“THE WOMB PEOPLE”:
DETECTION, TREATMENT, AND PREVENTION OF CERVICAL CANCER
WITH THE KHAYELITSHA CERVICAL CANCER SCREENING PROJECT IN
KHAYELITSHA, SOUTH AFRICA

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Acknowledgements:

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Without you, I probably would have been homeless.
Abstract

The current policy concerning cervical cancer screenings is not effectively addressing the specific needs of the female South African population. The program, as outlined by the South African Department of Health, is not sufficiently accessing women due to problems in availability, access, organization, and education. As women are living longer with HIV/AIDS, due to antiretroviral (ARV) treatment, they are becoming more susceptible to opportunistic infections that can lead to cervical cancer, such as Human strains of the virus can be prevented with administration of an HPV vaccination and advancement of precancerous lesions can be detected and treated with current technology. Cervical cancer screenings and HPV vaccinations are expensive, however, and many women are not properly educated about their gynecological options in South Africa.

The staff at the Khayelitsha Cervical Cancer Screening Project in the Khayelitsha township of Cape Town provides effective, women-friendly services to the community, offering cervical cancer screenings and tertiary-level treatment to the women of the township. In addition to providing a much-needed service to the community, the Project works as a research facility and is currently exploring the safety of HPV vaccinations on HIV-positive women in order to promote further research and awareness concerning cervical cancer and HPV. This study aims to describe the status of cervical cancer screenings in South Africa and explore the advances made by the center to better women’s health.
Introduction

Cervical cancer is the second most prevalent form of cancer to affect women in South Africa, with 6,700 women developing the disease and more than half of those dying annually\(^1\). It is the most common cancer to affect black women,\(^2\) accounting for 25% of cancer deaths, and more than half of the deaths in the world attributed to cervical cancer occur in developing countries\(^3\). In addition, women who are HIV-positive are thought to be three to five times more likely to develop cervical lesions that could become cancerous\(^4\). This is because women who are HIV-positive are more susceptible to opportunistic infections, such as cervical cancer, and have an increased risk of contracting the Human Papillomavirus (HPV)\(^5\), which is present in 99.8% of cervical cancer cases. This creates a high-risk environment for the acquisition of cervical cancer in South Africa where approximately 13.3%\(^6\) of the female population is living with HIV/AIDS.

Previously during apartheid, there was no national policy concerning Papanicolaou (pap) smears, which is a screening test to detect malignant and premalignant cells in the ectocervix. In the early 1990s, after the end of apartheid, the South African Department of Health developed the Cervical Cancer Screening Program, which allows for three free pap smears per lifetime in 10-year intervals, starting at the age of 30\(^7\). This plan was implemented because it was considered cost-effective, due to

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\(^1\) Stevens, M., Bomela, N., ‘cervical cancer- is vaccination the way to go?’ Democratic Nursing Organization of South Africa, Nursing Update, May 2008, p. 37
\(^2\) Ibid.
\(^4\) Ibid.
\(^5\) Stevens, M., Bomela, N., ‘cervical cancer- is vaccination the way to go?’ Democratic Nursing Organization of South Africa, Nursing Update, May 2008, p. 37
\(^7\) Department of Health, “National Guideline on Cervical Cancer Screening Programme,” Date unknown
limited resources, and safe because women with at least one negative cervical Pap smear have low rates of invasive cancer for ten or more years\(^8\). About 20-30\(^%\)\(^9\) of women in South Africa over the age of 30, however, make use of the cervical cancer screenings. This may be due to lack of public reproductive education surrounding cervical cancer or discomfort due to the invasive nature of the procedure. Currently, most healthcare resources are dedicated to the overwhelming burden of disease such as HIV/AIDS and tuberculosis, while health concerns surrounding issues such as cancer have faltered.

South Africa has yet to effectively address cervical cancer as a legitimate issue. The percent of cancer deaths due to malignant neoplasm of the cervix uteri has risen from 7.6\(^%\) in 2001 to 8.1\(^%\) in 2005\(^10\), suggesting that the implemented screening program is not effective in curbing the incidence of cervical cancer among women in South Africa. This situation is further exacerbated by the HIV/AIDS epidemic in South Africa, where women are developing fast-growing cervical cancer at younger ages. Professor Lynette Denny and her team of women at the Khayelitsha Cervical Cancer Screening Project, a research institution in a township outside Cape Town, are providing women in the community with cervical cancer screening services, training, education, and transport to enable women to better access the gynecological services that they should be entitled to.

The Khayelitsha Cervical Cancer Screening Project is also currently studying the effect of HPV vaccinations on HIV-positive women. The HPV vaccination, which protects against HPV strains responsible for 70\(^%\) of cervical cancer cases\(^11\), currently costs

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\(^8\) Alliance for Cervical Cancer Prevention, “Cervical cancer Prevention Fact Sheet,” ACCP, 2003  
\(^9\) Stevens, M., Bomela, N., “cervical cancer- is vaccination the way to go?” Democratic Nursing Organization of South Africa, Nursing Update, May 2008, p. 37  
\(^11\) Cervarix, [http://www.cervarix.com](http://www.cervarix.com)
According to Professor Denny, "If made widely available, it has the potential to reduce cervical cancer by at least 70 percent - probably more - and is going to be much more implementable than screening, but it is currently too expensive." The cervical cancer screening and HPV vaccination systems currently in place do not acknowledge the rising threat that cervical cancer poses for women, especially those living with HIV. As HIV-positive women are living longer due to antiretroviral treatment, it is necessary to look at the opportunistic infections, such as cervical cancer, that will affect HIV-positive women in the future and invent creative solutions to combat this looming threat.

**Methodologies**

*Primary Sources*

The information presented in this study is drawn from an array of primary and secondary data relevant to the topics of cervical cancer and prevention in South Africa, and specifically to the research and services provided by the Khayelitsha Cervical Cancer Screening Project based in Khayelitsha. Primary data was obtained through guided interviews, informal conversations, and participant observation at the Khayelitsha Cervical Cancer Screening Project, the Khayelitsha Site B Day Hospital, Groote Schuur Hospital, the University of Cape Town School of Medicine, the African Organization for Research and Training in Cancer (AORTIC), and youth clinics in the townships surrounding Cape Town. In the Khayelitsha Cervical Cancer Screening Project, a research organization based in the peri-urban township, Khayelitsha, information was acquired through participating in the patient recruitment process with community health practitioners.

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13 Ibid.
workers, observing health practitioners perform cytologic screenings and colposcopic examinations, organizing patient files, and attending preliminary screening appointment for prospective study patients. Members of the Project were also important educational resources concerning past and current research studies, cervical cancer, and the community. Facilitated interviews and informal conversations with the principle investigator, project coordinators, nursing sisters, and community health workers were also useful in obtaining data on the research and services provided by the Project as well as information concerning the current status of gynecological and general health services offered in South Africa.

Additional data was obtained through other organizations and institutions in the Western Cape that specialize in cervical cancer screening advocacy and education. Informal conversations and interviews were conducted at Groote Schuur Hospital, a state-funded facility that works in conjunction with the University of Cape Town Medical School, which shed light on the conditions of tertiary level facilities in the Western Cape. Interviews and discussions were facilitated at AORTIC with Belmira Rodrigues, the Africa Operations Manager, which was important to understand the large-scale initiatives to educate African communities about and advocate policy concerning cervical cancer.

Other primary sources included informal conversations with patients and study subjects from the Khayelitsha Cervical Cancer Screening Project, the Khayelitsha Day Hospital, and Groote Schuur Hospital to understand the views of the community concerning cervical cancer screening policies and patients’ attitudes towards reproductive health. All patients spoken to were middle-aged Xhosa-speaking women from predominantly poor backgrounds who lived in and around the township of Khayelitsha.
For ethical reasons, the names of the respondents spoken to at the hospital are not used because a woman’s reproductive and sexual health should remain a private matter.

**Secondary Sources**

Supplemental data included scholarly journals, research articles, books, pamphlets, and posters. Journals and articles were obtained through recommendations by the staff at the Khayelitsha Cervical Cancer Screening Project and online databases such as EBSCOhost and Google Scholar, which are peer-reviewed and considered legitimate search engines. Other articles were obtained through organizations that advocate for reproductive health and cervical cancer awareness, such as EngenderHealth, the European Cervical Cancer Association (ECCA), the Global Alliance for Vaccines Initiative (GAVI), Instituto Catala d’Oncologia (ICO), the International Agency for Research on Cancer (IARC), the International Federation of Gynecology and Obstetrics (FIGO), and Jhpiego. All publications used for this study pertain to cervical cancer, with an emphasis on screening and treatment methods and policy implementation.
I. Epidemiology and Natural History of Cervical Cancer

**Biology of the Cervix**

The cervix is the lower portion of the uterus that meets the upper portion of the uterus. It is cylindrical in shape and contains a slender canal that connects the vagina with the inside of the uterus. The cervix plays an instrumental role in many female reproductive processes, including menstruation, fecundity, childbirth, and pleasure.

Figure 1.1: Gross anatomy of the cervix

The major physiological components of the cervix consist of structures differentiated by location and cellular structure (Figure 1.1). The upper half of the cervix located above the vagina is known as the supravaginal portion, which meets the uterus at the internal os. The lower half of the cervix that protrudes into the vagina through the anterior wall is known as the portio vaginalis, which opens into the vagina through the external os. The visible portion of the cervix exterior to the external os is known as the ectocervix, and is easily seen through the vaginal canal. The portion around the external

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14 Sankaranarayanan, R., Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” *A Practice manual on Visual Screening for Cervical Neoplasia*, Chapter 1, p 2, 2003
os including the canal that leads to the uterus is known as the endocervix. The cervical stroma consists of dense, fibrous tissue containing vascular, lymphatic, and nerve supplies to the cervix, with extensive sensory, sympathetic and parasympathetic nerve endings lie within the endocervix.

The cellular composition of the endo-and ectocervixes consists of stratified squamous and columnar epithelium. The stratified squamous epithelium spans several layers and consists of glycogen-rich cells with small nuclei and make up a major part of the ectocervix. The thin layer of epithelial cells line the endocervical canal and secrete mucus that lubricate the cervix and vagina. The columnar epithelium meets the squamous epithelium at the squamocolumnar junction, whose location changes depending on factors such as age and hormonal status. The maturation process of the cervix begins during childhood, where the squamocolumnar junction is located close to the external os. The cervix enlarges and the endocervical canal elongates during puberty, exposing more

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Figure 1.2: A schematic diagram of further maturation of immature squamous metaplasia. Note that healthy immature squamous metaplasia develops into mature squamous metaplastic epithelium, while infection with high-risk HPV types can lead to the growth of atypical squamous epithelium, which can develop into precancerous lesions.

