...

*integrity, which includes the right (a) to make decisions concerning reproduction; and (b) to security in and control over their body.*¹⁴

UNDERSTANDING MEN'S VIOLENCE

As we have carried out research on women's experiences of gender-based violence in the region, there is also an emerging research base on men's attitudes and practices related to sexual violence. For instance, a survey of 435 men in a Cape Town township revealed that:

More than one in five men... reported

*that they had either threatened to use force or used force to gain sexual access to a woman in their lifetime.*¹⁵

A 2006 *Sonke Gender Justice* survey of 1,000 men in the greater Johannesburg area suggested that equal numbers of men support and oppose government efforts to promote gender equality, with 41.4% of men surveyed saying that the government is doing 'too much' to end violence against women and 38.4% of men saying it is 'not doing enough'.¹⁶ A recent representative sample of South African men found that 28% disclosed to have ever raped a woman – nearly 75% of these by the age of twenty and many multiple times. Nearly half reported to have ever perpetrated domestic violence, with one in six assaulting a woman in the last twelve months. Men who perpetrate violence against women are more likely than their non-violent peers to drink heavily, to have multiple partners, and to be HIV infected.¹⁷ This violence decreases women's ability to determine whether or not and how sex takes place and is the reason for the higher HIV infection rates amongst women who have experienced gender-based violence.

...rather than enlisting
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...rigid gender roles
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and well-being...

Men's violence against women does not occur because men lose their tempers or have no impulse control. Men who use violence do so because they equate manhood with aggression, dominance over women, and sexual conquest. Many times men who use violence were themselves victimised by violence in the home or community settings while growing up – or structural violence in the form of poverty. Often they are afraid they will be viewed as less than a 'real' man if they apologise, compromise or share power. So instead of finding ways to resolve conflict, they resort to violence.

These perceptions of manhood lead to high levels of violence against women and contribute to extremely high levels of male violence against other men.

As we have seen far too frequently in Africa, these harmful tendencies are exacerbated during times of war and in the period immediately following a conflict. During such times of lawlessness, stress and violence, both men and women are subjected to horrors and brutality on a large scale.

Undeniably, it is men who commit the majority of all acts of domestic and sexual violence. However, many men and boys are strongly opposed to this violence. Men are, of course, negatively affected by domestic violence and rape as well. Boys who live in homes where their fathers abuse their mothers are often terrified by their fathers, and the violence they commit; as a result they can experience problems with depression, anxiety and aggression that interfere with their ability to pay attention at school. Similarly, all men are affected when women they care about are raped or assaulted.

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MASCULINITIES AND HEALTH

As we seek to understand how violent and rigid gender norms and roles make women and girls vulnerable, it is also important to recognise that rigid gender roles jeopardise men's health and well-being. Contemporary gender roles encourage

men to equate risky sexual behaviour with manliness and, conversely, to regard health-seeking behaviour as *'unmanly'*. Studies indicate that traditional men's gender roles lead to *'more negative condom attitudes and less consistent condom use'* and promote *'beliefs that sexual relationships are adversarial'*.¹⁸ They encourage boys and men to equate being manly with the use of violence, alcohol and substance abuse, the pursuit of multiple sexual partners, and the domination of women.

In some settings, being a man means being tough, brave, risk-taking, aggressive and not caring for one's body. Men's and boys' engagement in some risk-taking behaviours, including substance use, unsafe sex and unsafe driving, may be seen as ways to affirm their manhood.

Life expectancy in much of Africa show women are living longer than men; in South Africa, life expectancy is at 49 years old for men, and 52.5 years for women. Men have consistently higher death rates as a result of tuberculosis; well over double that of women in countries such as Kenya, Cameroon, Rwanda and Zambia.¹⁹ Men die far more frequently than do women as a result of both unintentional and intentional injury; they are three and sometimes four times as likely to be a victim of a road traffic accident as women. While men commit violence against

women at alarmingly high levels across much of the continent, men use violence against other men at even higher levels. In South Africa men kill men at seven times the rate that men kill women²⁰. In Zimbabwe, 55 men out of every 100,000 men in Zimbabwe die as a result of violence, compared to 11 women; in South Africa it is nearly 120 men; Kenya it is 39 men, and in the Democratic Republic of the Congo, men are three times more likely than women to die as a result of violence and war.

Norms of men and boys as being invulnerable also influence men's health-seeking behaviour, contributing to an unwillingness to seek help or treatment when their physical or mental health is impaired. Men in some predominantly male institutions, such as police forces, the military or in prisons, also face specific risks, due to institutional cultures that may encourage domination and violence. In sum, prevailing notions of manhood often increase men's own vulnerability to injuries and other health risks, and create risks for women and girls.

While we are not used to looking at how gender plays into it – alcohol consumption is one key area where gender norms leave men and women vulnerable. Men's drinking particularly impacts on women in their roles as mothers, wives or partners or daughters of drinkers. The risks include violence, HIV infection, and an

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increased burden in their role as economic providers. A study on alcohol-related problems facing women in Lesotho, for example, found that the cultural position of women there facilitates a vicious circle in which women are at one time brewers of alcohol,

then sellers, then become excessive consumers, due to the problems created by their drinking husbands.²¹ Alcohol can also be part of power dynamics and hierarchies among men.

These are just a few examples of how gender norms play into other health issues – creating specific vulnerabilities for men and women.

...to move beyond gender binaries...

WHY WORK WITH MEN?

Gender equality, social justice, and sexual and reproductive health are not just ‘*women’s issues*’; they are equally vital to the health and well-being of women and men. Just as women suffer direct harm from gender inequality, so too do men.

Long-term success in engaging men in the ‘*struggle*’ towards gender equality lies in promoting not just a ‘*needs-based*’ approach, but also a ‘*rights-based*’ approach. Rather than enlisting men as partners in promoting gender justice, because they need to be more proactive for the sake of their own sexual and reproductive health, or because they should encourage women’s agency over their bodies and choices, men must realise their **right** to break free of the confines of rigid and violent gender constructions. Sylvia Chant and Matthew C. Gutmann, authors of *Mainstreaming Men Into Gender and Development*, write:

...to deny men’s rights is to deny the universality of human rights.

Viewing men’s active involvement in these spaces as a ‘*right*’ engenders a desire to fight for what they deserve. Men are much more likely to vest their interests in a rights framework, than in one that assumes men should promote gender justice and seek health only as a duty to women and their community. In other words, achieving gender equality requires us to help men and boys see why it is in

their interest too to overcome rigid and violent versions of gender.

Work to empower women, and to support the health of women is important. However, working with women is only half the story. To effect real social change, we must target both men and women.

Around the world, there have been successful initiatives working with men and boys. These efforts, by men in particular, have debunked the myth that all

men are the same. This work is testimony to the fact that most men are not violent by nature, but are also victims of their own socialisation in a social and political system that encouraged and promoted violence as a way of life, and provided them with few other role models for masculinity.

Work with men has demonstrated significant potential in contributing to building gender equality and improving men’s and women’s health.^{22, 23} However, most work with men has been local in scale and limited in scope. To be effective at the societal level – to transform the pervasive gender inequalities which characterise nations and regions around the world – efforts to transform men’s behaviour will need to be scaled up significantly. Policy processes and mechanisms are vital elements in any effort to involve men and boys in achieving gender equality.

