Clients' returning for cervical screening results:

A focus group study exploring the reasons why women spontaneously return for their results at the Khayelitsha Cervical Cancer Screening Project

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Declaration

MPhil thesis title:

Clients' returning for cervical screening results: A focus group study exploring the reasons why women spontaneously return for their screening results at the Khayelitsha Cervical Cancer Screening Project

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Dedication

This study is dedicated to the memory of Sr. Nocawe Kuse, nursing sister, friend, listener and wise woman of the Khayelitsha Cervical Cancer Screening Project.

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List of abbreviations

AIDS	Acquired Immune Deficiency Syndrome
CHC	Community Health Centre
CHF	Community Health Forum
CHSO	Community Health Services Organisation
CHW	Community Health Worker
CMC	Cape Metropolitan Council
DHS	District Health System
DNA	Deoxyribonucleic acid
DVI	Direct Visual Inspection
HIV	Human Immuno-deficiency Virus
HPV	Human Papillomavirus
KCCSP	Khayelitsha Cervical Cancer Screening Project
LEEP	Loop Electro-surgical Excision Procedure
MOU	Midwife Obstetric Unit
NGO	Non-Governmental Organisation
Pap Smear	Papanicoloau Smear
PAWC	Provincial Administration of the Western Cape
PID	Pelvic Inflammatory Disease
STI	Sexually Transmitted Infection
UCT	University of Cape Town
UNDP	United Nations Development Programme
WHO	World Health Organisation

Acknowledgements

My sincere thanks go to the participants who agreed to give of their valuable time to contribute to the focus groups. Without their voices and stories I would not have been able to write *this* story – hopefully a representation of how many women feel about using a women's health service.

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Terms of reference

This is the mini-dissertation for a Master of Philosophy degree in Maternal and Child Health, (MPhil: MCH) which is offered at the University of Cape Town's School of Child and Adolescent Health.

The dissertation component of the MPhil comprises one third of the degree. The other two thirds are comprised of coursework, which was successfully completed in 1999.

Although the thesis topic does not fall in the category of maternal health or of child health, the MPhil: MCH course co-ordinators gave their permission for me to undertake a study topic in women's health for the dissertation.

Work on this dissertation arose from my involvement as Project Manager for the Khayelitsha Cervical Cancer Screening Project (KCCSP) in 1998 and 1999. The Director of the Project, Professor Lynette Denny, and I were interested in the fact that women recruited to the Project seemed to return spontaneously for their screening results so frequently. We decided that qualitative research would provide a depth of understanding of this phenomenon. We hoped that findings from such research might inform development of the KCCSP as well as other screening initiatives, to improve follow-up rates and to enhance project workers' understanding of the population that they serve.

Professor Denny is supervisor of this dissertation.

Abstract

Introduction: Cervical cancer is integrally associated with the problems of poverty in the developing world. It is the most common cancer cause of death among women in these regions. In South Africa, the lifetime risk for black African women developing this cancer is 1 in 26. Rates for white women are 1 in 80.

Cervical cancer is largely preventable by screening for its precursor stages. However, cervical cancer screening in low-resource settings has only rarely been initiated and sustained. There are many barriers to the establishment of mass, organised screening programmes.

This study focuses on one aspect of the screening process: the clients' receiving of their screening results. For the most part, health providers in resource-poor settings rely on the clients themselves to return to the health service to receive their results and consequent arrangements for further care. Understanding those factors that impact upon clients' returning is therefore crucial to the success of the screening.

The Khayelitsha Cervical Cancer Screening Project (KCCSP) was established in 1996 to evaluate alternative screening tests to cytology. In addition, the Project has evaluated alternative screening algorithms to the traditional approach of cytology, colposcopy, biopsy and treatment, specifically, a "screen and treat" approach. This approach is expected to overcome some of the many barriers to women participating in screening programmes.

Aims and objectives: This study aims to investigate the phenomenon of the high spontaneous return rate in the setting of the KCCSP. Motivating and deterring factors are sought, both logistical and psychological, in the clients' personal contexts, as well as those related to their experiences of the Project.

Design: Exploratory study in the interpretive research paradigm located in a peri-urban informal settlement outside Cape Town, South Africa.

Sample: Volunteer sample of women enrolled in the KCCSP returning for their first set of screening results.

Methods: Four focus groups were conducted in Xhosa, facilitated by a Xhosa-speaking social worker from Khayelitsha who has experience in focus group work. Discussion guidelines were followed. The discussions were tape recorded and later transcribed before being translated into English by the facilitator. Analysis of the data draws on elements of both the grounded theory and the systems theory paradigms.

Results: The findings reveal that, for the most part, women present to the KCCSP in order to have general gynaecological problems addressed. Returning for results represents an extension of this need.

Obstacles to returning include problems with access to the clinic, the need to care for dependents at home and the competing priorities of housework and generating income. Factors that promote the returning for results are the imperative to understand the cause of, and have treatment for pre-existing gynaecological symptoms which cause high levels of anxiety. Related to this, women are motivated to have confirmed or refuted the diagnosis of a fatal disease, including cancer and HIV.

Certain qualities and design features of the KCCSP facilitate women returning for their results. These include the perceived superior quality of interpersonal communication between Project staff and clients and the efficient manner in which results are made available to clients.

Other promotive or obstructive factors that play a role in cervical screening service utilisation include; client attitudes towards traditional healers, a prevalent fear of hysterectomy, concern about privacy and gossip and a suspicious attitude toward caring health workers.

Conclusions: Women enrolled in the KCCSP have a personal health agenda with a different focus to that of the Project. Chronic gynaecological problems are frequently experienced and give rise to levels of anxiety about their being signs of serious pathology. Women have not had these fears or the symptoms adequately addressed at other health services. The need to have these issues properly managed represents a large enough motivating force to overcome many of the practical and psychological obstacles to utilisation of the KCCSP. The Project represents for women a general women's health service.

Chapter One

Introduction

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Introduction

This introductory chapter will provide a background to cervical cancer in low-resource settings. The discussion will cover the epidemiological patterns in South Africa, the risk factors and pathogenesis of the disease, the reasons why poor South African women are vulnerable and the problems associated with cervical screening in low-resource settings. This chapter will introduce the setting of the study, the Khayelitsha Cervical Cancer Screening Project, and will follow with an explanation of the research question and the motivation for the study.

1.1 Cervical cancer in low-resource settings

Cervical cancer is a preventable major cause of death, particularly in the developing world where 80% of cases occur and where it is the leading cause of cancer mortality in women. In these regions, the incidence is 470 600 cases per year compared to an incidence of 90 000 cases per year in developed regions of the world. Approximately 233 400 deaths from the disease occur annually (Parkin et al. 2001, pp. 153-156). The crude mortality rate in South Africa due to cervical cancer is 15.7 per 100 000 women. In Australia, this rate is 4.5 per 100 000 women (Pisani et al. 1999, p. 24).

Underreporting of cases in the developing world results, in part, from a lack of opportunities for diagnosis. Furthermore, there are very few population-based registries. The register in South Africa is tumour-based. Thus, the statistics quoted for South Africa and other developing countries probably underestimate the true extent of the problem (Sitas 1998, p. 15).

It may be argued that cervical cancer is a disease of poverty. The risk factors for cervical cancer are closely associated with socio-economic hardship. In resource-poor regions of the world, such as sub-Saharan Africa, South East Asia and Latin America, it is the commonest cause of cancer mortality in women (Parkin 1988, pp. 184-187).

Services for cervical cancer prevention seldom exist in these countries. Furthermore, women, disempowered by their rural, socio-economic or subservient gender status confront enormous obstacles to accessing health services for cervical cancer prevention even when these *do* exist. In developing regions, these services are frequently inaccessible geographically, financially and culturally.

Few services here are able to meet the infrastructural requirements of a comprehensive cytology-based (Pap smear) screening programme discussed below in section 1.1.4 (Denny 2000b, p. 16).

This study focuses on an aspect of cervical cancer screening – women's receiving of their results. This component to screening is crucial because without an adequate means to ensure that women receive their screening results, health workers are unable to provide the required recommendations for follow-up. This renders any screening endeavour completely ineffective. In resource-poor settings, methods of communication such as telephones, fax machines, or postal services are frequently unreliable or non-existant. Thus, for the most part, a further burden is placed on women to return on another occasion to the health service in order to receive their results.

1.1.1 Epidemiology, with particular reference to South Africa

Cancer of the cervix is the most common form of cancer in South African women and comprises 18.5% of all female cancers. Black women constitute 85% of all cases of cervical cancer. In 1997, 5 318 new cases were reported. The age standardised incidence rates (ASIR) of cervical cancer reported in the most recent South African cancer registry are 38.5/ 100 000 for black women with a corresponding lifetime risk (LR) of developing cervical cancer of 1 in 23. For white and "coloured" women, the ASIR is 15.9/ 100 000 with a LR of 1 in 59 (Mqoqi et al. 2003, pp. 10-18).

When compared to other regions, incidence rates in black South African women are similar to those found in the rest of Africa and "rank amongst the highest in the world". (Sitas 1998, p. 15). Rates for white South African women are comparable to those found in the UK or USA (ibid. p.15). The introduction of successful mass cervical cancer screening of women in resource-rich regions has contributed to the vast discrepancies in rates between developed and developing populations (Denny 2000b, p. 21).

1.1.2 Risk factors and pathogenesis

Cervical cancer is a disease of older women with the peak incidence occurring between 50 and 79 years of age, a time in women's lives when they fulfill vital social, cultural and economic roles in their communities. The precursor lesions, which do not cause symptoms, occur most commonly in younger women and may take 10-20 years to develop into invasive carcinoma. Lower grade precursor lesions have a better chance of regressing spontaneously than higher grade lesions. Younger age and an adequate immune system are associated with an increased chance of regression (Denny 1999, pp. 153-159).

Many of the risk factors for cervical cancer are characteristic of risk factors for sexually transmitted infections, in general.

The risk factors for cervical cancer include, among others, early age of first intercourse, multiple sexual partners or a partner with multiple partners, high parity, immune suppression from any cause, but in particular HIV and vitamin deficiencies, low socio-economic status and infection with STIs such as herpes simplex (Bloch 1996, p. 302; Wright et al. 1994, pp. 232-233; see appendix 1). Most of these risk factors are surrogates for persistent infection of the cervix with certain high risk types of human papillomavirus (HPV). This virus is now believed to be an essential aetiological factor in the pathogenesis of cervical cancer (Denny 2000b, pp. 27-31).

The risk factors for cervical cancer are intimately associated with the conditions in which poor women find themselves.

1.1.3 Why are poor women in South Africa vulnerable?

South Africa contains wide disparities in socio-economic development within its population. When compared to other medium development countries, South Africa shows a much higher than average Gross Domestic Product ratio of richest 20% of the population compared to the poorest 20% of the population (Bradshaw, Masiteng & Nannan 2000, p. 95). These disparities persist despite the transition to a democratically elected government and the termination of the apartheid regime in 1994. The poorest half of the population receives only 11% of the national income. This skewness of income distribution is echoed in the rest of the sub-Saharan region (*United Nations Development Programme Poverty Report 1998*, p. 45).

Although relative and absolute health expenditure in South Africa is higher than that in other medium development countries, this is undermined by high spending in the private sector, which serves a wealthy minority of the population (Bradshaw, Masiteng & Nannan 2000, p. 95).

Levels of poverty are shown to correlate highly with population group type *(Poverty and Inequality in South Africa*, cited in Bradshaw, Masiteng & Nannan 2000, p. 96). Governmental statistics released in 1999 showed that 61% of Africans, 38% of "coloureds", 5% of Indians and 1% of whites lived below the poverty line (*Statistics South Africa 1999*) and that 70% of the poor live in rural areas (*UNDP Poverty Report 1998*, p. 45).

Most health status indicators follow the same racial patterns. This is particularly noticeable for the infant mortality rate (IMR)[1] which is 47 for Africans and 11.4 for whites, and the under-5 mortality rate[2] which is 63.6 for Africans and 15.3 for whites (Day & Gray 2002, p. 439). Human Development Index (HDI)[3] values further describe this trend. In 1996, Africans had a HDI of 0.630, "coloureds" had an HDI of 0.698 and whites had an HDI of 0.858 (ibid. pp. 428-431).

Thus, discrepancies in health expenditure and health status can be seen to relate directly to levels of poverty, which in turn, relate to race.

Gender dimensions of human poverty mean that women are poorer than men with respect to health and education. In some societies, girls and women are less likely to receive adequate nourishment and health care. "These disparities result from gender-based inequalities in households, and are reinforced and supported by gender biases outside the household, such as in labour markets, credit institutions and the legal system." (*UNDP Poverty Report 1998*, p. 72)

The degree to which women are affected by poverty in the setting of this study is detailed in a 1989 household survey of women's health status in Khayelitsha by Hoffman et al. It showed that one third of women were living in shacks without access to water, sanitation or electricity. Forty percent of women were not living with a male partner. Levels of education were low, with 7% having no education and a further 39% having received some primary school education only. Unemployment levels were extremely high, with 45% being unemployed and a further 23% having informal employment. Almost half of women earn less than $60 per month. According to the calculations of degrees of urbanisation, 36% were classified as urbanised, 27% were rural, while 37% were transitional (1997, p.152)

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[1] The infant mortality rate is calculated per 1000 live births in the year of measurement.

[2] The under 5 mortality rate is calculated per 1000 children between the ages of one year and five years in the year of measurement.

[3] The HDI measures the average achievements of a population by measuring three aspects of human development. These are a long, healthy life, knowledge and a decent standard of living.

These socio-demographic factors were related to health status and use of health services. Poverty was found to be the "overriding factor affecting the health of the population" (ibid. p.149). Reported cases of diagnosed chronic illness were low, indicating undiagnosed disease in the area. Increasing age and increasing level of education were related to reported diagnosis of chronic disease.

This finding supports the tenet that education improves access to health services where diagnosis can take place. Knowledge of services was good, except for knowledge of cervical screening services. The groups of women most at risk for cervical cancer, i.e. older, less educated and less urbanised women were shown to have the least knowledge of screening services (ibid. p. 149).

The health status of the women from the survey was discussed in another paper in 1997 in which data relating in particular to social and reproductive health was discussed. Most women received considerable support from their neighbours, friends or relatives. However, child care support was poor and a large proportion of women was financially disempowered by their male partners.

More than half of women of childbearing age used contraception. Having had an adolescent pregnancy was reported in 53% of women and this was statistically related to lower levels of education. Less urbanised women had more pregnancies, were less aware of cervical screening, were less likely to have had a Pap smear, were less knowledgeable about where to undergo cervical screening, and were less likely to have heard of HIV/AIDS (Pick & Cooper 1997, pp. 45-55).

Poor South African women are made further vulnerable by the HIV pandemic where women constitute 59% of those infected and are least able to protect themselves from infection (Adar & Stevens 2000, p. 421).

It is estimated that between one in four and one in six women are in abusive relationships and that 80% of rural women are victims of domestic violence. In addition, South Africa has the highest number of reported cases of rape in the world (ibid. p. 411).

It follows that if the risk factors for cervical cancer and STIs, including HIV, are to be avoided, then women must be empowered to negotiate safe and consensual sex. However, lack of education, rural status, low social status, low financial status and an environment of violence against women combine to undermine women's ability to do so.

Primary prevention strategies to reduce cervical cancer ought therefore to occur in tandem with efforts at socio-economic upliftment of poor women. This daunting prospect has necessitated the focus of prevention to occur at a secondary level, i.e. cervical screening.

The next section will discuss the challenges of cervical screening programme development in low-resource settings.

The literature review of this study will show how the factors associated with poverty that predispose women to developing cervical cancer, further act as barriers to cervical screening uptake (see chapter 2).

1.1.4 Cervical screening in low-resource settings

> ...[It] is hard to decide between investing in the development of high quality screening programmes or to wait for new options in primary prevention. It might be more sensible to invest in improving access to health services and quality of medical care and in educating the population in making use of it. (Pisani et al. 1999, p. 28)

Cervical cancer may be prevented by screening the cervix with cervical cytology, the Pap smear, for the presence of the precursor lesions to cervical cancer. If these lesions are detected on a smear, their presence can be confirmed by colposcopic examination and histological sampling. Thereafter, the lesions can be treated at colposcopy, by removal of the lesions under local anaesthetic using the Loop Electro-surgical Excision Procedure (LEEP). Women require follow-up after treatment to assess for recurrence or persistence of pre-malignant disease, or progression to invasive disease. This cytology-based model for the prevention of cervical cancer is considered the "gold standard" and is by far the most common method of cervical screening worldwide (Denny 2000b, p. 16).

1.1.4.1 Cervical screening in developed countries

There is considerable evidence to show that mass cytology-based cervical screening programmes in developed countries have made a significant impact on the problem of cervical cancer. The degree of success of these programmes appears to be related to the extent of screening coverage of the population at risk, the target age of the women screened and the reliability of the cytology services (*IARC Working Group on Evaluation of Cervical Cancer Screening Programmes* 1986, pp. 659-664). Programmes are less successful when screening is spontaneous and opportunistic. In these circumstances, the women most at risk are not reached.

Further, the lack of a co-ordinated campaign involving education about cervical cancer prevention results in suboptimal follow-up and management of women with abnormal smears (Hakama & Louhivuori 1988, pp. 403-416).

1.1.4.2 Cervical screening in developing countries

For these reasons, screening in developing countries has made minimal impact on cervical cancer incidence and mortality (Miller 1992, p. vii). In particular, coverage in these regions is extremely poor, with a level of 5% of women quoted by the WHO in 1986.

Moreover, most screening activity in developing regions tends to target younger, less at-risk women, by taking place in antenatal, family planning and urban hospital-based settings. Screening is opportunistic with limited formal recruitment efforts to ensure coverage of high-risk women. Treatment and follow-up of those at risk is poorly co-ordinated (Parkin 1991, pp. 184-198).

1.1.4.3 Cervical screening in South Africa

These problems are characteristic of screening efforts in South Africa. Local researchers have shown that cervical screening receives low priority status in primary care settings. Furthermore, there are inadequate public health educational programmes to address the documented lack of knowledge of cervical cancer prevention in the population most at risk (Heysteck et al. 1995, p. 1 182; Leiman 1987, pp. 67-68; Emdon, Gerard & Jones 1884, pp. 289).

Women's misperceptions and lack of knowledge as barriers to cervical screening are discussed in the literature review of this thesis. One anthropological study examined the reasons for the problems of low coverage and loss of women to follow-up. The authors identified barriers to screening as fear of vaginal exposure, expectation of pain, being asymptomatic, and the gender of the screener. Cervical screening is associated with sexually transmitted infections and is thus considered to be a cleansing process and the disease associated with dirtiness and promiscuity (Wood, Jewkes & Abrahams 1997, pp. 287-293).

These factors have, in part, been responsible for the low rates of cervical screening coverage. On the one hand, while it has been shown that younger women, white women and urban women have been disproportionately highly screened (Cronje et al. 1989, p. 116; Bailie 1995, p. 8), low cervical screening coverage has been clearly documented, particularly in rural areas (London 1993, p. 175). A multi-centre study by Fonn et al. conducted in 1997 in each province of South Africa showed 80% of the 20 277 women recruited had never been screened (Fonn et al. 2002, p.154).

Of those women that *are* screened in South Africa, there are high rates of loss to follow-up (Bailie 1995, p.8; Khatree, Houlton & Moodley 1980, p358). Fonn et al showed how health providers contribute to this phenomenon. Misinterpretation of smear results by health personnel resulted in 15% of women with high grade pre-malignant disease, and 13% of those with cervical cancer, being overlooked for recommendation for colposcopic evaluation (Fonn et al. 2002, p. 154).

Until 2001, there had been no national organised screening policy. The new policy offers three free smears per lifetime, commencing after the age of 30 years and with a 10-year interval between each smear. The aim is to reduce the incidence of cervical cancer by 60% (Mqoqi 2003, p. 18). However, data from developed countries show that a 51% reduction in cumulative incidence is only achievable if 80% of the population of women over 35 years is screened (Miller 1992, p. 23). With the new policy, there has been no organised attempt to ensure adequate coverage of the target population.

The Western Cape province adopted the protocol that was to be used for the national policy as early as 1994. Smith, Moodley and Hoffman showed in 1998, in Mitchells Plain, a lower income district on the outskirts of Cape Town, that only 16% of the expected numbers of screening Pap smears were performed. Only 545 (37%) of the total number of 1 463 smears were performed on women in the target age range of 30-59 years. This occurred despite a well-developed public health infrastructure in this area.

The authors conducted a survey of nurses' knowledge, attitudes and practices concerning the screening policy, which identified possible reasons for the low coverage and inappropriate focus on younger women for screening. The vast majority (84%) of nurses had a negative attitude toward the policy, misunderstood its rationale and had a lack of familiarity with the natural history of cervical cancer Smith, (Moodley & Hoffman 2003, pp. 32-35).

1.1.4.4 Cervical screening in Khayelitsha

The screening activity in Khayelitsha, prior to the adoption of the Western Cape screening policy in 1994, occurred in Midwife Obstetric Units, family planning clinics and, less so, in the three primary health care clinics. The vast majority (72%) of women screened were under 30 years of age. After introduction of the policy, the number of smears for the area decreased from an average of 5 000 per year to 1 332 smears in 1995 (Denny 2000b, pp. 34-35). This was due to the virtual cessation of screening of pregnant women and those under 30 years. It appeared that the policy failed to receive the support of the nursing staff (M. Adamo, Director of Reproductive Health, PAWC, 2000, personal communication).

