

University of KwaZulu-Natal

School of Built Environment and Development Studies

Masters of Social Sciences (Development Studies)

Thesis Report

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‘Triple Jeopardy or Manifestations of Gendered Social Exclusions?’

A Study looking at Cervical Cancer Policy and Women Living with HIV in South Africa

July 2013

ABSTRACT

Background: Worldwide, it is poor women who are at greatest risk of cervical cancer. These patterns are resonated in South Africa where black women, particularly in rural areas are at heightened risk for cervical cancer. The rate of morbidity and mortality due to cervical cancer has increased and in the year 2000, deaths as a result of cervical cancer in South Africa exceeded maternal deaths. This increase in morbidity and mortality has been associated with the emergence of HIV and AIDS.

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. This research documents the challenges of implementing cervical cancer services in the context of HIV. It explores structural, gender, societal, social exclusion and practical barriers to implementing these services.

Methodology: The study was conducted using qualitative methods of enquiry which employed in-depth interviews to collect data from participants. Interviews were held with government officials, Section Nine institutions, non -governmental organisations working in the fields of cervical cancer and HIV/AIDS.

Results: The study found that South Africa does not have a comprehensive policy to address cervical cancer in women living with HIV neither does it have plans to enact such a policy. It found that cervical cancer was a marginalised disease. It also found that cervical cancer does not always form part of health priorities as it falls outside women as mothers' brackets. The study found that the social status and the level of participation and active citizenship of women living with HIV might be one of the reasons for lack of prioritisation of cervical cancer policies.

Conclusion: Cervical cancer is a marginalised disease because it affects women outside of their reproductive roles, can be defined as an STI and it affects women who live in the margins of society. Cervical cancer marginalisation could be linked to the discourse of lack of political will, advocacy and action in relation to women's health. Policies need to be nuanced from the perspectives of women living with HIV.

DECLARATION

This dissertation is submitted in partial fulfilment of the requirements for the degree of Masters in Development Studies, in the Graduate Programme in the School of Built Environment and Development Studies, University of KwaZulu-Natal, Durban, South Africa. I declare that this dissertation is my own unaided work. All citations, references and borrowed ideas have been duly acknowledged. It is being submitted for the degree of Masters in Development Studies, in the College of Humanities, Development and Social Sciences at the University of KwaZulu-Natal, Durban, South Africa. None of the present work has been submitted previously for any degree or examination in any other University.

Student signature

Date

ACKNOWLEDGEMENTS

I would like to acknowledge the contributions of all who made this study and report possible. While we cannot mention everyone by name, their contributions are greatly appreciated. In particular we would like to thank the participants in the study; the individuals, organisations and some state organs. I would like to particularly thank Professor Catherine Burns and Dr Mags Beksinska for their technical guidance.

I would like to thank Ms Zaynab Essack and Carla Pettit for editing the report. I would like to thank my supervisor Dr Kerry Vermaak for her patience and guidance. Thanks go to my colleagues, government, state officials; NGO officials, individual women and feminists my associates for sharing their insights on the issue researched.

Special thanks go to my daughter Mbali who gives me a reason and strength to think, reflect and engage every day. Last but not least I would like to thank my friends for their presence, love and courage, in particular Dr Vicci Tallis and Ms Ntombifuthi Zondi.

LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Anti-Retroviral Drugs
CDC	Centre for Disease Control
DoH	Department of Health
HPV	Human Papilloma Virus
HIV	Human Immunodeficiency Virus
NGO	Non -Governmental Organisations
SRH	Sexual and Reproductive Health

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CHAPTER 1: BACKGROUND AND OUTLINE OF RESEARCH PROBLEM

Cancer of the cervix is one of the most common cancers affecting women in developing countries, particularly in Sub-Saharan Africa (Moodley et al., 2006). It is reported that more than 80 per cent of cervical cancer deaths occur in developing countries (Denny, 2006). In South Africa, estimates indicate that 5743 women are diagnosed with cervical cancer every year and that more than 3000 women die of the disease (WHO/ICO, 2010). Worldwide, it is poor women who are most susceptible to 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 & Hoffman, 2009) to the extent that approximately 84 per cent of all South African women diagnosed with cervical cancer are black (Denny, 2006; Stevens & Adar, 2000) and between 60–70 per cent of women dying of cervical cancer are from rural areas (Arnolu, 2008).

Scientific and medical studies have confirmed that there is a relationship between cervical cancer and Human Immunodeficiency Virus (HIV) infection with several studies demonstrating an increased risk of cervical cancer in HIV-positive women. It has been reported that women living with HIV are not only at greater risk of contracting cervical cancer when infected with the Human Papilloma Virus (HPV) but that the cancer was more aggressive than in HIV-negative women (Denny, 2006). The studies also found a bi-directional relationship between cervical cancer and HIV infection in that women with cancer were much more likely to acquire HIV infection. Further, the incidence of HIV in women living with cancer is higher than the rate of HIV infection among women attending ante-natal clinics (Schoeman et al., 2006).

HIV-positive women are five to nine times more likely to contract HPV infection, which may develop into cervical cancer if left undetected and untreated (Moodley, 2006). Women living with HIV are also presenting with cervical cancer at a younger age, up to 10 years younger, compared to the general population or HIV-negative women (Denny, 2006).

Cervical cancer was listed as an HIV-related opportunistic infection and an Acquired Immune Deficiency Syndrome (AIDS) defining illness by the Centers for Diseases Control (CDC) in 1993 (CDC, 1993). It is argued that cervical cancer screening for HIV-positive women is a must (Franceschi & Jaffe, 2007).

South Africa currently does not have national policies which address cervical cancer prevention and treatment in HIV-positive women. This is problematic as policies facilitate the measurement of progress and hold the public service to account. Women can only enforce their rights in this area if there is a policy in place. A policy leads to development of implementation plans and allocation of budget. Where programmes are available, they are piecemeal, conducted on a small scale, poorly coordinated, dependent on non-governmental organisation (NGO) support, and not delivered as Sexual and Reproductive Human (SRH) rights but as a form of charity. Like the public sector, these integrated programmes emphasise Pap smears, paying scant attention to whether smear results are accessed or whether abnormal smears are treated. Pap smear is a cervical smear used as a tool in the detection of precancerous changes in the uterine cervix method of screening for cervical cancer (Leopold and Koss, 1993). This method is recognised by the South African Medicines Controls Council as is therefore the only authorised screening method in South Africa (Hoffman et al., 2003). These programmes also lack accountability and consistency (Cooper et al, 2004). In addition in South Africa, SRH rights issues pertaining to HIV-positive women are not prioritised and advocacy on these issues is also limited.

The South African women's lobby has been described as weak, and focused on practical needs as opposed to the strategic interests of women. The marginalisation of feminism in the South African liberation struggle and, by extension, the post-apartheid period, can also be credited for this silence with regard to women's SRH rights and women's health in general (Hassim, 2004).

HPV vaccines are licensed and registered in South Africa, but are not accessible through the public healthcare sector (Harries et al., 2009). 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). Further, as primary prevention interventions, these may be of no value to HIV-positive women because many already have HPV; therefore, secondary prevention efforts will have to be explored (Hale, 2009).

The impact of the HPV vaccine in delaying disease progression in HIV-positive women is unknown. The World Health Organisation (WHO) recommends that HIV-positive women should be provided with the HPV vaccine given their vulnerability to HPV-related diseases (WHO, 2008).

The WHO recommends that HIV-positive women should be screened annually for abnormal cells through a Pap smear (WHO, 2000). This guideline is not followed in South Africa due to multifaceted barriers, including limited advocacy and resources, an absence of coherent policies, and a lack of recognition of treatment issues for women, including HIV-positive women. Other contributing factors include social, health systems, human rights and political barriers. Sexual health, and in particular cervical cancer, has not attracted political interest of women's organisations in South Africa. In addition, policy discourse about women's health, particularly women's sexual and reproductive health, is limited (Hassim, 2004). The HIV/AIDS lobby has also emphasised women in their identities as mothers, which has directly impacted on cervical cancer not being prioritised in HIV/AIDS treatment advocacy and delivery work. Most women who are affected by cervical cancer are poor and marginalised women (Arnolu, 2008).

Cancer of the cervix is hidden in women's bodies. Further, it is associated with HPV, a sexually transmitted infection (STI) 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 (Stevens 2000). Cervical cancer affects women's reproductive organs; it may be culturally offensive, particularly because women do not always have adequate knowledge about their bodies. This is further compounded by the lack of basic information and awareness of cervical cancer as an opportunistic infection (Ibid.) There is a lack of understanding of how these factors impact on women's ability to seek screening and treatment services (Stevens, 2000).

Where treatment for cervical cancer is available, there have been concerns that treatment options like hysterectomies may potentially violate other SRH rights of HIV-positive women. Such options may perpetuate forced sterilisation of HIV-positive women via hysterectomy. Consequently, calls for HIV-positive women to claim their rights 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 the provision of treatment (Mthembu et al., 2011). Given that cervical cancer is an opportunistic infection, efforts are essential to increase access to prevention and treatment options.

With expanded access to antiretroviral (ARV) treatments, HIV-positive women are living longer and cervical cancer will increase the disease burden on these women. There is no clear policy or guidelines on how knowledge, prevention and treatment of cervical cancer should be addressed in HIV-positive women and there is an accompanying need to expand treatment and recourse for cervical cancer (Moodley, 2006).

There has been limited participation of HIV-positive women in treatment advocacy. When women have participated, it has not engendered women-specific treatment programmes and to date there is no evidence of such programmes having been developed. This could be credited to many factors including, that the traditional treatment movement prioritises women as mothers as opposed to women in their own right; the roles that have been assigned by HIV responses to women; and the fact that women assume the care burdens for others whilst ignoring their own health rights issues. Further, this could also be attributed to the fact that cervical cancer predominantly affects poor and marginalised women (Arnolu, 2008). Most women living with HIV fall into this category.

Research Objectives

Using women's rights and social exclusions frameworks, the research aimed to achieve two objectives, namely:

1. To explore current policy to address cancer of the cervix in the context of HIV; and
2. To explore policy and social barriers to integrating cancer of the cervix in HIV/AIDS prevention and treatment policies as well as advocacy in South Africa.

Preliminary Literature Study

Cervical cancer has been listed as an HIV-related opportunistic infection and an AIDS defining illness by the Centers for Diseases Control since 1993 (CDC, 1993). While there has been a considerable amount of research on cervical cancer in the context of HIV/AIDS, much of it has been from a biomedical, or health systems perspective.

The rate of morbidity and mortality due to cervical cancer has increased (Bomela & Stevens, 2009) and in the year 2000, deaths resulting from cervical cancer in South Africa exceeded maternal deaths (Hale, 2009). The Southern Africa region has one of the highest prevalence of HIV in the world and women account for almost 60 per cent of the HIV-infected population (Stevens, 2009).

It was also found that HIV-positive women were presenting with cervical cancer at a much younger age – up to 10 years younger than the general population or HIV-negative women (Denny, 2006). In addition, cervical cancer is killing more women than maternal death, in other words mortality due to cervical cancer is higher than maternal mortality (Hale, 2009). Therefore, biomedical and health systems approaches have been extremely useful in identifying cervical cancer as an opportunistic infection in women, and made out a solid case for programming in this area. However, social science studies in cervical cancer have been limited. There has been little research on how this identification of women as social and political beings serves as an enabler or barrier to the effective use of medical information generated to improve their lives.

Health systems barriers have been identified in research (Stevens 2000, Stevens and Bomela 2009) as hindering policy and programming on cervical cancer. However the complexities of health systems to HIV-positive women have not been tested to establish precisely how health systems should be improved or strengthened in order to deliver the rights to women excluded, for an example, the majority of women living with HIV. These women are excluded on the grounds of their gender, their disease and social status. The experiences of HIV-positive women in health systems have not been researched as a potential barrier to accessing cervical cancer services.

Literature on health programme integration was reviewed. Integration of SRH services was agreed upon at the 1994 ICDP conference. The terminology of integration is subject to different, sometimes disconcerting, interpretations. Post-apartheid South Africa has witnessed limited integration of health services, particularly those related to HIV and AIDS and SRH services at country level, owing to several difficulties, chiefly political commitment (Maharaj & Cleland, 2005).

There are numerous challenges to integration of SRH services in South Africa, chief amongst these are political commitment, health systems capacity, attitudes of health workers and behaviour of health-care service users (Maharaj & Cleland, 2005). Maharaj and Cleland (2005) point to historical difficulties and divisions of labour and power between national and provincial governments.

The fact that provinces possessed different resources and skills is one of the major challenges facing integration of health services (*ibid.*). Provincial and national discourses also addressed issues of budgets, consultations, and capacity with previously well-resourced provinces likely to have more budget bargaining power due to increased skills and experience. The issue of the provincial-national divide is also problematic; while policies are developed at national level, they have a limited role in policy implementation which is carried out by provinces (*ibid.*). Indeed in some instances it is local government that implements certain health programmes. Apart from this being costly it may also distort lines of accountability and engagement. There is yet another tier, where programmes are implemented by semi-private organisations contracted by the state. This may raise yet another set of issues in terms of accountability.

In another study conducted in Poland, Sobezak (2002) argues that the purpose of integrating services varies from inclusion grounds, efficiency, expansion, quality improvements, cost control, among others (Sobezak, 2002). Three actors concerned with power and stake in health systems are identified as the bureaucracy, the market as well as professional associations (*ibid.*). These could serve as disablers as well as enablers of integration (*ibid.*). It is further argued that integration could be driven by political changes, regime changes and introduction of new systems and programmes, for example, the drive to nationalise health systems (*ibid.*). The International Journal of Integrated Care advocates that societies should participate in the formulation of health policies and programmes. It argues that if societies are involved, societies utilising the services will take more responsibility for their health, and play a supportive role in health systems (Hunter, 2004).

Recent studies frame cervical cancer as a disease of poverty and marginalisation. For example, Anorlu (2008) outlines how socio-cultural and socio-economic issues expose women to cervical cancer.

Multiple-sex partners (including polygamy), early marriage, and having many children (also associated with early sexual debut), expose poor women to HPV, the virus which causes cervical cancer (Anorlu, 2008).

Work on poverty, marginalisation and cervical cancer has also been done in other countries, for an example, in Argentina. The findings of the work done in Argentina confirmed that poverty and inequality levels demonstrate that poor women do not easily access cervical cancer services. Research in Argentina demonstrated that marginalisation and inequality, particularly in health care, prevent poor women from accessing cervical cancer prevention and treatment (Arossi, 2008).

The fact that cervical cancer is not adequately prevented and treated, may lead to poverty being increased at familial and societal level, as women are heads of households and income earners (Tsu & Levin, 2008). Poverty and inequality, which lead to marginalisation and exclusion, do not only have roots in poverty, but fuel and sustain poverty as well, as sickness and death lead to loss of income and labour in the family, the community and broader society (Tsu & Levin, 2008). Poverty is both a cause and a consequence of marginalisation and exclusion (Ibid).

In South Africa, perceptions stemming from cultural beliefs and stigmas associated with cervical cancer as an STI could serve as a barrier for women being screened and treated (van Schalkwyk, 2008). Vaginal bleeding is the most common symptom of cervical cancer which is also a potential barrier as women are unlikely to report this, for fear of being judged.

Women tend to report other ailments instead of vaginal bleeding when going to the healthcare centres. Indeed, this is also against the backdrop of very low levels of awareness and knowledge of cervical cancer (van Schalkwyk, 2008). Other barriers identified in this study were that healthcare providers are likely to give women pain killers if they report vaginal bleeding, instead of screening to identify the cause of the bleeding and initiating treatment if necessary (van Schalwyk, 2008).

There is compelling evidence suggesting that cervical cancer is a disease of marginalisation and exclusion (cf. Arnolu 2008 & Dawson 2003). Here Arnolu (2008) and Dawson state that women who presented with cervical cancer were poor, living below the defined poverty lines, originating predominantly from rural areas in the context of South Africa (Arnolu, 2008; Dawson, 2003).

The research however does not speak specifically about marginalisation and social exclusion of HIV-positive women and how this contributes to cervical cancer not receiving priority in treatment of women, apart from compelling medical evidence that cervical cancer affects HIV-positive women more than HIV-negative women. In South Africa, between 1998–99, 84 per cent of women diagnosed with cervical cancer were black (Mqoqi et al., 2003). This suggests that cervical cancer is a disease of poor and marginalised women.

Some literature suggests that cervical cancer is a burden for women which are not prioritised by policy-makers (Bomela & Stevens, 2009). More recent literature has focussed on HPV vaccines, looking mainly at its acceptability and accessibility in developing countries. Policy guidelines have been developed around this area as well. There are also calls for more public information and communication strategies about the vaccine (Bomela & Stevens, 2009; Hale, 2009).

Vaccine advocates have also called for the involvement of HIV-positive women in the vaccine development and the establishment of mechanisms to provide access to the vaccine. There is however limited evidence to confirm that HIV-positive women will benefit from this. Policy proposals and guidelines have been enacted in order to detect, prevent and treat cancerous cells and cervical cancer in HIV-positive women. These policies and policy guidelines are being implemented in the global North. There have been challenges in adopting and implementing these policies in the South. It is worth mentioning that lack of policy implementation has been or is a concern for the broader population, but one would assume that this would receive priority since HIV infection changes the face of cervical cancer.

Denny (2006) mentions that prior to ARV access, cervical cancer was not often diagnosed in HIV-positive women because they were more likely to die of other infections before cancer developed. Since increased access to ARV treatment, cases of cervical cancer in HIV-positive women are likely to escalate.

Despite their increased risk for cervical cancer, there are no special provisions on cervical cancer screening for HIV-positive women in the South African National Strategic Plan 2007-2011, except one reference to cervical screening in a description of a “wellness care package” which states that the “Wellness care package includes: regular CD4 counts; opportunistic infections prophylaxis and treatment; cervical screening; advice on lifestyle, nutrition, contraceptive use and fertility” (The South African National HIV Strategic Plan on HIV, AIDS&TB 2007-2011).

The latest edition of the South African National Antiretroviral Guidelines (2010) 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 AND AIDS in adults and adolescents (2010) 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, 2010). 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, 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).

South Africa has been characterised with aggressive treatment advocacy for treatment, including ARV treatment and treatment of opportunistic infections; however, although cervical cancer is an opportunistic infection, it is yet to attract the attention of treatment activists. It could be argued that cervical cancer has to some degree been a victim of, or undermined by, maternal health-based treatment strategies which centre on women as mothers whilst ignoring other roles that women occupy in addition to ignoring sexual and reproductive rights of women. In the context of HIV-positive women, the conception of women as mothers is rooted in the ideology that drives the women’s organising movement in South Africa (Hassim, 2004).

To this end, there has been caution about HIV strategies which ignore human rights, and how these tend to fuel stigma in the process driving the violence and abuse of rights of infected individuals (Tallis, 2002). AIDS programming should focus on rights, particularly sexual, reproductive and other rights, because non-recognition of rights is the very reason women become infected with HIV in the first place (Tallis, 2002). A lack of recognition and protection of sexual and reproductive rights may cause women to die, undermining AIDS treatment efforts. The politics of power and lack thereof to use information and to implement behavioural strategies advocated by the behaviouralists' public health discourses, limit the rights discourse (*ibid.*). Not only do AIDS programmes deliver rights to women, but sometimes they actively take away women's rights, for example, espouse forced sterilisation of women living with HIV (*ibid.*).

Indeed this approach of limiting and ignoring HIV-positive women's SRH rights could be linked to the old patriarchal traditions of controlling the woman's womb (Oakley, 1984), of medicalising women's existence and bodies, and essentially reducing women to nothing but reproductive machines.

Linked to this work, the literature addressing social exclusion was reviewed in order to draw the argument that cervical cancer in the context of HIV does not attract the importance and priority it deserves. This can be partly attributed to exclusions which HIV-positive women are subjected to. Social exclusions are socially reproduced inabilities of people to participate in the politics and the communities in which they live due to their social and economic status (Chen, 2000).

Social exclusion is a creator of poverty but it also sustains poverty (*ibid.*). It locks people up in situations where they are unable to access spaces of power and influence; it puts them in situations where they are unable to explore and participate in what is known as social capital (Adato et al., 2006). People can be excluded on many grounds; relevant to the purposes of this work are the grounds of poverty, gender and disease. Social exclusion could also manifest itself as participation which is not to the benefit of those excluded, participation known as adverse participation or incorporation (Adato et al., 2006).

CHAPTER 2: METHODOLOGY

Research questions

The research asked the following key questions and sub-questions:

1. What is the ideology driving HIV programming in South Africa? What is the state and status of HIV-positive women, particularly pertaining to their exclusions from their community and political structures?
2. What are the barriers to integrating cervical cancer and HIV in policies? Specifically it aimed to explore policy, social and advocacy barriers.
3. How does poverty and social status contribute to cervical cancer not being prioritised in policies?

Study Design

This is a qualitative enquiry, which employed policy reviews and in-depth interviews to collect data from participants. This was considered the most appropriate approach or methodology to answer the research questions. The researcher orientation is social science with qualitative methods of enquiry.

Specifically the following policies were reviewed:

1. South Africa National Cervical Screening Policy, 2000
2. The South African National HIV Strategic Plan on HIV, AIDS&TB 2007-2011)
3. The South African National Antiretroviral Guidelines (2010)
4. The World Health Organization Guideline on Cervical Cancer and Women Living with HIV (WHO 2008)

The policy positions of chapter nine constitutional institutions, particularly, The Commission on Gender Equity and the Human Rights Commission, on these issues was also assessed.

Ethical approval and considerations

Ethics approval was obtained from the University of KwaZulu-Natal's Social Sciences Ethics Committee. Confidentiality of the participants was guaranteed. Participants had the right to remain anonymous and in some instances be identified by their institutions or sectors.

Participants were asked to sign consent forms and were informed of their right to withdraw at any stage during the interview.

Safety of the data

All interview recordings were coded using a password only the researcher had access to. The interview notes were also coded with no personal identities. The data files were shared with the recordings and transcripts all kept in the safe data storage. The researcher will store the data in a safe-locked facility in line with conditions of ethical clearance. The recordings and notes will be discarded after five years.