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15 Sankaranarayanan, R, Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” A Practice manual on Visual Screening for Cervical Neoplasia, Chapter 1, p 7, 2003.
columnar epithelial cells. During this ripening stage, the squamocolumnar junction is located in the ectocervix and is displaced from the external os. Eventually over time, however, the acidic vaginal environment destroys the columnar epithelial cells, which are replaced by new, metaplastic squamous epithelium. Through the reproductive period of a woman’s life, the squamocolumnar junction moves back towards the external os, due to the replacement of columnar epithelial cells with squamous epithelial cells. During this process, immature metaplastic squamous epithelial cells can develop into two cell types (Figure 1.2). In most women, they grow to be healthy, mature squamous epithelium. In some instances however, immature squamous epithelium can progress to dysplastic, or abnormal, squamous epithelial cells due to infection with some forms of human papillomavirus (HPV). This is the first step to the progression of precancerous cervical lesions, and in some cases, invasive cancer.

**Human Papillomavirus and Cervical Cancer**

Infection with high-risk types of HPV is considered to be the major risk factor associated with the development of cervical cancer. Approximately 99.7% of cervical cancer cases are associated with infection with one or more types of HPV\textsuperscript{16}, with 60% of cancer-related infections due to HPV type 16 (HPV-16) and an additional 10% due to HPV type 18 (HPV-18)\textsuperscript{17,18}. The virus works by integrating its viral genome into the chromosomes of the host cell, thus leading to the formation of cervical neoplastic cells\textsuperscript{19}.

\textsuperscript{16} Jhpiego, “Jhpiego: Preventing cervical cancer through cost-effective, innovative approaches.” \url{www.jhpiego.org}, date unknown.
\textsuperscript{17} Tan, J., “Prospects for a vaccine to prevent cervical cancer.” Preventing Cervical Cancer in Low-Resource Settings: From Research to Practice, Jhpiego, p. 33 2006.
\textsuperscript{18} Other high-risk types of HPV associated with CIN include 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, and 68.
Cervical neoplastic cells are almost always seen in the transformation zone\textsuperscript{20} where columnar epithelial cells are being replaced by squamous metaplastic cells. The immature, undifferentiated squamous cells are the ideal targets for viral coercion and so it is during the reproductive period of a woman’s life that she is most at risk for developing atypical cervical growth due to HPV infection. It has been shown that a product of HPV viral genes E6 and E7, oncoproteins E6 and E7 will bind and inactive cell tumor suppressor proteins p53 and pRB, which can lead to malignant conversion\textsuperscript{21}. It has also been shown that chromosomal instability occurs in cells expressing these oncoproteins, including monosomies, chromatid gaps, and aberrant chromosomes\textsuperscript{22}. These chromosomal changes can lead to cervical intraepithelial neoplasia (CIN), which is characterized by enlarged nuclei, irregularities in nuclear contour, and decreased cytoplasmic content. While most of these HPV-induced cellular irregularities regress to normal, if left untreated they may progress to CIN, characterized by varying degrees of squamous intraepithelial lesions (SIL) and dysplasia leading ultimately to invasive carcinoma (Table 1.1).\textsuperscript{23} Without any intervention, about 50% of cases of high-grade SIL progress to cervical cancer.\textsuperscript{24}

\textsuperscript{20} Sankaranarayanan, R, Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” \textit{A Practice manual on Visual Screening for Cervical Neoplasia}, Chapter 1, p 8, 2003.


\textsuperscript{22} Ibid., p. S4.

\textsuperscript{23} Sankaranarayanan, R, Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” \textit{A Practice manual on Visual Screening for Cervical Neoplasia}, Chapter 1, p 10, 2003.

### Classification System for Cervical Intraepithelial Neoplasia (CIN)

<table>
<thead>
<tr>
<th>CIN Type</th>
<th>CIN I</th>
<th>CIN II</th>
<th>CIN III</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dysplasia</td>
<td>Mild Dysplasia</td>
<td>Moderate Dysplasia</td>
<td>Severe Dysplasia (Carcinoma in situ)</td>
</tr>
<tr>
<td>Bethesda Classification</td>
<td>Low-grade intraepithelial lesion (LSIL)</td>
<td>High-grade intraepithelial lesion (HSIL)</td>
<td>High-grade intraepithelial lesion (HSIL)</td>
</tr>
</tbody>
</table>

Table 1.1: The Relationship between CIN and the Bethesda System

Some symptoms of advanced invasive carcinoma include “intermenstrual bleeding, postcoital bleeding, excessive seropurulent discharge, recurrent cystitis, backache, lower abdominal pain, oedema of the lower extremities, obstructive uropathy, bowel obstruction, and breathlessness due to severe anaemia and cachexia.” As the cancer progresses, it spreads to various organs, uncluding the vagina, bladder, and rectum. Renal failure is also common because the ureter is compressed by the invasive tissue, causing ureteral obstruction. The survival rate of women with Stage 1A carcinoma, characterized by cancerous invasion limited to the cervix, is 96-99%. If the cancer is diagnosed in stage IV, in which the cancer has spread to distant organs, the survival rate is 15-20%. These statistics suggest that if caught early, cervical cancer is easily managed, while if left untreated, cervical cancer is fatal within 2 years for 95% of presented cases.

**Immunity and Cervical Cancer**

Cervical cancer develops slowly and can take anywhere from 10 to 20 years to develop from precursor to invasive carcinoma. Young women under the age of 30 typically present with low-grade precancerous lesions, however 90% of these lesions

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25 Sankaranarayanan, R, Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” *A Practice manual on Visual Screening for Cervical Neoplasia*, Chapter 1, p 9, 2003
26 Ibid., p 11.
27 Ibid., p. 12.
regress to normal\textsuperscript{30}. Lesions in women who are over 30 years of age, however, are more likely to advance to high-grade precancerous lesions, with the mean age of women presented with high SIL being 30 years of age\textsuperscript{31}. The control of precancerous lesions is mediated by both “innate and adaptive immune responses\textsuperscript{32}” with cellular immune responses being the most important in controlling lesions caused by HPV. Professor Lynette Denny, the Principle Investigator of Gynecology Oncology Unit in the Institute of Infectious Disease and Molecular Medicine at University of Cape Town, commented that “There’s much more HPV-related disease in HIV-positive women and that’s because to clear the HPV infection, you need what is called cell-mediated immunity, which is precisely the immunity that the HIV virus attacks.\textsuperscript{33}” Lesion persistency, therefore, is associated with “genetic, iatrogenic, or acquired cell-mediated immune deficiencies\textsuperscript{34}”, such as human immunodeficiency virus (HIV) and autoimmune deficiency syndrome (AIDS). There is a higher prevalence of HPV infection in women who are HIV-positive than those who are HIV-negative. In a study conducted by Cu-Uvin et al. examining the prevalence of cervical HPV in over 1,000 women through the HIV Epidemiology Research (HER) study, the prevalence of HPV infection in HIV-positive women was 64\% as opposed to 28\% in HIV-negative women\textsuperscript{35}. Duerr et al. reinforces Cu-Uvin’s study by examining the presence of abnormal cell growths found in the HER and found that cervical intraepithelial neoplasia was present in 19\% of HIV-positive women and 5\%
in HIV-negative women\textsuperscript{36}. Despite this data, the South African Department of Health states “to date, studies on the association between invasive cancer of the cervix and HIV infection are inconclusive.”\textsuperscript{37} Studies strongly suggest that immune responses necessary for the regression of low-grade cervical lesions caused by HPV is jeopardized in women who are HIV-positive and according to Jhpiego, a research organization affiliated with Johns Hopkins University, “co-infection with HIV is associated with a five- to tenfold increase in severe dysplasia and carcinoma \textit{in situ}, the precursors of invasive cervical cancer.”\textsuperscript{38} This relationship between HIV infection and development of precancerous cervical lesions is especially pertinent to South Africa, where 13.3\% of the female population is living with HIV/AIDS\textsuperscript{39}.

\textit{Related Risk Factors and Trends in Cervical Cancer Incidence}

Other factors that increase the risk of developing precancerous lesions include “multiple sex partners, multiparity, long term oral contraceptive use, tobacco smoking, low socioeconomic status, infection with \textit{Chlamydia trachomatis}, micronutrient deficiency, and a diet deficient in vegetables and fruits.”\textsuperscript{40} There are 275,000 deaths annually due to cervical cancer, with 80\% of these fatalities occurring in the world’s poorest countries\textsuperscript{41}. The high incidence of cervical cancer in developing countries may also be attributed to the poor allocation of resources and lack of cervical cancer screening programs in place. In South Africa, the incidence of cervical cancer in women of all ages

\textsuperscript{37} Department of Health, “National Guideline for Cervical Cancer Screening Programme,” p. 1, date unknown.
\textsuperscript{40} Sankaranarayanan, R, Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s iodine (VILI)” \textit{A Practice manual on Visual Screening for Cervical Neoplasia}, Chapter 1, p 9, 2003.
is approximately 30.2\textsuperscript{42}, as opposed to the world incidence of 16\textsuperscript{43,44}. In addition, the cervical cancer mortality rate is 16.5 as opposed to the world mortality rate of 8.9\textsuperscript{45}. With incidence and mortality rates in South Africa about twice as high as those for the world population, it seems apparent that cervical cancer interventions for the country are not sufficient to handle the burden of the disease. With regular screenings and proper treatment methods, cervical cancer is preventable. Unfortunately, a large number of cervical cancer cases presented in these countries are diagnosed in advanced stages and thus have poor survival rates\textsuperscript{46}.

II. Cervical Cancer Prevention

Primary and Secondary Prevention of Cervical Cancer

Cervical Cancer is both a preventable and treatable disease. Prevention of cervical cancer is categorized by primary and secondary efforts to curb the incidence of cancer. Primary prevention eliminates the possibility of obtaining disease. In the case of cervical cancer, one would prevent its acquisition by eliminating the risk of being infected with HPV. This can be achieved either by abstaining from sexual intercourse or through an HPV vaccination. While regular condom reduces the chances of contracting HPV by 70\%\textsuperscript{47}, the virus is spread through contact of genital organs and does not involve sexual penetration. Condoms protect only the penis and leave other areas of the genitalia susceptible to contracting HPV. Secondary prevention stops the progression of the

\textsuperscript{42} Incidence rate per 100,000 women
\textsuperscript{43} Incidence rate per 100,000 women
\textsuperscript{45} Ibid
disease once the individual has already become infected. Routine screenings for cervical cancer precursors followed by appropriate treatment is an effective preventative measure in curbing the incidence of cervical cancer.

