 Agenda: Empowering women for gender equity
Publication details, including instructions for authors and subscription information:
http://www.tandfonline.com/loi/ragn20

Cervical cancer and women living with HIV in South Africa: Failure of AIDS treatment policy or gendered exclusions in health care?
Sethembiso Mthembu

To cite this article: Sethembiso Mthembu (2012): Cervical cancer and women living with HIV in South Africa: Failure of AIDS treatment policy or gendered exclusions in health care?, Agenda: Empowering women for gender equity, 26:2, 35-43
To link to this article: http://dx.doi.org/10.1080/10130950.2012.708624

PLEASE SCROLL DOWN FOR ARTICLE

Full terms and conditions of use: http://www.tandfonline.com/page/terms-and-conditions

This article may be used for research, teaching, and private study purposes. Any substantial or systematic reproduction, redistribution, reselling, loan, sub-licensing, systematic supply, or distribution in any form to anyone is expressly forbidden.

The publisher does not give any warranty express or implied or make any representation that the contents will be complete or accurate or up to date. The accuracy of any instructions, formulae, and drug doses should be independently verified with primary sources. The publisher shall not be liable for any loss, actions, claims, proceedings, demand, or costs or damages whatsoever or howsoever caused arising directly or indirectly in connection with or arising out of the use of this material.
Cervical cancer and women living with HIV in South Africa: Failure of AIDS treatment policy or gendered exclusions in health care?

Sethembiso Mthembu

Her Rights Initiative (HRI) was formed in 2009 by a group of feminist South African women. The Initiative is building from the knowledge and experience of its founding members who all identified the gap between HIV/AIDS policies and HIV-positive women’s experiences and the potential HIV-positive women represent in improving existing policies or recommending new ones to ensure women living with HIV/AIDS are able to access their sexual and reproductive rights in South Africa with the possibility of improvement for all women.

HRI is an advocacy organisation with a purpose of creating a world where women living with HIV have full access to and enjoy their human rights. The organisation’s main objectives are to advocate for the rights of women living with HIV, particularly positive women’s sexual rights, reproductive rights, and the right to be free from all forms of violence. HRI proposes various areas of work and strategies to achieve its goals. These include, amongst others:

- Research into HIV-positive women’s sexual and reproductive rights issues;
- Capacity building of women living with HIV and AIDS, including young women in leadership, advocacy and research;
- Policy advocacy;
- Assisting HIV-positive women access legal services;
- Strategic issue-based collaborations and networking, including engaging health care workers and professional bodies.

HRI policy review

HRI concluded a policy review on HIV-positive women and cervical cancer in response to the critical gap in women’s health policy and to raise awareness of the need to upscale treatment and prevention within an appropriate sexual and reproductive rights framework. This Reportback reports on the findings of the Policy Review and the verification workshops that were held by HRI.

Cervical cancer - Background and literature review

Cervical cancer is the second most common cancer affecting women worldwide and it accounts for 13% of all cancers in women (Odendal, 2011). Of the 500 000 women who develop cervical cancer annually, just over a half will die from it – with 85% of these deaths occurring among women in developing country contexts (Odendal, 2011). In South Africa, the WHO estimates that 5 743 women are diagnosed with cervical cancer every year and that more than 3 000 women die of the disease (WHO/ICO, 2010).

Worldwide, it is poor women who are at greatest risk of cervical cancer (Arnolu, 2008). These patterns are resonated in South
Africa where black women, particularly in rural areas, are at heightened risk for cervical cancer (Doyal and Hoffman, 2009) to the extent that approximately 84% of all South African women diagnosed with cervical cancer are black (Denny, 2006a; 2006b; Adar and Stevens, 2000) and between 60–70% of women dying of cancer are from rural areas (Arnolu, 2008). The rate of morbidity and mortality due to cervical cancer has increased (Bomela and Stevens, 2009) and in the year 2000, deaths as a result of cervical cancer in South Africa exceeded maternal deaths (Hale, 2009). This increase in morbidity and mortality has been associated with the emergence of HIV and AIDS (Bomela and Stevens, 2009). Sub-Saharan Africa has the highest HIV and AIDS prevalence in the world and women account for almost 60% of the HIV infected population (Bomela and Stevens, 2009).

Scientific and medical research studies have confirmed a relationship between cancer of the cervix and HIV infection. These studies demonstrate that HIV-infected women are at increased risk of pre-invasive cervical lesions (Chirenje, 2005). Further, HIV-infected women are substantially more vulnerable to Human Papillomavirus (HPV) infections compared to HIV-uninfected women (Franceschi and Ronco, 2010). HPV is the underlying cause of cervical cancer (Richter, 2011) and has been identified as being a necessary, but not sufficient cause of cervical cancer (Walboomers et al, 1999).