Data collection

Twelve respondents were purposively sampled or selected via snowball sampling where participants recommend other suitable candidates. The purpose of the selection of the sample was more about credibility as opposed to representativeness (Patton, 1990). There was also a selection of politically important research participants; the purpose of this was to increase the usefulness and utilisation of information generated by the research piece (Patton, 1990). This could be particularly seen in the department of health officials targeted for the work.

The sample of interviewees was diverse and included key civil society informants in the field of HIV and AIDS and SRH; representatives from health systems; human rights and women's rights organisations. The sample included the South African gender machinery the gender commission; and the ministry of women, youth and people with disabilities. Human rights sector organisations interviewed were the Human Rights Commission and the AIDS Legal Network. The Ministry of Health was interviewed. Organisations of people and women living with HIV; and organisations working with cancer issues were also interviewed.

Organisation	Type of Organisation	Position	Gender	Reason Interviewed	Date
1.Department of Health	Government	Chief Director for Maternal, Child and Women's Health	Male	Key informant on policy positions Politically appropriate	April 2011
2.Department of Health/ UKZN	Government/Academia	Principal Specialist/senior lecturer and Head: Gynaecologic Oncology, Nelson R Mandela School of Medicine and Inkosi Albert Luthuli Central Hospital, University of KwaZulu-Natal	Male	Expert in terms of medical academia Working at implementation level, tertiary level Had published widely on the subject Given his position the informant could provide valuable insights into policy limitations	October 2010
3.Commission on Gender Equity	Chapter Nine State Institution	Commissioner Responsible for KZN and Mpumalanga	Female	This body is responsible for monitoring the rights of women in government departments. Have a constitutional mandate to redress gender injustices. It was important for us to consider the position of women living with HIV in participating in policy and	March 2010

				attracting political attention by hearing the views of and the engagement of this body in the research exercise.	
4.*Human Rights Commission	Chapter Nine State Institution	Provincial Manager	Female	This body is responsible for monitoring human rights. Both HIV/AIDS and cervical cancer are human rights issues, so their contributions and positions would have been important for this work in terms of addressing the research questions.	May 2010
5.*Human Rights Commission	Chapter Nine State Institution	National HIV/AIDS Programme Manager	Male	The provincial commission made the referral. The respondent is in charge of HIV/AIDS in the commission, so his contributions were important. Responsible for monitoring human rights. Both HIV/AIDS and cervical cancer are human rights issues, so their contributions and positions would have been important for this work.	October 2010
6.AIDS Legal Network	Civil Society	Executive Director	Female	This organisation is a key civil society human rights organisation. They monitor HIV policy, mainly the NSP. Their insights	December 2010

				was sought to tackle the research question.	
7.Ministry of Women, Children and People with Disabilities/Former office of the Status of Women	Government	Provincial Head	Female	This body is responsible for monitoring the rights of women in government departments. Have a constitutional mandate to redress gender injustices.	November 2010
8.Cancer Association of South Africa	Civil Society	Provincial Manger, Pietermaritzburg KZN	Female	This organisation is leading in terms of cervical cancer service delivery and policy advocacy. It became important to hear their views and involvement on cancer and women living with HIV.	October 2010
9.Health Systems Trust	Civil Society	Researcher	Female	Health systems trust was directly involved in efforts to persuade DoH to integrate cervical cancer services in HIV policy. The person interviewed had conducted policy research on the issue in the Western Cape. She was regarded as a policy expert on the issue.	March 2010
10.National Association of	Civil Society	Provincial Coordinator, KZN	Female	This organisation lead people who are directly affected and impacted by the policy	November

People Living with HIV/AIDS				positions. It was important to gather the understanding and the level of involvement with the issue from this organisation in order to answer the research question.	2010
11.The Treatment Action Campaign	Civil Society	Gender Programme Manager, KZN	Female	The treatment action campaign is an organisation that is leading in terms of treatment for HIV and AIDS. Hearing their positions and involvement with the issue being researched was going to assist in tackling the research question at hand.	November 2010
12.UKZN's School of Gender Studies	Academia	Head Gender Studies	Female	The academic interviewed was very involved with HIV policy matters as it relate to women. It became important to gather the gendered views on the issue. The academic was also very well read on class issues relating to gender. It became important to try and gather her understanding of the gendered exclusion of the issue and the women affected by the issue.	March 2010

*The provincial manager of the HRC indicated that they have a dedicated person who works on HIV and AIDS issues in the national office and that interviewing this person will be critical. So the interview was set with the second HRC participant. It was hoped that the interview will generate more valuable information.

Interviews were held with women's organisations to investigate perspectives on rights as well as lack of policy related to cervical cancer and HIV. Their understanding and perceptions of the barriers to development and implementation of policy addressing cervical cancer were explored. The extent to which interviewees advocated for integration of cervical cancer treatment into their advocacy work was also explored. The nature and participation of women living with HIV in their organisations was also explored, particularly in terms of their engagement and participation in rights discourses, specifically sexual and reproductive rights. Key informants were selected on the basis of how knowledgeable they were on the research question (Patton, 1990). The researcher conducted her own data collection.

Position of the Researcher

The researcher is a feminist who identifies mostly with post-modernists and social democratic strands of feminisms. She has worked in HIV/AIDS HIV and AIDS at a personal and professional level. She has been part of the AIDS movement, in particular positive people at global and local levels for almost a decade. In this she has observed how issues move from being issues with a small 'p' to issues with a capital letter 'P'. The researcher has grown in apartheid South Africa and got politically conscious in post-apartheid South Africa is quite obsessed with the politics of inclusion and exclusion and how identities present and current are used to give legitimacy, delegitimise and also co-opt and also silence some groups and interests.

The researcher believes in that poverty is not just material poverty that it is multidimensional and that it can lead to exclusions and further poverty. She believes that poverty exclusions have gender dimensions and that diseases can in fact compromise these further, even in situations where on paper there is a guarantee of rights and non-discrimination. In order to minimise the researcher influencing the data the project considered the perception and the world view of the researcher.

This was to make sure that her conceptualisations were distinguished and separated from the findings emerging in the data. Emerging findings were also checked against other data, literature sources.

Data Analysis

Interviews were transcribed. The transcriber was someone who had not done the data collection. The participants had been given the option of speaking in their preferred language. In some interviews the participants used isiZulu to emphasise a point, or explain something. The interviews were translated by the researcher. The interviews were thematised and then coded as the first stage of post interview analysis. Data analysis process was:

1. Thematising of the interviews around plot and structure; the use of metaphors and linguistic devices; common patterns and themes; concentrating on the substance of the responses. The themes were initially created based on the research tool, but this was altered and new themes added as data was being plotted in different categories, new categories were emerging.
2. New and emerging themes were identified and listed. Special care was taken to understand and interpret what participants meant with their responses. This was done by reflecting on the interview context and the language used
3. Analysis of the range (individual differences) as well as the commonalities of the responses. Once all interviews were allocated into codes, particular differences relating to participants different positions, what they perceived as the interviewer's expectations and understandings were noted.
4. Analysis of the depth and extent of the participants' consistency and level of engagement within each interview;
5. Analysis of the influences of the listener. The nature of the question asked and the probing skill applied was considered. The presence and the knowledge of the interviewer were also considered here.
6. Analysis of the interviewer and researcher's conceptualisations and the connection between these and the findings emerging in the data; this was done to minimise researcher biases in the data analysis. Further each finding was also checked against literature and other findings elsewhere.

7. Analysis of the specific site context to the interview. Specific care was given to the location of the interview and how this influenced the responses. Analysis of the credibility of the findings as they began to emerge.

Saturation of Data

By the 5Th Interview it was clear that there was no policy addressing cervical cancer and women living with HIV in South Africa. The researcher continued with the interviews as she wanted to understand the barriers which were coming from different research participants. There researcher stayed in the field until there was data saturation (Barbie and Mouton, 2001). The researcher continued with the interviews after data saturation in order to get different nuances on the barriers and also recommendations. There was constant and prolonged engagement with data, during the interviewing process but also after the data collection, the processing and later the writing up phase. There is also sufficient material that is available for reference purposes.

Trustworthiness of the results

This section details the strategies employed to ensure the credibility, transferability, dependability and confirmability of this study.

Credibility

The study used research methods which are well established and have been in other studies of similar studies and also in other qualitative investigations (Shenton, 2004). The research project used credible qualitative research sampling techniques in identifying study participants. Purposive sampling techniques were utilised. The purpose of the selection of the sample was more about credibility as opposed to representativeness.

There was also a selection of politically important research participants; the purpose of this was to increase the usefulness and utilisation of information generated by the research piece.

The researcher made herself familiar with policies and the cultures of the institutions interviewed and also person to be interviewed before they interviews, in line with what Shenton(2004) prescribe as increasing credibility of a research undertaking(*Ibid.*).

The independence of the researcher was communicated to the participants. Tactics to ensure honesty in the interviews were also used. These included making participants comfortable, reassuring them of confidentiality, that they will not be identified by name, and that they have a right to withdraw their participation at any point of the interview (Shenton, 2004). Amongst other interviewing techniques utilised iterative questioning was applied during data collection, herein similar questions were posed slightly differently to check the responses are the same (Shenton 2004).

The researcher describe her own position is a strategy to help the reader determine the researchers credibility. The researcher's qualification and experience is also detailed in order the audience to determine her credibility (Shenton, 2004). The results of the study are also thickly described as a credibility strategy.

Transferability

The provision of a detailed description of the study context allows the reader to determine what comparisons can be reasonably made with a different context. The findings of the work can be applied in other contexts and settings, and with other groups, who are different from the groups researched in this study (Krefting, 1991). In line with what Shenton prescribe, the numbers of organisations who took place in the study are duly detailed, the type of people who participated including their positions, the nature and persons responsible for data collection, the data collection method employed are duly detailed, so is are the periods over which data collection took place (Shenton, 2004).

Dependability

Study materials, data, transcripts, notes, coded materials, interview notes and records are all available for record purposes and trail purpose in line with agreed practise of qualitative research (Barbie and Mouton, 2001). All research tools and processes are reported in detail.

This is to enable future to repeat the research, and gain the same results. The study design may be described as prototype model (Shenton, 2004).

Research materials are kept and can be verified to attest that conclusions, findings, interpretations refer to what is supported by the data and that there is coherence between data and the findings (Barbie and Mouton, 2001). The in-depth description of the study methodology is done such that it can be used to repeat the study.

Confirmability

As it would be the case above, all study materials will be made available for confirmability purposes. These include among others, raw data, processed data and analysis products, synthesis data reconstruction, also tools development information and also interview notes (Barbie and Mouton, 2001). All preliminary reports including though trails will be made available for confirmability purposes (Shenton, 2004). The information on how the research tools were developed is made available (Ibid.) Each finding was also checked against literature and other findings elsewhere and was referred back to policy documents reviewed for reference.

Limitations of this research

This research has limitations. One of the limitations of this work is the small sample size which limits the generalisability of the findings. The findings of this work are important nonetheless. The issue under investigation might not be a priority for some women living with HIV, but it is a priority as political commitment and participation is the driving force of policy formulation.

This research generates information which focuses on exclusion of women living with HIV, beyond definition, in a practical and adequately nuanced fashion, in order to generate policies which will address HIV, the disease, whilst addressing rights and other broader societal issues related to HIV infection. Issues of more pressing need and urgency could be treatment and poverty.

The research assumes that the barriers to delivery of this service are associated with politics, the fact that the affected are poor and marginalised with limited or no political voice or clout. This might be omitting other compelling reasons. The research did not intend to deeply interrogate the capacity of health systems; it is essentially and fundamentally interested in political commitment, or lack thereof.

CHAPTER 3: SOCIAL EXCLUSIONS AND WOMEN'S RIGHTS

Women's Rights in South Africa

In this part of the review of theoretical frameworks attempt to locate cervical cancer as it affects and impacts on HIV-positive women within the broader context of South Africa's women's rights. The women's movement in South Africa is heterogeneous. Therefore, the issues of interest to the movement will also be quite diverse (Hassim, 2004). There is no single entity in South Africa that can claim to represent all women's interests (*ibid.*). This heterogeneity could mean that there is contestation with regard to issues, ideological connections, identities, group identities and fate-based identities amongst others. South African women's organisations have not solely been structured according to identity of women as women, but other identities have played a role as well, for example, their identity as workers (*ibid.*). Traditionally, women's organisations were mainly issue-driven for example; around pass laws, welfare and beer hall riots. Political momentum created by women's responses to issues were not sustained post the campaigns (*ibid.*).

In the apartheid era, women's organising was linked to the nationalist project, organisations which were fighting for national liberation, which might have been because of organising, resources and legitimacy purposes. However, this was counterproductive for the feminists' project. The nationalists' project saw discriminatory oppression as the main problem. It did not apply the feminists' understanding of power and oppression. The project went on to be hostile against feminist thinking and politicking perceiving feminists as foreign and being inspired by the thinking of Northern, middle-class women. It was argued that the feminist project had no value in understanding and eradicating apartheid oppression (Hassim, 2004). Contrary to these perceptions by nationalists, feminism challenged the domination of male power, in all dimensions including politics and economics. In and of itself feminism was a transformation project (*ibid.*) while the aim of the nationalists' project was to eradicate political oppression expressed in apartheid policies. Therefore in retrospect feminism may have actually assisted the nationalists' project rather than diverting it. Later, the rejection of feminism was to have undesirable implications for women's struggles.

However, in the negotiating years, closer to liberation, academic feminists played a pivotal role in organising women within political parties in preparation for negotiations and the drafting of the Constitution (*ibid.*).

South African women's politics is intrinsically linked to the South African party political project, the South African political parties. South African women's politics is located in mainstream political parties. This is the product of the design of the African National Congress ("ANC") during what was seen as the negotiating period. In the nationalist project, women were seen in their role and identity as mothers, the '*mothers of the nation*' as it were. Women participated in the political project as members of the nation as opposed to them participating as women. This identity assisted with the framing of women's issues within the party (Hassim, 2004).

Nationalism was useful in the sense that it opened up spaces for women, but counter-productive in that women's inclusion within this framework was designed not to challenge gender and their participation was within the socially defined gender roles assigned to women (Hassim, 2006). Political engagement in the nationalist's space was the domain of men who were viewed as legitimate holders of power. In this arrangement women would therefore continue to depend on political systems to gain access to power and politics (Hassim, 2004). Power brokers and holders would effectively set agendas for women.

It is unlikely that in such situations, women will address what Molyneux (1998) calls strategic interests. It is also unlikely that women will challenge male power since it is male power that allows access to political space, currency and legitimacy. Sexual and reproductive rights were not part of the agenda (Hassim, 2004). Sexual and reproductive rights are about bodily autonomy, which would not have worked in concert with the *ANCified* feminism rather than problematised men's power in the private sphere was condoned. Issues of sexual and reproductive rights, including gender-based violence, had been categorically rejected and discredited by the ANC nationalists' movement, so it was hard to put these issues on the agenda (*Ibid.*).

This mind-set had a direct impact on sexual and reproductive rights. Considering that it was difficult for the ANC women's league to negotiate and attract participation of women it collaborated with other women's structures to form a National Women's Coalition, in order to see women's issues through the transitional and negotiating phases. The Coalition embarked on a process to formulate the Women's Charter which was to inform the constitutional development on women's issues. The Charter missed the constitutional deadline but the Coalition was still able to make some gains in that sexual and reproductive rights language found itself into the Constitution of the Republic of South Africa, 1996. Further, the government set up the Commission on Gender Equity to ensure that all government policies were aligned to gender (Waylen, 2004). Indeed the gains were also made in the enactment of the Termination of Pregnancy Act of 1998.

The outcome was not the one desired by organised women's groups, both in the ANC and in the National Women's Coalition. The ANC agreed that women's policy issues should be integrated in all policies rather than having it as a separate policy that focuses on women's issues (*ibid.*). The integration of women's issues in all policies resulted in a lack of policies, programmes and budgets that were focused on women, for example, women's health policy. Women's health was lumped with that of children, a fact which may be detrimental to women given that children get more social importance and sympathy than women, and in some instances, the rights of women will be overlooked in advancing children's rights. It was difficult to secure a space for participation of women in negotiations. Frustrated by the lack of women's representativity in negotiations, women opted to ensure their representativity at the expense of gender issues (Waylen, 2004).

The politics of quotas became more important than gender issues and was the dominant criterion when it came to allocating parliamentary seats. More women were sent as gender representatives, representing the female, the biology, as opposed to representing women's issues. Indeed the women were also representing political parties, which they were accountable to. Parties sent women to represent the interests of the parties in Parliament, not the interests of women. As indicated earlier, these were the very parties that had rejected some of the issues that women as a collective had identified as their agenda. Political parties were not accountable to the women or the Coalition as such.

They were essentially representing the policy framework that encourages women's issues to be mainstreamed as opposed to formulating women-specific policies (Hassim, 2005).

Indeed the women who were siphoned off to Parliament were the ones who were leaders and had technical skills in the Coalition; this left a vacuum in the Coalition resulting in the weakening of the movement. There was no longer a strong women's movement to monitor women's rights issues in government (Hassim, 2005).

Given the ideological underpinning of women's political home, the ANC, it was not possible for women's organisations to be strong advocates for sexual and reproductive rights. The discrediting of feminism meant that the ANC, and the women's lobby that created feminists, were founded on the acceptance of men's power in the private sphere. In its post-apartheid development trajectory, South Africa chose the gender and development approach (Walker, 2003). This meant that the focus was on gender as opposed to women's issues. In such a context, it was likely that the 'women as mothers' framework flourished and found its way into government policies and programmes. Further, the new dispensation committed what could be seen as 'political schizophrenia' where the state commits to women's rights, although it uses gender approaches when it comes to policies and programmes. The same state also commits to cultural and religious rights, which rights are more often than not in direct conflict with the rights of women (Walker, 2003).

It is unlikely that the women's rights movements will successfully negotiate in spaces where patriarchy is empowered by unwritten rules of culture and religion; women's rights are therefore likely to be side-lined. In this state of affairs, Walker (2003) identifies the politics of gender desks, where there is one desk looking exclusively at gender and essentially marginalising women's issues, removing these issues from the mainstream. Gender issues are not synonymous with women's issues (*ibid.*). It is striking that women's politics is mainly about economic emancipation and participation which is demanded and expressed in quotas (Hassim, 2006). Women survive by relying on policies and programmes which are mainstream and plug women in order to satisfy the female quota. This is unlikely to either safeguard women's rights or address gender inequalities.

International pressure, mainly from women's organisations, meant that South Africa could not ignore women's rights issues. In particular the Beijing Conference in 1995 and the ICDP Conference in 1994 put women and issues of reproduction at the centre of international development (Cooper et al., 2004). This era coupled with the wind of change in South Africa led to the formation of women's or gender units at universities. The international wave of women's rights and the responses from feminist academia led to the strengthening of calls for women-specific policies and new alliances were formed between feminist academia, the activists and women in political parties (Waylen, 2004). Post-apartheid South Africa saw the inclusion of women's issues in reproductive policies. These policies emphasised abortion and maternal health which were to be free of charge at delivery point. The abortion law was a strong move towards ensuring that women acquired control of their bodies. However, maternal health was still in line with the 'women as mothers' framework (Cooper et al., 2004). Given their status in the liberation movement sexual and reproductive rights remain marginalised in post-apartheid South Africa (Cooper et al., 2004).

Furthermore, there was no policy framework encompassing all women's health issues which perpetuated the development of piecemeal guidelines, like that of cervical cancer screening, which is not linked to any strategic policy or programme. This piecemeal approach is one of the reasons for the dismal failure of cervical cancer screening guidelines and the inability of women, including those advocating for women's health rights, to call the government to account. While abortion services are articulated and legislated as rights, there is an absence of health systems and policies that permit this right to be realised.

Further, it is difficult to fully realise the right to abortion services in the absence of a women's health policy because its delivery is dependent on the fulfilment of other rights within the ambit of women's health. While rights, health and equality are advocated for and safeguarded, this is not necessarily translated into policy budgets or implementation and monitoring plans. In 2004, ten years after democracy, the delivery of a cervical cancer service was grossly inadequate. There has also been poor delivery and inadequate realisation of coverage targets as stated in the guidelines (Cooper et al. 2004). Women's health was lumped together with that of children, the focus being on maternal services as opposed to women's health. Given that cervical cancer has always been the greatest killer of Black women (Adar and Stevens, 2000).

It is in order to think that the South African women's lobby would regard it as a gender injustice issue and prioritise it; however, this is not the case. Cervical cancer affects mainly rural women (Arnolu, 2008). It is rather disconcerting that the South African women's rights lobby is not prioritising this issue given its exaggerated rhetoric on the rights of rural women. One of the challenges stated by the participants of this research, including the Ministry of Health, was the fact there is no strong women's body that is advocating and claiming accountability *vis-à-vis* cervical cancer. The current policy suffers from the fact that it was not driven by a demand from women, and therefore it is not being monitored by women. Indeed this is partly because South Africa has a weak women's movement (Department of Health, Interview, April 2011).

In concluding this section it is fair to state that the South African women's rights movement is weak and ineffectual. The movement was created within the nationalist project. This led to the exclusion of other women and their issues. Within this project, women were viewed as mothers, which led to women's sexual and reproductive rights issues and issues of women's health outside their reproductive roles, not receiving the required priority. Cervical cancer is a sexual health issue and falls out of the maternal or 'women as mothers' framework. Women are prioritised in their motherly roles, in maternal services, mainly for the benefit of the child. This has led to a lack of focus, accountability and a complete denial of women's sexual and reproductive rights and women's health issues more broadly. Cervical cancer resides within this historical, political and policy framework.

Social Exclusions

For the purposes of this research, the literature on social exclusion was consulted in order to highlight that cervical cancer, in the context of HIV, does not attract the importance and priority it deserves partly because of exclusions which HIV-positive women are subjected to. Social exclusion is born of extended definitions of poverty which look at social power and the structures that drive and sustain poverty (Chen, 2000; Silver, 2007).