FROM PROGRAMMES TO POLICIES: ACHIEVING THE POTENTIAL OF GENDER EQUALITY

As work with men on gender gains visibility and traction, many governments across the world are beginning to develop ‘*male involvement*’ initiatives. Often these efforts are hampered by a lack of clarity about the goals of such work, and by the lack of a clear framework to inform such work. As a result, valuable resources, opportunities and goodwill are sometimes squandered.²⁴ While there are no universal policy solutions to

engaging men in achieving gender equality, there are some key principles and emerging examples.

We argue first and foremost that policy level approaches to engaging men and boys must:

- 1) Promote women's and girls' rights; they must be aligned with, and be part of, existing efforts to empower women and girls.
- 2) Enhance boys' and men's lives; they must make visible vulnerabilities that men face and help men and boys see benefits to themselves of transforming gender norms.
- 3) Be inclusive of and responsive to diversities among men, including issues of sexual diversity, different ethnic groups and social class differences, as well as include the specific needs of men in prison, men who migrate for work, men (and women) affected by conflict, among others.
- 4) Be relational; understand how gender norms and inequalities affect women and men and looking at ways that gender relations can be transformed by engaging both women and men.
- 5) Address the structural and social determinants of gender inequality, first and foremost income inequalities and the unequal division of labour.

These five interrelated commitments should guide the positive involvement of men in gender equality work.²⁵

Working with men and boys to achieve gender equality remains a relatively new approach. As more programmes engaging men and boys are implemented, a body of effective evidence-based programming has emerged, and has confirmed that men and boys are willing to change their attitudes and practices, and to take a stand towards achieving greater gender equality.

A FINAL NOTE: THE PROMISE OF A GENDER RELATIONAL PERSPECTIVE

The work of the *Sonke Gender Justice Network* and of *MenEngage* is ultimately based on a belief that change is possible – from the individual to the collective – and that achieving sustainable and true gender equality requires understanding that gender is relational. Indeed, our work is inspired by listening to stories of change from women and men, from the individual to the collective. For example, in recent interviews with men and women involved in economic empowerment programmes in Rwanda, a 44-year old man with a physical handicap, a subsistence farmer like his wife, said to us:

Used to be men in my community thought I was controlled by my wife because I let her go out by herself and have her freedom when she was coming to the savings and loan group. But then I joined too. I saw that she was able to buy vegetables and sell them in the market and the money was good for both us. Then I became a member and we both had access to credit and we pooled our money and we bought animals.

In rural Rwanda, as in much of rural Africa, animals (e.g., sheep, goats, pigs, and cows) bring more economic stability and more income than crop production alone. The man went on:

We invest together and we make more money. I never got to wear the clothes I have now. I have confidence in myself. I don't feel so self-conscious about my limp any more. And my wife seems to me more beautiful than she used to to me, and our children are happier.

In our direct work with men and women, we have heard numerous stories like this – cases of men who participate more than average in providing care for their children or relatives, or who are involved in advocacy or activism to promote women's

...men are much more likely to vest their interests in a rights framework...

...an investment in transforming gender relations...

rights. We have documented cases of men renouncing violence they previously carried out. We have also gathered stories of men previously involved in armed conflict, who have

become community leaders working to end violence against women. We seek to move from individual and programme-level change to collective, structural change. We hope to inspire and inform the large scale change at the policy level that must take place if we are to achieve the true promise of gender justice.

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For us to realise our common goal...

Men's organisations and gender transformation

The work of men's organisations, and the role they play in the 'struggle' for gender equality, remain contentious issues in the South African gender sector.

Cherith Sanger

During October 2009, I presented a short talk at the Men Engage Symposium in Johannesburg on the principles that should inform men's organisations' work from a 'woman' women's rights defender's perspective.

In preparing the talk, I thought it best to obtain the views of other women working towards gender transformation in order to express the movements' general views on the topic. This article incorporates those views.

I found that most of the women support men's organisations working towards gender transformation. My understanding of the reason for this is that not only women should contribute towards attaining equality between women and men, and that education and training of men and boys, which men's organisations are doing, is fundamental in striving for gender equality. Exclusively providing services and educating 'victims' on how to deal with the aftermath of inequality serves as more of an attempt to 'heal a wound', rather than find preventative measures and ways to uproot the cause of the problem.

Men taking steps to attain gender equality arguably indicates that men are taking responsibility for the difficulties and hardship that women face due to inequality. It is expected that men take

responsibility for gender inequality in South Africa, as the vast majority of women are subjected to violence, such as sexual violence, domestic violence and hate crimes by men; and the corporate or private sector is still mainly run by men who give women poor maternity leave benefits and make unfair decisions on sexual harassment matters, where most complainants are women. Women have claimed the 'struggle' towards gender equality as their own, with almost no support by men, or now, with the advent of men's organisations, very little support from men.

Due to South Africa's history of apartheid and sexism, we have what I think is best called a 'social hierarchy', with white men at the top of the ladder and black women on the lowest level of the ladder. Black women are the most vulnerable to unfair discrimination in light of lack of education and inherited economic disadvantages.

From a gender perspective, social constructions on gender have created adverse masculinity traits and inequality between women and men. This inequality has ultimately led to women being unfairly discriminated against on the basis of their sex and gender in various ways, ranging from women's lack of security of tenure, and unequal employment opportunities, to violence against women.

Due to privileges given to men under apartheid they still operate from a position of superiority in most spheres of life. It is this very privilege and superiority that gender transformation seeks to address. White women feminists are often criticised when working with poor black women, as the general perception is that their realities are better than that of poor black women's and they too operate from a position of power.

Being a white man thus creates an even greater gap in identifying with women's struggles. This issue can also be raised in terms of white men working with black boys and men, as well as foreign men from the so called '*first world countries*' working with local men and boys.

Men working towards gender transformation should continuously interrogate their own masculinities, privilege and position of power, irrespective of the extent of their gender consciousness. Men working with women must caution against drowning women's voices, dictating to women, and making decisions on behalf of women. The same principle should apply when men's organisations partner with women's organisations, as women are better or more appropriately placed to assist women.

With specific reference to men working with men and boys, it was raised that men need to be alive to the hetero-normativity under which society operates, to ensure

...contentious issues in the South African gender sector...

that hetero-normativity does not guide the education and training of men and boys, as it is one of the main evils that created adverse masculinity issues. Moving away from the standard of hetero-normativity also supports the advancement of LGBTI women's rights, which is often undermined by our laws and society, and which leads to the perpetuation of hate crimes against LGBTI women.

The other issue that was mentioned related to the '*re-victimisation*' of women, when men play the role of somehow '*saving*' women by assisting them, which perpetuates the notion of men being superior to women, even though many women are capable of providing the same assistance to women in need of it.

Men's organisations should also take steps to work more closely with women's organisations as partners to inform their own, and each others work. This is important in terms of addressing power issues amongst women and men working towards gender equality. It is also important in order to reap the benefits of partnering from a perspective of sharing resources

and gaining expertise in the various forms of work being conducted within the sector.

Specific issues were further highlighted in terms of funding given to men's organisations working towards gender transformation. It was said that funders seem to be keener on funding men's organisations working with gender issues, than women's organisations

...recognise that women have paved the path for the work that they do...

working with gender issues. The reason for this may be that funders are attracted to supporting men's efforts financially, as the gender sector is vastly constituted of women, rather than men; and men doing gender transformation work is seen as men 'fixing the problem', as compared to women needing to 'fix' and take responsibility for gender transformation. This issue is rather complicated, as we want to secure more funding for all gender equality organisations, as we all work towards the same goal. However, we do not want an unfair distribution of funding between men's and women's organisations, as this perpetuates the idea that men are 'better' decision-makers and are more 'capable' of effectively dealing with women's issues, than women are.