“Abnormal cervical cells have been found to occur at a younger average age in HIV-infected women and to progress to more serious stages if left untreated” (Rochon, 2008:19).

While much attention has been given to the rate of HIV infection in ante-natal clinics, researchers have noted that the rate of HIV-positive women living with cancer is higher (Schoeman, Van Wyngardt, Horn, Goedhals and Jourbert, 2006). Cancer of the cervix was listed as an HIV-related opportunistic infection and an AIDS defining illness by the Centers for Diseases Control in 1993 (CDCP,1993). While it is argued that cervical cancer screening for HIV-positive women is a must (Franceschi and Jaffe, 2007), in South Africa screening for cervical cancer is not yet incorporated into HIV treatment and advocacy programmes.

South Africa’s national cervical screening policy recommends three free Pap smears (screening for cervical cancer) at 10-year intervals for all women 30 years and older (Department of Health, 2000). However, reports suggest that this policy is restrictive, poorly implemented and particularly problematic in rural areas (Australian Government, 2010; Moodley, Kawonga, Bradley and Hoffman, 2006). Even in urban areas like Johannesburg, it has been reported that implementation is severely impeded as a result of resource shortages. Pap smear results took several weeks to return, and women were subjected to long waiting periods for further tests and treatment (Lockman, 2010). The national policy was developed before the link between cervical cancer and HIV/AIDS had been firmly established (Bomela and Stevens, 2009) and there is a critical need firstly, for a cervical screening policy in South Africa to be reviewed in the light of current research (Bomela and Stevens, 2009) and secondly, for a framework for addressing prevention and treatment of cervical cancer in women living with HIV.

Furthermore, where screening programmes are available, these are mostly fragmented, small-scale, dependant on non-governmental organisation (NGO) support, poorly coordinated and not delivered as part of sexual and reproductive rights but as part of charity programmes. Like the public sector, these integrated programmes emphasise Pap smears, which are secondary prevention measures. However, there is little emphasis on ensuring that women get access to their Pap smear results, that abnormal smears are followed up and treated, or that when women are diagnosed with cancer that they receive treatment and pain management. Given that most cancers may not be diagnosed, there is a need for pain management; however this has not yet featured in policy and programmes discourses. The current charitable programmes also lack accountability and consistency in the sense that they are
delivered as charity, not rights. The South African cervical screening policy was also not developed within a sexual and reproductive health rights framework which is a problematic omission for prevention and cure (Bomela and Stevens, 2009). This is typical of South Africa, a context where sexual and reproductive health rights issues pertaining to HIV-positive women are not prioritised and advocacy on these issues is also limited.

No policy on cervical cancer and HIV-positive women

While the Department of Health has embarked on a communications strategy to increase awareness on cervical screening in South Africa, this is not guided by a policy document nor is there evidence that they have secured the required resources and skills on the ground to improve uptake of services. In discussions with representatives from the Ministry of Health in 2011, it was confirmed that there are no immediate plans to develop a specific policy on cervical screening for HIV-positive women, especially given severe resource and structural constraints around women’s health issues. At the time, the representative acknowledged that a specific budget directed to women’s health and cervical cancer does not exist. Subsequently, the National Department of Health has convened a task group to review the National Guidelines on Cervical Cancer Screening of 2000. One of the issues that are to be addressed is the screening of HIV-positive women. The discussions with healthcare providers highlighted the constraints around implementation of cervical screening guidelines.

The absence of a community or human rights advocacy initiative on cervical cancer has meant that there is no movement to drive for upscaling of services, to serve as an oversight mechanism to both government and to the organisations implementing prevention and treatment programmes for cervical cancer.

Even organisations tasked with dealing with issues of women’s health, have reported to HRI that prevention and treatment of cervical cancer for HIV-positive women is not on their agenda.

National Strategic Plan

The World Health Organisation (WHO) issued a guideline in 2008 stating that women living with HIV should be screened for abnormal cells (Pap smear) once a year (WHO, 2008). Despite the increased risk for cervical cancer, there are no special provisions on cervical cancer screening for HIV-positive women in the HIV/AIDS/STD National Strategic Plan, except for one reference in description of a “wellness care package”:

“Wellness care package includes: regular CD4 counts; opportunistic infections prophylaxis and treatment; cervical screening; advice on lifestyle, nutrition, contraceptive use and fertility” (Australian Government, 2010:10).