Definition of Social Exclusion

Social exclusion is a phenomenon that is interested in social relations, particularly how these determine how social resources are governed, distributed and shared (Silver, 2007). Social exclusions are socially reproduced inabilities of particular groups of people to participate in the politics and the communities they live in due to their social and poverty status (Chen, 2000). It entails being in a position of disadvantage without being able to attract social solidarity in order to escape the state of disadvantage (*ibid.*).

Khosla (2009) offers yet another convincing definition, she sees exclusion as ‘an accumulation of confluent processes with successive ruptures arising from the heart of the economy, politics and society, which gradually distances and places persons and groups in a relationship of inferiority in relation to centres of power, resources and prevailing values’(page number for the quote). This definition captures the fact that exclusions are essentially cumulative processes that can be expressed politically or economically, that may affect groups and individuals, and that the outcome is inferiority in terms of public values, power and resources (Khosla, 2009).

How Exclusion is created

The acts of exclusion may be embedded in discrimination, rejection, eviction and ineligibility (*Ibid.*). Social exclusion operates not only through individual action but, most importantly, it operates through the action of institutions and policies (Bhalla & Lapayere, 1997). Exclusion from political spaces and organisations is a major indicator of social exclusions, particularly in sub-Saharan Africa (Gore, 1994).

Political exclusion means the denial of rights, including freedom of expression and the right to equality of opportunity, as well as denial of the ability to participate and to organise for strategic positive changes or social transformation (Bhalla & Lapayere, 1997). It is important to explore the nature and terms of participation of the poor in political spaces, discourses and structures. Woods (2003) asserts that the poor generally lack the ability to represent themselves and their interest in political spaces (Woods, 2003).

Social exclusion is the inability to participate in public spaces and social intercourses because of people's disadvantage, which not only defines them as different externally, but makes them feel different, so that they withdraw voluntarily or are withdrawn from being part of the community through exclusion (Hickey & Du Toit, 2007).

Social exclusions are multidimensional and they show the multidimensional nature of deprivation (De Haan, 1999). They include poverty, different forces of exclusion playing out differently at different times, but all are supporting, reinforcing and sustaining each other (Silver, 2007). Exclusion is a process of social isolation that strips away dimensions of social involvement. Social exclusions may mean the lack of social ties to social structures, including state services and institutions (Bhalla & Lapayere, 2007). Exclusion may also mean denial of rights of citizenship and to communities. Exclusions are also about power relations in society (Adato et al., 2006) in terms of who has power to decide on how resources are shared, who has access to such resources, and who should be in and out of the access brackets.

Social exclusions are not only linked to the existence of discriminatory practices, but importantly to the lack of action in enforcing rights (Adato et al., 2006). In the context of this research the discriminatory issues could be linked to womanhood, and women's HIV-positive status.

Implications of Social Exclusion

Exclusion may mean loss of social status, lack of recognition as well as humiliation (Silver, 2007). Social exclusions may be expressed through cultural boundaries and social institutions. Those who live outside or are seen to be transgressing these societal boundaries may be excluded. Indeed, their exclusion may have other excluding impacts (*ibid.*). In this understanding, issues of cultural appropriateness and inappropriateness are intertwined with resource allocation and deprivation (Hickey & Du Toit, 2007).

Essentially it is about loss of social entitlement, which makes it harder for those who are excluded to ask for what is due to them as members of society. Social exclusions hinder participation in the activities of a given society and may prohibit access to information, resources and social recognition (Silver, 2007).

Unable to participate in politics and communities, social exclusion locks people in situations where they are not able to access spaces of power and influence; it puts them in a situation where they are not able to explore and participate in what is known as social capital (Adato et al., 2006).

Inclusion as Social Exclusion

Where there is social exclusion there might be some social inclusion seen to be taking place, but as Adato et al. (2006) mention, this inclusion may be under unfavourable and exploitative conditions. This inclusion may also not necessarily benefit the excluded; however, it does provide opportunities for access to some practical necessities and opportunities, a phenomenon defined by Hickey and Du Toit (2007) as adverse incorporation.

Adverse incorporation is related to social exclusion. The term however is used mainly with reference to, or understanding of, power relations, history, social dynamics and political economy (Hickey & Du Toit, 2007). In this situation the excluded parties will be involved, but their involvement will be concerned with meeting practical survival needs.

This involvement will not be safeguarding rights and long-term needs of the excluded. It can be described as effectively postponing the harmful effects of exclusion instead of addressing them. This sort of engagement does not challenge or transform social relations that create and sustain exclusion. '*They become trade-offs for short-term security and long-term well-being*' (*ibid.*). Further in this sort of participation the terms of inclusion are not discussed with those concerned. Adverse incorporation is centred at power structures and may create a patron-client situation where the relationship is exploitative to the detriment of the client, yet it is hard for the client to escape this relationship (*ibid.*)

Clientelism is based on cultural and powerful institutional structures which make it hard for clients to leave, in other words, in clientelism-type situations, it is even harder to address exclusion, as people will not only be excluded, but they will be adversely incorporated, a situation which locks them into situations of deprivation with difficulty in breaking even. This sort of engagement may divide the voices and the urgency of the poor, making it really hard for them to organise around their issues.

Indeed, these may also lead to corruption, the creating of unnecessary and unplanned government projects in order to feed clientelism, a fact that diverts resources and hampers progress (Fanon, 1963). For the purposes of this research project, these might be driving exclusions even further.

In the same vein, Woods (2003) states that the poor are likely to be the fodder of adverse incorporation and are likely to be incorporated in order to ‘*trade off their agency in return for security*’ (*ibid.*). The incorporation of women in the struggle against apartheid does fit in with inclusion as a social exclusion agenda. As described earlier, the trade-offs that women made suggest that as a group, they might have been adversely incorporated. This is prevalent in the trade-offs made by advancing “race” rights as opposed to women’s rights during the apartheid era.

Social Exclusion and Poverty

The social exclusion approach is different from poverty because it goes beyond the materialist approach in measuring poverty and deprivation. Social exclusion introduces a social dynamic to poverty, it goes beyond material poverty, it advocates that material and social transformations are creators of poverty and therefore both should be considered in understanding it, and also in eroding and or mitigating poverty (Hickey & Du Toit, 2007). Social exclusion is interested in understanding how social honour by extension dishonours distribution of respect and social entitlements (*ibid.*) This is because social relationships are important in the allocation of resources (Adato et al., 2006).

The social effects of social honour and respect are important in terms of who has access to social resources. Social exclusion approaches can therefore help us include the analyses of gender, race, ethnicity, caste, human rights and political entitlements in the analysis of poverty (Johnston, 2009). Exclusion analysis can help us understand what qualifies for full social participation, citizenship and other social differences (Hickey & Du Toit, 2007). Poverty is not the only indicator of social exclusion (*ibid.*). The presence of poverty does not always mean that people will be excluded. People may be excluded even if they are not poor (Hickey & Du Toit, 2007) although by and large exclusion is the outcome of poverty.

There may be other identities and disadvantageous situations which might lead to exclusions, within the poor, for example, the people's identities as women, sex workers etcetera (Silver, 2007).

By extension, there might be solidarity and social entitlements to some of the poor but others may be poor and may not be seen as entitled to social resources. People can be excluded on many grounds; relevant for the purposes of this work are grounds of poverty, political participation, citizenship, gender and disease. Social exclusion could also manifest itself to participation which is not to the benefit of the excluded, participation known as adverse participation or incorporation (Adato et al., 2006).

Social exclusions can also be viewed from the gender lenses. Women are socially excluded as women (Khosla, 2009). This is because of the gender norms within cultures, women's public participation and indeed the fact that women are generally excluded from the economy (*ibid.*). HIV-positive women may be excluded over and above just being women because of living with HIV – exclusion can manifest itself along the lines of disease and difference. Given the moral nature of the HIV epidemic, HIV-positive members of society may be seen to have transgressed societal norms. Their undesirable behaviour might be seen to have contributed to their situation, leading them to be undeserving of social goods.

Social exclusion may lead to the excluded being more vulnerable to diseases (Silver, 2007). Khosla (2009) states that the impacts of HIV infection have been studied more so from the perspectives of stigma and discrimination as opposed to from the lenses of social exclusions. This has been useful but there are a limitation in that stigma is an act of exclusion that can only be credited to the community because it cannot be regulated, neither can it be measured. Therefore structures of society may not take responsibility for stigma. Further, stigma cannot be addressed by laws or government programmes. This is because stigma emphasises individual perceptions as opposed to rights violations. Exclusions in the context of AIDS have been used in other parts of the world. What has been the focus of these exclusions are the differing levels of marginalisation between people living with HIV with different social identities, for example, sex workers.

Social Exclusion and Social Policy

Policy formulation is a political action of deciding what problems are deserving of change or action, what needs changing and what is the institutional framework to use in order to achieve the change (Beland, 2007). Therefore, policy formulation is a contestation of different interests and powers. Social exclusion is important here because it helps policymakers determine social problems and solutions on issues they see as important (*ibid.*). This illustrates that the whole process of policymaking is a power-laden political process. Even at the level of problem defining, there is political power and by implication those who have no power might be left out of this process.

The policy choices might be thought to improve the situation of the poor, but in actual fact they might be pushing them further into the margins. This is partly because policies made for the poor or social services are more often than not value-laden and popular values sometimes exclude the marginalised (Beland, 2007).

The stakeholders who are outside the government could be seen as representing the interests of civil society, but this might not be the case. They might represent some interests of certain populations and might miss the marginalised and excluded in the community. Stake-holding in itself is an exercise of power and competition of interests including suppression of other interests. Those stakeholders with political and social clout will have their agendas taken more seriously. In this stake-holding there might be co-opting and gate-keeping, which means it will be even harder for some interests to be placed on the agenda. Social exclusion analysis can give the policymakers the opportunity to think about the phenomenon termed intellectual blind-spots, the fact that addressing one policy matter might in fact cause other matters to be relegated to the periphery of the policy agenda (Beland, 2007).

Citizenship affords mainly political and civil rights. These rights are more in concert with the capitalist project. In recent years, there has been an addition of social rights in the citizenship discourse. Social rights essentially improve and provide cushioning for inequalities created by capitalism amongst the other functions it serves. Social rights could mean those who are paying taxes might pay higher taxes in order to finance social spending (Ellison, 2009). This might be seen as interfering with liberty rights of the taxpaying individuals (*ibid.*).

If welfare and social services are delivered in the context of citizenship, they are likely to be impacted on by the unevenness and inequalities which are characteristic of citizenship. The rights discourse might also promote the 'rights for all' and the universal rights in these inequalities and exclusions may be created in the sense that 'for all' might exclude the marginalised groups and the minorities.

In this their social and indeed the civil and political rights of the marginalised groups might be compromised, as they will not be able to take part and benefit, in their capacities as members of the collective and citizens, in the social intercourse and in accessing resources.

Whilst social rights may be due rights, they also sharply contradict capitalism and neo-liberalism as they promote state spending and state delivery of services (Ellison, 2009). As a result, it is likely that there will be a great deal of contradiction in the national dispensation discourse as policymakers will make policy commitments which are discordant with the neo-liberal project. This could explain why some rights are not realised and enforced.

Stigma and Social Exclusions

Stigma and social exclusions may co-exist. It is said that stigma associated with HIV may exacerbate exclusions. For example, poor women may face exclusion from the economy, political systems and community life in general (Khosla, 2009). This particular exclusion might increase these women's vulnerability to HIV infection. Their exclusion will increase if their HIV status becomes known (*ibid.*). Therefore exclusions are fuelling and sustaining each other. This point is important in the South African context where the level of poverty and marginalisation is high, such that it becomes an issue to theorise about social exclusions, because the majority of people are excluded anyway (Adato et al., 2006). This shows that HIV-positive women may actually be excluded because they are poor and they will be excluded further because they are HIV-infected and thus guilty of deviant behaviour, a fact that depreciates their social value. HIV infection can mean, as I suggest with cervical cancer, that HIV-positive women might not be attracting social solidarity and importance in order to access services in relation to HIV infection. This could mean that while their rights are realised on paper, exclusions could be a result of unenforced rights (Hickey & Du Toit, 2007).

As defined in the dynamism of exclusion, disease or being diseased may lead to further exclusion and marginalisation. Cervical cancer is a disease of the poor and the marginalised. In the US those who are mainly affected by this disease are living below the defined poverty line (Arnolu, 2008). In South Africa those affected are mainly rural women and black women (Denny, 2006; Stevens & Adar, 2000). Similarly HIV infection is a disease of poverty and marginalisation (Adar, 2000).

It has to be stated that HIV affects mostly young women and that these women are likely to be poor because of their age and loss of protection, that comes from losing their childhood, but also because young women do not necessarily possess social or political clout. The situation may be the same for older women who are highly affected by cervical cancer. Cancer was marginalised because it was affecting older women, women who have passed their reproductive age, and therefore women who do not attract much social value (Department of Health, Interview 2011).

Cervical cancer comes as a double-burden to women. Three dimensions to exclusion can be identified, namely, exclusion because they are poor, exclusion because they are women, younger and older, and exclusion because they have HIV. As noted above, biomedical studies confirm that HIV infection is more prevalent in cervical cancer patients (Moodley, 2006; Hale, 2009). However this link is not present in HIV programming where there is more emphasis on HIV and maternal services, where the focus is mainly on saving the lives and promoting the health of infants. It can be concluded in this way: healthcare services may prioritise children to the detriment of women.

I argue that cervical cancer in HIV-positive women is marginalised because women living with HIV are socially excluded because they are HIV-positive, because they are women and because the majority of them are poor. More often than not their participation is not to their benefit. HIV policies have taken into account other opportunistic infections that do not solely affect women, but cervical cancer finds itself on the perimeter. Women with HIV make up the greatest numbers in HIV and AIDS organisations who are advocates for treatment, but in this instance they have not advocated for what is in their interests, as women. In addition, the political, gender and human rights machinery has not picked up this issue of exclusion and

gender discrimination because it is clearly not affecting the population which has access to the political space.

CHAPTER 4: FINDINGS POLICY

This chapter will review the policy environment for cervical cancer and HIV in the South African context. Current policies were reviewed and interviews with the Department of Health ('DOH') undertaken. An interview with a department of Health heading the Directorate named, Maternal and Child Health became the key interview for this section as this interview addressed core policy and structural issues within the Department of Health. The informant here could be defined as purposefully targeted informant, politically important case and also information rich case in qualitative research (Patton, 1990).

Policy Environment and Department of Health activities

The current policy recommends three pap smears to a woman in her lifetime, and recommends more smears in certain cases, for example, when the woman is HIV-positive as the department acknowledges that HIV infection changes the face of cervical cancer:

'Yes.... three pap smears, a pap smear every ten years ... until the age of 50 ... we had a 19 year old who actually died of cervical cancer and she was HIV positive, anyone can get cervical cancer these days and the cancer is much more aggressive in HIV positive women than other women' (Department of Health, 2011).

While it is argued that cervical cancer screening for HIV-positive women is a must (Franceschi & Jaffe, 2007), in South Africa screening for cervical cancer is not incorporated into HIV treatment and advocacy programmes. South Africa currently does not have national policies which address cervical cancer prevention and treatment in HIV-positive women. This is problematic as policies facilitate the measurement of progress and hold the public service to account. Women can only enforce their rights in this area if there is a policy in place. A policy leads to development of implementation plans and allocation of budget. At the initiation of the present research, there were reports that the Ministry of Health was revising the cervical cancer policy to take into account new challenges presented by HIV infection (Bomela, 2009). The challenges presented by HIV are that of increase in the rate of vulnerability to cervical cancer, the reductions of the age at which women are at risk, and the increased need for treatment and prevention of cervical cancer.

However, this policy focuses mainly on early identification by screening using pap smears and treatment of abnormal smears.

The official Department of Health position on the cervical cancer policy was sought through interviews. The department stated that there was no policy change intervention that was being explored (Department of Health, 2011). They felt the current policy was sufficient and was in line with the WHO policy:

‘The policy was developed before the WHO recommendation on HIV positive women and cervical cancer; is not tied to the current policy. We have continued with our current policy ... once a patient is diagnosed as being HIV positive she should go and have a pap smear’ (Department of Health, 2011).

The department was wary of the policy formulation process. They felt this might take long and consume more resources. It was argued that the focus should be on service delivery rather than policy. The department felt that what is really needed are mechanisms for ensuring capacity at delivery level, and ways of increasing accountability and monitoring at that level. Reports of guidelines being formulated specifically for HIV-positive women were not corroborated by the Department (Department of Health, 2011). While this view is rational from the implementation front, it is limited in that in a public service environment it is difficult to allocate resources unless there is political commitment to the need and political commitment can be expressed by policy.

Structural Barriers

South Africa does not have a policy or specific focus on women’s health. The health policy of South Africa follows the gender mainstreaming approach which assumes that if health services are available to all, women will also benefit. Women’s health status is measured mainly through the indicators of maternal and child health (Department of Health, April 2011). This is in line with the ‘women as mothers’ framework described in Chapter 3. Consequently, there are no specific policies, programmes and budgets committed to women’s health. The department of health official registered the fact that most of the budget for health programmes is sourced from external donors:

‘The South African Treasury does not deem women’s health as crucial and important government function so that it affords it a budget allocation. The people who decide how much money you get is the Treasury, the Treasury will not fund organisations that don’t bring in money, women’s health does not bring in money, they spend it’ (Department of Health, interview, 2011).

This compromises the programmes because the priorities of the donor agencies are prioritised at the expense of national priorities:

‘Yes, one of the policies ... you see women’s health in general unfortunately does not get the budget that says this is for women and maternal health, they get left out of the budget, they don’t have a specific budget and the budget is controlled centrally, there is no budget for HIV, for instance if you think of contraception, there is no budget that provides for that service, it’s not specific to provide that service, it provides contraceptives there is no budget for women’s health in general, there is no budget for women’ (Department of Health, Interview, 2011).

The official noted that the donor-funded programmes were problematic as they are vertical; they focus on one particular issue, and lack coherence with the national health goals. The official was also concerned that the Department spends considerable amounts of time servicing the demands of the donors, for example by providing surveillance and statistical information. He was particularly concerned that the Ministry was spending more of its time counting dead women instead of saving their lives:

‘The Department of Health spends more time counting the people who are dying rather than helping and preventing people from dying’ (Department of Health, 2011).

‘You cannot use the funding for other things, if the money has been allocated for a certain thing it has to be used for that, if it’s been allocated to HIV it can only be used for HIV, we rely so much on donors now’ (Department of Health, Interview, 2011).

The official also noted that structures concerned with women’s rights were not at the forefront in calling for and ensuring health programmes for women. The disjuncture between the Legislature and Executive in relation to women’s health was also acknowledged.

It was noted that it was difficult to get the structures dealing with women's rights and human rights within the state, interested in women's health issues and working with the Department of Health officials to improve the situation on women's health:

'The woman's department has no assistance, nothing is happening, what should be happening is not happening. So many women are dying and they are not even being told what they are dying of ... the powers that be always ask – what do you need this money for? They don't even know the cost of pap smears, for pap smears to work you need the biopsies, all the follow up work that goes with them and you also need a health worker that has been trained for that' (Department of Health, Interview 2011).

Therefore, it is clear that there is a need for more coordinated and concerted efforts to advance women's health rights between and amongst state structures.

Although it was not explicitly articulated, there was a sense that the 'women as mothers' approach may have failed women and that it was time for this ideological stance to be reconsidered:

'Many countries struggle to deal with sexual and reproductive rights. When you look historically women have been judged as non-beings, except to bear children, this is where most of the politics come from. Whereas that maternal death is judged as important, if that mother dies then the child lives that is the politics' (Department of Health, 2011).

Health Systems Barriers

Barriers were also identified at the health systems level. At this level, there is general lack of focus on women, and a lack of respect for the women who use the services. Issues of accountability and lack of follow-up were also put across as barriers:

'I should be but it is not, sometimes you take a pap smear and the woman come back for the pap smear results and the results are lost, there is no follow up, often women do not follow up their results and sometimes their results are abnormal and the clinics do not take down phone numbers so they don't even call the women if their pap smears are abnormal. You have to have the permission of the CEO in order to make a simple phone call. There is just no follow up on pap smears.'

Those are some of the things we need to improve; just because you have had your pap smear it does not mean that you will be fine’ (Department of Health, 2011).

There are issues of capacity of staff to deal with the demand but also to fulfil their duties as health professionals:

‘We need a lot more training and we need special colleges for the training of the nurses and they need specialised training, there is now more aggressive cancers’ (Department of Health, 2011).

The Department of Health noted that training of personnel should be prioritised:

‘The people who are taking the pap smears are not trained in HIV and the people who are trained in HIV were never trained in women’s health’ (Department of Health, 2011).

There was an indication that too few doctors are able to deal with cervical cancer patients:

‘... but how many gynaecologists do we have? In the whole of Mpumalanga we have three working for the department, in the whole of the Northern Cape we have only got one, that complicates things even more, gynaecologists and obstetricians are becoming less and less now, you are more at risk of being sued and you pay a higher insurance premium, people are just not going into that field at all. Gynaecologists pay the second highest insurance premiums; they are second only to plastic surgeons. So there are not many of them’ (Department of Health, 2011).

Equipment in hospitals and clinics was also raised as a concern. The same concern was raised by the medical professionals who participated in the interviews. Interestingly the Department of Health representative did not dwell much on cancer treatment but rather on primary and secondary prevention. There were also concerns about different levels of hospital and provincial resourcing of hospitals. Clearly there has to be a way to monitor that the services are available at hospital level.

It was noted that cervical cancer is marginalised in the health systems in particular, and in society in general. It was noted that previously cervical cancer was a disease that affected older women who are beyond their reproductive years:

‘Cervical cancer usually affects a woman past the child bearing age, men will just go and get a brand new wife, that is how the gender power is ... for women, the women have already produced the children, when you look – a woman who becomes post-menopausal starts to challenge the territory of the man, the older female ...’