...must caution against drowning women's voices, dictating to women, and making decisions on behalf of women...

that women have made. The counter argument to this issue is that it needs to be considered in light of the nature of the work being conducted by the organisation, the media contacts

...addressing power issues amongst women and men working towards gender equality...

A similar issue was raised in regard to the media coverage that men's organisations are getting over women's organisations. It was said that the media attention that men's organisations get undermines the gains

of the organisation, and the capacity of the organisation.

In conclusion, men's organisations must recognise that women have paved the path for the work that they do, and must acknowledge and act on our concerns so that we can improve our working relationships with each other, in order for us to realise our common goal. Finally, we must steer away from

marginalising men's organisations, as this will compromise our principles, which are largely based on equality for all.

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Choices tend to be limited for women...

Sexual and reproductive rights of women in polygamous unions

Global statistics indicate that women account for more than half of the 33 million people living with HIV worldwide. Two thirds of these live in Sub-Saharan Africa, where women are even more affected, accounting for over 60 percent of all people living with HIV.¹ Statistics also suggest that HIV prevalence rates amongst married women are rising, which is linked to both women's greater biological susceptibility to HIV infection and behavioural and social factors that further fuel the vulnerability of women.²

Lydia Mavengere

This article will argue that while women in general, and married women in particular, are at a growing risk of HIV transmission, women in polygamous unions are even more vulnerable. Susser (2001) argues further that *'many women who contract AIDS only have one partner, usually their husband'*.

Central to the realisation of sexual and reproductive rights, is the concept of choice. This refers to the choice of whether or not, with whom and when to have sex, and how to engage in sex³. The concept of choice further implies that women have the right to choose whether or not to marry into the polygamous union. However, such choices tend to be limited for women for a number of reasons.

In the first instance, as argued by Radebe [2009:30], marriage and marital choices are not only severely limited for most women, but also impact greatly on women's HIV risks.

...gender inequalities and imbalances as well as the 'prescriptive concept' of marriage, are to be understood as obstacles to HIV prevention...

The reality in most African societies is that a woman only gains respect based on the fact that she is married; with such respect growing depending on the social and financial standing of her husband. Subsequently, women who are single, past a certain age, divorced, or single parents are often stigmatised

and discriminated against. Given this reality, a large number of women may *'choose'* or *'feel forced to'* enter into some marital situation, no matter what the conditions are.

In addition, where stigma and discrimination do not *'force'* women into marriage, the need for financial support may impact on women's *'choices'* to enter into marital relationships. Von Struensee [2005] notes that *'financial dependence created from a lack of resources can pressure women into entering polygamous marriages'*. It is important to note that this article is not intended to critique the concept of polygamous marriages, but to explore the extent to which women within such polygamous unions are in a position to fully embrace their sexual and reproductive rights, and its impact on women's human rights.

DEFINING POLYGAMY

For the purposes of this article, polygamy simply refers to a man having more than one wife. Practiced customarily, the senior wife could choose who the successive brides should be.⁴ In some families, this practice could expand to a situation in which the new bride spends time with the senior wife and other women elders of the extended family to be taught of the *'rules of the home'*, especially how the husband should be treated. Such a practice is rather strict in that it becomes a communal system of *'checks and balances'*, on acceptable and unacceptable behaviour in the communal home.

Historically, migration in terms of labour has fuelled

informal polygamy, with men moving from different parts of South Africa to the mines and the cities in search of employment.

Such high levels of mobility across the socio-economic spectrum create spatially fluid households and families 'stretched' across space in both rural and urban areas, or even living in different countries.⁵

Polygamy in its various forms exists throughout the social spectrum of South Africa for historical and other reasons. Exploring polygamy in Africa, Walter [2009] argues that

All of these accounts offer food for thought about gender and gender equality, and questions some of our assumptions about polygamy. It's a choice say proponents – but stories show women who expected to be the only wife, women pressured by husbands and family, or who lacked the economic power to disagree – and none of these offer choice, even if the person says 'yes'.

Yet, some accounts show there can be a different side, with families living in harmony. They also show that rigid gender roles not only cause problems for women, but for men also. As it stands, men face incredible pressure to reproduce quickly, provide for families, and be the glue that holds the family together.⁶

Ovis [2005:3] further notes that

...social need may contribute to more women viewing polygamy as a means

...growing awareness of women's human rights stands to challenge previously accepted customary practices in Africa...

...women in marital unions, especially in polygamous unions, have little recourse to claim and enjoy their sexual and reproductive rights...

of evading poverty...[as] the majority of rural women may still only access resources through men.

Exploring the issue of polygamy in the context of poverty, then South Africa's Deputy Minister of Health, Madlala-Routledge, commented:

An issue of growing concern for African women is the issue of polygamy within the context of high levels of poverty and communicable diseases. Although women are said to participate willingly in these practices, the question needs to be asked whether they are just seeing it as an escape from poverty.⁷

Whether women are engaged in 'formal' or 'informal' polygamy, an argument could be made that especially in light of HIV risks, polygamous relationships are as much a 'driver' of the HIV and AIDS pandemics as any other multiple concurrent relationship.⁸

Thus the practice of formal and informal polygamy creates a network of simultaneous or 'concurrent' sexual relationships that links sexually active people not only to one another but also to the partners of their partners – and the partners of those partners and so on – creating a giant web that can extend across huge regions. If one member contracts HIV, then everyone else may too. Polygamous men generally seek out young women, even as they themselves age. In this way, formal and informal polygamy pumps the virus from one generation to the next. [Von Struensee, 2005]

In the context of HIV prevention it is further argued that

*Given the exercise of formal and informal polygamy, the alarming effect is that traditional approaches to HIV prevention do not meet the needs of married women, as wives cannot control the faithfulness of their husbands, and because they find it difficult to negotiate condom use.*⁹

IMPLICATIONS FOR WOMEN'S SEXUAL AND REPRODUCTIVE RIGHTS AND HEALTH

Despite the legal and policy measures protecting the rights of women in South Africa, gendered inequalities, largely fuelled by socio-cultural values and a general lack of knowledge of women's sexual and reproductive rights, women's access to, and realisation of these rights remain rather limited. The South African Constitution¹⁰ guarantees everyone the right to life (Section 11), the right to equality and non discrimination (Section 9), the right to bodily and psychological integrity (Section 12), the right to human dignity (Section 10), and the right to privacy (section 14) – yet, despite these constitutional guarantees, many women, especially women in polygamous unions, are not in the position to exercise their rights.

A polygamous union will have at least three people; the husband, the senior wife and the junior wife, and is a highly hierarchical system. A scheduled sexual life, which forms part of the 'rules' of polygamous unions, arguably erases the concept of choice of whether or not, with whom, when and how to engage in sex, as sexual encounters are 'acts' to be performed at the scheduled times. Women become providers of sex for the purpose of reproduction, rather than sexual pleasure.

Radebe [2009:29] argues that 'there is also the societal

misconception that a

marriage certificate

means the right to

sex', further impacting

on women's 'ability' to

exercise their right to

choose, since married

women, especially in

the cultural context of

ilobolo payments, are

expected to provide sex on demand and to bear children.

However, the societal expectations and cultural pressures for women in polygamous unions to bear children does not end after the birth of a child, as women find themselves in an ongoing 'power struggle' for respect and acceptance. If, for example, the

senior wife has five children, the junior wife

has to either match or better that number.