The latest South African National Antiretroviral (ART) Treatment Guidelines (DoH, 2010a) recommended that HIV-positive women, who are not yet eligible for ART, receive an annual Pap smear. In addition, the Clinical Guidelines for the Management of HIV/AIDS in Adults and Adolescents (DoH, 2010b) recommend that all HIV-positive women receive cervical cancer screening on diagnosis, and if normal every three years, irrespective of ART status. Abnormal Pap smears should be repeated according to the result (Department of Health, 2000). While this policy has been implemented in the Western Cape, where HIV-positive women are eligible for annual Pap smears from the time of their diagnosis (Batra, Kuhn and Denny, 2010), there is little evidence that other South African women already on ART “would have access to free cervical screening beyond that offered under the national cervical cancer programme” (Australian Government, 2010).

In South Africa, there are several barriers to the implementation of annual Pap smears for HIV-positive women including, limited advocacy and resources, an absence of coherent policies on cervical cancer and women living with HIV and women’s health broadly, and a lack of recognition of treatment issues for women, including women
living with HIV. Sexual and reproductive health is arguably also marginalised because the ideological stance on sexual and reproductive rights has not been challenged by a weak women’s movement (Hassim, 2004).

Other contributing factors include social, health systems, human rights and political barriers. Sexual health, and in particular cervical cancer, has not attracted the political interest of women’s organisations in South Africa. Further, there is limited policy discourse on women’s health, particularly sexual and reproductive health components. The HIV/AIDS lobby has also prioritised women in their identities as mothers. Therefore, cervical cancer has not been prioritised in HIV/AIDS treatment advocacy and delivery work. Most women who are affected by cancer of the cervix are poor and marginalised women who are unable to demand health rights and services, partly because of power and knowledge issues. Women with more resources are able to access services in the private sector which may inadvertently serve to limit the advocacy for the services in the public sector.

While it is argued that cervical cancer screening programmes are difficult to implement in low-resource settings for various reasons:

“the scale-up of antiretroviral therapy in low-resource countries provides an unprecedented opportunity to develop cervical cancer screening programs because women receiving antiretroviral therapy are observed on a regular basis, they can also receive the continuity of care needed for cervical cancer screening” (Franceschi and Jaffe, 2007:511).

Cancer of the cervix is hidden in women’s bodies (Widmark, Lagerlund, Maina Ahlberg and Tishelman, 2008). Further, it is associated with HPV, a sexually transmitted infection which may result in stigmatisation of cervical cancer (Dyer, 2010). Therefore affected women may refrain from publicly speaking about cervical cancer or demanding prevention and treatment services. Cervical cancer affects reproductive organs, and as a result it carries cultural barriers, particularly because many women do not have adequate knowledge about their bodies. There is also lack of understanding of how the socio-cultural context impacts on affected women’s ability to seek screening and treatment services. This is compounded by a lack of basic information and awareness of cervical cancer as an opportunistic infection among HIV-positive women. Where treatment for cervical cancer is available, there have been concerns that treatment options like hysterectomies may potentially violate other rights of women living with HIV. This practice may perpetuate forced sterilisation via hysterectomy of HIV-positive women – therefore calls for women living with HIV to claim their right to prevention and treatment of cervical cancer should be cognisant of the need to safeguard and monitor other rights which may be jeopardised as a result of provision of treatment.

Testing of preventative vaccines

Two preventive HPV vaccines have been licensed and registered in South Africa and they offer “great potential for primary prevention of cervical cancer” (Harries et al, 2009:38). However, HPV vaccines are not accessible through the public healthcare sector (ibid). While there has been much civil society advocacy on vaccines, it is not clear whether these will be safe and effective (Rochon, 2008) or even accessible to women living with HIV (Hale, 2009). Somewhat ironically, while HIV and HPV have burdened women disproportionately, with around 20 million women living with HIV and 500 000 new cases of cervical cancer diagnosed every year, there is no published data evaluating the immunogenicity, safety or efficacy of HPV vaccines in women, although clinical trials are currently underway.

The World Health Organization (WHO) recommends that HIV-positive women should be provided with the HPV vaccine given their vulnerability to HPV related diseases (WHO, 2010). However, the engagement of women living with HIV on this issue to date has been grossly inadequate. There are also no clear messages that are communicated to women living with HIV with regards to cervical cancer issues. There is little evidence of deliberation on whether women living with HIV will be prioritised for vaccines, in the public or private sector, should evidence suggest that
A vaccine might mitigate the impact of cervical cancer in HIV-positive women.

Access to prevention and treatment for cervical cancer must be increased given that cervical cancer is an opportunistic infection.

