

A study of the health seeking behavior of women on treatment for cervical cancer in Grey's Hospital

A dissertation submitted to the

Department of Public Health Medicine
Nelson R. Mandela School of Medicine

**University of KwaZulu-Natal
Durban, South Africa**

In partial fulfilment of the requirements for the
Master in Public Health

By:

Olubukola Adejumo

Supervisor: Dr Anna Voce

November 2012

As the candidate's supervisor, I have read the dissertation and given approval/ have not given approval for submission for examination.

.....
Supervisor: Dr AS Voce

Date:

Department of Public Health Medicine
Nelson R Mandela School of Medicine
University of KwaZulu-Natal
South Africa

DECLARATION

I Olubukola Adejumo declare that:

- (i) The research reported in this dissertation, except where otherwise indicated, is my original work.
- (ii) This dissertation has not been submitted for any degree or examination at any other university.
- (iii) This dissertation does not contain other persons' data, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.
- (iv) This dissertation does not contain other persons' writing, unless specifically acknowledged as being sourced from other researchers. Where other written sources have been quoted, then:
 - a) Their words have been re-written but the general information attributed to them has been referenced;
 - b) Where their exact words have been used, their writing has been placed inside quotation marks, and referenced.
- (v) Where I have reproduced a publication of which I am an author, co-author or editor, I have indicated in detail which part of the publication was actually written by myself alone and have fully referenced such publications.
- (vi) This dissertation does not contain text, graphics or tables copied and pasted from the Internet, unless specifically acknowledged, and the source being detailed in the dissertation and in the References sections.

Signed:

Date:

ACKNOWLEDGEMENTS

I would like to extend my appreciation to all the people who have contributed to the completion of this study. In particular, I would like to thank the following individuals:

Dr Anna Voce, my supervisor, for her guidance, mentoring and encouragement.

The cervical cancer patients from Grey's Hospital who availed themselves to be interviewed regarding their health seeking behavior in relation to their present condition.

Sincere thank you to the staff of Radiation Oncology at Grey's Hospital for their assistance in patient selection for the research.

My husband, Henry, and two beautiful daughters that I had during the Masters' programme, Chisom and Mmesoma: you guys made everything worthwhile.

My parents, Prof O. Adejumo and Mrs. O A. Adejumo for their encouragement and support through my years of study.

Colleagues at Jackpersad and Partners in Ethekewini Hospital for their understanding while I had to take time off work for data collection.

Data assistants: Zanele Nxumalo and Nelisiwe Fikeni and Translators: Ntombazane Blose and Thobile Mtshali

Tonya Esterhuizen, the statistician, for her guidance through my data analysis.

ABSTRACT

Background

According to the Programme for Appropriate Technology in Health (PATH), global statistics show that nearly half a million new cases of invasive cervical cancer are diagnosed each year. More than a quarter million women die of this disease annually, with the highest incidence and mortality rates being in developing countries. In South Africa a woman's risk of developing cervical cancer is one in 26. Each year 6 700 women develop cervical cancer while 3 700 die from the disease annually.

The overall aim of this research was to determine the patterns of health seeking behaviour of women being treated for cervical cancer.

The specific objectives were to:

- Describe the health service utilization characteristics of patients being treated for cervical cancer.
- Describe the need factors associated with decision to seek care.
- Describe the enabling factors associated with decision to seek care.
- Describe the predisposing factor associated with the decision to seek care.
- Analysis of factors associated with health seeking behavior in women treated for cervical cancer.

Methods

An observational study with a descriptive and analytic component was undertaken. The study was conducted in the Oncology Department of Grey's Hospital, which is a referral hospital located in Pietermaritzburg from the Umgungundlovu, Umzinyathi, Zululand, Uthukela and Amajuba Health District which has a population of 995 303. All patients treated for cervical cancer within the study period, who provided informed consent for their participation in the study, were enrolled. The total number included in the study was 109.

Descriptive statistics were used to explore frequencies emanating from the data. Pearson Chi square tests were used to explore the relationship between

two categorical variables and the p -value was used to decide how much evidence there was against the null hypothesis. Odds ratio was also used as a measure of risk to compare whether the probability of a variable is the same for the outcome variables. Regression was performed on the variables that were found to be statistically significant to the outcome variables in the bivariate analyses.

Results

The variables that most influenced health seeking behaviour and that still remained statistically associated with the outcome variables under the multivariate analysis were found to be age, marital status, employment status, social support for medical treatment, educational level, knowledge of Pap smear screening and recognition of cervical cancer.

Conclusion

The study achieved its aim of determining the patterns of health seeking behavior of women being treated for cervical cancer at Grey's Hospital. It also identified that proper implementation of HPV vaccination and cervical screening programme can be an entry point to address the incidence and presentation of cancer at advance stages, as well the treatment of precancerous lesions of the cervix in the women of reproductive age. An awareness campaign, support for women to undergo screening program and availability of health centers is also recommended. All recommendations need to be considered by the department of health and appropriate authorities in South Africa to minimize the widespread of cervical cancer.

TABLE OF CONTENTS

DECLARATION.....	III
ACKNOWLEDGEMENTS	IV
ABSTRACT	V
TABLE OF CONTENTS	1
LIST OF TABLES.....	5
LIST OF FIGURES	6
LIST OF APPENDICES.....	7
ABBREVIATIONS AND ACRONYMS.....	8
DEFINITION OF TERMS	9
1. BACKGROUND.....	10
1.1 Introduction.....	10
1.2 Problem Statement.....	12
1.3 Scope of the Study	12
1.4 Research Aim and Objectives	13
1.5 Overview of Research Report	13
2. LITERATURE REVIEW	15
2.1 Introduction.....	15
2.2 The Epidemiology of Cervical Cancer	16
2.3 Burden of cervical cancer.....	16
2.3.1 In the Developed World	17
2.3.2 In the Developing World	17
2.3.3 In South Africa.....	18
2.4 Risk Factors Associated with Cervical Cancer	19

2.5 Cervical cancer in women living with HIV	20
2.6 Clinical Presentation	21
2.7 Stage Characteristics	21
2.8 Prevention and Management of Cervical Cancer.....	22
2.8.1 Prevention perspective	22
2.8.2 Curative Perspective	25
2.8.3 Prognosis	26
2.9 Health Seeking Behaviour	27
2.9.1 Factors influencing health seeking behaviour	29
2.9.2 Knowledge and Health Seeking Behaviour	30
2.9.3 Recognition of symptom and health seeking behaviour	30
2.9.4 Age and Health Seeking Behaviour	30
2.9.5 Socio Economic Status and Health Seeking Behaviour	31
2.9.6 Alternative Medicine	31
2.10 Conclusion	32
3. RESEARCH METHODOLOGY	34
3.1 Introduction.....	34
3.2 Study Setting.....	34
3.3 Study Design.....	34
3.4 Study Period.....	35
3.5 Study population	35
3.6 Study Sampling Strategy and Sample Size	35
3.7 Variables Measured	36
3.8 Data collection	37
3.9 Questionnaire Design	37
3.10 Data management and data storage.....	39

3.11 Data analysis.....	39
3.11.1 Descriptive statistics on all variables	39
3.11.2 Bivariate Analysis	39
3.11.3 Multivariate Analysis	40
3.12 Mechanism to ensure validity and reliability of study	40
3.13 Ethical Considerations.....	41
3.13.1. Ethical approval and permissions.....	41
3.13.2. Ethical principles supported by the study	42
3.14 Limitations of the study	42
3.15 Conclusion	43
4. RESULTS	44
4.1 Descriptive summary of predisposing factors	44
4.2 Descriptive summary of enabling factors	45
4.3 Descriptive summary of need factors	46
4.4 Descriptive summary of health seeking choices	47
4.5 Findings of bivariate analyses	48
4.5.1 Analyses of outcome variable ‘Preferred health care provider’	49
4.5.2 Analyses of outcome variable ‘action at first symptom for current condition’	50
4.5.3 Analyses of outcome variable ‘ever had Pap smear in relation to other condition’	52
4.5.4 Analyses of outcome variable ‘age of first Pap smear’	53
4.5.5 Analyses of outcome variable ‘ever referred for Pap smear’	55
4.5.6 Analyses of outcome variable ‘diagnosis made through routine Pap smear’	57
4.6 Multivariate analysis	58
4.7 Conclusion	60
5. DISCUSSION AND CONCLUSIONS	62
5.1 Introduction.....	62
5.2 Predisposing factors associated with the decision to seek care.....	62

5.3 Enabling factors associated with decision to seek care	64
5.4 Need factors associated with decision to seek care	66
5.5 Health service utilization characteristics of patients being treated for cervical cancer and analysis of factors associated with health seeking behaviour in women treated for cervical cancer.....	68
5.6 Future Research	70
5.7 Summary and Conclusion	70
REFERENCES	72
APPENDICES	79

LIST OF TABLES

Table 1.1: Incidence of cervical cancer in South Africa, Southern Africa and the World, in 2002..	11
Table 1.2: Mortality of cervical cancer in South Africa, Southern Africa and the World, in 2002....	11
Table 2.1 Summary statistics for cervical cancer, 1993 - 1995	19
Table 2.2 Staging system of cervical cancer	22
Table 4.1 Descriptive summary of predisposing factors	44
Table 4.1 (cont). Descriptive summary of predisposing factors.....	45
Table 4.2 Descriptive summary of enabling factors.....	45
Table 4.2 (cont). Descriptive summary of enabling factors	46
Table 4.3 Descriptive summary of need factors.....	46
Table 4.3 (cont). Descriptive summary of need factors	47
Table 4. 4 Descriptive summary of health seeking choices	47
Table 4. 4 (cont). Descriptive summary of health seeking choices	48
Table 4.5 Bivariate analyses of 'preferred health provider for general health' care tabulated with predisposing factors, enabling factors and need factors	49
Table 4.6 Bivariate analyses of 'action at first symptom for current condition' tabulated with predisposing factors, enabling factors and need factors	50
Table 4.6 (cont.) Bivariate analyses of 'action at first symptom for current condition' tabulated with predisposing factors, enabling factors and need factors	51
Table 4.7 Bivariate analyses of 'ever had Pap smear in relation to other condition' tabulated with predisposing factors, enabling factors and need factors	52
Table 4.7 (cont.) Bivariate analyses of 'ever had Pap smear in relation to other condition' tabulated with predisposing factors, enabling factors and need factors	53
Table 4.8 Bivariate analyses of 'age of first Pap smear' tabulated with predisposing factors, enabling factors and need factors	54
Table 4.9 Bivariate analyses of 'ever referred for Pap smear' tabulated with predisposing factors, enabling factors and need factors	55
Table 4.9 (cont.) Bivariate analyses of 'ever referred for Pap smear' tabulated with predisposing factors, enabling factors and need factors.....	56
Table 4.10 Bivariate analyses of 'diagnosed through routine Pap smear' tabulated with predisposing factors, enabling factors and need factors	57
Table 4.10 (cont.) Bivariate analyses of 'diagnosed through routine Pap smear' tabulated with predisposing factors, enabling factors and need factors	58
Table 4.11 Multivariate logistic regression predicting likelihood of outcome variable	59

LIST OF FIGURES

Figure 2.1 Management of cervical cancer (FIGO, 2005).	25
Figure 2.2 The Health Care Utilisation Model (Andersen, 1995).....	28
Figure 2.3 Expanded health utilization model (Meyer-Weitz et al., 2000).....	28

LIST OF APPENDICES

Appendix 1. 1 Postgraduate Education Committee Approval	79
Appendix 1. 2 Biomedical Research Ethics Approval.	80
Appendix 1. 3 Chief Executive Officer of Grey's Hospital Approval.	82
Appendix 1. 4 Department of Health's Research Approval.	83
Appendix 1. 5 Letter of permission.....	84
Appendix 1. 6 Information document	85
Appendix 1. 7 Informed Consent	86
Appendix 1. 8 Questionnaire to patient	87
Appendix 1. 9 Checklists	92

ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
CIN-	Cervical Intraepithelial Neoplasia
DOH	Department of Health
HIV	Human Immune Deficiency Virus
HPV	Human Papillomavirus
HSIL	High- grade squamous intra-epithelial lesions
LSIL	Low-grade squamous intra-epithelial lesions
PATH	Programme for Appropriate Technology in Health
SIL	Squamous Intraepithelial Lesions
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

DEFINITION OF TERMS

Adenocarcinoma: Invasive tumour with glandular and squamous elements intermingled (FIGO, 2005).