Moreover, great emphasis is placed on the

sex of the child, with more respect given to

the woman who gave birth to more sons, and

thus, provided 'heirs' to the union.

While some would argue that in a

polygamous union the burden on a woman

to reproduce is often reduced, given the fact

that a number of women are now sharing

the responsibility of reproduction, others would argue that the

pressure to have children is highly competitive in a polygamous

union, further exacerbating the prevailing threats to women's

health¹¹.

Further exploring the impact of polygamous unions on

women and women's rights, Von Struensee [2005] notes that

...although polygamy itself is not a prohibited practice

under international human rights law, it reaches other

fundamental rights, such as the right to dignity, the right to

...while the burden of stigma related to women's marital status in Africa is high, stigma tied to rejection is even worse...

...the concept of bodily and psychological integrity does not exist for women in polygamous unions...

equality within the family and the right to equal protection under the law. It also tends to perpetuate women's low social and economic status by forcing women to share valuable resources with their husband's other wives and children.

Or, as argued by Kehler [2006:6]:

It is the gendered context of society, defining females as 'inferior', as she is the 'weaker sex' as the ones who are socialised to become good women, and who should respect the male head of the household at all times that creates an environment in which women are not in a position to make choices, let alone informed choices.

In reality, a polygamous union is not a 'democracy', where everyone's wishes are taken care of, but instead an 'autocracy', with one man ruling over all members of the union and making decisions, including sexual decisions, on behalf of his multiple wives. Thus, the concept of bodily and psychological integrity does not exist for women in polygamous unions.

In addition, it could be argued that the risks of HIV

transmission in any sexual relationship is now multiplied by the number of people involved in a polygamous union. And again, it is the man who makes decisions as to whether or not to prevent the risks of HIV transmission on

behalf of the women in polygamous unions. Considering that many women enter into polygamous unions to escape poverty

and to gain the social status of marriage, women in polygamous unions are likely to be financially dependant, with little negotiating power.

Furthermore, women in polygamous unions are least in the position to make any claim, regarding property or inheritance in the event of divorce or the death of the shared husband. In reality, any effort to articulate her rights within the confines of a polygamous union may potentially lead to her rejection from the union. Following the argument that polygamy today is most common in rural communities, women rejected and leaving a polygamous union will encounter many problems within their rural community, including being stigmatised and discriminated against.

While the burden of stigma related to women's marital status in Africa is high, stigma tied to rejection is even worse, as women are often labelled as 'that woman who was rejected'. Thus, to avoid rejection and 'divorce' from the polygamous union, women may 'opt' not to attempt to claim their rights and to remain within the union, irrespective of the conditions and risks associated with living in a polygamous relationship.

CONCLUDING REMARKS

Despite the recognition and protection of women's rights in South Africa's constitutional and legislative framework, women in marital unions, especially in polygamous unions, have little recourse to claim and enjoy their sexual and reproductive rights – not only greatly impacting on women's sexual and reproductive health in general, but also on women's risks to HIV transmission.

Discussing the gaps between women's rights and women's realities in the context of HIV risks and vulnerabilities, Kehler [2006:3] argues that

...the gendered context of society defines sex and sexuality for women, largely as a means to reproduce, and women

...women find themselves in an ongoing 'power struggle' for respect and acceptance...

as the ones, who are passive recipients of sexual choices and decisions of their male counterparts. Subsequently, women are seldom in the position to negotiate conditions of sex, even less so, safer sex, and thus are seldom in a position to prevent HIV infections.

**...a scheduled sexual life...
erases the concept of choice
of whether or not, with
whom, when and how to
engage in sex...**

Although growing awareness of women's human rights stands to challenge previously accepted customary practices in Africa, women that live by these standards remain lone voices in today's reality. Von Struensee

[2005], quoting Zimbabwe's Justice Anthony Gubbay who warns that radical reforms 'might alienate the more traditional and conservative elements in the society' and 'backfire on the very women we are seeking to protect', notes:

Proposals to ban harmful customary or traditional or religious practices may be incremental, will not be static and must be left open to progressive review in light of changing times and social acceptance. Nonetheless for reasons of presenting a full debate someone should always advocate for the most progressive reform.

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The power to 'opt out'...

Musings on HIV testing of women¹

In the past couple of years, there have been calls for expanded and/or increased uptake of HIV testing. South Africa is today reporting the increased numbers of people who are taking an HIV test. Justifications for such calls vary, ranging from access to HIV treatment, as HIV testing is viewed as a good entry point to HIV medication; HIV testing as part of maternal health, in the form of the prevention of mother to child transmission programmes; to HIV testing as part of a healthy lifestyle and a good entry point for HIV-related behaviour change.

Promise Mthembu

It is clear that HIV testing is now also promoted in the context of citizenship, in that a 'good citizen' is responsible and takes an HIV test. Nowadays, HIV tests are also more and more commercialised and are taken out of the public health sphere, with HIV testing facilities in communities, churches, schools and at rallies.

HIV testing policies, nationally and internationally, are said to, or should be, in line with human rights standards.

The latest policy guidelines on

provider-initiated HIV testing states that, at a very minimum, consent, confidentiality and counselling should be adhered to at the level of provision of an HIV test; as such, the three Cs, as these are programmatically known, are to be adhered to.

It would appear, however, that HIV testing programmes mostly target the poor, the vulnerable, and those who are less in the position to 'opt out' of the test. There are also many concerns that the principles of consent, confidentiality and

counselling might only be available on paper and not in real life HIV testing situations. Looking at the risk of rights abuses in the context of HIV testing, I am yet to hear debates about whether or not HIV testing programmes are permitted to lead to harm, in that they are subjected to principles of doing no harm.

...concerns that the principles of consent, confidentiality and counselling might only be available on paper and not in real life...

I think we all are in agreement that South Africa is a grossly violent society. Unless, of course, we are subscribing to the African Renaissance Project, which rejects African men as violent and/or rapists, and/or paying tribute to the 'New Man' that has apparently emerged in South Africa; one wonders, what happened to the 'old man'? I think we also would agree that there is a co-relationship between violence against women and HIV infection; although we seem to assume at times that this violence fades away, once a woman is diagnosed with HIV. An example for this would be the rape support services available, if at all, to women who either disclose their HIV positive status or are testing positive for HIV. The need for support seems

to cease right there and then, and positive rape survivors are often left to fend for themselves.

I recently followed a debate on the radio calling for alleged rapists to be forcefully tested for HIV. It was interesting to me that these calls were made by the Ministry of Women, Children, Youth and Persons

with Disabilities, largely based on the misguided notion that this would support women who have been raped. I eagerly waited for the debate to also talk about what positive women who are raped should do – but in vain. Should they claim their right to know the HIV status of the rapist? Should they feel guilty that they might have infected someone with HIV? Should they worry about being prosecuted for infecting the rapist? What should positive women do and where should positive women go for support?

As I continued to indulge with the issue of HIV testing and specifically the issue of compulsory and/or 'forced' HIV testing, I think of pregnant women. And while HIV testing policies do not allow for 'forced'

HIV testing, I fear that in the context of HIV testing during pregnancy many women are indeed 'forced' to test. Yes, women have the right to 'opt out' of an HIV test; however,

'opting out' can only become a reality for women, if healthcare centres are no longer places of powerlessness, as already proclaimed by the Gender AIDS Forum's research in 2004. We

need to ask and interrogate if women really have the power to 'opt out', before we celebrate the many pregnant women who are testing for HIV.

