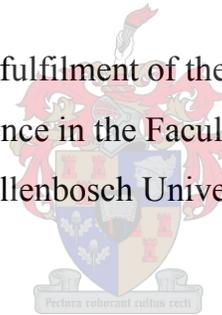


**AWARENESS, KNOWLEDGE AND EXPERIENCES OF  
WOMEN REGARDING CERVICAL CANCER IN RURAL  
KWAZULU-NATAL, SOUTH AFRICA**

**Beauty Hlengiwe Ndlovu**

Thesis presented in partial fulfilment of the requirements for the degree  
of Master of Nursing Science in the Faculty of Health Sciences at the  
Stellenbosch University



**Supervisor: Dr ELD Boshoff**

**March 2011**

## **DECLARATION**

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By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

23 March 2011

## ABSTRACT

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### **Title**

Awareness, knowledge and experiences of women regarding cervical cancer in rural KwaZulu-Natal, South Africa.

### **Background**

Cervical cancer has been identified as the second most common cancer in women and contributes to the high mortality rate in women. Among all cancers in women, cervical cancer is rated the second most common cancer in women worldwide. In poorly resourced settings, access to services offering cervical screening is still a challenge and it is estimated that more than 50% of women in developing countries have never had a single screening test for cervical abnormalities.

### **Purpose**

The purpose of this study was to assess women's awareness, attitudes and experiences regarding cervical smear testing and for cervical cancer in rural KwaZulu-Natal and to better understand factors influencing access to and utilization of cervical cancer screening services by rural women.

### **Methods**

The method employed was a descriptive study using a questionnaire to collect quantitative data. The sample consisted of 69 women aged 30 years and above, was taken from women who were enrolled in the on-going Microbicide Clinical Trial and attending follow-up clinic visits between July and August 2009. The primary outcome measure for the analyses was who has been screened for cervical cancer and this was assessed from the previous history reports of the women. The secondary outcome measure was to investigate knowledge and perceptions regarding cervical cancer and screening. Socio-demographic factors associated with having been screened were also explored.

**Results**

Out of 69 women, only N=13 (18.8%) reported ever screening for cervical cancer. More than half of women who had never screened reported lack of information as a barrier to screening N=50 (71.4%). Older women aged 35-45, 45 and above were less likely to screen compared to women aged 30 to 34 years of age (OR: 0.06). Having an educational background seemed to increase the likelihood to screen, twice if a woman had primary education (OR 2.0) and almost three times (OR 2.67) if a woman had a secondary or a higher education. More than half of the respondents considered themselves at risk for cervical cancer N=42 (60.8%) and almost all showed a willingness to screen in the future N=64 (93%).

**Conclusion**

Most of the women in this study had never been screened for cervical cancer in their lifetime as reflected by n=55 (82%) while only n=14 (18%) ever screened for cervical cancer. The results of this study cannot be generalised to the population due to the small sample size. However, there is need to facilitate comprehensive health education and the implementation of cervical screening programmes to target women in rural communities to contribute to the success of the cervical screening programme. The results of this study showed that 60% of respondents were informed by health care professionals on cervical cancer screening. Health care workers also should play a vital role in educating communities on cervical cancer and on the benefits for cervical cancer screening, through reaching all patients who utilise health care services with cervical cancer information and also communities through outreach programmes.

## OPSOMMING

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**Titel:** Vrouens se bewustheid, houding en ervarings van smeertoetse en servikale karsinoom in die landelike gebiede van KwaZulu-Natal

### **Agtergrond**

Servikale kanker is geïdentifiseer as die tweede mees algemene karsinoom in vrouens en dra by tot die hoë sterftesyfer in vrouens. Van al die tipes karsinoom wat by vrouens voorkom, is servikale karsinoom die tweede mees algemene karsinoom onder vrouens wêreldwyd. Die beskikbaarheid van dienste wat servikale smeer toetsing bied, is nog steeds 'n uitdaging in arm gebiede en daar word geskat dat meer as 50 % van vrouens in ontwikkelende lande nog nooit 'n toets vir enige servikale abnormaliteite gehad het nie.

### **Doel**

Die doel van hierdie studie was om vrouens se bewustheid, houding en ervarings van servikale smeer toetsing en van servikale karsinoom in die plattelandse gebiede van KwaZulu-Natal te toets en om 'n beter begrip te kry van faktore wat 'n invloed het op toegang tot en gebruik van servikalesmeer toetsing by vrouens in landelike areas.

### **Metode**

Die metode wat gebruik is, is 'n beskrywende studie waarin gebruik gemaak is van vraelyste om kwantitatiewe data te versamel. Die monster het bestaand uit 69 vrouens, ouderdom 30 jaar en ouer, wat deelnemers was aan die "Microbicide Kliniese Navorsingsprojek" en wat opvolgbesoeke by klinieke gehad het tussen Julie en Augustus 2008. Die primêre bevinding, wie al ooit vir servikale karsinoom getoets is, is bereik deur die inligting in die laboratorium verslae van die vroue na te gaan. Die sekondêre bevinding was om die deelnemers se kennis en persepsies aangaande servikale karsinoom te toets. Sosio-demografiese faktore wat verband hou met of deelnemers ooit getoets is, is ook ondersoek.

## **Resultate**

Van die 69 vrouens, het slegs N=13 (18.8 %) gerapporteer dat hulle ooit getoets is vir servikale karsinoom. Meer as die helfte van die vrouens wat ooit getoets is vir servikale karsinoom het gerapporteer dat 'n gebrek aan inligting 'n weerhoudende faktor was tot die toetse, N=50 (71.4%). Ouer vrouens tussen die ouderdom van 35 – 45, 45 en ouer was minder bereid om te toets in vergelyking met vrouens tussen die ouderdom van 30 tot 34 (OR: 0.06). Dit blyk asof skoolonderrig die kans op toetsing verhoog, vrouens met primêre skoolopleiding se kans dat hulle getoets is, is twee keer groter (OR 2.0) en amper drie keer meer (OR 2.67) as 'n vrou sekondêre onderrig of hoër onderrig ontvang het. Meer as die helfte van die respondente dink hulle loop 'n risiko om servikale kanker te kry N=42 (60.8%) en feitlik almal was bereid om hulle te laat toets in die toekoms N=64 (93 %).

## **Bevinding**

Die meeste vroue in hierdie studie n=55 (82%) was nog nooit in hul leeftyd getoets vir servikale karsinoom nie terwyl slegs n=14 (18%) ooit getoets was vir servikale karsinoom. Die resultate van hierdie studie kan nie veralgemeen word nie, aangesien die navorsingspopulasie as gevolg van die klein steekproef te klein was. Nietemin is daar 'n behoefte vir die fasilitering van omvattende gesondheidsopvoeding en die implementering van servikalesmeer toetsing programme. Die resultate van hierdie studie het aangedui dat 60% van die respondente deur professionele gesondheids werkers ingelig is met betrekking tot servikalesmeer toetsing. Gesondheidswerkers behoort 'n vitale rol te speel in die opvoeding van gemeenskappe in verband met servikale karsinoom en die voordele van hiervan deur alle pasiënte wat gesondheidsdienste benut in te lig omtrent servikale karsinoom en ook deur middel van gemeenskaps-uitreikings programme.

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## ACRONYMS AND ABBREVIATIONS

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CI	Confidence Interval
Pap	Papanicolau smear test
HPV	Human Papilloma Virus
OR	Odds Ratio
HIV	Human Immuno-deficiency Virus

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# CHAPTER 1:

## ORIENTATION TO THE STUDY

### 1.1 INTRODUCTION

Cervical cancer forms in the tissues of the cervix (the organ connecting the uterus and vagina). It is usually a slow-growing cancer that may not have symptoms but can be found with regular Pap tests (a procedure in which cells are scraped from the cervix and looked at under a microscope). Cervical cancer is almost always caused by Human Papillomavirus (HPV) infection. Cervical cancer is malignant neoplasm of the cervix uteri or cervical area. It may present with vaginal bleeding but symptoms may be absent until the cancer is in its advanced stages (WHO/ICO Information Centre on HPV and Cervical Cancer, 2009). Treatment consists of surgery (including *local excision*) in early stages, and chemotherapy and radiotherapy in advanced stages of the disease.

Pap smear screening can identify potentially precancerous changes. Treatment of high-grade changes can prevent the development of cancer. In developed countries, the widespread use of cervical screening programs has reduced the incidence of invasive cervical cancer by 50% or more (American Cancer Society, 2009:10). Human Papilloma Virus (HPV) infection is a necessary factor in the development of nearly all cases of cervical cancer.

Cervical cancer is a typically slow-growing cancer that may not have symptoms but can be early diagnosed by doing a Pap smear. The burden of disease due to transmissible diseases such as HIV and Human Papilloma Virus (HPV) is increasing especially in developing countries. Research has shown that HPV is the cause of about 70% of all cervical cancers (WHO/ICO, 2010). Leroy, Ladner, De Clercq, Meheus, Nyiraziraje, Karita and Dabis (1999:104), and Tate and Anderson (2002:881) have shown a statistical significant relationship between HIV, HPV and cervical abnormalities. According to the World Health Organization (WHO) Information Centre on HPV and Cervical Cancer, 2009 report, cervical cancer is currently the primary cancer in women in South Africa with an annual new case incidence of 6 742, in African women. It is estimated that the annual number of new cases worldwide, is as high as 493 243. Deaths due to cervical cancer amount to 273 505 women worldwide and 3 681 in South Africa (WHO/ICO Information Centre on HPV and Cervical Cancer, 2009).

Knowledge about the disease and risk factors are therefore important in determining appropriate health seeking behaviours with the aim to prevent invasive cancer and reduce mortality rates. Chapter one orientates the reader to the rationale of the problem and an overview of the research methodology on familiarity of women regarding cervical cancer.

This research study will provide insight into the knowledge level and experiences of rural women to screening and cancer, and also explore the factors influencing access to screening services.

## **1.2 RATIONALE**

The South African policy on cervical screening recommends that all women over 30 years of age should have three free Pap smears at ten-year intervals. This screening campaign is aimed to achieve 70% coverage by 2010 (Kawonga & Fonn, 2008:32). It is regrettable to state that coverage remains sub-optimal and it is estimated that more than 50% of women in South Africa never had a single screening test for cervical abnormalities.

A study conducted in rural KwaZulu-Natal to determine baseline data regarding knowledge about risk factors for cervical cancer showed a low uptake of the Pap smear test and a low level of knowledge on the prevention of cervical cancer, risk factors, and the uptake of cervical screening. The study reported that only 6% had knowledge on all the risk factors while 65% knew only one of the risk factors of cervical cancer. Less than half (49%) of these participants correctly stated that the Pap smear screening test is used for early detection of cervical cancer and only 18% had ever been screened for cervical cancer (Hoque, Hoque & Kader, 2008:112).

A further concern is mentioned by Bärnighausen, Tanser & Newell (2009:407), where they state that there is no decline in the high HIV incidence in Kwa-Zulu Natal, which strongly relates to the higher incidence of HPV and cervical cancer in the area.

## **1.3 PROBLEM STATEMENT**

The problem identified is that more than 50% of rural women in South Africa have not been exposed to cervical screening and there is a lack of knowledge regarding risk factors related to cervical cancer and the screening for and prevention of cervical cancer.

#### **1.4 RESEARCH QUESTION**

The question that the researcher wishes to answer is what are the factors influencing women's awareness, knowledge and experience of cervical cancer and cervical cancer smear screening in the rural population of KwaZulu-Natal?

#### **1.5 AIM OF THE STUDY**

The overall goal of the study was to explore and describe factors contributing to women's awareness, knowledge and experiences regarding cervical cancer and cervical cancer smear screening.

#### **1.6 OBJECTIVES**

The specific objectives were to

- determine the rate of screening for cervical cancer among women aged 30 years and above in rural KwaZulu-Natal,
- explore and describe the knowledge and perceptions of women on cervical cancer and cervical cancer smear screening in this rural population.
- identify and characterise socio-demographic factors associated with accessing cervical cancer screening services by women aged 30 years and above,

#### **1.7 RESEARCH METHODOLOGY**

The methodology used in this study was a descriptive design with a quantitative approach. The self-designed structured questionnaire was used to collect quantitative data on awareness, knowledge and experiences of rural KwaZulu-Natal women on cervical cancer and cervical cancer screening. The sample was a convenience sample as eligible women, aged 30 years and above, who were already randomized to the Microbicide clinical trial at the three UMkhanyakude district clinics were asked to participate as they came to the clinics.

The research instrument was piloted on a sample of five women who were comparable to sample respondents in terms of socio-demographic and geographic characteristics. This was conducted in July 2008 at Somkhele Clinic.