Cervical screening techniques are most commonly performed through cytologic tests, also known as Papanicolaou (pap) smears. Screening involves exposing the cervix with a speculum and collecting cervical cells using an Aylesburg spatula, which effectively collects cells from the squamous epithelium and transformation zone where cervical abnormalities are most common. Collected cells are smeared and fixed on a slide. Prepared slides are sent to a laboratory where they are analyzed under a microscope. Cytologic testing is shown to be moderately sensitive and highly specific in detecting HSIL, however this depends on the purity of the sample and the skill of the technicians who read the slides. Women are referred for a colposcopy if there are any atypical cells found in the cytologic testing. In this procedure, a healthcare provider inspects an illuminated and magnified cervix with a colposcope and takes a biopsy of suspected lesioned tissue for pathological examination. If CIN is found in the biopsy, the woman is referred for CIN treatment, which currently includes cold knife conization, hysterectomy, large loop excision of the transformation zone (LLETZ), laser ablation, electrofulguration, and cryotherapy.

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49 Also known as loop electrosurgical excision procedure (LEEP).

Successful Interventions in Developed Countries

An example of a successful cervical cancer screening intervention was examined in the 1960s by the International Agency for Research on Cancer (IARC)\textsuperscript{51}. The organization examined mortality trends associated with cervical cancer and the effectiveness of well-organized screening programs in the Nordic countries- Denmark, Finland, Iceland, Norway, and Sweden. The cumulative mortality rates for all of these countries fell between the years of 1965 and 1982. The most drastic decrease occurred in Iceland, which had the widest target age range for screening, where mortality rates fell 84%. The cervical cancer intervention included cytologic testing and referral for colposcopy and treatment if atypical squamous cells were found.

The American College of Obstetrics and Gynecology\textsuperscript{52} recommends that women receive their first cytologic screening 3 years after first sexual intercourse or at age 21, whichever event comes first. They also suggest that women receive cytologic screenings yearly until the age of 30, in which women can begin receiving screenings every 2 to 3 years. They do not suggest an upper age limit to stop cytologic screenings, however they do comment that post-menopausal women have a lowered risk of developing abnormal cervical cells. Different guidelines apply for women who are HIV-positive. For example, women are screened with cervical cytology and if results are normal, then the screening is repeated 6 months later. If the results of the second cytologic evaluation are still normal, the patient can begin annual screenings. There are, however, no guidelines for how long HIV-positive women should be screened annually, but Joel Palefsy, an infectious disease specialist at University of California-San Francisco, suggests that “it


seems reasonable to continue annual screening for a long time, if not indefinitely, because these women are at especially high risk for persistent HPV infection, acquisition of new HPV types, or reactivation of previously latent HPV types.\textsuperscript{53} The American Society for Colposcopy and Cervical Pathology (ASCCP) guidelines suggest that HIV-positive women be referred routinely for colposcopy if found to have atypical squamous cells of undetermined significance (ASC-US) upon cytologic evaluation\textsuperscript{54}.

Cervical cancer screening interventions are successful in developed countries because they possess the infrastructure to implement these programs. Women generally have access to regular and repeated screenings, which is important because of their moderate sensitivity. Developed countries also possess the technology and trained laboratory analysts to process cytologic screenings. Access to reliable communication outlets is also important in that women can be contacted for follow-up treatment or referrals. Effective cytologic screening requires “lab infrastructure, trained cytotecnologists and pathologists for processing slides and reporting, internal and external quality control, and a system for communicating the results to the women. High quality training, continuing education, and proficiency testing of personnel are essential to ensure reliable testing.”\textsuperscript{55} There are even more requirements for effective CIN treatment, including access to colposcopy and surgical equipment.

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\textsuperscript{54} American Society for Colposcopy and Cervical Pathology, “Colposcopy guidelines for HIV-positive women.”

III. Cervical Cancer Screenings in the Context of South Africa

*South African National Policy Towards Cervical Cancer Screenings*

The South African Department of Health entitles women to 3 free pap smears per lifetime in 10-year intervals beginning at the age of 30. Women screened for the first time at age 55 or more will only have one pap smear in their lifetime if the first smear is normal. Screenings for diagnostic purposes, however, would be free for the patient since it is not included in the regular screening scheme. The total cost for cytologic consultation and laboratory analysis amounts to about R100 – 200 per visit, and due to the burden of other diseases, such as HIV/AIDS and TB, the South African government is unable to provide women with free, annual pap smears at clinics and hospitals. The current policy is based on research from Europe in the 1960s (Table 3.1). Researchers found from the study that if women were given pap smears annually between the ages of 35 and 65, therefore providing them with 30 cytologic screenings in their lifetime, it would reduce the cumulative incidence of cervical cancer by 94%, while if one were to provide cytologic screenings every 3 years, therefore allowing women to have 10 free cytologic screenings, it would reduce the cumulative incidence by 91%. “94% and 91% are statistically similar,” says Professor Denny, “so really the ideal screening interval is three yearly,” as recommended by the American College of Obstetrics and Gynecology. It has also been found that if women are screened every 10 years, therefore allowing them 3 screenings in a lifetime, the cumulative incidence of cervical cancer is reduced by 64%.

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57 Lynch, K. Observation at the Khayelitsha Cervical Cancer Screening Project, April
58 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuur Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
60 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuur Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
which is still a significant decrease in the acquisition of the disease. This screening system is believed to be the most cost-effective policy for cervical cancer screenings in the country. There is no national policy in place regarding cervical cancer screenings for HIV-positive women; however, the Western Cape recommends that HIV-positive women receive annual cervical cancer screenings.

### Relationship Between Number of Pap Smears and Incidence of Cervical Cancer

<table>
<thead>
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<th>Total number of smears per lifetime</th>
<th>Reduction in cumulative incidence of cervical cancer (%)</th>
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<td>94</td>
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<tr>
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<td>3</td>
<td>64</td>
</tr>
</tbody>
</table>

Table 3.1: Data the South African Department of Health used to create their cervical cancer screening policy.

### Effectiveness of the Implemented Policy

Theoretically, since the implementation of the current South African national health policy for cervical cancer screenings, there should be a 64% decrease in the cumulative incidence of cervical cancer in the country, but only if 100% of the female population is being screened. The national target is to screen at least 70% of women nationally, however only 20 – 30% of women are currently accessing these services. The percent of cancer deaths due to malignant neoplasm of the cervix uteri has risen from 7.6% in 2001 to 8.1% in 2005, suggesting that the implemented cervical screening program is not effective in curbing the incidence of cervical cancer among women in South Africa. There are many possible reasons for the low screening rate in the country,
including lack of education on cervical cancer prevention, transportation costs, and lack of trained health workers. In most developing countries, such as South Africa, cytologic screening is only accessible to a relatively small proportion of women who know about the services and can afford to use them. Cervical cancer is a universal threat to all women, however the incidence of cervical cancer is high in developing countries because of the poor implementation of screening programs. Professor Denny comments that “We [South Africa] have the same incidence of cervical cancer today than was found in Sweden in the 1950s, and then they introduced the mass screening programs which dramatically reduced the incidence of the disease. It’s not something special in developing countries, it is just that we don’t screen.” She goes on to say that the National Guidelines for cervical cancer in South Africa is merely a policy, “but not a program, and I think we haven’t implemented it… it requires a lot of effort and political will and a health system committed to doing that.”66

IV. Bettering Women’s Health in South Africa with the Khayelitsha Cervical Cancer Screening Project

The Khayelitsha Cervical Cancer Screening Project was established in 1996 under the supervision of Professor Lynette Denny in order to explore alternatives for cytologic screenings for the prevention of cervical cancer. The Project was established inside the boundaries of the Khayelitsha Site B Day Hospital and functions out of converted shipping containers donated by the Cancer Association of South Africa. The project is staffed by a variety of doctors, community health workers, nursing sisters, and project

66 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
coordinators who, in addition to performing research, provide gynecological services to the women of Khayelitsha.

The Cervical cancer Screening Project is based in Khayelitsha because it is one of the largest townships in Cape Town and has the population to support large-scale research projects. In addition to having a good sample size for study, Professor Denny says “it was an area at the time with virtually no services, so we were particularly interested in accessing women who hadn’t had pap smears and to see if we could set up some alternative systems to pap smears for preventing cervical cancer.” Since its advent in 1996, the project has screened over 16,000 women in 4 major projects and through a free cytologic screening service to the community. The project also provides a general women’s health service, which “ranges from helping women who are victims of domestic violence to dealing with HIV to other common medical problems, such as diagnosing diabetes and referring to the appropriate health care facilities.” The Cervical Cancer Screening Project in Khayelitsha exposes the challenges concerning the current gynecological policies, while at the same time making efforts to improve the availability and access of these services.

*Increasing Availability of Cervical Cancer Screening Services*

A research study was conducted in 1999 by the Khayelitsha Cervical Cancer Screening Project examining the effectiveness of alternatives to cytologic screening that

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67 Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
68 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuur Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
69 Ibid.
could be used for resource-poor settings\textsuperscript{70}. The study recruited 2944 women from Khayelitsha between the ages of 35 and 65 years. The women were screened using a combination of pap smears, HPV DNA testing, direct visualization after application with 5\% acetic acid solution (VIA), and cervicography to evaluate the sensitivity and specificity of each the techniques. Women with squamous intraepithelial lesions were referred for further treatment to receive a colposcopy.

A. Visual Inspection with Acetic Acid (VIA)

Visual inspection with acetic acid is the most widely evaluated visual screening test for squamous intraepithelial lesions. A solution of 5\% acetic acid can be applied to the cervix with a cotton swab and lesions appear acetowhite to the naked eye after 1 to 2 minutes\textsuperscript{71}. VIA is inexpensive, requires only acetic acid and a light source, involves little training, does not need a laboratory infrastructure, and yields results in a matter of minutes. The mechanism of action entails a chemical reaction between the acid and cellular proteins, causing coagulation\textsuperscript{72}. Areas of increased nuclear activity and DNA content, such as cervical neoplastic cells, show the greatest protein precipitation. High levels of coagulation block the normally red stroma of the cervix and are visualizing as white lesions along the transformation zone. Normal squamous epithelium does not show coagulation because the superficial layer of the epithelium is sparsely nucleated, and this contains a low cellular protein content. In the study, VIA was accompanied by


\textsuperscript{71} Lynch, K. Observation in Colposcopy Clinic, Groote Schuur Hospital facilitated by Professor Lynette Denny. Observatory, Cape Town, 10:30 am, April 17, 2009.