...when will women have the power to 'opt-out' and to decide for themselves?...

There is also the question if persuasive counselling practices are paying off, or if business-like models of HIV testing, the 'economy of targets' and quantified efficiency, really are changing the AIDS world. We hear that counsellors are evaluated by the numbers of people tested a day – productivity economics in operation indeed. Is this perhaps 'coercion' in action, I wonder? Are we possibly manipulating the vulnerability and 'powerlessness' of women we claim is the problem and leads to the very HIV infection, amongst all the other adverse

effects of such vulnerability and powerlessness? If this is indeed 'the problem', why are we perpetuating it and when will women have the power to 'opt-out' and to decide for themselves? Will this happen in our lifetime? Are we really

empowering pregnant women by 'counselling' them to test for HIV during pregnancy? We do not know the answers to all these questions – maybe just as well.

...are we possibly manipulating the vulnerability and 'powerlessness' of women...

At times, I think there is a belief at play linking power to an HIV positive diagnosis, especially for women. A woman, who does not have HIV or has not tested for HIV is agreed to be vulnerable, poor, and has difficulty negotiating for her survival sex; she is raped and beaten.

And then, for some reasons in the eyes of AIDS programmes, it seems that if you introduce an HIV positive diagnosis into the equation, a woman suddenly has this 'power' to make decisions, to protect, refuse, act, and take charge – an HIV positive diagnosis appears to be this amazing ingredient for women's instant empowerment.

In short, many programmes seem to assume that a positive HIV diagnosis gives power to women; gives power to challenge healthcare workers; to negotiate safer sex, after successfully disclosing their HIV positive status; power to reduce maternal deaths, and to 'save' children from HIV and poverty; and last, but not least, the power to challenge and stop violence from their male partners, their families and the societal systems. And remember, women do not have this power before the HIV positive diagnosis; this power appears to come with being diagnosed with HIV – at least that seems to be the assumption of many HIV programmes that expect positive women to use condoms to 'protect' their partners, and not to breastfeed to 'protect' their children, irrespective of the potential abuse and violations women are subjected to.

*... 'opting out' can only become
a reality for women, if healthcare
centres are no longer places of
powerlessness...*

I am deeply concerned about these kinds of programmes that assume that positive women have 'power'. An HIV positive diagnosis does not give women power, instead it places women at a worse position than they were before the

diagnosis. In reality, positive women are more vulnerable, marginalised, and prone to violence, with little hope of redress, and structural and community solidarity, because of a positive HIV status.

And so, I remain confused, angered and deeply concerned about programmes, proclaimed to be for the benefit of women, whose design are far removed from women's realities of 'power' and whose success seems to be more based on violating and 'forcing' women to 'opt-in' to the offer of HIV testing, than on 'empowering' women to make informed choices.

FOOTNOTE:

1. An earlier version of these 'musings' were published in the *Mail & Guardian* on 04 December 2009.

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Pervasive societal attitudes must change...

Engendering the response to HIV and AIDS in India

At the outset of the HIV epidemic in India in the 1980s, women were generally considered to be a 'low risk' group, as compared to 'high risk' populations, such as intravenous drug users (IDUs), men who have sex with men (MSM), and female sex workers (FSWs). However, assuming neat distinctions between populations of high and low risk of HIV is simplistic; the reality is that there are intersections between populations. Each individual does not necessarily fall into only one category; for example, MSM may also be married and transmit the virus to their female spouses.

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Tyler Crone and Sai Subhasree Raghavan**

INTRODUCTION

These complex interactions have contributed to the increased 'feminisation' of the HIV epidemic in India, with a steadily increasing infection rate amongst women, who make up approximately 39% of people living with HIV/AIDS.¹ A significant number contracted the virus while married or in monogamous sexual relationships: 95% of married India women report having had one lifetime sex partner.² With only one sexual partner, these women are not engaging in high-risk behaviour, but they are nonetheless at risk due to the high-risk behaviour of their husbands, who may be MSM or IDUs, or in unsafe sexual activity with several partners. The transmission route of HIV in India is still predominantly sexual – responsible for 87.4% of the 2.47 million cases – which further increases the risk of women contracting HIV.³

In recent years there certainly has been an increased focus on the gender dimensions and its impact of HIV in India, but the discussions around engendering the HIV response in India have focused largely on a binary conception of gender, of female and male. Gender is not a biological designation, but rather a socially constructed conception of the attributes associated with being female and male. Gender is a spectrum

and a binary comprehension of it ignores key populations that have traditionally been marginalised, most notably men who have sex with men and transgender people. Therefore, although the focus on engendering the HIV response should focus largely on women, the empowerment of other marginalised gender groups that are similarly disempowered, because they are viewed as 'feminised', must be concentrated on as well, as the vulnerabilities of all of these populations are interconnected.

In order to effectively reduce the vulnerabilities of women, pervasive societal attitudes must change. The traditional roles of man/woman, husband/wife, provider/homemaker, must be re-imagined. Although gender dynamics cannot be equalised in a single generation, interventions encouraging specific behavioural changes and focusing on empowerment can have a large impact on reducing the vulnerability of women to HIV. Analysing the HIV response from a gendered lens is not just about focusing on women as female, but also about emphasising the social forces that place individuals in marginalised situations.

To create effective targeted interventions to change the behaviour of dominant social groups and empower marginalised groups, the historical underpinnings of gender dynamics in the Indian context must be understood. An understanding of the theoretical background of gender in India will help to inform interventions that aim to equalise the power differential between women and men.

This paper provides a brief background of the historic

...marginalisation...is the
fundamental issue that
keeps women from fully
accessing the right to
health...

good practices to mainstream gender into HIV responses, and suggests ways to move forward.

GENDER THEORY IN THE INDIAN CONTEXT

Women's increased vulnerability to HIV is based both on physiological factors, as well as on traditional gender roles, which place women primarily as '*passive caregivers*'. It can be argued that it is the secondary role of women in Indian society – idealised as the mother, taking care of her children, husband, and extended family – that increases the vulnerability of women to HIV across the country.

In order to fully understand these interwoven vulnerabilities, it is important to first understand the difference between gender, sex, and sexuality. '*Gender*' can be defined as the behavioural, cultural, or psychological traits typically associated with one sex.⁴ The concept of '*gender*' is distinct from '*sex*', which can be defined as biological forms differentiated by reproductive organs and denoted in most species as '*female*' and '*male*', and '*sexuality*', which refers to the sexual interests of an individual.⁵

Traditional gender roles have frequently been used to exert social control by one gender over the other, of resources, and in extreme cases, of individual bodies. These power dynamics have

conception of gender in India, followed by a review of the vulnerabilities of women. In addition, this paper explores some of the issues regarding women that must be tackled, puts forward examples of

historically been partially rationalised using arguments about social roles, based on biological sex characteristics, such as child bearing. Because HIV is primarily a sexually transmitted disease in India, it is important to understand these distinctions and the impact that these categories have on an individual's vulnerability to HIV.

This section will explore gender

representations in Indian texts. As the record of a dominantly patriarchal society, Indian history and philosophy centres on the lives of men;

however, female figures have also been shown in positions of power and agency throughout. We review this history in order to better understand the creation of current cultural dynamics and traditional gender roles that influence women's vulnerability to HIV.