Carcinoma in situ (CIS): Cancerous cells are confined to the cervix and have not spread to other parts of the body (FIGO, 2005).

Cervical Intraepithelial Neoplasia (CIN) / Squamous Intraepithelial Lesions (SIL) - SIL and CIN are two commonly used terms to describe precancerous lesions or the abnormal growth of squamous cells observed in the cervix. SIL is an abnormal result derived from cervical cytological screening or Pap smear testing. CIN is a histological diagnosis made upon analysis of cervical tissue obtained by biopsy or surgical excision (FIGO, 2005).

High-grade cervical lesions: High-grade cervical lesions are defined by a large number of precancerous cells on the surface of the cervix that are distinctly different from normal cells. They have the potential to become cancerous cells and invade deeper tissues of the cervix (FIGO, 2005).

Low-grade cervical lesions (LSIL/CIN-1): Low-grade cervical lesions are defined by early changes in size, shape, and number of abnormal cells formed on the surface of the cervix and may be referred to as mild dysplasia, LSIL, or CIN-1 (FIGO, 2005).

1. BACKGROUND

1.1 INTRODUCTION

Cervical cancer is the third commonest cancer among women worldwide but not the leading cause of cancer deaths among women (Ferlay et al., 2010). According to the Programme for Appropriate Technology in Health (PATH), global statistics show that nearly half a million new cases of invasive cervical cancer are diagnosed each year. More than a quarter million women die of this disease annually, with the highest incidence and mortality rates being in developing countries (WHO, 2009). In South Africa a woman's risk of developing cervical cancer is one in 26. Each year 6 700 women develop cervical cancer while 3 700 die from the disease annually (Stevens, 2008).

Cervical cancer can be detected through early screening before it progresses to invasive cancer. In the early 1990s, one of the policies developed in South Africa focused on women's access to equitable healthcare and to ensure that all women had access to a Papanicolaou test (Pap smear). The 'three in a lifetime over 30' policy was developed because cervical cancer is believed to be a slow growing cancer and a Pap smear at the ages of 30, 40 and 50 was regarded as a way to manage this epidemic (DOH, 2000).

The national guidelines for cervical screening were introduced in South Africa in 2000, in order to reduce the incidence of carcinoma of the cervix. The primary aim of developing the guidelines was to detect and treat the pre-invasive stage of the disease, reduce the morbidity and mortality associated with cervical cancer and ultimately reduce the excessive expenditure of scarce health funds spent on the treatment of invasive cancer of the cervix (DOH, 2000).

The tables below give some figures on incidence and mortality of cervical cancer in South Africa, Southern Africa and in the World, for the year 2002 (WHO, 2009).

Table 1.1: Incidence of cervical cancer in South Africa, Southern Africa and the World, in 2002

Indicator	South Africa	Southern Africa	World
Crude incidence rate	30.2	30.2	16.0
Age-standardised incidence rate	37.5	38.2	16.2
Cumulative risk % ages 0-64 years	2.8	2.8	1.3
Standardised incidence ratio	226.0	229.0	100.0
Annual number of new cancer cases	6,742	7,698	493,243

Standardized rates have been estimated using the direct method and the World population as the reference. Rates per 100,000 women per year.

Table 1.2: Mortality of cervical cancer in South Africa, Southern Africa and the World, in 2002

Indicator	South Africa	Southern Africa	World
Crude mortality rate	16.5	17.5	8.9
Age- standardised mortality rate	21.0	22.6	9.0
Cumulative risk % ages 0-64 years	1.6	1.7	0.7
Standardised mortality ratio	234.0	252.0	100.0
Annual number of deaths	3,681	4,455	273,505

Standardized rates have been estimated using the direct method and the World population as the reference. Rates per 100,000 women per year.

From the tables above, the incidence rate of cervical cancer are higher in Southern Africa than the rest of the world (ASIR = 30.2 /100 000 and 16.2/100 000). Also Mortality rate is higher in Southern Africa when compared to the rest of the world (ASIR = 17.5 /100 000 and 8.9/100 000).

Various studies has been done in the area of cervical cancer, in 2005–06, 100% of primary health care clinics in South Africa had health professionals trained to conduct pap smears, yet the screening rate was only 1.3%, with many women admitted to oncology wards at such an advanced stage of disease that palliation was the only treatment option left (Denny, 2005).

Robin et al., (2007) found cervical cancer to be one of the most preventable cancers that affect women of all age groups, but the highest incidence is found among women aged 40-59 years. Human Papillomavirus (HPV) infection is a necessary factor in the development of nearly all cases of cervical cancer. The study by Waktola et al., (2005) found that cervical cancer generally takes many years to develop. Walker et al., (2002) found that most women with a diagnosis of cervical cancer have either not had regular Pap smear tests or have not been followed up after detection of an abnormal smear.

This study will look at the knowledge of women with regard to cervical cancer, the factors that inhibit early detection and routine pap smears and other risk factors associated with cervical cancer.

1.2 PROBLEM STATEMENT

The underlying factors inhibiting early detection of patients presenting with cervical cancer may comprise:

- Inadequacies in the type of health care choices or treatment action sought by women with symptoms of cervical cancer.
- Lack of information about early detection and recognition of the signs and symptoms of the disease, hence presenting in advanced stages.
- Various factors influence the decision to seek health care.

Programmes will be most effective if they are based on local assessments of:

- (a) The epidemiology of cervical cancer in the population;
- (b) Current management of cervical cancer in health care settings;
- (c) Health seeking behaviour in the population, i.e. what people do and where they go when they suspect they have a symptom (Isaac, 2005).

This study addresses the third of those assessments, utilising the Andersen-Newman Health Seeking Behaviour Model (Andersen, 1995) as an underlying conceptual framework.

1.3 SCOPE OF THE STUDY

This exploratory study aims to describe and analyse the health seeking behaviors of patients with cervical cancer and to explore the association between health seeking behavior and various explanatory variables.

The study is conducted in Grey's Hospital, located in Pietermaritzburg, in the Umgungundlovu Health District of KwaZulu-Natal. Grey's Hospital provides 20% regional and 80% tertiary services, and provides referral services to the western half of KwaZulu-Natal, covering 5 health districts. Results from this study will add to the knowledge required to understand the health seeking behaviors in the population.

1.4 RESEARCH AIM AND OBJECTIVES

The overall aim of this research is to determine the patterns of health seeking behaviour of women being treated for cervical cancer.

The specific objectives are to:

- Describe the health service utilization characteristics of patients being treated for cervical cancer.
- Describe the need factors associated with decision to seek care.
- Describe the enabling factors associated with decision to seek care.
- Describe the predisposing factor associated with the decision to seek care.
- Analyse factors associated with health seeking behavior in women treated for cervical cancer.

1.5 OVERVIEW OF RESEARCH REPORT

This chapter has presented the background of the study, the problem statement, the aim and objectives of the study, and the conceptual framework. Chapter two presents a review of the literature, covering the natural history of cervical cancer, the objectives of cervical screening programs, the burden of the disease worldwide and in South Africa, the presentation of the disease, risk factors and management of cervical cancer and the Health Seeking Behaviour Model in relation to screening and early detection of cervical cancer.

Chapter three describes the methodology employed in the study.

Chapter four present the findings of the study, while chapter five contains the discussion of the results, with concluding remarks and recommendations. The appendices present letters of permissions for the conduct of the study and the study instruments used for data collection.

2. LITERATURE REVIEW

2.1 INTRODUCTION

This chapter examines concepts that are related to the study and offers a literature review that applies to cervical cancer and health-seeking behaviour. Help-seeking is used in many different contexts. Help-seeking and seeking help are used interchangeably in the literature and often are discussed in the context of health-seeking behaviour. Theoretical literature that assists in understanding the concept of help-seeking will be explored.

The health-seeking behaviour of women with cervical cancer is presented in the context of the following issues:

- Natural history of cervical cancer
- The burden of disease
- Cervical screening
- Risk factors associated with cervical cancer
- Clinical presentation and management of cervical cancer
- Factors associated with decision to seek care
- A conceptual framework for health-seeking behavior

A Literature search was conducted of electronic databases (Science Direct, Google Scholar, Nexus, CINAHL®, EBSCO, and Pub Med) and electronic journals (The International Journal of Gynaecology and Obstetrics, Reproductive Health Journal, Journal of the American Medical Association, Research Updates and Nursing Update) using the following search terms: Cervical cancer statistics; Burden of disease; Cervical screening AND South Africa; Incidence of cervical cancer; Health behaviour model; Prevention and Management of cervical cancer, Decision to seek care, Age and cervical cancer, Knowledge of pap smear. The reference list at the end of identified literature was also used to identify further literature from the World Health Organisation and the South African Department

of Health. The search was limited to articles published in English from 1993 – 2009.

The referencing system used is the Harvard referencing system.

2.2 THE EPIDEMIOLOGY OF CERVICAL CANCER

Many studies have been done in the area of cervical cancer epidemiology. According to Robin et al., (2007), cervical cancer is malignant neoplasm of the cervix uteri or cervical area and referred to as one of the most common cancers in women both in South Africa and worldwide. It is also one of the most preventable. Cervical cancer affects women of all age groups, but the highest incidence is found among women aged 40-59 years. Human Papillomavirus (HPV) infection is a necessary factor in the development of nearly all cases of cervical cancer (*Ibid.*). Other important risk factors are increased parity, oral contraceptive use and immune-suppression.