#### **1.8 DEFINITIONS**

For the purpose of this study the following terminology is defined and further explained.

**Awareness**

Awareness is described as appreciation, familiarity, knowledge, observation or understanding (Oxford Concise English Dictionary 1995). For this study awareness meant “being familiar and also knowledgeable about cervical cancer and cervical cancer smear screening.” It also relates to the experience and perceptions influencing the uptake of cervical screening services.

**Cervix**

The cervix is the lower part or neck of the uterus forming the opening to the vagina. It is divided into 2 parts, namely the endo-cervix, internal part and ecto-cervix, the outer part that is next to the vagina (Pocket Medical Dictionary, 2003: 57).

**Cervical cancer**

Cervical cancer relates to the actual neoplasma cancerous cell changes in the cervix commonly referred to as carcinoma in situ (cancerous growth localised) and invasive cancer (cancer spreads to nearby organs).

**Cervical screening**

For the purpose of this study cervical screening relates to early detection of pre-cancer lesions through a Papanicolau smear (Pap).

A Papanicolau test is a screening tool used to detect cervical abnormalities. Mucus and cells are collected from the ectocervix and endocervix, by scraping and then fixed onto a glass slide and sent to the Cytopathology laboratory for assessment (American Cancer Society, 2009: 10).

**1.9 SUMMARY**

Chapter one has given the introduction and orientation of the study, the research problem, goals, methodology and design, the ethical considerations and the further outlay of the research report, as well as the operational definitions. The next chapter will discuss a comprehensive review of literature on the topic and related matters of the study.

## CHAPTER 2: LITERATURE REVIEW

### 2.1 INTRODUCTION

Chapter one addressed the orientation to the study as well as the purpose thereof, and a synoptic overview of the research methodology that was implemented in this research. A detailed literature search was conducted using Pub Med, and the relevant literature was reviewed. The output of the review is aimed at conceptualising the history and present status of cervical cancer, the uptake of screening services and factors influencing access. Where relevant, studies conducted in other countries were reviewed and important findings briefly summarised to explain the extent of the problem and related factors in other areas. This chapter provides a comprehensive overview of the literature on the topic: *Awareness, Knowledge and Experiences of women regarding Cervical Cancer*.

### 2.2 CERVICAL CANCER

Cancers can be caused by DNA (Deoxyribo-Nucleic Acids) mutations (gene defects) that activate cells promoting cell division (oncogenes). Sometimes this could be caused by inactivation of tumour suppressor genes, resulting to abnormal proliferation of cervical cells. Cancer of the cervix occurs as a result of abnormal cell changes in the tissue layers of the cervix. It may appear as a cauliflower-like growth that bleeds easily on contact (Smeltzer & Bare, 2004:1379).

Hawes, Critchlow, Faye Niang, Diouf, Aissatou, Touré, Kasse, Dembele, Coll-Seck, Kuypers and Kiviat, (2002:555) and Khan, Castle, Lorincz, Wacholder, Sherman, Scott, Rush, Glass and Schiffman, (2005:1073) have shown that the most common risk factor for cervical cancer is the Human Papilloma Virus (HPV), which is thought to produce proteins that cause proliferation of cervical lining cells leading to cancer (American Cancer Society, 2009:1).

Cervical cancer usually starts in the cells on the surface of the cervix, involving columnar or squamous cells. The cells mostly affected are squamous cells. Progression of pre-cancer lesions (dysplasia) is usually slow and detection of early pre-cancer lesions can easily be achieved through Pap smear testing and is 100% treatable (Cervical Cancer Health Guide, 2008:2). If left undetected, pre-cancer lesions can develop into cervical cancer and eventually

spread to adjacent organs such as the uterus and ovaries, bladder, intestines and liver. The Human Papilloma Virus (HPV) spreads through sexual intercourse and is responsible for almost all cervical cancers (Cervical Cancer Health Guide, 2008:2). In countries where resources are allocated to prevention initiatives the prevalence and mortality of cervical cancer is lower, for an example in developed countries. Screening for cervical cancer is important so as to ensure early detection of pre-cancer lesions to reduce the incidence of mortality due to cervical cancer in the population (Adanu, 2002: 286). Knowledge and the attitude of the women to smear testing are important in improving the understanding of factors influencing the uptake of diagnostic services available.

### **2.2.1 Cervical cancer risk factors**

Different cancers have various risk factors. It is important to note that although the presence of cervical cancer risk factors increase the odds of a woman getting cervical cancer in her lifetime, not all women exposed to risk factors develop cancer. Several risk or predisposing factors were identified and discussed.

#### *2.2.1.1 Human Papilloma Virus (HPV)*

The most important risk factor for cervical cancer is the sexually transmitted HPV. HPV infection is mostly prevalent in young women under 30 and less in older women over 30 years. There is currently no cure for HPV infection apart from management of lesions or growths caused by HPV infection (American Cancer Society, 2009:1). HPV type 16 and type 18 cause approximately 70% of incidences of cervical cancer worldwide, although there are variations across countries. Early studies have shown a relationship between HPV and cervical neoplasma. In a study conducted in Denmark 1998, women with high risk of HPV infection had a 33-fold increased risk of cervical neoplasma compared to HPV-negative women. In the same study it was found that HPV test has a higher sensitivity than a Pap smear test (Kjaer, 1998:2). Women who were HPV positive for type 16 and 18 were found to be at a higher risk of developing cervical cancer lesions when followed over a 10-year period (Khan, Castle, Lorincz, Wacholder, Sherman, Scott, Rush, Glass and Schiffman, 2005:1073). This further suggests evidence of HPV as a significant risk factor for cervical cancer.

#### *2.2.1.2 Weakened Immune System*

Chirenje, Loeb, Mwale, Nyamapfeni, Kamba and Padian (2002:766); Hawes, Critchlow, Faye Niang, Diouf, Aissatou, Touré, Kasse, Dembele, Sow, Coll-Seck and Kiviat (2003:566); and Leroy, Ladner, De Clercq, Meheus, Nyiraziraje, Karita and Dabis (1999:104), concur that the

highest burden of pre-cancer lesions is among HIV infected women and in some cases co-existence of HPV infection also increases this risk. In addition to HIV seropositivity as a risk factor, Ruche, Ramon, Mensah-Ado, Bergeron, Diamondé, Sylla-Koko, Ehouman, Touré-Coulibaly, Welffens-Ekra and Dabis (1998:2403), argue that other factors significantly associated with cervical lesions should also be considered, such as smoking, parity (given birth) three times or more three, low educational level and non-usage of oral contraceptives. Conversely, early sexual debut and multiple sexual partners, which are known to be risk factors for cervical cancer, were not associated with increasing risk in this study (Ruche et al., 1998:2403). Some studies have shown a significant association between recurrences of cervical dysplasia after therapy or a hysterectomy in women who are HIV infected (Tate & Anderson, 2002:881). Therefore, there is an increasing concern for cervical cancer screening for women living with HIV, though this remains a challenge for low-resource settings. The National Health Departments should encourage Pap smear testing for all patients who are HIV infected to facilitate early diagnosis and prompt management.

#### *2.2.1.3 Smoking*

The risk of developing cervical cancer is doubled in smoking women compared to non-smokers due to exposure to high levels of carcinogens in smoke. Carcinogens are thought to damage the DNA of cervical cells, leading to cervical cancer (American Cancer Society, 2009:2). It is of interest to learn how women smokers and non-smokers perceive their risk. In a study conducted among 722 women ranging between 20 and 64 years, smokers did not perceive themselves to be at high risk. The intention to attend a cervical screening was similar among both groups of smokers and non-smokers (Marteau, Hankins and Collins, 2002:20); although smoking among African women is not highly prevalent, there is a need to raise awareness in all communities in this regard. In South Africa smoking among women contributes 7.70% of cervical cancer (WHO/ICO Information Centre on HPV and Cervical Cancer, 2007:1).

#### *2.2.1.4 Other risk factors*

The other risk factors include: a family history of cervical cancer, early sexual debut, age, a lack of regular Pap smear testing, as well as the number of pregnancies (American Cancer Society, 2009:4; Ruche, Ramon, Mensah-Ado, Bergeron, Diamondé, Sylla-Koko, Ehouman, Touré-Coulibaly, Welffens and Dabis, 1998:2401). In a study conducted in Mali among women with invasive cancer, an increase in the number of pregnancies increased the risk of

cervical cancer, this relationship was statistically significant. In addition early sexual debut increased odds of invasive cancer (Bayo, Bosch, de Sanjose, Munoz, Combata, Coursaget, Diaz, Dolo, van den Brule and Meijer, 2002:206).

#### *2.2.1.5 The link between cervical cancer and HIV and AIDS*

The HIV incidence remains high in this rural KwaZulu-Natal population and has remained high over a 5 year period, from 2003-2007. The results from a large population-based longitudinal surveillance in this rural population showed the overall incidence of 3.4 per 100 person-years (Confidence interval 3.1-3.7). These results were similar to those reported in a longitudinal population-based study in another rural population, 4.9 and 2.2 per 100 person-years in women and men respectively (Bärnighausen, Tanser & Newell 2009:407). Both HIV and cervical cancer are regarded as sexually transmitted infections which initially do not show symptoms until the progression of the disease. Research studies suggest that the lifespan of women living with HIV is elongated through the use of HAART (highly active antiretroviral therapy), which results in an increased risk of contracting cervical cancer (Health Systems Trust, 2009:1).

The relationship between HIV and cervical cancer has been established through several studies conducted in Africa on HIV negative/ HIV positive women. HIV positive women with cervical pathologies quickly progress to invasive cancer compared to HIV negative women (Health Systems Trust, 2009:1, Chirenje et al., 2002:766, Ruche et al., 1998:2401, Franceschi & Jaffe, 2007:510). Franceschi and Jaffe (2007) further emphasize the need for offering cervical screening to all women who are HIV positive so as not to miss the opportunity of preventing invasive cancer. HPV has been identified as an important risk factor for cervical cancer. Alternative methods to reduce the incidence of invasive cervical cancer resulting from HPV infection have been researched and explored. As a result two vaccines have been developed to curb the risk of cervical cancer caused by HPV. The challenge would be dissemination of information to the communities about the vaccine coupled with availability issues in resource-poor settings (Moodley, 2009:12).

### **2.3 CERVICAL CANCER PREVALENCE AND BURDEN**

The information below provides a comprehensive overview of the global cervical cancer prevalence and burden.

The global prevalence of cervical cancer is estimated to be 2.3 million and the incidence to be 500000. Cervical cancer is the second leading cause of cancer in females in developing countries and first in developed countries. The Human Papilloma Virus (HPV) contributes to over 70% of all cervical cancer cases, of which 41-67% is high-grade lesions and 16-32% are low-grade cervical lesions. Cervical cancer screening is important to diagnose pre-cancer lesions early. The crude incidence rate and standardized incidence ratio is estimated to be 16 and 100 per 100000 women respectively. The mortality rate of cervical cancer is estimated to be 8.9 per 100000 females globally and the cumulative risk to be 0.7%. The risk of cervical cancer tends to increase with age, reaching the peak point in 35 per 100000 women from 55-64 years age groups. This rate is doubled in South Africa (WHO/ICO Information Centre on HPV and Cervical Cancer, 2007:5-14).

### **2.3.1 The prevalence and burden of disease in South Africa**

In South Africa cervical cancer incidence has doubled compared to the global estimates and has the highest rate compared to other cancers at 30.2 per 100000 females followed by breast cancer at 27.0 per 100000 females. The number of new cases is higher in women aged 15-44 and gradually decreases with age, conversely the death rate increases with age, since pre-cancer lesions may take years to develop to invasive cancer. More than 80% of cases diagnosed with HPV are found to have higher-grade lesions or cervical cancer; 88.4 and 93.8% respectively (WHO/ICO Information Centre on HPV and Cervical Cancer, 2007: 8-15).

### **2.3.2 The Burden of disease in KwaZulu-Natal**

In KwaZulu-Natal between 1997 and 2001 about 48% of the total deaths reported were due to degenerative diseases, including the central venous system (CVS) and neoplasma. In females neoplasma was ranked the second cause of mortality contributing to about 14% of deaths. Among those females dying from cancer the most common cancer is that of the reproductive system, cancer of the cervix (KwaZulu-Natal Epidemiology Bulletin, Department of Health, 2003:4).