(Department of Health, Interview, 2011).

Given the identity of women as mothers, women are more valued when they bear children; this social value is sharply expressed in health programmes. Cervical cancer has never been prioritised because of this very reason. This makes society reluctant to invest resources in a woman. As noted by the Department of Health above, if an older woman dies there is not much loss felt; she can easily be replaced by a younger woman in the family situation (Department of Health, Interview, 2011). With this state of affairs, it is unlikely that this kind of cancer will receive community sympathy and solidarity that might inspire advocacy. There were even concerns that because of a lack of gender monitoring, coupled with a lack of focus on women’s issues, well-meaning health programmes marginalise cervical cancer even further:

‘We don’t even know how many women are dying in this country, we depend on the government to tell us and we believe them and we ask ourselves – how come?’ ... ‘It is about gender again, it is not about the concern for women, when questions are asked it is just swept under the mat, I was sitting on the ethics committee in UKZN and when we asked questions they were never answered, it is not about the well-being of women’

(Department of Health, Interview, 2011).

One way of identifying abnormalities in the woman’s reproductive system is by performing visual inspections. However, the Department of Health representative noted that syndromic management of sexually transmitted infections, where a person who presents with symptoms for one infection is treated for all infections, means that visual inspections are not performed on women. The Department felt that it was not likely that HIV programmes will address cervical cancer, given their vertical approach, insistence on ARVs as a solution, and their funding source. The Department noted that they had never had any interaction with HIV-positive women on the issues. They noted with concern, that HIV-positive women bombard the HIV department canvassing for care work tenders.

They also noted that none of the HIV treatment bodies had registered cervical cancer prevention and treatment as a woman's health issue or called the Department to account in any way.

Integration of Sexual and Reproductive Health Rights in Health Services

Participants were asked to provide their perspectives on integration of sexual and reproductive rights and health in HIV and AIDS services. The participants registered concerns with the state of sexual and reproductive rights of HIV-positive women, particularly that services were not integrated:

'... if one goes for HIV testing or if one goes for rape or something, what she is going to be given is maybe a PEP, she will not be told about STIs, or if she is HIV-positive there are few people who will advise that person to go for cervical cancer screening ... Also we can say that there are no resources to perform these screening services in some areas' (Civ1, Participant, Pietermaritzburg, October 2010).

'There is no integration. If you find out that someone has HIV she has to go to another clinic for STIs or others' (Civ2, Participant, Durban, November 2010).

Participants also noted that sexual and reproductive health services were not a priority and identified a historical trend to this:

'It is not acceptable, if someone needs and wants those services, it is really not acceptable, the department needs to improve, really with sexual and reproductive issues they are really not a priority in South Africa and they have not been a priority for a very long time' (Participant, Durban, March 2010).

Provinces versus National

Respondents also noted differences between national and provincial levels in that the national policy does not always reflect what is happening at provincial level. Provinces could respond by policy actions much quicker than the national government. It was noted that the cervical cancer policy of the Western Cape Province had taken some of the challenges brought about by HIV and AIDS on board:

‘The national one does not accommodate HIV-positive women; however there is some, for instance the Western Cape Provincial Policy which accommodates HIV-positive women ... The Western Cape policy looked at age, the national one is saying that at the age of 30 is when one can commence with cervical cancer screening and due to HIV and AIDS challenges, Western Cape acknowledges that and reduced their age to 20 years. ... And also HIV-positive women should be screened annually; however the last time I spoke to the Director of Sexual and Reproductive Health in the Western Cape they are reviewing that annual screening. They want see that after one has shown a normal smear if she is HIV positive maybe after year, then it can be reduced to three years, they want to shift from annual to three years and they also consider the clinical situation of the patient’ (Participant, Durban, March 2010).

This reality says a lot about ‘the character of the South African provinces and the level of access to public resources. Clearly this could be credited to the inherited health systems and the level of skill and responsiveness in different provinces’ (Maharaj & Cleland, 2005). There appears to be more communication between policymakers and researchers in the Western Cape:

‘I think there is a lot of research that is happening around the Western Cape’
(Participant, Durban, March 2010).

Engagement by Department of Health with civil society organisations on the policy on cervical cancer

The research aimed to understand whether participants had engaged in any Department of Health policy efforts or discourse on the issue. The majority of the organisations in this study indicated some interaction with the Department of Health (‘DOH’) on cervical cancer, HIV-positive women and AIDS. A few organisations, mainly the government-linked organisations, indicated that they had had no engagement with the DOH on this issue.

Engagement with the Department was of varying nature and degree. Some organisations indicated that they engaged with the DOH at policy level. Others reported only informal engagement with the DOH, by asking questions at public meetings.

The DOH has responded to the issue of cervical cancer in HIV-positive women and has initiated some policy process at national level. However, one participant indicated that the policy discussion was focused mainly on the issue of pap smears, access to them and educating women about them. Further, the participant was not happy about the snail's pace in the DOH's policy process. The lack of communication on the part of the DOH may suggest a lack of accountability, for example:

'... there are delays and there is no communication from the Department of Health about the way forward, about how they should contribute and try and make the policy as quick as possible' (Participant, Durban, October 2010).

Some organisations were engaging with the DOH at service provision level:

'We get the statistics to validate that assumptions of the Department of Health and also to check whether there are programmes that are rolled out in line with what the statistics say' (Participant, Pietermaritzburg, October 2010).

This organisation also monitors the DOH despite having a very close working relationship with them. They also serve the role of creating community awareness on cervical cancer. They use their own research to inform their programmes. However, there are challenges in persuading women to screen for cervical cancer:

'When we go out for community outreach we always go with the Department of Health, where we have mobile clinics, we have a tent where women can go but it's difficult for women to go' (Participant, Pietermaritzburg, November 2010).

Research elsewhere has suggested that the lack of social science about women and how they perceive their bodies and supporting programmes could be barriers in preventing and treating cervical cancer (Stevens, 2000). There is a need to educate women about their bodies so that they are able to notice changes and abnormalities. Cervical cancer programmes should address these barriers. Like other ailments, user-friendly, accessible and possible controlled screening methods should be explored and encouraged.

It is likely women's refusal to screen could be used as an excuse or could lead to women being blamed for cervical cancer. It is commendable that some charitable organisations are able to partner with the DOH to provide services.

However this may present some challenges including that those charities may not be held accountable. Whilst these efforts are well-intentioned, they might also block possibilities for effective government programming. The fact that these organisations partner with the DOH could mean that some advocacy opportunities are missed because they might not talk publicly on issues of public interest in efforts to safeguard their cordial relationship with the government.

Some of the organisations have never interacted with the DOH. This is indicative of the silence and lack of political clout surrounding cervical cancer and HIV-positive women. What is interesting is that prior to HIV becoming an issue, cervical cancer was a disease that affected mainly black South African women (Cooper et al., 2004). It is therefore expected that organisations addressing gender equity and justice will prioritise this issue. In this case the DOH was not being monitored as it should have been by other state structures in relation to this issue. This organisation reported *‘looking at the gendered nature of HIV and AIDS programmes and STI and the State prevention programmes and management programmes, but definitely not cervical cancer’* (Participant, Durban, March 2010).

Clearly there was no focus on HIV-positive women because had it been, the issue of cervical cancer would have been picked up. However, the openness and the non-defensiveness of this participant clearly show willingness to engage on this issue:

‘I think if you can send through information and motivation for the work that the (name of the respondent organisation reserved) should be doing, in other words lobbying for and we can monitor the Department of Health and insist that they include it as a gendered aspect of HIV and AIDS we could draft that letter tomorrow and send it. So use us ... I think engage with our HIV and AIDS Committee and you can note that this is an issue of great concern in the sector, it is a particular gendered issue, the Department of Health is failing to comply with its international obligations in this regard, we are far behind in terms of what all the other countries have undertaken, you feel that South Africa needs to work this into our policy processes and you call on the CGE to put pressure on and demand a response from the Department of Health on what they are doing and put pressure on them to include it, you send us a letter like that and we will do it’ (Participant, Durban, March 2010).

This quote indicates a lack of engagement from both HIV-positive women and chapter nine institutions like the commission on gender equality. The respondent notes that the DOH might be not meeting its international obligations; it can only be assumed here that these obligations refer to those directly linked to women. This presents yet another opportunity for advocacy. Some of the participants' organisations registered their dissatisfaction with the DOH's policy on cervical cancer, including the age at which pap smears are recommended, that pap smears are expensive, that women often do not get their smear results or that provision of results are severely delayed. Other challenges were noted such as a lack of responsibility and timely response from the DOH's side in relation to cervical cancer policy and services:

'So even if they do the pap smear they don't get their results so what is the point ... The chances are that they will be abnormal, their immune and CD count is so low that they are more likely to be getting cervical cancer ... Depending on what the results are, mostly in Maritzburg you will find that those people are referred to Grey's Hospital for cancer treatment, but often it is found very late that they have cervical cancer, so they have to remove the whole uterus and things' (Participant, Pietermaritzburg, October 2010).

What is striking about this particular organisation is that they absorb some of the effects of an inappropriate policy. As articulated earlier this approach has its own challenges for policy advocacy. The organisation did not mention anything about holding the Ministry of Health to account for late treatment, 50% of smear results not being returned to women, and women having to lose their uterus in the process. There was no discussion about instances where the treatment needed is beyond removing the uterus:

'The removal of the uterus is also not guided by clear guidelines given that there aren't any; it is likely that it becomes the prerogative of the individual doctor. Whilst this is good in terms of benefiting the women it may have challenges' (Participant, Durban March 2010).

In the Western Cape it was discovered that the removal of uteruses was offered as a first line treatment for some young HIV-positive women (Bomela, 2009). Further, little is said about cervical cancer treatment or treatment of abnormal smears. In other work, women felt that their fertility was prematurely taken away as a result of hysterectomies as first line treatment (Mthembu et al., 2011 forthcoming).

Barriers to Policy

However, the present research wanted to understand specific barriers to developing a policy and programmes to address cervical cancer in HIV-positive women.

Participating organisations were asked to identify exact barriers to a policy on cervical cancer in HIV-positive women. Some organisations cited a lack of knowledge and awareness as a barrier to policy.

Capacity issues were also listed as a challenge. Some argued that the DOH may suffer from a capacity deficit which is why they had not developed a policy to address cervical cancer in HIV-positive women. Issues of internal advocacy processes and prioritisation were also cited as possible barriers:

‘I don’t know whether it is ignorance within the department, I don’t know for how long they have not complied, not incorporated, I don’t know whether that is just a capacity issue, that people who are driving those processes are not as familiar with the sets of issues, it might not be recognised as a political priority, politicians know that we need to comply but it is clearly not being packaged and presented for political adoption. I also think at capacity level as well that people within the Department of Health are not presenting it as a political issue, a priority issue in a convincing way so that their own internal advocacy processes are not sufficient to catch the attention of policymakers and to make it a priority issue’ (Participant, Durban, March 2010).

Monitoring and compliance were also identified as potential barriers to policy, especially given that those tasked with the responsibility of ensuring compliance were not fulfilling their responsibilities:

‘If we are obliged to ensure that they comply then we have to do it, so I don’t know to what extent in their own monitoring and analysis of compliance, how thorough they are in the process, how familiar they are with all the protocols and all the minuscule detail of that. So it could be capacity, knowledge, all of that has probably resulted in the failure to identify it as a priority issue and possibly’ (Participant, Durban, March 2010).

The respondents felt that there was limited advocacy from the HIV and AIDS lobby. Relationships between the HIV and AIDS lobby and the DOH also made it difficult for the two sectors to engage on these issues:

‘I don’t know to what extent or how active the HIV and AIDS sector itself has been in terms of surfacing this as a priority issue, in gathering the information and putting it before political and policy stakeholders and demanding a response.

I don’t know if it’s a new issue or a long standing grievance, I don’t know what the reaction has been, I don’t know if it has been influenced by some of the politics in the relationship between some of the AIDS civil society sector and the state, I don’t know if it’s been brought to Barbara Hogan’s attention, she would be someone who would surely take it up. Has the issue been packaged the right way and put before the right people, I would ask that’ (Participant, Durban, March, 2010).

Other participants were not sure what the barriers to policy were. They felt that evidence that should compel the Department to act is available but that the DOH was not acting on the issue:

‘... I don’t know what the barrier is for the Department of Health to linking those two. I don’t know, I really don’t know’ (Participant, Pietermaritzburg, October 2010).

‘In my opinion I think it’s because the screening of the cervical cancer is not accessible and also the Department of Health want to be pushed, even to include the TB as an opportunistic infection, there was a number of people who died because of TB and who were HIV-positive, there were a number of activist who were pushing them to include TB. Maybe if we can stand up as women living with HIV and AIDS and voice out and make sure that we push the Department of Health to include the cervical cancer in the HIV and AIDS programme, to do whatever we can as women, most of the time it’s as if we are silent on these issues’ (Participant, Durban, November 2010).

The participants described their perceptions on the silence surrounding the issue of cervical cancer. It was reported that given that cervical cancer affects women’s bodies, it is not regarded as an AIDS-related issue.

The issues around HIV-positive women being unable to organise themselves was reiterated as a barrier to policy as were concerns that organisations of people living with HIV were led by men. It is clear that HIV-positive women feel they will be able to advocate for their issues if they organised independently or, at the very least, held management positions in these organisations (assuming that a management position is a position of power):

‘Firstly most of our organisations are led by males, females are the majority but we are not in power, most of the time you listen to your leader but the people who are in management and if they don’t prioritise those issues, they will be there on the shelves, it does not affect the management directly. What causes us to be silent is that cancer is not treated like HIV and AIDS, we don’t have the majority of people with cancer, we have HIV-positive women and AIDS who have cancer but it’s like no one creates a safe environment for us to voice it out’ (Participant, Durban, November 2010).

The barriers stated above are mainly programmatic. The DOH shed some light onto what could be classified as systematic barriers to such a policy. However, the Department is not advocating for a new policy; it is striving for better implementation of the existing policy. The medical expert working on cervical cancer noted that there were barriers to resourcing cancer services because there was not enough public accountability on the issue. He noted that the public is not holding the health system to account for women’s health issues.

One of the barriers stated was the silence around cervical cancer and HIV-positive women:

‘One of the main barriers and which is always a tricky one, that is lack of discussion, if there is a specific policy on positive women and cervical cancer it could be read by implication that only HIV-positive women are in need of certain needs which are related to cervical cancer which we know is not right ... So from that point of view I am not necessarily a strong supporter of providing an issue but have one strong advocate so that the frame work is in place which caters for everyone’s needs and focuses deeply on different needs of HIV-positive women compared to women living without’
(Participant, Cape Town, December 2010).

This participant indicates the barrier to be lack of dialogue. As it can be seen the participant is advocating a dialogue that is about cervical cancer for all women as opposed to only HIV-positive women.

‘I am not sure that having a separate policy for positive women’s needs in relation to cervical cancer screening and treatment is necessarily getting priority in this context, having another empty policy which looks good on paper but with no implementation does not help in any way’ (Participant, Cape Town, December 2010).

Like the DOH this participant does not think a new policy is the solution especially given that policy processes take a long time. Of importance is that services are available to HIV-positive women. However, is it possible to have programmes in place if there is no political commitment to the issue? Is a policy not an expression of political commitment?

Mechanisms in place to monitor HIV and AIDS programmes from gender perspectives

Participants were asked about their awareness of any policies and/or mechanisms that have been implemented to monitor HIV and AIDS programmes from gender perspectives.

Participants noted that they were not aware of mechanisms that had been put in place to protect women’s rights in the context of AIDS. If HIV and AIDS is affecting and impacting women differently and more than men, the expectation is to have policies and legal frameworks that list the rights of women that are potentially in danger as a result of AIDS, and have these protected.

‘Most of the programmes have been trying to co-ordinate, network rather than to check on the effectiveness and the implementability of the programmes and the betterment of people’s lives due to the programmes’ (Participant, Durban, March 2010).

This illustrates the need to go beyond coordinating efforts to ensure that programmes adequately respond to women’s needs.

Department of Health’s (DOH) priorities in relation to HIV-positive women

Participants indicated that they had no knowledge of the DOH’s priorities with regard to HIV-positive women:

‘I don’t know if they have made priority statements or commitments at a policy level, I am not familiar with that at all’ (Participant, Durban, March 2010).

Even organisations that had some involvement in cervical cancer at community and educational level, as well as organisations working on issues related to HIV-positive women, indicated that they had not been made aware of the DOH's priorities.

Some of the respondents indicated that the DOH's focus is on the prevention of mother-to-child transmission ('PMTCT'). However, such programmes focus on the unborn baby and keeping babies HIV-negative with few benefits for HIV-positive women.

'I for one think there is lack of political commitment with these issues and especially issues that affect women, issues of women have taken a back seat somehow and you end up wondering why, the minister is a woman but I have never heard her in her speech mentioning something like this or even raising these issues, I feel very disappointed. The issues are just not being raised; I also don't think the NGOs have been very successful in raising these issues with her either ...' (Participant, Johannesburg, October 2010).

This quote illustrates the level of concern with the fact that ministries meant for women's rights issues have not raised this issue. The participant cites the lack of political commitment as a larger part of the problem and also contends that civil society has not been vocal enough to get this issue out in the public. It is likely that if there were louder voices and political utterances, the issues of HIV-positive women would have been addressed. Given this participant's position, it should be easy for his organisation to work closely with the Ministry in question but this is not the case:

'The Ministry has been there long enough for these kinds of issues to be raised, but nothing is happening, the Ministry lacks commitment and vision but at the same time the NGOs are not doing enough and the civil societies like churches have not done enough and the political organisations have not done enough with relation to this particular issue' (Participant, Johannesburg, October 2010).

CHAPTER 5: FINDINGS

This chapter presents findings from interviews with the various organisations on cervical cancer in HIV-positive women, presented according to the specific research questions.

HIV-Positive Women's Social Status

The research wanted to understand whether the social status of HIV-positive women was related to cervical cancer not being addressed. Some agreed that cervical cancer in women was not addressed because of their low social status. The response given here relates to women as a group and not necessarily as HIV-positive women:

'It affects women and women are of a lower class and men are only interested in accessing their vaginas and when their bodies and faces sag they go looking for a younger one ... There is no regard or value placed on women' (Participant, Durban, March 2010).

Some participants felt that there was no relationship between social status and the position of cervical cancer; they felt that the issue was the gender struggles and discriminations within the HIV and AIDS organisations. According to the respondent these organisations are characterised by lack of gender sensitivity and responses. It is of interest that social status is seen as independent of gender status by this particular respondent. The language of discrimination is used, but it is assumed to be independent of social class:

'No, I would not say so, I don't think there is a perception that positive women are socially inferior so therefore we will not take up this policy issue, I think it's a breakdown at the policy conceptualising and formulation level, whether it's been taken up and championed by the sector adequately might come from discrimination and gendered nuances within the movement itself, that more emphasis is being placed on generic and broader applying issues and the fact that it is seen as a woman's issue is not being taken up by men and women and by organisations, I am sure there are politics within HIV and AIDS organisations and a struggle to get the gender particular issues surfaced and get them adequate attention' (Participant, Durban, March 2010).

The social status of women is compromised by HIV infection and the status of HIV-positive women in HIV and AIDS lobby organisations. So, the social and gender status might be said to be responsible for cervical cancer in HIV-positive women being marginalised as a policy and advocacy issue:

‘I think the social status of women has something to do with it, which is way low and anything extra you put onto the already stigmatised sex decreases your social status, so firstly you have a lower status because you happen to be born with a vagina then you happen to be diagnosed with HIV which lowers your status even further, you may prefer to have sex with other women which lowers your status even further, it goes back to the fact that women are not equal creatures in our society’ (Participant, Durban, March, 2010).

The research wanted to establish what respondents’ perspectives were on poverty and its relationship to cervical cancer, if any. By poverty the research aimed to use what the participants understood poverty to mean. In participants’ discussions, poverty was understood as material poverty, with awareness that this sort of poverty will constrain access to community opportunities, spaces, political attention and audiences, as well as political clout. Participants noted that poverty impacted on cervical cancer in HIV-positive women in different ways, including that poverty increases women’s vulnerability to HIV and AIDS and cervical cancer. It was further argued that poverty could prevent an individual from taking precautionary measures, for example, taking a pap smear. Even for those who are exposed to information and have assessed their risks, poverty might hinder them from accessing the necessary tests and it might limit care options:

‘Yes, poverty does play a part, if you are HIV-positive you do realise that you need to have Pap smear done every year but you cannot afford it so you go to a clinic for free but you don’t get your results. You then don’t know what is happening or what your results are and you cannot afford to go somewhere else ... you rely on your clinic which means you must have missed out on a couple of years of testing or screening’ (Participant, Pietermaritzburg, November 2010).

Poverty was also understood to mean lack of funding for the organisations that are advocating for women’s rights. Participants also made direct linkages between being poor and one’s inability to speak for oneself in a public space:

‘Poverty always links access to resources, access to information, yes there is talk that you can make those links greater to women living with HIV but I would be reluctant to support these kinds of arguments too loudly. Poverty certainly impacts on the level of rights’ abusers who are presented with this on a daily basis’ (Participant, Durban, March 2010).

Here poverty was said to be part of the equation, but it was stated with caution as the language of poverty can be detrimental to women; it can be used as an excuse to deny rights and to condone violations of rights.

Women’s Contributions to HIV and AIDS and the Impacts of such Contributions

The research wanted to establish what has been the main role of women in HIV and AIDS responses and how this has impacted on women. There was a resounding response that women’s responses were mainly in care provision, for example:

‘Bearing the burden of care, raising families, stepping into the role of deceased parents, grandmothers taking on grandchildren and raising families again, looking after people who are living with AIDS, most of the home-based care movement is probably on the backs of community women, unrecognised, unfunded and unsupported’ (Participant, Durban, March 2010).

This reference to women as carers is in line with what Mann and Tarantola (1996) refer to as the Triple Jeopardy. This quote illustrates the burden that HIV and AIDS has placed on women of different ages. It illustrates how women’s roles in their homes and in their communities have been manipulated to cover the burdens of care. The care work is often not paid for nor recognised (*ibid.*).