Ancient and medieval texts

Power dynamics in some ancient Indian texts, including the *Vedas* and *Upanishads*, show women taking an active role in dialectical discourse. In the *Brihadaranyaka Upanishad*, for example, women are presented as arguing companions, including in debates between the male Yajnavalkya and the female scholar Gargi, as well as with his wife, Maitryi.⁶ The representations of women's position in ancient Indian society are often contradictory within these texts; for example, in the *Manava-Dharmasastra*, certain passages state

...a discussion of '*gender*'
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access to care...

that women must be honoured, while others lay down strict laws for their dependence on men.⁷ As Ruth Vanita explains in her discussion of these texts, contemporary definitions of ‘men’ and ‘women’ have hardened in comparison to ancient texts in which gender is seen as much more fluid, especially in its relationship

...challenging social,
gender, and power
inequalities, in order
to ultimately address
power issues in sexual
relationships...

with sexuality.⁸ Visible and active roles for women do not figure significantly into mediaeval Indo-Muslim texts that emerged during India’s medieval period. However, the practice of separating

and veiling women from men, known as *purdah*, which was already practiced in some areas of northern India, increased in popularity during this period.

Colonial texts and modern media

At the time of independence, women’s role in India was becoming increasingly vocal – the idea of gender equality is enshrined in the preamble to the Indian constitution.⁹ There were more women involved in the national movement for Indian independence than in the Russian and Chinese revolutionary movements combined, and India’s first female Prime Minister was elected in 1966.¹⁰ The rise in prominence of women in South Asian politics around this time is notable both for its feminist implications and for the way it maintained gender dynamics – certain women clearly gained a more powerful place in society, but they obtained that place primarily through relationships with their husbands or fathers.

Women’s role in Indian society is changing quickly. The

impact of feminism – of theories both from within the country and imported from abroad – has changed the way that people living in India view gender, especially in urban settings. In an essay on middle class Indian sexuality, Padhke characterises what she calls the ‘modern urban sexy middle class progressive but respectable women’, demonstrating the way in which Indian femininities reflect both western influences and traditional Indian culture.¹¹

Historical representations of gender and vulnerability to HIV

It is important to understand the history of the construction of gender in the Indian context in order to understand the current gender roles that are assigned to women, the ways in which this impact on their vulnerability to HIV, and what can be done to reduce those vulnerabilities. History shows that women’s role in society – and even basic concepts of ‘women’ and ‘men’ – have changed over time. Sub-cultures within India have shown considerable acceptance of the importance of women’s participation in society, and it has been argued that increasingly conservative restriction of the roles of women and feminised populations has arisen in the last century, influenced by Hindu fundamentalist, Muslim Moghul, and British Christian Victorian systems of thought. These restrictions have led to the disempowerment of women, which has in turn reduced their ability to negotiate for their own right to sexual autonomy and health. In order to empower women to reduce their vulnerability to HIV,

...HIV and gender parity
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it is necessary not only to give them basic tools such as education, condoms, and medicine, but also to grant women an equal place in society, in terms of such basic rights as property ownership and literacy, as well as the social freedom to act on these rights.

...women who own property or control assets are more able to cope when crises arise and are less likely to face violence at home...

WOMEN AND HIV

In 1985, one-third of people living with HIV globally were women. In 2004, one-half of people living with HIV globally were women.¹² This dramatic increase in the proportion of women living with

HIV necessitates a greater focus on women. Though the number of women living with HIV in India, at 39%, is lower than the global average, it is growing and must be addressed.

The physiological vulnerabilities of women to HIV

Physiologically, women are more susceptible to HIV than men, because of greater mucous membrane exposed during penile-vaginal intercourse, more fluid exchange from male to female, and higher viral content in male sexual fluids. HIV transmission from a man to a woman is two to eight times more efficient than from a woman to a man.¹³ Young women are especially vulnerable, because of the developmental changes accompanying adolescence.¹⁴ The previously held contention that a woman's normal vaginal tract lining is an effective barrier to HIV has been questioned by new research that shows that open lesions and breaks are not the only way that the virus can enter, but that healthy lining is also susceptible.¹⁵

THE SOCIOECONOMIC IMPACT OF HIV ON WOMEN IN INDIA

Socioeconomic factors that result in women's vulnerability to HIV include a lack of education about sexual health, denial of control over their bodies when negotiating sexual relations, limited access to economic opportunities resulting in lack of autonomy, and multiple household caretaking roles.¹⁶ Women bear disproportionate burdens and disadvantages in the following areas: care and domestic work, medical treatment, formal education, stigma and discrimination, and knowledge of HIV and AIDS.¹⁷

Compared to men, women spend more time performing household work, child care, and care of the sick and elderly. There is a large difference in the time spent on these activities by women 60 years and older, with women of HIV infected households bearing the extra load of taking care of infected family members and house work, resulting in less time for relaxation and self-maintenance.¹⁸ In terms of access to education, girls 6 to 18 years old in positive households are more likely to be withdrawn from school, mostly in order to take care of younger siblings and perform housework.¹⁹ More than 40% of the sampled HIV-positive women have no say regarding if, and when, they have sex or use a condom.¹⁹

Further, among the general population, including people living with HIV, women are less likely to seek hospitalisation than men. Possible reasons for this include the fact that women may be less likely to take minor ailments seriously,

...the response to the HIV epidemic must be a part of larger movements for the rights of women...

avoid going to the doctor so as not to disrupt household routine, may not have, or be given, the economic means to do so, and in households where both men and women are ill, more importance is given to the man's health. In regard to opportunistic infections, the number of women's illnesses that remain untreated is higher than that of men's, even though nearly the same percentage of men and women suffer from the same diseases.²¹

While only 1.9% of males living with HIV are asked to leave home after testing positive, 5.5% of female people living with HIV are told to leave home. Also, in households where most of the family is not supportive of people living with HIV but the spouse is, women are more likely to be supportive (12.4%) than men (8.5%).²²

Women widowed as a result of HIV and AIDS, 60% of whom are younger than 30 years, face particularly difficult challenges. The average income of an HIV affected widows' household (Rs. 39,711) is significantly less than that of other HIV affected households (Rs. 51,111), which is most likely due to the direct effect of the death of an income earner. The number of widow households below the poverty line is significantly higher than other households, with fewer having basic amenities. Many widows of HIV affected households are forced to liquidate assets and loans in order to pay for medical and funerary expenses.

...independent studies need to be conducted in order to yield unbiased statistics on the use and effectiveness of female condoms...

Further, positive widows face stigma and discrimination from their family and community on two counts: as a widow and as a woman living with HIV. 90% of these widows no longer live with their

husband's families after the death of their husbands; only 9% of widows receive financial support from their husbands' families; and nearly 79% of the widows were denied a share of their husbands' property.²³

A recent survey revealed that amongst the general population, fewer women than men have heard about HIV and AIDS, with a large difference when it comes to details of the disease, in that more men (63%) than women (51%) knew that HIV and AIDS can be prevented; where to go for voluntary HIV testing (52% men and 36% women); and all modes of transmission (58% men and 54% women).²⁴

TAKING ACTION: PAST, PRESENT, AND FUTURE

Targeted interventions must address the specific vulnerabilities of women to HIV more holistically, putting a larger emphasis on the empowerment of women. Several approaches to interventions can be utilised in order to work towards achieving this goal. This section discusses specific issues that must be addressed, provides examples of successful interventions, and explores ways to move forward.

While focusing on HIV prevention efforts, it is recognised that care, support and treatment programmes are equally important and must be designed and implemented in a gender equitable manner. Many of the suggestions outlined below would, therefore, also apply to care, support and treatment programmes.

...continued interventions promoting female controlled prevention options, such as the use of female condoms, are key to preventing the chain of HIV transmission...