## **2.4 CERVICAL SCREENING IN SOUTH AFRICA**

When the Papanicolau smear (Pap) test was introduced as one of the cervical cancer screening methods, the health authorities in most countries adopted this screening method in their annual screening policies. In developed countries this was mainly the responsibility of the

health care workers to keep a national register and mail invitation letters to women as reminders for annual smear tests when due. Historically, in developing countries, however, funds were mostly channelled to the management of the late stage cancer as opposed to early detection measures. Women were thus left at risk due to inadequate preventive care (Lovejoy, 1996: 128).

The World Health Organization has stipulated the target of women for cervical screening to be those aged 30 and above and also recommended reducing the number of cervical cancer smears to one per woman per lifetime. The South African National Department of Health proposed a total of 3 cervical cancer smears per lifetime beginning at age 30 and above and also that these are spaced at 10 year intervals. The premise behind this policy is that cervical cancer develops over time; it may take 10-20 years for a pre-cancer lesion to progress to cervical cancer. Younger women under 30 years usually present with low grade lesions that regress to normal over time. The mean age of patients with high-grade lesions is 30 years and the time estimated for progression to invasive cancer is 10 years. If a cervical cancer smear is sensitive enough it should be able to diagnose cervical abnormality early enough so as to facilitate preventive measures. Women with abnormal cervical smear results require referral for colposcopy and for further management (Department of Health: National Guidelines on cervical cancer, 2000:3).

The South African National Cancer Control Programme was adopted as the official government policy in 1997 and its implementation is decentralized to provincial and local structures. The challenge of inadequate resources e.g. poor transport systems, lack of accessible laboratories and also low uptake of this service is still evident in some provinces. The Department of Health has estimated that in order to achieve 70% coverage of the population, over five million women would need to be screened over the next 10 years. Some of the cervical screening challenges are that most women in developing countries only seek health care when they are in the advanced cervical cancer symptomatic stages (Moodley, 2009:11-12).

## **2.5 LITERATURE TO EVALUATE WOMEN'S KNOWLEDGE, AWARENESS AND EXPERIENCES REGARDING CERVICAL CANCER AND CERVICAL CANCER SCREENING.**

Various studies have been conducted globally to evaluate women's awareness of cervical cancer and screening practises. In a qualitative study conducted in West Virginia to evaluate awareness and knowledge of cervical and breast cancer among women, it was found that women were more knowledgeable about breast cancer than cervical cancer. Some of the common misconceptions were on the frequent use of tampons during menstruation as the cause of cancer. Some also believed that women who had a hysterectomy performed, regardless of the indication, do not require cervical screening in the future (Lyttle & Stadelman, 2006:4). These misconceptions could negatively impact on the future uptake of cervical screening services. Barriers to screening were mostly cost-related as women in developed countries are expected to pay in order to access such services. The other barriers were fear of the unknown, embarrassment, denial, lack of time and lack of transportation.

Lack of motivational factors were cited and therefore there is a need for further interventions such as increased educational campaigns by health care professionals, the buddy system where the relative or friend could accompany each other to the health care service and motivation by health care providers to encourage women to go for testing. Women also advised that educational campaigns should be varied e.g. that television programs, the radio, mail and contact sessions be utilised and they also emphasized the importance of varying educational techniques by various educators to cater for different age groups (Lyttle & Stadelman, 2006:4-5).

In a quantitative study conducted to assess knowledge, perceptions and attitudes of health care professionals in the U.S.A, findings were that most professionals are knowledgeable about risk factors of cervical cancer. However, they cited the lack of time and resources in offering educational information on cancer to patients. Preventive counselling to reduce the risk of cervical cancer was viewed as of less importance to the professionals (Tessarro, Herman, Shaw and Giese, 1996:272). This implies that no matter how knowledgeable health care professionals are, sharing information with patients and communities is of greater benefit to reduce the risk of cervical cancer.

Most studies conducted globally have indicated lack of knowledge and awareness in women regarding cervical smear testing and cervical cancer. This has resulted in a low uptake of screening services. In a qualitative study conducted among women aged between 21 and 56, most women had a poor knowledge of cervical cancer (Wong, Wong, Low, Khoo and Shuib, 2009: 51). Most of them had heard of cervical cancer previously but were not aware that it could be prevented. Only a few older, married women were aware that if cervical cancer is detected early it could be managed. The role of the Pap smear in early detection was also poorly understood. Only less than half of women recognized the risk factors. Most surprisingly, most of these women thought the Pap smear is performed to diagnose sexually transmitted infections, and the procedure itself was not well understood (Wong *et al.*, 2009: 51). These findings indicate that a lot needs to be done to increase public awareness, knowledge and insight of women regarding the importance of early screening for cervical cancer. Educational messages should reach all women regardless of educational level, race or socio-economic status. Most of the women who participated in the above study had a secondary education. This shows that the educational level would not contribute much to the assimilation of health education messages.

In a study conducted in Nigeria amongst professionals, other public servants and students, the level of awareness of cervical screening was average (52.8%), however only 7.1% had ever done a Pap smear test. The most common reasons given for not doing a Pap smear test included the lack of awareness (46%), fear of a bad result and some felt there was no need for it (Ezem, 2007:94-96). One would expect the level of awareness to be higher in this sample. However, this result attests to findings from other countries. Women do not access screening services despite awareness about such services. In most cases the proportion of women who had ever had a Pap smear is far less than half of the women who reported an awareness of the Pap smear. Almost half of the women in a study conducted in Ghana reported doing a Pap smear, because the doctor asked for it as part of patient management. Results also showed that although 93% of women have heard of cervical cancer, only 37% of those had adequate knowledge about this disease. Of those with adequate knowledge, only 8.5% have ever had a Papanicolaou (Pap) smear done (Adanu, 2002: 487). In a study to evaluate availability of screening services in African countries it was found that 95% of health institutions at all health care levels had basic infrastructures to perform cervical cancer screening (Chirenje, Rusakaniso, Nyamapfeni, Kamba and Padian, 2001:127-128).

Earlier studies conducted in South Africa (Cape Town) also revealed a lack of knowledge on cervical cancer and Pap smears. None of the women interviewed knew what a cervix was; however, they could easily recognize the word Pap smear and link it to cancer of the uterus. Most women thought the Pap smear was done to diagnose infections, infertility and also to clean the uterus following severe vaginal bleeding or miscarriage. Only a few participants linked Pap smears to cervical cancer diagnosis. The reasons for doing a Pap smear are mostly linked to ill health and also as per nurse instructions. This indicates that the use of the Pap smear as a screening test for early pre-cancerous lesions is poorly understood. Some of the obstacles to Pap smear verbalized by women are: fear, embarrassment, lack of time and stigma (Abrahams, Wood and Jewkes, 1996:14-21). The study conducted in the rural KwaZulu-Natal population showed similar results (Hoque, Hoque and Kader, 2008:113-115).

The uptake of cervical screening is still very low despite these services being cost-free in most regions. Research evidence suggests that factors such as knowledge, attitude and awareness play a vital role in the utilizing of this service. There is also no significant difference between women who attend and non-attenders in respect of knowledge (Twinn, Shiu and Holroyd, 2002:379). This indicates that lack of education and knowledge does not exist as a main barrier to women attending clinics for cervical cancer screening. In a survey conducted to assess barriers and women experiences to pap smear testing in the same geographic area in KwaZulu-Natal, women displayed that they had information about the need for cervical screening. In almost all women interviewed, the motivator for cervical screening was the invitation they got from the professionals and also the pelvic symptoms they experienced (Wood & Jewkes, 1996:9). The same study found an association between promiscuity and cervical cancer, which may result, in low utilization of the screening service (Wood & Jewkes, 1996:10). A recent study (2008) conducted in one of the tertiary institutions in KwaZulu-Natal reported a lack of knowledge regarding cervical cancer and cervical screening. Less than half of the students had heard of cervical cancer and the risk factors were poorly understood. Half of the students mentioned HPV as the main cause of cervical cancer. The main reasons for not doing a cervical screening test were fear and being healthy (Hoque & Hoque, 2009: 21-24). The above implies that there is a need for health education and making the communities aware of the importance of cervical cancer screening so as to increase the utilization of cervical screening services. Unlike the other countries, the issue of cost as a barrier to screening was perceived differently in KwaZulu-Natal; professionals who interviewed patients did not identify the cost for the smear as a problem. They explained that

women often interpret “no charge” with poor quality service. This is unfortunate as most women benefit from free primary health services and the bulk of the women in this area are unemployed. Barriers that surfaced were mostly the lack of trained staff to provide service and education, as well as women’s reluctance and fear caused by misunderstanding and lack of motivation and anxiety. The other important barrier was the lack of adequate communication with clinicians, especially of the referring hospital. This then had a negative impact on an appropriate follow-up care of patients. In addition, when referred, women often resisted attending further investigations following abnormal smears (Wood & Jewkes, 1996: 14-15).

## **2.6 ACCESS AND UTILISATION OF CERVICAL SCREENING SERVICES**

The prevalence of cervical cancer has been greatly reduced through successful cervical screening programmes especially in developed countries. Most developing countries are still faced with challenges of implementing such services. Success depends on a number of factors, such as coverage of the right target women, excellent follow-up service, early management of pre-cancer lesions and resource availability (Pollack, Balkin, Edouard, Cutts and Broutet, 2007:57). Research conducted in other countries among women who had cervical cancer has shown a significant relationship between age and failure to screen, older women are more likely not to screen compared to younger women. The other important factors to be considered to ensure that cervical screening contributes to prevention of invasive cancer are: diagnostic failure whereby the screening test is unable to detect precancerous lesions due to poor techniques. The aim also is reaching a greater percentage of women who have not had a recent Pap smear. This is to diagnose undetected precancerous lesions early before the condition develops into cervical cancer (Leyden, Manos, Geiger, Weinmann, Mouchawar, Bischoff, Yood, Gilbert and Taplin, 2005:677). There is a need to periodically review health services to ensure that all factors influencing access to these services are addressed.

Studies conducted in Africa show that above 95% of health care institutions have basic infrastructures to conduct cervical screening. Most screening was provided on demand through family planning services. The most common barriers to providing cervical screening tests were a lack of a clear policy and procedures, and also staff competencies. Most smears were evaluated in tertiary hospitals and this caused delays in turnaround times of results.

Most women commonly screened were below 25 years and also women with invasive cervical cancer (Chirenje et al., 2001:128-129).

Data from the Western Cape, South Africa, indicates that in the year 2005, 45 997 (74%) of the total women screened were over the age of 30 years. Abnormalities were detected in 7.3% of the Pap smears taken. This is encouraging although much needs to be done to reach 100% of eligible women. In KwaZulu-Natal 28 760 Pap smears were performed in 2005, accounting for 26% of the target. This indicates that a large pool of women remains unscreened. Reaching the 70% National target coverage remains a challenge. The other factor is that a low percentage of women who have ever done a smear test are not informed of the purpose of the test (Moodley, 2009:12).

## **2.7 SUMMARY**

From this comprehensive review of literature it is apparent that cervical cancer screening knowledge is essential as a health promotion strategy. The burden of disease due to cervical cancer is high and also poses a challenge to the overburdened health care systems in developing countries. This review formed the basis for the questionnaire and the research design that was utilized in this study. Few studies have been conducted in this province to assess the level of knowledge, awareness and attitudes of women to Pap smear testing and cervical cancer. This study will add to the body of knowledge, which would help in re-enforcing prevention messages and cervical cancer information. It would also provide a basis for exploration of key issues through a qualitative approach in the future. In the next chapter the methodology implemented for this research study which explored women's awareness, knowledge and experiences regarding cervical cancer in rural KwaZulu-Natal, South Africa were discussed.

## **CHAPTER 3: METHODOLOGY**

### **3.1 INTRODUCTION**

Chapter two provided a comprehensive overview of the literature on the topic: *women's awareness, knowledge and experiences regarding cervical cancer and screening* and related matters. This chapter describes the methodology that was used in this study. According to Burns and Grove (2001:26) research methodology is “the application of all steps, strategies and procedures for gathering and analysing data in a research investigation in a logical and systematic way”. This can be defined as the research plan that guides the research. It involves a research design, sampling methods, data collection methods and analysis, and ethical considerations.

### **3.2 THE PURPOSE OF THE STUDY**

The aim of this study was to assess women's awareness, attitudes and experiences regarding cervical cancer smear screening and cervical cancer in rural KwaZulu-Natal, and to better understand the factors that influence access to and utilization of cervical screening services by rural women. In resource-poor settings, access to services offering cervical screening is still a challenge and according to Adanu (2002:486), it is estimated that more than 50% of women in developing countries have never had a single screening test for cervical abnormalities.