\textsuperscript{72} Sankaranarayanan, R, Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” A Practice manual on Visual Screening for Cervical Neoplasia, Chapter 1, p 13, 2003
cervicography\textsuperscript{73} as a means of quality control to ensure the best possible reading, and 2.5X magnification using a handheld magnification device in order to see whether magnification of the cervix yields better results. VIA was found to have equal sensitivity to cytology, with the ratio of VIA to cytology being 0.85, however, VIA was found to have lower specificity, with the ratio of false-positive rate of DVI to cytology being 4.7\textsuperscript{74}.

B. Visual Inspection with Lugol’s Iodine (VILI)

Visual inspection of the cervix can also be done with the application of Lugol’s Iodine (VILI), which is similar to the Schiller’s iodine test used in the 1930s and 1940s for detecting cervical neoplasia\textsuperscript{75}. In this procedure, iodine is applied to the cervix in the same manner as acetic acid, however the mechanism by which iodine operates is different. VILI depends on the interaction between iodine and glycogen\textsuperscript{76}. Squamous metaplastic epithelium is abundant with glycogen and iodine is glycophilic. Therefore, application of iodine to the cervix results in the uptake of iodine into the cells, turning healthy squamous epithelial cells dark brown. Cervical intraepithelial neoplastic cells are poor in glycogen, since abnormal cells have a high ratio of nuclear to glycogenated material. These abnormal cells are visualized as mustard-yellow upon inspection\textsuperscript{77}. VILI has equal specificity as and greater sensitivity than VIA\textsuperscript{78}. Both of these techniques are routinely used as colposcopic techniques to visualize lesions that require biopsy or further

\textsuperscript{73} Cervicography includes a 35-mm photograph of the cervix after reapplying 5% acetic acid.
\textsuperscript{75} Sankaranarayanan, R, Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” A Practice manual on Visual Screening for Cervical Neoplasia, Chapter 1, p 1, 2003.
\textsuperscript{77} Lynch, K. Observation in Colposcopy Clinic, Groote Schuur Hospital facilitated by Professor Lynette Denny. Observatory, Cape Town, 10:30 am, April 17, 2009.
treatment, however, research completed by organizations such as the Khayelitsha Cervical Cancer Screening Project have looked at these methods as alternatives to cytologic screenings as well. Visual inspection with acetic acid is used by colposcopists to evaluate the grade of lesions. CIN I lesions appear as small, white pimples. CIN II lesions appear as large, white patterns. CIN III lesions appear as large, solid white portions of the cervix. Visual inspection with Lugol’s Iodine is used to show well-defined borders of lesions regardless of the grade of the lesion. Application of iodine is especially useful for removal of lesions using LLETZ since the entirety of the lesion is exposed.

C. HPV DNA Test

The HPV DNA test used by the cervical cancer screening project is a biochemical test that detects viral protein markers for certain strains of HPV DNA, specifically “high oncogenic risk” HPV types. HPV DNA screening test was performed using two sensitivity markers- a high positive cut-off was defined as samples containing at least 10 times as much HPV DNA as the positive control (>10X), while a low positive cut-off was defined as any sample containing HPV DNA greater than the control (>1X). HPV DNA testing at a low cut-off was found to be as sensitive as cytology, however, HPV DNA testing at a high cutoff was found to be as specific as cytology. HPV DNA testing would be useful for low-resource settings because it does not require skilled laboratory

79 Flowaday, C. Informal conversation guided by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00 am, April 24, 2009.
80 Ibid.
81 Types 16, 18, 31, 33, 35, 45, 51, 52, and 56.
technicians to evaluate the results and is easier to perform than cytology. HPV DNA Testing would also be useful because it identifies not only women who have lesions, but women who have the greatest risk of developing precancerous lesions and can be followed up more closely than other women. The disadvantages lie in cost, and require laboratory and storage facilities for samples.

<table>
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<tr>
<th></th>
<th>Total Treated</th>
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<tr>
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<td></td>
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<td>Low grade SIL</td>
<td>No disease</td>
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<td>2.3</td>
<td>2.2</td>
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<tr>
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<tr>
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<td>10.5</td>
<td>2.0</td>
<td>1.7</td>
<td>6.8</td>
</tr>
</tbody>
</table>

Table 4.1: Proportion of women screened who would be treated correctly and those who would be overtreated by each screening test in the absence of colposcopy, as performed by the Khayelitsha Cervical Cancer Screening Project.

D. Evaluation of Alternatives

These alternative methods of cervical cancer screenings, however, have yet to be considered as national policy for a variety of reasons. According to Professor Denny, “To this point, [these methods] have all been experimental. It takes a long time to prove that your intervention is going to be successful. I think the reason why it hasn’t been implemented in South Africa is because there hasn’t been that much data or knowledge, and now that’s all coming out… It’s a question of translating research into practice.”

Cervical cancer screening alternatives are currently not offered at the Project because as a research institution, they must offer state regulated services to women and cytologic

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85 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuur Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
screenings remain the approved method of screening by the Department of Health. Olivia Briton, one of the Project Coordinators for the Khayelitsha Cervical Cancer Screening Project commented that the HPV DNA Test used in the trials in 1999 would not be implemented in South African national policy because it is more expensive than a pap smear\textsuperscript{86}. While a pap smear may cost around R100 – R200, the HPV DNA test for cervical cancer costs around R200 - 300\textsuperscript{87}. Other limitations of the use of HPV DNA testing are the possibility of overtreatment. HPV DNA testing only tests if high-risk strains of HPV are present, not cervical lesions. Some women may present with high-risk HPV DNA, but may not actually have any cervical abnormalities. Professor Denny suggests that this may not be a problem, however. “We know we are overtreating women,” she says, “but we didn’t show an increase in severe complications and women found it very tolerable and acceptable in our experience.”\textsuperscript{88} While HPV DNA testing may not be a useful alternative due to cost and infrastructure issues, visual inspection with acetic acid “wasn’t more expensive, but that didn’t prove to be as effective as doing the HPV DNA testing,” according to Olivia Briton. Visual inspection with acetic acid must be closely monitored, due to the subjective nature of the test, as opposed to the objective results obtained through HPV DNA testing, however, “if you’re in a low-resource setting, and you’re really out in a rural area with absolutely nothing, then yes, [visual inspection with acetic acid] is definitely better.”\textsuperscript{89} While these alternative methods are not necessarily appropriate for large urban areas where cytologic services are available, these

\textsuperscript{86} Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
\textsuperscript{88} Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
\textsuperscript{89} Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
screening methods could be used in areas like the Eastern Cape and Mpumalanga, where they lack the infrastructure to make cytologic services available to their female populations. While visual inspection with acetic acid may not be the most effective screening technique, Dr. Paul Blumenthal from Johns Hopkins University comments that, “Cervical cancer prevention is not about doing the best test. Cervical cancer prevention is about doing the best test that you can do” and in some low-resource settings, VIA may be the best test available.

*Increasing Access of Cervical Cancer Screening Services*

A. Transportation

Cervical cancer screenings do not merely involve cytologic testing, it requires that the patient return for results, and if abnormal cytology is found, then they must go for treatment. In Khayelitsha, it is particularly difficult for women to return to the clinic for their results because of time constraints and transportation costs. Research is currently being done at the Khayelitsha Site B Day Hospital to evaluate the return rate of patients who receive pap smears. Current findings are suggesting that the “return rate for patients coming for pap smears is extremely low and you find that people just don’t come back to see their results.” Professor Denny believes one of the reasons why women don’t return for their results because it is difficult to access facilities, especially when there “could be a sick relative, there could be work issues, there could be children issues. There are a lot of logistical issues that need to be dealt with. It’s not as easy as popping into a car or

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91 Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
popping into the underground and going to the next place. It is more complex. The Khayelitsha Cervical Cancer Screening Project assists their patients and study subjects with an informal transport system run by the community health workers of the project. Ayesha Sassman, one of the Study Coordinators at the project, says merely picking them up is not enough to have patients return for follow-up visits. She stresses the importance of tracing study individuals and maintaining contact to ensure their return to the clinics for follow-up visits. She says, “They don’t generally come back so we need to coax them a bit- give them a call or two, sometimes go out tracing them in the car to try and find them, and often they don’t come back and you need to either call them or leave them messages on their phone.” Most clinics in South Africa, however, do not possess the infrastructure to trace their patients or retrieve them from their homes, so the efforts made by the Khayelitsha Cervical Cancer Screening Project represents a very special arrangement between the research institution and the community they serve. Professor Denny comments that this is one of the ironies of research. “Research is always much more richly supplied with resources and there is absolutely no doubt that the women in our project get a much better deal.” She admits, “It’s not really sustainable though. It’s fine once you’ve got funding but you can’t really supply that kind of service on a sustainable basis unless you were in an extremely well-resourced community,” in which townships, such as Khayelitsha, that is not necessarily the case.

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92 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
93 Lynch, K. Observation at Khayelitsha Cervical Cancer Screening Project, 10:30, April 7, 2009.
94 Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.
95 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
B. Access to Treatment Centers

If screening services are hard to come by in rural, low-resource areas, then treatment centers are almost non-existent. Colposcopy services are only offered in tertiary centers. According to Professor Denny, “Throughout the nine provinces in South Africa, colposcopies are limited to the major hospitals.” This becomes a problem in using cytology-based programs because the next step in treatment is referral to a colposcopy clinic. For the inhabitants of Khayelitsha, the nearest colposcopy clinic is located at Groote Schuur Hospital in Cape Town, approximately 30 kilometers away. In places like the Eastern Cape, which is predominantly rural with few resources, primary healthcare institutions are the major source of treatment for patients. According to Olivia Briton, anything requiring treatment of cervical neoplastic lesions “means that [the patients] pretty much have to go to Port Elizabeth, and even then they don’t necessarily receive the treatment and must go to Cape Town.” In Khayelitsha, this situation has been rectified by providing tertiary-level colposcopy services at the Cervical Cancer Screening Project. Patients do not have to spend money on transportation into the city, and it also relieves some of the burden on the local hospitals. Sister D., the chief professional nurse from the project, says, “at the Day Hospital, one [healthcare provider] has to see 80 people in a day and how are you going to get through all 80 unless you give each of them 15 to 20 minutes of your time?” Dr. Claire Flowaday from the project explained that it is very uncommon for clinics to offer colposcopy because most gynecologists in South Africa are only trained in colposcopy for 2 weeks. Because of this, even trained gynecologists

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96 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuur Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
97 Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
98 Name of the individual has been changed for reasons of anonymity.
99 Sister D., Personal interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 2:00, April 23, 2009.
usually refer their patients to colposcopist specialists for treatment. Dr. Flowaday has been training under Professor Denny for the past 6 months and provides much-needed colposcopy services to the community of Khayelitsha through the project.