Involve women in needs assessments and programme designs

The specific contexts of vulnerabilities of women can best be understood through participatory community assessments, which illuminate the interconnected sources of vulnerability, allow women to express their concerns, and contribute to the development and implementation of programme responses.²⁵

As with many vulnerable and marginalised populations, there is a lack of understanding and data on behaviours and dynamics of women, making these populations socially less visible and resulting in their denial of access to appropriate services to prevent the spread of HIV. There is a critical need to conduct more assessments of specific risks and needs of these populations, and to involve women in the process. Confidentiality is crucial and researchers need training and sensitisation with regard to women's dynamics and issues.²⁶

Utilise gender equality indicators and sex-disaggregated data

Though meant to be neutral, the process of monitoring and evaluation can never be a fully neutral process, as it is often undertaken by individuals with internalised biases. Therefore, it is crucial for more women to be involved in the process, and to input into developing indicators to monitor and measure progress.²⁷ In doing this, utilising not only quantitative indicators, but also qualitative ones, is important in order to evaluate cultural values and social attitudes in relation to gender issues.

Furthermore, collecting quantitative and qualitative data that is disaggregated by sex and gender is vital to meaningfully monitor and evaluate programmes that are focused on addressing the underlying vulnerabilities of women and the inequalities they face.²⁸ Disaggregating targets is but one of the means to ensure that the implementer is conscious of the importance of taking steps to guarantee that women have equal access to services.

Further, disaggregating data on results compared to targets is vital to provide a metric of whether or not target groups are receiving adequate services.²⁹

Toolkit: UNIFEM's 'Mainstreaming the National AIDS Response: Mainstreaming Gender and Women's Human Rights into the 'Three Ones''³⁰

This report outlines criteria for ensuring a gender-sensitive monitoring and evaluation system, in accordance with the UN's 'Three Ones' principles. Three primary points for strengthening the gender sensitivity in a national monitoring and evaluation system include:

- Using gender-responsive budgeting to track government spending on the national AIDS response
- Building the capacity of central statistical offices, research centres, and gender focal points to disaggregate data by gender
- Developing qualitative indicators to analyse factors, such as cultural values and social attitudes, and perceptions of gender power relations

Give women the tools to negotiate and control their sexual encounters

Approximately 40% of positive women do not have a say in choosing when, how, and if they have sex and whether or not they or their partner use a condom.³¹ Continued interventions promoting female controlled prevention options, such as the use of female condoms,

are key to preventing the chain of HIV transmission. There is also a need to empower girls and women by improving their knowledge and understanding of sexuality and sexual health. Facilities for the treatment of sexually transmitted infections must be made more available by strengthening existing reproductive and child health services.

Feasibility Study: Female Health Company and Hindustan Latex Limited Partnership ³²

In 2002, the Female Health Company and Hindustan Latex Limited formed a partnership to launch and begin manufacturing female condoms within India. They conducted a study to assess the accessibility and feasibility of female condom use in India, including amongst a sample of female sex workers, MSM, and eligible couples across three states. Their study findings point to the potential of female condoms to become a mainstream family planning tool:

- 50% of women liked the female condom, because they said it could be used when their husbands refused to wear a male condom
- 36% of female sex workers had difficulties inserting the female condom during the baseline study, but this dropped to 0% after eight weeks of usage
- 11% of female sex workers were able to convince their clients to use the female condom at baseline, which increased to 58% at the end of the study, partly a result of effective training and counselling during this period

Female Condoms

Women often do not have the power to control the conditions

of sexual relations and may not always be able to negotiate the use of the male condom. Clearly, distribution and promotion of male condoms, as well as education to emphasise the importance of men's responsibility, must continue parallel to the increased marketing and availability of female condoms. Women often have more success in negotiating the use of female condoms, which remains the only viable female-initiated method for protection against STIs, including HIV, and unwanted pregnancies. Thus, scale-up of female condom availability should continue in India, to ensure universal access to this tool.

Further, independent studies need to be conducted in order to yield unbiased statistics on the use and effectiveness of female condoms among Indians.

Microbicides

Continued research and development of topical microbicides – substances which reduce infectivity of viruses or bacteria – have the potential to yield a highly effective alternative or supplement to condoms. Even though a highly effective microbicide has not yet been developed, this may soon change, as a number of research efforts are underway.

New technologies have historically been met with initial scepticism. In order to ensure timely roll-out, interventions should be planned at present to smooth the way for microbicide introduction, as and when they become available.³³ Further, studies need to be conducted to determine societal

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biases...**

views of microbicides and to determine the feasibility of widespread use.

Continue to empower female sex workers

The incidence of HIV in the general female population is growing, and hence, interventions must be targeted specifically for this group, but there also must be a continued focus on reducing the transmission of HIV through female sex work. NACO estimates that there are 831,677 to 1,242,819 female sex workers (FSWs) in India, 8.4% of who were infected with HIV as of 2005.³⁴ Several programmes and campaigns to empower female sex workers through mobilisation and collective action, which have already emerged in India, should be replicated widely.

relating to HIV are common to those identified by women's groups as priorities, including access to services and resources, education, freedom from violence, and recognition as key partners in society.³⁶

Organisations, such as the Positive Women Networks, provide members with support, promote the rights of women living with HIV, and sensitise society about their needs.³⁷

Women's rights and equality must be emphasised and the

**...confidentiality is crucial
and researchers need
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Good Practice: Sonagachi ³⁵

The Sonagachi project, initiated in 1992 in Calcutta, India, by the All India Institute of Hygiene and Public Health, began as a relatively small-scale HIV prevention project, but has become a larger movement. This initiative has not only helped to reduce the incidence of HIV amongst female sex workers and their clients, through increased contraception availability and education, but has also empowered female sex workers to organise themselves and demand their rights. Activities include:

- Establishing health centres that provide free STI screenings, which female sex workers are encouraged to frequent for testing, even when asymptomatic, and distribute condoms
- Training of peer educators on sexual health and safer sex practices, out of which a formal performance group, including male and transgender sex workers, was created and has built a public identity for sex workers, a step towards normalising their place in society

Continue to focus on the rights of women and sexual minorities

The response to the HIV epidemic must be a part of larger movements for the rights of women. For women, the key issues

Convention on the Elimination of Discrimination Against Women (CEDAW) revisited.³⁸ This should involve a multisectoral effort, combining the efforts of government departments, such as the National Commission for Women, NGOs, and the private sector.

Equality in content and implementation of law and policy must be ensured, with training for the public and private sectors on gender issues.³⁹

In order to address the particular vulnerabilities of positive widows, more self-help groups and micro-credit schemes should be targeted at this group, to empower widows living with HIV and to break the chain of transmission of HIV. For example, after hearing from the Society for Rural Development and Protection of the Environment (SRDPE) in Tamil Nadu, one particular self-help group decided to include people living with HIV as members in their group, save rice to be distributed to families of HIV affected households, who are unable to work, and educate their children to not discriminate others based on HIV status.⁴⁰

Across Asia, a strong link between women's rights to property and inheritance and vulnerability to HIV is emerging.⁴¹ Women who own property or control assets are more able to cope when crises arise and are less likely to face violence at home. Property and assets can act as collateral for credit, allowing positive widows to better deal with the financial impact of the disease, and allow them to keep their children in school longer. However, in India women are generally unable to own or inherit land and property, as a result of inadequate statutory laws, as well as cultural beliefs and practices. In response to this, groups, such as the Global Coalition on Women and AIDS, are focusing on promoting women's property rights.⁴²

Mainstream gender equity

Ultimately, the most important shift that needs to occur in order to decrease the vulnerability of women to HIV is a shift in societal norms regarding gender equity, in order to change the power differential between women and men. This needs to occur on a national level, as well as at the local level.