### **3.3 THE RESEARCH OBJECTIVES**

This study was guided by the following objectives to:

1. determine the rate of screening for cervical cancer among women aged 30 years and above in rural KwaZulu-Natal;
2. explore and describe the knowledge and perceptions of women on cervical cancer and cervical cancer screening in this rural population.
3. identify and characterize socio-demographic factors associated with accessing screening services in women aged 30 years and above and

### **3.4 THE RESEARCH DESIGN**

A research design “guides the researcher in planning and implementing the study in a way that is most likely to achieve the intended goal” (Burns & Grove 2001:223). This was a descriptive study, using a questionnaire to generate quantitative data to gain insight into participants’ awareness, knowledge and experience relating to cervical cancer and cervical cancer screening.

A descriptive study aims to quantify the problem, giving detailed information and also taps into perceptions of communities and groups. Some literature describes descriptive studies as hypothesis-generating studies since they bring out questions for further research about situations. The benefit of conducting such studies is that information obtained assists direct planners and service providers in service planning and resource allocation (Katzenellenbogen, Joubert & Abdool-Karim, 1999:89).

This was a descriptive study using a structured questionnaire (Appendix A) to collect data and some open-ended questions which were added to the questionnaire to further explore opinions and perceptions. Experienced and knowledgeable registered nurses in the Microbicide clinical trial clinics who were utilized for research and the researcher administered the survey questionnaires. These nurses were already trained in cervical cancer screening since it was offered as a standard of care to all Microbicide clinical trial participants. In addition the researcher conducted extra two days training on the cervical cancer protocol including the questionnaire and the informed consent process. Training sessions were evaluated through mock interviews, where data collectors were asked to conduct interviews on each other using the study questionnaire. This helped the researcher to identify any training gaps that had to be addressed before actual data collection, e.g. correct adherence to interviewer instructions, skip questions, correct phrasing of questions and recording.

### **3.5 STUDY POPULATION AND SAMPLING**

The Africa Centre for Health and Population studies is one of the 6 sites involved in a multicentre trial-Double-blind, placebo-controlled Microbicide clinical trial, testing Microbicide gel –PRO-2000/5 for safety and efficacy in preventing vaginally acquired HIV. This site is situated in UMkhanyakude District, Mtubatuba, in rural KwaZulu-Natal. The Microbicide trial commenced in March 2006 with a target to enrol 1200 women and ended follow-up in August 2009. Women were recruited from district family planning and

immunisation clinics. Those who met the inclusion criteria were randomised into three study arms, namely PRO 2000 0.5%, PRO 2000, 2% and Placebo gel. Women enrolled in this trial were followed up over a period of a year, returning to clinic every month for follow-up care. They completed follow-up at different time points. The last group of women completed follow-up on 28 August 2009. All the women who participated in the Microbicide clinical trial were offered cervical cancer screening through a Pap smear at enrolment as a standard of care procedure in this trial. The researcher then identified this group of women as a sample for the cervical cancer study, to further explore the role of prior screening and knowledge on this subject.

The initial target for the cervical cancer study was 120 participants, 10% of the Microbicide trial participants. However there were delays in Ethical committee approval, the cervical cancer protocol was initially submitted in June 2008 and only granted Ethics approval in June 2009. Data collection commenced on 06 July 2009. Only six hundred women were still on clinical follow-up during that period, a convenience sample of 69 women who agreed to be part of the cervical cancer study was obtained. Women were recruited from the three clinics at the UMkhanyakude district in rural KwaZulu-Natal, Madwaleni, Mtuba and KwaMsane clinics. This was a convenience sample as eligible women who were already randomized to the Microbicide clinical trial were asked to participate as they came to the clinics.

### **3.5.1 Inclusion Criteria**

The following inclusion criterion was used to enrol women to this study:

- Women enrolled in the Microbicide clinical trial attending clinic for Microbicide trial follow-up care between 06 July and 07 August 2009.
- Participants attending MDP trial clinics aged 30 years and above.
- The three clinics selected for sampling were all in the UMkhanyakude district in rural Kwazulu-Natal province.

### **3.6 RELIABILITY AND VALIDITY**

Assessment of reliability is done to ensure that the research instruments measure consistently and accurately with repeated measures (Gerries & Lacey, 2006:376). Katzenellenbogen, Joubert & Abdool-Karim, 1999, defines reliability as “the degree of similarity of the information obtained when a measure is repeated”. The researcher tested the questionnaire by giving it to colleagues who are working in the same clinics (these colleagues were not part of

the study) to determine if all interpreted the questions similarly. According to Katzenellenbogen, Joubert and Abdool-Karim 1999:124), validity is defined as the ability of an instrument to measure the variables that it is intended to measure. The questionnaire was piloted on a sample of 5 women, aged 30 years and above, attending the family planning (reproductive health clinic) at Somkhele clinic. Assessment of reliability is done to ensure that the research instruments measure consistently and accurately with repeated measures (Gerries & Lacey 2006:376). Katzenellenbogen, Joubert and Abdool-Karim (1999:124), define validity as the extent to which a measure actually measures what it is meant to measure. Attempts were made to improve and evaluate validity and reliability in this study. This was ensured through standardization of the method of data collection, training of research nurses who were collecting data, supervision and control.

Nurses who were assisting with data collection were trained on the cervical cancer protocol to ensure the high quality of data and also standardization of data collection. Quality control of completed questionnaires was done by the researcher. The researcher checked questionnaires for completeness, consistency and legibility and where necessary meetings were held with the interviewers to clarify inconsistencies. Inconsistencies identified and clarified at the beginning of the study were partial adherence to interviewer instructions, e.g. incorrectly asking skip questions.

### **3.7 THE RESEARCH INSTRUMENT AND DATA COLLECTION**

Data collection was through a self-designed structured questionnaire. The questionnaires were formulated in English and translated into the language that is spoken by the target sample i.e. isiZulu by the research nurses who are trained registered nurses and the researcher during an interview (Cervical Cancer Questionnaire: Appendix B). The instrument was a self-designed structured questionnaire with mainly closed-ended questions and a few open-ended questions. The questionnaire was typed legibly and was divided into 3 sections, namely section 1: Socio-demographics, section 2: knowledge/awareness, section 3: perceptions and experiences. Socio-demographic characteristics considered were age, marital status, educational status- highest level attained, employment status, earnings, and sexual/reproductive history. Knowledge and awareness was obtained from general knowledge questions on cervical cancer description, whether it is preventable and how, the cervical screening test type and frequency of cervical cancer screening tests. Perceptions and

experiences were elicited from the history of previous cervical screening, experiences and willingness to screen for cervical cancer in the future.

Research nurses who assisted in data collection are registered nurses who received two days additional training on cervical cancer protocol, the informed consent process and questionnaire administration. The extra training was conducted to ensure good data quality and standardization of the data collection process. Staff training was evaluated through simulated interviews. Literate participants were allowed to complete a questionnaire on their own with the assistance from the interviewer. The interviewer and the literate woman who chose to record her own responses both had copies of the questionnaire. The interviewer then read out questions systematically to ensure the woman answered all questions as required. Women were asked (open and closed questions) about their knowledge, perceptions of cervical cancer and cervical screening. The history and experiences of previous cervical screening were sought as well as barriers to cervical screening were identified.

### **3.8 THE PILOT STUDY**

A pilot study is defined by Van Ort (1981), quoted by Burns and Grove (2009:44), as a “smaller version of a proposed study that is conducted to refine the methodology”. It could be performed in various stages of a research process. In this study this only involved piloting the questionnaire during the early stages of the questionnaire formulation.

The research instrument was piloted on a sample of five women who were comparable to sample respondents in terms of socio-demographic and geographic characteristics. This was conducted in July 2008 at Somkhele Clinic and resulted in the following benefits: the time taken to complete the questionnaire was established; statements and questions that were misinterpreted by the respondents were re-worded and corrected.

### **3.9 THE ROLE OF THE RESEARCHER**

The researcher was involved in protocol development, questionnaire design, the training of three registered nurses from each clinic on the cervical cancer protocol, a standardized method of data collection including administering the consent, data collection. The researcher also did quality control of data collection, analysis of data and report writing. All completed questionnaires were sent to the researcher at the end of each day to be quality controlled for completeness, accuracy and consistency. Data was then captured on an excel spread sheet by

the researcher in preparation for data analysis. Data analysis was performed once data capturing of all questionnaires were complete.

### **3.10 ETHICAL CONSIDERATIONS**

Research involving human subjects should always be guided by good clinical practice and human right principles to ensure protection of participants. Some of the ethical responsibilities of researchers are to maintain privacy, informed consent-ensuring that there is voluntary participation, protection of participants, informing participants what the study is for, how information will be used and whether there is any potential risk expected (Katzenellenbogen *et al.*, 1999:89).

This study which explores women's awareness, knowledge and experiences with regards to cervical cancer in rural KwaZulu-Natal was approved by the Stellenbosch University, Faculty of Health Sciences, Human Research Ethical Committee (HREC) on 9 March 2009 and 2 April 2010 respectively (Appendices C01 and C02) and the study site project leader. The respondents were asked to be part of the study after detailed information pertaining to the study was explained to them. They were asked to sign an informed consent form as proof of their voluntary participation.

#### **3.10.1 Confidentiality and Anonymity**

The researcher used screening and trial numbers already allocated to these participants as identity numbers, since no names were used on any of the questionnaires except informed consent documents. Full participant names were used on the informed consent forms, and these were kept locked separately from the questionnaires. The participants were assured of confidentiality of their information during an informed consent process and privacy was maintained throughout. Completed questionnaires were transported from the clinics by the Africa Centre driver to the office in a well secured box to avoid unnecessary loss. Data capturing was done by the researcher and the electronic spread sheet was saved in a password controlled excel folder.

#### **3.10.2 The consent**

The study information sheet was translated into the language spoken by participants, namely, isiZulu, and was made available to all participants (IsiZulu participant information sheet and consent: Appendix C03). Illiterate participants were assisted by interviewers to read the information sheet to them. Participants were encouraged to ask questions to ensure clarity of

the study information. At the end of the information session volunteers were asked to sign the consent document as proof of voluntary participation and also to acknowledge their understanding of the study information. Illiterate participants were asked to put a thumb print as a signature. The information sheets and a copy of the signed informed consent form were provided to participants to take with them.

### **3.11 DISSEMINATION OF RESULTS**

The researcher has an ethical obligation to make research results available to all stakeholders; this includes participants, district clinic staff, the district hospital and the local community. The researcher will use feed-back systems in place at the Africa centre for this purpose such as community meetings, formal meetings with the hospital board and clinic staff, road shows and the Umbiko community magazine. A copy of the final report will be made available to the Hlabisa district hospital.

### **3.12 SUMMARIZING THE SAMPLE DATA**

The primary outcome measure for this analysis was whether these women had ever been screened for cervical cancer (Q13, section 3-have you ever screened for cervical cancer (prior to joining the trial?)) The primary outcome measure was assessed from the history of previous cervical screening obtained, which was either “yes” or “no”. The secondary outcome measure employed in the analyses reflected knowledge and perceptions of women with regards to cervical cancer and cervical screening. Knowledge was determined through the general knowledge about cervical cancer, cervical cancer risks and cervical screening, Q7-12: Section 2: Q7. What do you understand by cervical cancer? This was an open-ended question where respondents were expected to state in their own words what cervical cancer is., Q8 what basic test is conducted to screen for cervical cancer? Respondents were expected to choose from 3 responses given. Q9 Do you have information about cervical cancer screening, if so where did you get this information? Q10 Mention at least 3 risk factors for cervical cancer, Q11 Can cervical cancer be prevented? “Yes” “no” or don’t know. Q11a if yes to q11, how? Respondents who knew cervical cancer could be prevented were expected to state how in Q11a. Q12-How often do you think women should screen for cervical cancer- four responses were given to choose from. If a woman had reported previous screening her experiences and also intention to screen in the future were explored, also if no prior cervical screening was reported reasons were explored (Q13-15b). Q13a if answer to Q13 (ever screened for cervical cancer) was “no” women were expected to give reasons-choose from responses given. Q13b

if answer to Q13 was “yes” the woman was expected to share her experiences, through choosing from responses given or specify. Q14 cervical cancer risk established-“Do you think you are at risk of cervical cancer? Q15-15b were on establishing future intentions to screen- Q15 Would you screen for cervical cancer in the future?, and also where the woman intended to go for screening Q15a, if not reasons were established, Q15b. Socio-demographic factors associated with previous screening for cervical cancer were explored to establish associations.

Demographic and socio-economic characteristics included age, highest educational level achieved employment status, monthly earnings and marital status. Age was assessed as categorical variable (30-34, 35-44, 45+, year age groups) throughout the analysis. Highest educational level achieved was also assessed as categorical variable (no education, primary education, secondary education, matriculation or above). In addition, education was evaluated as a categorical variable (no education, primary, secondary or higher throughout). Employment status was categorized as a binary variable namely being unemployed versus being in either part-time or full-time employment. Earnings (women who were employed) were classified as categorical variable (R500 or less, R501-R1000, R1001-R2000, R3000+). Marital status was treated as a binary variable of being married or unmarried.