In 2002, only 550 smears were taken in Khayelitsha, excluding those taken as part of the KCCSP (City of Cape Town 2002).

1.1.4.5 The problems with cytology-based screening

Successful cytology-based screening programmes require a relatively sophisticated health infrastructure which can provide the following features:

- adequate field facilities with appropriately trained health personnel
- wide coverage of the target population at regular intervals and means to contact these women on an individual basis
- well functioning management and information systems
- a cytology service with mechanisms for quality assurance, audit and training of technicians
- a referral system for colposcopic assessment and management of women with abnormal smears and follow-up for those who have been treated for pre-invasive disease
- community participation and acceptance
- programme planning that occurs at national level with an in-built call and recall system
- a cancer registry to monitor the impact of the programme.

(Denny 2000b, pp. 39-40; *Planning Appropriate Cervical Cancer Control Programs* 1997, pp. 2-7 – 4-14)

No resource-poor countries have been able to provide such a complex system for mass screening. Cytology-based screening initiatives have thus failed in these regions.

Even less complex efforts at cervical screening in these regions face considerable obstacles. According to Professor Denny, these barriers include poorly developed health care services, where the focus of care is generally on curative rather preventive care, an overwhelming burden of diseases causing competing health needs, limited financial and human resources and war and civil strife. The latter disrupts existing health care services, causes displacement of people and the creation of refugees. Widespread poverty and the disempowerment of women are also cited as significant barriers to screening and these are discussed elsewhere in this dissertation (2000b, pp. 41-45).

The Khayelitsha Cervical Cancer Screening Project developed from a need to search for methods of cervical screening that will overcome the many barriers to cytology-based screening in low-resource settings.

1.2 The Khayelitsha Cervical Cancer Screening Project

The Khayelitsha Cervical Cancer Screening Project (KCCSP) is a community-based research project that has been in operation since 1996. I was employed as Project manager in 1998 and 1999, during phase 2 of the Project.

Researchers are evaluating alternative strategies for cervical cancer prevention in low-resource settings. Investigations are based on alternative screening modalities to the cytology-based Pap smear. Recently, the research has evaluated treating women on the basis of the screening results, in a randomised controlled trial. This "screen and treat" approach provides all services, by trained nurses, at primary care level, at one visit. This obviates the need for women to return for their screening results, be referred for confirmatory diagnosis by highly-trained medical staff at a tertiary gynaecological centre and then possibly, be referred for yet a further appointment for LEEP.

The intention of the Project is to document the effectiveness, safety and acceptability of these alternatives for screening and pre-malignant disease management.

Health promotion, using a variety of techniques, forms an integral part of each aspect the Project's operations.

During phase 2, participants were screened using four screening tests for pre-malignant disease. Tests for sexually transmitted infections (STIs) were also undertaken. All women consented to provide a blood sample for anonymous-linked HIV testing[4]. The results for all of the tests (except for HIV), were available at three different stages. Study participants were given a patient card with dates given for the receiving of their results. Women were offered three options for retrieving their results: by telephone, by attending the Project personally or via a messenger.

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[4] Anonymous-linked HIV testing occurs when HIV results are stripped of any identifying information, but are linked to clinical data during statistical analysis. Thus, those who provide the blood sample for this type of testing are not able to receive their results.

These occasions of contact with the Project were recorded in the Project logbook. Thus, a figure of 69.1% was calculated for the proportion of women who spontaneously returned personally, or via a messenger, or telephoned for their first set of results 2-7 days after screening, as arranged. Women with positive screening results who did not return for these, were traced at their contact addresses by the community health workers (CHWs). Treatment was provided to those who tested positive for any STIs.

Women who tested positive for any screening test were offered colposcopy at the Project. This colposcopic examination of the cervix, provided by Professor Denny, the Project director, allowed for confirmation of the screening tests, the use of histological sampling of the cervix as well as treatment of pre-invasive lesions, if necessary. Follow-up examinations were provided for those who had undergone treatment.

1.3 The research question: Why *do* so many of the women return spontaneously for their results at the KCCSP?

Against a background of well-understood obstacles to cervical screening uptake[5], staff at the KCCSP were surprised to note the relatively high spontaneous return rate of 69.1% for the first set of results at the KCCSP.

By comparison, research by Bailie showed that in Khayelitsha, only 31% of women undergoing a Pap smear in the public health services of the area, returned to the screening service or initiated contact in order to get this result (1994, pp. 144-151). Another cervical screening research project that ran in Khayelitsha in 1993, offered Pap smear results one day after screening took place. The spontaneous return rate of the women with high grade pre-malignant lesions was 34% (Megevand et al. 1996, p. 926). In Zimbabwe, only 19% of 419 women in a rural district hospital returned to the service after cervical screening, as requested. This number included those who had been traced (Thistle & Chirenje 1997, pp. 246-251).

The most obvious possible explanation for the relatively high rate of return at the KCCSP is that certain features of the Project per se provided incentive for women to overcome the barriers that they face. These features may have attracted women to utilise the service fully. Many of the positive features of the Project are related to the fact that services are offered in the context of research.

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[5] These will be discussed in chapter 2.

The extent of the funding for this research enabled the employment of a wide range of carefully trained staff. The CHWs and nurses spoke the same language as the clients and shared similar backgrounds to many of the clients. In addition, the service of a medical officer, on most days, dedicated to addressing general health and sometimes, social needs, may have contributed to the attractiveness of attending the Project.

The high staff to client ratio allowed for time for staff to develop relationships with the women attending. In this environment, the women waiting frequently developed camaraderie among each other.

Refreshments were offered to those required to wait before being seen and music or audio and video tapes with educational material were played in the waiting area.

Another possible significant factor contributing to the spontaneous return rate of women attending may have been the health promotion emphasis of the Project. At each stage of participation in the Project, clients were educated, engaged in conversation and encouraged to inquire about cervical screening and related issues. These interactions occured in the women's own language, Xhosa.

The features of the Project that are described above are seldom encountered at South African public health services where cervical screening mainly occurs opportunistically in the setting of busy antenatal or family planning clinics (Bailie 1994, p. 144).

Thus, the high spontaneous return rate may be accounted for, in some part, by the high standard of service delivery and functional accessibility of the KCCSP. However, other reasons, unrelated to the Project, may have been relevant and require investigation.

1.4 Motivation for the study

There is a body of literature describing the reasons women in developing countries *do not present initially* to cervical screening services when these are available. Some research provides data regarding factors that *promote* cervical screening uptake. The barriers and promoters of service utilisation will be discussed in more detail in chapter 2 of this thesis.

In most areas of South Africa, the public health infrastructure exists to provide a cytology-based cervical screening service, despite the need for some improvements in health system functioning (Fonn 2002, pp. 148-156). A vital component of the health system functioning for cytology-based programmes is the process by which women receive their smear results.

Most screening services in low-resource settings, where postal and telecommunication systems are unreliable or non-existent, as is the case in many parts of South Africa, require clients to return to the place of screening for their results. Logically, the obstacles that women face in *presenting* for screening will therefore exist for their *returning* for results.

However, the fact that women have had initial contact with the screening service adds extra dimensions to their experiences and perceptions of cervical screening. These may impact particularly negatively or positively on their returning for their results.

It is crucial for health programme planners and managers to develop an appreciation of the range of factors, both client-related and service-related, that influence women's *returning for results*. It appears that little is documented about this particular aspect of health seeking behaviour, particularly in an African setting.

This, together with the high prevalence of cervical pathology and problems with service delivery, makes deeper investigation of client perceptions, attitudes and personal circumstances affecting their behaviour, particularly germane.

This study was motivated by a perceived need for an examination of the issue of returning for results. It was felt that a focus group study would enable an exploration into the personal reasonings, attitudes and perceptions that informed the women's decision to return.

It is suggested that if the phenomenon of spontaneous returning at the KCCSP can be better understood, this knowledge may generate ideas for further improvement of the service and a further increase in the spontaneous return rate. Some lessons learnt may be applicable to screening services in other settings.

Chapter Two

Literature review: Participation in cervical screening programmes – the barriers and promoters

Literature review:
Participation in cervical screening programmes – the barriers and promoters

The barriers to cervical cancer screening in developing countries are discussed by Professor Denny, director of the KCCSP, in her PhD dissertation. They include competing health needs, limited human and financial resources, poorly developed health care services, services which focus on curative rather than preventive health care, war and civil strife, the infrastructural requirements of cytology-based screening, widespread poverty and the fact that women are uninformed and disempowered (Denny 2000b, pp. 41-45).

This literature review will focus on the latter two factors and explore the *problems* associated with the utilisation of cervical screening services when they *are* available. This chapter will also provide a critique of the literature describing those factors that *promote* cervical screening service utilisation. The review draws on local research as well as research from other countries. No studies were found that describe, in particular, the factors that promote the spontaneous returning for screening results as distinct from the factors that promote attendance for screening or follow-up after receipt of results. However, it follows that many obstacles and promoting factors are common to all these aspects of service utilisation.

This chapter will also provide a brief discussion of qualitative research that was undertaken at the KCCSP at the end of 2001 (Women's Perspectives on Cervical Cancer Screening and Treatment 2002). In addition, there will be a section discussing research from a recent multicentre South African study on the prevalence of pre-cancerous lesions and cervical cancer. In this study, all regions of South Africa obtained a very high rate of women's receiving their screening results (Fonn et al. 2002, pp. 148-156).

The findings from the literature will be counterpoised against the findings of the study for this dissertation in the discussion, chapter 7.

2.1 Barriers to participation in cervical screening programmes

Several forces seem to militate against the utilisation of cervical screening services in low-resource settings. For the purposes of this review, the obstacles to participation in cervical screening programmes will be classified as patient-centred or health service-related.

2.1.1 Patient-centred problems

Most of the reviewed research focuses on problems related to *users* of screening services as opposed to *service*-related problems. The studies identified categories of client-related obstacles to screening uptake. These included socio-demographic factors, levels of knowledge and psychological factors.

2.1.1.1 Socio-demographic factors

Low socio-economic status

There is evidence in the international literature that low socio-economic status is related to a lower likelihood of undergoing cervical screening (Fylan 1998, p. 1510; O'Malley, Forrest & Mandelblatt 2002, pp. 144-154).

The majority of women in Khayelitsha, like those attending the KCCSP, encounter significant socio-economic hardship. This is substantiated, in part, by the demographic data that is available from the enrolment form, which is detailed in table 1. The participants suffer under the burdens of high levels of unemployment, low levels of education and poor living conditions (Denny 2000a, p. 828).

A 1989 household survey of women in Khayelitsha, gathered data on demographic, socio-economic, health status and health service utilisation of 722 households (Cooper et al. 1991, pp. 423- 427; Cooper et al. 1991, pp. 428-432; Hoffman et al. 1997, pp. 149-157). Some of the findings are described in section 1.1.3 of this dissertation.

Significant determinants of having had a Pap smear were a level of education beyond 10 years (odds ratio [OR] 1.88, p = 0.006), not having a rural home (OR 3.19, p = 0.000) and use of contraception (OR 1.52, p = 0.023). Women's lack of knowledge of where to obtain a cervical smear was significantly associated with having less than 6 years education (OR 1.52, p = 0.035) and being urbanised for less than 11 years (OR 1.41, p = 0.048) (Pick & Cooper 1997, p. 51). The researchers describe the quadruple oppression of women in Khayelitsha, on the basis of race, social class, gender and recent urbanisation. Thus, it follows that the disempowerment of women gives rise to numerous obstacles to accessing health care.

During phase 1, at the KCCSP, of the 842 women who required colposcopy on the basis of their screening results, only 77 (9.1%) were lost to follow-up (Denny 2000b, p. 98). A significant reason for this may be the fact that colposcopy was offered on site on the days women were requested to return for their results. This convenience obviated the need for a second phase of referral to occur.

Socio-demographic factors were analysed for association with women who *were* lost to follow-up. Loss to follow-up signifies women with positive screening results, who failed to return for their results and were further unable to be traced successfully. Therefore, this group did not undergo the required colposcopic examination. Hence, the group is characterised by women with a high risk of cervical pathology, by virtue of their positive screening results, and by those experiencing obstacles to adherence to the Project protocol.

A univariate analysis showed that those who were significantly less likely to return for follow-up were those women not born in Cape Town ($p = 0.007$), those who used alcohol ($p = 0.03$), those who had no children ($p = 0.01$) and those who lived in unserviced sites[6] ($p = 0.03$). The link between poverty and health service utilisation is made again.

However, there was no association between loss to follow-up and age, marital status, employment, level of education, age of first sexual intercourse, smoking and use of contraception (ibid. p. 105).

Older age

Other studies, all in developed countries, but concerned with lower-income groups of women, have shown older women are less likely to adhere to initial screening as well as follow-up recommendations (Fox, Arnsberger & Zhang 1997, pp. 199-209; White 1995, pp. 659-666).

In concordance with screening data from the Khayelitsha health district (Denny 2000b, pp. 34-35), Blesch and Prohaska showed that numerous studies around the world, have shown older women consistently to have fewer Pap smears and a greater likelihood of never having been screened. The authors give numerous suggested reasons for this, some of which are relevant to the South African setting. These include "missed opportunities" where cervical cancer screening is overlooked by primary health providers during non-gynaecological visits.

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[6] Unserviced sites are undemarcated plots of land on which self-erected shanty dwellings have been constructed. No amenities are provided.

Fear, cognitive barriers (e.g. embarrassment, feeling the test was personally inappropriate, negative perceptions about the procedure) and social barriers (e.g. husband objected), were also cited as obstacles to screening in older women, although these apply to women of all ages and in differing socio-economic settings as well.

However, problems within health systems were considered the primary causes of older women missing screening. These problems include communication failures with potential candidates, difficulties in arranging appointments and inconvenient clinic locations. Cervical screening interventions rarely target older women effectively. This could be achieved by identifying potential candidates and actively encouraging their participation (1991, pp. 141-147).

Elias and Sherris reviewed the burdens that ageing women face in developing countries. These burdens may impact on their use of health services by decreasing their accessibility to these services. The burdens include the lifelong effects of sexual bias and low social status and the emotional and economic responsibilities associated with their role as family care givers. The latter may involve responsibility for the care of ageing parents, older husbands and orphaned or abandoned children, particularly in the context of the HIV/AIDS pandemic (2003, pp. 64-65).

Transport, loss of income and child care

It appears that accessing health services constitutes significant challenges for poor women, even in peri-urban areas. Although the Project is situated in a busy area of Khayelitsha, many women are forced to walk for long distances or pay ill-afforded rates for public transport to attend the clinic. Those who are employed, especially temporarily employed, risk the loss of income for the day spent attending, or the threat of the loss of their jobs. Lerman et al. cite the practical barriers to attending for colposcopy in a low-income North American setting as being cost, transportation and child care issues (1992, p. 330).

Many women in Khayelitsha are responsible for the care of young or sick children, grandchildren and parents (Personal discussions with clients attending the KCCSP, 1999). Pick and Cooper showed in Khayelitsha that, in 60% of cases, the mother was the usual care-provider for children, followed by the grandmother, in 15% of cases. Should these women not be available to provide care (such as would be the case in order to attend a health service), then 27% of women had no-one on whom to rely (1997, p. 49).

A recent study of health-seeking practices among poor peri-urban pregnant women in Cape Town showed a range of barriers to attending for an antenatal booking, which may similarly apply to attending for cervical screening. These include lack of time, economic factors such as lack of transport money, being discouraged to attend by employers, being paid at work only for work done, the difficulty in getting transport, the effort required to travel distances to the clinics, the weather and difficulties in arranging for child care (Abrahams, Jewkes & Mvo 2001, p. 244).

2.1.1.2 Poor knowledge and misperceptions about reproductive health issues

Contemporary mythologising around gynaecological and cancer-related health matters may also constitute serious barriers to the uptake of screening services. Local qualitative research has shown that levels of knowledge of reproductive health matters in groups of indigent black African and "coloured" women are "extremely poor" (Ishmail 1999, p.10-12).

Low levels of knowledge and misperceptions were prevalent in other South African research of low-income women. One study showed that only 4 (4.5%) out of 89 obstetric in-patients at a public hospital in Johannesburg had heard about cervical smears (Emdon, Gerard & Jones 1984, pp. 289-290).

Three further South African studies explored experiences and barriers to cervical screening uptake. A series of in-depth interviews was conducted in rural areas of three different provinces in South Africa in 1996; two studies consisted of black African women and the third, of so-called "coloured" women. Women of all ages were recruited, including those who had been screened as well as those who had not been screened, both in clinic settings and in the women's homes.

The studies had many common findings. The research showed that the participants commonly considered cervical cancer to be a stigmatised condition that was associated with having low morals. Coupled to these concepts was the issue of "dirtiness". The commonly perceived function of a Pap smear was to "clean" the womb of infections and cancer, and the "dirtiness" was acquired through having many sexual partners. For many women, their experiences of gynaecological symptoms were attributed to having a "dirty womb".

Many women presented for cervical screening on the basis of gynaecological symptoms they were experiencing. The underlying motivation for screening for some was the perceived informative nature of the Pap smear with regard to these problems, "it will tell you that your womb is dirty, that there's a tumour...or that your womb must be removed because you will get cancer." (Abrahams, Wood & Jewkes 1996; Wood & Jewkes 1996a; Wood & Jewkes 1996b).

Fylan conducted an English language literature review of psychological aspects of cervical screening and colposcopy from research published between 1982 and 1997. Numerous studies, including those in lower-income settings, cited poor levels of understanding of cervical screening issues, particularly the concept of pre-cancer. A high proportion of women receiving notification of an abnormal smear result believed they had cancer (Fylan 1998, pp. 1509-1514). Fylan outlined the predominant psychological responses to the processes involved in cervical screening. These are discussed further in the next section.

2.1.1.3 Fear and anxiety

Fear of embarrassment or pain was given as a reason for not participating in cervical screening programmes in eight separate studies (mainly quantitative) from different regions of the world (Fylan 1998, pp. 1509-1514).This was echoed in the findings of all four qualitative South African studies mentioned above (Ishmail 1999, p.10-12; Abrahams, Wood & Jewkes 1996; Wood & Jewkes 1996a; Wood & Jewkes 1996b).

Several other authors have shown adverse psychological consequences of positive screening results in a variety of different clinic settings. These have included anxiety and distress, and impairments in mood, daily activities, sexual interest and sleep patterns (Wilkinson, Jones & McBride 1990, p. 440; Stewart et al. 1993, p. 280-282). Lerman et al. showed that women in a lower-income community in North America were least likely to attend for follow-up colposcopy when these symptoms were most pronounced. This trend was independent of a variety of variables including age, other demographic factors, sexual history or having had a previous Pap smear. However, the study population was particularly young with 63% of respondents aged 15-24 years (1991, pp. 658-662).

2.1.2 Health service-related problems

Health service-related obstacles to cervical screening uptake are well-documented. Many of the systems failures, in South Africa, relate to the inability of the public sector to meet the infrastructural requirements of a cytology-based screening service. Furthermore, the overwhelming burden of diseases, such as HIV and Tuberculosis, constitute competing health needs. In addition, limited financial and human resources contribute to these constraints. These are further discussed in section 1.1.4 of this dissertation.

This section will focus on other service-related obstacles to cervical screening, including inaccessibility of services, abusive and uncaring behaviour, poor knowledge and the gender and language of service providers.

Past negative experiences with the health services serve as a deterrent to attendance. Staff at many of the state-operated community health services typically feel overworked and demotivated. They are faced with a variety of presenting complaints and are untrained or the facilities are under-resourced to deal with these adequately (Staff at Community Health Centres and clinics in Cape Town, 1998-2003, personal communication). Clients spend long, uncomfortable hours waiting for services that they then perceive to be lacking.

This situation is highlighted by Palmer, who drew from quantitative (household survey) as well as qualitative (focus group discussion) data to explore why low-income groups in South Africa so frequently pay for the services of private health providers. Numerous themes emerged that present an indictment against the public health sector in this country. The themes of patients' perceptions include the following: patients get improved quality and choice from paying for a health service; the treatment that patients receive in the public sector is not effective; the public health service is unequipped to address patients' needs; and patients are treated in an unacceptable, frequently abusive manner in the public sector (1999, pp. 95-102).

2.1.2.1 Inaccessibility of services

Many of these identified problems with public health services were underscored in the study, mentioned previously, by Abrahams, Jewkes and Mvo who examined the health care-seeking practices of pregnant women in peri-urban low-income areas of Cape Town (2001, pp. 240-247).

Their findings reveal that significant barriers are created by the set quota system of numbers of women accepted for booking visits at the public sector Midwife Obstetric Units (MOUs). This limitation on available opportunity to book, results in women needing to negotiate a safe escort through dangerous areas in the dark. This is done in order to arrive at the MOUs between midnight and 6:30 in the morning, to ensure being accepted in the quota. Further, as MOUs serve women from particular geographical catchment areas, women do not have the option to seek care at other MOU sites (ibid. p. 244).

Similar quota and catchment area constraints exist for general public health care services in the South African health system and therefore impact negatively on accessibility to cervical screening.