Cervical cancer generally takes many years to develop (Waktola et al., 2005). The majority of women are likely to develop only mild dysplasia, which usually regresses, particularly among women under age 35. Invasive cervical cancer has prolonged, asymptomatic pre-invasive stages, which can be easily detected and treated accordingly. Indications of the pre-invasive stages are readily identified through cancer screening because it takes 10–15 years for pre-invasive stages to progress to invasive cancer (*Ibid.*).

2.3 BURDEN OF CERVICAL CANCER

According to a study conducted in 187 countries between 1980 and 2010, undertaking the annual age-specific assessments, global cervical cancer incidence increased from 378 000 (256 000-489 000) cases per year in 1980 to 454 000 (318 000-620 000) cases per year in 2010 a 0.6% annual rate of

increase. Cervical cancer death rates have been decreasing but the disease still killed 200 000 (139 000-276 000) women in 2010, of whom 46 000 (33 000-64 000) were aged 15 to 49 years in developing countries (Foreman et al., 2011).

2.3.1 IN THE DEVELOPED WORLD

In economically developed countries, cervical cancer is less common, especially where screening programmes have been in existence for several decades (Chirenje, 2005). Cervical cancer is ranked the 12th most common cancer diagnosed among women aged 20 to 34 and women 35 to 49, it ranks third in incidence. The age standardized incidence rates decreased by 50% over a period of 25 years and mortality rates by 73% over 50 years unlike in the lesser developed countries (Parkin et al., 2002).

2.3.2 IN THE DEVELOPING WORLD

According to Chirenje (2005), the highest incidence rates are observed in Latin America and the Caribbean, sub-Saharan Africa, and South and South East Asia, where cervical cancer is responsible for up to 22% of all new cases of cancer among women every year, equivalent to an age-standardized incidence of 31 per 100 000. Cervical cancer rates in Africa, especially in black females, are among the highest in the world (Denny, 2005). Incidence rates observed in South African black women in 1997 are similar to those reported in Kyadondo, Uganda, whilst those in South African Asian females compare with those in India. Furthermore 80 percent of women diagnosed or referred with cervical cancer in these countries have the disease in its advanced stage (*Ibid.*). Peltzer (2001) reports the age-standardized rates for East African countries as amongst the highest in the world and more than three times the rates in Europe and North America.

According to a study in Nigeria, 80% of cases present in Stage III with an incidence rate of 25/100,000. At the time of the study, there were 32 million women aged 15–64 years old in Nigeria.

If a one-time screen were to be conducted over a year, 8,000 new cases of invasive cervical cancer would be detected. The lack of effective screening programmes to detect precancerous conditions, are said to be the possible factors for the observed higher incidence rate of cervical cancer in developing countries (Peltzer, 2001).

2.3.3 IN SOUTH AFRICA

South Africa's cancer mortality review of deaths from 1949-1990 suggest that screening disproportionately benefited white women who are the population group at lowest risk of cervical cancer (Bailey et al., 1996). The annual number of deaths from cervical cancer in white women peaked in the late 1960s at 133, and then began a steady decline, reaching 102 in 1986-90.

Among 'Coloureds', however, there was a steady increase in annual deaths throughout the entire period under review from 55 in 1949-1955 to 219 in 1986-1990. Most of this increase occurred among Coloured women over 34 years of age. A similar increase, from 8 to 25 deaths/year, was recorded among Asian women during this period. Incidence rates for cervical cancer in black females are similar to rates found in the rest of Africa and in other developing countries, and rank amongst the highest in the world. Incidence rates for Whites are comparable to rates found in the UK or the USA (Bailey et al., 1996). Therefore the assumption is made that the decline in cervical cancer mortality among white women during this period coincided with the introduction of cytological screening in the mid-1960s.

Between 1993 and 1995, an average of 3387 new cases of cancer of the cervix was reported in South Africa (Statistical Notes, 2000). Deaths from cancer of the cervix were reported in 1994 by Statistics South Africa (StatsSA, 1994) to be

1,497. The crude incidence rate was 17/100 000 and the age standardized incidence rate was 22/100 000. Significant population differences exist between black and white females: the lifetime risk among black women was 1 in 34, whereas in white women 1 in 93, representing approximately a threefold difference. In Asian and coloured females the lifetime risk is 1 in 50. The table below illustrates the data:

Table 2.1 Summary statistics for cervical cancer, 1993 - 1995

	N	%	CRUDE	ASIR	CUM RISK	RISK
Asian	49	8.9	12.1	15	1.8	54
Black	2,140	31.2	17.8	26.5	3	34
Coloured	177	22.9	12.9	17.7	1.9	52
White	261	2.7	12.9	10.8	1.1	93
	3,387	14.8	16.6	22	2.4	41

N = Average 1993 - 1995; CRUDE = Crude incidence rate, per 100 000;

ASIR = Age standardized incidence rate, per 100 000; CUM RISK = Risk of developing a cancer in one's lifetime (0-74 years); RISK = Life risk as one x number of people.

Source: Statistical Notes, 2000

2.4 RISK FACTORS ASSOCIATED WITH CERVICAL CANCER

There are several risk factors for developing cervical cancer. The major risk factor is through HPV infection. According to Bosch (2005), HPV infection is primarily acquired through the early initiation of sexual intercourse, a history of multiple sexual partners and a history of sexual transmitted infections.

Early onset of sexual activity is thought to be associated with high risk for cervical cancer because, during puberty, cervical tissue undergoes a variety of changes that may make the area more vulnerable to damage.

Waktola et al., (2005) report that lower socio-economic status has been associated with a higher risk of developing cervical cancer, probably due to lack of access to good health care and Pap-smear tests. They also reveal that cigarette smoking increases the risk of cervical cancer, especially among long-term smokers. Smoking constituents have been found in cervical mucus.

It has also been found that most women with a diagnosis of cervical cancer have either not had regular Pap smear tests or have not been followed up after detection of an abnormal smear (Walker et al., 2002).

According to the study, not undergoing regular Pap tests is the greatest risk factor for a poor outcome in women who develop cervical cancer.

2.5 CERVICAL CANCER IN WOMEN LIVING WITH HIV

Many studies worldwide have shown a higher prevalence of cervical intraepithelial neoplasia (CIN) among women living with HIV than among women who test negative for the HIV virus. In one study, CIN was present in 19% of women living with HIV and only in 5% of the HIV-uninfected women (Duerr et al., 2001).

Silverberg and Abrams (2007) report that infection with HIV weakens the immune system and reduces the body's ability to fight infections that may lead to cancer. According to the study by Engels et al., (2008), people infected with HIV have a substantially higher risk of some types of cancer compared with uninfected people of the same age. Three of these cancers are known as “acquired immunodeficiency syndrome (AIDS)-defining cancers” or “AIDS-defining malignancies”: Kaposi sarcoma, non-Hodgkin lymphoma, and cervical cancer. The study found that people infected with HIV are at least five times more likely to be diagnosed with cervical cancer.

Massad, et al., (2008) report that people infected with HIV are also infected with other viruses that cause certain cancers like the Human Papillomavirus (HPV) which causes cervical cancer. The study found that infection with HPV is more common among people infected with HIV than among uninfected people.

A more recent study conducted on the utilisation and outcomes of cervical cancer prevention services among HIV-infected women in Cape Town, South Africa,

also showed a high prevalence and incidence of pre-cancerous cervical lesions in women infected with HIV. The study showed that women with lower CD4 counts were more likely to have abnormal Pap smears (Batra et al., 2010).

2.6 CLINICAL PRESENTATION

The starting point for most health seeking behaviour is recognition of symptoms. Cervical cancer may be asymptomatic, mildly symptomatic or highly symptomatic.

Symptoms that may occur include: continuous vaginal discharge, which may be pale, watery, pink, brown, bloody, foul-smelling; abnormal vaginal bleeding between periods, after intercourse or after menopause; periods become heavier and last longer than usual. Symptoms of advanced cervical cancer may include: pelvic pain, heavy bleeding from the vagina and leaking of urine or faeces from the vagina (Chiu, et al., 2005).

2.7 STAGE CHARACTERISTICS

Fayed (2008) identified cervical cancer as having five different categories in its staging system. The system used in the study was referred to as the "FIGO" system (International Federation of Gynaecology and Obstetrics). The staging system begins at 0 and ends at IV, with 0 meaning the very early stages of cancer, while IV being advanced.

See table on the next page for an illustration of the stages.

Table 2.2 Staging system of cervical cancer

0	Carcinoma in situ, intraepithelial neoplasia.
I	Carcinoma strictly confined to the cervix.
Ia	Invasive cancer identified only microscopically. All gross lesions, even with superficial invasion, are stage Ib cancers. Invasion is limited to measured invasion of stroma ≤ 5 mm in depth and ≤ 7 mm in width.
Ia1	Measured invasion of stroma ≤ 3 mm in depth and ≤ 7 mm in width.
Ia2	Measured invasion of stroma > 3 mm and ≤ 5 mm in depth and ≤ 7 mm in width.
Ib	Clinical lesions confined to the cervix or preclinical lesions greater than Ia.
Ib1	Clinical lesions ≤ 4 cm in size.
Ib2	Clinical lesions > 4 cm in size.
II	Carcinoma extends beyond the cervix but not to the pelvic wall; carcinoma involves the vagina but not as far as the lower one third.
IIa	No obvious parametrical involvement.
IIb	Obvious parametrical involvement.
III	Carcinoma has extended to the pelvic wall; on rectal examination no cancer-free space is found between the tumour and the pelvic wall; the tumour involves the lower one third of the vagina; all cases with a hydronephrosis or non-functioning kidney should be included, unless they are known to be related to another cause.
IIIa	No extension to the pelvic wall, but involvement of the lower one third of the vagina.
IIIb	Extension to the pelvic wall and hydronephrosis or non-functioning kidney, or both.
IV	Carcinoma has extended beyond the true pelvis or has clinically involved the mucosa of the bladder or rectum.
IVa	Spread to adjacent organs.
IVb	Spread to distant organs.

Source: International Federation of Gynaecologists and Obstetricians, 2005

2.8 PREVENTION AND MANAGEMENT OF CERVICAL CANCER

2.8.1 PREVENTION PERSPECTIVE

Prevention falls into two main categories - primary and secondary prevention. These are described in terms of avoiding the development of cervical cancer. Primary prevention involves behavioral choices a woman can make on her own without outside treatment or testing done by a healthcare worker to minimise the risk of cervical cancer. The Department of Health suggests five different forms of primary prevention that women should practice in their own lives to reduce the probability of acquiring cervical cancer. They are as follows: stop smoking, use of barrier methods during intercourse to prevent the spread of HPV and other

sexually transmitted Infections (STIs), postpone sexual activity to an older age, effectively manage STI, HPV vaccination and decrease parity (DOH, 2000). Evidence also indicates that limiting one's use of oral contraceptives may also be a possible form of primary prevention (*Ibid*).

Secondary prevention involves a screening test which can detect pre-cancerous cells of the cervix so that a woman may be treated before she actually develops cervical cancer. Secondary prevention is aimed at the detection and treatment of precursors. Modelling data from South Africa suggests that even screening women just once in their lives, at age 35 could reduce cervical cancer mortality by 26 percent (Miller, 2006). Pillay (2002) identified that in South Africa, there are problems with current cervical screening uptake, including low coverage and loss of screened women to follow-up.