Dr. Blumenthal said, “Testing by itself has no intrinsic preventative value. It is only by linking testing to treatment that you close the circle of prevention.” Screening for cervical cancer, either by cytologic, VIA, or HPV DNA testing, is useless if women are not accessing the proper treatment. A solution to this problem may lie in an innovative approach to cervical cancer screening and treatment known as the “screen-and-treat” method. Research has recently been completed in establishments such as the Khayelitsha Cervical Cancer Screening Project to examine the safety and efficacy of this new approach.

C. The “Screen-and-Treat” Approach

The “screen-and-treat” approach involves screening women for atypical cervical squamous cells by using VIA, VILI, or potentially, HPV DNA testing. VIA and VILI offer immediate results, and so instead of referring the patient for colposcopy at a tertiary clinic, one would eliminate the diagnostic step and treat patients in the same visit using cryotherapy. Unlike LLETZ, the standard procedure in hospitals in South Africa, which surgically excises the affected cervical tissue, cryotherapy, involves freezing the abnormal cervical tissue with a liquid coolant, such as carbon dioxide or nitrous oxide. Cryotherapy has been used for over 40 years as a method of treatment for cervical

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100 Flowaday, C. Informal conversation guided by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00 am, April 24, 2009.
dysplastic cells and is considered to be “safe, feasible, acceptable, and effective” in low-resource settings. Cryotherapy doesn’t require electricity and uses simple, inexpensive equipment that can be used by trained non-physicians, such as midwives and nursing sisters. The procedure is painless, thus requiring no anesthetic, with a cure rate of cervical lesions being 89 – 95%. While cryotherapy is a safe, effective mode of treatment for moderate lesions, it may be less effective for large lesions that cover over 75% of the cervix or those that extend into the endocervical canal. Patients with advanced-stage cervical lesions should be referred to the proper treatment centers, so it is preferable to detect early lesions for the screen-and-treat approach to be most cost effective. The “screen and treat” approach is considered to be cost-effective and cost-saving in that “the costs of implementing a program are less than the amount currently spent on caring for women with cervical cancer because they eliminate costs associated with follow-up visits and loss to follow-up.”

The use of HPV DNA testing followed by cryotherapy yields a greater decrease in the incidence of cervical cancer than other alternative methods, however cost and the need for follow-up visits makes implementation of this method difficult. A new HPV DNA test, however, is being manufactured and will be available in the near future. The new test, careHPV made by QIAGEN, costs $5.00 per test and does not require as much laboratory infrastructure as the previous test. According to Professor Denny, “It’s done on site and requires two and a half hours to get a result… A woman comes in, you take a sample, you test her, she waits two and a half hours, and if it is positive you do

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107 Ibid.
108 QIAGEN, www.qiagen.org
cryotherapy." While this new method of cervical cancer screening appears promising, Ayesha Sassman from the project points out that even though it costs $5.00 per test, you have to consider that you must first “convert $5.00 into South African rands. It is one thing that it is costing you in dollars, but you have to multiply that by 8, depending. Once again it becomes something that, with these exchange rates, it cannot be done." Olivia Briton believes that it could eventually be implemented as a screening policy in South Africa, but “it will take some time.” It takes time and effort to convert research into national practice, but if the “screen-and-treat” approach can be properly implemented, it would provide many women with an accessible treatment method that would eliminate complicated infrastructure and unnecessary transportation requirements.

Education and Training

A. Training Healthcare Providers

Many of the reasons why cervical cancer screening programs are not properly implemented in some areas may be due to insufficient training and education of healthcare providers. When the Khayelitsha Cervical Cancer Screening Project began in 1996, there were virtually no gynecological services offered to the community. According to Olivia Briton, “We’ve basically set up the services for them,” teaching nursing sisters and doctors in and around the Day Hospital how to perform pap smears and gynecological examinations. In previous studies, participating doctors taught theoretical and practical training courses for healthcare workers in the Day Hospital. The

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109 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
110 Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.
111 Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
112 Ibid.
Cervical Cancer Screening Project also works closely with the Day Hospital, offering expert help and advice to the healthcare workers. The chief professional nurse, Sister D, who was also trained by the project as a colposcopist nurse, helps train other nursing sisters how to perform pap smears. Most of the healthcare workers come to the screening project for training. She explains that the nursing sisters “were trained to do pap smears during their training, but they haven’t been practicing, so it’s about honing the skills that they already have and showing them the right procedure in taking cervical smears.” She goes on to say that “Sometimes it is difficult for the hospitals and the day hospitals to pull staff out to go to training courses, so at least if we are here at the primary healthcare setting and they do have people that are interested, they are more than welcome to come in and polish their skills.” Not all primary healthcare facilities offer training to the extent of the Khayelitsha Cervical Cancer Screening Project; however, this provides an example of a successful intervention that, if proper training is put into place, a successful service can be offered to the community.

B. Community Education and Advocacy

Community education is also important for the development of successful cervical cancer screening programs to emerge. Professor Denny believes that one of the major reasons why cervical cancer screening programs fail in South Africa is because women are not informed about what a pap smear is and its significance in women’s health. “They just have a pap taken and are told to come back, but the don’t get told why,” she says, “And if you have a screening process, you need to inform women, and I think we are

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113 Sister D., Personal interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 2:00, April 23, 2009.
very bad at doing that. Phumzile, a 29-year old patient presented at the colposcopy clinic at Groote Schuur Hospital on April 17, 2009, had confirmed HSIL and received LLETZ treatment for her lesions. Her doctor suggested she receive a pap smear in 2002, when she first found out about her HIV status. She was not informed in what a pap smear entailed and had heard rumors from her friends that the procedure was very painful. She commented, “The sisters at the clinic are rough,” but was grateful for the intervention, stating, “I had to go because I need to know I am ok, that I am healthy.” Another patient presented at the hospital, Thembi, was a 28-year old HIV-negative woman who returned for a check-up after her LLETZ procedure. She received her first pap smear in 2003 because she had an STD and said she was not intimidated by the procedure the first time, explaining, “How could I be scared about something I know nothing about?” She too was glad for the intervention because it was an opportunity to learn more about her health. Thando is a 31-year old mother living with HIV. She had heard about pap smears previously, but the clinic told her she could not receive one until she turned 30 years old. She received her first pap smear a year ago, around the same time she discovered her HIV status. High-grade lesions were confirmed in biopsy, and she was presented at the colposcopy clinic to have her lesion removed by LLETZ. While she was glad to have had the procedure performed, it is unfortunate that she had attempted to receive a pap smear in earlier years, possibly when she had low-grade lesions, as opposed to the high-grade lesions found in her first pap smear. Regardless,

114 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuur Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
115 Name of the individual has been changed for reasons of anonymity.
116 Lynch, K. Observation in Colposcopy Clinic, Groote Schuur Hospital facilitated by Professor Lynette Denny, 10:00 am, April 17, 2009.
117 Phumzile, Informal conversation facilitated by Kirsten Lynch. Colposcopy Clinic, Groote Schuur Hospital, Observatory, Cape Town, 10:30, April 17, 2009.
118 Name of the individual has been changed for reasons of anonymity.
119 Thembi, Informal conversation facilitated by Kirsten Lynch. Colposcopy Clinic, Groote Schuur Hospital, Observatory, Cape Town, 11:00, April 17, 2009.
Thando said, “I’m sore [from the procedure], but I’m happy to have it done because I know people die from cancer\textsuperscript{120}.” These testimonies show that with proper information, women are happy and willing to access gynecological services. Professor Denny commented “if a woman knows that she has an abnormality in her cervix that could cause cancer, she’ll be [at the clinic] pretty quickly for treatment\textsuperscript{121}.”

Evidence from Khayelitsha suggests that if women are informed and reminded regularly about their gynecological appointments, then they are more likely to return for follow-up visits. According to Professor Denny, “in our situation, in my study, women knew why they had to come back and we had a very high return rate\textsuperscript{122}.” Project Coordinator, Ayesha Sassman, echoes this sentiment, saying, “For the purposes of this study we are obliged to cover all the bases… Obviously we have a better return [for the study] because we go and find them and we call them and leave messages.” While the members of the cervical cancer screening project are not obligated to expose as much information to non-study patients, “we always tell them everything and why its important to come back, why results are so important to know about. It’s choice\textsuperscript{123}.” The chief professional nurse, Sister D. also believes that the studies have been important for exposing women to cervical cancer screenings, saying that women from previous studies return for screenings later in life. “We still get clients. A study concluded in 2006 when the data was closed, but we still get clients coming in for all sorts of things, like when

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\textsuperscript{120} Thando, Informal conversation facilitated by Kirsten Lynch. Colposcopy Clinic, Groote Schuure Hospital, Observatory, Cape Town, 11:15, April 17, 2009.

\textsuperscript{121} Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.

\textsuperscript{122} Ibid.

\textsuperscript{123} Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.
\end{flushleft}
they would have lower abdominal pain." The project’s presence in community has been an educational source for the women of Khayelitsha. The more women who become acquainted with the studies and services offered, the more likely they will share this information with their neighbors and friends. Ayesha Sassman commented “Professor Denny has been in this community for 13 years, so we are well known. We are known as the ‘womb people,’ the ‘healers of the womb,’ so women come here to get pap smears, or they come here to get their wombs cleaned so they can have babies.” Besides word of mouth, the members of the Khayelitsha Cervical Cancer Screening Project reach the women community through local television and radio broadcasts. Radio Zibonele. The radio station serves the population of Khayelitsha and features a health program on Tuesdays where nursing sisters and community health workers from the project visit to talk about the importance of pap smears and getting screened.

C. Language and Health

Language also functions as an important aspect of education and advocacy in the township of Khayelitsha. The mother tongue of most individuals in the community is Xhosa, and it is particularly worthy to educate women about the importance of cervical cancer in this language to the community. Ayesha Sassman, a white woman, spoke about recruiting patients for the study at the project, saying, “I’ve gone out addressing crowds and they’ve just stared at me blankly with no responses… It’s definitely better to have people conversing in the language that the people understand and that they are

124 Sister D., Personal interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 2:00, April 23, 2009.
125 Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.
126 Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
comfortable” Phumzile, the colposcopy patient mentioned earlier, said that her English is not proficient, but must learn to speak it in order to talk to most people. Professor Denny takes great care in ensuring her clients understand what procedures are being performed on them. She speaks Xhosa, but not with as much depth as she would like, however it is impossible for a patient to fully understand her in English if it is their second language. For this reason, she has a nursing sister assist her with her colposcopies who is fluent in Xhosa and can fully explain the procedures to her patients. Many English vocabulary words for gynecological terms are very different in Xhosa and English, making English explanations difficult. For example, the word “cervix” in Xhosa is umlomo wesibeletho, which literally translates to the “mouth of the womb,” and so if a medical practitioner were to explain cervical screenings, the patient may not understand to what she is referring. The Khayelitsha Cervical Cancer Screening Project ensures that women participating in studies are read consent forms in Xhosa by a first-language Xhosa-speaking sister. The Project is staffed by community health workers and nursing sisters whose first language is Xhosa. When women receive pap smears or colposcopic examinations at the project, the doctors ask the patient if she would like someone to explain the process in Xhosa so that they are able to fully understand the procedures.