In the study above, women found it difficult to attend when services were available only during working hours. This is echoed in studies elsewhere, such as Scotland (Campbell, MacDonald & McKiernan 1996, pp. 94-97) and among low-income Mexican-American women. In the latter study, factors such as inconvenient service provider hours as well as having to wait too long to get an appointment or for the consultation, constituted significant barriers to attending for cancer screening (Lobell et al. 1998, pp. 301-308).

2.1.2.2 Service providers' abusive and uncaring behaviour

Abusive behaviour by MOU nursing staff was commonly reported in the study above. Further, accounts of labour and delivery featured the twin problems of abuse and neglect. Abusive behaviour included being shouted at, being beaten or threatened with beatings and being ordered to clean the floor. Many women reported delivering without any staff in attendance. The women's reports were confirmed by interviews with midwives (Abrahams, Jewkes & Mvo 2001, p. 245). Abusive behaviour by nurses towards patients in South Africa has been reported elsewhere (Fonn et al. 1998, pp. 697-702; Mathai 1997; Jewkes, Abrahams & Mvo 1998, pp. 1 781-1 795).

Van der Walt reports an impression of "alienation" in nurse-patient relationships in Tuberculosis clinics in Cape Town. The interactions between nurses and patients were often characterised by their impersonal nature or an attitude of disapproval on the part of the staff (1998, pp. 43-49).

2.1.2.3 Service providers' poor knowledge

Two South African studies of cervical screening services highlighted significant deficiencies in levels of knowledge of service providers.

The first study by Smith, Moodley and Hoffman in 1998 is discussed in section 1.1.4. The vast majority (84%) of nurses had a negative attitude toward the screening policy; they misunderstood the rationale of the policy and lacked familiarity with the natural history of cervical cancer. Furthermore, 25% of the 51 nurses surveyed reported not understanding Pap smear results at all, and only 36% were able to understand all results (2003, p. 32-35).

A study by Fonn et al. in 2000, which is discussed further in section 1.1.4 and 2.4, showed a high rate of error in recommending appropriate follow-up for all types of smear results. Of particular concern, is that 15% of high-grade pre-malignant disease smears and 13% of smears with invasive cancer were incorrectly identified as requiring a repeat Pap smear. It is unclear from the article whether these errors occurred at laboratory level or at nursing level in the clinics (2002, pp. 154-155).

2.1.2.4 Service providers' gender and language

Several studies report that unavailability of a female screener deters women from attending for screening (Summers & Fullard 1995, pp. 277-281; Campbell, MacDonald & McKiernan 1996, pp. 94-97; McKie 1993a, pp. 1 228-1 234; McKie 1993b, pp. 972-979; Lee 2000, pp. 168-175). In South Africa, female nurses in primary care clinics perform most smears. Thus, it is unclear whether the gender of the screener plays a role in obstructing access to screening in the local setting. No local data were found to support this view.

Studies of low-income women, in a variety of settings, show that a significant barrier to full participation in primary care services is an inability of the service providers to be able to speak the language of the client. This language barrier to cervical screening attendance was identified in six different ethnic minority groups in east London (Naish, Brown & Denton 1994, pp. 1126-1128) and among minority women in the U.S.A. (Lobell et al. 1998, p. 302).

Crawford provided a report in 1994 of her investigation of the problems associated with language barriers between mothers and staff in Cape Town's paediatric hospital outpatients department. She noted the anxiety and distress in black mothers unable to negotiate the hospital system or unable to participate adequately in consultations with health workers. This was due to the staff's inability to speak the women's language, Xhosa. Crawford asks, "If patients go to doctors [or nurses] for healing: to be accepted, reassured, and helped to place their illness in a context where they can grasp it, understand it and take steps to recover their health, then we must ask where is healing in this [where language barriers exist] discourse of power, knowledge and control?" (1994, p. 3). She places the problem of language in the South African context where the "ethnocentric and monolingual nature of the health system can only be understood in the context of the social, economic and political construction of apartheid society in which black people's voices were actively suppressed" (ibid. p. 6).

2.2 Promoters of participation in cervical screening programmes

This section discusses Fylan's recommendations for overcoming the problems associated with participation in cervical screening programmes (1998, pp. 1509-1514). In addition, reference is made to other studies.

2.2.1 Provision of information

It is noted in numerous studies that women report a need for information about cervical screening issues and that such information results in increased rates of attendance for primary screening (Campbell, MacDonald & McKiernan 1996, pp. 94-97; McAvoy & Raza 1991, pp. 833-836). It is suggested that the provision of information may reduce anxiety, increase confidence in service provision and improve rates of follow-up (Stewart et al. 1994, pp. 583-585).

2.2.2 Quality of communication

Communication with women in a screening setting should take into consideration prevalent fears and misconceptions. These should be addressed in person or by telephone and information should be provided clearly to account for the effects that anxiety has by decreasing absorption and retention of data (Fylan 1998, p.1 512).

McKee reviewed the literature on adherence with follow-up recommendations and concluded that primary care providers can positively influence timely follow-up by anticipating fears, including the fear of cancer, when women hear of their abnormal results. Other fears to anticipate include the fear of pain during colposcopy and the fear of loss of sexual or reproductive function The author recommends that health providers can target their efforts at ensuring adequate follow-up by focusing on groups that are more likely to default, including black women, women with less than a high school education and women of low socio-economic status. Health providers should speak directly with the women about their results and emphasise the pre-cancerous nature of most lesions. Women should be actively prepared for colposcopy by describing the procedure and its complications. Similarly, fears about treatment should be addressed (1997, pp. 574-577).

2.2.4 Consideration of health beliefs

In the survey above, having the belief that one should attend health services for check-ups when feeling well was associated with increased adherence to cancer screening. In women over 65 years, the belief that surgery for cervical cancer causes faster growth of the cancer, was associated with a significantly decreased adherence to screening recommendations (O'Malley, Forrest & Mandelblatt 2002, pp. 146; 150).

Fylan suggests that health providers should use the health belief model to develop a deeper understanding of their clients' health seeking behaviour with respect to cervical cancer screening. This includes an appreciation of women's motivations, beliefs about susceptibility to cervical cancer, the severity of pre-cancerous disease and cancer, and beliefs about the benefits versus the costs of participating in screening. Many of these beliefs have been shown, in other studies, to predict cervical screening behaviour (Williams, Abbott & Taylor 1997, pp. 45-56; Orbell & Sheeran 1993, pp. 417-433). This further underscores the need for appropriate provision of information to clients.

Further, participation in screening programmes is more likely when women believe their health is controlled by themselves, rather than by others or by chance. Thus, women should be encouraged "to take responsibility for their own health and be an active participant...rather than a passive attender" (Fylan 1998, p. 1512).

2.3 Qualitative research on women's perspectives at the KCCSP

An independent research consultant, Ineke Meulenberg-Buskens, in collaboration with Professor Denny and EngenderHealth, the organisation that manages the Project's funding, conducted a qualitative research project in November 2001, after the focus group work for this study was completed. The title of the unpublished report is, "Women's Perspectives on Cervical Cancer Screening and Treatment: Participatory Action Research in Khayelitsha, South Africa" (2002).

The aim and underlying themes of the research were very similar to those for this dissertation: "to explore issues around attending for cervical screening...[particularly examining] what makes women seek out screening services; what are women's experiences with cervical cancer prevention screening and treatment, and how can we use this information to design services that will encourage women to attend?" (Ibid. 2002, p. 5).

A range of methods was used to collect data from participants and staff, including workshops, focus groups, interviews and informal discussions and observations.

An important finding was that neither knowledge about cervical screening, nor a perceived need to care for the self, was sufficient motivation for most women to utilise the Project. Rather, for most women, the major motivating factor to attending was the perception that they were ill. This real or perceived illness was, for the most part, unrelated to cervical cancer. Women felt that rather than attending other health services for these problems, they would prefer to attend the "healing" facilities of the KCCSP, despite knowledge of the Project's limited scope.

For most women, the crucial "Rubicon" was coming for screening in the first place. Women described considerable obstacles that they had to overcome in order to attend. The particular barriers of fear and shame associated with vaginal exposure were predominant, rather than fear of the procedure or the possibility of discovering cancer. The authors describe how this stems from the traditional notion that a woman's vagina is ugly, dirty and has to remain hidden. These feelings of fear and shame are instilled by objections from partners and the wider community.

The reputation of the Project in the community assisted women in overcoming the barriers to participation in the screening. This reputation consisted of the clinic being known as a "service *for* women, *by* women" where a "sisterhood among the patients and staff" existed.

Further, the Project was perceived, unlike other health facilities, to offer a holistic service where "they heal you; they treat you with respect; they help you to learn; and they comfort you in your time of need." (2001, p. 6) This holism was likened to the nature of care that traditional healers utilise. The authors note that the health promotion efforts at the KCCSP incorporate use of traditional discourse and thus provide a bridge between the bio-medical and traditional knowledge systems.

After attending for screening, levels of fear subsided and high satisfaction with the service enabled excellent follow-up rates, acceptance of treatment and resulted in participants encouraging others to attend. Peer support operated strongly in another form where previously screened participants escorted newcomers to the Project until they overcame their initial fears.

Women felt recognised and appreciated as participants in the Project. This resulted in a high level of reported trust in staff and the information they provided.

The research concludes that many features of the KCCSP may contribute to the success of "screen and treat" facilities in other low-resource settings. These include the educational strategies, the woman-centredness, the links with the community, the supportive and understanding staff and the design of the screening and treatment process. The major strength is described as the fact that the Project provides holistic healthcare which "resonates with the health seeking behaviour of the women it aims to attract" (2002, p. 10).

2.4 A high rate of receiving results in a South African multicentre study

Fonn et al. conducted a multicentre cervical screening study which started in 1997. It was designed to formulate an affordable population cervical screening programme in South Africa. The intention was to screen 100 000 women in different regions of the country (Denny 2000b, p. 37). From this work, a prevalence study of cytological abnormalities was published on the 20 603 smears that were taken (Fonn et al. 2002, pp. 148-156).

In this study, the authors reported that 92.9% of women received their results. This contrasts with data from other African settings. The rates of returning for results were 31% in the Khayelitsha public health services (Bailie 1994, pp. 144-151), 34% in a 1993 Khayelitsha cervical screening research service (Megevand et al. 1996, p. 926), and 19% in a Zimbabwean rural district hospital (Thistle & Chirenje 1997, pp. 246-251). The rate for returning spontaneously for the first set of screening results at the KCCSP was 69,1%.

In the Fonn et al. study, data was collected from the women attending to ascertain the motivation for having a Pap smear. It appears that women were not able to give multiple reasons in the survey questionnaire. The two most common reasons were "to confirm health/exclude cancer" (86, 4% of respondents) and because of a "current gynaecological problem" (9% of respondents). The pattern does not concur with the findings in the qualitative study of the KCCSP above, nor with the research findings for this dissertation.

In the Fonn et al. study, only 70.5 % of the population screened attended the service specifically for a Pap smear. Almost half (49.8%) of the women reported the gynaecological symptom of a vaginal discharge, underscoring high levels of gynaecological symptomatology in the population. It is not mentioned whether these symptoms were addressed at the initial screening visit.

No information was given regarding the interactions between staff and participants. It is not clear whether participants were paid to attend for screening or follow-up or whether they had transport costs remunerated.

No trends for age were given for women receiving their results. The distribution of the study population was relatively young with 28.9% between 20 and 30 years and only 15.4% over 50 years of age. This may account, in part, for the high return rate as older women, as discussed previously, are known to face particular barriers to health service utilisation.

The fact that this study was conducted more recently than the others cited for returning rates above, raises the question of whether there has been a possible temporal shift in health seeking behaviour of women in South Africa.

Chapter Three

The setting of the study

The setting of the study

This focus group study took place within a community-based research project, the Khayelitsha Cervical Cancer Screening Project (KCCSP), in a poor settlement of predominantly African, Xhosa-speaking people, on the outskirts of Cape Town, South Africa. In order to place the research for this dissertation in context, this chapter will provide information on the area of Khayelitsha and describe the KCCSP.

3.1 Khayelitsha

Khayelitsha is a sprawling and rapidly developing peri-urban informal settlement, 30 km outside of Cape Town. Although a bustling hive of human activity, Khayelitsha is a poorly developed district with considerable social, economic and health problems.

Mortality and morbidity profiles are unacceptable and considerable ongoing fragmentation of health care, inappropriate and inadequate infrastructure and a harsh economic climate, have all posed significant challenges to the community and those involved in its development.

3.1.1 History

Since 1948, the previous apartheid government supported a series of laws such as the Influx Control Law and the Pass Laws that facilitated the forcible displacement of African people to designated rural "homelands" and tightly controlled any migration from these impoverished areas to the cities. The vision was to develop separate states for white and black South Africans, but to allow for the use of African labour in areas that were designated white.

Despite the many restrictions, many African people did migrate to the cities. Due to a lack of provision of housing, numerous squatter camps developed in the peri-urban environment. Some of these were established as legitimate townships for Africans. In Cape Town, other less well-established squatter camps consisted of an unstable and migratory population. These areas represented a threat to the apartheid ideal that the Western Cape be maintained as an area for white and so-called "coloured" communities (Wilson & Ramphele 1989, pp. 203-233).

Citing the Group Areas Act and the Prevention of Illegal Squatting Act, the Government in 1982 announced that squatting "would not be accepted" (Harrison & McQueen 1983, p. 1). In 1983, a new strategy for black housing was realised in the planning and building of Khayelitsha.

The intention was to confine the African population to the periphery of Cape Town, to provide legitimacy to the demolishing of illegal squatter camps, and more easily arrange repatriation to the "homelands" of the time (ibid. p. 1).

The political unrest in Cape Town's squatter camps in the early 1980s resulted in the forced removals of many people who were then made to resettle in Khayelitsha. Thus the growth of Khayelitsha's population far exceeded that which was intended by the government.

Despite resistance to its development, Khayelitsha has burgeoned dramatically since the early 80's. Present estimates of the population size range from 350 000 – 900 000 (Dyanti & Frater 1998, p. 1). More accurate measurements of population size and demographic information are impossible. This is due to the extent and variability of flux of the community in its migration to and from rural areas, particularly the former "Transkei" homeland in the Eastern Cape.

Unfortunately, although the tools of Apartheid have been dismantled, development has not been able to keep up with the basic needs of those living in the area. Numerous socio-economic and political factors have contributed to the ongoing burden of poverty facing the people living in the area.

3.1.2 Socio-economic and demographic profile of people living in Khayelitsha

Khayelitsha consists of a range of different areas with an associated range of socio-economic characteristics. In the "towns" within Khayelitsha, people live in brick houses. In the "sites", people live on a plot of land in self-erected constructions of wood, corrugated iron and plastic with an external tap with running water, a flush toilet and refuse removal. The growing areas of "unserviced sites" are informal shack developments on vacant land without any amenities or infrastructure. From population estimates in 1997, it was shown that 19.2% of residents lived in houses, 54.9% live in serviced shacks, while 25.9% lived in shacks with rudimentary services or no services at all (Dyantyi & Frater 1998 p. 2).

The photographs on the next pages show examples of typical housing and the environment of Khayelitsha.

Figure 1. Khayelitsha housing and environment

A household survey in 1997 indicated that the majority of people have been living in Khayelitsha for longer than five years. However, a high proportion of adults born in the Eastern Cape indicates the strong connections with that province (Dyanti & Frater 1998, p. 14). From population estimates in 1996, 20.2% of the female population were between the ages of 35 and 65 years (the age range of women eligible for recruitment to the KCCSP) (Mash 1996, p. 6).

Unemployment levels are high with 45% of adults completely unemployed and 22% informally employed (ibid.). Income levels are extremely low with approximately 54% of households earning less than R1000 per month and 23% earning less than R200 per month in 2002. Only 14% of adults have completed secondary school education, 74% have completed junior school, and 8% have received no schooling (City of Cape Town 2002).

3.1.3 Mortality and morbidity

Poor social and environmental conditions have resulted in a state of pervasive ill health that is reflected in the data on mortality and morbidity.

Khayelitsha has the highest number of murders in the Cape Town Metropolitan area (Mash 1996, p. 11). In 2002, assault by firearm and assault by a sharp object were the top two causes of death in the district and accounted for 314 and 240 reported deaths respectively for that year (City of Cape Town 2002).

The infant mortality rate (IMR) is 43 per 1000 live births as compared to 30 per 1000 live births for the Western Cape and a national rate of 59 per 1000 live births (City of Cape Town 2002; Day & Gray 2002, p. 438). By international comparison, the IMR in the United Kingdom calculated for 1995-2000, is 6.1 per 1000 live births (*World Health Statistics Annual 1996* 1998, pp. A5).

In 2002, death from HIV/AIDS was the third major cause of death accounting for 240 reported deaths (City of Cape Town 2002) and the prevalence of HIV infection derived from antenatal testing results was 25% (*Antenatal Survey Results 2002*). It is believed that the HIV epidemic directly accounts for 50% of the current tuberculosis burden in South Africa (Kironde & Bamford 2002 p. 293).

Death from pulmonary tuberculosis constituted the fifth major cause of death in Khayelitsha for 2002 accounting for 214 reported deaths. The rate of tuberculosis is among the highest in the country. In Khayelitsha there were 584 cases per 100 000 people in 2001 (City of Cape Town 2002) while the national prevalence was 526 per 100 000 cases (Kironde & Bamford 2002, pp. 281-282).

3.1.4 Women's health data

Data on maternal health indicators show a teen pregnancy rate of 6% of live births (City of Cape Town 2002) as well as a rate of multiparity (deliveries in women with four or more previous births) of 5% (Mash 1998, p. 11).

Data on women's use of contraceptive and general health services is provided in section 1.1.3 of this dissertation.

Data on cervical screening is provided in section 1.1.4.4 of this dissertation.

3.1.5 Health service structure

The fragmentation of the health services in Khayelitsha is responsible for a significant amount of inefficiency and ineffectiveness in health care delivery. The community frequently expresses dissatisfaction with the bipartite (local authority and provincial administration) service system, an inheritance of the apartheid government (staff and patients of Michael Mapongwane Day Hospital 1998-1999, personal communication). Efforts are currently underway to integrate health care into a decentralised district health system.

At present, the public health services are co-ordinated by two large state organisations. These are the Community Health Services Organisation (CHSO), managed by the Provincial Administration of the Western Cape (PAWC), which provides largely curative services at the 3 community health centres (or day hospitals), and the City of Cape Town, a local authority body, which provides largely preventive services at 8 different clinics. There is no district hospital. The KCCSP is located at the newest community health centre, Michael Mapongwane Day Hospital.

3.1.6 Traditional healers

Not much information exists regarding the numbers of traditional healers in Khayelitsha. Nyangas (herbalists), iqirhas (sangomas) and others, operate from homes, herbal shops and traditional practices. Some training of traditional healers also takes place in these settings.

Traditional healers are respected members of the community and are consulted either as an adjunct to allopathic healers, or as a first-line source of comfort and cure (Pretorius 1999, p. 250).

3.2 The Khayelitsha Cervical Cancer Screening Project

The KCCSP has been in operation in Khayelitsha since the beginning of 1996. It is a research project aimed at establishing alternative strategies for cervical cancer prevention in low-resource settings. The Project has evaluated alternatives to the Pap smear for screening for cervical cancer and its precursors. More recently, the Project is evaluating alternative treatment options for the precursors of cervical cancer. The study is evaluating treating women with positive screening tests. Women are treated by trained nursing sisters, using cryotherapy at a primary care level.

My participation in the Project occurred during phase 2, from July 1998 to the end of 1999. Unless otherwise specified, the description below refers to this period in the KCCSP's development.

3.2.1 The role players

The director of the Project is Professor Lynette Denny, a gynaecological oncologist based at the tertiary level teaching hospital in Cape Town, Groote Schuur Hospital. She works in collaboration with a pathologist and an epidemiologist at Columbia University, New York. The study was approved by the Institutional Review Boards of Columbia University and the University of Cape Town. The Project is funded by the Bill and Melinda Gates Foundation and this funding is managed by EngenderHealth, a North American reproductive health NGO.

The Project employed an all-woman team of an administrator, 2 nursing sisters and 3 community health workers (CHWs) during the second phase. These women live in Khayelitsha or in neighbouring informal settlements and suburbs and are all first-language Xhosa speakers, the predominant language of Khayelitsha residents.

The community health workers all have minimal secondary school education and were trained for their roles during their employ at KCCSP.

Staff were supported in their work, professionally. Regular in-service training was conducted to teach the research protocol. Discussions took place on protocol issues, staff interactions with women, ways in which to maximise the return of women and ways in which to minimise the defaulting of women for follow-up. The staff's particular insights were integral to the development of these systems.

My responsibilities, as project manager and medical officer, included the supervision and evaluation of data collection as well as the cleaning and coding of the data. In addition, I was responsible for the supervision and upgrading of the tracing system and the health promotion activities. I attended to any general medical problems that were presented by the clients. Frequently, I would assist various staff by performing some of their tasks for them, e.g. screening, taking blood, recruiting, client education. I was assistant and trainee to Dr Denny for the colposcopy (microscopic examination of the cervix) that was performed on site. Thus, I was intimately involved in relating with all members of staff and with the operational management of the Project on a daily basis.