Arguably this sort of work distorts the costs of aid to the country and to women. How can the full cost be known if most of the work is done by women in their homes and in their communities?

‘The impact of that on the economy of families, this burden is shifted to them, the impact on that on woman’s labour, women are again having to contribute and give freely of their time and it keeps women from being active in the community in other components, out of the informal economy, takes them away from trying to sustain their own livelihoods and their families’ livelihoods, so it places extreme pressure on families, ironically of the most poor’ (Participant, Durban, 2010).

‘Women are carers, let me change that. Given the gender distinction of society, what she does and what he does works in any society and it works in our society very nicely, women are the ones who care for the young ones, the sick ones, the needy and these responsibilities are in no way changed the moment a woman is diagnosed with HIV ... You have multiple layers of burden put onto women, I have to care for my sister because she is younger, then my sister is diagnosed with HIV and I have to look after her more, then I am diagnosed with HIV and I have the extra burden of having to take extra care of myself plus my sister, women carry the burden’ (Participant, Cape Town, December 2010).

Women are carers. They are expected by society to do so. They are socialised to provide care and feel that taking care of others is their responsibility. The government also takes advantage of this reality and *‘is failing to provide adequate care’* (Participant, Cape Town, December 2010), in the sense that where it does not provide services, there is an expectation and even encouragement that women will take on the burden:

‘... government is largely relying on and basically abusing women at a community level, knowing that women will make way and sort themselves out, because government does not provide funds to home-based care does not mean that the community will stop doing home-based care. Women will find a way to provide home-based care’ (Participant, Cape Town, December 2010).

Clearly the role of women as caregivers has the potential of negatively impacting other opportunities. As illustrated here, women may not be able to seek economic opportunities. This sort of engagement may also impact on women’s activism. Women might be stuck in their caregiving roles, denying them time to think about and act on their vulnerabilities and issues related to HIV/AIDS, with cervical cancer being one such issue.

The fact that care work is not paid nor funded might potentially mean that it is low-scale work which does not attract political actors or politicians. This could mean that women's concerns are confined in localised spaces which might pose a barrier to women's organisations:

'In most AIDS organisations women are the ones who are doing all the work, they are the ones who are doing everything ... Making sure people are aware of the virus and making sure that people are taken care of, women have done a lot' (Participant, Pietermaritzburg, November 2010).

'... I have found that many people who have come forward with their HIV status and being more active about it, it is 80% women and only 20% male, that does make a difference in the sense that they have contributed quite heavily in giving HIV the face but also being activists within the field' (Participant, Durban, March 2010).

Although women are crowding AIDS organisations, are the faces of AIDS, and represent the statistics this does not mean that women necessarily hold positions of power in these organisations:

'The management are the ones who are planning most of the activities and the women are the foot soldiers most of the time, in the boardroom where most of the decisions are taken you will find men, even if there is a woman that woman is either thinking like the men or she will be over powered by those men' (Participant, Johannesburg, October 2010).

The outcome of such an engagement of women has led to women being 'suppressed' and their 'voices are not heard' (Participant, Johannesburg, October; 2010).

While others argue that with AIDS care work women have been able to cross certain social and cultural boundaries, in the instance of this research it is viewed as having undermined women's strategic interests. Women have been so preoccupied and overwhelmed by caring that they have not had time to engage with their own issues.

Women interact with the AIDS policymakers largely on issues of care. Doing care work also means that women are subjected to other forms of organisational subordination.

Women's Rights Broadly in relation to HIV

Participants were asked whether women's rights were broadly respected in HIV and AIDS responses.

One participant stated:

'That is hard to say. I am not sure if women's rights have been protected. I don't think they have been protected as such' (Participant, Pietermaritzburg, October 2010).

There were also clear calls for women-specific responses to HIV/AIDS:

'We know that women carry the burden of care. We know that women have greater difficulty in accessing treatment and services in particular cases. Women have a right to have their gendered needs adequately addressed in health policy and health programmes and responses. Women have different vulnerabilities, different needs and a different situation so policy should be nuanced to accommodate that. I think the particular impact of HIV on women needs to be surfaced; you can't just have a general HIV and AIDS programme. We know that women are more vulnerable than men in certain cases. Above their right as an ordinary citizen of South Africa and their right to health care, I think those particular gendered nuances would need to be addressed' (Participant, Durban, 2010).

Therefore, monitoring women's rights should go beyond ensuring that women are citizens but also ensuring that they are healthy citizens. This may be achieved if health policies and programmes are nuanced from different women's perspectives, taking their vulnerabilities and their gendered bodies into account.

Women's Rights in relation to Cervical Cancer

The participant notes that there is mention of women's vulnerability, but this mention and acknowledgement tends to be lost in policy and programme analysis to the extent that *'in real life there is no focus on women'* (Participant, Cape Town, December 2010).

The research project wanted to investigate participants' perspectives on whether cervical cancer would be treated differently if it affected men and children.

Here cervical cancer was treated beyond its relation to HIV, but as a disease in its own right.

Participants felt that the general practice is that diseases which only affect women receive less research funding:

'Probably, we could be cynical and say that issues that impact predominantly or solely on women tend to not get the research funding and don't tend to be prioritised, if we did an audit of research funds and looked at what funding is set aside for health interventions that primarily or solely target women in oppose to the general population that men benefit from, I am quite confident that the picture will reveal that it's under-funded' (Participant, Durban, March 2010).

Similarly, Tallis (1999) found that treatment issues for HIV-positive women were not known because women are not always prioritised in research. Reasons for non-inclusion are many and include that the women are not always primary beneficiaries of treatment or biomedical research (Tallis, 1999). This fact is not only in relation to HIV, but other diseases. It would appear that the marginalisation of cancer in the context of HIV is also embedded in the sense that most HIV research has not prioritised women's opportunistic infections, mortality and treatments.

Participants provided examples of interventions which were targeting men, and the fact that these were receiving more priority, not just in South Africa but in other countries as well:

'What I have noticed in South Africa is that whatever is affecting men the government stands up very fast, finds the resources, makes sure that that thing is treated, but if you look at male circumcision they put more and more resources, they do it all over the countries, they promote it, they don't care what it does to women. If cervical cancer was affecting both genders I am sure there would be a policy and programmes and they would have the resources available, something big' (Participant, Durban, March 2010).

Participants also suggested that the government was more responsive to issues affecting children to the extent that they may ignore women's issues:

‘If you are pregnant the most important thing is the foetus inside you, not you. If you do want to take the HIV test they tell you – what about your baby, you are doing this for your baby, what about me as a woman, it’s not about me as a woman. It is not about what I want or need as a woman’ (Participant, Durban, November 2010).

However, participants argued that if cervical cancer affected children it would still receive less attention than if it affected men, for example:

‘We are a society that hates children so much, no, I don’t think so. No society hates children as much as we do, look at how much we abuse children, possibly if men were to suffer from it, if men was to have this then there would be a huge programme, everything would come to a stop and we would invest billions and billions of rands into understanding it, sharing information, programmes, policies, departments on it. If it had something to do with their penises which they hold dear, if they were told that if their penis was to come into contact with such a ... in any case if it was something related to their penises it would be a huge thing, there would be a Viagra story around it’ (Participant, Durban, March 2010).

Participants felt that children, women as mothers, or women in maternal care might be getting more health attention and resources compared to women generally. Cervical cancer is not associated with pregnancy or saving infants. This might cause marginalisation of the disease even further as it falls out of the framework of ‘women as mothers’. The participants agreed that cervical cancer would be treated with greater priority if it affected men and children, but that men would be given more priority.

Issues of women receiving government health prioritisation also came up. Indeed this is in line with the ‘women as mothers’ framework which was described in the literature review. The above findings reflect potential barriers to a policy which will address cervical cancer in HIV-positive women in South Africa. Some barriers relate to the nature of the two diseases and how actors working in these fields have responded to and framed the issues. Most relate to systematic, social and gendered barriers to policy.

Civil Society Organisations' Position on Cervical Cancer and HIV-Positive Women

Most of the organisations and individuals included in this research did not have a policy position on cervical cancer for HIV-positive women. For those who did, these positions were not necessarily written down in a policy format. Some organisations had only recently taken a policy stance on the issue and most organisations were unaware of cervical cancer as an issue for HIV-positive women.

When organisations were aware that cervical cancer was an issue for HIV-positive women, they generally had not developed positions or strategies to address this issue from their organisational perspectives:

'Truly speaking we do not have an official position but I am the one who has been given the task to develop the document on HIV and AIDS and cervical cancer. I was given the task on a number of opportunistic infections which affect women, at the moment I am still consulting other people, by the end of December I hope there will be something tangible' (Participant, Durban, November 2010).

This suggests that even though the respondent took responsibility for the lack of position on the issue, the organisation in question did not necessarily prioritise this issue. This is reflected in the fact that the task of looking at several opportunistic infections affecting women was assigned to one individual, the provincial coordinator of a national organisation. In this instance, treatment issues for women were delegated to women, who possibly did not have the capacity to address them as suggested by the fact that she had to consult with others. This data also suggests that the organisation may lack capacity to absorb programmes.

Another respondent conceded that while the HIV and AIDS committee may have deliberated on the issue, she had never heard of it nor had developed a position on it:

'... perhaps an HIV and AIDS committee would be familiar with the issue but we have not formulated a position on that at all to my knowledge' (Participant, Durban, March 2010).

This suggests that some issues relating to HIV and AIDS do not reach the attention of the organisational strategy because of the issue desks within organisations.

However, it has been noted elsewhere that issue desks are likely to be manned by people who do not necessarily have the required skills or power to monitor the issue or attract the level of attention that the issue should receive (Walker, 2003).

One respondent noted that pap smears were covered by their organisational strategy. The strategy also covered issues of female condoms and the impact of male circumcision on women:

‘It is there, in the organisational strategy plan, the pap smear is there also and the impact of male circumcision on women and the female condom issue, at the moment the female condoms are not accessible to women’ (Participant, Pietermaritzburg, November 2010).

It was encouraging that this organisation’s strategy was looking at a variety of issues facing women in the context of HIV/AIDS. However, their focus was very much on practical needs. Practical needs are healthcare commodities rather than strategic issues that will change the situation and position of women in society or address inequalities in health (Molyneux, 1998). It is also interesting that the organisation has reacted to the effects of male circumcision on women, one can only assume, on the ability of women to ensure women’s safety, however there is a question to be asked as to whether it is productive for women to spend time analysing the effects of male circumcision on their lives instead of focusing on their treatment and prevention needs. It could be asked whether this is not a ploy to distract women’s intellectual energies and resources. In this organisation’s position, the strategy seemed to view pap smears as an end in itself.

However, pap smears are a means to an end. Therefore an effective strategy will include primary prevention strategies, with the qualification that most HIV-positive women would not be eligible for primary prevention measures. As a secondary prevention measure, pap smears must be followed by the provision of smear results, the treatment of abnormal smears and cells, the treatment of cancer, and the provision of pain management. Given that research suggests that HIV-positive women progress to cervical cancer faster than HIV-negative women, time is an important factor in developing an effective strategy.

Others argued that the nature of their organisation meant that they did not have a policy on cervical cancer but were working on the issue at a programmatic level:

‘We do not have a policy for this cancer of the cervix, we are a research organisation, we do policy briefings, that are the way we talk to the policymakers, and we write articles, to make the policymakers see that this is an urgent issue’ (Participant, Durban March 2010).

This respondent also noted that she had persuaded her organisation to engage the DOH to review its policy on cervical cancer as she realised that the current policy did not accommodate HIV-positive women:

‘I am personally working on cancer of the cervix, our organisation in most cases focuses on trying to analyse the existing policy that we have, the national cervical cancer screening policy that we already have, that was my focus when I started here, through analysing that I found out that this policy does not accommodate HIV-positive and AIDS women so that is what we are trying to articulate now and talk to the Department of Health on how this policy can be reviewed in order to accommodate and meet the challenges of today’ (Participant, Durban, March 2010).

Despite the lack of a policy position in some organisations, they were still concerned about cervical cancer:

‘The Cancer Association is very concerned because cervical cancer is the number one killer of all cancers and in the world it is number two. But in South Africa because of HIV we are number one. Absolutely, that is why we go to communities, we have a mobile clinic where we do pap smears and breast exams’ (Participant, Pietermaritzburg, November 2010).

Some human rights organisations which are tasked with protecting the rights of HIV-positive people, including protection from discrimination, argued that it was not their organisational responsibility to have a position on cervical cancer in HIV-positive women. They cited their organisation’s structural constraints:

‘Unfortunately as an organisation from where we are sitting I cannot communicate directly to the minister or government’ (Participant, October 2010).

These organisations also perceived women's HIV and AIDS related as peripheral issues and they relied heavily on civil society bodies to pioneer this issue.

While on paper this particular human rights organisation has full access to government structures including Cabinet, it relied on partnerships with other organisations to come up with positions and/or act on certain human rights issues:

'I have a couple of organisations that I am actually partnering with, we have the Treatment Action Campaign which I believe is doing something, we have section 27 which is based in Johannesburg, Sonke Gender Justice, we also have Engender Health, although Engender Health I have never done much with them, they look at women empowerment and that kind of thing, we have issues with NAPWA so I will not say much about them, they don't see eye to eye with TAC' (Participant, Durban, March 2010).

The statement above reflects the dark side of what Mc Nair (2003) refers to as definitional power which serves as capital for civil society organisations (CSOs) that do not usually have resources to market themselves. CSOs create themselves as the credible source of information on a topic, such that they are a point of reference each time the issue comes to the public sphere (McNair, 2003). CSOs have fashioned themselves as credible sources of information and agenda setters in relation to HIV and AIDS to the extent that issues not prioritised by CSOs are not taken seriously.

The reality is that both Sonke Gender and Justice and Engender Health are promoting men's health or at least participation or engagement of men in health and in gender-based violence (Sonke Gender Justice, 2011). It is therefore of great concern that government human rights structures rely on these agenda setters for policy directions and positions.

It is assumed that being accountable to these organisations is being accountable to HIV-positive women. Clearly issues of gender, male pacting, access to public spaces and power come into play.

Organisations' Work Priority on Women and Sexual and Reproductive Rights

Participants were not aware of any stated priority on women's rights in their organisations:

'I recently checked that out I must say, it does not really put women per se in the centre, they just gloss it over as gender issues and take for granted the gender issues which include women ... gender issues tend to be confused with women issues' (Participant, Durban, March 2010)

Most of the organisations in the study did not have a specific focus on sexual and reproductive rights. However, some did report having interacted with issues that they considered as sexual and reproductive rights although they did not have such programmes *per se*.

The consciousness of HIV and cervical cancer as sexual and reproductive rights issues was also not yet developed. Other organisations reported not having developed their work on sexual and reproductive rights. These rights sounded rather peripheral in one of the participant organisations:

'Around sexual rights it is more about gender rights and discrimination around the LGTB sector, we have been very vocal and we have taken up the cases of beating and killing of lesbians in townships and we have taken the case to the equality court of discrimination against a male gay couple who were barred from entering a night club, so we have taken up a few cases around sexual orientation' (Participant, Durban, March 2010).

The lack of organisational focus on sexual and reproductive rights was not surprising given the assertion that the South African feminists rejected sexual and reproductive rights as Western (Hassim, 2004).

Gender appears to be replacing women's rights as a way of advancing the rights of women. In this context it may become difficult to develop advocacy that is expressly nuanced from women's health needs.

Some of the respondents stated that their organisations had not yet considered working on sexual and reproductive rights or approaches. Others were working in sexual and reproductive rights:

'My organisations understand a lot more about sexual and reproductive rights issues'
(Participant, Durban, March 2010).

One interviewee reported that they were developing an HIV and AIDS and gender strategy:

'... the strategy will not only focus on HIV/AIDS, it will focus on anything that has an impact on HIV and AIDS and we have identified the relevant stakeholders like men, men will be part of for rolling out this strategy' (Participant, Pietermaritzburg, November 2010).

Therefore, this organisation hoped that gender goals met sexual and reproductive rights goals and that addressing gender will mean ensuring sexual and reproductive rights. In the gender discourses of this particular organisation, women's rights are conflated with men's rights. It would appear that the strict focus on women's rights – a defining feature of this organisation – is relegated to paper despite this organisation's strict mandate to work on women's rights. This could be credited to the challenges of working with gender approaches which are useful in understanding women's oppression but have lost their political undercurrent and can be counterproductive to women's rights (Tallis, 2009). The level of resources that men's organisations occupy in the gender space was also of great concern.

The work of these organisations can be counterproductive in the sense that they may be apologists for males and thereby undermine women's issues and voices whilst not addressing the problem of patriarchy or power over women's bodies and lives. They may occupy spaces that are meant for women, like they do in this instance. They offer easy solutions and may be attractive to governments and donors.

Organisations focusing on gender may offer counter-solutions to women's issues as their approach is that of society and gender rather than of women, for example:

‘Oh yes, especially the pastor’s wives, we need to get people of faith involved. Yes, it’s integrated in all our programmes, you will find it in our 16 day campaign, and it is integrated in women’s rights. When you talk about rights to integrate, we also talk to men about that, we have a provincial men’s forum, in district we have that as well. We follow the health calendar; there is condom week, that is sexual and reproductive health, even when we talk to men about lobola we integrate’ (Participant, Pietermaritzburg, November 2010).

The participant views women’s rights as removed from the 16 Days of Activism Campaign. While the campaign is supposed to be primarily about women’s rights, women’s rights are only integrated in the campaign. The participant can detail how men are organised from the provincial up to the district level and how they engage with men. There is no mention of an organised women’s body that the respondent is collaborating with. Even more disconcerting, is that the respondent is engaging pastors’ wives as representatives of women. There are a lot of ideological and class issues that this raises. If women engage as preachers wives they might not be involved in their identity and rights as women.

There is also a possibility that this engagement marginalises issues that really matter to women in favour of those advocated by the rightful owners of the space, in this instance, the preachers.

It is also likely that issues of sexual and reproductive rights might not feature in this engagement. Of further concern, is that this engagement might promote moralistic ideas. More often than not moralistic ideas tend to be in sharp contrast with rights and are exclusionary; therefore they might marginalise women even more and might create fertile ground for rescuing approaches to women’s development and rights.

Given its status as an opportunistic infection, cervical cancer might not be in the radar of this sort of engagement. Further, this sort of engagement might marginalise the interests of other women in this government organisation. It is a matter of concern that state institutions which are set primarily to advance the interests of women have men as programme participants and beneficiaries.

It must also be emphasised that organisations which did not focus on sexual and reproductive rights are those which can be seen as state entities and those working in service delivery.

The latter are in the business of delivering sexual and reproductive rights commodities; they do not see their mandate as rights agencies but rather as healthcare delivery service organisations.

The focus on gender is in line with South Africa's ideological standpoint on women's rights and development as noted by Walker (2003). The focus is on gender rather than women (Walker, 2003). It is disconcerting because women are likely to disappear completely from the gender framework.

Lack of Coherence and Collaboration between Civil Society Organisations

In terms of knowledge of other organisations working on cervical cancer in HIV-positive women, responses varied. Most participants knew some organisations working on this issue, while some did not know of any.

One participant reported that as HIV-positive women they have started to organise independently because of a lack of focus on the issues affecting HIV-positive women in her organisation, which is primarily an organisation for people living with HIV/AIDS:

'... No ... to be honest that is why we as women in the organisation decided to stand up for ourselves ... Most of the programmes were not assisting us as women, so there was nothing, even at present there is nothing, except for the sexual rights workshops. Yes, we do the sexual rights workshops and sexual and reproductive rights workshops but there is nothing more than that' (Participant, Durban, November 2010).

This assertion could fit in the popular understanding that women or people with HIV need information, that if you workshop them on the issues then access will be available. This also says a lot about the capacity of advocacy organisations that are advocating for people living with HIV.

In this instance, these organisations are co-opted such that they become centres for ideological enforcements and government information distributors as opposed to being rights monitors. There was overwhelming agreement that cervical cancer is a sexual and reproductive rights issue and that it should be addressed as such.

This was despite the fact the majority of organisations interviewed admitted to never considering working on sexual and reproductive rights of HIV-positive women although their organisational identities were primarily about safeguarding the rights of HIV-positive people and the rights of women.

Most of the respondents did not know any organisations who were working on the issue which is indicative of, and confirms, the marginalised status of this issue. This also confirms the lack of advocacy and awareness on the issue:

‘There are a few small organisations that are vocal on these issues, but as a general issue it’s not an issue which is discussed in women’s organisations ... It always takes one organisation to make a lot of noise about one issue before a whole group of organisations is prepared to take it on as their issue to include it in their list of items’ (Participant, Durban, March 2010).

It is noted that each issue has pioneer organisations; cervical cancer in HIV-positive women has not become a flagship issue for any of the organisations working in HIV and AIDS issues. Particularly important is that women’s organisations have not taken up this issue. Participants also observed that traditionally, women do not always take up issues which are specific to them. It is of concern that women’s organisations do not represent or advocate on issues relating to HIV-positive women. In addition, issues of other marginalised women such as sexual minorities are also excluded:

‘I think women’s organisations are excluded and marginalised, and they are not included, we exclude by default, more often than not these women that we are representing are not inclusive of positive women, they are not inclusive of sex workers, they are not inclusive of lesbian or bi-sexual women or transgender women, so there is the normal marginalisation that happens but unfortunately that is also reflected and mirrored in civil society, these exclusions just don’t fall away’ (Participant, Durban, March 2010).

The role of Chapter 9 Institutions in addressing Cervical Cancer as it affects HIV-Positive Women

Participants were asked to define what they thought should be the role of section 9 institutions on this issue. Section 9 institutions are organisations which are constitutionally mandated to advance the rights of all South Africans, with some specifically addressing the rights of certain populations (Government Communications Service, 2011). They include amongst others the Commission on Gender Equity ('CGE'), the Human Rights Commission ('HRC') and the Office of the Public Protector (Government Communications Service, 2011).