As cited by Robin et al., (2007), cervical screening can identify potentially precancerous changes. The most common screening method, which involves cervical cytology, is the Papanicolaou test, also called Pap smear, Pap test, cervical smear, or smear test. The Papanicolaou smear is a screening test used to detect premalignant and malignant processes in the ectocervix.

The Pap smear could help detect significant changes which can be treated, thus preventing progression to invasive cervical cancer.

According to the South African National Guidelines on Cervical Cancer Screening (DOH, 2000), the objectives of screening are to reduce the incidence of carcinoma of the cervix, primarily by detecting and treating the pre-invasive stage of the disease, and to reduce the morbidity and mortality associated with cervical cancer. The guideline also reveal that the target population for screening in South Africa are women 30 years and older and the health service delivery target is at primary level health-care facilities.). DOH (2000) has proposed that women at age 70 and older with an intact cervix, who have had three or more documented, consecutive, technically satisfactory negative cervical cytology

tests, and no abnormal or positive cytology test within the 10 year period prior to age 70, could elect to cease cervical cancer screening.

According to the National Comprehensive Cancer Network, cervical cancer screening should begin approximately three years after the onset of vaginal intercourse and begin no later than 21 years of age (Walker et al., 2002)

In South Africa, according to a study by Fonn, et al. (2002) investigating age-specific prevalence rates of cancer of the cervix in women presenting for screening, it was found that 80% of the sample had never had a Pap smear before, and just over 91% had not had a Pap smear in the last 5 years. A population of 468 women were screened and 11 (2.42%) were found to have low-grade squamous intra-epithelial lesions (LSIL), with an average age of 33.1 years; 366 (1.8%) had high-grade SIL (HSIL) and were statistically significantly older at 37.97 years of age; and 92 (0.47%) were found to have cytologically diagnosed invasive cancer, and were significantly older, with an average age of 51.3 years. A clear relationship was found between age and LSIL, with younger women having a high rate of LSIL which decreases with increasing age.

Although much progress has been made in reducing mortality rates and improving survival through screening programmes, cancer still accounts for more deaths in people younger than 85 years worldwide (Jemal et al., 2008). Early detection can improve patient outcomes in terms of survival rates and more effective treatments (American Cancer Society, 2000; Campo, Comber, & Gavin, 2004). In the case of self-discovered cancer symptoms, early detection depends on patients promptly seeking help from a healthcare professional. Conversely, evidence shows that many women delay help seeking for self-discovered cancer symptoms (Bish et al., 2005).

According to Moodley (2006) women in South Africa have shown that having had a Pap smear significantly reduces the risk of cervical cancer when compared with

women who had never had the test. The author also found that, in those who had ever had a test, the odds of cancer were 70% lower. The reduction in risk decreased to 60% once 10 years had passed since the last Pap smear, and to 50% after 15 years. The protective effect increased from 60% for one smear to 80% for two or more. In light of the result of the study, Pap smear was found to be an effective measure to reduce the high incidence of cervical cancer among South African women. It was estimated that if all women had been screened, 70% of cases of cervical cancer would have been prevented.

2.8.2 CURATIVE PERSPECTIVE

The curative aspect of the treatment to cervical cancer refers to therapies and treatments provided to the women with the intent to improve symptoms and cure the disease. The diagram below depicts the management of cancer as illustrated by the International Federation of Gynaecologists and Obstetricians (FIGO) in 2005.

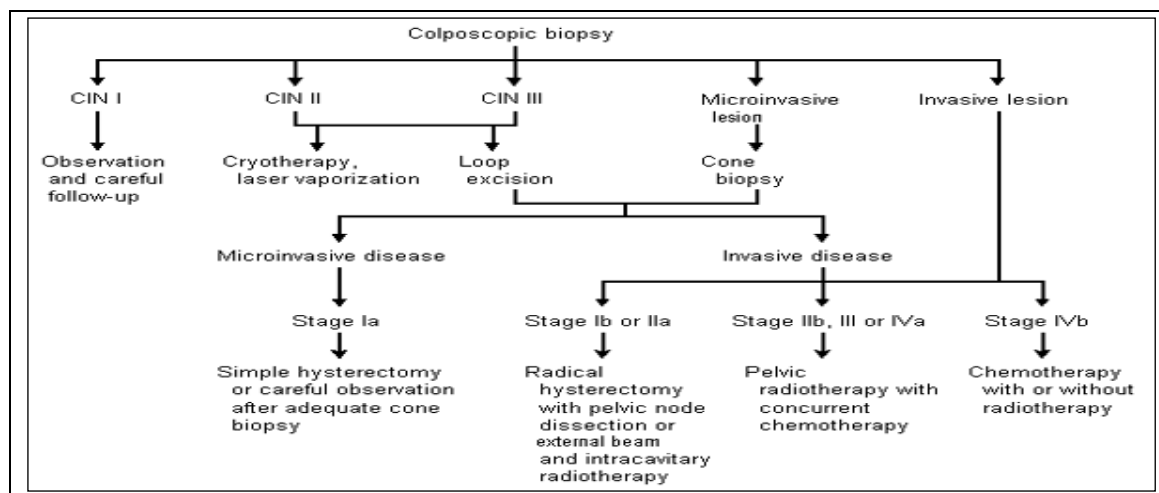


Figure 2.1 Management of cervical cancer (FIGO, 2005).

Surgery: Simple hysterectomy is used to treat stages 0 and IA cervical cancers. Usually only the uterus is removed, although occasionally the fallopian tubes and ovaries are removed as well. In a radical hysterectomy, the uterus and adjoining

tissues, including the ovaries, the upper region of the vagina near the cervix, and the pelvic lymph nodes, are all removed. These operations are used to treat stages IA2, IB, and IIA cervical cancers, particularly in young women. Following a hysterectomy, the tissue is examined to see if the cancer has spread and requires additional radiation treatment (Omigbodun, et al., 2005; Fayed, 2008).

Radiation: Radiation therapy which involves the use of high-dosage rays or other high-energy waves to kill cancer cells, often is used for treating stages IB, IIA, and IIB cervical cancers, or in combination with surgery. With external-beam radiation therapy, the rays are focused on the pelvic area from a source outside the body. With implant or internal radiation therapy, a pellet of radioactive material is placed internally, near the tumour. Alternatively, thin needles may be used to insert the radioactive material directly into the tumour (Fayed, 2008).

Chemotherapy: This involves the use of one or more drugs to kill cancer cells; it is used to treat disease that has spread beyond the cervix. Most often it is used following surgery or radiation treatment. Stages IIB, III, IV, and recurrent cervical cancers usually are treated with a combination of external and internal radiation and chemotherapy (Fayed, 2008).

Alternative treatment: Biological therapy sometimes is used to treat cervical cancer, either alone or in combination with chemotherapy. Treatment with the immune-system protein interferon is used to boost the immune response. Biological therapy can cause temporary flu-like symptoms and other side effects. Some research suggests that vitamin A (carotene) may help to prevent or stop cancerous changes in cells such as those on the surface of the cervix. Other studies suggest that vitamins C and E may reduce the risk of cervical cancer (Fayed, 2008).

2.8.3 PROGNOSIS

The prognosis of cervical cancer depends on the stage. The American Cancer Society (2000) suggests that with treatment, the 5-year relative survival rate for

the earliest stage of invasive cervical cancer is 92% and the overall (all stages combined) 5-year survival rate is about 72%. Recurrent cervical cancer detected at its earliest stages might be successfully treated with surgery, radiation, chemotherapy, or a combination of the three. Thirty-five percent of patients with invasive cervical cancer have persistent or recurrent disease after treatment.

2.9 HEALTH SEEKING BEHAVIOUR

Health seeking behaviour is part of a wider concept, health behaviour. Health behaviour includes all those behaviours associated with establishing and retaining a healthy state. While little has been written specifically on health behaviour in relation to cervical cancer, there is an extensive literature on health behaviour in general. This brief review will focus on models of health behaviour in order to suggest a simple model for approaching cervical cancer health behaviour in this study.

In public health, the most utilised models from social psychology are the Health Belief Model, the Theory of Reasoned Action and its later development to the Theory of Planned Behaviour. Most known from medical sociology and medical anthropology are, respectively, the Health Care Utilization or Socio-Behavioural Model by Andersen. All models contain associations of variables which are considered relevant for explaining or predicting health-seeking behaviours (Sheeran & Abraham, 1995; Conner & Sparks, 1995; Andersen & Newman, 1997; Kroeger, 1993).

The socio-behavioural or Andersen model (Andersen & Newman, 1997) groups, in logical sequence, three clusters or categories of factors i.e. predisposing, enabling and need factors - which can influence health behaviour (Andersen, 1995). Later versions have extended the model to include other health care sectors, i.e. traditional medicine and domestic treatments (Meyer-Weitz et al., 2000).

The model assumes that health seeking behaviour is the result of interaction between characteristics of individuals, population and the surrounding environment. A diagrammatic representation of the health care utilisation model is depicted below:

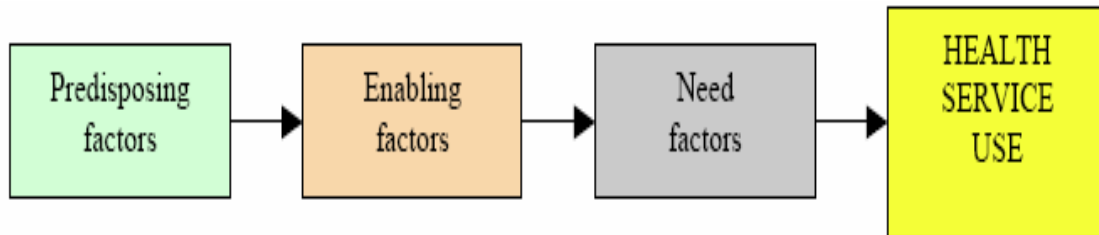


Figure 2.2 The Health Care Utilisation Model (Andersen, 1995)

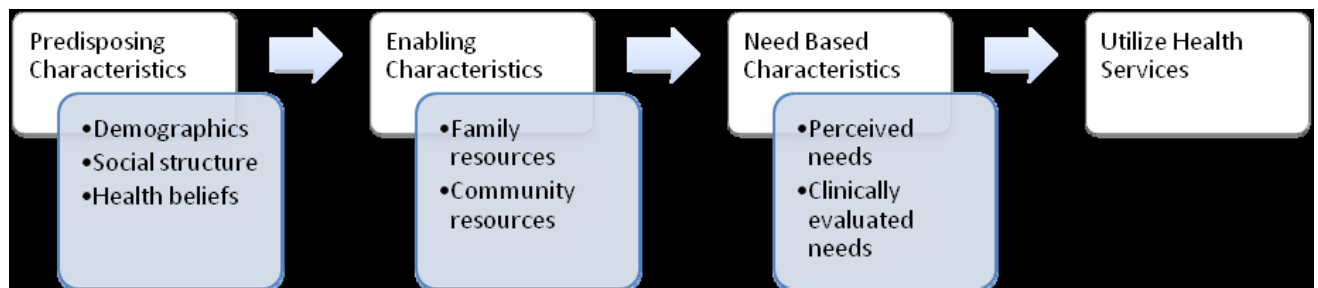


Figure 2.3 Expanded health utilization model (Meyer-Weitz et al., 2000)

The concepts illustrated in the model are explained below:

- Predisposing characteristics include age, religion, marital status, status in the household, educational level, employment, prior experience to illness, health belief, knowledge of the care delivery system and illness which are often influenced by cultural values.
- Enabling resources refer to attributes specific to the individual or the community e.g. income, cost, access to regular source of care, availability of services, health insurance, social network support.
- Need variables reflect illness levels that require the use of services. Needs can be perceived by the individual and are influenced by cultural beliefs and values (e.g. perceived health status, disease severity, limitation of activity which could be total number of sick days for a reported illness, total number of days in bed and or days missed from work).