Other variables included age of sexual debut, parity and contraception. The age of sexual debut was represented by categorical variable with sexual initiation below 15, between 16 to 19, or 20 + years of age. Parity was reported as ordinal categorical variable (0, 1-3, 4-5, 5+). Contraception usage was reported as binary variable of using or not using any method of contraception. Contraceptive type was also reported as (pills, injectable, sterilization, condom or other).

All questionnaires were inspected for completeness and consistency of responses e.g. whether all questions were answered, skip questions followed accurately, legibility of handwriting. Questionnaires were transported by the Africa Centre driver from the clinics to the Africa Centre (where the researcher works) each day and captured into the Microsoft Office Excel 2007 spread sheet by the researcher.

### **3.13 DATA ANALYSIS**

Data was extracted from Microsoft Excel 2007 and analysed in STATA 10 (Stata Corporation, College Station, Texas, USA) and the SAS statistical programme for Fishers Exact test. The above test is used to classify objects in two different ways (categorical data) to

examine the significance of the contingency between the two kinds of classification (Fisher, 1922:87-94). Descriptive statistics (mean, standard deviation, percentages and frequency distribution) was used to analyse quantitative data to determine central tendency and variation in the data. The overall proportion of women screened for cervical cancer through a Pap smear was established. In addition this proportion was broken down per socio-economic, demographic and sexual behaviour variables.

The relationship of periodic screening for cervical cancer with demographic, socio-economic characteristics was evaluated in bivariate analysis using the Pearson-Chi Square test. Statistical significance between the group who had been screened and those who have never been screened for cervical cancer was analysed using Fisher's Exact test and expressed in odds ratio, p-value and the confidence interval. The p-value was set at a significant level  $<0.05$ . For all values less than 5, the Chi square test was not sensitive to pick up differences, thus the Fisher's Exact test was used to determine p-values (age-group, educational level, sexual debut, contraceptive method and pregnancies).

### **3.14 LIMITATIONS OF THE STUDY**

This study enrolled women who were recruited from the district family planning and immunisation clinics and participating in the Microbicide clinical trial. These women had to fulfil a certain criteria to be randomised to the Microbicide clinical trial. Some of the basic enrolment criteria used was: They had to be HIV negative, non-pregnant, sexually active (at least 2 sex acts in a week), willing to receive condom use counselling, age 18 years and above, willing to attend clinic for scheduled follow-up visits, etc. Information and selection bias might have occurred as women were recruited from primary health care clinics, so this study might have underestimated patients who never sought care and those who normally seek care from other providers. The researcher initially planned to recruit and enrol 120 participants. However, due to time constraints, the final sample size was 69 participants. Logistical issues of limited time negatively influenced the sample size. The small sample size may have masked real differences between the groups that could not be detected due to very wide confidence intervals in some analyses. As a result of the small sample size the results could not be generalised to the population.

**3.16 SUMMARY**

In this chapter a comprehensive description of the research design, sampling procedure, data collection technique, data management and analysis methods have been explicitly presented. Data obtained from these analyses will be presented in the next chapter.

## CHAPTER 4: ANALYSIS AND PRESENTATION OF THE RESULTS

### 4.1 INTRODUCTION

The results of the research project exploring the knowledge, awareness and perceptions of women on cervical cancer and screening, and also determining associated factors are reported in this chapter. The results of the analyses are presented per study objective and described in tables where stated. The sample size for the analyses was 69 women.

### 4.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS

**Table 4.1: Age-Group in women enrolled in cervical cancer study in rural KwaZulu-Natal n=69**

<b>Age group</b>	<b>Response n=69</b>	<b>%</b>
30-34	25	10.1
35-44	25	36.2
45-59	37	53.4
Total	69	100%

This study enrolled women from age 30 and above. The age of the women ranged from 30 to 59 years (Table 1), with a mean age of 44.5 years (Standard Deviation: 7.34).

**Table 4.2: Educational Status in women enrolled in cervical cancer study in rural KwaZulu-Natal n=69**

<b>Education</b>	<b>Responses n</b>	<b>%</b>
No education	18	26.0
Primary education	35	50.7
Secondary/Higher	16	23.0
Total	69	100%

About a third of the sample, n=18 (26.09%) had no education, while n=35 (50.7%) had primary education and n=16 (23.19%) had secondary or higher education (Table 2).

**Table 4.3: Employment status in women enrolled in cervical cancer study in rural KwaZulu-Natal n=69**

<b>Employment</b>	<b>Responses n</b>	<b>%</b>
Unemployed	51	73.9
Employed	18	26.0
Total	69	100%

According to table 3 most of the respondents n=51 (73.9%) were unemployed, while only n=18 (26%) were employed.

**Table 4.4: Monthly Earnings in women enrolled in cervical cancer study in rural KwaZulu-Natal n=18**

<b>Earnings</b>	<b>Responses n</b>	<b>%</b>
R500 or less	11	61.1
R1000-R2000	2	11.1
R3000 +	1	5.5
Refused to disclose	4	22.2
Total	18	100%

About two thirds of the sample were unemployed n=51 (73.9%) and n=18 (26.1%) were either employed full-time, part-time or self-employed. Of those who were employed, n=1(5.9%) was earning R3000 and above, and n=2 (11.8%) were earning between R1000 and R2000. The majority were earning R500 or less n=11 (35.3%) while n=4 women (23.5%) refused to disclose their monthly earnings (Table 3 & 4).

**Table 4.5: Sexual debut age in women enrolled in cervical cancer study in rural KwaZulu-Natal n=67**

<b>Sexual debut</b>	<b>Responses n</b>	<b>%</b>
<=15 Years	9	13.4
16-19	36	53.7
20+	22	32.8
Total	67	100%

Sexual initiation was reported as age 15 or less by n= 9 (13.4%) women, while more than half n=36 (53.7%) of the sample reported sexual initiation between 16 and 19 years of age. Only n=22 (33%) reported sexual debut from 20 years of age and above (Table 5). Two women did not disclose their sexual debut age.

**Table 4.6: Marital status in women enrolled in cervical cancer study in rural KwaZulu-Natal  
n=69**

<b>Marital Status</b>	<b>Responses n</b>	<b>%</b>
Married	39	56.5
Single	30	43.4
Total	69	100%

Just above half of the sample were married n=39 (56.5) and n=30 (43.5%) were single (Table 6).

**Table 4.7: Previous pregnancies in women enrolled in the cervical cancer study in rural  
KwaZulu-Natal n=69**

<b>Pregnancies(Gravid)</b>	<b>Responses n</b>	<b>%</b>
None	2	2.8
1-3	17	24.6
4-5	22	31.8
5+	28	40.5
Total	69	100%

Only n=2 (2.9%) of the sample had never given birth, whilst n=28 (40.6%) reported five or more births (Table 7).

**Table 4.8: Contraception in women enrolled in the cervical cancer study in rural KwaZulu-Natal n=49**

<b>Contraceptive method</b>	<b>Responses n</b>	<b>%</b>
Condom	10	20.4
Injectable	16	32.6
Pills	9	18.3
Sterilised	14	28.5
Total	49	100%

The majority of women were on contraceptives, n=49 (71.0%) and only n=20 (28.9%) were not using any method of contraceptives. The most commonly reported method of contraception was injections (Depo provera / Nur Isterate) n=16 (32%) (Table 8).

#### **4.3 THE EXTENT/LEVEL OF SCREENING FOR CERVICAL CANCER AMONG WOMEN AGED 30 YEARS AND ABOVE IN RURAL KWAZULU-NATAL**

**Table 4.9: The report of previous screening for cervical cancer characterized per socio-demographic characteristics in rural women (69) aged 30 years and above enrolled in the study.**

<b>N=69</b>	<b>Frequency</b>	<b>Ever been screened</b>		<b>P- value</b>
		<b>No</b>	<b>Yes</b>	
<b>Age group</b>				
30-34	7 (10.1%)	3(5.4%)	4 (30.8%)	0.012
35-44	25 (36.2%)	23 (41.0%)	2 (15.4%)	
45+	37 (53.4%)	30 (53.6%)	7 (53.8%)	
<b>Marital status</b>				
Married	39 (56.5%)	31 (55.4%)	8 (61.5%)	0.69
Single	30 (43.4%)	25 (44.6%)	5 (38.5%)	
<b>Educational</b>				
None	18 (26.0%)	16 (28.6%)	2 (15.4%)	0.61
Primary	35 (50.7%)	28 (50.0%)	7 (53.8%)	
Secondary+	16 (23.0%)	12 (21.4%)	4 (30.8%)	

<b>Sexual Debut*</b>				
N=67	9 (13.4%)	8 (14.8%)	1 (7.7%)	0.91
<=15 years		28 (51.9%)	8 (61.5%)	* 2 values
16-19 years	36 (53.7%)		4 (30.8%)	missing
20 and above	22 (32.8%)	18 (33.3%)		
<b>Family Planning</b>				
None	20 (28.9%)	14 (25.0%)	6 (38.5%)	0.33
Yes	49 (71.0%)	41 (75.0%)	8 (61.5%)	
<b>Contraception method N=49</b>				
Condom	10 (20.4%)	7 (17.1%)	3 (37.5%)	0.04
Injectable		16 (39.0%)	0 (0)	
Pills	16 (32.6%)	6 (14.6%)	3 (37.5%)	
Sterilized	9 (18.3%)	12 (29.3%)	2 (25.0%)	
	14 (28.5%)			
<b>Gravid</b>				
(Pregnancies)	2 (2.8%)	2 (3.6%)	0 (0)	0.196
None	17 (24.6%)	11 (19.6%)	6 (46.2%)	
1-3	22 (31.8%)	18 (32.1%)	4 (30.8%)	
4-5	28 (40.5%)	25 (44.6%)	3 (23.0%)	
5+				
<b>Employment</b>				
Unemployed	51 (73.9%)	44 (78.6%)	7 (53.9%)	0.22
Employed	18 (26.0%)	12 (21.4%)	6 (46.1%)	

Out of the 69 women enrolled in this study, only n=13 (18.8%) reported having ever been screened for cervical cancer in their lifetime, and n=56 (81.1%) of the sample had never screened for cervical cancer. The sample was comprised of women from age 30 and above, above half n=37 (53.6%) of women aged 45 years and above had never been screened for cervical cancer, the p-value suggests a significant statistical difference (p=0.012). A greater proportion of married women n=8 (61.5%) reported having been screened for cervical cancer compared to n=5 (38.5%) for single women. Half of women with primary education n=28

(50.0%) had never been screened, however just above half n=7 (53.8%) reported ever been screened. Only n=2 (15.4%) women with no education reported ever been screened for cervical cancer. The greater proportion of women who reported sexual initiation between 16-19 years had never been screened n= (51.9%) while n=8 (14.8%) of the sample who reported sexual initiation as age 15 or less had never been screened. A third of women who reported sexual initiation from age 20 and above had never been screened n=18 (33.3%). Just above half n=8 (61.5%) of women who reported family planning had ever been screened, compared to a third n=6 (38.5%) of the sample who were not on any form of contraception. None of the women using injectable contraceptives had ever been screened. Women who were using other forms of contraceptives reported previous screening in almost proportional percentages, condoms n=3 (37.5%), pills n=3 (37.5%) and sterilization n=2 (25.0%). The p-value=0.04 suggests a significant statistical difference in the groups. The proportion of ever being screened for cervical cancer was almost half n=6 (46.2%) in women who reported 1-3 pregnancies and decreased with increasing number of pregnancies, 4-5 pregnancies n=4 (30.8%) and 5+ pregnancies n=3 (23.0%). The reports of prior screening per employment status was almost equal, unemployed n=7 (53.9%) and employed n=6 (46.1%). Reporting of prior screening for cervical cancer characterized per socio-demographic factors is shown in table 9.