The women recruited for participation in the Project were volunteers, aged 35 – 65 years. Most of them lived in Khayelitsha or nearby informal settlements where the recruiting took place. However, participation was not limited to women from these areas and other women from further away would attend after hearing about the KCCSP through word of mouth. Exclusion criteria for participation were women who were pregnant, who had undergone cervical screening in the last 5 years (if they knew the result of that screening) and any women who had undergone treatment to the cervix in the past or had had a hysterectomy.

Table 1 on the next page shows the socio-demographic data of the 2754 women who were included in the KCCSP study.

Table 1

Socio-demographic profile of 2754 women who were included in phase 2 of the KCCSP

Characteristic	No.
Median age in years	39
Born in Cape Town (%)	186 (7)
Moved to Cape Town within previous year (%)	504 (18.3)
Resident in Cape Town for >5 years	1 969 (71.5)
Education (%)	
No school	252 (9.2)
Some primary school	854 (31.0)
Some high school	1 378 (50.0)
High school graduate	270 (9.8)
Dwelling (%)	
House	966 (35.1)
Shack on serviced site	1 544 (56.1)
Shack on unserviced site	244 (8.9)
Employed (%)	1 153 (41.9)
Married (%)	1 250 (45.4)
Sexual partners in last month (%)	
0	693 (25.2)
1	2 055 (74.6)
2	6 (0.2)
Current contraception use (%)	
Injection	409 (14.9)
Pills	87 (3.2)
Condom	13 (0.5)
Other	4 (0.1)
Tubal ligation	654 (23.7)
None	1 587 (57.6)
Cigarette smoking (%)	147 (5.3)
No alcohol intake (%)	2 524 (92)
Treated for STIs in the last year (%)	799 (29)
Median no. of pregnancies (range)	3 (0-15)
Median no. of live births (range)	3 (0-13)
Median age in years of first sexual intercourse (range)	17 (10-30)
Median no. of lifetime sexual partners (range)	2 (0-20)

3.2.2 The site of the Project and its facilities

Phase 2 of the KCCSP took place at a new, well-utilised public day hospital (community health centre [CHC]), Michael Mapongwane, in Khayelitsha.

Three interleading consulting rooms were used for blood-taking, screening, administrative tasks and client consultation. Colposcopic examinations took place in a mobile caravan that was parked outside a back entrance to the CHC, and was nearby the screening consulting rooms.

The laboratories linked to UCT medical school and Groote Schuur Hospital (GSH) were used for the Project. Women with tertiary gynaecological problems, including cervical cancer were referred to GSH for management.

3.2.3 The development of community participation

Prior to establishing the Project, Professor Denny consulted a number of community-based role players. The organisations contacted included Community Health Forums (CHFs), primary health care services and non-governmental organizations, including the Association for Traditional Healers.

3.2.3.1 The Community Health Forums

The CHFs consist of members elected from the community. These forums usually consist of a range of health personnel as well as local political party representatives. They report issues of concern to the community at mass meetings, and at these forums the general response is acknowledged. Enthusiastic approval for the Project was noted at these mass meetings.

The community did, however, express their concern about the testing for HIV. This was designed into the research protocol to establish the association of HIV disease with pre-cancerous and cancerous lesions of the cervix. The community raised the issue that knowledge of an HIV positive status frequently leads to individuals being ostracised by their families and local communities. It was felt that it would be better if neither the researchers, nor the women recruited for the project, knew of their HIV status. This recommendation was duly accepted and the project design was adjusted in order to make the HIV testing completely anonymous. When women chose to know their HIV status, they were referred to the CHC for testing.

3.2.3.2 Traditional healers

Meetings were arranged with the Association for Traditional Healers in Khayelitsha. Their approval and support for the Project were given. Many traditional healers offered to refer clients for screening where appropriate.

Both the CHFs and the Association for Traditional Healers received regular feedback regarding the results of the Project.

In general, the organisations mentioned above, as well as other NGOs and general practitioners in the area, generated numerous referrals to the Project. The Project thus came to be seen as a comprehensive women's health service. Women were referred for general gynaecological problems and not solely for cervical screening purposes. These problems were addressed by Professor Denny or me.

3.2.3.3 Focus groups

In the early stages of the project, Project co-ordinators arranged two focus groups with local women. One group consisted of participants of the Project who had already been screened and the other group consisted of traditional healers. A Xhosa-speaking social researcher facilitated the groups. She was the same facilitator for the study of *this* dissertation.

The aim of the discussions was to explore the barriers to women seeking Pap smears. The findings were intended to inform the development of health promotion materials such as radio dramas, videos and photo comics as well as the interactive health promotion that occurred between Project workers and participants or potential participants.

The barriers identified by the participants included apathy, reluctance to "open one's legs" for the screening, low valuation of their bodies and sexuality and low expectations of treatment at health services. Male figures such as husbands and fathers-in-law were perceived to be controlling and it was felt that care should be taken not to challenge this authority too greatly.

Traditional healers seemed well informed about the symptoms of cervical cancer and many said they were able to cure the disease in the early stages. This group appeared supportive of local clinics, but was not overly confident about western healing methods in general (Risi, Crawford & Everett 1998).

Thus, the process of community participation was not merely centred on gaining permission. Rather, it allowed for the establishment of channels of communication and for the sharing of valuable information between stakeholders in women's primary health care. It developed into an educational process for both the community and the service providers and continued in a dynamic and changing fashion.

3.2.4 The study design of the KCCSP

The design of the investigation was a cross-sectional screening study. The components of the study are discussed below.

3.2.4.1 Recruitment

Numerous different means of recruitment were employed.

For the most part, CHWs recruited women by engaging with the general clients of the CHC in the large central waiting area. However, other local day hospitals and clinics, taxi ranks, train stations, bus stops and nearby shops were also used as areas for recruitment efforts. Two CHWs trained for the task, used loud hailers and visual aids to get people's attention. All men and women were addressed in an informal manner and those that did not fulfil the enrolment criteria were encouraged to understand the principles of cervical screening in order to participate in the maintenance of the health of their wives, sisters, mothers and friends. Women were encouraged to attend the clinic with a friend or relative who might also benefit from screening. Fliers detailing the clinic venue and screening times were distributed. Those who expressed interest in participating were escorted to the clinic rooms or given directions.

The recruited women were then, in smaller groups of 3 – 7 women, involved in further discussions and explanations with one of the nursing sisters, in a more private setting outside the Project's clinic room. Frequently, spontaneous conversation ensued, with a free-flow of questions and comments.

The local and national radio and newspapers were used as forums for the discussion of cervical screening and other women's health issues and to inform women about the Project. The local radio station, Zibonele Radio, conducted "phone-in" programmes and interviews with various members of the Project staff.

I organised and facilitated several workshops on cervical cancer prevention with doctors and nurses working elsewhere in Khayelitsha as well as with local women's organisations.

The focus groups, discussed in section 3.2.3.3 above, were conducted to explore the understandings, misconceptions and fears of local women. This enquiry as well as the more informal day-to-day interactions that staff had with women revealed many useful lessons that impacted on the nature of the recruitment. It became clear that anxiety about screening was reduced when a clear understanding was offered about the rationale and process of the screening. Incorporation of the wider family, particularly men, into decision-making regarding screening and treatment was facilitated by inviting those family members to attend the Project with the women and to attend the educational talks.

The way in which treatment of precursor cervical lesions was explained was adapted to take into account a general distrust of surgical methods as well as a belief that cancer is a "poison" that needs to be drawn out of the body. Those women that consulted with traditional healers were concerned that the Project staff would disapprove of this practice. CHWs made it clear that this was not the case, and that we had established collaborative relationships with traditional healers in the community (Denny 2000b, p. 73).

3.2.4.2 Informed consent and enrolment

One nursing sister was dedicated to the consenting process and the taking of blood. Initially, she would speak with the 3-7 women waiting to be seen in chairs outside the clinic room doors. Here, in more detail, she would discuss the nature and the purpose of the project protocol, the taking of blood for HIV, and check eligibility criteria. She would give an indication of the time delay until each would be seen.

Then, she would take each woman separately into the clinic room for a private consultation. Here, she would discuss further the Project's procedures and answer any queries or address any fears that may have arisen.

The sister would then give to each client, two consent forms, written in Xhosa – one for participation in the Project's protocol as a whole, and the other for the taking of blood for HIV. Both literate and illiterate clients would have the consent forms explained to them before they signed or made their thumbprints. Each participant was assigned a unique study number.

After consenting and giving blood, the client would be ushered to another corner of the room where their names and Project numbers were entered into an enrolment log, and on to the laboratory request forms, the specimen containers and the Pap slide. Their contact details were documented.[7]

The CHW responsible for this process completed a detailed, structured socio-economic and demographic questionnaire with each woman.

Each woman was given a patient card (see appendix 2) that recorded her name, Project number and the dates for her to return or to telephone for her screening results. Results of the screening tests and clinical notes were entered onto the card, which was retained by each participant.

3.2.4.3 Screening

The screening process began with women placing a swab into the vagina prior to the examination. This was the self-testing for high risk types of HPV and was supervised by the screening sister. Thereafter, examination was performed in the lithotomy[8] position and began with the visual inspection of the vulva. Then, a speculum was passed and the vagina and cervix examined with the naked eye.

Then, four separate screening tests for cervical cancer and its precursors were performed. These tests were the following;

- The Direct Visual Inspection (DVI) of the cervix after application of 5% acetic acid (vinegar)[9].
- A conventional Papanicolaou (Pap) smear.
- The endocervix[10] was sampled with an endocervical brush. This was the clinician-obtained sample for HPV DNA testing.
- Cervicography. This is a 35-mm photograph taken of the cervix after reapplication of the vinegar.

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[7] At enrolment, when the client's contact details were requested, an additional set of contact information was sought for a neighbour, friend or next of kin. This was to facilitate access to the client should she fail to return for her next appointment.

[8] A supine position with the legs suspended in stirrups.

[9] The application of vinegar was, for the vast majority of women, not painful, but rather experienced as a cold sensation. The cervix was inspected, with and without the use of a hand-held magnifier, for the reaction that acetic acid confers to premalignant cervical disease. The presence of this so-called aceto-white lesion would constitute a positive screening test.

[10] The mucous membrane lining the canal of the cervix.

In addition, the participants were tested for three sexually transmitted infections (STIs), including Trichomonas vaginalis. The aim of this testing was to establish whether the presence of STIs affected the diagnostic capabilities of some of the cervical screening tests.

3.2.4.4 The giving of results

Women were referred for colposcopy, at the Project site, if any one of the four screening test results were positive. Thus, after screening, if the woman had an aceto-white lesion seen on DVI, she would be offered a colposcopy appointment within 2 – 7 days of being screened.

The other screening tests and the results of the testing for infections were available at three later stages. This was a function of the time it took for the specimens to be processed in the different laboratories. As discussed above, the women's cards detailed the three dates she should return, or when she should telephone for her results.

The results of the clinician-obtained sample for HPV DNA and Trichomonas vaginalis were available within 2 – 7 days of being screened. The Pap smear result was available within 2 weeks. The last results were available 1 – 3 months after screening as these were tests that included the photographs (cervigrams) that were sent to the U.S.A. for development and interpretation. The other STI results were available at this last date.

A protocol for the treatment of STIs was followed and, if necessary, women were given medication and condoms free of charge. Staff counseled those women regarding the prevention of STIs, the risks of HIV infection and the need for partners to receive treatment.

All members of staff were trained in the giving of results, although the project manager and administrator were chiefly involved with this task. Both positive and negative results were carefully explained as necessary. Each return visit or telephone call was recorded in one of the Project's data files.[11] To ensure women were contactable for future results, the women's contact details, and those of a friend or relative were double-checked at each visit.

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[11] For the purposes of this paper, the phrase "returning spontaneously for results" signifies either telephonic or personal contact with the project by the client or client's messenger on the days specified for receiving the first set of results.

3.2.4.5 Colposcopy

Colposcopy is the microscopic examination of the cervix and is usually performed by a medical doctor who has undergone extensive training for the task. Dr Denny, and on occasion, the author, performed the colposcopic examinations at the Project.

The specially-modified microscope is mounted on a stand and placed between the woman's legs while she is lying in lithotomy position. The doctor passes a speculum and examines the cervix after applying acetic acid and or iodine, through the different lenses of the externally-placed microscope.

Depending on the signs noted on colposcopy, a protocol was followed for the sampling (biopsy) or treatment of premalignant lesions (Loop Electro-surgical Excision Procedure-LEEP) of the cervix.

3.2.4.6 Tracing

A systematic tracing system existed for those clients with positive screening results who failed to return spontaneously for their results on the given dates, and hence did not undergo the required confirmatory colposcopic evaluation according to the protocol. Other women who were traced were those that did not return for positive biopsy results or those that did not return for their check-ups after having undergone LEEP treatment.

On three afternoons of the week, two CHWs telephoned these clients, where possible, or drove to their homes, in the Project car, in order to remind them of the need to return to the Project. When the women were not at home, a written reminder (see appendix 3) was left under the door, with a person staying in the home or with a neighbour. No results of any tests were written on the reminder note.

In August 1998, Dr Denny and I redeveloped the tracing system and incorporated a form (see appendix 4) for the CHWs to fill in for each traced patient. The new form required data to be recorded stating the reasons given by the clients, if contacted, for not returning for results spontaneously. The number and dates of attempts to contact the women were recorded and the date of eventual attendance at the Project was noted (if tracing was successful).

If three to four successive attempts at contact with a woman were unsuccessful, the woman was removed from the tracing register.

It was common for women to give false addresses for their contact information. Project staff felt that this phenomenon related to women's experiences under the apartheid regime, where the authorities used contact information to arrange raids and arrests of those contravening the laws of the time. Further, it was surmised that women who gave false addresses, may have been afraid that their screening results would be given to other household members or neighbours.

3.2.5 Health promotion

At each stage of the Project protocol, particular emphasis was placed on communication and health promotion – whether in large groups, smaller intimate groups or on a one-to-one basis.

The enrolment and screening processes as well as the time clients spent waiting to be seen, were opportunities used by the Project team for informal engagement with clients on cervical screening and other women's health issues. Participation was welcomed and this process resulted in clients' volunteering other health problems and encouraging their friends and relatives to attend the Project. Clients would spontaneously begin assisting with the education of other women waiting and would embellish with their own experiences, or those of their acquaintances. Tea, coffee and biscuits were served to the groups of waiting women.

In addition to the methods discussed previously, various other activities developed.

The project manager during Phase 1, Dr. Liliana Risi, together with some researchers in the field, ran the focus groups, discussed in 3.2.3.3, during 1997. The material from these focus groups gave rise to the development of a fictionalised account of the women's experiences in the form of a video, radio play and a photocomic.[12]

The story centres on two women whose friend has died of cancer of the cervix. The concept of the preventability of the death as well as the decision-making of the friends to go to the clinic for screening, are incorporated. The story depicts both their positive and negative experiences at the clinic and the responses of their elders, husbands and traditional healers. This radio play was aired on the local radio station and was also played for women at the Project, while they were waiting to be seen for screening or colposcopy.

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[12] The photo comic and radio-play were evaluated in order to ascertain the impact on women's decisions to undergo cervical screening. The findings were that the *comic did not* impact on screening behaviour, but the *radio-play was* associated with an increase in women attending for screening (Risi et al. 2004).

Carefully designed visual aids such as posters and an anatomical paper-mâché model of the womb and vagina, were used to assist in the explanations of cervical pathology and screening.

The photographs on the next pages show the staff and health promotion activities at the KCCSP during phase 2.

Figure 2. Project staff with colposcopy caravan

Figure 3. Mama Bayti, community health worker, educating with model of uterus.

Chapter Four

Aims and objectives

Aims and Objectives

4.1 Overall aim of the study

The study aims to offer an understanding of the factors that affect the health-seeking behaviour of clients when returning for their results, in order to improve the development of cervical screening service delivery at the KCCSP and in other low-resource settings.

4.2 Objectives of the study

1. To describe what contextual factors in the participants' lives constitute obstacles or contribute to their returning spontaneously to the KCCSP for their screening results.

2. To analyse the attitudes, perceptions and beliefs that contribute towards women returning spontaneously to the KCCSP for their screening results.

3. To describe how the participants experienced their initial encounter with the KCCSP and how this affected their returning to the Project.

4. To provide relevant information for use in the evolution of the Project in order to improve the spontaneous return rate of clients.

Chapter Five

Methods

Methods

Discussion of the methodology will centre on the reasons qualitative methodology, and specifically, the focus group discussion technique was used. Methods used for analysis of the data as well as quality control measures will be covered. In addition, the details of the organisation of *this* study's focus groups will be detailed.

5.1 Reasons for using qualitative methodology

The theoretical framework utilised in this study is the interpretive research paradigm. Researchers using this approach "assume that people's subjective experiences are real and should be taken seriously, that we understand others' experiences by interacting with them and listening to what they tell us, and that qualitative research techniques are best suited to this task....to help us better understand the social world we live in" (Terre Blanch & Kelly 1999, p. 123).

Thus, it follows that in order to address the objectives of the study, a qualitative approach was felt to be more likely than quantitative investigative tools to yield the in-depth nature of information that was sought.

If one were to explain the relatively high spontaneous return rate in terms of overt behaviour, i.e. a compliance of the women with the clinic staff's instructions to return, one may miss some of the more vital meanings of the phenomenon. Valuable information of this sort can not be gleaned from explicit deductions or statistical research methods. These methods may reveal *how many women* believe or are motivated by, or obstructed by certain variables *pre-conceived by the researcher.* Data may be generated with figures reflecting proportions of women with access to transportation or clients' recall of health information received. This would provide a unidimensional insight into the situation.

In order to evaluate the complexity of community health initiatives, methods should be used which illuminate the *context* of the service and its clients (Goodman 2001, pp. 293- 301). This is particularly true when one examines cervical screening participation, with its associated constructs such as accessibility, stigma, fear and taboo.

Where statistical analysis provides a breadth of information, qualitative investigation yields a depth of understanding. It is clear that a more complex exploration of motivations, experiences, obstacles and enabling factors is required in order for useful lessons to be learnt about the women's returning for their results. Subjectivity is inherent in this type of research. The respondents' experiences, personal views and belief systems are examined.

"The personal and social meaning that people use to structure their lives cannot be treated as a statistical variable...." (Katzenellenbogen, Joubert & Abdool Karim 1997, p. 176).

Research objectives using qualitative techniques are broad, with the emphasis placed on investigating the complexity of relevant factors in their context (Katzenellenbogen, Joubert & Abdool Karim 1997, p. 177). In order to meet the objectives for this paper, both logistical constraints and enabling factors were sought, as well as the attitudinal and perceptual factors at play.

While the findings in qualitative research may not necessarily be extrapolated to circumstances beyond the field of investigation, the richness of the data elicited can generate ideas for service design in the same or similar settings. The data should stimulate further questioning, establishing hypotheses for future qualitative and quantitative research.

The decision to use qualitative methodology is supported by other local and international bodies of research on health-seeking behaviour in the context of community-based health programmes. There are several local and international examples of such work examining reproductive or sexual health programmes in low-resource settings. Many studies utilise focus group discussions as the data collection method (Ishmail 1999; Williams, Abbott & Taylor 1997; Harrison et al. 1998; Ndulo et al. 2000, Go et al. 2002).

5.2 Reasons for using the focus group method to collect data

This method involves a number of people meeting in a group where discussion is stimulated under the guidance of a non-partisan facilitator.

The researcher designs a topic outline with suggestions of questions, prompts and checks, but emphasises that the facilitator should allow for the topics to be covered in the most natural and least directed way.

The considerable limitations of the focus group method are acknowledged in the section on limitations in the discussion chapter. Despite these, this method was chosen for its suitability within the research setting of the study and for its ability to generate the type of data that was sought.

Focus groups are suitable for exploring people's knowledge and experiences. The method allows for examination "not only of *what* people think but *how* they think and *why* they think that way" (Kitzinger 1995, p. 299). Focus groups are particularly useful when assessing health behaviours as well as people's experiences of disease and of health services (ibid. p. 299).

Stimulation of discussion among the participants is crucial to the success of the focus group. Participants' interactions – anecdotes, jokes and the feelings behind the responses are sought for examination. The different narrative types that are used allow for the identification of shared and common knowledge and thus this methodology is particular sensitive to cultural variables (ibid, p. 300).

The focus groups should invoke the revelation of opinions, ideas and facts that may not have been offered spontaneously from in-depth interviews or questionnaires. Social situations may be simulated which may generate more direct representations of how people are feeling (Terre Blanch & Kelly 1999, p. 127).

Quantitative investigation would clearly reveal lists of obstacles to returning and superficial pre-constructed categories of reasons given for returning. However, the focus group technique offers insight into the ways in which the participants perceive the obstacles and how and why arrangements were made to overcome these barriers. The free-flow of discussion among participants allows for women to raise and explore issues such as sexuality, race, gender and suspicion of health workers. The complex roles of fear, superstition and community-related factors can be explored.

These issues may otherwise have gone undetected, or been suppressed in a more structured research context (Katzenellenbogen, Joubert & Abdool Karim 1997, p. 177-178). Validity may be compromised as a result of the respondent being removed from her natural setting and her feeling threatened by the intimacy of more formal research processes.

"Studying the attitudes, opinions and practices of human beings in artificial isolation from the contexts in which they occur should be avoided" (Pollack, cited in Flick 1998, p. 116).

Thus, alternative qualitative methods would have been unsuitable to the research question of this study.