- Health service use involves treatment actions: home remedies (herbal, pharmaceuticals), pharmacy, over the counter drugs from shops, traditional healers, private medical facilities, public health services or private health facilities.

All the factors included in the model above are "explanatory variables" and can interact, leading to differences in individual health behaviour for different conditions and on different occasions.

The important issues pertaining to health service utilisation in relation to cervical cancer include: the recognition of symptoms; the perception of cervical cancer symptoms and the threat of disease; the extent to which women avail themselves for screening programs; treatment resources: and if physical proximity, monetary costs of taking action, time, effort, and beliefs in the efficiency of recommended health care itself influences their health seeking behaviour.

2.9.1 FACTORS INFLUENCING HEALTH SEEKING BEHAVIOUR

Kang et al., (2009) reached consensus that the factors associated with health seeking behaviour included the impact of disease on the quality of life, lack of embarrassment in talking about symptoms, and attitudes toward healthcare use. De Nooijer et al., (2001) identified lack of knowledge, social support, and interpretation of symptoms, fear, age, socioeconomic status and gender as issues influencing health seeking behaviour.

There are several reasons for late presentation, namely: ignorance about symptoms; fatalistic attitude; readiness to attribute to cancerous disease to supernatural causes; and low coverage of the population by health care services especially in rural areas (Kang, et al., 2009).

2.9.2 KNOWLEDGE AND HEALTH SEEKING BEHAVIOUR

Lack of knowledge has an impact on health seeking behaviour of women presenting with cervical cancer. The international literature suggests that the level of knowledge is an important factor prompting both participation and repeat participation in a range of cultural groups in screening programmes. This lack of knowledge has been shown to limit choices in health seeking behaviour (Lee, 2000).

2.9.3 RECOGNITION OF SYMPTOM AND HEALTH SEEKING BEHAVIOUR

In a study by Hopkinson et al., (2006), it was reported that individuals failed to recognise symptoms experienced over many months prior to their diagnosis as serious regardless of their disease stage and their social background. Symptoms were generally attributed to everyday cause and not taken as an indication of ill-health.

According to Omigbodun et al., (2005), the most common symptoms related by Nigerian women were lower abdominal pain, and a complex of severe lower abdominal pain with vaginal discharge, itching, and irregular dark or smelling menses. The latter was considered by the women to be due to promiscuity. The treatment reported was herbs in the first instance and then, if ineffective, western drugs such as antibiotics were sought. The study (*Ibid*) also found that the severity and frequency of symptoms are important factors in determining health-seeking behaviour.

2.9.4 AGE AND HEALTH SEEKING BEHAVIOUR

According to Holoroyd et al., (2004), older women do not consider themselves as being at risk of cervical cancer because of their perception that being no longer sexually active did not put them at risk of cervical cancer. This was compounded by a lack of knowledge of the risk factors associated with cervical cancer. Elderly women above 65 years were significantly less likely to have ever had a pap

smear than younger women. For younger women, being in poor health increased the odds of Pap smear screening, while for elderly women, being in good health increased the odds of screening.

2.9.5 SOCIO ECONOMIC STATUS AND HEALTH SEEKING BEHAVIOUR

A study from India showed that disease severity and economic status predict whether medical care is sought. Most studies on health seeking behaviour carried out in other populations have identified economic status as the primary predictor of health service utilisation (Pillai, et al., 2003).

A study by O'Malley et al. (2006) examined whether patients with medical/health insurance benefits are more likely to be diagnosed with late-stage cervical cancer than women not enrolled in medical aid. In the study, women intermittently enrolled in medical aid or not enrolled at the time of their diagnosis were at greatest risk of a late-stage diagnosis, suggesting that more outreach to at-risk women is needed to ensure access to screening services.

Pillai et al. (2006) agreed that economic status was one of the primary predictors of health seeking behaviour in accessing health care.

2.9.6 ALTERNATIVE MEDICINE

There are many reasons why users prefer alternative medicines. In a study conducted by Astin (1998), it was found that beside being more educated and reporting poorer health status, the majority of alternative medicine users appear to be doing so, not so much as a result of being dissatisfied with conventional medicine, but largely because they find these health care alternatives to be more congruent with their own values, beliefs, and philosophical orientations toward health and life.

In addition, other researchers argued that users of herbs or supplements are more likely to engage in healthy behaviours and appear to be a more health-conscious group. Income was also found to be another significant discriminator affecting the use of complementary medicine but did not predict initial or continued complementary medicine use (Sirois & Gick, 2002).

The relationship of traditional to modern medicine is crucial in cervical cancer control, as attitudes towards traditional medicine will also have an impact on control programmes (Meyer-Weitz et al., 2000).

2.10 CONCLUSION

This chapter has provided an overview of the existing literature on cervical cancer and factors determining health seeking behaviour by women with cervical cancer. It looked at the epidemiology of cervical cancer and risk factors associated with cervical cancer and also in respect to the HIV epidemic. The burden of disease was established looking at the clinical presentation, prevention and management. In addition, this chapter has presented the rationale for prompt health seeking, providing evidence that early detection of cervical cancer is very important in the disease progression. Furthermore, it presented the factors that affect prompt health seeking and the type of health seeking. Finally, a conceptual framework for understanding health seeking behaviour was discussed.

This study is designed to determine the type of health seeking behaviour sought amongst women presenting with cervical cancer at Grey's hospital. The decision to seek health care may be influenced by various factors; there may be inadequacies in the type of health care choices or treatment action sought amongst these women or they may be uninformed about early detection and recognition of the signs and symptoms of the disease, hence presenting in advanced stages. The following chapter presents the methodology use in the

study to establish the factors influencing health seeking choices amongst women with cervical cancer at Grey's Hospital in KwaZulu-Natal.

3. RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter describes the methodology used to assess the health seeking behaviour of women admitted for radiotherapy at Grey's Hospital, Pietermaritzburg, KwaZulu-Natal and to determine factors influencing the behaviour. The chapter presents the study design, the study setting, the study period, the study population, the variables measured in the study, the data collection procedures and instruments, the measures taken to ensure study validity, data management and storage processes, data analysis, and the ethical considerations in this study. Finally, the study limitations are discussed.

3.2 STUDY SETTING

The study was conducted in the Oncology Department of Grey's Hospital, which is a referral hospital located in Pietermaritzburg in the Umgungundlovu Health District in KwaZulu-Natal. Grey's Hospital provides 20% secondary level services, and 80% tertiary level services. The tertiary level referral services are offered to the Western part of KwaZulu-Natal. This includes five health districts with a total population of 3.5 million. Grey's Hospital is a 530-bedded hospital and patients are referred to this hospital from the Umgungundlovu, Umzinyathi, Zululand, Uthukela and Amajuba Health District, comprises seven local authority areas (KZNhealth, 2009). Cervical cancer patients staged from stages IIB would usually be referred to this hospital for further management.

3.3 STUDY DESIGN

An observational study with a descriptive and analytic component was undertaken. This type of design enables the quantification of the problem regarding the health seeking behavior of patients with cervical cancer and then to

explain the situation by looking at the association between the health seeking behavior and various explanatory variables (Leedy & Ormond, 2005).

3.4 STUDY PERIOD

The protocol of the study was submitted to the Postgraduate Education Committee (Ref: PG02/07) and full approval was granted on the 5th June 2009 (Appendix 1.1). The protocol was also submitted to the University's Biomedical Research Ethics Committee (BREC) (Ref: BF 080/08) and full ethical approval was obtained on the 14th May 2009 (Appendix 1.2). Furthermore, the protocol was submitted to the Provincial Department of Health's Research Management Division (Ref: HRKM038/09) and permission for the study to proceed was received on 7th April 2009 (Appendix 1.3), subsequent to obtaining full ethical approval from BREC. Permission to undertake the study in Grey's Hospital was sought from the Hospital Manager and this was obtained on 24th March 2009 (Appendix 1.4).

Data were collected from 1st June to 3rd August 2009.

3.5 STUDY POPULATION

The study (target) population was all women over 18 years of age, receiving treatment for cervical cancer at Grey's Hospital in 2009. No sampling was done.

All cervical patients receiving treatment were eligible to participate in the study as the treatment duration is usually for 6 weeks.

3.6 STUDY SAMPLING STRATEGY AND SAMPLE SIZE

All patients treated for cervical cancer within the study period, June to August 2009, who provided informed consent for their participation in the study, were

enrolled. The total number included in the study was 109 and these were determined to be sufficient for the study, as discussed with the statistician. Only two patients were excluded due to their poor health status, which did not enable them to consent to participating in the study.

3.7 VARIABLES MEASURED

According to the stated objectives, data was collected on predisposing characteristics, enabling factors, need factors and health care utilization.

The predisposing characteristics included age, marital status, status in the household, household size and educational level. Questions were asked on factors that reflect illness levels, i.e., perceived health status, disease severity, recognition of symptoms, and knowledge of disease.

To describe the enabling factors associated with the decision to seek care, data was collected on resources available to the individual e.g. income, access to regular source of care, financial resources to purchase services, and social support.

To describe the need factors associated with decision to seek care data were collected on knowledge of cervical cancer and its causes, knowledge about Pap smear, understanding Pap screening and diagnosis and also the recognition of symptoms of cervical cancer including the perceptions of their state of health.

To describe the characteristics of patients being treated for cervical cancer, data were collected on treatment actions and health care utilisation. For example, home remedies (herbal, over-the-counter pharmaceuticals), traditional healers, private medical facilities and/or public health services.

3.8 DATA COLLECTION

Data were collected over a period of 9 weeks. Patients were accessed from the Oncology Department and each interviewed individually by the researcher and two research assistants.

An interviewer-administered questionnaire, containing both closed- and open-ended questions was utilized (see Appendix 1.8). The personal contact facilitated responses and quality information and also enabled respondents with low literacy levels to participate in the study. In the development of the questionnaires, questions were developed for each category in the conceptual framework. Questions were translated from English into isiZulu for isiZulu speaking participants and back-translated to English by reliable language experts.