#### 4.4 FACTORS ASSOCIATED WITH BEING SCREENED FOR CERVICAL CANCER IN WOMEN AGED 30 YEARS AND ABOVE

**Table 4.10: Factors associated with having been screened for cervical cancer in women aged 30 years and above in rural KwaZulu-Natal**

N=69	Ever been screened:		Odds Ratio [95% CI]	p-value	Adjusted odds ratio CI
	No	Yes			
<b>Age group</b>					
30-34	3 (5.4%)	4 (30.8%)	1		
35-44	23 (41.0%)	2 (15.4%)	0.06 [0.008-0.52]	0.01	0.09 [0.010-0.79]
45+	30 (53.6%)	7 (53.8%)	0.05 [0.03-0.97]	0.05	0.12 [0.03-1.49]

<b>Marital status</b>				
Married	31 (55.4%)	8 (61.5%)	1	
Single	25 (44.6%)	5 (38.5%)	0.78 [0.23-2.27]	0.69
<b>Educational level</b>				
None	16 (28.6%)	2 (15.4%)	1	
Primary	28 (50.0%)	7 (53.8%)	2.0 [0.37-10.8]	0.42
Secondary+	12 (21.4%)	4 (30.8%)	2.67 [0.42-17.05]	0.30
<b>Sexual debut</b>				
<=15 years	8 (14.8%)	1 (7.7%)	1	
16-19 years	28 (51.9%)	8 (61.5%)	2.29 [0.25-21.09]	0.47
20 and above	18 (33.3%)	4 (30.8%)	1.78 [0.17-18.53]	0.63
<b>Employment</b>				
Unemployed	44 (78.6%)	7 (53.9%)	1	
Employed	12 (21.4%)	6 (46.1%)	3.14 [0.89-11.1]	0.07

The researcher was assisted by the Stellenbosch statistician to analyse data in SAS statistical programme using Fisher's Exact Test to explore significant differences in the two groups, women who ever screened for cervical cancer and those who had never screened for cervical cancer. When comparing women who had reported having been screened for cervical cancer to women who had never been screened, Table 10, the only factor that was significantly associated with screening was age in univariate analyses. Older women aged 35 to 44; 45 and above were significantly less likely than women aged 30 to 34 years to screen for cervical cancer (OR: 0.06; 95% CI: 0.008-0.52), and women aged 45 years and above (OR: 0.18; 95% CI: 0.03-0.97). Single women were less likely than married women to go for cervical cancer screening, but this difference was not statistically significant. The level of education achieved seemed to increase the likelihood to screen, twice if a woman had primary education (OR 2.0) and almost 3 times (OR 2.67) if a woman had secondary and higher education; however this difference was not statistically significant.

Employed women were 3 times more likely to screen for cervical cancer compared to unemployed women, but the difference was not statistically significant (p=0.07). Other

factors considered but not presented as they contained values more than 1 were contraception and gravid. In multivariate analysis factors with a p-value of 0.1 or less were considered. Women aged 35 to 44 remained significantly less likely than women 30 to 34 years to screen for cervical cancer (aOR 0.09; 95% CI: 0.10-0.79). The result of factors associated with previous screening for cervical cancer is presented in Table 10.

#### **4.5 KNOWLEDGE, PERCEPTION AND ATTITUDES ON CERVICAL SCREENING AND CERVICAL CANCER OF WOMEN AGED 30 YEARS AND ABOVE**

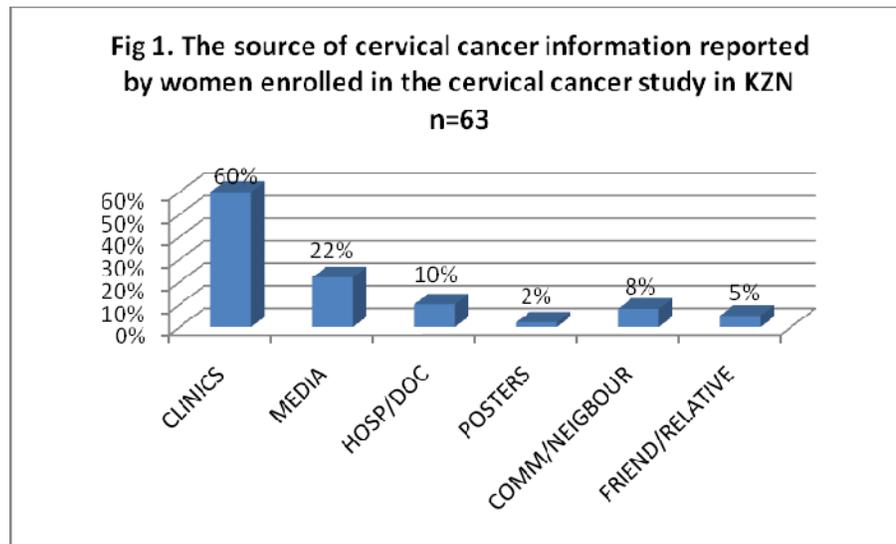
##### **4.5.1 Knowledge about cervical cancer and the main source of information**

**Table 4.11: Cervical cancer description by women aged 30 years and above enrolled in the study survey in rural KwaZulu-Natal n=69**

<b>Cervical Cancer description</b>	<b>n</b>	<b>%</b>
Could not give a cancer description	22	32%
Bad/fatal disease of the uterus curable if diagnosed early	22	32%
Sores or growths in the uterus	13	19%
Irregular/heavy per vaginal bleeding	10	14.5%
Lower abdominal pain or per vaginal discharge	2	2.9%
Caused by having multiple sexual partners	1	1.4%
Know disease but has never seen someone affected	1	1.4%

A greater percentage of the sample reported having information on cervical cancer and screening n=63 (91.3%). However, when asked to describe cervical cancer n=22 (32%) of the respondents could not. Of those who had some information about cervical cancer, a greater percentage n=22 (32%) of respondents gave a general description of a bad disease or fatal disease of the uterus which is curable when diagnosed early. Responses given on the description of cervical cancer are presented in table 11.

#### 4.5.2 The main source of cervical cancer information



**Figure 4.1: The main source of cervical cancer information reported by women enrolled in the cervical cancer study in rural KZN.**

The main source of information was obtained at the clinics (district and MDP clinics) n=38 (60.3%), some got information from the media n=14 (22%), hospital or private doctors n=6 (10%), relatives or friends n=3 (5%) and community or neighbours n=5 (8%). Only one (2%) who responded mentioned posters as the source of cervical cancer information (Fig 1.)

#### 4.5.3 Cervical cancer risk factors, screening and prevention

**Table 4.12: Knowledge of cervical cancer risk factors, screening and prevention by women aged 30 years and above, enrolled in the cervical cancer survey in rural KwaZulu-Natal n=69**

Variables	Responses	n	%
<b>Have information on cervical screening</b>	No	6	10.7%
	Yes	63	89.2%
<b>Cervical cancer screening test</b>	Don't know	7	24%
	Blood	2	2.9%
	Pap smear	48	69.5%
	Urine	2	2.9%
<b>Risk factors knowledge</b>	Sufficient answers (3 correct responses)	4	24%
	No/wrong answers	40	57.9%
	Insufficient answers (one or two correct)	25	36.2%

<b>cervical cancer preventable</b>	Yes	42	60.9%
	Don't know	21	30.4%
	No	6	8.7%
<b>Prevention methods n=42</b>	Early screening/management	28	66.7%
	Treating STIs	6	14.2%
	Protected sexual intercourse	5	12.0%
	Surgical removal of the affected part	3	7.1%
<b>Frequency of cervical cancer screening</b>	Every 2 years	5	7.25%
	Every 6 months	33	47.8%
	Yearly	14	20.3%
	monthly	15	21.7%
	3 times in a lifetime from age 30	2	2.9%
<b>Total</b>		69	100%

When asked to give at least three risk factors for cervical cancer, only n=4 (5.8%) gave sufficient and correct answers. More than half of the sample n=40 (57.9%) did not give a single response or else gave wrong responses. About a third gave one of the three required responses n=25 (36.2%). The most commonly stated risk factors were: early sexual debut n=18 (62%), smoking n=8 (28%), untreated sexually transmitted infections n=15 (52%), multiple births n=10 (34%). None of the respondents mentioned HPV as a risk factor. Others cited signs of invasive cancer as risk factors, for an example heavy or irregular menses and offensive vaginal discharges.

When asked about a cervical cancer screening test n=17 (24.6%) did not know, however, above half n= 48 (69.5%) knew a Pap smear screening test. Just a few mentioned blood and urine as cervical cancer screening tests, 2 (2.9%) respectively. Only n=2 (2.9%) knew that women should at least screen 3 times in their lifetime from age 30. Almost half n=33 (47.8%) thought women should screen every 6 months, yearly n=14 (20.3%), or every 2 years n=5 (7.25%). Some thought women should screen for cervical cancer monthly or every 3 months n=15 (21.7%).

Above half of the sample n=42 (60.9%) knew that cancer of the cervix can be prevented, n=21 (30.4%) did not know and n=6 (8.7%) said it cannot be prevented. Of those who knew it can be prevented, a greater percentage correctly stated that early screening (Pap smear) and

early management can prevent cervical cancer n=28 (66.7%). Other preventive measures stated were treating sexually transmitted infections, protected sexual intercourse, and surgical removal of the affected part. Data is tabulated in Table 12.

#### 4.5.4 Cervical cancer screening perceptions and knowledge thereof

**Table 4.13: Cervical cancer screening perceptions and women's knowledge thereof enrolled in the cervical cancer study in rural KwaZulu-Natal n=69**

<b>Variables</b>	<b>Responses</b>	<b>N</b>	<b>%</b>
<b>Perceives self at risk</b>	No	27	39.2
	Yes	42	60.8
<b>Ever been screened for cervical cancer</b>	No	56	82
	Yes	13	18
<b>Reasons for not screening</b>	Did not have information	48	85.7
	Told procedure painful	6	10.7
	Too embarrassed to expose private parts	2	3.5
<b>Intention to screen in the future</b>	No	5	7
	Yes	64	93
<b>Reasons for unwillingness to screen for cervical cancer in the future</b>	Told had no cancer	2	40
	Had a hysterectomy performed	2	40
	Felt the procedure was too embarrassing	1	20
<b>Ideal screening centre/institution</b>	District clinics	46	72
	Hospital	13	20
	Private doctor	5	7.8

Above half of the sample n=42 (60.8%) considered themselves to be at risk of cervical cancer, however n=27 (39.2%) did not. Despite a greater percentage perceiving themselves at risk only n=13 (18.8%) had ever been screened in their lifetime and n=56 (81.1%) had never been screened. The reasons that were given for not screening previously was that they did not have information n=48 (85.7%) and n=6 (10.7%) were told the procedure is painful. Others were too embarrassed to expose their private parts n=2 (3.5%). Only one cited negative attitudes of health care providers as a barrier to screening. Some women thought one should only screen when one has symptoms. Of those who screened previously no negative attitudes or experiences were reported except for one who reported not receiving results following a screening test. Intentions for future screening were established and almost all but five women

were willing to test n=64 (93%). The most common service provider sited as ideal was the district clinic. Women who had no intention to screen in the future gave various reasons. They said they had a hysterectomy performed n=2 (40%); they said they were told that they had no cancer n=2 (40%); one felt the procedure was too embarrassing n=1 (20%) (Table 13).

#### **4.6 SUMMARY**

In chapter four the socio-demographic characteristics of women who enrolled in the cervical cancer awareness and knowledge study and also instances reflecting cervical screening history have been described. The extent/level of cervical cancer screening and associated factors have also been explained. The analysis showing factors associated with having had screening for cervical cancer versus never having had screening has also been described. Finally, a description of knowledge, perceptions and attitudes has been presented and described. The next chapter will have a discussion of findings, including an explanation of overarching factors and implications where appropriate, the conclusion drawn and recommendations suggested.

## **CHAPTER 5: DISCUSSION AND RECOMMENDATIONS**

### **5.1 INTRODUCTION**

The study was aimed at determining factors influencing access to cervical screening services and utilization of such services. Knowledge and perceptions of women on cervical cancer and screening and socio-demographic characteristics influencing screening were also determined and characterized. This chapter discusses findings of the study, the extent to which they may be generalizable, the limitations of the study and recommendations are subsequently suggested. The discussion is presented in three sections according to the objectives of this study, namely socio-demographic characteristics, the rate of screening for cervical cancer and factors associated with previous screening for cervical cancer and knowledge, and perceptions on cervical cancer and screening.

### **5.2 FINDINGS**

#### **5.2.1 Socio-demographic characteristics of women**

The sample for the analyses included n=69 women from age 30 and above. Although this is a small sample size, it is not inconsistent with demographic and socio-economic data that has been previously reported in this rural geographic area. The sample comprised mainly middle aged women since the study exclusively enrolled women from age 30 and above. This age group is consistent with age intervals as laid down in the National cervical screening programme (Moodley, 2009:11). More than half n=51 of the sample had some form of education, though almost half of the sample had only achieved primary education. The greater proportion of women were unemployed, however, this factor could not have hindered women from accessing district health services for screening since the services are provided free of charge.