With expanded access to ARVs, HIV-positive women are living longer and cervical cancer may increase the disease burden on these women. There is no clear policy and guideline on how knowledge, prevention and treatment of cervical cancer should be addressed in HIV-positive women. There is also a need to expand treatment and recourse for cervical cancer.

Further, there has been limited participation of HIV-positive women in HIV and also cervical cancer treatment advocacy. When women have participated, their participation has not produced women-specific treatment programmes and there is no evidence of such programmes developed to date. One reason for this is that the traditional treatment movement portrayed women as mothers rather than women in their own right. Further, the roles that have been assigned by HIV responses to women, the fact that the women assume the care burdens for others whilst ignoring their own health rights issues, are all contributing factors. This could also be credited to the fact that cancer of the cervix, affects mostly, marginalised and poor women. Most women who are affected by cervical cancer do not have access to political power and to decision makers. Cervical cancer could be viewed as the disease of marginalisation, poverty and exclusion. It could also contribute to an increase in women’s mortality that is unaccounted for.

Conclusions and recommendations from the policy review

“The dictum that prevention is better than cure is particularly relevant for cervical cancer” (Thomas, 2008). Therefore data on the safety and efficacy of HPV vaccines in HIV-positive women is sorely needed. HIV-positive women are also at increased risk for cervical cancer and may present for cancer at a younger age. Therefore consideration should be given to: at a minimum, updating the cervical cancer screening policy to include annual Pap smears for HIV-positive women, or developing a policy specific to HIV-positive women and cervical cancer that harmonises guidance from the South African National Antiretroviral Guidelines (2010) and the Clinical Guidelines for the management of HIV/AIDS in adults and adolescents (2010). As the overarching plan for HIV/AIDS in South Africa, the National Strategic Plan should make specific recommendations on the prevention and treatment of cervical cancer in HIV-positive women. There is an urgent need to develop a co-ordinated advocacy initiative to drive cervical cancer as a priority for all South African women, and especially HIV-positive women, to hold government accountable for implementing guidelines and for informing women about their right to access these services, in a value-free environment.

In line with HRI’s strategy, the policy review solicited input from women living with HIV on the issue. This was done through conducting validation workshops on cervical cancer and women living with HIV. The validation workshops were held with women living with HIV in order to:

1. Assess whether the policy review on cervical cancer and women living with HIV was in line with what is available to women in terms of cervical cancer prevention and treatment programmes in the context of HIV treatment;
2. Solicit the experiences and views of women living with HIV on the issue;
3. Solicit recommendations from women living with HIV on the issue.

Validation workshops

Validation workshops were conducted in four South African provinces namely, the Eastern Cape, KwaZulu-Natal, Gauteng and the Western Cape with support from the African Women’s Development Fund and Mamacash. The workshops were held between September and December 2011.

The workshops were co-hosted with Positive Women’s Network (Gauteng), AIDS
Legal Network (Western Cape), and South Africa Partners (Eastern Cape) to ensure sustainability of advocacy at a local level and also to encourage organisations to take up the issue of cervical cancer as one of their advocacy issues. The co-hosting was also designed as a step to strengthen relationships and collaboration between HRI and the organisations as HRI believes in building solidarity between women living with HIV, organisations who are working in HIV/AIDS, human rights and other feminists’ organisations. Validation workshops included the presentation of sexual and reproductive rights, their link to human rights and women’s rights, a review of all the rights instruments, including HIV-specific instruments and country-specific commitments, particularly the HIV/AIDS Charter and the South African Bill of Rights. The rationale for HRI’s use of this framework in advocating for cervical cancer and how these rights are linked to other needs of women living with HIV in South Africa was also described.

Women were asked to provide recommendations for the Ministry of Health and HRI on the issue.

At the workshops, cervical cancer as a disease was described from the perspective of HIV-positive women and the HRI draft policy review was also discussed. Medical perspectives were presented by an invited medical practitioner or a Department of Health official. In order to ensure that the workshop was a safe space for women to engage, medical personnel were only invited to present the medical perspectives.

In Gauteng and KwaZulu-Natal, cervical cancer and the policy position were presented by medical personnel, although the presenter in Gauteng did not cover the official mandate as she was not an employee of the Department of Health. The medical personnel were asked questions in relation to women’s experiences and policy. The workshops also solicited opinion and discussion from the participants on cervical cancer via group exercises which focused on what the important issues were for women on, prevention (primary and secondary), treatment and palliative care, their experiences accessing services, and their level of knowledge, among others.