Clinical notes were used to ascertain the correct clinical diagnosis and the stage of cervical cancer as documented by a medical officer. A checklist was used in reviewing the clinical notes (see Appendix 1.9).

3.9 QUESTIONNAIRE DESIGN

A structured questionnaire was selected to collect data. The questionnaire was developed using information from the literature reported in Chapter 2, engaging the problem statement and research questions that emanated from the literature review.

Demographic data: Questions 1 to 5 explored personal information of respondents in terms of their age, racial group, residential areas, marital status, educational level, the location of respondents and religion.

Socio economic status: Questions 6 and 7 looked at the employment status of respondents and categorised respondents by household income.

Household population and decision to seek health care: Questions 8 and 9 ascertained the number of people in respondents' households and who makes the decision to seek health care in the family.

General use of health care facilities: Questions 10 and 11 assessed if respondents have access to health care, the type of health care accessed, and if any barriers are encountered in accessing health care.

Knowledge of cervical cancer and its causes: Question 12 and 13 measured the extent to which respondents are knowledgeable of cervical cancer.

Knowledge about Pap smears: Respondents' knowledge about Pap smears was explored in Questions 14 to 17.

Understanding screening and diagnosis: Questions 18 and 19 were used to assess if respondents' diagnosis was made through the routine cervical screening program and if they understood their diagnosis and health condition.

Recognition of symptoms of cervical cancer and perceptions of state of health: Question 20 and 21 ascertained respondents' ability to recognise the symptoms of cervical cancer and respondents' perception of their general state of health.

Health seeking and factors affecting health service utilization: Question 22 and 23 determined what respondents did when they first noticed symptoms and what support system is available to them since their diagnosis.

Stage of Cancer: Question 24 and 25 reported on the stage of cancer of respondents and HIV status as recorded by the oncologist at time of presentation.

3.10 DATA MANAGEMENT AND DATA STORAGE

Double data entry was performed by the researcher, using Microsoft Excel and the Statistical Package for the Social Sciences® (SPSS) version 15.0. No discrepancies between data were noted. Epical 2000 was used to calculate odd ratios from the pre-tabulated data.

Data were stored on a personal computer, using a password to prevent unauthorized access.

Back-up copies of the data were saved on a personal flash disc and were also password protected to maintain security. The paper tools were kept safely in a personal case. Data will be kept in a safe place until the results of the study are published.

3.11 DATA ANALYSIS

The data were analysed using SPSS version 15.0. Data were analysed quantitatively. The descriptive and analytical analyses performed are described below.

3.11.1 DESCRIPTIVE STATISTICS ON ALL VARIABLES

Descriptive statistics provided a descriptive summary of the sample and the variables measured. The variables were categorical, and was summarised through the use of frequency distributions. Summaries are presented in tables.

3.11.2 BIVARIATE ANALYSIS

Bivariate analyses were implemented to detect associations between outcome and independent variables. The outcome variables were converted to categorical binary variables in order to conduct the bivariate analyses.

Various outcome variables that were identified include: Preferred health provider for general health care; Action at first symptom for current condition; Ever had a Pap smear in relation to other condition; Age of first Pap smear; Ever referred for Pap smear; and Diagnosed for cervical cancer through routine Pap smear.

The independent variables were drawn from the predisposing, enabling and need factors by grouping similar categories. The data were converted to binary categorical variable, summarized in two-by-two tables and the odds ratio, *p*-value and Pearson Chi square were calculated.

Pearson Chi square tests were used to explore the relationship between two categorical variables. The Odds ratio was also used as a measure of risk to compare whether the probability of a variable is the same for the outcome variables.

3.11.3 MULTIVARIATE ANALYSIS

Regression analysis was performed with the independent variables found to have a statistically significant association to the outcome variables in the bivariate analysis. Regression analysis includes techniques for modelling and analyzing several variables, when the focus is on the relationship between a dependent variable and one or more independent variables. Regression analysis helps to understand how the typical value of the dependent variable changes when any one of the independent variables is varied, while the other independent variables are held fixed (Freedman, 2005).

3.12 MECHANISM TO ENSURE VALIDITY AND RELIABILITY OF STUDY

This section deals with the potential biases in this study and how they were controlled for.

- **Information bias:** This might have been introduced in the data collection stage. The data was not collected by same person. The interpretation of the

question may have become distorted. Some patient records may have been incomplete and some information may have been missing. All patients interviewed may not have been representative of all women with cervical cancer in the districts; this would not have given the real picture of the study.

How controlled for: to control for information bias, the researcher and research assistants went over the questionnaire before they were administered in order to ascertain what each question was meant to collect. The questionnaire was also translated from English to isiZulu and back translating was done in order to deal with the language barrier and possible confusion.

- **Selection bias:** This could have been introduced in the study design phase.

How controlled for: Patients were selected because they were readily available at the time of study. The study population was all women over 18 years of age, receiving treatment for cervical cancer in the Oncology Department of Grey's Hospital at the time of data collection. Therefore this included all patients enrolled for treatment in the period of study.

- **Management bias:** Errors may occur in the study analysis phase, when data is manually captured from questionnaires and tests.

How controlled for: To control for management bias, all data were stored, captured and analysed in similar ways. Data were double entered in Excel and the Statistical Package for the Social Sciences® (SPSS) to control for capturing errors.

3.13 ETHICAL CONSIDERATIONS.

3.13.1. ETHICAL APPROVAL AND PERMISSIONS

All the necessary approvals and permissions were obtained (see section 3.5).

3.13.2. ETHICAL PRINCIPLES SUPPORTED BY THE STUDY

To ensure good quality research, the following ethical principles were observed in the design of the study protocol and its implementation:

- **Confidentiality and anonymity** was maintained by assigning a numerical code number to each questionnaire administered. Participants were interviewed in a separate consulting room to maintain privacy and confidentiality. No record was kept of the records reviewed.
- **Principle of autonomy:** all necessary information pertaining to the research was made available and discussed with the hospital manager, staff and patients. A written informed consent was obtained from each subject in the language they understood.
- **Principal of beneficence:** no overt harm was inherent in the design of the study. The research was designed with the intent of determining the health seeking behaviour of patients with cervical cancer. Revealing inadequate early health seeking may carry unintended negative consequences. The feedback to the hospital and department will include identifying opportunities for health promotion and community awareness on early symptoms recognition.
- **Obligation to feedback:** the results of the study will be fed back to the hospital on completion of the study

3.14 LIMITATIONS OF THE STUDY

Due to the inability to access a wider population because of cost and time constraints, the sample was drawn from that part of the population which is close to hand. Patients were selected because they were readily available at the time of study. Using such a sampling strategy results in not being able to make generalizations about the total population because it may not be representative enough. This may have affected the internal validity of the study. It is not possible to determine to what degree the patients in the sample are representative of all patients with cervical cancer in the all five districts.

For the purpose of this study, the study population comprised all women over 18 years of age, receiving treatment for cervical cancer in the Oncology Department of Grey's Hospital and also mainly patients who are at the end stage of the disease. Like many other studies, the ability to survey a comprehensive sample of the population has its limitations therefore the information only revealed the view of patients in a part of the province who are referred to Grey's Hospital. It is possible that demographics have an effect on the results.

Moreover given logistical and budgetary limitation, this study cannot be considered as representative of all patients in the KwaZulu-Natal Province.

There was a national medical practitioner strike during the period of study. This might also have affected the attendance of the women in the oncology unit.

3.15 CONCLUSION

This section described the methodology used in this study. It stated the study site, the study design, the study period, the study population and sampling. It went on to describe the variables measured in the study, the data collection procedures and instruments, the measures taken to ensure study validity, data management and storage processes, data analysis, and the ethical considerations in this study. Finally, it discussed the study limitations.

4. RESULTS

This chapter presents the results of the study according to the study objectives. The main aim of the study was to determine the health seeking behaviours of women with cervical cancer admitted for radiotherapy at Grey's Hospital, Pietermaritzburg, KwaZulu-Natal, with the following objectives:

1. Describe predisposing factors associated with the decision to seek care.
2. Describe enabling factors associated with decision to seek care.
3. Describe need factors associated with decision to seek care.
4. Describe health service utilization characteristics of patients being treated for cervical cancer.
5. Analyse factors associated with health seeking behavior in women treated for cervical cancer.

The results obtained are presented in the form of descriptive summary of the different factors, bivariate analyses and multivariate analyses.

4.1 DESCRIPTIVE SUMMARY OF PREDISPOSING FACTORS

Predisposing factors are factors that make respondents susceptible to the outcome of interest. Table 4.1 presents data on age, marital status, educational level, household size, and household decision maker.

Table 4.1 Descriptive summary of predisposing factors

Items		Frequency N=109	Percentage
Age category (in years)	21-30	8	7.3
	31-40	22	20.2
	41-50	28	25.7
	51-60	39	35.8
	60 and above	12	11.0
Marital status	Single	52	47.7
	Widowed	19	17.4
	Married	38	34.9

Table 4.1 (cont). Descriptive summary of predisposing factors

Items		Frequency N=109	Percentage
Educational level	None	32	29.4
	Primary	44	40.4
	Secondary	30	27.5
	Graduate	3	2.8
Number of people in the household	1-4	41	37.6
	5-8	52	47.7
	9 and above	16	14.7
Decision maker	Self	49	45.0
	Husband	24	22.0
	Parents/in law	15	13.8
	Other	21	19.3

The major findings are that the age distribution of the women is between 30 to 60 years of age, most women were not married, almost half of them have only primary school education and the average number of people dwelling in each household is between five and eight. Almost half of the women made their own decision in respect of the seeking care.

4.2 DESCRIPTIVE SUMMARY OF ENABLING FACTORS

Enabling factors refer to attributes specific to the individual. Enabling factors provide the means or opportunity for an individual to seek health care. Data was collected on employment status, barriers to accessing regular health care, and social support for medical treatment. Table 4.2 presents descriptive data on enabling factors identified as associated with the decision to seek care.

Table 4.2 Descriptive summary of enabling factors

Items		Frequency N=109	Percentage
Employment status	Full time	10	9.2
	Part time	5	4.6
	Casual	24	22
	Unemployed	58	53.2
	Self employed	12	11.0

Table 4.2 (cont). Descriptive summary of enabling factors

Items		Frequency N=109	Percent age
Barrier to accessing regular health care	Cost	26	23.9
	Distance	9	8.3
	Transport	4	3.7
	Attitude health workers	8	7.3
	No barrier	62	56.9
Social support for medical treatment	Yes	103	94.5
	No	6	5.5

Most women are unemployed. However the majority of women reported no barrier to accessing regular healthcare, while a majority also reported having social support for medical treatment.

4.3 DESCRIPTIVE SUMMARY OF NEED FACTORS

Need factors reflect perceived illness levels that are thought to require the use of health services. Needs can be perceived by the individual and can be influenced by cultural beliefs and values. Table 4.3 presents data on need factors which include how respondents perceived their general state of health, their reported knowledge of cervical cancer and causes, diagnosis understanding, recognition of cervical symptoms, their disease severity in terms of stage of cancer and HIV prevalence as recorded from record reviews.