In the Day Hospital, the family physician allows medical school students from the Stellenbosch Medical School to meet with patients and present their symptoms to the physician. Students were observed taking the medical history of the patient and assessing their symptoms, however, when they came across a puzzling aspect of the examination,

127 Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.
128 Denny, L. Informal Conversation facilitated by Kirsten Lynch, Colposcopy Clinic, Groote Schuure Hospital, April 17, 2009
129 Lynch, K. Observation, Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 10:00 am, April 24, 2009.
they proceeded to speak to each other in Afrikaans, which some of the patients did not understand. Patients appeared uncomfortable with this intervention because they were unable to understand what the medical students were discussing with one another\textsuperscript{130}. Full disclosure to patients in a language they understand is key for creating a safe and comfortable environment for both the patient and the healthcare provider. Fortunately, schools like the Stellenbosch Medical School and University of Cape Town School of Medicine are now incorporating Xhosa into the first year curriculum, allowing students to be able to communicate to a certain extent with the majority of the Western Cape community.

\textit{Organization and Advocacy}

A. Patient Information

Research concerning cervical cancer screenings and innovative programs for low-resource areas has recently been a new development. Statistics concerning cervical cancer incidence and mortality over the years, in addition to HPV prevalence in South Africa is difficult to come across, and many of these are non-existent. Belmira Rodriguez, the African Operations Manager from the African Organization for Research and Training in Cancer (AORTIC), says, “We don’t have proper statistics- it is quite outdated\textsuperscript{131}.” Within the Khayelitsha Site B Day Hospital, files and patient information and poorly organized. Patient cytologic reports are loosely alphabetized and disorderly. On one occasion, a patient returned for her cytologic report, but the results had yet to be processed, so the patient had to return the next week to retrieve her report. When the second patient arrived to receive her cytologic report, she did not have her personal file and thus had to return in

\begin{itemize}
    \item \textsuperscript{130} Lynch, K. Observation, Khayelitsha Site B Day Hospital, Khayelitsha, 1:00 pm, April 8, 2009.
    \item \textsuperscript{131} Rodriguez, B. Informal conversation facilitated by Kirsten Lynch, AORTIC, Mowbray, Cape Town, 11:00 am, April 16, 2009.
\end{itemize}
a week to obtain her report. Patient information was maintained on a database at the cervical cancer screening project, but was not immediately accessible to the pap sister at the Day Hospital. Denny comments, “it’s a disaster. It’s just so badly organized and that’s something that I have brought to the attention of the authorities and we’re going to tackle it.” While the Day Hospital and the cervical cancer screening project associated with it do not have abundant resources for a sophisticated logging system, Professor Denny rebutted, “It is bad management. It doesn’t matter where you work, you can always have a system. There are no excuses. It is just sloppiness." Organization of patient files is vital for tracking and monitoring the health and behavior of these individuals. Sister D. From the project in Khayelitsha says, “It all boils down to taking adequate history, of which I think the public health service to that extent fails.” If a patient presents with lower abdominal pain and requests a pap smear to detect cervical cancer, it is necessary to evaluate her medical history to see if there are any other underlying problems that can aid in diagnosing and treating the patient. “If they had their last pap smear 6 months down the line and now she wants another pap smear, you must use your discretion because it means nothing would have changed from 6 months to now… you would have to be assessed for something other than cancer of the cervix." Proper bookkeeping and organization would ensure that resources are being used for proper testing and treatment.

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132 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
133 Sister D., Personal interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 2:00, April 23, 2009.
B. International Organization

Efforts are also being made to organize cancer organizations and clinics on a global level. AORTIC is currently working with a Pfizer fellow to locate cancer organizations on the continent of Africa\textsuperscript{134}. Currently, there are about 4,000 organizations in the database, but it has been difficult to find most of the clinics and organizations because many of them don’t have websites or phone numbers. The aim for this database is to incorporate more African representatives for cancer conferences and to profile the activity of each organization. According to Belmira Rodriguez, the Africa Operations Manager of AORTIC, there is a lack of collaboration among organizations because they compete for funds. If these organizations could work together to push cancer as a legitimate healthcare issue, national governments throughout Africa may begin to allocate resources to effective cancer policies. Within South Africa, there are a few isolated projects throughout the country, in addition to the cervical cancer screening Project in Khayelitsha, performing research on cervical cancer screening strategies in East London and Limpopo, however there are no organized coordinated efforts being made to campaign for effective cervical cancer screening policies.

\textbf{V. The Future of Research for Cervical Cancer Prevention and Treatment}

\textit{The HPV Vaccination}

While much research has been done concerning secondary methods of cervical cancer prevention, including alternative methods for screening and single-visit

\textsuperscript{134} Lynch, K. Informal conversation with Belmira Rodriguez at AORTIC, April 16, 2009.
approaches to increase the number of women accessing gynecological services, new research is now being conducted looking at primary prevention methods, namely the HPV vaccination. The Khayelitsha Cervical Cancer Screening Project is conducting the first study to evaluate the safety and efficacy of the HPV vaccine, Cervarix, on HIV-positive women. Studies suggest that HIV-positive women are at an increased risk of acquiring HPV, making them more susceptible to developing cervical cancer. As HIV-positive women are living longer due to antiretroviral treatment, it is necessary to look at the opportunistic infections, such as cervical cancer, that will affect HIV-positive women in the future.

The HPV vaccine has been shown to be effective in reducing the rates of initial infection with HPV-16 and HPV-18, the two HPV strains responsible for 70% of cervical cancer-related infections, in healthy young women. The safety and efficacy of the vaccine, however, has not been documented in immunocompromised individuals. Before any future large-scale immunizations can take place, studies must be done to ensure that HIV-positive women will accept the vaccine, since these are the women that can benefit most from this form of therapy. Professor Denny points out that the vaccine creates a “hyper-immune environment\textsuperscript{135},” and if women with damaged immune systems, like those living with HIV/AIDS, than the vaccine may not be as effective as in HIV-positive patients as it is in HIV-negative patients. Joel Palefsy suggests, however, “theoretically, there should be relatively little impact on humoral immune responses in HIV-positive women… but it is not known if these women will remain protected\textsuperscript{136}.” Studies must first address whether or not the vaccine will be safe for HIV-positive women before

\textsuperscript{135}Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuur Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
addressing its efficacy, which the Khayelitsha Cervical Cancer Screening Project hopes to establish.

The study, sponsored by the Cervarix manufacturer, GlaxoSmith Kline (GSK) Biologicals, S.A., is in its early phase of research. The Khayelitsha Cervical Cancer Screening Project is currently recruiting HIV-positive and HIV-negative women between the ages of 18 and 25 in Khayelitsha for the study. Professor Lynette Denny is acting as the Principle Investigator with Ayesha Sassman and Olivia Briton acting as Project Coordinators. Recruitment is done through local radio stations, community newspapers, church groups, adult education centers, shopping malls, clinics, and hospitals in the area surrounding Khayelitsha. Ayesha Sassman says the most recruitment success has been found through the youth centers. “It’s the age group we are looking for so we are concentrating our efforts on them.” The women that generally go out for recruitment are the community health workers and nursing sisters. Ms. Sassman emphasized the importance of having Xhosa-speaking women recruit the participants because it makes the participants more comfortable with the study.

The volunteer recruitment process through the youth clinics are done predominantly through the Khayelitsha Site B Youth Clinic, which is close to the

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137 Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
138 Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.
139 During the consultation process, a nursing sister reads the 19-page consent form to the participant, which takes approximately thirty minutes. The consent form includes an explanation of what HPV is in addition to a diagram of the female reproductive organs and an explanation and identification of the cervix to the patient. After the form is read to the patient, the nursing sister administers a questionnaire in Xhosa in order to see if the patient fully understands the protocol. Out of the 12 questions presented on the questionnaire, 8 need to answered correctly. If a patient does not answer at least 8 questions, the nursing sister must re-read the entire consent form back to the patient, and the patient must re-take the exam. This process is repeated until the patient has answered a sufficient number of questions. The consultation process is important because the cervical cancer screening project wants to ensure that the patient understands exactly what the study is about and how the study affects the patient, as an individual. Some aspects of the study worth noting is that if a patient believes she is HIV-negative during the consultation process, but tests positive for HIV during the initial examination period, she is immediately excluded from the study and is referred for appropriate counseling. During the actual experiment, HIV-positive women are randomly assigned either the HPV vaccine or a placebo, and those participants who are given the placebo during the trials are entitled to the actual vaccine after the trial if they so choose.
Cervical Cancer Screening Project site, and the Khayelitsha Site C Youth Clinic. The Site B Youth Clinic is usually packed with young adults waiting to see the nursing sisters. On one occasion, a young girl was seen performing male and female condom demonstrations for the men and women waiting in line. The patients were engaged in the demonstration, asking questions and making suggestions to the woman. After her demonstration, one of the community health workers from the project stood up and discussed HPV vaccinations and the study at the Cervical Cancer Screening Project in Xhosa and asked for those interested to meet her after the discussion. One interested woman made plans to meet with the community health worker for an initial evaluation later that week. The Site C Youth clinic, which was further away, functioned as a duel youth clinic and youth center. The clinic was spacious with brightly colored walls and had a pool table in the waiting room. On one side, there was a door labeled “The Chill Room” which was used for health education. While there were no candidates at this youth center, one of the community health workers stressed the importance of these facilities. “People don’t want to go to the clinic and see their mother’s neighbor there. They use these clinics. The resources are here and available, so it is up to the individual to use them.” While Khayelitsha remains an under-resourced community, it is apparent that many efforts have been made in recent years to make health services available to the public, with the development of the Day Hospital and the Youth Clinics that appear to be well-used.