The employment rate was also very low, with only n=18 (26%) of women being employed either part-time or full-time. However, the analyses included a high sample of unemployed women, although this may be expected given that the microbicide study clinics were primarily open during work hours. This high unemployment rate is a cause for concern and reflects a challenge in reaching the millennium target of achieving permanent and decent work for all,

including women, and also halving the proportion of people who suffer from hunger by 2015. This could negatively impact on access to health care services (including cervical screening services), especially where women are required to pay transport fees. Contrary to expectations it was encouraging to note that over half of these women (71%) were accessing contraceptives. This high proportion might have been influenced by participation to the Microbicide clinical trial, where women were strongly counselled to use contraceptives. The goal of achieving universal access to reproductive health by 2015 is possible, given the high contraceptive prevalence in this rural population (KwaZulu-Natal health website, Millennium Development Goals (MDG) indicators, 2008).

### **5.2.2 The rate of screening and factors associated with having been screened for cervical cancer**

Despite a greater percentage (60.8%) of women perceiving themselves at risk of cervical cancer, a very low percentage (18.8%) had ever been screened in their lifetime. Research conducted in other countries have shown similar results, in most cases women thought one needs to go for a test as a result of a recommendation by a health professional (Adanu, 2002:487-488; Ezem, 2007:95). Moodley (2009) re-iterates that, in reality women in developing countries usually attend health care for cervical smear when the disease is symptomatic and progressed to advanced stages. Both women and health care workers attest to women accepting cervical cancer screening when they are symptomatic as opposed to a health screening test (Wood & Jewkes, 1996:10; Leyden, Manos, Geiger, Weinmann, Mouchawar, Bischoff, Yood, Gilbert and Taplin, 2005:677; and Hoque, Hoque and Kader, 2008:112). The research studies have shown a high HIV incidence in this rural KwaZulu-Natal population 3.4 per 100 person-years from the years 2003-2007 (Bärnighausen, Tanser and Newell, 2009:406), and the risk of cervical cancer is also high. However, the cervical screening frequency does not correlate to the risk. The cervical cancer screening frequency also needs to be revised especially for HIV exposed and infected women since the literature suggests that disease progression to invasive cancer usually occurs ten years earlier in HIV positive women (Health Systems Trust, 2009:1; Franceschi & Jaffe, 2007:511).

There are very few differences between women who had been or had never been screened for cervical cancer. This is possibly indicative of a generalized low utilization of cervical screening in this population especially in relation to low awareness levels on cervical cancer and screening in KwaZulu-Natal. There was a greater concordance among the various local

studies in the low cervical screening rates in women (Abrahams, Wood & Jewkes, 1996:22; Moodley, 2009:12). A study conducted in KwaZulu-Natal did not find any significant predictor for doing a Pap smear among respondents; however this study was conducted among university students (Hoque & Hoque, 2009:22). This may be indicative of a general awareness, knowledge and access problem irrespective of educational background.

Women with lower socio-economic status were less likely to go to clinics for screening for cervical cancer, although this difference was not statistically significant. This raises concerns since government primary health care services are provided free of charge. It is not clear whether this is linked to perceptions in the community about free health services, and addressing this might shed some light on reasons for this relationship. Older women between the ages 35-44 were less likely to screen for cervical cancer compared to younger women. Leyden et al., (2005) found similar results. This is of great concern since at these ages women should at least have received a second Pap smear (according to the National screening programme). According to Abrahams et al., (1996: 8), “*early screening services focused on family planning attenders and women using antenatal services*”. Even when considering this earlier focus, with more than half n=49 (71%) of the sample reporting using family planning, one would expect that a greater proportion of women were reached with this educational information at some stage. Evidence from prior research indicates that hearing about cervical screening does not always translate to higher usage of the screening service (Adanu, 2002:487; Twinn, Shiu and Holroyd, 2002:382; Abrahams, Wood and Jewkes, 1996:12; Hoque, Hoque and Kader, 2008:113). There should be a considerable amount of packaging messages in line with the target population coupled with re-enforcement of messages. The focus should be on all women receiving comprehensive health services including screening for cervical cancer. This study recruited women who were already utilizing primary health care services, therefore one would expect the utilization for cervical screening to be higher than the result presented.

The odds of cervical screening were less in single women compared to married women. Studies conducted elsewhere have shown a significant difference of cervical screening and marriage, with married women more likely than single women to screen for cervical cancer (Twinn et al., 2002:379; Leyden et al., 2005:677). This could be attributed to differences in risk perceptions by marital status. In other studies women explained the role played by marital partners as vital to the utilizing of screening (Twinn et al., 2002:380; Ezem, 2007:95).

Wong et al., (2009) also reported that married women had a higher recognition of cervical cancer risk factors than unmarried women. The health educational initiatives on cervical cancer should not only target women since male partners have a potential of playing a vital role in increasing utilization of this service.

### **5.2.3 Knowledge and perceptions of women on cervical cancer and screening**

Women who were enrolled in this study were exposed to some education on cervical cancer screening, since this service was provided as standard of care to all Microbicide clinical trial participants. Despite this exposure, the level of knowledge was still low in this group. A greater proportion of women who had never tested cited lack of awareness as the main reason. According to Moodley (2009:11-12), the main barriers to testing in developing countries are a lack of awareness of the disease and screening, women not availing themselves of screening services and lack of political will to provide the service. Dissemination of information should focus on all women especially eligible women (aged 30 years and above in the South African context). Women seem to remember messages re-enforced, this is evidenced by more than two thirds (n=15) of women stating that the Pap smear should be conducted every three months. Women in this cohort were screened for sexually transmitted infections (STIs) every three months through pelvic examination and cervico-vaginal sample collection. There is a possibility that the Pap smear cervical cancer screening test, which was conducted once at enrolment, was confused with the three monthly screening for STIs that were conducted as part of the microbicide clinical trial procedures. This indicates that re-enforcement of positive and correct messages could be helpful to motivate women to screen for cervical cancer. It is of vital importance to carefully package cervical cancer and screening messages and also to ensure that the wider female population is reached. Lyttle and Stadelman (2006:6), also found uncertainty on the frequency of cervical screening tests with women reporting that cervical screening should be performed six monthly. The basic screening test was known by more than half of the sample, however it is worrying to note that despite women having been exposed to the same screening test, still almost 30% did not know the basic cervical cancer screening test. Earlier studies conducted in the same rural population found similar results (Wood & Jewkes, 1996:9). There is a great need to empower women to understand their health care needs and also basic screening procedures so as to increase the uptake of this service.

It was encouraging to learn that a greater proportion of women received cervical cancer information from the clinics or community health workers. Hogue and Hogue, (2009:22); Ezem, (2007:95); Abrahams et al., (1996:29); Lyttle and Stadelman, (2006:3) found similar results. Conversely, Wong, Wong, Low, Khoo and Shuib, (2009) reported that lack of recommendation by health care providers hindered women in screening for cervical cancer. In addition, preventive counselling to reduce the risk of cervical cancer is viewed as of less importance by health professionals in other settings (Tessarro, Herman, Shaw and Giese, 1996:272). Only one woman stated that she got cervical cancer information from the posters. This further intensifies the need for all health care professionals who come into contact with women to include cervical cancer and screening information in the health talks. Women showed lack of understanding of the basic female anatomical parts; they vaguely described cervical cancer as a bad and fatal disease without mentioning the cervix. Wood and Jewkes (1996:16) found similar results in earlier studies conducted in this population. It is important to explore terminology used by women to refer to female parts, adjust and use these in the health educational talks.

Lack of sufficient knowledge was demonstrated by more than half (57%) of women not knowing risk factors for cervical cancer. The danger of not knowing risk factors is that chances of prevention of behavioral risk factors are almost non-existent. This then results in a greater proportion of women at risk of cervical cancer. Literature reports that HPV is a significant risk factor for cervical cancer (Khan, Castle, Lorincz, Wacholder, Sherman, Scott, Rush, Glass and Schiffman, 2005:1073; Chirenje et al., 2002:766). The same premise may apply about ignorance on whether cancer can be prevented or not. This study showed that women knew that cancer could be prevented. Women (60%) of the sample also correctly stated that cervical cancer could be prevented through early screening and management. This would form a basis for motivating women to screen for cervical cancer. Willingness to screen in the future was also a strong factor in this sample. Conversely, in other populations, lack of willingness to test is attributed to perceived lack of personal susceptibility to cervical cancer (Wong et al., 2009:50). Lyttle and Stadelman (2006:4), reported misconceptions for future screening like a previous hysterectomy regardless of the reason. There is need to scale up health education on cervical screening services and also access to such services so as to increase impact in reduction of cervical cancer incidence and mortality due to invasive cancer.

### **5.3 BIAS AND LIMITATIONS**

Information and selection bias might have occurred as women were recruited from primary health care clinics, so this study might have underestimated patients who never sought care and those who normally seek care from other services. The HIV positive status was an exclusion criterion for enrolment to the Microbicide clinical trial from which the sample for this study was drawn. It was, therefore, not possible to explore whether there are any differences in knowledge and perception levels in women who are HIV positive. The current national screening guideline does not discuss frequency of screening for HIV positive women. This should be included and also communicated to the wider population so as to correct misconceptions around cervical cancer.

The researcher aimed to enrol 120 women in this study, but due to time constraints ended up with a sample of 69 respondents. However, this sample is representative of the women eligible for cervical screening as per the National cervical screening policy. The non-probability convenience sampling might have decreased the samples' representativeness of the population and also offered little opportunity to control for biases. The small sample size may well have masked real differences between the groups that could not be detected due to very wide confidence intervals in some analyses. The weakness of this analysis is that the sample is small and results cannot be generalizable to other populations in which studies on cervical cancer knowledge and perceptions are conducted.

### **5.4 CONCLUSION AND RECOMMENDATIONS**

The sample for this study was drawn from women who were participating in the Microbicide clinical trial in which cervical screening was offered as a standard of care. However, this study revealed that there is limited information about cervical cancer, risk factors and cervical screening among this population. Also these results suggested poor dissemination of information by health care professionals. Women in rural populations rely mostly on health care professionals to educate and recommend health care practices that are beneficial in terms of health promotion. Women stated lack of information as the main barrier to screening; most surprisingly these women were recruited from health care services. Cervical screening initiatives should aim to reach women who have never had a Pap smear done and all eligible women.

Information pamphlets or posters should be user friendly i.e. translated to the local language and also distributed to the female population as widely as possible. The health managers should review packaging of information so as to simplify complex terminology when necessary to enhance understanding by all women. The use of audio-visual aids presented in the local language (for example video clips in clinic/hospital waiting rooms) should be reinforced. Cervical cancer and screening messages should form part of the basic health education package offered to all women, irrespective of their health status. Mini surveys should also be periodically conducted to elicit the level of understanding on cervical cancer and the importance of screening. Information obtained would then assist health professionals to further improve the screening services.

The national screening guideline should be revised to include cervical cancer screening in HIV positive women, and also resources should be scaled up in line with the HIV prevalence in this population. This should be coupled with staff training and periodic in-service education, but also revision of basic health programs would also be necessary. Health educational initiatives should also target men since studies suggest that male partners could play a vital role in increasing the awareness of this service. It is recommended that further large scale studies be conducted to focus on exploring health care resources that influence access across the district so as to better understand reasons for the low uptake of the screening service in this rural community.

## **5.5 CONCLUDING REMARK**

Most of the women in this study had never been screened for cervical cancer in their lifetime as reflected by n=14 (18%) ever screened and n=55 (82%) never screened for cervical cancer in this study. The results of this study cannot be generalised to the population due to the small sample size. However, there a need to re-inforce a comprehensive health education and cervical screening programme to target women in rural communities and to ensure the success of the cervical screening programme. The results of this study showed that 60% of respondents were informed by health care professionals on cervical cancer screening. Health care workers also should play a vital role in educating communities on cervical cancer and on the benefits for cervical cancer screening, reaching all patients who utilise health care services with this information and also communities through outreach programmes. Attempts should be made to reach women who rarely visit health care services, for example, through increasing health campaigns in partnership with other organizations in the area.