Table 4.3 Descriptive summary of need factors

Items		Frequency N=109	Percentage
Perception of general state of health	Excellent	6	5.5
	Good	70	64.2
	Fair	21	19.3
	Poor	12	11.0
Knowledge of cervical Cancer	Sexually transmitted disease	9	8.3
	Cancer like any other	41	37.6
	Disease from other conditions	3	2.8
	I don't know	56	51.4
Knowledge on causes of cervical cancer	Disease caused by virus	15	13.8
	Punishment or act of God	34	31.2
	Bewitched	2	1.8
	Disease from HIV/AIDS	39	35.8
	I don't know	19	17.4
Understanding of the Diagnosis	Yes	96	88.1
	No	13	11.9

Table 4.3 (cont). Descriptive summary of need factors

Items		Frequency N=109	Percentage
Recognition of cervical cancer symptoms	Yes	10	9.2
	No	99	90.8
Stage of cancer	2b	28	25.7
	3a	33	30.3
	3b	42	38.5
	4a	6	5.5
HIV status	Positive	46	42.2
	Negative	28	25.7
	Unknown	35	32.1

Most women perceived their health status as good. Just over half of the women did not have knowledge of cervical cancer, neither did they understand nor recognise the symptoms of cervical cancer. Almost half the women were HIV positive and more than half the women interviewed were in the advanced stages of cervical cancer.

4.4 DESCRIPTIVE SUMMARY OF HEALTH SEEKING CHOICES

Data were collected on health seeking choices. These data include preferred health provider for general health care, action at first symptom for current presenting condition and choice of treatment actions (herbal, pharmaceuticals, traditional alternatives and clinic/hospital), action taken prior to diagnosis (Pap smear screening).

Table 4. 4 Descriptive summary of health seeking choices

Items		Frequency N=109	Percentage
Preferred health provider for general health care	Clinic/Hospital	86	78.9
	Home remedy	12	11.0
	Traditional alternative	11	10.1
Action at first symptom for current condition	Home remedies	15	13.8
	Over the counter	13	11.9
	Traditional healer	6	5.5
	Health worker	75	68.8
Ever had Pap smear in relation to other condition	STI Screening	27	24.8
	Family planning	9	8.3
	Cervical cancer symptoms	67	61.5
	Other	6	5.5

Table 4. 4 (cont). Descriptive summary of health seeking choices

Items		Frequency N=109	Percent age
Age at first Pap smear (in years)	21-30	8	7.3
	31- 40	22	20.2
	41- 50	28	25.7
	51-60	39	35.8
	61 and above	12	11.0
Ever had routine Pap smear	Yes	54	49.5
	No	55	50.5
Ever referred for Pap Smear	Yes	85	78.0
	No	24	22.0
Diagnosed through routine Pap smear	Yes	23	21.2
	No	86	78.9

The majority of women preferred and utilised health institutions for general health care but did not undergo routine Pap smear for early detection of cervical cancer. More than half of the women only had a Pap smear once the cervical cancer symptoms were present.

4.5 FINDINGS OF BIVARIATE ANALYSES

The following outcome variables were measured in the study.

1. Preferred health provider for general health care
2. Action at first symptom for current condition
3. Ever had a Pap smear in relation to other condition
4. Age of first Pap smear
5. Ever referred for Pap smear
6. Diagnosed for cervical cancer through routine Pap smear

The outcome variables and predisposing factors, enabling factors and need factors were measured to identify the association that exists between them. Variables were converted to categorical binary variables in order to conduct the bivariate analyses. With the view of the descriptive analyses, few of the variables have been left out during the bivariate tabulation because they do not have any implication in the analysis.

4.5.1 ANALYSES OF OUTCOME VARIABLE 'PREFERRED HEALTH CARE PROVIDER'

The table below presents bivariate analyses performed with the dependent variable 'preferred health provider' in relation with the independent variables 'predisposing factors', 'enabling factors' and 'need factors'.

Table 4.5 Bivariate analyses of 'preferred health provider for general health' care tabulated with predisposing factors, enabling factors and need factors

		Other provider	Health worker	OR	95% CI	Chi square	p- Value
Predisposing factors	Age in years						
	>50	10	38				
	≤50	13	48	1.64	[0.65:4.15]	1.11	0.29
	Marital status						
	Single	12	59				
	Married	11	27	0.50	[0.20:2.7]	2.16	0.14
	Educational level						
	≤ primary	18	59				
	> Primary	5	27	1.65	[0.55:4.90]	0.82	0.37
	No of people in the household						
Enabling factors	>6	32	2				
	≤6	21	54	41.14	[9.04:187.16]	40.94	<0.01*
	Decision maker						
	Self	11	36				
	Other	12	50	1.27	[0.51: 3.21]	0.26	0.60
	Employment status						
	Employed	8	44				
	Unemployed	15	42	0.51	[0.20:1.33]	1.95	0.16
	Barrier to access to health care						
	Yes	16	50				
Need factors	No	7	36	1.65	[0.61: 4.41]	0.99	0.31
	Social support for medical treatment						
	Yes	15	85				
	No	8	1	0.02	[0.00: 0.19]	27.08	<0.01*
	Perception of general state of health						
	Good	19	58				
	Fair	4	28	2.29	[0.71: 7.38]	2.01	0.15
	Stage of cancer						
	>3	17	64				
	≤3	6	22	0.97	[0.34: 2.78]	0.00	0.96

Statistically significant associations depicted in Table 4.5 include:

- Where there are more than six people in the household, respondents were 41 times more likely to make use of other providers rather than health workers for their general health care (p -value <0.01).
- Where respondents received social support for medical treatment, they were 20% less likely to consult other providers for general health care (p -value <0.01).
- *level of statistical significance has been set at ≤ 0.05 ; other provider means herbal, pharmaceuticals, traditional alternatives; Single women includes divorced, widows

4.5.2 ANALYSES OF OUTCOME VARIABLE 'ACTION AT FIRST SYMPTOM FOR CURRENT CONDITION'

The table below presents bivariate analyses performed with the dependent variable 'action at first symptom for current condition' in relation with the independent variables predisposing factors, enabling factors and need factors.

Table 4.6 Bivariate analyses of 'action at first symptom for current condition' tabulated with predisposing factors, enabling factors and need factors

		Visit to other provider	Visit to health worker	OR	95% CI	Chi square	p -Value
Predisposing factors	Age in years						
	>50	19	32				
	≤ 50	10	48	2.85	[1.17:6.92]	5.57	0.02*
	Marital status						
	Single	14	57				
	Married	15	23	0.38	[0.16:0.90]	4.95	0.03*
	Educational level						
	$\leq$ primary	21	56				
Enabling factors	> Primary	8	24	1.13	[0.44:2.89]	0.06	0.80
	No of people in the household						
	>6	6	28				
	≤ 6	23	52	0.48	[0.18:1.33]	2.03	0.15
	Decision maker						
	Self	18	29				
	Other	11	51	2.88	[1.20:6.92]	5.78	0.01*
	Employment status						
	Employed	21	36				
	Unemployed	8	44	3.21	[1.27:8.10]	6.41	0.01*

Table 4.6 (cont.) Bivariate analyses of 'action at first symptom for current condition' tabulated with predisposing factors, enabling factors and need factors

		Visit to other provider	Visit to the health worker	OR	95% CI	Chi square	p- Value
Enabling factors	Barrier to access to health care						
	Yes	16	27				
	No	13	53	2.42	[1.02:5.75]	4.09	0.04*
	Social support for medical treatment						
Need factors	Yes	24	77				
	No	5	3	0.19	[0.04:0.84]	5.70	0.02*
	Perception of general state of health						
	Good	17	60				
	Fair	12	20	0.47	[0.19:1.16]	2.75	0.09
	Knowledge of definition on cervical cancer						
	Yes	12	38				
	No	17	42	0.78	[0.33:1.84]	0.32	0.57
	Stage of cancer						
	>3	27	54				
	≤3	2	26	6.50	[1.44:29.44]	7.31	<0.01*
	HIV prevalence						
	Positive	10	36				
	Negative	6	22	1.02	[0.32:3.19]	0.00	0.97

*level of statistical significance has been set at ≤ 0.05 ; other provider means herbal, pharmaceuticals, traditional alternatives; single women includes divorced, widows

For 'action at first symptom for current condition', several statistically significant associations were detected:

- Women older than 50, women that made the decision themselves to seek care, employed women, women that experienced barriers to accessing health care, and women with stage of cancer above 3 are more likely at first symptom to visit other providers instead of health workers.
- Women who are single and have social support for medical treatment are less likely at first symptom to visit other providers instead of health care workers.

4.5.3 ANALYSES OF OUTCOME VARIABLE 'EVER HAD PAP SMEAR IN RELATION TO OTHER CONDITION'

The table below presents bivariate analyses performed with the dependent variable 'ever had Pap smear in relation to other condition' in relation with the independent variables predisposing factors, enabling factors and need factors.

Table 4.7 Bivariate analyses of 'ever had Pap smear in relation to other condition' tabulated with predisposing factors, enabling factors and need factors

		Other condition	Cervical cancer symptom	OR	95% CI	Chi square	p-value
Predisposing factors	Age in years						
	>50	21	30				
	≤50	22	36	1.15	[0.53: 2.47]	0.12	0.72
	Marital status						
	Single	17	54				
	Married	26	12	0.15	[0.06: 0.35]	20.50	<0.01*
Enabling factors	Educational level						
	≤ primary	36	41				
	> Primary	7	25	3.14	[1.21: 8.11]	5.86	0.02*
	No of people in the household						
	>6	16	18				
	≤6	27	48	1.58	[0.69: 3.60]	1.20	0.27
Need factors	Employment status						
	Employed	34	23				
	Unemployed	9	43	7.08	[2.89:17.24]	20.41	<0.01*
	Barrier to access to health care						
	Yes	15	28				
	No	28	38	0.73	[0.33:1.61]	0.62	0.43
Need factors	Perception of general state of health						
	Good	29	48				
	Fair	14	18	0.78	[0.34:1.79]	0.35	0.55

Table 4.7 (cont.) Bivariate analyses of 'ever had Pap smear in relation to other condition' tabulated with predisposing factors, enabling factors and need factors

		Other condition	Cervical cancer symptom	OR	95% CI	Chi square	p- value
Need factors	Knowledge of definition on cervical cancer						
	Yes	24	26				
	No	19	40	1.94	[0.89:4.23]	2.83	0.09
	Stage of cancer						
	>3	12	16				
	≤3	31	50	1.21	[0.51:2.89]	0.18	0.66
	HIV status						
	Positive	12	34				
	Negative	16	12	0.26	[0.10:0.72]	7.14	<0.01*
	N=74						

*level of statistical significance has been set at ≤ 0.05 ; Single women includes divorced women and widows

For 'ever having Pap smear in relation to other condition', statistically significant associations were detected with marital status, educational level, employment status, and HIV status.