The formality of unstructured or in-depth interviews proceeds from the greater degree of direction of the discussion by the interviewer and the direct relationship that is established between the interviewer and respondent. These interview techniques are suited to studies where detailed information from individuals is required (Katzenellenbogen, Joubert & Abdool Karim 1997, p. 177-178).

If questionnaires are presented in structured interview form or by self-administration, this may lead to incomplete and poor quality data. Written tools have the attendant problem of the varying literacy levels of the responders. This thereby decreases the reliability and completeness of the findings (Kitzinger 1995, p. 299). This issue is particularly relevant in the setting of the KCCSP where 9% of participants had no schooling and 31% had some primary level schooling only (Denny et al. 2002, p. 1 702).

Participant observation would have proven particularly difficult due to the researcher's roles as Project manager and medical officer of the KCCSP. It is unlikely that active involvement in the participants' lives would have been tolerated, much less, enabled the observation of natural behaviour of the participants.

5.3 Methods used to analyse the data

No one particular paradigm of analytic interpretation was utilised in this study. Rather, a balance was maintained in the type of perspectives adopted to gain understanding.

A tension was maintained between description (the participants' perspective) and interpretation (the researcher's constructing of new ways of understanding). A balance between context and theory was sought. In other words, cultural terms of reference were counterpoised against aspects of social constructionism in an effort to "draw on theoretical frameworks for making sense of situated events" (Kelly 1999b, p. 405).

On the one hand, a systems theory approach was also employed to understand the returning for results phenomenon as a function of the context in which it occured (Lindegger 1999, pp. 257-260). Here, some pre-existing theoretical frameworks are acknowledged. For example, the analysis of the participants' health-seeking behaviour drew on the constructs of poverty, discrimination and quality of health care. On the other hand, the data was searched for evidence to refute or support the original theories.

In addition, an analysis of narratives was incorporated. This assumes that "people construct and live a narrative for their lives that is often dramatically challenged by the onset of major health changes accompanying disease" (ibid. p. 259).

Thus, by spanning both the contextual and theoretical orientations, an attempt was made to integrate the parts of the findings into a coherent account. In so doing, it was hoped that an understanding of the subjective experience could be developed and that an interpretation of this understanding could be generated (Kelly 1999b, pp. 398-420).

The analysis drew heavily upon the grounded theory approach. Central to this paradigm is that data collection and analysis occur concurrently and that the research findings arise from the data as opposed to any preconceived theoretical framework (Charmaz 1999, pp. 109-126).

The particular tools of grounded theory that were used are described below.

5.3.1 Preliminary content analysis and initial coding

After each group, the facilitator, ND, assisted with some initial analysis of the data. We looked to see what we could define and discover from the data. Broad emerging issues and ideas were developed. Variations, similarities, emphases, participants' interpretations and negative cases were sought. As many different avenues as possible were pursued (Charmaz 1999, pp. 113-116).

This preliminary content analysis enabled the development of certain hypotheses which could be tested in subsequent focus groups, the so-called iterative approach (Greenhalgh & Taylor 1997, p. 3). An example of this is the theme of the suspicion that the health workers at the Project had a hidden agenda. When this issue was raised in the first focus group, it could be tested, in a non-directive manner by the facilitator, in subsequent focus groups. While the hypothesis that other women had these suspicions was confirmed in some respects, it was refuted in others.

5.3.2 Focused coding

The limited set of themes or codes that was developed from the preliminary analysis was applied to the complete set of focus groups. New, more complex sub-categories were built from a deeper, more selective and conceptual level of analysis. These new categories emerged from an examination of all the data available, including variations in the data.

Thus, negative cases were sought for each category. This process continued until the general categories were explicated or exhausted by the development of sub-categories (Charmaz 1999, pp. 116-120).

Some of the categories developed from my own analytical interest, e.g. the good treatment received at the Project compared to other health service providers promotes the returning for results. Other categories developed from the narratives and language of the participants, e.g. the common belief that they were suffering from cancer or a fatal illness.

The discussion was interpreted to gain a deeper understanding about how the participants felt about their experiences at the Project, the motivation behind their returning for their results, the obstacles they encountered and the factors that facilitated their return. The participants' statements or stories that best embodied the concept of these categories were used to illustrate the themes.

Thus, as is the nature of qualitative research, this study's results are not readily distinguishable from the discussion (Greenhalgh & Taylor 1997, p743). This raises the question of validity and whether the conclusions drawn are justified by the results. In order for validity to be upheld, the analysis must explain well the reasons why people behave in the way they do, i.e. the reasons for returning must make good sense. The explanation must be comprehensible to a thoughtful "participant in the setting". Finally, the explanation must cohere with what is already known, i.e. the barriers and promoters to cervical screening utilisation (Mays & Pope, cited in Greenhalgh & Taylor 1997, p743).

5.4 Quality control measures used

During the process of the research, certain quality control measures were used to enhance the validity of the study.

5.4.1 Validity and credibility

The positivist approach which uses randomised and non-randomised experimental designs focuses on eliminating threats to internal validity. Qualitative research, by definition, can not utilise statistical techniques to ensure validity.

A range of techniques were used to enhance the validity of the study. These included reference to other qualitative interview studies exploring barriers to cervical screening in South Africa (Abrahams, Wood & Jewkes 1996; Wood & Jewkes 1996a; Wood & Jewkes

1996b; Ishmail 1999). Qualitative work arising from the KCCSP was also closely scrutinised. This included the unpublished data from focus group work conducted in 1997 that explored the barriers to women seeking Pap smears (Risi, Crawford & Everett 1998) and participatory action research conducted in 2002 which is discussed in section 2.3 (*Women's Perspectives on Cervical Cancer Screening and Treatment* 2002).

The role of the group facilitator provided another method of validation. The facilitator is a Xhosa-speaking social worker, living and working in Khayelitsha. She had assisted with the groups that were run at KCCSP in 1997, discussed above. She was not an employee of the Project, which provided a degree of control over untoward influences and bias. However, her role in the community and her previous experience working with the Project contributed to the internal validity of the data, i.e. the coherence.

She fulfilled the role of co-investigator for this study in as much as she was offered the opportunity to confirm or deny the preliminary analysis that was generated at the completion of each group and at the end of the final analysis. This process thereby contributed to a degree of quality control and thus, an effort was made to ensure inter-observer reliability (Greenhalgh & Taylor 1999, p. 6).

This was extended further by the involvement of a qualitative research consultant who was commissioned by EngenderHealth. She wrote a preliminary report on the findings of the focus groups, which served to provide further inter-observer reliability for many of my own findings.

Other techniques that were employed to enhance the credibility of the work include prolonged involvement, persistent observation and peer debriefing.

5.4.1.1 Prolonged involvement

I had prolonged involvement within the context of the study, as manager of the KCCSP for one year prior to undertaking the investigation and previously, as a medical student and doctor working with clients from poor peri-urban settlements of Cape Town. This has enabled the opportunity to "learn the culture" of the participants and the culture of community-based health services (Robson 1994, p. 404).

5.4.1.2 Persistent observation

Persistent observation was facilitated by my role in the Project as well as the quality of interaction of other staff members with clients. In my year-long experience as medical officer at the KCCSP, I had the opportunity to engage with Project participants in the context of the variety of roles I needed to adopt. As medical doctor, I dealt with the physical problems of the women. As Project manager, I assisted with such tasks as screening, giving of results and educating participants about the Project procedures. Many themes, which were observed over time by the other Project staff and me, were generated spontaneously within the focus group discussions.

5.4.1.3 Peer debriefing

During the development and design of the research, ongoing exposure to colleagues and peers of the analysed material provided opportunity for peer debriefing. These included ongoing interactions with a qualitative researcher who had been involved with the focus group work at the KCCSP in 1997, as well as the director of the KCCSP, my thesis supervisor.

5.4.2 Transferability

Transferability corresponds to the external validity or generalisability of the research. In order for a study to be transferable, the researcher must provide a thick description or full data base with full specification of the theoretical frameworks. Thereafter, the onus shifts to the reader interested in making generalisations (Robson 1994, p. 405).

In this study, the literature review and sections on Khayelitsha and the KCCSP contextualise the study and thereby constitute this database. Discussions of theoretical frameworks within the explication of the methodology and the discussion chapters, further lay out the information needed for the reader's transferability judgements. However, the researcher accepts some of this responsibility by making recommendations for service design in other screening settings in chapter 9.

5.4.3 Dependability

Dependability, which is analogous to reliability, is secured by the variety of triangulation techniques employed, as discussed above. Furthermore, an audit of the research processes reveals clarity, a systematic approach, good documentation and safe-guards against bias (Robson 1994, p. 406).

5.4.4 Confirmability

Confirmability relates to the objectivity of the data and can be formally tested by use of an external audit process (Robson 1994, p. 406-407). This was not possible given the scale of this study. However, the raw data, analysis products, synthesis products, process notes, proposals and focus group development information were collected and well maintained in keeping with the standards such an audit would require.

5.5 Organisation of the focus groups

The details of the development and organisation of this study's focus groups appear below.

5.5.1 Development of the researcher

Having had no previous experience of qualitative research, I embarked upon a programme of familiarising myself with this type of inquiry.

Apart from theoretical reading, I attended a participatory research workshop and qualitative data analysis workshop – both run by Ineke Meulenberg-Buskens, an experienced international qualitative research consultant. Thereafter, I consulted with her personally on some of the conceptual facets of the study. She remained a regular source of advice through the development of the study design and analysis. In addition, colleagues involved in qualitative social and health research provided opportunities for discussion, inquiry and inspiration.

Throughout the research process, I engaged in ongoing discussion with Project staff and other researchers. Thus, my personal development as a researcher occurred in tandem with the triangulation and inter-observer reliability measures.

I made personal notes about my feelings, frustrations and motivations. This created opportunity for self-reflection and conscientisation regarding my role in the study. While qualitative research can not, by its very nature, exclude observer bias, exploring my own ideological and cultural perspectives enabled me to raise awareness of these.

As Project manager, I clearly had vested interest in the participants' speaking favourably about their experiences at the Project. However, in the analysis of the data, I actively sought for examples where women expressed disapproval with aspects of the Project.

5.5.2 Time and place

Four focus groups were conducted in August 1999. Each group consisted of 4-6 clients who had spontaneously returned for their first set of results. The dates selected for the focus groups were four days specified for returning for results that were convenient for the facilitator to attend.

The focus groups were held in a private, large consulting room in the Midwife Obstetric Unit (MOU) which is attached by a covered walkway to the Michael Mapongwane Community Health Centre (CHC), where the KCCSP is situated. Although on the same property as the CHC, the MOU is commonly accepted to operate under a different health authority and is only linked to the CHC in terms of its location.

5.5.3 Selection and recruiting

One of the Project's community health workers (CHWs), MB, recruited women on a first-arrive-first-offer basis. Guided by a recruiting checklist, she completed a verbal consent process, in private, with each potential responder (see appendix 5). This was to ensure that the client understood her participation would not jeopardise or enhance her treatment within the Project.[1]

Although this represents a very small sample, preliminary analysis revealed saturation of the data that had been generated from the four groups. Furthermore, the logistical constraints of funding, the availability of the facilitator and competing operational needs within the Project prohibited the organisation of further groups.

Participants were not financially remunerated for their contribution.

5.5.4 The participants

The total number of participants was 19.

Numbers of women returning for their first set of results were too small to allow for purposive sampling, i.e. the creation of homogenous groups according to sub-categories of women.

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[1] Approval for the KCCSP was obtained by the University of Cape Town Research Ethics Committee and the Institutional Review Board of Columbia University, New York. Ethics approval for *this* study was granted by UCT, within the same provision of ethical approval for the KCCSP study.

This would have allowed for participants to be grouped according to characteristics such as age and educational status etc. This might have minimised the possible creation of internal hierarchies. When this occurs, group dynamics may inhibit certain members from contributing and thus skew the information obtained.

However, by *not* having internally or externally homogeneous groups, a wide range of characteristics of women were incorporated into the sample. Some researchers describe how diversely constituted groups may facilitate exploration of heterogenous perspectives within the group (Kitzinger 1995, p. 300; Kelly 1999a, p. 389). The mixture of the types of group participants allowed for the women to critically appraise each other's assertions and experiences.

5.5.5 The discussions

All participants were offered refreshments while waiting for the focus groups to start. The facilitator conducted the groups in Xhosa, the language of all the participants. The researcher was not present during the discussions.

The facilitator followed a pre-designed discussion guide (see appendix 6).

After a brief, standardised introduction, the facilitator attempted to establish rapport among the participants by opening the discussion with the practical circumstances of their returning that day. This relatively neutral topic was thought to be an unthreatening way of beginning to relate experiences surrounding the returning for results.

The first in-depth phase of the discussion centred on the participants' experiences of different aspects of the Project. This was further explored by probing for particularly unusual or new things that were encountered at the first visit if these did not arise in conversation spontaneously.

Thereafter, the participants were asked whether they would have recommended attending the Project to others. The reasons for this decision were explored. It was felt that this would reveal more about how the participants *themselves* regarded the Project. The participants were then asked to compare the Project with other health services. This was intended to elicit characteristics that were felt to be particular to the Project and relevant to the high spontaneous return rate.

Thus the discussion was brought full circle to topics that were discussed at the start of the focus group. The repetition of enquiry, differently phrased and occurring at a later, more comfortable stage of the focus group, was aimed at providing a deeper layer of information to that obtained at the beginning.

The discussion came to conclusion with a request for the most pertinent factors that contributed to the women's returning. A summary and thanks were given prior to closure of the group.

During the group discussions, the facilitator would seek clarification on some issues to avoid misrepresentation. Her prompting was poised so as not to lead the groups. She consciously avoided being judgmental and interrogative.

5.5.6 Audiotaping, transcription and translation

The facilitator made notes regarding body language, expressive tone and group dynamics during and after each focus group. All focus groups were audio taped. The facilitator transcribed the tapes and provided clarification about the meanings of expressions or phrases when these were unclear. Her notes were incorporated into the transcripts.

The facilitator translated her transcriptions directly into English. In order to avoid re-interpretation of the women's primary meanings, the author did not rephrase these translations into orthodox or conventional English. Rather, they are quoted unchanged in the results chapter of this study.

Chapter Six

Results: The focus group findings

Results: The focus group findings

This chapter describes the findings from the focus groups. These findings group themselves into five major relevant categories which form the basic structure of this chapter. The sub-categories are shown in the chapter sub-headings.

The categories are: obstacles to participation in the Project, promoters of participation in the Project, the attitudes, perceptions and beliefs of the participants, the participants' experiences of the Project and traditional healers. Within each major category, sub-categories emerged. A summary of the key findings are listed below in Table 2.

The socio-demographic profile of the study participants is shown in Table 3 on the next page. The table compares the socio-demographic data to that of the full range of participants of phase 2 of the KCCSP.

Table 2: Summary of the key findings of the study

- Women experience chronic symptoms, often gynaecological, that initiate their presenting to the KCCSP and returning for results.
- Women often believe their symptoms to be indicative of a serious, life-threatening disease.
- Women have not received satisfactory information about their symptoms from other health care providers.
- Women are anxious to understand the cause of their symptoms or to receive a diagnosis.
- Women will overcome significant logistical obstacles to achieve this understanding.
- Certain organisational factors of the KCCSP made it particularly convenient for women to return.
- Women are conditioned to experiencing abusive treatment from health care providers and are often suspicious when this treatment is caring.
- Women have an acute sense of privacy regarding their health and are concerned about gossip.
- Concerns about hysterectomy are very prevalent and pervasive.
- Attitudes towards traditional healers vary and do not seem to impact on the participants' health-seeking behaviour.

Table 3: Socio-demographic profiles of the study populations.

	19 women in the focus group study	2754 women in the KCCSP (phase 2)
Characteristic	No.	No.
Median age in years	41	39
Born in Cape Town (%)	1 (5.3)	186 (7)
Moved to Cape Town within previous year (%)	7 (38.9)	504 (18.3)
Resident in Cape Town for > 5years	10 (58.9)	1 969 (71.5)
Education (%)		
No school	3 (15.8)	252 (9.2)
Some primary school	7 (36.8)	854 (31.0)
Some high school	8 (42.1)	1 378 (50.0)
High school graduate	1 (5.3)	270 (9.8)
Dwelling (%)		
House	7 (36.8)	966 (35.1)
Shack on serviced site	11 (57.9)	1 544 (56.1)
Shack on unserviced site	1 (5.3)	244 (8.9)
Employed (%)	7 (36.8)	1 153 (41.9)
Married (%)	9 (47.4)	1 250 (45.4)
Sexual partners in last month (%)		
0	2 (10.6)	693 (25.2)
1	17 (89.4)	2 055 (74.6)
2	0	6 (0.2)
Current contraception use (%)	9 (47.4)	1 167 (42.4)
Cigarette smoking (%)	1 (5.3)	147 (5.3)
No alcohol intake (%)	17 (89.5)	2 524 (91.6)
Treated for STIs in the last year (%)	1 (5.3)	799 (29.0)
Median no. of pregnancies (range)	5 (1-10)	3 (0-15)
Median no. of live births (range)	4 (1-8)	3 (0-13)
Median age in years of first sexual intercourse (range)	18 (15-21)	17 (10-30)
Median no. of lifetime sexual partners (range)	3 (1-9)	2 (0-20)

6.1 Obstacles to returning for results

Although the Project clients were offered the option of telephoning for their results, the majority of clients preferred not to use this, even when they were able to do so.

Many of the obstacles to returning that were encountered were logistical. However, it seemed that most of the women had managed to organise solutions to overcome these obstacles in order to attend.

The facilitator suggested that logistical problems, e.g. childcare issues and unsympathetic employers, may have accounted for some women not returning to the Project spontaneously. In response, the participants implied that these reasons for not returning were groundless due to alternative arrangements that could easily have been made. "No, you can ask your neighbour to look after your child, or take her with."

A few raised the option of telephoning for results to overcome logistical difficulties. In fact, one woman stated that only major impediments would prevent her from returning, "Not unless I am sick or there is a death in my immediate family."

Most women had a series of difficulties relating to their attending the clinic. The determination of many participants was expressed in one woman's comment, "Nothing would have prevented me..."

6.1.1 Getting to the clinic

Almost all the women related problems they had faced with geographical access. Some had gone to great lengths in order to travel to the clinic.

Distance was a problem for many. One woman's home was "very far from this clinic, but I told myself that I have to go". Another woman who also lived a distance from the clinic said, "I had no money [for taxi fare], but I told myself I am going to walk."

The cost and availability of transport constituted obstacles for some. One woman, unemployed, and unable to pay for transport, had walked for about an hour to the clinic. Her son and grandchild had escorted her as she was afraid of getting lost and had poor eyesight. Taxi fare for another woman did not constitute an obstacle, as she had received her pension money on the morning she was due to attend the Project and she had used this money for transport.

Other arrangements that were made to attend included borrowing money from a friend to pay for taxi fare and completing household chores late the night before in order to leave early enough the following morning to walk the distance to the clinic.

Personal safety was an issue mentioned by a few women. They mentioned the need to arrange for escorts to the clinic to ensure protection as "there is a lot of mischief". However, it was noted by one woman that the time that is required of clients to return, 11am, obviated the need for "the company of someone" that would be necessary if they had had to leave early in the morning.

6.1.2 Care of dependents at home

A few women mentioned arrangements that had had to be made to ensure supervision and care of children left at home. One woman had left her two children with a neighbour. Another left three children and four grandchildren at home, but mentioned the time required of her to arrive at the clinic (11am) was convenient as, "I organised everything for them before I came."

6.1.3 Housework

Some women had to make adjustments to their household chores.

> I was supposed to be doing my washing, but I left it...I have to rush back [to do the washing] after my results because I am going home [to the Eastern Cape] on Sunday.

6.1.4 Employment

A few women need to ensure accommodation was made at work. "I was supposed to be at work today, but I realised that I have to come and be told what are my results. I was interested in getting them, so I will get to work late." This woman was insistent that her employer be accepting of her need to attend the clinic. Another woman had arranged with her manager, a change in shift at the restaurant where she worked.

6.2 Promoters of participation in the Project

It emerged from the discussion on returning for results, that perceived health problems and symptoms provided the predominant motivating forces. In particular, understanding these symptoms or receiving a diagnosis prompted many to return.

The ability of the Project staff to communicate well, especially in comparison to experiences with other health care providers, also served as a factor that promoted returning. Lastly, some organisational aspects of the Project made it easier for the women to return.

6.2.1 Health problems

When the group facilitator tried to elucidate the reasons why the women returned for their results on that day, the participants responded without distinguishing between their reasons for presenting initially and their reasons for returning. Most women spoke of the reasons they presented to the clinic in the first place and inferred that these same reasons precipitated their return.

It appears that the majority of women presented to the Project because they had been experiencing physical symptoms. In fact, all women participants complained of a symptom or set of symptoms that were gynaecological in nature. Having symptoms seemed to be the chief motivating force behind presenting to the clinic in the first place, despite a reasonable understanding displayed by most women, of the cervical screening objectives of the service. "I became interested because I am not well."

It is interesting to note that very few women placed emphasis on a need for relief of their symptoms. Rather, many women felt driven to *understand* the cause of their perceived suffering. This motivation was responsible for their presenting to the Project in the first place, or emerged after their initial encounter with the Project.