One interviewee reflected on their organisation's role as a section 9 institution:

'We have an oversight role and a monitoring role, one of our jobs is to monitor the state response to gender equality, we have got to ensure that gender equality is addressed by the state, one of our roles is to assess because we can't transform the country on our own, one of our roles is to assess what the state is doing to address gender equality in the form of its policies, legislation, programmes that it implements, so we can review and make comments on legislations and make recommendations to parliament and where we see a policy gap or omission or contrary to international obligations, contrary to the constitution or a complete lack of mentioning gender like the Eskom tariff increase proposal.

It is our obligation to bring it to the attention of the state and we have substantial powers to be able to do that, we can make submissions but we can demand information, we can subpoena and we can litigate. It is to monitor health policies whether they are gender-specific or silent, they do take care of gender issues. If they have a programme we monitor them. It is our facilitation, monitoring and co-ordinating role, if we identify a gap we advise that that gap should be filled' (Participant, Durban, March 2010).

The role and the powers of this institution are progressive towards the advancement of women's rights. It is however disconcerting that in this instance they have chosen to deal with electricity matters. Indeed women will benefit but electricity is not quite a strategic gender interest, which will advance women and gender equity goals. Questions are to be asked about the mandate and the accountability of the organisation in question.

‘If the issue is critical we can implement anything, like I said we could make a submission to parliament, to the portfolio committee, who deals with health and say that we feel this is a critical issue and we could support initiatives of local HIV and AIDS organisations who are doing work in this field and call for a response from the state. We can be present at parliament and make a submission before the committee, we can write to the department which I am suggesting is our first step, although we might copy the portfolio committee just so that they are aware of it as well and request information and if they fail to respond we can subpoena them, our intention is to ensure that gender is adequately addressed in programmes and policies, to make sure that the constitutional principles are upheld and to ensure that international obligations and commitments towards gender equality and eradicating discrimination are adequately addressed in policy and legislation’ (Participant, Durban, March 2010).

Cervical cancer has been missed in the mandate of this organisation apart from research indicating that cervical cancer is the greatest killer of women and that more women are dying of cervical cancer than in maternal services (Hale, 2009). Research also shows that cervical cancer is affecting mostly Black South African women (Mqoqi, 2003).

It is therefore expected that under the goals of racial equity, cervical cancer will be prioritised in organisations such as the one quoted above. Indeed there will be a legitimate expectation that cervical cancer should be prioritised under the banner of discrimination and justice as well.

Some participants noted that section 9 institutions have not responded to the issue:

‘I have not seen them active in articulating cervical cancer, I have not seen them bringing up an awareness, in the clinics you never see any poster that shows a linkage between cervical cancer and HIV and AIDS, I have not seen any posters from any gender or woman’s organisations or departments on cervical cancer’ (Participant, Pietermaritzburg, November 2010).

The role of these institutions was clearly acknowledged, but some criticisms of them were also shared including concerns about the independence of the gender machinery:

‘Lack of absolute independence of chapter 9’s institution and mandate to monitor and demand accountability or criticise, chapter 9 institutions are funded by government so there will always be a limitation and they will not speak out against government policies, due to the lack of adequate, positive experiences in trying to utilise any of the chapter 9 institutions, I also think that civil society and community based organisations are trying to utilise these and these are the kinds of things that these institutions should provide’ (Participants, Cape Town, December 2010).

One participant noted that these organisations need to do more themselves. There were concerns that NGOs are taking on the work, but since they are not equipped to do so, they are not doing enough. There is also another drawback to NGO delivery. NGOs provide services as charity and since they are not legally bound to do so, they may not be held accountable for the services they provide. NGOs may also provide services outside of the nationally agreed rights framework. Their charity might be subject to conditions, for example, repentance or bargaining of some rights.

In addition, NGOs may block advocacy that is meant to engender lasting changes and/or solutions. This is not in any way suggesting that NGOs have no role as often they are the only way in which civil society is able to participate. However, they should not be left with the responsibility to implement programmes.

Other participants felt that one of these institutions should change the way it works in order to improve the situation of women. The participant was clearly stating that this institution should be more involved in issues related to sexual and reproductive rights. One of the participants felt that this very organisation might not have a clear understanding of gender. The participant was also not comfortable with the reactionary nature of the sector:

‘I do not think they know even themselves, gender issues are very broad, without wanting to put blame onto the movement, the women’s movement and the human rights movement, there is a tendency of reacting to whatever incident or case that comes to the fore. ... You take a case and run with it like crazy, but what happens is that you don’t then have time to look at cancer of the cervix issues and HIV issues, my thinking around it would probably be given that there is such a broad spectrum of gender issues.’

I mean what makes up a woman's body and looking at a woman's body for instance looking at different types of women because it might be a woman's body but not all women are the same' (Participant, Durban, March 2010).

The participant recommends regrouping these organisations and the women's movement at large. She states the importance of appreciating the differences in women's bodily needs and urgencies. She is cautious of the gender races and marathons and cautions against the assumption that all women understand women's urgencies.

In this she could be recommending that women in positions of power who represent women's interests might not necessarily be equipped to do so. Therefore it becomes important to get the issues from the women who are affected by the issues. Indeed this has its limitations in the sense that women who are marginalised by material, political and disease poverty might not have access to people, including women in powerful positions:

'Having a vagina does not qualify you to know about the issues that people experience, in my observation, I might be wrong but that has been the trend, as long as you have balls and a chest that is enough for you to be given a position on women's health and when you get there you have no clue of what you should be doing and how you should be doing it' (Participant, Durban, March 2010).

One participant felt that the section 9 organisations should be challenging the gender issues such as the way women acquire HPV:

'With the HP virus which is linked to cervical cancer, the HPV virus is carried by men even though it does not affect them but we get it from them so it increases with women, so if there is two men who have it can be transmitted to 10 women and there is no way of knowing if the guy has that virus because it does not affect them at all. There is a test but it's a very painful and expensive test, they have to scrape the cells from the scrotum, apparently it is very painful and very expensive, whereas a pap smear is easier and less expensive, the test for men for the HP virus privately is about R800, whereas you can get a pap smear for about R150' (Participant, Pietermaritzburg, October 2010).

Based on this, cervical cancer is caused by a virus which originates from men and is passed on to women. There are no interventions to screen men for this virus and prevent them from passing it on to women, which then increases disease burden, suffering, and possibly stigma faced by women. The arguments of cost and pain cannot be viewed as valid arguments for not screening men for HPV.

There were also feelings that section 9 organisations, particularly those with women's right mandates, should be leading the advocacy for prevention and treatment of cervical cancer in HIV-positive women.

The respondent noted that HIV-positive women should be standing up to call for these organisations to address cervical cancer, although concerns about the inaccessibility of these organisations were noted.

Civil Society Priorities in relation to HIV and Cervical Cancer

This particular participant noted that even civil society, for example, churches, were not raising their voices in calling for prevention and treatment of cervical cancer. HIV and AIDS has been a site of political rumblings and competition in South Africa, but interestingly, cervical cancer in relation to HIV-positive women has not been raised in political parties.

'There is the NSP and according to the NSP we are not focussing on prevention ... we are acknowledging women's greater risk to HIV but it does not mean that our programmes and resource allocations from a government point of view necessarily reflect that in any way so I think yes – government does recognise and acknowledge which is progress in itself, because it was not like this five years ago, women's specific needs and risks based on the context of HIV, it is the translation of that knowledge into programming which has the potential to change the impact of the status quo, that is where it starts falling apart' (Participant, Cape Town, December 2010).

Lack of Leadership

The research also found that there was lack of leadership from among women living with HIV. The participants were asked whether they knew any HIV and AIDS organisations which were founded for and by women living with HIV. There was limited knowledge of organisations of HIV-positive women. Some organisations had no knowledge of groupings or organisations of HIV-positive women. Some respondents were only aware of mainstream organisations, such as NAPWA.

Participants who were organising inside the mainstream organisations expressed their frustration with working in these settings:

‘Maybe those women are frustrated like me. It is so difficult for an outside person to understand what is happening inside these organisations. Do you know what is sometimes happening is – for instance there is a woman’s gathering to which you are invited and you know the women’s issues and they know that we will raise these issues and they will send someone who will be quiet, they know so and so will not raise these issues, she will be quiet in a meeting so send her to represent the organisation’ (Participant, Durban, November 2010).

The frustration expressed here is internal as well as external. The organisations are not able to address women’s issues, at the same time they wish to protect their reputation by ensuring that their limitations are not known to the external world. Clearly this means that women’s issues are further marginalised by the politics of representation and delegation within organisations.

Issues of fear were registered as issues of concern. Although women know what the issues are, they would rather not register them as issues because raising them – if they are not priorities for their organisations – could be seen as going against the organisational priorities:

‘For me I will go back to the issue of fear, I think other women in this organisation have this fear, we are depending to these people, it is like I don’t want to lose my job, it is about the job, it is not about the women’s rights, I don’t want to lose my job, I don’t want to be unemployed. The years come and go and you are still here and there is no difference’ (Participant, Durban, November 2010).

Exclusion from Institutions

Organisations with constitutional authority to work on women's issues acknowledged that in their view, issues are more important than identity and that they work with groupings of women without necessarily being concerned about their HIV status. Here HIV-positive women are suggested to be like all women and that issues of HIV-positive women are the same issues of all women. Whilst this may be partially true, HIV-positive women do have additional issues that affect them because of their HIV status, over and above what they face as women.

This is indeed a demonstration of a lack of acknowledgement of HIV-positive women as a political identity, or at the very least, a vulnerable group in the population of women. It confirms the political status of HIV-positive women in so-called women's dispensation. There was an expectation that the mainstream organisation would have a women's wing, although it was also expressed that the capacity and priority of the organisation might affect the efficiency of this 'women's wing':

'But there might be sub sets, like committees under NAPWA, they must have a women's wing or something ... Facing their own political problems within an institution, sufficient staff, sufficient capacity, sufficient resources, prioritising their programmes within the overall mandate of an organisation ...' (Participant, Durban, March 2010).

This participant argued that the mandate of the organisation is not accountable to women or women's issues. Women's issues are seen as an external mandate of the organisation that is for people living with HIV. This fact does not seem to have been problematised by this particular organisation.

In the main, HIV-positive women are not organised in South Africa. Some of the reasons for this are stated above. Some of them relate to issues of poverty and not having time or resources to organise for strategic political action. Some of this is embedded in their status as women, and further compromised because they are HIV-positive. The politics of HIV-positive women are seen through the lenses of general mainstream organisations.

This has its limitations; it was established in the present research that these are not always safe and effective spaces for women wishing to organise themselves or raise their voices. It is interesting that there is an expectation that women's issues will be desked (a special desk or committee of the issues set in the organisation's structures) in these organisations. The downside of desked issues is illustrated above. These issues hardly attract the strategies and the programmatic priorities of organisations. If anything, desked issues are susceptible to further marginalisation.

Participants were asked about the nature of participation of HIV-positive women in their organisations. Some participants felt that there was no need to have specific participation as long as HIV and AIDS is prioritised in their organisations.

'HIV and AIDS is up there in our five priority thematic areas, we have five areas and gender and HIV and AIDS is there, it's there on its own merit and each of the other thematic areas, gender and poverty and gender based violence have to take the impact of HIV and AIDS within those particular sectors themselves, I think issues relating to HIV and AIDS are there as one of the priority programme areas for the [Name of the organisation withheld] ... Whether or not women within the ... [Name of the organisation withheld ...] are HIV-positive choose to disclose that they are positive is another matter altogether, I don't know of any women staff member who has done that, I know that there would be no discrimination from an employment perspective, we could not do that, we are a constitutional body' (Participant, Durban, March 2010).

Although HIV was one of the thematic areas of this particular organisation, and it has been mainstreamed in other areas of work, the organisation reported not to have worked with HIV-positive women as a group or a constituent.

Participation of HIV-positive women was reported to be low to non-existent in organisations in this study. The responses given were about participation of HIV-positive women as staff members. Discrimination was thought of as workplace-based discrimination. Indeed, there has been increased focus on addressing workplace-based discrimination of HIV.

This could be linked to the strong labour movement and the availability of lawyers to take on labour-related HIV cases, among other reasons. This is commendable but at the same time it is important that other forms of discrimination are addressed.

HIV-positive women were also not participating in cervical cancer organisations, although these organisations had reported that 50% of the people they serve are actually HIV-positive women. It was reported that these organisations were focused on cancer and had no intention of integrating their work to that of HIV and AIDS and the organisations preferred not to be associated with HIV:

‘In this organisation its kept very hush hush, we are scared to even touch HIV, [...] (name of the organisation withheld) ... believes that HIV has been touched so much whereas cancer has not been touched so much but the mistake we are making as an organisation is that we are not finding an integration that we can work towards, we are narrow-minded and just thinking cancer but not integrating’ (Participant, Pietermaritzburg, October 2010).

It is of concern that respondents from organisations of people living with HIV also registered the inability of engagement of HIV-positive women as an issue:

‘The majority of the staff here are women and the majority are HIV-positive women and AIDS. But the challenge is that everyone has that fear, we discuss the issues when we are alone as women, when it is time to challenge the management it will be one woman, the environment is not conducive to women, most of the time women do not raise what they want, most of the time they keep quiet and do whatever has been said. If you are told that a project is not budgeted now where will you get the budget for that? And if you ask why it was not included in the proposal you just don’t get an answer’ (Research Participant, Durban, November 2010).

In one of these organisations, the respondent noted that HIV-positive women are involved, but their involvement depends, assumingly on what is the agenda on the table:

‘... It is mostly sexual abuse and human rights’ (Participant, Pietermaritzburg, November 2010).

The participation of HIV-positive women was a ‘frustrating’ reality in this particular organisation. HIV-positive women were working on human rights issues; however, only one of these rights was explicitly mentioned. The question is which rights are women working on if their issues of life and death are not addressed? Sexual violence has been a topical issue in AIDS circles. What is striking is that whilst this issue is important in addressing women’s issues, it is not an issue for HIV-positive women. The current sexual violence programmes systematically exclude HIV-positive women.

Organisations were asked to comment on their interactions with support groups or organisations of HIV-positive women. Organisations reported working with gay and lesbian groups in exploring issues of sexual orientation and discrimination, but not with groups of HIV-positive women. This suggests that it is possible for this particular organisation to work with groups of marginalised women. It was not clear, however, whether the gay and lesbian groups had approached this organisation or if the contact was made the other way round. Perhaps HIV-positive women as a group had not approached this organisation for collaboration.

The work done was around violence rather than disease. It could be said, with this sort of work, that the target is normally society rather than policies, so it is safe work to do on the part of the section 9 organisations and other government agencies. It was also interesting that the groups had interacted with issues of care, working with home-based care groupings, and looking at the gendered care burden.

Internalised and Voluntary Exclusion

Given that cervical cancer affects mostly HIV-positive women, HIV treatment in South Africa has been characterised by activism for rights and treatment. This research sought to understand why HIV-positive women had not advocated for this issue or for change in the cervical cancer policy in South Africa.

The participants noted different reasons for non-engagement of HIV-positive women on this issue.

'Firstly, for me, the environment is not conducive, we have been fighting this for years, like yesterday we had a meeting where we are trying to form the positive women's organisation which will be separate from all these organisations, hopefully it will be able to address all these issues, most of us are women who are living with HIV and AIDS and some of us are living with cervical cancer and other diseases, so we really understand what is happening and what are the challenges, we hope to be pushing as women, there will be no one controlling us at the end of the day, no one will say you were not supposed to say that, that is not our position as an organisation. If you are in an organisation sometimes you have to protect the organisation at the expense of yourself as an HIV-positive woman' (Participant, Durban, November 2010).

This respondent illustrates the challenges in women organising. The issue has been registered but it has not been incorporated into organisational priorities. This demonstrates the lack of power that HIV-positive women face in the so-called organisations of people living with HIV. It is also clear that women engage because of bread and butter issues as opposed to engaging because of politics of gender or women's rights.

The mandate and accountability for these organisations, it can be deduced, does not necessarily come from or include women's rights. If it did, why would an HIV-related opportunistic infection such as cervical cancer be excluded?

Why would women feel a need to organise independently for this issue as if it was a satellite issue? There is an assumption that if women organise independently there will be change. This might not necessarily be the case. As noted earlier most women's HIV and AIDS organisations focus on issues of care provision. It is unlikely that policy change will be effected by this sort of engagement. The above quote also illustrates the dark side of created spaces for women (cf. Hassim, 2006).

The organisations of people living with HIV are not spaces demanded by HIV-positive women, they are created spaces, originating from the GIPA principle of 1995. This agenda did not have HIV-positive women in the centre, but men living with HIV who were demanding a space on the AIDS policy table.

This declaration led to the formation of what is known as ‘national networks’, which work closely with governments and nationally-recognised AIDS lobbies protecting the rights of people living with HIV, but not HIV-positive women *per se* (GNP+ 1995). National networks have been at odds with sexual and reproductive rights of HIV-positive women. Because of their relationship with the national lobby, they adopt national priorities and ideologies which are removed from women’s realities and rights. There has been evidence of national networks working against the rights of women, for example, the national network in Botswana drives a policy agenda which discourages HIV-positive women from conceiving by firing those who conceive whilst in its employment or that of its partners (Bomela, 2009).

The protection of organisation by not mentioning what your issues are may imply that the organisation is not in support of your issue, so this particular organisation was not in support of HIV-positive women advocating for cervical cancer treatment and prevention, partly because, as stated above, the organisation has a destructively cordial relationship with the government and advocating for cancer might be interpreted as challenging the government which in turn might harm its relationship with government. This sort of arrangement does not only exclude women but may also infringe the rights of HIV-positive women.

Some participants felt that HIV-positive women were not addressing the issue because of race, class and political issues:

‘I think it’s a class issue which is a political issue which is a race issue. Starting on your race for starters, depending on the fact that you are woman, even men of a lower class has better access to information and better priorities. Our gender roles have been structured so that we prioritise and use our resources dependent on our gender roles and not what we need and value for instance, some of the values that we hold are values that have been enforced on us. What I am trying to explain is, even if we were to get information on cancer of the cervix it will take long to get to the people, men access the job market better than women and once they access they get paid better than women, even if they were to be paid equally as women, they don’t have the problem of putting food on the table, they don’t have a conscience. Mozambique is very different to us, the men put food on the table there. Women have so many responsibilities, not only your children but also your grandchildren so a whole lot of information passes you by’ (Participant, Durban, March 2010).

This illustrates the differing oppressions that women face within the existing oppression, class and race classifications. The responsibilities and roles that women have as people of lower status also means that it is difficult to have time to think about what matters to you as a woman. Race also has a direct relationship to cervical cancer.

Black South African women seem to be at increased risk of cervical cancer (Cooper et al., 2004). Indeed racial and gender discrimination may be at play here. If one were to apply the backward thinking applied in many South African political contexts, one would blame apartheid for this phenomenon.

Without suggesting that apartheid has no bearing on this given its discriminatory policies based on race, gender and access to health services among others, cervical cancer is also being marginalised and de-prioritised as a disease in post-apartheid South Africa. Evidence of this can be seen in the programming and lack of monitoring, including appalling delivery of commitments made towards addressing cervical cancer (Cooper et al., 2004).

Exclusion from Institutions

The research also wanted to understand why organisations working on access to treatment have not prioritised this issue, given that it sits squarely with HIV and AIDS treatment. It was argued that issues need to be prioritised at an organisational level, and that those organisations might prioritise certain issues over others with cervical cancer not making it onto the agenda:

‘Probably because of their own internal jostling, if we are going to grab the politicians’ attention we will grab them with one issue, what is that one issue going to be? They picked up the mother to child issue but I am sure there are a lot of competing issues within the movement and different people arguing about what should be a priority issue, if we have only got a minute to capture people’s attention we cannot give them a list of 20 issues, what are going to be our top three, does the gendered issue make it to the top three. I guess it’s the pressure on them to get the priority issues in and then their own internal politics and nuances around recognition of the gendered issues’ (Participant, Durban, March 2010).

Participants also noted that these organisations have never really taken on board any issues relating to HIV-positive women.

‘What issue did we ever raise that only affected HIV positive women? It’s not only cancer of the cervix, we are not raising anything that is a reality for HIV positive women, what about sexual and reproductive rights of positive women in a sense of am I allowed to have sex or not allowed to have sex, which leads to issues of prevention for positive women, is anyone making noise about that, what about pregnancy for positive women, there are so many issues that we choose to be silent about ... We don’t care about women, as creatures, as beings. We don’t care about the specific needs or realities of any social group of women’ (Participant, Cape Town, December; 2010).

Representation and Participation of Women living with HIV

The research found that HIV-positive women were participating in structures, that they were represented by their spokespersons, but this presentation was not yet evident at policy levels. HIV-positive women are involved in campaigns that influence policies and such demonstrations and campaigns are vehicles towards changing policy and influencing interventions.

Questions were asked about the level of information that the women have in order to make decisions about policy issues, and how much feedback they were getting to effect these changes. There were also questions about whether these women had a mandate to canvass these issues on behalf of other HIV-positive women and whether there was accountability to HIV-positive women. There are other liberal organisations who claim to represent the interests of HIV-positive women. Although most of these organisations are women-led, they are paternalistic and tend to use HIV-positive women to legitimise their causes. In so doing they marginalise HIV-positive women further whilst not addressing their concerns. Cervical cancer is not only marginalised by organisations of people living with HIV nationally, but also internationally.

Advocacy for this opportunistic infection has not been forthcoming. Quite strikingly, even Northern HIV-positive women have not prioritised the issue, partly because they have access to prevention and treatment.

The positive women's lobby of the South relies on the North for resources and agenda-setting. In this arrangement of relationships, issues of importance to the South are hardly on the agenda.

There are known historical differences between HIV-positive women themselves. There have been disagreements about African HIV-positive women advocating for the incorporation of children's issues in what is essentially a feminist agenda of HIV-positive women whilst Northern women view these spaces as spaces of feminist engagement.

It is however striking that in the North organising of women is also linked to practical needs, such a childcare, welfare benefits and immigration issues, among others.