The recruitment criteria for HIV-positive women have been the most challenging aspect of the study. Some of the criteria require that women be generally healthy, have had at most 6 sexual partners, not be pregnant, nor have had tuberculosis (TB), or

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140 Anonymous Community Health Worker, Informal Conversation, Khayelitsha Site C Youth Clinic, Khayelitsha, 11:00 am, April 2, 2009.
HPV\textsuperscript{141}. According to Olivia Briton, “We’ve got the patients and recruitment is going well, but because of the criteria being so strict, it’s jolly difficult to get the required number of eligible patients into the study\textsuperscript{142}.” There has been an 80% screening failure, suggesting that women are interested in being a part of the study, but due to criteria constraints, many cannot participate. She says that some of the eligibility criteria that has been most difficult to satisfy includes women who already have cervical diseases and women who are in stage advanced stages of HIV who “just aren’t healthy enough to participate in this study. Most research studies, you need healthy participants\textsuperscript{143}.” Ayesha Sassman says that the criterion that excludes most participants is “definitely the amount of sexual partners. Keep in mind, we are looking at women who are between the ages of 18 and 25, with 6 being the maximum amount of sexual partners. That is by far the one that trips us up every single time\textsuperscript{144}.” This eligibility requirement is important because the more sexual partners an individual is exposed to, the greater risk one has of developing different strains of HPV. The project requires that there be 30 HIV-positive and 20 HIV-negative participants in the study, however, the strict criteria is proving to be a major obstacle in continuing the study.

While the HPV vaccine revolutionizes primary prevention of cervical cancer, implementation of the vaccine will prove to be difficult in the South African context. The major barrier to large-scale HPV immunization programs is cost. A full course of HPV vaccinations will cost $360 per person, which is more than most people in South Africa are able to afford. Professor Denny notes that “The Hepatitis B vaccine was available in

\textsuperscript{141} Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.
\textsuperscript{142} Ibid.
\textsuperscript{143} Ibid.
\textsuperscript{144} Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.
the developed world for 20 years before it came to the developing world, and it was only until it came down to 25 United States cents a shot did it become widely available. The lack of research done on the vaccine also makes it difficult to assess its usefulness in the future. Ayesha Sassman comments that “It’s only been 2 years and we don’t have a lot of data yet. It’s too soon to say if it’s going to be widely used because the results are not in yet.” Professor Denny says that because the HPV vaccine is preventative, as opposed to therapeutic, “to see the benefit of the vaccine, you will need to wait a while, for 30 or 40 years.” In addition to cost and research shortcomings, the HPV vaccine may be difficult to implement in rural areas because the full course of the vaccine requires 3 shots spread out over time, which may be difficult for adults to obtain because of transportation difficulties. Despite these setbacks, the HPV vaccine shows a lot of promise in curbing the incidence of cervical cancer by stopping it at its source. This could provide valuable preventative treatment for women at high risk of developing cervical cancer. The first step, however, is to provide the research that establishes its importance as a preventative tool that is safe and effective for women to use.

**Conclusion**

Dr. Mahmoud Fathala, the former president of the International Federation of Gynecology and Obstetrics (FIGO) once said, “Women are not dying because of disease we cannot treat… they are dying because societies have yet to make the decision that

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145 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
146 Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.
147 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
their lives are worth saving. Cervical cancer is a preventable disease that women, predominantly in developing countries, are still dying from. Cervical cancer is the second most common cancer to affect women in Africa, destroying the lives of mothers, grandmothers, wives, daughters, sisters, and friends. While small organizations, such as the Khayelitsha Cervical Screening Project, have implemented programs to make cervical cancer screening and treatment services available to local communities, South Africa requires national mobilization on the part of society to demand that cervical cancer be considered as a legitimate threat to the livelihoods of women all over the country. Research has proven that it is possible to prevent cervical cancer in low-resource settings without the expensive infrastructure required from cytology tests, and while these methods may not be applicable to the urban townships in the Western Cape, these services could be implemented in the rural areas of the Eastern Cape and Limpopo where gynecological services are scarce.

The cost of radiotherapy, which is recommended to treat all forms of cancer, is $250,000 to set up and $35,000 annually to treat about 1,000 patients per year. If the annual number of new cervical cancer cases is 6,742, than it would cost approximately $245,000, or about R 2,450,000 per year to treat invasive cancer using radiotherapy. This would also require specialized radiation oncologists and physicists and risks significant morbidity. These costs, in addition to the amount allocated for the cervical cancer screening policy currently in place, amounts to a huge sum that creates a financial and medical burden on the country. New research is pointing towards an HPV DNA test

that would cost $5 per test, and if used in conjunction with cryotherapy, it could provide screening and treating services in one visit. If more women are educated about screening and can access these services easily, than the incidence of cervical cancer would drop significantly, thus decreasing mortality rates. If this were to happen, the government would not have to spend R 2,450,000 every year treating preventable cervical cancer.

According to Professor Lynette Denny, “You’ve got to set up infrastructure and you’ve got to get government on your side. South Africa believes it has the capacity to do pap smears, although in reality that has not happened." Evidence shows that the current national policy is not effective in curbing cervical cancer in South Africa and research is proving that screen and treat approaches with a cheaper HPV DNA test in addition to cryotherapy is effective and requires little infrastructure. The only work that is left to do is to “get the government on our side.” According to Sister D. from the Cervical Cancer Screening Project in Khayelitsha, “reproductive health has the least speciality that is not getting a lot of attention in the healthcare system… because it is reproductive health, it is not seen as a priority, and all illnesses should be treated as equal and the same.” Sister D. believes that “we need a vigilant female higher up that would press the matter as a matter of urgency because it doesn’t get attention." With international organizations advocating effective cervical cancer policies across the globe and with the availability of the HPV vaccine, cervical cancer may be meeting its end, but there is a long way to go. “I think we are looking at this at a very critical juncture in history,” Professor Denny explains, “We’ve only been able to prevent cervical cancer up to this

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151 Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.

152 Sister D., Personal interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 2:00, April 23, 2009.
point using secondary prevention. Now we have primary prevention with a vaccine but it’s still very elusive… and there’s a lot of work to be done, but there’s a lot of hope\textsuperscript{153}.

The tools with which to act are currently available to prevent cervical cancer and eradicate the disease. It is now “up to society,” as Dr. Fathala said, to use these tools and advocate for change.

\textsuperscript{153} Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuur Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.
Limitations of the Study

The information obtained through the Khayelitsha Cervical Cancer Screening Project provided valuable insight into the challenges facing proper implementation of a cervical cancer screening program in South Africa and into research being done to better the status of gynecological services in the country. Data obtained through the project represent the biases of the members of the organization and of the institutions that fund their research. While the Cervical Cancer Screening Project has made a great difference in the community of Khayelitsha, it represents a unique arrangement between academics and health providers and possesses resources that are not available to the majority of clinics in this country. The project’s success is in part due to its proximity to the University of Cape Town and Groote Schuur Hospital, making a similar project irreproducible in most settings outside of Cape Town. While the project has been able to increase access, availability and education concerning cervical cancer screenings, this is not necessarily the case for other clinics and research organizations in the country.

The Western Cape, which has access to the greatest number of resources, has implemented a cervical cancer screening policy that differs from the National Guidelines concerning cervical cancer screenings, so the data presented represents cervical cancer screening programs unique to the Western Cape. In addition, the township surrounding Cape Town, where the project is based, caters to a predominantly urban, Xhosa-speaking population, and the cervical cancer strategies implemented were adjusted to meet the needs of this specific community of women.

It was difficult to obtain usable information for this study concerning current research due to confidentiality issues surrounding the HPV vaccination trials, so data was
limited to the recruitment and selection process surrounding the study. The study concerning the HPV vaccination among a cohort of HIV-positive women is sponsored by the pharmaceutical company, GlaxoSmithKline (GSK) Biologicals, S.A. Recorded information, therefore, was carefully monitored by the Project Director to ensure the proper representation of the funding institution and the research project itself.

Those interviewed included members of the Khayelitsha Cervical Cancer Screening Project, and thus their opinions reflect those of the organization that the work for. The project was initiated due to a perceived lack of resource for the community of Khayelitsha, which may reflect biases against the current gynecological services offered to the country. Unfortunately, due to time constraints and duration of the study, it was difficult to create trusting relationships with patients, and so they may not have disclosed as much information about themselves due to unfamiliarity with the facilitator.

Literary resources used for the study were obtained through cervical cancer screening advocacy organizations, such as EngenderHealth and Jhpiego, and thus represent the agendas of their respective institutions. Many articles obtained were written, or co-written, by members of the Khayelitsha Cervical Cancer Screening Project. Many of these articles were based off of studies done and the Project, and thus represent biases associated with the organization.

The biases and opinions of the author are represented throughout the study, reflecting her belief that all women should be given available and accessible gynecological services regardless of her status or upbringing.
Recommendations for Further Study

This study focused on a unique cervical cancer screening program in the Western Cape. Despite lags in cervical cancer prevention in this province, it is one of the well-resourced, provinces in the nation. Further studies may include examining the availability and accessibility of gynecological services offered in more rural and low-resourced settings, such as the Eastern Cape, where some of the previously mentioned cervical cancer screening alternatives may be more applicable. Similar research organizations to the Khayelitsha Cervical Cancer Screening Project are currently being implemented in the Eastern Cape and Limpopo. It would be interesting to see how effective these projects are in providing much-needed cervical cancer screening services to the communities there. It would also be worth looking into the differences between the quality of gynecological services offered in the public and private sector, as well as the amount of women in the private sector accessing these services as opposed to women in the public sector.

One major problem presented at the Screening Project in Khayelitsha was poor management of patient files and low patient return rates. A recommendation for further study would be to investigate why women tend not to return for results or treatment. Clinics and day Hospitals could be looked at as possible educational resources for women to learn about the importance of cervical cancer screenings and treatment. Advances within the Khayelitsha Cervical Cancer Screening Project could also be further investigated to see the results of the HPV vaccine study for HIV-positive women.
Summary and Review of Essential Texts

Explores alternatives to pap smears, including HPV DNA testing, direct visual inspection after application of a 5% acetic acid solution, and cervicography to find the most cost-effective method for cervical cancer screening.

Study determines the safety and efficacy of screen-and-treat approaches as an alternative to cervical cancer screenings. This experiment was performed at the Khayelitsha center, and provides an important resource for the kind of work that will be done there. This study also stresses the importance of linking screening and treating for health providers.

This article defines different forms of secondary prevention for cervical cancer. Denny and Sankaranarayan list the difficulties in implementing traditional cytologic screening in low-resource settings and why alternative methods are more appropriate for these settings.

Department of Health, “National Guideline on Cervical Cancer Screening Programme,” Date unknown.
This publication gives insight on the current legislation concerning cervical cancer screenings and provides the backdrop with which this study is conducted against.

This booklet contains information discussed at the 2005 Jhpiego Conference held in Bangkok, Thailand, examining alternative methods of cervical cancer screenings. The book addresses advantages and disadvantages in implementing different techniques, and offers suggestions on how different screening services can be implemented.