Primary and Secondary Education

HIV and gender parity issues must be discussed in school, starting from a young age, so that children are raised with the belief that all people should be treated equally. Incorporating programmes on HIV and AIDS education, gender sensitivity, and other '*soft skills*' in national curricula has, thus far, been difficult.⁴³ The Indian HRD Ministry's proposed Adult Education Programme has faced considerable resistance, but is already being implemented in some states.⁴⁴ Since the taboo nature of sex and HIV and AIDS education has made mainstreaming difficult, couching these topics in a more general curriculum of health and hygiene education may be an effective means to ensure their inclusion.

Feasibility Study: ActionAid⁴⁵

ActionAid conducted a study of two regions in India and Kenya that have state-sponsored HIV curricula, and catalogued the attitudes of teachers, students, parents, and other stakeholders. From these findings, ActionAid makes the following recommendations:

- HIV education must target all sectors of society, including families, religious leaders, and the media
- HIV education materials should avoid an overly scientific approach and instead should stimulate the understanding of the human side of HIV, and should be centered on local resources, statistics, and case studies
- Focus should be placed on challenging social, gender, and power inequalities, in order to ultimately address power issues in sexual relationships

National Media Campaigns

National media campaigns can be utilised to discuss issues of gender and HIV and AIDS, in order to expose a vast number of Indians to these issues. Several toolkits are available providing guidance on how to mainstream these issues into the media, such as Inter Press Service International Non-Profit Association's *Gender, HIV/AIDS, and Rights: A Training Manual for the Media*.⁴⁶

Good Practice: Breakthrough⁴⁷

The NGO *Breakthrough* conducted a multimedia campaign called '*Is This Justice?*' to reduce stigma against women living with HIV in India, running television, radio, billboard, and newspaper advertisements addressing this issue. Breakthrough evaluated the shift in attitudes of the target populations. The research found significant shifts with the following percent increases in the number of people holding the following opinions:

- Women are unable to negotiate safer sex (10%)
- Women need family support and the right to shelter (28%)
- Women are blamed for not sexually satisfying their husbands (10%)
- Women are expected to stay with their HIV positive husbands (22%)

...the specific contexts of vulnerabilities of women can best be understood through participatory community assessments...

CONCLUSIONS

The vulnerabilities to HIV that women encounter arise from deep-rooted inequalities. A discussion of '*gender*' in the health context, or of '*engendering the HIV response*', as this paper carries forth, is by definition not just about women and girls, but fundamentally reflects on societal power dynamics and how they affect equitable access to care. Health is a human right, but in order for a person to act on

that right, that person must have a voice in society. Marginalisation – social forces that keep individuals at the edges, illiterate, landless – is the fundamental issue that keeps women from fully accessing the right to health. In order for women to claim their full right to autonomy and health, they must be counted as full and equal members of society, and this will require continued changes in the way that gender is conceived and acted upon, both in Indian society and around the world.

...positive widows face stigma and discrimination from their family and community on two counts: as a widow and as a woman living with HIV...

Focused targeted interventions alone will not reduce vulnerability to HIV. A broad-based approach as outlined in this paper, with interventions at every level – from community to national, in informal and formal sectors, and utilising a wide range of techniques – is required to most effectively reduce vulnerability.

FOOTNOTES:

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In conversation with Cebile Dlamini¹

Cebile Dlamini is the Programmes Manager at Swaziland Positive Living (SWAPOL).

TC: How did you get involved in HIV work?

CD: As a young woman, I am passionate about women's issues. Considering that Swaziland is having the highest HIV prevalence in the world, I wanted to advocate especially for issues of women living with HIV and AIDS in rural communities. So I felt that by involving myself in HIV work, it would be a forum, and opportunity for myself to voice out the issues that are of concern to women living with HIV and AIDS in rural communities.

TC: What is something that you see as most promising around women and HIV in Swaziland, what inspires you?

CD: First and foremost, it is the issue of empowerment. If we look at HIV, there are two driving forces; there is poverty and there is also the issue of culture, because Swaziland is a Kingdom and we have a strong cultural background. For instance, men are allowed to have multiple partners. So being empowered as a young person and a young woman, it helps to make an informed decision. Women now, at least, have organisations that they can identify with, and they can be able to access information, so that whatever they are doing, they decide on something that they know about.

TC: What has been the biggest challenge for you working in this field?

CD: I think it is the environment we are working in, we cannot

easily advocate for women's issues, even if the issues are clearly identified. For instance, if you want to target Parliament to push on women's issues, the environment is not conducive for you to do that. As a result, you will find that they do not see you as a person working towards achieving the overall goal of the country to reduce the HIV prevalence rates. Instead, if you advocate for women's issues, they see you as somebody who is a threat, somebody who is an opposition, and somebody who is disrespectful – yet, you are trying to work together with them, in order to reduce the HIV prevalence rate.

TC: Is there a recent experience that highlights this challenge?

CD: Recently, we had a scenario where a Swazi MP recommended that in order for Swaziland to be able to fight HIV, women living with HIV should be branded on their buttocks, so that when a man want to engage in sexual intercourse with a woman, they can first check on the buttocks and know the woman's HIV status. Then we were wondering what kind of advocacy is that? Why is the MP doing that?

We understand that there are programmes, even at SADC level, whereby MPs are mobilised and invited into meetings, so that they can discuss the issue of HIV, but this, we did not understand. So, when we engaged the MP, Parliament was very silent and not taking a stand on that issue. Instead, it was a personal conversation between

our organisation and the MP; we did not hear about the government's position on this. We did not even hear the speaker of Parliament engage with us, so that we can try and understand the concept behind this comment; so that we can try and understand why the MP was saying that; and try and see or forge a way forward to engage the different portfolio committees that are within parliament – so that we can try and work together. Though, the MPs are elected by the women in rural communities, when they are within Parliament, they do not push the agendas that concern women.

TC: *Did anyone else stand with SWAPOL, when you were speaking out against this policy or proposal to brand positive women on the buttocks?*

CD: Not really. The issues of advocacy involve a lot of risks in Swaziland. Some people do appreciate what we are doing, but moving the agenda forward is a difficult issue, because there is that Terrorist Act that has been put in place, which is an act that is trying to silence our voices. And so, most probably, many organisations are afraid that if they are seen pushing certain agendas, they can be declared as 'terrorist organisations', which can lead to organisations being de-registered. That is the threat we are facing now.

TC: *What has been your biggest achievement?*

CD: When I joined SWAPOL, we were four of us. We were in a small office, we had two agendas – to mobilise the community and to give knowledge. But since then, I have seen SWAPOL growing. Currently, we have 19 officers and we are occupying a big place; we have a number of programmes and interventions that are happening – so the growth for now is a big achievement. When I look back, I see that SWAPOL has grown so much and we are happy about this. And for me personally, I am happy to have contributed to that growth of the organisation.

TC: *If you can see one change in the broader AIDS response in Swaziland in the next year, what would it be?*

CD: I want to see gender issues to be mainstreamed into all HIV interventions. I believe that if we not address women's issues and women's empowerment as an HIV prevention method, we are missing the point.

FOOTNOTE

1. The interview was conducted by Tyler Crone (TC) of the ATHENA Network.



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