6.2.1.1 Symptoms

Many women complained of itching. "I am worried about this itching of the womb and pubes." It was often described how the itching was associated with other symptoms.

> The itching around my vagina… comes to my arm…something hot in my arm...sticking in my arm...burns my arm…I can't sleep at night.

Many also complained of lower abdominal pains. One claimed that these pains had been so severe that,"I had to drag my legs…they called for an ambulance". The same woman said she had seen a doctor to discover the reason she had had three miscarriages – she had been told that her womb was dirty. "A baby doesn't survive in a dirty place…there is a chance for me to get another miscarriage. That is what worries me – that brought me here."

One woman had attended the Project in attempt to discover the reason for her amenorrhoea. "I wanted to know what is happening to me. Is there anything wrong with me?" This woman believed that the results she would receive would inform her whether she was pregnant or not.

6.2.1.2 Imperative to know the cause of a physical ailment

When the cause of the symptom or symptoms was not elucidated at the screening visit, it was hoped that this would be revealed together with the results of the screening, at the return visit. It is not clear whether the women raised the problem of their symptoms with Project staff or whether it was assumed that the results of the tests performed would provide explanation for their ailments. In the motivation for returning, there seemed to be a great emphasis, on *understanding* the underlying cause for the symptoms.

One woman reported that, "... you have to follow all the steps [the Project protocol] until the end and until you know exactly what you are suffering from". Gaining access to information seemed to be the most important driving force for many women. One answered, "...for the purpose of getting information and reasons about this itching business", while another said, "... to know exactly what it is that I have because things start small and become big".

It appeared that information was sought to allay pre-existing fears about perceived disease. "I am so worried. I wish I could be told what the problem is." One woman explained why she had returned, "…so that I can be able to face what I am suffering from, even if I have AIDS". And another, "…because I want the right information about myself – what is it that I am suffering from".

One woman inferred that no obstacle was too great to prevent her returning, "I don't care about anything. What I care about is to know what my illness is, so that even if I die, I know what the cause is."

One woman volunteered for enrolment because, "I wanted to know what I am suffering from." A doctor at the day hospital had seen her for an "infection and discharge". From previous discussion with her, it seemed that she did not fully accept the doctor's explanation of the cause of her discharge and after hearing about cervical cancer from the KCCSP recruiters, she was concerned that she may have undiagnosed cancer. Thus, she was returning to discover whether she did indeed have cancer or not.

6.2.1.3 Other

There were a few miscellaneous health-related reasons given for returning for results. "...I came here because my neighbour advised me to come, so I am forced to come back." This comment was not explored so it is unclear why this woman felt "forced" to return. Another woman also returned as a result of someone else's direction, "I was threatened by my sister – saying that my womb is going to be taken out."

The experience of a family member of one woman led to her to seek prevention for herself.

> My cousin died of cervical cancer. What surprised me is that she was a nurse. I don't know what happened – why didn't she have a test?

6.2.2 Good treatment received compared with other health care providers

Almost all of the women indicated experiences with other health care providers that were perceived as unsatisfactory to them. This was contrasted with the perceived good quality of care at the KCCSP.

6.2.2.1 The gentleness and care of Project staff

The manner of relating of the staff at the Project was noted by many of the participants.

> I appreciate the way they handle us in this project. They explain every procedure they are doing and we are not used to that in other hospitals. You are shouted at...

Another woman compared the gentleness of Project staff to the verbal abuse received at other facilities.

> [They] are kind, they can explain. They don't rush you. They don't shout at you for a lost folder...these are not like others in other hospitals – they have humanity and they are the same [empathic], with kindness.

Many others highlighted this comparison.

> You don't get shouted at [at the KCCSP]. If you are scared, they don't say 'Yhey! Yhey!' (demonstrating, she slaps her hand on her thigh) 'I am helping you. Don't give me troubles.' No, they don't do that here. They say, 'Sorry Sisi, there is nothing to be afraid of. It doesn't hurt.' And you calm down, even if you were jumping. Here the nurses are free.

A few women seemed incredulous that some clients do not return as, "The nurses here talk softly to us. They explain everything. They are not rough where I could say maybe it is the treatment. The treatment here is good."

Many women noted that staff satisfactorily answered questions. "...[They] answer carefully and clearly."

A group of women questioned whether the caring behaviour was a function of the novelty of the clinic. "I don't know whether it's because this is a new project. They are not like others, in other clinics." Further, many participants shared a skepticism about the Project changing. One woman noted the lack of overcrowding and convenient time for attending and queried, "We don't know what is going to happen when it is known to everybody."

6.2.2.2 Poor management by other health providers

One woman mentioned a lack of success of previous treatment. "I have been attending many doctors at home [Eastern Cape]. They didn't know the cause...used to give me tablets but I didn't get any relief." This woman travelled to Cape Town especially to have her problem addressed at the medical services there. She had attended a private general practitioner in Khayelitsha who referred her to the Project.

Another woman had visited several health providers. A private doctor had given her tablets that had not helped her symptoms of dizziness and painful "lower parts". She then had attended a day hospital where she had received some other medication that had produced some relief. Thereafter, as she was not feeling entirely well, she returned to the private doctor and asked him for an injection as her "feet are a little numb and cold". He then referred her to the KCCSP. The explanation she gave of not having her problems addressed adequately was, "I assume he doesn't touch the lower parts of the body."

Another woman who had attended a local clinic on numerous occasions for ongoing lower abdominal pain, had been given a range of different medication and been told finally, not to return as "they [the staff] are tired now".

One woman related the situation of cervical cancer in the rural area from where she came. She mentioned the high frequency of deaths due to cervical cancer and the mystery enshrouding the disease. "People don't talk about it until she [a woman dying of cervical cancer] is finished." She went on to describe the reaction of nurses in the rural hospitals. "Disgust is shown on their faces and they shout, 'What is it with you in your area? Why are you all suffering from this?' "

She contrasted the dire situation in the rural areas where there are few clinics and where the diagnosis of cervical cancer is made "very late" with the fact that, "but now, here, this [cervical disease] is checked before it can get worse and I think it can be helped...I wish it [screening] can come to my area..."

6.2.3 The time of the day required to return for results

Many women mentioned how the time, 11 am, that they were due to return for their results made attending the clinic particularly convenient by assisting them in overcoming some of the logistical obstacles. They noted how it was necessary to arrive extremely early in the morning (4 am) if one hopes to be seen by a doctor at the day hospital. "You don't have to wake up as early as the other side."

6.2.4 The short waiting period

Several women related freely, without prompting, the positive feature of the short waiting period prior to screening. "They are quick because they care for us." And when the wait was longer than expected, "If they are delayed, they explain and ask for forgiveness...so the Project is different from other clinics and hospitals."

6.2.5 Telephoning for results

One woman was impressed with the option given of telephoning for results, "...the sisters here care. They say if a person can't come for other reasons, she is free to phone. I don't know whether others don't phone, because I was told I can phone if I have a problem, even if I haven't come." She went on to say that she had decided to attend in person for her first set of results and that she would be away in the Eastern Cape for the others.

A fellow participant retorted, "My interest is to get first hand information. I don't want to get news from a phone and I want to be able to ask questions of the doctor face-to-face."

6.3 The attitudes, perceptions and beliefs of the participants

The women raised three main concerns regarding returning for results. These were firstly, a suspicion that the Project staff were hiding information or had a hidden agenda, secondly, that a diagnosis of cancer, AIDS or a fatal disease was to be given and thirdly, that hysterectomy may be advocated as a necessary treatment.

Other problematic issues arising from the women's experiences of the Project emerged. It is not clear whether these impacted on returning for results. They included, the taking of blood for HIV, aspects of the enrolment questionnaire, aspects of the screening process and the problem of gossip.

6.3.1 Suspicions towards Project staff

The reasons for the participants' becoming suspicious included, the kindness of the Project staff, the belief that the true diagnosis of a serious or incurable disease would be difficult for staff to relay openly and honestly, and the receiving of tea and biscuits.

The manner in which the women were treated by staff was seen as highly atypical and therefore their intentions, untrustworthy.

> These nurses are too kind in so much as I had suspicions that there is something that is going to happen. In fact I am not used to getting too much kindness. They care over [too much]. They are the opposite of the other side [the day hospital]...[there] you get shouted at, but here, you are brushed calm, given biscuits and tea. No, I am not used to that.

Most women in two of the four focus groups spontaneously discussed the possibility of the staff being dishonest in the giving of results. "I don't wish them to hide anything from us. They have to tell us everything straight." And, "They don't need to be afraid to tell me."

It seems that the women believed that staff would be hesitant to disclose information regarding the diagnosis of a serious disease or cancer and many women believed that they indeed had such a life-threatening illness. Following this, one woman suggested, "Maybe that is the reason why we are not going to be given our results. Maybe they don't want to scare those who are already scared."

While waiting for the session to begin, the members of one focus group had become concerned that they had been called aside to be told that "we have something that cannot be cured". They had wondered what motivation was behind their receiving tea. "Why this kindness?" And, "We thought we can't be helped, so now we are being calmed." The group had been concerned about having been given biscuits and that these biscuits appeared peculiar to them. "What sort of biscuits are these, because they are not the usual ones, the colour and all that."

6.3.2 Diseases: cancer and AIDS

A high proportion of the women assumed that they were suffering from a severe disease. There was a great degree of anxiety expressed about this.

One woman said, "I wanted to know if I don't have cancer or whatever, even AIDS." Another echoed, "I am interested in knowing what I have so they can give me some advice as to how to handle this cancer, or if it's AIDS." One woman spoke of her fear of cancer destroying her womb and of the possibility of there not being a cure, leaving her with "...no other way but to let it rot at home and die, if I have to die".

One woman mentioned that a male relative had "threatened" her that she may have AIDS, when she discussed returning for her results with him. Her response was, "I told him I don't care. I want to know. People scare you...saying that it may happen that they discover that you have AIDS."

Two women in separate focus groups raised concern with the ability of the screening to pick up cancer. "In fact, even if she checked me [the nurse's screening], I can't say that I don't have cancer. No one knows how this cancer develops."

One woman who said, “No-one is safe, even if that cancer can be checked,” also wondered whether, “these problems with wombs are not caused by these contraceptive injections”.

When the participants were asked to suggest possible reasons for other women not returning spontaneously to the Project for their results, the predominant thoughts included the fear of being told of a serious or incurable disease.

In particular, the fear of treatment for cancer was a common thread throughout this discussion. “Other people are afraid of going to hospital because you are burnt [radiotherapy]. If it’s burnt, you don’t survive.” Another woman emphasised, “I prefer that the place or part of me that has cancer be removed not ironed [radiotherapy].” One participant described the consequent isolation and sadness of women with fatal diseases.

The discussion about causes for not returning seemed to echo and reconfirm *the participants’ fears*. However, these concerns seemed, in many instances, to be *motivating forces* behind their returning as opposed to barriers to returning.

6.3.3 Hysterectomy

Although the facilitator did not initiate the topic, concern about the possibility of needing a hysterectomy was raised in all the focus groups. The women centred their discussion of treatment on hysterectomy. This occurred despite their having indicated how they had received information regarding removal of “the spot if it is discovered in its initial stage”, i.e. local treatment of pre-cancerous disease, and despite the fact that hysterectomy is not discussed by Project staff as part of routine health promotion, “I am worried today...I may be told that I have to go to the hospital – maybe my womb will be taken out...”

The women seemed to be divided as to how they would respond to such a possibility. However, all had strong feelings on the matter. Again, there seemed to be an almost universal underlying assumption that a serious disease was present which may warrant such a treatment.

On the one hand, some of the women felt that hysterectomy would be a positive and practical solution to their physical problems. “How can you keep something that will kill you?” Another participant was equally pragmatic, “If removing it [the womb] will give me relief, I prefer that than leaving my children so young.”

On the other hand, some women believed that hysterectomy would be inappropriate in all situations. "People are saying that if it [the womb] is removed, you can't be a right person." A few women claimed that no woman could survive without a womb and that they would refuse a hysterectomy if this were suggested. One woman stated that those who claim to have had a hysterectomy have been "paid to say that, to cheat us".

One person expanded on her reason for refusal of a hysterectomy. She said that the womb would have to be "scratched and scratched until it is removed" and that she would "remain with an opening in that place". Another woman stated, "I would rather stay and die with it..."

A degree of fatalism was expressed by some. "[If] you are going to die, you are to die...God rather come and take me," and that removal of the womb would not make any difference. Then, echoed by another, "When my date [to die] comes – no one lives without a womb – so I must wait for my date."

The issue of being able to bear children was discussed in one focus group. The women expressed a fear of not being able to conceive.

When considering the possible reasons for some women not returning to the Project, a few mentioned the fear of hysterectomy. One participant informed, "One woman told me that she is afraid of being diagnosed as having cancer, because maybe the doctor may say her womb needs to be removed. She said she will die if it can be removed."

6.3.4 Gossip

A few women expressed a fear of gossip should neighbours or friends discover they had attended the Project.

One woman spoke of the consequences of advising neighbours or friends to attend for screening.

> She will go to someone else and gossip, saying that, 'Have you heard about her – does she not have AIDS?' ...[When] you explain everything to your neighbour, the neighbour will change the statement and tell someone else.

Others also discussed the gossip that would ensue about fatal diseases should neighbours be informed about their (the participants) attending the clinic. Many described their fear of the "nurses' car"[14] coming into their area, "What are they going to say when they see the nurses' car...people will say I have got AIDS." A second woman agreed, "Surely my neighbour will say I have got something." It appeared, from this conversation, that some women returned to the clinic for results to avoid gossip.

Some women objected to being asked for a neighbour's contact details during enrolment.[15] "In fact, we have no relationship with our neighbours...she is not aware of the fact that her name is here." Some indicated that they would prefer a family member's name to be used as a contact, instead of a neighbour's, in order to protect privacy.

6.3.5 Referring others to the Project

When asked whether the women would recommend attending the Project to neighbours or family, there was a mixed response. Here, the participants revealed some interesting concerns that emphasised the relevance of other sub-themes.

Some were concerned about the implications of others' knowing that they had been involved in any way with the Project (see section 6.3.7 on gossip). "I am not sure what she is going to say after I have told her about myself."

Some women saw the benefits of advising others to attend, "...you don't need to hide helpful information. You have to share it with others so that it can help them." Another woman went further to say, "I want other people to know, because if they don't know, they can die of something that could have been prevented."

It appears that many women had attended the Project in the first place on someone else's recommendation and that many had themselves already recommended attending to others.

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[14] Community Health Workers drive to the addresses of women who fail to return spontaneously for their results and who need further investigation for positive results. They leave written reminders to return to the clinic if the woman is not at home. When necessary, these reminders are left with neighbours.

[15] A neighbour's or next-of-kin's details are asked of each woman during enrolment. The intention is to facilitate the tracing process. When the woman can not be contacted, the tracing staff attempt to contact her neighbour or next-of-kin in order to deliver the reminder message to return to the clinic for results.

One woman had been recommended to attend the Project by her sisters. However, they had not wanted to return for *their own* results. "My sisters are afraid of being told that they have AIDS".

Those who had been involved in referring seemed to have particular views about the women that they had selected or would select for referral. Those that were identified as being most at risk for cervical cancer included married women, because, "...men go everywhere and bring problems home, like diseases" [16] ;older women and rural women.

One woman went so far as to say that the rural women who would have problems with being able to afford to travel and stay in Cape Town could stay with her brother-in-law.

6.4 The participants' experiences of the Project

The study participants gave detailed accounts of their experiences of different aspects of the Project. These experiences may or may not have constituted obstacles or promoters of their returning to the Project. However, the experiences appeared to impact on the women's relationship with the Project.

6.4.1 Taking blood for HIV

Many women expressed dissatisfaction with the anonymous taking of blood for HIV. Almost all of these women gave indication of an in-depth understanding of the reasoning explained to them by the blood-taking nursing sister and many gave a detailed account of the consenting process. Although consent was granted in each case, the chief objection of the participants seemed to be that the HIV results would not be made available to them.

One woman's comment typified this standpoint, "They are doing it to see the rate of AIDS in Khayelitsha, but we won't be given the results and that hurts me, but I kept quiet."

Two women, taking a practical view, went further to complain that not receiving the blood results would deny them the opportunity of medical management should this be necessary. "What I would like to know...why they don't give us the results of our blood samples so that we know early what we are suffering from to be able to be treated in time."

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[16] The sexually transmitted component to the aetiology of cervical cancer is not discussed as part of the health promotion activities at the Project unless clients make direct queries about this.

The other woman considered it wasteful to give blood in these circumstances. "[The staff are] not telling you what they have discovered and yet you could be helped if there is something."

One woman, a traditional healer, indicated an in-depth and accurate recall of the counselling she had received for the blood taking, including that blood was taken for HIV. However, she seemed to believe the blood was taken for the detection of cancer and, "to my disappointment", the blood was taken anonymously and she was not given her result on the same day. She was concerned that *two* bottles of blood had been taken and wondered *where* they would be sent, surmising that they would be taken to a hospital and used for transfusion purposes. She went on to say that without linking a name to the blood, she may receive someone else's blood should *she* require a transfusion. She said that her questions to the Project staff regarding these issues had been ignored.

6.4.2 The enrolment questionnaire

A few women indicated apprehension regarding the sexual history component of the enrolment questionnaire. "One of the questions that shocked me was the question about men in my life – how many men I have slept with (the group laughs). That question I never expected." Another woman had a similar response and laughing, said, "No, that confused me, this question of men. I kept quiet."

6.4.3 Experiences of the screening process

Many women indicated that they had been very anxious about being screened. This was true for both those that had been told about the process and those that said that they had *not* been informed about it. One woman, who fell into the latter category, explained that she was "shaking by the time I got there".

Most women went on to acknowledge that their fear had been unfounded. "I was so afraid of the process, my body was shaking, but everything went smoothly."

Different aspects of the women's experiences of the screening process were emphasised in the focus groups.

6.4.3.1 Expectation of pain

An expectation that the screening would be painful was almost universal. "I always heard about this screening of the cervix, but I was afraid, thinking it was painful... I waited in fear."

Another woman admitted, "I was frightened a lot. She (the screening nurse) was so careful and I discovered that it is not painful."

Some of the preconceived ideas about the screening arose from discussion with others at the clinic or with people in the community. While waiting to be seen, one woman had spoken to others who had undergone the speculum examination, "In fact we are threatened [cautioned] by others, even before you get to the doctor... They said it is very painful." Thereafter, she had thought to herself that if she had not had "this problem, this pain", i.e. her presenting symptoms, she would have gone home and forgone being screened. However, she had feared that she would be turned away from the day hospital at a later stage if she had "run away".

Another woman responded that, "... I didn't care – whatever they do to me, if it's going to be helpful." As a neighbour had explained to her the process, "I didn't take what others were saying into consideration."

6.4.3.2 Vaginal exposure and the stirrups

Some women commented on the vaginal exposure and the use of stirrups during the examination. The tone of the discussion reflected a combination of fear, humour and embarrassment.

"... you need to open your legs and lift your dress, and then there are these belts [stirrups]." A fellow participant responded, "Yhoo! Yhoo!", (looking away and shuddering). A third member of the group said, in mitigation of the process, "She put on the belts [stirrups] nicely, because she sees that you are afraid."

Some seemed to joke about the experience in a dramatic sort of a way. "... I was asked to get to bed. I was opened (laughing), and that was done. You know when you are sick, you tolerate everything that is done to you." Another woman retorted, "You are on you back and your legs are tied up," (the group laughs).

6.4.3.3 Race and gender of the screener

A proportion of women commented on the race and gender of the screener. Those that did discuss this issue all believed it preferable that the screener be white and a woman.

> [If] it is a black person, I don't feel comfortable, but if it is a white person, I relax because I don't care about her. I tell myself that I will never meet her anywhere.

The reason for the racial preference seemed linked to the anonymity that a screener's whiteness would confer. It was perceived as unimportant if a white screener were to breach confidentiality (and this seemed to be expected), as the likelihood of encountering the screener or the people to whom he or she would speak, seemed slim. "I won't mind if he talks to other whites because he will never see me again."

However, some women mentioned how their initial negative attitude toward a black screener changed. "When I arrived, I discovered that it is a black person who is doing this and I didn't like that." After being asked how she felt about being screened by the black nurse, the same woman said, "What a nice lady. She explains everything – she talks to you." Here, the abilities of the screener to communicate fully in the client's own language, and to show empathy are linked to her race and thus seem to supersede the woman's primary reservations about this.

The problem of race of the screener at the Project was mitigated by the fact that she was a woman. "I didn't care, more especially I was handled by a lady. I was going to hold my body if it was a man. It is difficult opening your legs to a man – it's too difficult" (group laughs) In support of this, another woman stated that one should not "be tense" if one is examined by a woman, "even if she is white". She went on to say that it "scares you" to be examined by a black man as, "He may remind you of your husband or he may talk to his friends about you." A second woman agreed, "The worse part of it is they take a long time, and your legs are wide open. Think about a black man looking at you for this period."

One woman related a story of her attending another day hospital where she saw a black male doctor who wanted to perform a Pap smear for her. She had left the clinic before he had had a chance to perform the smear as, "Being a black man, because you know we don't trust them, he will expect me to open my legs to him." She went on to say that after the doctor had asked her about her sexual history, she had been afraid that he would have sex with her and laughing, said, "Remember, they close the curtain." The women did not seem to have similar reservations about potential white male screeners.