Some felt that HIV-positive women should play a role in policy formulation. In the same vein there were also calls for men-led organisations to be involved in formulating policy:

'We are seeing men's leadership in the gender equality feel them, I am reading fantastic reports by Sonke Gender Justice and looking at addressing men's role in addressing gender equality, I don't see any reason why they should not be involved in these types of health issues as well' (Participant, Durban, March 2010).

This was a demonstration of confusion about women's rights and gender. It comes across as disingenuous to expect a male-led and focused organisation to have a role in a policy space that should be for women, also given that by and large this policy issue has been marginalised. It would appear that this proposal advocates the co-option or paternalistic taking over of HIV-positive women's issues by organisations who have power and who have essentially used their power to constrain the space for women's advocacy in many respects. The research asked questions about why HIV-positive women were not addressing the problem, since it was affecting them.

Responses varied. Some respondents felt that being in an organisation means that you have to speak to the priorities of the organisation and protect the organisation. Others felt that a lack of response might be because HIV-positive women are not aware of their risks for cervical cancer:

‘Are we even sure that women living with HIV are fully informed and knowledgeable about their greater risk in the context of cervical cancer, or are we assuming that every woman with HIV is aware of these greater risks?’

Maybe we are assuming incorrectly that because these women are living with HIV [they] are aware of their greater risk to cervical cancer’ (Participant, Cape Town, December 2010).

Issues of stigma and discrimination were also argued as reasons why women are not speaking to the issues affecting them:

‘Also I think at a community and at a social level right now we have issues of survival, if my status comes out am I going to be beaten to death, and from a prioritising point of view my own survival at an immediate level is always one thing that I will make noise about’ (Participant, Cape Town, December 2010) .

The research discovered that HIV-positive women have not targeted public spaces for this issue because of lack of knowledge:

‘I think as well with cancer there is not a lot that people know about, I think it is lack of education about the cancer disease and the belief that cancer only happens in older generations and not having full understanding of the integration between HIV and cancer ... I don’t think they have the full understanding of how that happens, there are people now who believe if you have HIV you will get cancer but they don’t fully understand how that is linked together, I think it’s the lack of understanding of the disease’ (Participant, Pietermaritzburg, October 2010).

Lack of awareness and education were cited as reasons for HIV-positive women not responding strategically to the issue. There is limited understanding of the relationship between cervical cancer and HIV. The lack of integration is one reason why women know little about it. Lack of integration is therefore a double-jeopardy: it leads to both death and to limited awareness and advocacy. Further, there are prescribed structures within which to raise issues relating to HIV policy.

If there is limited support or lobbying for the issue, that issue will be marginalised. These spaces are characterised by tough negotiating, politicking and bargaining. Again, because of lack of organising and recognition of HIV-positive women as a political force to be reckoned with, HIV-positive women sit on these structures, but do not necessarily represent the interests of HIV-positive women.

This resonates with the perspective that having a vagina does not automatically translate into you being an advocate for women's rights, as argued earlier by one participant.

'I know the (South African National AIDS Council) SANAC Women's Sector, they are leading the whole thing. HIV-positive women are part of the SANAP Women's Sector ... There is something that confuses me in South Africa, every leader will say – "we want women to lead, we want the best for women" – and practically they don't mean that, but always when they are speaking, even in SANAC the chairperson is a man, when a woman raises an issue they will always support the issue verbally but when it comes to let's do the real thing you will hear the Women's Sector saying they are frustrated because they don't do what they said they would do. Women will not be treated equally in South Africa and it will be a long journey' (Participant, Durban, November 2010).

This is a classic example of adverse incorporation of HIV-positive women in organisations. The women are represented at the highest HIV policy decision-making body but are not able to articulate their issues. Because of their involvement, by implication they are party to decisions taken; it is likely that most of these decisions are in contrast with what would be defined as their struggles. The participants share the South African HIV and AIDS Council ('SANAC') as a classic example of this. In this organisation there are many sector interests. There is also a women's sector and the sector of people living with HIV.

'Political party modus operandi is applied in running this organisation. The elections, people are elected into positions of power because of their political lobbying within their sectors. The organisation is manned by bureaucracy and service providers, trade unions; social structures on the rights of the political spectrum, there are varying and sometimes conflicting interests of women and interests of other groupings. Participation in this structure is tricky. High volume documents are speculated to be read prior to meetings. Most women cannot cope with the volume and the technicality of these. Capacity building is not provided accountability is also not provided for.'

There is intense fighting in the sector of people living with HIV. This is the fighting of males living with HIV over ideological issues. The fighting makes the sector ungovernable.

Essentially the fighting of the males hinders participation of women with HIV as they also have to be divided along the differing ideology lines' (Participant, Follow-up interview, Durban, December, 2010).

The participant announced that as a result of infighting and difficulty in raising women's issues she was starting a new organisation.

'Partly, because the way it is addressed is not the way I would love as a woman, it's more on social grants and for me the social grant will not make a difference in a woman's life, I know it can help me as a young woman but I also need to be empowered, I need to be myself, not to depend on someone, for me the issue of social grant – I know it helps people living with HIV and AIDS but also it creates the dependency syndrome' (Participant, Durban, November 2010).

It can be extrapolated that women will stay in organisations even if they do not benefit from them because they have access to other social help. Practical needs are considered to be hindering advocacy. This could also be interpreted as the expression of the ideology of some of the organisations of people living with HIV. They promote access to food and by implication social grants, as they are sharply opposed to advocacy for strategic issues, e.g., access to treatment and, as stated above, women's issues and voices. It will be difficult for HIV-positive women to advocate for their sexual and reproductive rights in these sorts of environments. It is also unlikely that these organisations will take on issues of HIV-positive women.

The research asked participants to identify the reasons why women do not organise independently given the constraints in organising within mainstream organisations.

'Maybe associating yourself with a larger, more powerful institution will advance your cause more, their voice on their own might be too small, I think probably confidence and capacity issues, it takes a lot of guts to start up an organisation, to seek funding for it, it's a very competitive arena to secure donor funding, its dwindling,

I am sure there is a lot of donor funding available through for gender and AIDS related work, the smart donors who are funding that work always want to see something about gender and women.

I don't know whether they are being astute and saying let's rather come in with the horse and then we will raise our issues or go it alone. There might not be experience, hold on let me take that back, there might not be experience of running an organisation but HIV people are everywhere and of course they are leading organisations, they are running programmes so there must be the skill and expertise there ... it is women who have power, especially HIV-positive women, it's the majority of women and it shows we have power in our hands but it is like we don't priorities our needs. We don't mobilise ourselves, we are not united, if women are united within this organisation I am sure by today we should be very far with our needs as women' (Participant, Durban, March 2010).

Recommendations from the Research Participants

The research participants were asked to recommend solutions to the issues discussed. They recommended the following:

Policy interventions

There is a need for policy intervention and different stakeholders could play a role. There is a clear role for the CGE to champion the issue with HIV and AIDS organisations that are concerned with these issues. Those organisations could begin by meeting around the table and invite the CGE to join; present their standpoint on the issue and what the international obligations are; determine what the policy gaps are; list the interventions that various institutions have tried to get a response to and what the outcome has been so far; discuss what can be done to take things forward and plan a mini campaign around that. The CGE can then verbalise the complaints they have received and call on the Department of Health for a response on these issues, explain why nothing has been done and how they intend to remedy it. Then further actions can be planned resulting from these responses.

The solution is to have a policy and to popularise that policy to all women living with HIV and other women to make ensure that health staff, nurses and doctors are aware of this policy and they practise what is in the policy. Sometimes policies are not communicated to health practitioners at grassroots level, i.e. nurses are often unaware of policies because no one seems to care. Even clinic managers are unaware of some policies. If you ask them if they know about a particular policy they will say ‘No, my boss did not tell me. I am waiting for the training.’

Awareness Raising

Within the HIV and AIDS sector there is a need for awareness around the issue, how invasive it is, how many HIV-positive women are affected and what the statistics and concomitant implications are.

There is a need for awareness so that it becomes a recognised critical area. It needs to be prioritised within the AIDS sector itself so that organisations within the AIDS sector are doing more to make it more visible, to make it politically attractive and to prioritise it in their programmes, calling for intervention. There is an aspect of policy intervention, a mobilising awareness component within the AIDS sector itself and possibly even an outreach awareness programme.

It is uncertain whether HIV-positive women are told that they are at greater risk. In follow-up visits, these women need to be informed that since they are HIV-positive they are ten times more likely to contract cervical cancer and they must avail themselves of the services offered by the clinic. They should be encouraged to go for pap screening. There is a need for increased health outreach programmes so that positive women are made aware that they are more at risk and are alerted to the preventative measures like pap screening that exist to support women in that regard.

Advocacy for Sexual and Reproductive Rights

It is imperative to raise this issue more broadly from the perspective of sexual and reproductive rights in order to get the information across loud and clear. The issue is broader, today it is a medical condition, and tomorrow it will be another. We need to step back and put things back into the broader context, ensuring protection of, respect for and accessibility of sexual and reproductive rights for women from the day they are born.

Evidence Generation

It is important to have other documentation from an extenuatory level. Statistics are an important and powerful tool for any form of advocacy but it is also important to have data regarding women's experiences as part of the argument on women who, due to lack of knowledge, facilities, and early diagnosis, are living with HIV and cervical cancer. Nothing is more scary or depressing than having an argument or theory and no one listens because they ask for the evidence. We need to have evidence beyond statistics.

CHAPTER 6: DISCUSSION

This chapter considers how the findings of this study (presented in Chapter 5) are supported by the theoretical frameworks (outlined in Chapter 3) as well as the new concepts that the present study findings suggest for these frameworks.

Cervical cancer is a disease of the poor and the marginalised in both developed and developing countries like the US (Arnolu, 2008) and in South Africa (Denny, 2006; Stevens & Adar, 2000). Similarly, HIV infection is a disease of poverty and marginalisation (Adar, 2000). However, poverty is not the only indicator of social exclusion (*ibid.*) and does not always mean that people will be excluded. People may be excluded even if they are not poor (Hickey & Du Toit, 2007). There may be other factors which might lead to exclusions among the poor, for example, gender, or occupation, in particular sex workers (Silver, 2007). HIV-positive women might be relegated to this category given the sexual nature of HIV infection. In the case of younger women exclusion could occur because of their age and loss of protection that results from losing their childhood, but also because young women very seldom attract social or political clout. The situation may be the same for older women who are highly affected by cervical cancer (Department of Health, 2011). Cervical cancer was marginalised because it affects older women who have passed their reproductive age, and therefore who do not attract much social value (Department of Health, 2011). Cervical cancer comes as a double burden to women. Three dimensions to exclusion can be identified, namely, poverty, gender, and HIV infection.

This suggests that HIV-positive women may actually be excluded because they are poor and because they are HIV infected, which is interpreted as reflecting deviant behaviour which depreciates their social value. As with cervical cancer, HIV infection may mean that HIV-positive women might not be attracting sufficient social solidarity and importance in order to access HIV-related services.

Marginalisation and exclusion of HIV positive women

This part of the discussion hopes to tackle one of the research objectives which sought to interrogate and understand the ideology driving HIV programming thus far, the state and status of women living with HIV in society and how this impacts on the state and status of cervical cancer as an opportunistic infection as well as an STI affecting women.

The acts of exclusion may be embedded in discrimination, rejection, eviction and ineligibility (*ibid.*). The social status of HIV-positive women makes it harder for them to challenge the issues and ensure their issues are addressed. This is because of the stigma they face as a result of their HIV-positive status, which makes them wary to voice their issues publicly because in so doing their status will be revealed. Stigma and social exclusions may co-exist and HIV-related stigma may exacerbate exclusions. For example, poor women may face exclusion from the economy, political systems and general community life (Khosla, 2009). This particular exclusion might increase these women's vulnerability to HIV infection. Their exclusion will increase if their HIV status becomes known (*ibid.*). Therefore, exclusions are fuelling and sustaining each other. This factor is important in the South African context where the level of poverty and marginalisation is high, such that it becomes an issue to theorise about social exclusions, because the majority of people are excluded anyway (Adato et al., 2006).

As noted previously, biomedical studies confirm that cervical cancer is more prevalent HIV-positive women (Moodley, 2006; Hale, 2009). Routine cervical cancer screening would provide another opportunity for identifying and treating HIV-positive women, particularly older women. This service would offer opportunities for care similar to those presented by the antenatal care service offered to child-bearing women.

Adverse Incorporation

Issues of adverse incorporation were also registered in the study, mainly in the contexts of provision of care. The study found that women were mainly involved in providing community care in the context of HIV/AIDS, this being one of the most prominent ways of women's involvement in HIV/AIDS. While these are good community gestures, they lock women in care roles making it difficult for them to challenge their situations.

Women become subsidiaries of failed policies at the expense of their own rights as women. It was observed that women provide care for others, which prevents them from thinking about and demanding their rights as women. This could also fall in the category of adverse incorporation as defined by Hickey and Du Toit (2009). With care giving, women are developing some relationship with the government, a relationship where they benefit from care stipends and resources. However, they are not being compensated for their work, and they cannot challenge the government on issues which affect them as they rely on stipends for survival. This sort of engagement does not challenge or transform social relations that create and sustain exclusion. *'They become trade-offs for short-term security and long term well-being'* (ibid.). With this type of participation the terms of inclusion are not discussed with those concerned. Adverse incorporation is centred at power structures and may create a patron-client situation where the relationship is exploitative to the detriment of the client, yet it is hard for the client to escape this relationship (Hickey & Du Toit, 2009).

This sort of inclusion is likely to develop to what is known as clientelism. Clientelism is based on cultural and powerful institutional structures which make it difficult for clients to leave, and therefore, it is even harder to address exclusion because people are not only excluded, but adversely incorporated too. This locks them in situations of deprivation making it difficult for them to break even. This sort of engagement may divide the voices and the urgency of the poor, making it almost impossible for them to organise around their issues. Indeed, these may also lead to corruption, the creating of unnecessary and unplanned government projects in order to feed clientelism, which diverts resources and hampers progress (Fanon, 1963). In the context of this research, these might be driving exclusions even further. In the same vein, Woods (2003) states that the poor are likely to be the fodder of adverse incorporation and are likely to be incorporated in order to *'trade off their agency in return for security'* (ibid.).

The incorporation of women in the struggle against apartheid fits in with inclusion as a social exclusion agenda. As described earlier, the trade-offs that women made suggest that as a group, they might have been adversely incorporated. This is prevalent in the trade-offs made by advancing 'race' rights as opposed to women's rights during the apartheid era.

Social exclusions hinder participation in the activities of a given society and may prohibit access to information, resources and social recognition (Silver, 2007).

As a result of their social status, HIV-positive women are denied access to information and public resources to prevent and treat cervical cancer because of the lack of their recognition as a social group which deserves social goods.

Self-exclusion

Issues of wanting to belong and sometimes having to access practical needs mean that women will participate in organisations even if they realise that it is not in their interests. This is in line with the practice of self-exclusion. The study found that there was lack of leadership from among HIV-positive women to organise, and monitor policies, government, and civil society structures that are meant to protect their rights.

Social Exclusion and Poverty

This study found that bread and butter issues cloud the judgements of HIV-positive women in deciding on their participation in organisations. Poverty was found to prevent women from accessing information about their health and it reduced the time available for women to think about and know their bodies to enable them to take action when they see differences. This resonates with exclusion and poverty referred to above. Participants cited a lack of organisational funding as a poverty-related matter that prohibits HIV-positive women from organising independently. Poverty was also seen as facilitating women's focus on politics and survival for now, and not what long-term policy and participation really means to them.

Participation of women living with HIV in organisations

Exclusion from political spaces and organisations is a major indicator of social exclusions, particularly in sub-Saharan Africa (Gore, 1994). Exclusion may also mean denial of rights of citizenship and access to communities. Exclusions reflect inherent power relations in society (Adato et al., 2006) in terms of who has power to decide on how resources are shared, who has access to such resources, and who falls in and out of the access brackets.

Social exclusions are not only linked to the existence of discriminatory practices, but more importantly are linked to the lack of action in enforcing rights (Adato et al., 2006).

In the context of this research, the discriminatory issues could be linked to womanhood, and women's HIV-positive status.

Political exclusion means the denial of rights, including freedom of expression and the right to equality of opportunity, as well as denial of the ability to participate and to organise for strategic positive changes or social transformation (Bhalla & Lapayere, 1997). It is important to explore the nature and terms of participation of the poor in political spaces, discourses and structures. The poor generally lack the ability to represent themselves and their interests in political spaces (Woods, 2003). The opinions of the informants interviewed were that in government structures, HIV-positive women were largely invisible. The three government institutions interviewed all reported having no formal interaction with HIV-positive women. Two of the three structures are responsible for gender and human rights advancement and both reported not having thought of HIV-positive women as a group, nor having programmes that seek to protect and advance the rights of this particular group. The structures were not aware of the issues affecting HIV-positive women. All organisations interviewed, including government and civil society, did not have a specific focus or priority list of issues or programmes focused on HIV-positive women.

This confirmed the lack of political clout that HIV-positive women, and by extension their issues, might face. This also confirmed the inability of HIV-positive women to attract the attention of policymakers and those tasked with the responsibility of protecting their rights. This reflects exclusion at a political level.

The two government institutions also stated that they do not have specific sexual and reproductive rights programming within their organisations. They reported working on mainstream human rights issues, and also gay rights.

This points to the fact that; the status of cervical cancer might be a symptom of the lack of enforcement of women's rights. While these rights are guaranteed their delivery is not evident in government programmes and policies. This is in line with Adato, *et al.* (2006) assertion that social exclusion might be as a result of the lack of enforcement of rights.

This exclusion has meant that HIV-positive women are unable to reach out to these organisations as a way of claiming their rights and holding these institutions accountable. There were reports that there had never been any substantial argument for evaluating or monitoring HIV and AIDS policies from gender or women's perspectives. Indeed this is indicative of the status of women's rights but also of the culture of not enforcing rights which in itself drives and fuels social exclusion.

In women's organisations, HIV-positive women were not represented and their issues had not attracted the interest of this sector. Some of the organisations who participated in the study were providing services to HIV-positive women but did not want to be associated with HIV. As a result, they did not engage HIV-positive women so that their voices could improve the services provided to them. The study also found that there was lack of coordination and collaboration between and amongst organisations working in HIV and AIDS.

Social Exclusion and Social Policy

This research aimed to identify barriers to integration of cervical cancer in HIV/AIDS, policy and political commitments. The research considered how these issues fit in with non-delivery of cervical cancer prevention and treatment services in the context of HIV.

Policy formulation is political action to decide what problems are deserving of change or action, what needs changing and what institutional framework should be used in order to achieve the change (Beland, 2007). Therefore, policy formulation is a contestation of different interests and powers. Social exclusions are important here because they help policymakers determine social problems and solutions on issues they deem important (*ibid.*). This illustrates that the whole process of policymaking is a power-laden political process. Even at the level of problem defining, there is political power and by implication those who do not have power might be omitted from this process. The opinions of people who participated in the study were that HIV-positive women were not represented in policy formulations. They had not been seen by structures advancing gender rights, human rights and organisations working with AIDS as a social group that deserves attention, and in many instances they were not even recognised as a social group.

Policy choices should focus on improving the situation of the poor, but in reality they could result in further marginalising the poor. This is partly because policies or social services designed for the poor are more often than not value-laden, and popular values sometimes exclude the marginalised (Beland, 2007).

The value-laden nature of policy could be related to the social value of prioritising children in relation to women's rights in HIV/AIDS. Further, it is related to the fact that women's health should be prioritised when they are carrying children because children are more socially valued and entitled to greater rights than women who are not pregnant. Indeed, the study participants understood Prevention of Mother-to Child Transmission ('PMTCT') as the main department of health priority in relation to HIV-positive women. It also found, in line with the literature, that policies meant for HIV-positive women might be emphasising women as mothers, ensuring safe reproduction. However, these policies simultaneously marginalise women's issues, like cervical cancer. The absence of women's voices has meant that the issues of women are not prioritised by HIV policy.

The stakeholders who are outside government structures could be seen as representing the interests of civil society, but this is not necessarily the case. They might represent interests of certain populations and might miss the marginalised and the excluded in the community. Stake-holding in itself is an exercise of power and competition of interests including suppression of other's interests. Those stakeholders with political and social clout will have their agendas taken more seriously. In this stake-holding there might be co-opting and gate-keeping, which means it will be even harder for some interests to be placed on the agenda. This may be a factor at play in relation to women living with HIV. There are organisations which at a policy table detail issues of HIV treatment; however these organisations reported not having advocated for cervical cancer as an opportunistic infection that affects HIV-positive women.

It was interesting that women participate in these very organisations and that they are aware of cervical cancer as an issue that needs prioritisation because it affects them; yet they accepted its de-prioritisation and remained engaged in these organisations as they were making gains in other areas of their lives.

Citizenship affords mainly political and civil rights (Ellison, 2009). Citizenship and political rights are more aligned with the capitalist project. In recent years, there has been an addition of social rights in the citizenship discourse.

Social rights essentially improve and provide cushioning for inequalities created by capitalism, amongst the other functions it serves. Social rights could mean those who are paying taxes might pay higher taxes in order to finance social spending (Ellison, 2009). This might be seen as interfering with liberty rights of the taxpaying individuals (*ibid.*).

If welfare and social services are delivered in the context of citizenship, they are likely to be impacted on by the unevenness and inequalities which are characteristic of citizenship.

The rights discourse might also promote 'rights for all' and universal rights. This may perpetuate inequalities and exclusions because 'for all' might exclude marginalised groups and minorities. The social, civil and political rights of marginalised groups might be compromised, as they will be unable to take part and derive benefit in their capacities as members of the collective and citizens, in the social intercourse and in accessing resources.

Whilst social rights may be due rights, they also sharply contradict capitalism and neo-liberalism by promoting state spending and state delivery of services (Ellison, 2009).

Therefore, a great deal of contradictions exists in the national dispensation discourse as policymakers make policy commitments which are at odds with the neo-liberal project. This is potentially one of the reasons why some rights are not realised and enforced. The lack of full participation of HIV-positive women in policy could mean that their rights of citizenship are not fully respected.