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## APPENDICES

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### Appendix A: Questionnaire

**Title: Women's awareness, knowledge and experiences regarding cervical cancer and cervical cancer screening in rural KwaZulu-Natal.**

(dd/mm/yyyy)

Cervical cancer survey questionnaire		Date filled: <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> / <input style="width: 20px; height: 20px;" type="text"/>	
Screening number:	Initials:	Year of Birth/ Age:	Trial number:
<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>	<input style="width: 20px; height: 20px;" type="text"/>

**Interviewer: Complete this CRF for participants aged 30 years and above ONLY. Read all questions verbatim and allocate the correct answer from the selection. Translate to local language as appropriate. Boxed type is instructions to the interviewer. Type in italics is to be answered by the interviewer from the information provided by the volunteer.**

#### Section 1: Socio-demographics

1	What is your marital status?	<i>Married</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Single</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Divorced</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Widowed</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Other</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Specify</i> _____	
2	What is the highest standard of education attained?	<i>None</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Primary ( Grade1-7)</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Secondary (Grade 8-10)</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Completed Matric</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Completed tertiary</i> <input style="width: 20px; height: 20px;" type="checkbox"/> <i>Student</i> <input style="width: 20px; height: 20px;" type="checkbox"/>	

## Questionnaire continued...

**Title: Women's awareness, knowledge and experiences regarding cervical cancer and cervical cancer screening in rural KwaZulu-Natal.**

Cervical cancer survey questionnaire		(dd/mm/yyyy)	
		Date filled: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
Screening number:	Initials:	Year of Birth/ Age:	Trial number:
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

3a	How can you describe your employment status at present?	<i>Employed full-time</i> <input type="checkbox"/> <i>Employed part-time</i> <input type="checkbox"/> → <i>Unemployed</i> <input type="checkbox"/> <i>student</i> <input type="checkbox"/> <i>Other</i> <input type="checkbox"/> <i>Specify</i> _____	<input type="checkbox"/> Q2b <input type="checkbox"/> → Q2b <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
3b	If answer to Q3a above is "yes" . How much do you earn per month?	<i>R500 and less</i> <input type="checkbox"/> <i>R501-R1000</i> <input type="checkbox"/> <i>R1001-R2000</i> <input type="checkbox"/> <i>R2001-R3000</i> <input type="checkbox"/> <i>More than R3000</i> <input type="checkbox"/> <i>Specify</i> _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
4	Are you on any method of contraception?	<i>Yes</i> <input type="checkbox"/> <i>No</i> <input type="checkbox"/>	<input type="checkbox"/> → Q4b <input type="checkbox"/>

4b	If answer to Q4a "yes" specify method.	<i>Pills</i> <i>Injectable Depo</i> <i>Injectable Nur Isterate</i> <i>Sterilised (self or partner)</i> <i>Condom (male or female)</i> <i>Other</i> <i>Specify</i> _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
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## Questionnaire continued...

**Title: Women's awareness, knowledge and experiences regarding cervical cancer and cervical cancer screening in rural KwaZulu-Natal.**

Cervical cancer survey questionnaire		(dd/mm/yyyy)			
		Date filled: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>			
Screening number:	Initials:	Year of Birth/	Age:	Trial number:	
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	

5	Have you ever been pregnant?		<i>Yes</i> <input type="checkbox"/> → 5b <i>No</i> <input type="checkbox"/> → Q6
5b	If answer to Q5 "yes" explain your parity.		0 <input type="checkbox"/> 1-3 <input type="checkbox"/> 4-5 <input type="checkbox"/> Above 5 <input type="checkbox"/>
6	How old were you when you first started sexual intercourse.	Age ( specify)	<input type="text"/> <input type="text"/>

**Section 2: Knowledge/ Awareness**

7	What do you understand by cervical cancer?	<hr/> <hr/> <hr/> <hr/> <hr/>		
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8	What basic test is conducted to screen for cervical cancer?	<i>Blood test</i>	<input type="checkbox"/>	
		<i>Urine test</i>	<input type="checkbox"/>	
		<i>Pap smear test</i>	<input type="checkbox"/>	
		<i>Don't Know</i>	<input type="checkbox"/>	

## Questionnaire continued...

**Title: Women's awareness, knowledge and experiences regarding cervical cancer and cervical cancer screening in rural KwaZulu-Natal.**

Cervical cancer survey questionnaire		(dd/mm/yyyy)	
		Date filled: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
Screening number:	Initials:	Year of Birth/ Age:	Trial number:
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

9	Do you have information about cervical cancer screening?, if so where did you get the from information?	Yes No	<input type="checkbox"/> <input type="checkbox"/>	
		If yes(Specify): _____		
10	Mention at least 3 risk factors for cervical cancer _____ _____ _____ _____	Answer correct /sufficient Answer insufficient Unable to judge	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
11	Can cervical cancer be prevented?	Yes No Don't Know	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	→ Q11a
11a	If answer to Q11"yes" how?	_____ _____ _____ _____ _____ _____		

Questionnaire continued...

**Title: Women's awareness, knowledge and experiences regarding cervical cancer and cervical**

Cervical cancer survey questionnaire		(dd/mm/yyyy)	
Date filled: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>			
Screening number:	Initials:	Year of Birth/ Age:	Trial number:
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

**cancer screening in rural KwaZulu-Natal.**

12	How often do you think women should screen for cervical cancer?	6 monthly  Yearly  Every 2 years  3 times in lifetime, from age 30 Other, specify _____ _____ _____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	
	<b>Section 3: Perceptions and attitude</b>			
13	Have you ever screened for cervical cancer (prior to joining the trial)?	Yes  No	<input type="checkbox"/> <input type="checkbox"/>	

## Questionnaire continued...

**Title: Women's awareness, knowledge and experiences regarding cervical cancer and cervical cancer screening in rural KwaZulu-Natal.**

Cervical cancer survey questionnaire		Date filled: <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
Screening number:	Initials:	Year of Birth/ Age:	Trial number:
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

13a	If answer to 13 above is "no" give reasons.	<i>Tick all that apply</i> No facilities available <input type="checkbox"/> Did not have information <input type="checkbox"/> Told procedure is painful <input type="checkbox"/> Did not have time <input type="checkbox"/> Other <input type="checkbox"/> Specify _____ _____		
13b	If answer to Q13 above is "Yes" describe your experiences.	Attitude of care provider negative and non-caring <input type="checkbox"/> <input type="checkbox"/> Procedure painful <input type="checkbox"/> <input type="checkbox"/> Procedure embarrassing <input type="checkbox"/> <input type="checkbox"/> Results not received/explained <input type="checkbox"/> <input type="checkbox"/> Other <input type="checkbox"/> <input type="checkbox"/> Specify _____ _____ _____	Y/N	



\_\_\_\_\_ End of form \_\_\_\_\_

## **Appendix B – Participant information leaflet and consent form**

TITLE OF THE RESEARCH PROJECT: Women’s awareness, knowledge and experiences regarding cervical cancer and cervical cancer screening in rural KwaZulu-Natal

**REFERENCE NUMBER:N08/08/206**

**PRINCIPAL INVESTIGATOR: Beauty Hlengiwe Ndlovu**

**ADDRESS: 3 Cooper Road, Empangeni, 3880**

**CONTACT NUMBER: Work: 035 550 7655; Mobile: 072 268 2875**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

**This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.**

### **What is this research study all about?**

- *This study will be conducted among 120 women enrolled in MDP301 clinical trial attending clinics for follow-up care between July and August 2009). These clinics are KwaMsane, Madwaleni and Mtubatuba.*
- *This study aims to find reasons that encourage or discourage women from testing for cervical cancer. These will be obtained through asking questions about cancer screening, experiences and knowledge about cervical cancer. The study of this nature is important as information obtained will be used to recommend alternatives or improvements in the present method of cervical screening service provision and promotion.*
- *Women (30 years and above) will be asked to participate in the study as they come to the MDP clinic. Full Information about this study will be given in your local language*

*and you will be asked to sign an informed consent to participate. Once full informed consent is obtained the researcher will then administer the questionnaire using local language understood by participants. All data obtained will be kept secured in a lockable cabinet until the analysis stage. The questionnaire administration will take approximately 10 minutes.*

- *There will be no randomization for this study. Participants will be asked to participate as they come to the clinic, this will be convenient sampling.*
- *No medications will be used in this study as it is not an intervention trial.*

**Why have you been invited to participate?**

- *You are invited to participate in this study to share your experiences, knowledge and perceptions of screening for cervical cancer and cervical cancer. According to the National cancer screening programme women should start screening for cervical cancer from age 30 and above, that is why this study will target women of your age.*

**What will your responsibilities be?**

- *You are asked to give true and honest answers to all questions asked. You will not be judged for answers given but where the researcher feels she/he needs to correct misconceptions she/he will do so after the interview.*

**Will you benefit from taking part in this research?**

- *There will be no direct personal benefit linked to participation in this study, however, information obtained might be used to improve cancer screening services and health promotion in the future.*

**Are there any risks involved in your taking part in this research?**

- *No major risks are envisaged through your participation in this study. Some minor risks could be spending a longer time than you expected in the clinic.*

**If you do not agree to take part, what alternatives do you have?**

- *Your participation in this study is voluntary, your non-participation will not jeopardise any health care you may seek in the future.*

**Who will have access to your medical records?**

- *Information collected will be treated as confidential and protected. All source documents will be kept locked in a filing cabinet. For trial participants screening numbers will be used. The research nurses collecting data and the researcher will have access to the information collected. Once analysed, information will be used in a publication or thesis, however, your identity will remain anonymous.*

**What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?**

- *Since this is a descriptive study and not an intervention study, no adverse events are anticipated, thus issues of insurance cover are not addressed.*

**Will you be paid to take part in this study and are there any costs involved?**

*No, you will not be paid to take part in the study but your transport and meal costs will be covered for each study visit. (NB re-imburement already covered for participants in the MDP trial) There will be no costs involved for you, if you do take part.*

**Is there anything else that you should know or do?**

- *You can contact the Committee for Human Research of the University of Stellenbosch at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.*
- *You will receive a copy of this information and consent form for your own records.*

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled (*Women's awareness, knowledge and experiences regarding cervical cancer and cervical cancer screening in rural KwaZulu-Natal*).

**I declare that:**

- I have read or had this information and consent form read to me and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2008.

.....  
Signature of participant

.....  
Signature of witness



**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did/did not use a translator. (*If a translator is used then the translator must sign the declaration below.*)

Signed at (*place*) ..... on (*date*) ..... 2008

.....  
Signature of investigator

.....  
Signature of witness

**Declaration by translator**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of IsiZulu.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her questions satisfactorily answered.

Signed at (*place*) ..... on (*date*) ..... 2008

.....  
Signature of translator

.....  
Signature of witness



## Appendix C - Ethical approval: Stellenbosch University



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

9 March 2009

Mrs. BH Ndlovu  
Dept of Nursing

Dear Mrs. Ndlovu

**RESEARCH PROJECT: "Women's awareness, attitudes and experiences to smear testing and cervical cancer in rural KwaZulu-Natal."**

**PROJECT NUMBER : N08/08/206**

It is my pleasure to inform you that the abovementioned project has been provisionally approved on 8 March 2009 for a period of one year from this date. You may start with the project, but this approval will however be submitted at the next meeting of the Committee for Human Research for ratification, after which we will contact you again.

Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary to make their final decision.

**Please quote the abovementioned project number in all future correspondence.**

Please note that a progress report (obtainable on the website of our Division) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

**Please note that in line with the recent changes to research ethics guidelines, including the Declaration of Helsinki, the CHR requires that all researchers specifically request and motivate for a "waiver of informed consent" for retrospective clinical audits.**

Federal Wide Assurance Number: 00001372  
Institutional Review Board (IRB) Number: IRB0005239

The Committee for Human Research complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Kind regards

  
Mrs. M. Davids  
Committee for Human Research  
**RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)**  
Tel: +27 21 938 9207 / E-mail: mertrude@sun.ac.za

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**Appendix D – Ethical approval: Research development and support**

02 April 2009  
Mrs BH Ndlovu  
Nursing Science

**MAILED**

Dear Mrs Ndlovu

"Women's awareness, attitudes and experiences to smear testing and cervical cancer in rural KwaZulu-Natal"

**ETHICS REFERENCE NO: N08/08/206 RE: RATIFICATION**

At a meeting that was held on 01 April 2009, the Committee for Human Research ratified the approval of the above project by the Chairperson.

Yours faithfully

**MRS EL ROHLAND**

RESEARCH DEVELOPMENT AND SUPPORT

Tel: 021 938 9677 / E-mail: elr@sun.ac.za

Fax: 021 931 3352

22 November 2010 15:16



**S**ERVICES

- English/Afrikaans
- \* Translations
- \* Editing
- \* Proof-Reading
- \* Academic Manuscript Preparation
- \* Archival Research
- \* Transcriptions from Archived Documents



Member: South African Translators' Institute (SATI)

3 Beroma Crescent  
Beroma  
Bellville 7530  
24 September 2010

*TO WHOM IT MAY CONCERN*

This letter serves to confirm that the undersigned

**ILLONA ALTHAEA MEYER**

has proof-read and edited the document contained herein for language correctness.

(Ms IA Meyer)

SIGNED