6.4.3.4 The self-testing

Some women commented on "the stick", or self-testing component of the screening. Most were disconcerted that the swab had to be inserted by themselves.

"What shocked me was the stick part. It is long and thin – you have to insert it underneath. I have never experienced that, it is for the first time." Another woman said, "I was so afraid of that stick. I thought it would break inside – so much so that the sister had to insert it." Some of this fear seemed to be associated with a lack of understanding of anatomy. One woman said that she was not afraid initially, but became so when it was demonstrated to her "how to put this stick underneath", She was concerned about "the parts that I don't know of that are underneath".

However, another woman stated, "I wasn't afraid of anything. Even the stick meant nothing to me."

6.4.3.5 Use of the speculum

Many women expressed fear of the speculum, but most were placated after having undergone the examination.

Some women discussed the "fish-like thing". One said, "That thing that is like a fish…it frightens me…I wanted to get up and go at the moment it is wide open."

Most of the women went on to agree that their fears were unfounded, especially when they could no longer see the instrument. "When you look at it, you get frightened, but when the doctor [nurse] uses it, you can't see it, it's not a problem." Another agreed, "She put in that thing inside, but it was not painful. I didn't look at it."

One woman complained about the temperature of the device, "…something very cold was inserted inside my womb. It was as cold as if they were putting ice. Eh! Is this painful? No, I felt nothing painful." Another remarked that her experience of the speculum at the Project was not as painful as her experiences in the past, "They have another system now that is right and mild."

Only one woman declared that the examination itself had turned out to be painful. "It was painful to me, more especially when she inserted that thing. I don't know the name."

6.4.3.6 Taking of photographs/ cervicography

A few women mentioned that they had not been informed about the fact that photographs would be taken as part of the screening process.

This was particularly disconcerting for some. "I didn't like the idea of photos being taken without my consent, and not knowing where they are going to be taken to." This woman described the screening process as being "painless" but, "The only thing I disliked was having photos taken." This highlighted potential problems with the consenting process.

6.4 Traditional healers

The facilitator asked the participants how they viewed the role of traditional healers in cervical screening and disease. In addition, without prompting, spontaneous discussion about traditional medicine was woven into the focus groups on numerous other occasions.

The participants expressed a range of beliefs about traditional healers and womb problems or cancer. These included the suitability of traditional healers to address these problems, the opinion that only Western medicine is suitable and a more inclusive view that incorporated the use of both Western and traditional practices.

Few women took the purely traditional stand. One of these commented that she had been advised to attend a traditional healer for her problems (a range of genito-urinary symptoms), as "...this doesn't concern Western doctors".

One woman, who was a traditional healer, expressed a degree of mistrust of the whole screening process, "this issue of five treatments [screening tests]", and having to return for her results on different dates. She went on to explain that her own approach is to tell her clients about their ailments as indicated to her in a vision. In this way she diagnoses immediately and offers help if she is able. If she can not help, she refers the client to another traditional healer.

On being asked whether she ever refers her clients to Western practitioners, she replied, "We work hand in hand with doctors." In keeping with her background, this woman mentioned that she had considered "witchcraft" as a cause of her presenting symptoms (itchy discharge and pain).

Those that expressed a lack of faith in traditional healers seemed to relate this to difficulties with "cancer" per se. "But people these days prefer to go to the doctors and hospitals for cancers." One woman noted the complexity of the cancer problem, "But this issue is very difficult. Because this type of cancer is inside, so you need to come to hospital because they [traditional healers] can't see inside."

When a woman commented on the cause of the high prevalence of cervical cancer in the rural area from where she came, she described how traditional healers there believe the cause to be a poison. This initiated a conversation where all members of the focus group expressed a lack of faith in traditional practice. One woman asserted that by attending a traditional healer, "they just give you medicine and that delays you from getting to the hospital...[by which time] you are already worse."

One woman was able to reconcile traditional and Western practice as having different roles to play at different stages of disease.

> Hospital is the right place, but people do go to traditional healers. But the hospital is the only thing that can help when it's starting or in the early stages. But if it has already overpowered you, if the hospital can not help, traditional healers do try to cure cancer, but it's only trial and error.

Chapter Seven

Discussion

Discussion

This discussion of the study will include a list of its strengths and a description of its limitations. Thereafter, the findings will be discussed within the context of each of the four objectives of the study.

7.1 Strengths of the study

The strengths of the study relate to the backgrounds of the group facilitator and the primary researcher as well as several aspects of the design of the methodology. These have been discussed in the methods chapter and include the use of the focus group method and techniques used to ensure quality control. Some of these strengths may also be considered as limitations.

The demographic data of this study's participants revealed that the groups, selected on a first come first serve basis, reflected a range of demographic characteristics. These are comparable to the socio-demographic profiles of the total sample of women within phase 2 of the KCCSP (see table 3). Hoffman et al. conducted a household survey in 1996 of 661 women in Khayelitsha. The socio-demographic details of her study are similar to those of this study and the KCCSP (1997, pp. 149-157). Thus, although small, the study sample reflected the demographic profiles of much larger studies in Khayelitsha.

7.2 Limitations of the study

The major limitations of this study relate to the following: the use of the focus group method; the small size of the study and the lack of use of purposive sampling; the selection of the sample which did not include women returning for their second or third set of results and those that did not return spontaneously; the role of the main researcher; the issue of informed consent; and the fact that the participants' words were translated.

7.2.1 The focus group method

There are numerous limitations to the use of the focus group method in qualitative research. When compared to in-depth interviews, the data that is generated is generally of lower quality and more difficult to interpret as much less is known about the background of each participant. Probing in the group situation becomes very difficult (R. Jewkes, thesis examiner, personal communication). When focus groups are highly structured, they can generate data that is narrowed or thinner than would otherwise be generated (ibid.). In this study, the discussion guidelines were reasonably focused, but were used loosely in order to maintain a broad structure for the proceedings.

Other limitations of focus groups concern the personal and interpersonal dynamics at work within the session. These include the marginalisation of certain people, the domination by some members, the avoidance of particular topics and the concentration span and comfort level of the participants (Kelly 1999a, p. 389; Ferreira & Puth 1988, p.181).

Although some authors claim that focus groups may attempt to recreate a natural social setting (Terre Blanch & Kelly 1999, p.127), others state that organised group discussions are unnatural and thereby limit the nature of the interactions observed (Ferreira & Puth 1988, p.181).

As with all qualitative methods, the material acquired from focus groups, may not be generalisable beyond the universe of the study (ibid. p. 182).

7.2.2 The small size of the study and the lack of purposive sampling

As discussed in the methods chapter, logistical constraints meant that only four focus groups were conducted, with a total of 19 participants. This small study sample limits the ability of the research to provide an in-depth understanding of the context of decision-making in the participants' lives.

However, as mentioned previously, more in-depth and robust qualitative analysis of a larger and similar group produced similar findings to this study (*Women's Perspectives on Cervical Cancer Screening and Treatment* 2002).

The second limitation regarding sampling was that purposive sampling was not utilised. A bigger number of participants may have facilitated the creation of internally homogenous groups, such as young versus older women, educated versus less educated women.

This may have allowed for the emergence of themes that pertain to certain groups in particular. To wait for enough women to return spontaneously in order to divide them into internally homogenous groups would have created too great an inconvenience for the women and for the running of the Project.

In order for purposive sampling to occur, women would have had to be recalled at a later date, specifically to attend for focus group participation. In this way, homogenous groups of participants may have been arranged. This would have required funding to remunerate women for the cost of their transport, loss of income and time.

7.2.3 No sampling of women returning for their second or third set of results

Only women who were returning for their first set of results were sampled. Sampling women who were returning for the second and third sets of results may have provided an understanding of the reasons for attrition of spontaneous returning over time.

7.2.4 No sampling of women who did *not* return spontaneously

The study is limited by the fact that women who did *not* return spontaneously for their results were not included in the focus group discussions. These women may well have had an entirely different set of barriers to adherence with the Project protocol. Furthermore, they may have experienced the Project differently at the first visit, or they may have had different sets of perceptions and attitudes towards the Project and their health. Although the women who *did* return were offered an opportunity to conjecture about the behaviour and beliefs of those who *did not* return, clearly the non-returners themselves would have been better able to provide insight into these factors. Thus, the findings of this study may provide insight into the health-seeking behaviour of adherent women, and may enable services to consider factors that should promote adherence. However, generalisations may not easily be made regarding the experiences, motivations, beliefs and obstacles of non-adherent women.

There are substantial logistical problems with tracing non-returners for participation in focus group discussions. Logically, the obstacles to their returning would have applied similarly to their participation in a focus group study. Funding for this study did not allow for the tracing or remuneration of non-returners for their participation in focus groups.

7.2.5 The role of the main researcher

A potential source of bias in this study, in terms of interpretation of the data, was my role as Project manager and the possibility of investing in positive versus negative outcomes. While this possibility cannot be excluded, I took a critical stance towards the data and subjected myself to extensive peer review as mentioned previously.

7.2.6 Informed consent

Although a verbal consenting process took place (see section 5.5.3), the findings from two of the group discussions showed a suspicion among the women that the Project staff had established the groups in order to delay or avoid informing the women of their results. While this may denote a problem with the comprehensiveness and clarity of the consenting process, it may rather reflect the participants' inherent suspiciousness of health workers.

7.2.7 Translated meanings

It may be considered a limitation of the study that the focus group participants' expressions were filtered through the translation process. It is possible that some of the primary meanings of the women's statements may have been lost. However, this was offset by their interacting with a first-language Xhosa speaker as facilitator, who in addition, was proficient in English.

7.3 Meeting the objectives of the study

The focus group findings are discussed below within the framework of each of the study objectives.

7.3.1 The obstacles to returning spontaneously

Although the study participants consisted of women who were able or willing to return to the Project, it appeared they encountered significant obstacles in doing so. It would be reasonable to assume that those women who *did not* return spontaneously to the Project would have encountered similar obstacles, but may not have been able to overcome these, for unknown reasons.

The logistical obstacles cited by the group participants all related to the effects of poverty. They included problems with getting to the clinic, i.e. paying for transport, a long distance to walk to the clinic and the risk to personal safety in travelling to the clinic.

Other factors that posed challenges to attending were the need to secure alternative care for children at home, the need to ensure necessary housework was completed prior to leaving for the clinic and the problems with sacrificing attendance at work.

These logistical barriers to cervical screening among poor women are well documented in the local and international literature (Pick & Cooper 1997, p.49; Abrahams, Jewkes & Mvo 2001, p. 244; Campbell, MacDonald & McKiernan 1996, pp. 94-97; Lerman 1992, p. 330). However, many women in this study took extraordinary measures to overcome these problems in order to attend.

Although some women overcame psychological, social and cultural obstacles in order to attend the Project initially, they did not consider these to be barriers to their returning for results.

7.3.2 The attitudes, perceptions and beliefs that contribute towards returning to the Project

The attitudes, perceptions and beliefs that contributed to the women's returning to the Project seemed to be responsible for their attending the Project initially for screening.

The women often held contradictory thoughts and beliefs simultaneously. In particular, they were able to describe the rationale for the Project's screening but at the same time they had persisting beliefs about having serious illnesses.

7.3.2.1 Perceptions of chronic gynaecological symptoms

The motivating factors that contributed to the women's attendance at the Project related to their common experiences of chronic gynaecological symptoms, rather than for primary cervical cancer screening. These symptoms had not been adequately addressed by other health providers and the women expressed a strong need to understand the underlying causes.

The presence of gynaecological symptoms appears to be pervasive among poor women according to other studies. In 1990, the Global Burden of Disease study attempted to estimate the burden of reproductive ill-health in certain world regions. In sub-Saharan Africa, 39.7% of the disability-adjusted life years (DALY)[18] lost by women aged 15-44 years were attributable to reproductive ill-health. The value for India was 27.4%, while the value for Established Market Economies was 8.6% (Murray & Lopez, cited in Bhatia & Cleland 2001, pp. 1 065-1 066).

Bhatia and Cleland criticise the DALY approach for an excessive reliance on expert judgement for disability weights and a corresponding neglect of people's own perceptions of their conditions. They undertook monthly community-based interviews with 421 women in India for a year. Details of illness symptomatology and health-seeking behaviour were obtained. They showed that reproductive ill-health accounted for half of all illness-days and for 31% of total curative health expenditure. This underscores the problem of underestimation in the DALY approach as well as the extremely high prevalence of reproductive health problems in developing countries (2001, pp. 1 065-1 069).

Gynaecological symptoms have been shown to affect the presentation to cervical screening services. In a large, Mexican case-controlled study, the authors showed that a significant proportion of women presented for cervical screening because they experience gynaecological symptoms and not because they used the screening programme as a routine, preventive health action. The same group of women had a high risk of cervical cancer. Their samples consisted of 630 cases of cervical cancer and 1 005 controls. It was shown that those women who had a history of Pap smear use, who did not seek testing due to gynaecological symptoms and who received their Pap results, had a 2.63 times lower risk of developing invasive cervical cancer (OR=0.38; 95% CI: 0.28-0.52) (Hernández-Avila et al. 1998, pp. 370-376).

A multicentre South African study by Fonn et al. showed that only 9% of their participants (1 757 women) were motivated to have a smear because of a current gynaecological problem. However, only 70.5% (13 762 women) attended their screening clinics specifically to have a smear and almost half (49.8%) reported having a vaginal discharge (2002, pp. 150-152).

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[18] The DALY is a health index used to determine the national burden of disease. It reflects both non-fatal outcomes and mortality by measuring the potential years of life lost due to disability or death at a given age. Disease-specific severity weightings are used.

These apparent inconsistencies are discussed in more detail in section 2.4. A reasonable explanation for the findings is that women presented to their screening services primarily in order to have their gynaecological problems addressed, and that having a smear represented a necessary, but secondary step to take in order to meet this need.

Pick and Cooper's household survey of 659 Khayelitsha women showed that 18% (119 women) reported having received treatment for a gynaecological illness during the preceding three months. No socio-demographic factors had any influence on the incidence or prevalence of gynaecological illness (1997, p. 50).

The prevalence of STIs in the women enrolled in phase 2 of the KCCSP was high: 20% were positive for high-risk types of HPV, 7% were HIV positive, 2% were infected with Neisseria gonorrhoea, 4% with Chlamydia trachomatis and 19% with Trichomonas vaginalis (Denny et al. 2002, p. 1704).

Most of these infections may be responsible for a range of gynaecological symptoms. While the STI screening results for the focus group participants were not ascertained, it is possible that these infections were responsible, in part, for the symptoms they were experiencing. In the acute phase, STIs may cause symptoms of vaginal discharge, itch and pain. Pelvic inflammatory disease (PID) may cause an acute febrile illness associated with severe pelvic pain and general malaise. PID may, in the long term, result in infertility and chronic pelvic pain. Nearly all of the symptoms that the women at the KCCSP brought forward for attention related to menstrual irregularities, infertility and chronic pelvic pain.

A New Zealand study of women presenting to medical services with chronic pelvic pain showed that women reported problems with diagnosis, communication with the doctor, lack of information and inappropriate treatment. "There is a sense of increasing loss of control as repeated visits to the doctor do not produce an understanding of the pain." Women of lower socio-economic status were found to be more likely to experience these problems (Grace 1995, p. 521).

All of the focus group participants of *this* study complained of gynaecological symptoms, only some of which may be attributable to current or previous STIs. Many of the participants reported the same problems with other health services as those reported in the New Zealand study. Furthermore, it appeared that the focus group women had a strong need to have their symptoms finally and adequately explained. The women were anxious to have their grave interpretations of these symptoms refuted or confirmed. The Project represented a place where this explanation could take place.

A significant part of my job description as Project manager included the management of the research and non-research-related health needs of the women recruited to the KCCSP. A large proportion of the women complained of a range of medical and gynaecological problems, e.g. infertility, diabetes, asthma etc. These were all addressed by me by either providing on-site care or referral where appropriate. This feature of the Project appeared to be well known in the community and may have contributed to the participation of women in the Project.

7.3.2.2 Pessimism and fatalism

The women showed a profound sense of pessimism in the interpretation of their physical symptoms. These were commonly believed to be indicative of a serious, life-threatening disease such as HIV/AIDS or cancer.

Many women further revealed a sense of fatalism about their perceived illnesses and the possibility of treatment by hysterectomy. This sense of lack of control over their physical destinies suggests that many women feel disempowered by their symptoms and at the mercy of health service providers.

It is not clear whether women who are not involved in the KCCSP experience this pessimism and fatalism. It may be said that the women's exposure to the health education material and screening process at the Project gave rise to their dismal interpretations. It is possible, rather, that the pessimism and fatalism arises from the women's experiences of poverty, oppression, ill-health and lack of information. Further research is required to elucidate the prevalence and origins of these beliefs in women of Khayelitsha.

Bailie conducted a community based survey of 165 women between the ages of 15 and 65 in Khayelitsha. His sample included those who had had a Pap (37%) as well as those who had not (63%). Almost half (46%) of the sample of women had a fatalistic attitude toward getting cancer and most (83%) would undergo hysterectomy if indicated for its treatment. These attitudes were not analysed in order to compare for the effects of having been screened or not (1994, pp. 140-145).

One in-person interview study of 452 older Mexican-American women showed that fatalism about cancer and screening does *not* affect the use of screening (Randolph, Freeman & Freeman, 2002). However, other researchers suggest that fatalism and pessimism are prevalent among the poor and impact negatively on the use of screening services (Parham & Hicks 1995; O'Malley et al. 2002; Facione et al. 2002; Lee 2000).

One study, from the U.S.A., showed significant associations between fatalism and increased age, decreased educational level and race. A univariate analysis among African-American women revealed that fatalism was associated with non-compliance with mammography screening (Mayo, Ureda & Parker 2001, p. 71).

Another North American study using ethnographic interviews (121 women) and a telephone survey (1 225 women) showed that immigration, education levels and insurance status predicted fatalistic beliefs. These beliefs were independent predictors of Pap smear use by Latinas but not by women classified as "Anglo". Fatalism in Latinas was significantly associated with not wanting to know whether they had cervical cancer (Chavez et al. 1997, p. 418). This contradicts the findings of this study.

Helman notes that there are both positive and negative sides to belief. There are those beliefs and behaviours, acquired by growing up within a particular society, which contribute to stress, and which may negatively affect health behaviour (1994, pp. 303-309). Indeed, gynaecological symptoms, pessimism and fatalism are shown in other studies to inhibit cervical screening service uptake.

However, in the setting of *this* study, these experiences and attitudes, although distressing for the women, seem to provide a *positive* effect on health-seeking behaviour by providing motivation to attend.

7.3.3 Women's experiences of the Project and how these affect their returning

The focus group women uniformly expressed extremely positive views of the Project. However, the women showed some level of mistrust of Project staff, concerns about the testing for HIV, and concerns about privacy and gossip. Both negative and positive perceptions and attitudes to the Project appeared to contribute to the women's returning.

7.3.3.1 Women's preferences and satisfaction

Logistical convenience

The study participants stated how many design features of the KCCSP made it particularly convenient for them to attend. These included being able to arrive at the clinic at a relatively later time in the morning to that required in other public health services, the short waiting period before being seen by staff and the option of telephoning the Project for their results. The cited conveniences were contrasted to experiences of the public health service. This underscores much of the literature on logistical barriers to service uptake in poor or older women (Abrahams, Jewkes & Mvo 2001; Lobell et al. 1998; Blesch & Prohaska 1991).

Gender and race

The women reported a preference for the screening to be performed by a woman. This correlates with other studies internationally (Lee 2000; Campbell, Macdonald & McKiernan 1996). Locally, Bailie's survey in Khayelitsha, mentioned above, showed that 80% of 165 interviewed women preferred a female doctor or nurse to perform the screening test (Bailie 1994, p. 143).

Many women initially stated a preference for the screener to be white by linking this preference to the anonymity conferred by a screener of a different race. However, for some, this view changed after experience with the black woman screener and her ability to communicate so well. "She talked to me, calmed me down. She is so nice."

Many women noted as positive attributes of the Project the fact that the screener and all the other staff members were all women and first-language Xhosa-speakers. This seemed to impact on the high quality of communication that was reported by the participants. These findings are echoed in the qualitative research study undertaken at the Project in 2001 (*Women's Perspectives on Cervical Cancer Screening and Treatment: Participatory Action Research in Khayelitsha, South Africa* 2002).

The quality of communication

It can be seen that a high quality of communication is integral to the way in which the women are received at the Project. The women emphasised the gentleness of the staff, the willingness to answer questions and the fullness of explanations given. "[They] have humanity and they are the same [empathic], with kindness."

Many spoke of their anxiety about screening, about expectations of pain and embarrassment about vaginal exposure. These attitudes and beliefs are commonly noted in the literature on barriers to screening and follow-up, locally and abroad (Lerman 1991; Ishmail 1999; Wood & Jewkes 1996a+b; Fylan 1998). However, the focus group participants spoke of being enabled to overcome these obstacles by the gentle guidance and treatment from the Project staff.

The women frequently noted large disparities between the quality of interaction with the Project staff compared to their experiences with other health providers. There appeared to be an almost uniform experience of abusive encounters with other health providers. Further, women were dissatisfied with the explanations given for their ailments by these providers.