Cervical cancer, as a sexual and reproductive rights issue which is delivered under the ambit of health rights, with health being a social right, could be affected by the forces of the market and prioritisation. It might be subject to being delivered as a favour or a privilege because of economic considerations. There is a possibility that cost-benefit analyses are applied and render this service too costly to be provided, mainly because it is for the benefit of women, minus their reproductive roles. This could mean that while their rights are realised on paper, exclusions could be a result of un-enforced rights (Hickey & Du Toit, 2007).

I argue that cervical cancer in HIV-positive women is marginalised because HIV-positive women are socially excluded because they HIV-positive, because they are women, and because the majority of them are poor.

More often than not their participation is not to their benefit. HIV policies have taken into account other opportunistic infections that do not solely affect women, but cervical cancer is relegated to the sidelines.

Women with HIV make up the greatest numbers in HIV and AIDS organisations who are advocates for treatment, but in this instance have not advocated for what is in their interests as women. Furthermore, the political gender and human rights machinery has not picked up on this issue of exclusion and gender discrimination. It is clearly not affecting the population which has access to the political space.

CHAPTER 7: CONCLUSIONS & RECOMMENDATIONS

A policy which incorporates cervical cancer in HIV treatment does not exist. There is no drive from the government to formulate such a policy. The department of health is of the opinion that the current policy is sufficient as it recommends more pap smears in certain situations, HIV infection included, although this is not mentioned in the policy. There is a mention of pap smears in the HIV and AIDS treatment guidelines. These are however limiting as they mean that women will have access when they start their ARV treatment programmes. Both the policy and the treatment guidelines emphasise a pap smear which is essentially secondary prevention, both documents are not clear on the provision for treatment of abnormal smears, treatment of the actual cervical cancer, as well as pain management.

Whilst the arguments for not embarking on a policy of intervention, issues of time, resources and possibility of implementation are valid, there is still a need for a policy. A policy will allow budget allocation, will bring legal claim to the women and such policy will facilitate accountability.

Policy Environment

The research recommends policy proposals to integrate cervical cancer with HIV services and the development of policies and interventions to address the exclusions faced by HIV-positive women in their communities, in political structures, including gender machinery and structures of people living with HIV.

The policy environment is designed to reflect South Africa's ideology towards women. Women's health is mainstreamed in general health, and when this is not the case, women's health, but only in so far as it relates to child health, is given specific attention in the provision of maternal health services. South Africa has no budget for women's health *per se*; neither does it have specific goals targeted at women's health. This calls for the review of gender mainstreaming and calls for policies that will focus directly on women. There is a need for specific women's health policies and programmes including budgets and monitoring.

One of the concerns is that women are not calling for their health needs; neither are they monitoring government programmes on health and on cervical cancer in particular. There is a need to mobilise women around their health rights.

In line with the objectives of this work, this work has generated information which strengthens the case to advocate for the integration of cervical cancer services into HIV services, framing it as a social exclusion and marginalisation issue, an access to treatment issue, as well as a sexual and reproductive rights issue.

There is also a need to advocate for government institutions tasked with the issues of women and rights to take up the issue of cervical cancer as well as all other women's health policy issues.

This research is enriching the field by bringing in more gendered, political, and broader women's rights discourses into the debate of cervical cancer and women's health.

The South African Treasury has to be engaged to make women's health a national priority through allocation of budgets. There is a need for South Africa to analyse gender discrimination through health lenses in order to root out and redress gender discrimination in health.

Marginalisation of Cervical Cancer

The policy position from the ministry of health, policy reviews and literature reviewed for the purposes of this work revealed that cervical cancer is marginalised as a disease. This is linked to the fact that it only affects women. Indeed this marginalisation of cancer occurred before it was associated with HIV.

It is likely that cervical cancer might be further marginalised given its association with HIV-positive women. Cervical cancer is marginalised because it affects women. Before the HIV and AIDS epidemic, cancer was a disease for older women. It normally affected women in their 50s or beyond.

By this age women would have passed their reproductive age, and would no longer be important in society. It is marginalised also because treatment of cervical cancer, even in younger women, does not save children. So it falls outside the 'women as mothers' framework. Cervical cancer also becomes marginalised because it is an STI. This research discovered that current syndromic approaches to STI management exclude and marginalise cervical cancer.

This programme encourages treatment of all STIs if a person presents with one. The programme is completely gender blind.

This has meant that tables are prescribed but vaginal inspections are no longer part of STI care. Abnormal lesions can be seen through visual inspection. The syndromic approach has marginalised cervical cancer as it does not mention it, and makes it harder for visual inspections to be performed. It would appear that cervical cancer suffers the double jeopardy of gender discrimination because it is not associated with child bearing and it is not always considered in STI programmes. A clear evaluation of gendered stereotypes and roles of women has to be undertaken with the purpose of pointing out gendered discrimination in health care. There is a great need to evaluate and monitor all programmes from the perspective of women's rights and gender to maximise benefit and reduce harm to women.

HIV-Positive Women Excluded

The research found that although HIV-positive women participate in organisations of people living with HIV, their voices and issues are marginalised. They do not participate in these structures representing their identities and issues as women living with HIV. The issues in these organisations are prioritised by others. Issues of wanting to belong and needing access to practical needs meant that women will participate even if they realise that it is not to their advantage as women.

In government structures, women living with HIV were largely invisible. The structures reported not having had formal interactions with women living with HIV or their issues.

This confirmed the inability of positive women to attract the attention of policymakers and those tasked with the responsibility of protecting the rights of the very women, marginalised women, and women living with HIV. This is exclusion at a political level.

The exclusion has meant that women living with HIV have also been unable to reach out to these organisations as a way of claiming their rights and holding these institutions accountable. There were reports that there had never been any substantial evaluation or monitoring of HIV and AIDS policies from gender or women's perspectives.

In women's organisations, women living with HIV were not represented and their issues had not attracted the interest of this sector. There is a need to build bridges and solidarity. The gains which HIV positive women will make in the areas of cancer for instance will benefit all women.

In AIDS policy structures, examples of adverse incorporation were registered. Here women are participating but to their detriment. Their participation is marked by their presence but is not full and effective participation as they do not fit in the environment and are unable to raise their issues. This is tokenism. This sort of participation gives the impression that they are at the table, but in reality they are not.

Issues of women and care were also raised. While these are good community gestures, they lock women into care roles, which make it even harder for them to challenge their situations. They become the subsidisers of failed policies at the expense of their own rights as women. The social status of women as women but also as women living with HIV make it harder for them to challenge the issues and ensure that their issues are addressed. This is because of the stigma they endure for being HIV-positive. This makes them fear engaging the public with their issues as their status will become known. Even if the status is known, their low social status makes it harder for them to claim what is essentially due to them, their health rights. These women are socially excluded. The exclusion prohibits them from being part of the community collective and benefitting from being part of that collective.

Poverty is also a contributing factor. The research found that women engage in certain organisations because they get grants. The research also highlighted that poverty takes up so much of women's time leaving them with no time to take care of their own needs.

Poverty also leads women to participate in organisations even if they realise that it is not beneficial to them. Bread and butter issues also cloud the judgements of positive women in deciding to participate in organisations. Lack of funding is also mentioned as a poverty-related matter that prohibits women living with HIV from organising independently.

Awareness

Lack of awareness among positive women was listed a major challenge. There is a need to increase women's knowledge of cervical cancer and other women-specific opportunistic infections in the communities of women living with HIV. The awareness however should be coupled with the availability of services. Women should be able to use the information they have for their benefit.

This calls for specific programmes to educate women about cancer and other illnesses. There is a tendency to cite lack of awareness as an excuse for not providing services. Lack of awareness may also be used to blame women for their situation. This should be prevented. State organisations responsible for women's rights were found not to have an interest in women living with HIV as a group. Some of these structures were found to be working with men before addressing the needs and rights of women, i.e. the very reason they were formed. These organisations were not collaborating. The ability of these institutions to respond to issues was raised as an issue. Their independence from government was also raised as a hindrance to their accountability. Their level of honesty on non-responsiveness was also noted, indicating that the owners of the problem had, for the reasons stated earlier, not engaged with them on the issues.

Women as mothers dominate South Africa's health discourses. There is a need to have an open debate about this in an effort to shift this ideology. The current ideology has placed women in difficult positions *vis-à-vis* their rights.

There is need for further evidence generation. There is more evidence on this issue at the biomedical and statistical level. Human evidence is required to inspire more advocacy efforts on the issue.

There is a need to strengthen the capacity of women living with HIV to organise and to participate. There is a need for social inclusion interventions to recognise this group as a marginalised group and find ways of enhancing their full membership in the community and as citizens.

There has to be acknowledgement that organisations of people living with HIV are not always safe spaces for women living with HIV. The AIDS lobby like all other structures should be subjected to gender monitoring.

Cervical cancer presents solidarity between HIV-positive women and other women. This has to be harnessed. There is a need to make resources available for women-specific issues, and to advance women's health rights. There is a need for a specific women's health policy and budget; this has to be driven by women's priorities and health needs. There is also a need to use the law to enforce these rights.

There is a need to look at HIV from behind the lenses of stigma and discrimination but there is also a need to consider social exclusion lenses as these might improve policy responses to HIV and AIDS.

There is a need to consider viewing HIV and AIDS from women's rights perspectives as well. The current frameworks, especially the gender frameworks, need reviewing given that they are evidently making it more difficult for women to enforce their rights, in particular in relation to sexual and reproductive rights.

There is a need to forge ways and means to hold the chapter 9 institutions more responsive and accountable to issues of women's health, in particular with regard to cervical cancer.

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Appendices

Appendix (i)

Copy of Informed Consent

My name is Promise Mthembu. I am a Masters Student at the University of KwaZulu-Natal's School of Development Studies, based in Howard College Campus in Durban. I am working on a research project which is trying to understand the social as well as policy barriers to integrating cancer of the cervix in HIV prevention and treatment policy.

Purpose of the Study

The study aims to find out more about the barriers to formulating policies which integrates prevention and well as treatment of cancer of the cervix in women living with HIV, given that cancer of the cervix is defined as an opportunistic infection, affecting HIV infected women.

Objectives of the Study

The research hopes to achieve the two objectives:

1. The research will explore why there is no policy to address cancer of the cervix in the context of HIV,
2. The research will also explore policy barriers and social barriers to integrating cancer of the cervix in HIV and AIDS prevention and treatment policies as well as advocacy in South Africa.

Procedure

You have been selected and qualify to take part of in these discussions. To ensure confidentiality all what will be discussed will be kept in confidence. The interview will take approximately one hour. The interview will be audio-taped. This is a requirement for study participation. You will be asked to share your organizations and personal insights on why cancer of the cervix is not linked to HIV services. The researcher will ask you about policy barriers, social and advocacy barriers to integrating cancer of the cervix and HIV into policies. You will be asked to talk about barriers of the policy linkages. All discussions will be confidential. It is possible that the researcher may contact you again to ask for follow-up or confirmation questions or to give you feedback on the process.

Risks associated with participating in the study

There are no physical risks related to participating in this study.

How will being part of the study help me?

You will not benefit directly from being part of this study. However your contributions will help us to understand how advocacy for cancer of the cervix prevention and treatment could be improved. This information will be used to lobby for HIV treatment policy which incorporates sexual and reproductive rights, particularly cancer of the cervix.

How will I know what happens to the research?

A report will be written on the findings of the research. The researcher will contact you to give you a copy of the research report. In addition, there may be academic papers that are written about the study to provide guidance to other researchers, advocacy groups and policy makers.

Will I be compensated in any way?

You will not be compensated for your participation in the research. Your transport costs may be re-imbursed.

Will my interview be kept confidential?

Your right to keep your identity and that of your organization private will be protected. The researcher will not tell anyone that you were part of this study. All study information will be identified only by individual participant code numbers and will be kept confidential in locked file drawers in the researcher's offices. The information will only be available to study staff as part of routine checks to ensure that the study is being conducted in a professional way. It will also be available to study staff for the analysis. Data files from the interviews may be sent via email to other study staff, the study supervisor. They will not have any names or personal identifiers. They will be password protected. Study results will be reported in summary form so that no individual participant can be identified.

Digital recording

If you agree to participate, the researcher will ask you for your permission to record your interview on the tape. The interview will be confidential; it will only be identified only by an ID number. Individual names will not appear on the disk or the transcript of the interview. No

one except the researchers will have access to the digital recording/disk or the transcript of the interview

What are my rights?

Your participation in the study is entirely voluntary. No one can force you to participate. If you do not participate, or if you later decide to stop participating, nothing bad will happen to you and your organization, you will not be prejudiced in any way. If at any time in the study you feel uncomfortable or wish to stop your participation, you may do so.

If the researcher infringes my rights-what should I do?

This study has been approved by KwaZulu-Natal Research Ethics Committee. The Ethic Committee's mandate is to make sure that no one is harmed as part of the research.

If you have any questions about your rights as a research participant, or any complaints you can call the Research Ethics Committee of the University of KwaZulu-Natal.

Study Supervisor, Ms Kerry Vermaak at UKZN'S school of Development Studies, Telephone Number: +27(0) 31 260 22 87. Email: vermaak@ukzn.ac.za

The UKZN Humanitarian Ethics Committee, Ms Phumelele Ximba: Telephone Number: +27(0) 31 2603587. Email: ximbap@ukzn.ac.za

If you have any questions about the study now or in the future you could also contact Promise Mthembu at +27(0) 31 702 0606 or +27(0) 82 628 2746. Email: mamthembu@telkomsa.net

You will be given a copy of this consent to keep.

Documentation of Consent

I voluntarily agree to participate in the research study described above.

Print Name

Date

Signature

I have discussed the research with this participant, in my opinion, this participant understand the benefits, risks and alternatives (including non-participation) and is capable of freely consenting to participate in this research.

Print Name

Signature of Person Obtaining Consent

Date

Appendix (ii)

Copy of in-depth interview guide

Participant Identification Number	
Interviewer	
Date of interview (dd/mm/yy)	
Interview start time	
Interview stop time	

Thank you for agreeing to talk with us today. My name is _____. I am from _____.

We are interested in talking with you today about your organizations policy and position on prevention and treatment of cancer of the cervix in the context of HIV. I hope that you will tell us what you feel is important. The discussion will take maximum one hour.

For our benefit, we will be digitally recording the discussion so that we can play it back later to remember and understand better what you said. After this one-to-one discussion, we may re-contact you at a later stage to clarify issues that have arisen from the discussion.

Now I would like to ask you questions about your organization

Section 1: Organizational Profile I will start by asking you some questions about your organization		
	Questions	Response
1.1	What is your position in this organization?	
1.2	When was your organization formed?	_____ (years)
1.3	Where does your organization work (Province & town/city)?	
1.4	How many people work in your organization? Staff members?	1 = Board Female 2= Board Male 3= Positions 4 = Women staff members 5= Positions 6 = Male staff members 7= <i>SPECIFY</i> _____

1.5	How can you describe your organization?	1 = HIV AND AIDS organization 2 = Women's Rights organization 3 = Sexual and reproductive rights organization 4 = Section 09 organization 5 = Other SPECIFY _____
1.6	Does your organization do any advocacy work on women's issues?	Which specific issues?
1.7	What are your organizations priorities issues, particularly in relation to women?	
1.8	What are the programmes you are currently running?	

Section 2: Organizations knowledge and positions on the cancer of the cervix in the context of HIV infection

	Questions	Probes
2.1	<input type="checkbox"/> Could you explain what your organization's position on cancer of the cervix in the context of HIV?	In relation to other conditions such as TB?
2.2	<input type="checkbox"/> What does your organization think about the DOH's current policy on cancer of the cervix in relation to HIV? <input type="checkbox"/> Staff members?	<input type="checkbox"/> Activities <input type="checkbox"/> Policy prioritization
2.3	<input type="checkbox"/> What is your organizations policy on cancer of the cervix in the context of HIV?	
2.4	<input type="checkbox"/> Do you currently have programmes on this issue?	<input type="checkbox"/> If not; why? <input type="checkbox"/> What sort of programmes are these? <input type="checkbox"/> What motivates the choice of these programmes?

2.5	<input type="checkbox"/> What has been your organizations involvement in the policy discussion around cancer of the cervix and HIV in South Africa	<input type="checkbox"/> None <input type="checkbox"/> Help draft a policy <input type="checkbox"/> Sent a written report/brief
2.6	<input type="checkbox"/> What have been the outcomes of such involvement? <input type="checkbox"/> How do other organizations feel about the outcomes of their involvement?	<input type="checkbox"/> How do you feel about these outcomes?
2.7	<input type="checkbox"/> What does your organizations strategic plan say about cancer of the cervix in the context of HIV?	<input type="checkbox"/> Don not have a plan <input type="checkbox"/> What do you think would be your organization's strategic response on this issue?

Section 3: Cancer of the cervix and Sexual and Reproductive Rights

	Questions	Probes
3.1	<input type="checkbox"/> What is your organization's understanding of sexual and reproductive rights?	<input type="checkbox"/> What are these rights?
3.2	<input type="checkbox"/> Does your organization address sexual and reproductive rights Issues of women living with HIV?	<input type="checkbox"/> If so, which ones? <input type="checkbox"/> What motivates your choice of the issues? <input type="checkbox"/> If not why?
3.3	<input type="checkbox"/> Do you think the HIV AND AIDS Programmes have sufficiently integrated sexual and reproductive rights?	<input type="checkbox"/> If yes, how? If no, what do you think are the reasons?
3.4	<input type="checkbox"/> How would you see treatment of cancer of the cervix becoming a sexual and reproductive right for women living with HIV and other women?	<input type="checkbox"/> If cannot see it becoming a right, why not?

3.5	<input type="checkbox"/> How has your organization been including cancer of the cervix in the sexual and reproductive rights work?	<input type="checkbox"/> If not, why not?
3.6	<input type="checkbox"/> Do you know whether other organizations have been including cancer of the cervix as sexual and reproductive rights in their work?	
3.7	<input type="checkbox"/> What do you think are the reasons for including or not including cancer of the cervix in their work?	

4. Advocacy /gender barriers to policy

	Question	Probes
4.1	<input type="checkbox"/> What could you describe as gender machinery's role in HIV and AIDS policies?	
4.2	<input type="checkbox"/> Would you comment about women's rights in the context of HIV in South Africa?	
4.3	<input type="checkbox"/> Could you describe what you understand to have been this sectors contribution to HIV and AIDS Policy	<input type="checkbox"/> What do you think are the reasons for choosing these interventions
4.4	<input type="checkbox"/> How could you describe as key women's contributions to HIV/AIDS up to this point?	<input type="checkbox"/> <input type="checkbox"/>
4.5	<input type="checkbox"/> Are you aware of any mechanisms which are designed to monitor the protection and advancements of women's rights in the context of HIV?	<input type="checkbox"/> If you are what? <input type="checkbox"/> How would you evaluate these mechanisms?
4.6	<input type="checkbox"/> What can you describe as the outcome of this nature of involvement and outcome?	<input type="checkbox"/> How do you feel about this outcome?
4.7	<input type="checkbox"/> What can you describe as the reasons for this nature of contribution or outcome?	<input type="checkbox"/>
4.8	<input type="checkbox"/> What does DOH see at the priority issue for women living with HIV?	
4.9	<input type="checkbox"/> What would you consider as barriers to having a policy which will address cancer of the cervix in the context of HIV?	<input type="checkbox"/> How does poverty play a role in this?

4.10	<input type="checkbox"/> Is your organization working on addressing these?	<input type="checkbox"/> If yes; how? <input type="checkbox"/> If not; why not?
4.11	<input type="checkbox"/> In what ways; if any would an ordinary woman is able to address these barriers?	
4.12	<input type="checkbox"/> Would the situation be different if men were equally affected?	<input type="checkbox"/> How?
4.13	<input type="checkbox"/> Would you consider treatment of the cervix to be more important if were saving the lives of the babies, was part of maternal health?	

Section 5 : Social Exclusion of women living with HIV

	Questions	Probes
5.1	<input type="checkbox"/> Could you describe the nature of participation of women living with HIV in your organization?	<input type="checkbox"/> If not; why?
5.2	<input type="checkbox"/> Do you know of any groupings of HIV positive women in your community? Nationally?	
5.3	<input type="checkbox"/> How could you describe the nature of participation of women living with HIV in HIV/SRH policy formulation?	<input type="checkbox"/>
5.4	<input type="checkbox"/> In what way do you think that the role of women has prevented women living with HIV to address this issue as it affects them directly?	<input type="checkbox"/> Probe the responses.
5.5	<input type="checkbox"/> What do you think are the reasons for such participation?	
5.7	<input type="checkbox"/> What impact do you think is the impact of such participation?	
5.8	<input type="checkbox"/> In your opinion what could be the barriers to positive women's participation?	<input type="checkbox"/> If not, why not
5.9	<input type="checkbox"/> In your opinion; what are women living with HIV advocating for?	<input type="checkbox"/> Why do they prioritize these issues?

5.10	<input type="checkbox"/> In your opinion; why women living with HIV are not advocating for prevention and treatment of the cancer of the cervix?	
5.11	Do you think the participation of women living with HIV will change or mitigate this situation?	
5.12	<input type="checkbox"/> In your opinion, why are other organizations advocating for HIV treatment and rights in the context of HIV not advocating for cancer of the cervix in the context of HIV infection?	<input type="checkbox"/> If yes, where? What is the nature of their organization? <input type="checkbox"/> What are the main issues they address? <input type="checkbox"/> If not what do you think are the reasons?
5.13	<input type="checkbox"/> In your opinion does the social status of women and poverty has an impact on their ability to participate?	<input type="checkbox"/> How? <input type="checkbox"/> What impact?

Section 6: Future		
	Questions	Probes
6.1	<input type="checkbox"/> What do you think should be done in addressing cancer of the cervix in the context of HIV?	<input type="checkbox"/> Is there anything you would like to share as a solution?

This is the end of our interview. Thank-you for your time.