Issues that were registered

In line with the policy review position that basic information and awareness of cervical cancer as an opportunistic infection among HIV-positive women is unavailable, women at the workshop identified a need for more information on cervical cancer. Despite being aware of women affected by cervical cancer, most workshop participants did not know that cervical cancer is an HIV-related issue. However, some reported that cancer affected them personally, with some having a pending diagnosis and others having had hysterectomies.

Women felt that information should be available at both clinic and support group levels. Women registered difficulty in discussing gynaecological issues with healthcare providers because of HIV care being centred around ARV treatment only.

Some women raised concerns that delays in diagnosing cancer are problematic because they lead to unnecessary stress and, in some instances, loss of life. Young women reported being discouraged from requesting Pap smears, with healthcare workers preferring to rather offer Pap smears to older women. Consistent with findings reported in the policy review, workshop participants expressed concern that where smears were taken, the results will not be available. In some instances, where smears were abnormal, further treatment was not made available. The referral system was also reported as problematic because it takes time and women are subjected to repeat tests if they are referred.

Some women reported having had hysterectomies without being informed of the other alternatives open to them. In other words, hysterectomies were provided as the first line of treatment of cervical cancer in women living with HIV. Women were concerned that the health service had not diagnosed the cancer before recommending hysterectomies. There were also concerns
raised that in some instances the biopsy results will come back as clear but the hysterectomy would still be performed. Some women associated this practice with forced sterilisation of women living with HIV and this practice proved to be more prevalent in one hospital in Gauteng. These concerns corroborate the hypotheses in the review that cervical cancer may be used to legitimate sterilising HIV-positive women via hysterectomy.

Women also reported complications which they had suffered as a result of hysterectomies, including hormonal problems, lack of menstruation, and in one instance not being able to control urination.

The issues raised have been reported to the HRI advisory committee and also referred to the Women’s Legal Centre for possible litigation. This will mean a new strategy in the advocacy of this project, that of litigation. The Women’s Legal Centre advised the HRI to convene a meeting of medical experts to advise HRI and the Women’s Legal Centre on this matter. Based on the advice, the Women’s Legal Centre will then make a decision on whether to litigate or not.

Health care workers

In all four provinces efforts were made to have direct discussions with the healthcare professionals, in particular the managers, on the delivery of cervical cancer services for women living with HIV. This was only possible in one province, KwaZulu-Natal. In the Eastern Cape and Gauteng, healthcare workers participated in the workshop, but they did not speak from the official point of view. In these provinces the healthcare workers confirmed that there is no policy guiding their treatment of cervical cancer in HIV-positive women. They reported that what they see in the numbers and ages of HIV-positive women presenting with cancer requires policy attention. Some reported to have seen guidelines on cervical cancer screening but felt these were limited as they only mentioned Pap smears and did not have clear implementation plans. The fact that there is no policy and/or concerted efforts to address the lack of implementation was reported as a barrier to service delivery and accountability.

The healthcare workers who participated reported that the culture of integrated service delivery amongst them had generally deteriorated. This has led, amongst other problems, to women not accessing the services.

The health workers also complained that HIV services focussed on ARV treatment and that other aspects of women’s health were not integrated.

A further complaint by healthcare workers was that cervical cancer services were not located in the hospitals; one worker reported that there was one driver who had a responsibility of ferrying patients from one point to the other. This meant that patients had a long wait to be transported which might interrupt or delay the patient accessing treatment.

Challenges that were noted via interviews with the head of oncology of one of the tertiary hospitals in Durban included the following:

1. Lack of equipment, inadequate funding and lack of accountability of managers and planners.
2. Basic delivery matters and the fact that a certain creed of obstetrician are allowed to engage in some discussions and some are not and only some are authorised to conduct certain procedures. This practise means that if that particular doctor is not available, the procedure will not be performed.
3. Unlike other diseases, there is no community or human rights advocacy for cervical cancer.
4. Waiting lists and pain management.

Healthcare workers stated that cervical cancer in HIV-positive women progresses faster than in women not living with HIV, yet the average waiting period is between six months to two years for treatment. On the second visit women are normally worse off and already in severe pain. They confirmed that a woman’s HIV status makes it harder for her to be prioritised for treatment.

Our interaction with the official encouraged his unit to lodge a letter of complaint.
References


WHO/ICO Information Centre on HPV and Cervical Cancer (HPV Information Centre) (2007) ‘HPV Information Centre, Human Papillomavirus and to the Human Rights Commission. This is a limited effort, but the workshop made the unit realise that health delivery issues on cervical cancer for women are human rights issues. This is a strategic building block for advocacy in this area.


SETHEMBISO MTHEMBU is one of the guest editors of this edition of Agenda.