These findings concur with those from many other South African studies (Fonn et al. 1998; Mathai 1997; Abrahams, Jewkes & Mvo 2001; Palmer 1999).

The contrasting experience at the Project represented, on the whole, a pleasant surprise. However, the positive attributes were interpreted, by some, with suspicion.

7.3.3.2 Trust and suspicion

It seems that the prevalence of unsatisfactory experiences with health services had conditioned some women into expecting negative encounters with the Project. When the encounter of the first screening visit was explicitly pleasant, many women seemed to be conditioned into assuming an implicit ill-will on the part of the Project staff.

> These nurses are too kind in so much as I had suspicions that there is something that is going to happen. In fact, I am not used to getting too much kindness.

Wood and Jewkes state that the majority of the women they interviewed in KwaZulu Natal province had undergone a smear because they trusted the health workers' authority in recommending this, despite a limited knowledge about cervical screening (1996a, p. 3).

Daniel explains that because medical science represents a mystery and hence a possible danger to many, it "must convince its public of both the excellence of its practice and the moral integrity of its practitioners. The powerful must be good, or, at least, seen to be good" (1998, p. 218). She states that trust is the beginning of co-operation. However, co-operation (and here we may read "adherence" to medical recommendations) may also result from other motivations such as fear and self-interest.

In medical science, knowledge is profoundly linked with power. Therefore, compliance with recommendations may not necessarily occur for explicit reasons. Furthermore, where power has been abused, as is the case in the recent history of apartheid South Africa, there are numerous reasons why the women may mistrust medical authority, yet still comply with it.

Some women felt that the Project staff would not give them their results honestly and fully. Although this was coupled to a mistrust of the apparent "kindness", the suspiciousness also seemed related to the women's underlying fears that they had cancer or some other serious illness. Returning for results may have thus represented a wariness of the Project as well as an intent to discover the "truth" about underlying conditions.

In addition, there was a prevalent concern about the taking of blood for anonymous-linked HIV testing, despite evidence to show that the explanation for this had been well understood. Some women felt affronted by not having access to their HIV results and this was linked to the possibility of being denied access to treatment should they, in fact, be HIV infected. It is not surprising, therefore, that those women, who strongly valued knowing their HIV test results, would return spontaneously for their cervical screening results.

7.3.3.3 A concern for privacy and a fear of gossip

Some women appeared to be returning for their results in order to pre-empt being traced. These women knew that the "nurses' car" was used for tracing. They were anxious that this would provide an opportunity for their neighbourhood communities to conjecture about their ill-health, in particular, whether they have HIV/AIDS. Related to this was the concern about giving a neighbour's contact details for tracing purposes.

Several women displayed an acute sense of privacy when they described discomfort at responding to the questions in the enrolment form that were related to sex.

Some women objected to the taking of photographs of the cervix. This appeared to be linked to a concern about genital exposure.

This concern was noted in the findings of the research conducted at the KCCSP in 2001 (*Women's Perspectives on Cervical Cancer Screening and Treatment: Participatory Action Research in Khayelitsha, South Africa* 2002). This research, as well as that mentioned above, found that the women's perceptions of their genitals were those of "dirtiness" and "ugliness". Furthermore, there were strong cultural norms against vaginal examination, which was experienced as a very stressful procedure (ibid. p. 26).

These findings concur with those of other qualitative research in differing regions of South Africa. Women make problematic associations between smears, "womb" cancer and promiscuity (Abrahams, Wood & Jewkes 1996; Wood & Jewkes 1996a+b). It follows, therefore, that the prevalent stigmas attached to sexuality, genital infections, including HIV, and diagnosis of cancer present significant causes for concern for women.

Although the concerns about privacy may not necessarily have impacted on the women's decision to return to the Project, they contribute toward a fear of exposure, literal and metaphorical. Understanding and retrieving their own results in person may thus represent an attempt to "reclaim" ownership of the women's private information that has been "given" to the Project.

7.3.4 The implications for the Project in order to improve spontaneous returning

The findings show that there are many positive features of the Project that may impact on spontaneous returning. These should be maintained and reinforced. On the other hand, several aspects of the findings reveal faults with the Project. These should be addressed adequately, both from an ethical point of view, and in order to improve the quality of service delivery.

7.3.4.1 Re-enforcing the positive

The overriding perceptions of the focus group participants regarding the Project are extremely positive.

These perceptions include aspects of the Project design that maximise convenience for the women and assist them in overcoming many of the logistical barriers to attending that are associated with poverty. These features of the Project could be discussed more explicitly in the recruiting and enrolment processes. This might thereby assist in attracting more women to present for screening and to return for their results.

The quality and quantity of interactions between the staff and the women were highlighted in this study as well as the other qualitative study at the Project (*Women's Perspectives on Cervical Cancer Screening and Treatment: Participatory Action Research in Khayelitsha, South Africa* 2002). The importance of the interactions are further emphasised by Fylan in her recommendations for improving participation in cervical screening programmes. These recommendation arose from a comprehensive analysis of the world literature on women's attitudes, knowledge and behaviour to cervical screening and colposcopy (1998, pp. 1 509-1 514).

Thus, staff should receive ongoing training and support in communication and counselling skills. This process should be informed by the findings of these studies regarding the prevalent fears, concerns and needs of the women.

The Project design should incorporate a comprehensive women's health service. This would address the fact that many women present to the Project and appear to return to the Project in order to have addressed underlying physical, particularly gynaecological, ailments.

As mentioned previously, the Project manager addressed and treated non-research related health problems as the women raised them. Providing such a needed service more explicitly may improve recruitment. Moreover, it may facilitate greater transparency in communication between staff and the women and thereby further improve these relationships.

A dedicated slot in the Project protocol could be created for the Project medical officer or a nursing sister to enquire about health problems and to address these. Clearly, these changes are costly in terms of time and human resources. However, the evidence from this and other studies seems to indicate that the benefits of improved attendance may outweigh these costs (Fonn et al. 2002; Bhatia & Cleland 2001; Grace 1995).

7.3.4.2 Changing the negative

The findings raised certain negative features of the Project that require examination and improvement.

Firstly, there are several parts of the findings that indicate that the women have very basic misunderstandings, despite all the health promotion and counselling they have received through the Project. These misunderstandings relate to the taking of blood for anonymous-linked HIV testing and the taking of photographs of the cervix. The processes of informed consent and counselling should be altered to address these common concerns and misinterpretations. Staff should attempt to engage with the women more specifically on these issues in an effort to ascertain their attitudes towards them. Thereafter, any fears or concerns may be more effectively addressed.

Secondly, Project staff should be made aware of the suspicion and lack of trust that seem to exist in paradox with the praise and appreciation for the Project. Although these concerns appear to contribute to the women's spontaneous returning, they require to be addressed adequately. More full explanations regarding the rationale behind tracing, the enrolment form questions, HIV testing, cervicography and the treatable nature of pre-cancerous cervical disease could be discussed. Every effort should be made to reassure women that their privacy will be well-maintained within the Project.

All staff members should be briefed regarding the findings of this research. These should be discussed as part of a carefully managed process of self-reflection, positive re-enforcement and development. Staff should be empowered to realise the degree to which they can impact on the negative and positive features of the Project.

Chapter Eight

Conclusions

Conclusions

Cervical cancer is a disease of poverty. It is highly prevalent in developing regions. The risk factors are intimately connected with the poverty and the disempowerment of women in these areas. Furthermore, health services in resource-poor countries have been unable to provide the necessary infrastructure required of cytology-based screening services and hence, the Pap smear has made minimal impact on the incidence and mortality of cervical cancer.

The KCCSP is undertaking research to establish the effectiveness of alternatives to cytology-based screening that may be more useful within the context of low-resource settings. These alternatives seek to develop a nurse-provided "see and treat" approach to pre-cancerous disease. This will obviate the need for many of the infrastructural requirements of cytology-driven services. Women will not be required to return to the service for their results in order to receive recommendations for follow-up.

Until these alternative methods are well-established, most of the developing world must rely on the Pap smear for cervical screening. Therefore, processes must be created for poor women to receive their smear results. Where postal and telecommunication systems are unreliable, non-existent or too costly, women will be required to return to the screening services for these results and management recommendations.

This study aimed to provide an in-depth understanding of the factors that affect the health-seeking behaviour of women in the process of retrieving their screening results. It was felt that useful lessons could be learnt by examining these factors in the context of a screening service where the spontaneous return rate was particularly high.

The investigation was required to elicit the complex attitudinal, perceptual and contextual concerns of women returning. Therefore, the qualitative method of focus group discussions was used in order to yield this depth of information. The women's concerns were related to their own set of circumstances as well as to their experiences of the Project itself.

The six main conclusions of the study are summarised under each of the sub-headings below.

8.1 The Project promotes cervical screening uptake by providing information, a high quality of communication and patient satisfaction.

The vast majority of women expressed high levels of satisfaction with the provision of information, the quality of communication and the logistical organisation of the Project.

At the KCCSP, much emphasis is placed on engaging meaningfully with the women at each stage of the process. This may have contributed to the high rate of spontaneous return to the Project for results.

8.2 The women had chronic gynaecological symptoms that affected their participation in the Project.

In an unscreened population of poor women, non-cervical related health problems are pervasive. Although the aim of screening services is to assess "well women", there are few "well women" in poor communities. Therefore, any screening initiative should provide a more comprehensive service than merely screening.

The Project represented a place where the women's symptoms could be properly addressed. This reputation may have existed prior to the women's first visit, and seemed to be confirmed by their experience of this initial contact.

Thus, the focus of the KCCSP, which is to research cervical screening alternatives, is not in accordance with the motivations of the women, which are to have symptoms addressed. If a comprehensive women's health service can be maintained, this divergence may not matter. Rather, it may be used to improve participation in the Project.

8.3 The women believed their symptoms indicated a serious or life-threatening disease.

The women appeared to have significant anxieties that their symptoms related to an underlying serious disease. This provided motivation for them to attend the Project in order to confirm or refute their interpretations. To achieve this understanding, the women went to extraordinary measures to overcome obstacles in order to attend.

Furthermore, there was a prevalent fear of hysterectomy. Many women believed they might need to undergo a hysterectomy in order to treat their perceived illnesses. This deepened their levels of anxiety.

8.4 Information from other health providers about the symptoms had been unsatisfactory.

Many women had sought the help of other health service providers in both the public and private sectors. These interactions with other health workers were perceived as particularly inadequate, on an interpersonal as well as a practical level. In contrast, the quality and quantity of interaction between staff and participants at the Project made the women feel that they would receive the information that they required.

8.5 The women had negative suspicions about the Project.

Almost all the women in the study discussed extremely negative experiences with other health providers. They went further to compare this to the care and kindness that they experienced from staff at the KCCSP. This contrast appeared so great as to lead many women to distrust the motives of the Project staff and to believe that they had a hidden agenda.

Certain features of the Project per se may have contributed to these suspicions. These include the taking of blood for anonymous-linked HIV testing, the intimate nature of some of the enrolment form questions, the cervicography, the giving of alternative contact addresses and the tracing of women at their homes, by car. These processes seemed to undermine the women's acute sense of privacy and raise concerns about gossip.

8.6 Certain organisational factors of the KCCSP make it particularly convenient for women to attend.

The women noted many logistical obstacles to attending and took special measures in order to overcome these. However, the women explained that certain structural features of the Project facilitated their participation. These included the relatively later time required for arriving at the clinic, the short waiting time and the option to telephone for results.

Chapter Nine

Recommendations for cervical screening service design in low- resource settings

Page

Recommendations for cervical screening service design in low- resource settings

This study took place within the context of a well-resourced research project, in the setting of a poor peri-urban settlement. However, the findings have generated certain cost-effective, low-technology recommendations that may be useful in the design of cervical screening services in low-resource settings.

9.1 Comprehensive women's health services

Cervical screening programmes should be integrated into comprehensive women's health services. Alternatively, cervical screening programmes need to take into account the unmet health care needs of poor women.

There is considerable evidence from this and other studies to indicate that poor women suffer a significant physical and emotional burden related to gynaecological symptoms. Further, many ill-afforded resources of the women and the health services are spent in attempting to address these problems, frequently unsuccessfully. The development of primary level comprehensive women's health services in the public sector may minimise the wastage of these precious resources.

These services may more easily manage mass cervical screening programmes and ensure a greater coverage of target populations.

9.2 Staffing

The staff at the services should be comprised of women who are able to speak the language of the clients and who are sensitive to their clients' contexts and concerns. Well-trained community health workers should be incorporated into these services in order to fill the roles of health educators and peer group educators in ways that cohere with local cultural, social and economic factors (Manderson & Mark 1997, p. 30). This may relieve the load on more highly-paid, highly-trained medical staff with respect to health promotion, and the giving of explanations, reassurance and results.

9.3 Emphasis on health promotion

Women require quality information and relief from their anxiety about the symptoms they experience. These needs are equal to the need for alleviation of the symptoms. In order to address women's non-physical needs, women's health services should incorporate interactive and dynamic health promotion activities. These could include the use of drama and narrative. Women should be afforded the opportunity to interact with each other and with staff about issues of concern.

9.4 Emphasis on ongoing, high quality communication

Women's health services should place an emphasis on ongoing and high quality communication with their clients. This process should arise from grass-roots involvement and ongoing liaison with the community in order to obtain community support and co-operation. Women's needs should be assessed prior to service implementation.

Staff should agree to communicate with women at each stage of the screening process, as part of their duties. Staff should be sensitive to prevalent cultural concerns and the previous experiences of their clients. Reassurance of women should include discussion about issues of privacy, the preventable nature of cervical cancer and explanation of the concept of pre-cancerous disease.

Women should be encouraged to participate in the screening process by communicating their concerns and assisting others in overcoming theirs. This participation may assist in the building of self-esteem and empowerment of poor women (Manderson & Mark 1997, p. 30).

9.5 Efficiency in giving of results

Every effort should be made to ensure that women are able to receive their results in an efficient manner. When women are aware that this will occur, they may be more likely to return to the service for these results.

The organisational structure of services should be designed to incorporate options for receiving results that facilitate access for poor women. Flexibility within programme design may determine successful outcomes and programme sustainability (ibid.).

9.6 Final comment

Efforts are underway to dispense with cytology-based screening in low-resource settings. Until that time, where postal and telecommunication systems cannot be used, service providers will rely on women to return for their screening results. If women do not receive their smear results, cervical screening programmes will be ineffective and wasteful of resources.

It is therefore crucial in the design of these services that every effort is made to assist women in overcoming the barriers to retrieving their results. Services should incorporate cost-effective, low-technology methods to promote women's full participation.

Chapter Ten

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Appendix 1

Risk factors for cervical cancer

- Early age at first intercourse (especially before 16 years)
- Multiple sexual partners or partner with multiple sexual partners
- Sexually transmitted diseases
- Human papillomavirus (HPV) infection
- Herpes simplex virus infection
- Early age of first pregnancy
- Parity
- Cigarette smoking
- Oral contraceptive use
- Low socio-economic class
- Human immunodeficiency virus
- Immune-suppression from any cause
- Vitamin deficiencies
- Interval since last Pap smear

(Bloch 1996, p. 302; Wright 1994, pp. 232-233)

Appendix 2

Patient card

(two sides - translated from Xhosa)

Khayelitsha Cervical Screening Project Michael Mapongwana, Harare, Khayelitsha Ph: 363 1365		
Name:	Patient no:	Date Enrolled:
Address:		
Cervical screening results. Please return for your results. The dates below indicate when you should return.		
Test	Date results available	Time
DVI/HPV/Trich		
Pap smear		
Cervigram/Infections		

Doctors'/Nurses' notes:

Appendix 3

Reminder note

(translated from Xhosa)

Michael Mapongwana Hospital – room 15 B
Harare
Khayelitsha
Phone: 363 1365

CERVICAL SCREENING

Dear Mama

Please will you return to the clinic on Thursday at 12 o'clock or Friday at 8 o'clock in order to be examined or to receive your results.

It is important to come to see the doctor for your health.

Thank you

Dr Denny, Dr Honikman, Sister Kuse

Appendix 4

Tracing form

Name: **Patient no:**

Address:

Date visit one: **Patient found:** **Yes** **No**

If Patient found, date she will come?

Reason she did not come for follow-up (tick box):

Too busy
Work problems
Family problems
Transport problems
Patient ill
Patient does not want to come
Patient did not realise she had to come back
Other

If Patient not found, what is the reason?

Address does not exist
Patient not known at that address
Patient in Transkei
Patient at work
Other

Date visit two:
Date visit three:
Date visit four:

Did patient come for follow-up? **Yes** **No**

Comments:

Appendix 5

Checklist for focus group recruiting

Patient number:

Please respond to the questions below with “yes” or “no”

1. Is the woman returning, untraced, for her first set of results ? ....
2. Is the woman unconcerned about the requirement of waiting for her results to be given to her after the focus group is finished ? ....
3. Does the woman understand that the focus group is an informal discussion among a group of clients about their experiences, and will last one to two hours ? ....
4. Does the woman understand that she is under no pressure to join the focus group and that her decision, either way, will not affect her treatment ? ....
5. Does the woman understand that the focus groups are for a research project about the experiences of clients of the KCCSP? ....
6. Does the woman understand that the focus group will not be a test of understanding or ability ? ....
7. Does the woman understand that the person who will be running the focus group is not employed by the KCCSP and that she is Xhosa-speaking ? ....
8. Does the woman understand that her identity will be kept confidential if she agrees to join the focus group ? ....
9. Does the woman agree to join the focus group ? ....

Any comments about the woman’s responses in the recruiting interview?
....
....
....
....

Appendix 6

Discussion guidelines for focus groups

1. **Introduction** (about 10 minutes)

Greeting.
Introduce yourself (mention that you are not involved as an employee of the KCCSP).
Thank group for agreeing to participate.
Explain what a focus group is and that everyone *can* participate.
Explain that there are no right or wrong answers.

Explain the **purpose** of the focus group:

> We are interested to know about your reasons for returning today.
>
> So, today we would like to talk about these reasons as well as any difficulties or concerns you have about returning.
>
> We would also like to understand more about your experiences at the KCCSP.

Your opinions and feelings are what matter. This discussion is not a test in any way.

You can agree or disagree with each other and you can change your mind.

Please feel comfortable to say how you really feel.

Explain the **procedure** of the focus group:

> Tape recorder
> Confidentiality
> What will happen to the information (i.e. a report)
> What the research will be used for
> Feel free to respond without being asked to do so
> One person to talk at a time
> Time expected to last 1-11/2 hours

Participant Introduction: "Just to get to know each other a bit better..."
Each woman tells her name and who stays with her in her home.

2. **Rapport - building - opening discussion on circumstances of returning today** (20 minutes)

You have all been recruited, enrolled and screened at the KCCSP and today you are here for your first results.

a. **Can you tell us about getting to the clinic today?**
(Possible prompts; Any difficulties in coming today? Any sacrifices that were made for coming today? How did you deal/overcome the difficulties/sacrifices?)

b. **Can you tell us some of the reasons why you decided to return to the clinic today?**

c. **What were your feelings about coming to the clinic today?**

d. **What did you expect was going to happen when you arrived?**

3. **Indepth phase I: Experiences of the service** (25 minutes)

We are interested in understanding how you experienced your time at the project.

a. **Can you tell us anything about your experiences on the day you came for screening? Anything that was good/ difficult for you?**
(Prompts: What do you remember about the day?
How did you feel when you arrived?
" " " " during the recruiting?
" " " " during the blood-taking?
" " " " while you were waiting?
" " " " during the enrolling?
" " " " during the screening?
How did you feel in yourself when you left the project?)

b. **Did you learn anything new during your time at the Project? What did you learn?**

c. **Would you recommend to your sister or neighbour to come to the Project? What reasons would you give for recommending/ not recommending?**

d. **How were your experiences at the Project different from your experiences at other clinics and hospitals?**

4. In-depth Phase II: Problems with returning for results (25 minutes)

Clinic workers have told us that some women come back for their results and some do not come back. We would like to know why some do not return so that we can perhaps improve on the situation.

a. **What is your opinion on this? What reasons can you think of why some women do not return? What do you think about these reasons?**
   (Prompt only if participants do not come up with own suggestions;
      work problems, concern or suspicion about possible treatment, traditional healers, too busy)

b. **Did you have any reasons that may have prevented you from coming? What were these? How did you overcome them?**

5. Closure (10 minutes)

Take a minute to think about the reasons you came today for your results.

(Give a minute's silence)
Now, at the end of our talk - can you tell us what were the most important reasons why you came today? Any other reasons?

Short summary
Thanks
Close the discussion

Appendix 7

Summary of the key findings of the study

- Women experience chronic symptoms, often gynaecological, that initiate their presenting to the KCCSP and returning for results.
- Women often believe their symptoms to be indicative of a serious, life-threatening disease.
- Women have not received satisfactory information about their symptoms from other health care providers.
- Women are anxious to understand the cause of their symptoms or to receive a diagnosis.
- Women will overcome significant logistical obstacles to achieve this understanding.
- Certain organisational factors of the KCCSP made it particularly convenient for women to return.
- Women are conditioned to experiencing abusive treatment from health care providers and are often suspicious when this treatment is caring.
- Women have an acute sense of privacy regarding their health and are concerned about gossip.
- Concerns about hysterectomy are very prevalent and pervasive.
- Attitudes towards traditional healers vary and do not seem to impact on the participants' health-seeking behaviour