This study evaluates HPV DNA testing as an alternative to cervical cancer screenings in low-income settings. This provides a greater understanding of the kinds of experiments performed by the Khayelitsha Cervical Cancer Projects. The HPV DNA test is considered to be the most promising cervical cancer screening method for the future.

This article suggests that immunocompromised women, such as those living with HIV/AIDS, are at a greater risk of developing HPV infection and abnormal cell cytology. Palefsky presents a multitude of studies that confirm this hypothesis. The article also examines the possibility of using the HPV vaccine for HIV-positive women, which is exactly what the Khayelitsha Cervical Cancer Screening Project is studying.

Sankaranarayanan, R., Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” A Practice manual on Visual Screening for Cervical Neoplasia, Chapter 1, 2003. This source provides useful information concerning the gross anatomy and cellular composition of the cervix. This article also describes the mechanism with which alternative methods of cervical cancer, such as VIA and VILI, work.

Villa, LL, “Biology of genital human papillomaviruses.” International Journal of Gynecology and Obstetrics, Supplement 1, Chapter 1, S3-S7, 2006. This article describes the structure of HPV and how it alters normal cell cytology upon infection. This source provides useful background reading on the development of cancerous precursors due to HPV infection. This article also shows the importance of proper immune responses in eradicating HPV-induced cell proliferation, suggesting a link between immunocompromised individuals and increased risk of cervical cancer.

Bibliography

Primary Sources

Anonymous (Community Health Worker), Informal Conversation, Khayelitsha Site C Youth Clinic, Khayelitsha, 11:00 am, April 2, 2009.

Briton, O. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 12:30, April 23, 2009.

Denny, L. Informal Conversation facilitated by Kirsten Lynch, Colposcopy Clinic, Groote Schuure Hospital, April 17, 2009.

Denny, L. Personal Interview conducted by Kirsten Lynch. Groote Schuure Hospital, Observatory, Cape Town, 1:30 pm, April 21, 2009.

Flowaday, C. Informal conversation guided by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00 am, April 24, 2009.

Lynch, K. Observation in Colposcopy Clinic, Groote Schuure Hospital facilitated by Professor Lynette Denny. Observatory, Cape Town, 10:30 am, April 17, 2009.

Lynch, K. Observation at Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 10:30, April 7, 2009.

Lynch, K. Observation at Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 10:00 am, April 24, 2009.

Lynch, K. Observation, Khayelitsha Site B Day Hospital, Khayelitsha, 1:00 pm, April 8, 2009.

Phumzile, Informal conversation facilitated by Kirsten Lynch. Colposcopy Clinic, Groote Schuure Hospital, Observatory, Cape Town, 10:30, April 17, 2009.

Rodriguez, B. Informal conversation facilitated by Kirsten Lynch, AORTIC, Mowbray, Cape Town, 11:00 am, April 16, 2009.

Sassman, A. Personal Interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 11:00, April 24, 2009.

Sister D., Personal interview conducted by Kirsten Lynch. Khayelitsha Cervical Cancer Screening Project, Site B Day Hospital, Khayelitsha, 2:00, April 23, 2009.

Thando, Informal conversation facilitated by Kirsten Lynch. Colposcopy Clinic, Groote Schuure Hospital, Observatory, Cape Town, 11:15, April 17, 2009.
Thembi, Informal conversation facilitated by Kirsten Lynch. Colposcopy Clinic, Groote Schuure Hospital, Observatory, Cape Town, 11:00, April 17, 2009.

Secondary Sources


Sankaranarayanan, R, Wesley, R.S., “Anatomical and pathological basis of visual inspection with acetic acid (VIA) and with Lugol’s Iodine (VILI)” A Practice manual on Visual Screening for Cervical Neoplasia, Chapter 1, p 1-14, 2003.

Stevens, M., Bomela, N., ‘cervical cancer- is vaccination the way to go?” Democratic Nursing Organization of South Africa, Nursing Update, May 2008, p. 37


Appendix A: List of Important Terms

**Carcinoma in situ:** High-grade squamous intraepithelial lesions that have yet to penetrate the cervix.

**Cervarix:** HPV vaccine developed by GlaxoSmithKline Biologicals, SA

**Cervix:** The neck of the womb where the lower portion of the uterus meets the upper portion of the vagina.

**CIN:** Cervical Intraepithelial Neoplasia. Represents potentially pre-malignant transformation and abnormal growth of squamous cells on the surface of the cervix.

**Columnar Epithelium:** Epithelial layer of the cervix lining the endocervical canal. Cells secrete mucus that lubricates the vagina.

**DVI:** Direct Visual Inspection (also known as VIA)

**Dysplastic Squamous epithelium:** Abnormally matured squamous epithelium. HPV infections cause dysplastic squamous cell maturation.

**GSK:** GlaxoSmithKline Biologicals, S.A.

**HPV:** Human Papillomavirus. Small DNA viruses that infect various epithelial tissue, namely those of the reproductive organs. “High-risk” strains of HPV are responsible for 99.7% of cervical cancers.

**HSIL:** High-grade squamous intraepithelial lesions.

**LEEP:** Loop electrosurgical excision procedure (also known as LLETZ)

**LLETZ:** Large loop excision of the transformation zone (also known as LEEP)

**LSIL:** Low-grade squamous intraepithelial lesions.

**Metaplastic Squamous Epithelium:** Newly formed, healthy squamous epithelium that replaces columnar epithelium as the cervix ages.

“**Screen-and-Treat” Approach:** Cervical cancer preventative method where patient is screened and treated in one visit.

**SIL:** Squamous intraepithelial lesions.

**Squamocolumnar Junction:** Intersection where squamous epithelium meets columnar epithelium on the cervix.
**Squamous epithelium**: Glycogen-rich epithelial layer of the cervix located on the ectocervix.

**VIA**: Visual Inspection with Acetic Acid (also known as DVI)

**VILI**: Visual Inspection with Lugol’s Iodine
Appendix B: Interview Questions

Questions for Principle Investigator, Professor Lynette Denny, of the Khayelitsha Cervical Cancer Screening Project:

How did the Khayelitsha Cervical Cancer Screening Project get started?

Have there been an increase in women accessing services and education?

Besides doing research, does the project offer services to the community?

Are there any reasons why the alternatives you’ve studied haven’t been used instead of the traditional cytologic screenings?

Why are the return rates at the Day Hospital so low?

Are there any educational services provided to encourage women to get screened?

Why do you think the incidence of cervical cancer is so high in developing countries?

How could the HPV vaccine interfere with women who are HIV positive? Are there any considerations to give men the HPV vaccine?

Do you think South Africa has the resources to maintain the current policy?

Considering the success with Khayelitsha, do you think similar research units could be implemented in other provinces?

What do you think it will take to make the HPV vaccine more widely available?

Questions for staff at the Khayelitsha Cervical Cancer Screening Project:

Does the Khayelitsha Cervical Cancer Screening Project work closely with the Day Hospital?

What aspects of the eligibility criteria are most difficult to satisfy for this study?

What are some of the difficulties faced with previous trials concerning pap smears?

How do you recruit women for these studies?
What are some of the advantages and disadvantages of the alternative screening methods?

Since the advent of the project, does it seem like more women are knowledgeable about pap smears?

Are there any educational services offered by the day hospital?

Does the project work with training other doctors and nurses?

Why don’t you think these services aren’t given as much attention as other health services?

**Questions for Belmira Rodriguez from AORTIC:**

Is AORTIC involved in any of the implementation strategies associated with the new cheaper HPV DNA testing?

Is AORTIC involved in distribution of HPV vaccines for low-resource settings?

What kind of training is being done in South Africa for cervical cancer screenings?
Appendix C: Photographs

Photographs of the view taken from the Khayelitsha Cervical Cancer Screening Project located besides the Site B Day Hospital in Khayelitsha. The township is one of the largest in Cape Town and houses a mainly Xhosa-speaking population. The majority of the citizens of Khayelitsha live in informal housing, as viewed here. Homes like these stretch out as far as the eye can see from the Cervical Cancer Screening Project. For most people living in the heart of Cape Town, Khayelitsha is mostly seen while driving along the highway, but for the inhabitants here, these photographs represent the grim reality of poverty and lack of resources. The community health workers and nursing sisters from the project commonly fetch patients from homes like these, and bring them to the project for cervical cancer screenings and treatment.

(Photographs taken Thursday, April 2, 2009)
Photographs of a typical day inside the Khayelitsha Site B Day Hospital. Many patients wait in line all day to see a health practitioner. The Khayelitsha Cervical Cancer Screening Project helps alleviate the burden of the hospital by performing pap smears and colposcopy when possible. The hospital is always a busy place, however, and patients must arrive extremely early in the morning to be able to speak with a doctor.

(Photograph taken Thursday, April 23, 2009 at 1:00 pm.)
Location of the Khayelitsha Cervical Cancer Screening Project. The organization operates out of converted shipping containers.

An example of one of the examination rooms inside the Khayelitsha Cervical Cancer Screening Project containers
(Photographs taken Thursday, April 23, 2009)
Appendix D: Important Forms and Documents Pertaining to the Khayelitsha Cervical Cancer Screening Project

Document I: Cytology Report

Patient information is recorded on this form for cervical cancer screenings.

Document II: Histopathology Report

Cervical sample data is recorded on this report for further inspection of abnormal cell cytology.

Document III: Patient Reminders

Notes in Xhosa are sent to the homes of patients to remind them of their next examination.

Document IV: Non-Project Unscheduled Visit Form

Form to be filled out for un-scheduled visits if a patient feels that they are ill.

Document V: Temperature Log

Log maintains a record of the temperature of various tests, which are kept in an office. The desired range is anywhere between 4 degrees C and 30 degrees C, however, the metal containers during the summer can cause the office to heat up to as great as 40 degrees C.

Document VI: Doctor’s Notice

This document is a notice signed by doctors to be given to the employers of patients if they are too sick to attend work.

Document VII: Patient Information Form

This form is given to the patient after meeting with a health provider. The card tells the patient what was done and when to come back. It is also useful if a
patient decides to go to a different clinic, so that the doctors will know what
treatment they have received.

Document VIII: Non-Project LEEP Form

Form is to filled out if a patient has received LEEP treatment for cervical lesions.

Document IX: Colposcopy List

The Khayelitsha Cervical Cancer Screening Project records patients with
abnormal cervical cells.

Document X: Tracing Logs

Document tracks the whereabouts of the patients so they can be easily reached if
they require follow-up treatment. This is especially important for patients with
high-grade lesions that must be treated immediately. Tracing is a method unique
to the Khayelitsha Cervical Cancer Screening Project, not to the hospital.