- Single women, who are primary school leavers, and employed women are more likely to ever had Pap smear in relation to other condition.
- Women who are HIV-infected are less likely to ever have had Pap smear in relation to other condition.

4.5.4 ANALYSES OF OUTCOME VARIABLE 'AGE OF FIRST PAP SMEAR'

The table below presents bivariate analyses performed with the dependent variable 'age of first Pap smear' in relation with the independent variables predisposing factors, enabling factors and need factors.

Table 4.8 Bivariate analyses of 'age of first Pap smear' tabulated with predisposing factors, enabling factors and need factors

		Age of first pap smear >50	Age of first pap smear ≤50	OR	95% CI	Chi square	p-value
Predisposing factors	Age in years						
	>50	36	15				
	≤50	1	57	0.04	[0.01:0.33]	16.61	<0.01*
	Marital status						
	Single	47	24				
	Married	26	12	0.90	[0.39:2.10]	0.06	0.81
	Educational level						
Enabling factors	≤ primary	43	34				
	> Primary	30	2	0.08	[0.02:0.38]	14.68	<0.01*
	No of people in the household						
	>6	22	12				
	≤6	51	24	0.86	[0.37:2.03]	0.11	0.73
	Employment status						
	Employed	28	29				
Need factors	Unemployed	8	44	5.31	[2.13:3.26]	13.33	<0.01*
	Barrier to access to health care						
	Yes	17	26				
	No	19	47	1.6	[0.72:3.64]	1.36	0.24
	Social support for medical treatment						
	Yes	55	35				
	No	8	11	2.16	[0.79:5.90]	2.32	0.09
Need factors	Perception of general state of health						
	Good	23	54				
	Fair	13	19	0.62	[0.26:1.47]	1.18	0.27
	Knowledge of definition on cervical cancer						
	Yes	36	14				
	No	37	22	1.53	[0.68:3.44]	1.06	0.30
	Stage of cancer						
Need factors	>3	50	31				
	≤3	23	5	0.35	[0.12:1.02]	3.92	0.04*
	HIV status						
	Positive						
	Negative	41	5				
	N=74	13	15	9.46	[2.88:31.07]	16.09	<0.01*

*level of statistical significance has been set at ≤0.05

For 'age of first Pap smear', statistically significant associations were detected with age, educational level, employment status, stage of cancer and HIV status.

- Women that are older than 50, primary school leavers, women with stage of cancer above stage 3 are less likely to have their first pap smear.
- Women who are employed and who are HIV-infected are more likely to have their first pap smear at age 50 and above.

4.5.5 ANALYSES OF OUTCOME VARIABLE 'EVER REFERRED FOR PAP SMEAR'

The table below presents bivariate analyses performed with the dependent variable 'ever referred for Pap smear' in relation with the independent variables predisposing factors, enabling factors and need factors.

Table 4.9 Bivariate analyses of 'ever referred for Pap smear' tabulated with predisposing factors, enabling factors and need factors

		Yes	No	OR	95% CI	Chi square	p-value
Predisposing factors	Age						
	>50	47	4				
	≤50	40	18	5.29	[1.65: 16.91]	9.06	<0.01*
	Marital status						
	Single	18	53				
	Married	4	34	0.35	[0.11: 1.11]	3.38	0.06
	Educational level						
	≤ Primary	10	67				
	> Primary	12	20	4.02	[1.51: 10.67]	8.43	<0.01*
	No of people in the household						
Enabling factors	>6	1	34				
	≤6	22	52	14.38	[1.85: 11.75]	10.31	<0.01*
	Decision maker						
	Self	12	35				
	Other	10	52	0.56	[0.22: 1.44]	1.47	0.22
	Employment status						
	Employed	16	36				
	Unemployed	6	51	0.26	[0.09: 0.74]	6.92	<0.01*

Table 4.9 (cont.) Bivariate analyses of 'ever referred for Pap smear' tabulated with predisposing factors, enabling factors and need factors

		Yes	No	OR	95% CI	Chi square	p-value
Enabling factors	Barrier to access to health care						
	Yes	15	28				
	No	7	59	0.22	[0.08: 0.60]	9.53	<0.01*
	Social support for medical treatment						
	Yes	21	79				
	No	1	8	0.47	[0.06: 3.97]	0.50	0.47
Need factors	Perception of general state of health						
	Good	13	64				
	Fair	9	23	1.93	[0.73: 5.10]	1.77	0.18
	Knowledge of definition on cervical cancer						
	Yes	14	36				
	No	8	51	0.40	[0.15: 1.06]	3.50	0.06
	Stage of cancer						
	>3	36	15				
	≤3	57	1	23.75	[3.01:187.62]	16.61	<0.01*

*level of statistical significance has been set at ≤ 0.05

For 'ever referred for Pap smear', statistically significant associations were detected with age, educational level, number of people in the household, employment status, barrier to accessing health care and stage of cancer.

- Women that are above the age of 50, primary school leavers, women with households with more than 6 people and women with advance stage of cervical cancer are more likely to have been referred for Pap smear.
- Women that are employed and have difficulty in accessing health care are less likely to have being referred for Pap smear.

4.5.6 ANALYSES OF OUTCOME VARIABLE 'DIAGNOSIS MADE THROUGH ROUTINE PAP SMEAR'

The table below presents bivariate analyses performed with the dependent variable 'diagnosed made through routine Pap smear' in relation with the independent variables predisposing factors, enabling factors and need factors.

Table 4.10 Bivariate analyses of 'diagnosed through routine Pap smear' tabulated with predisposing factors, enabling factors and need factors

		No	Yes	OR	95% CI	Chi square	p- value
Predisposing factors	Age						
	>50	41	10				
	≤50	44	14	0.77	[0.31:1.92]	0.32	0.56
	Marital status						
	Single	51	20				
	Married	34	4	3.33	[1.05:10.61]	4.49	0.03*
	Educational level						
	≤ primary	62	15				
	> Primary	23	9	0.62	[0.24: 1.61]	0.98	0.32
	No of people in the household						
Enabling factors	>6	30	4				
	≤6	55	20	0.37	[0.11: 1.17]	3.03	0.08
	Decision maker						
	Self	41	6				
	Other	44	18	0.36	[0.13: 0.99]	4.12	0.04*
	Employment status						
	Employed	47	5				
	Unemployed	38	19	0.21	[0.07: 0.62]	8.91	<0.01*
	Barrier to access to health care						
	Yes	29	14				
	No	56	10	2.70	[1.07: 6.83]	4.59	0.03*
	Social support for medical treatment						
	Yes	77	23				
	No	8	1	2.39	[0.28: 0.12]	0.68	0.40

Table 4.10 (cont.) Bivariate analyses of 'diagnosed through routine Pap smear' tabulated with predisposing factors, enabling factors and need factors

		No	Yes	OR	95% CI	Chi square	p- value
Need factors	Perception of general state of health						
	Good	63	14				
	Fair	22	10	0.49	[0.19: 1.26]	2.25	0.13
	Knowledge of definition of cervical cancer						
	Yes	30	20				
	No	54	5	7.20	[2.45:1.13]	15.22	<0.01*
	Stage of cancer						
	>3	65	16				
	≤3	20	8	0.62	[0.23: 1.65]	0.94	0.33

*level of statistical significance has been set at ≤0.05

For 'diagnosis made through a routine pap smear', statistically significant associations were detected with marital status, employment status, household decision maker, barrier to accessing health care and knowledge of definition of cervical cancer.

- Women that are single, have barriers in accessing health services, that have knowledge about cervical cancer are more likely to be diagnosed with cervical cancer through a routine pap smear.
- Women that are employed and women that make decision for themselves are less likely to have being diagnosed through a routine pap smear.

4.6 MULTIVARIATE ANALYSIS

A logistic regression analysis was performed with variables found to be associated at the level of statistical significance to the outcome variable in the bivariate analyses.

Table 4.11 Multivariate logistic regression predicting likelihood of outcome variable

	β	Standard Error	WALD	DF	P-Value	ODDS RATIO	95% C.I.	
							LOWER	UPPER
Logistic Regression predicting likelihood of 'preferred health care provider'								
No of pple in household	1.35	0.79	2.90	1	0.09	3.85	0.82	18.18
Support for med. Rx	22.63	14210.37	0.00	1	0.99	6.71	0.00	0.00
Constant	-21.20	14210.37	0.00	1	0.99	0.00		
Logistic Regression predicting likelihood of 'action at first symptom for current condition'								
Women >50 yrs	-0.78	0.66	1.40	1	0.25	0.46	0.13	1.66
Marital status	-1.06	0.59	3.24	1	0.07	0.35	0.11	1.09
Employment	0.25	0.73	0.11	1	0.74	1.28	0.30	5.39
Decision maker	-1.27	0.57	5.06	1	0.03*	0.28	0.09	0.85
Barrier to health	-0.98	0.51	3.69	1	0.06	0.38	0.14	1.02
Treatment support	1.48	0.84	3.11	1	0.08	4.41	0.85	22.97
Stage of cancer	-0.12	0.58	0.04	1	0.84	0.89	0.28	2.78
Constant	1.55	1.05	2.18	1	0.14	4.72		
Logistic Regression predicting likelihood of 'having Pap smear in relation to other condition'								
Marital status	-18.77	4370.89	0.00	1	0.99	0.00	0.00	0.00
Education	16.73	5678.47	0.00	1	0.99	1.84	0.00	0.00
Employment	-1.27	1.09	1.37	1	0.24	0.28	0.03	2.36
Constant	21.29	4370.89	0.00	1	0.99	1.77		
Logistic Regression predicting likelihood of 'age at first Pap smear'								
Women >50 yrs	39.34	6254.63	0.00	1	0.99	1.22	0.00	0.00
Education	-19.27	4415.55	0.00	1	0.99	0.00	0.00	0.00
Employment	18.29	4415.55	0.00	1	0.99	8.77	0.00	0.00
Stage of cancer	-1.79	0.87	4.24	1	0.04*	0.17	0.03	0.92
Constant	-37.26	6254.63	0.00	1	0.99	0.00		
Logistic Regression predicting likelihood of 'ever referred for Pap smear'								
Women >50 yrs	0.99	.075	1.77	1	0.18	2.70	0.63	11.65
Education	-1.41	0.75	3.76	1	0.05*	0.25	0.06	1.02
Household no	19.80	6586.76	0.00	1	0.99	3.99	0.00	0.00
Barrier to health	-1.36	0.62	4.86	1	0.03*	0.26	0.08	0.86
Stage of cancer	-0.24	0.59	0.17	1	0.68	0.79	0.25	2.50
Constant	1.91	0.77	6.10	1	0.01	6.76		
Logistic Regression predicting likelihood of 'diagnosis made through routine Pap smear'								
Marital status	-1.86	0.84	4.92	1	0.03*	0.16	0.03	0.81
Employment	-2.82	0.77	13.52	1	<.01*	0.06	0.01	0.27
Decision maker	-2.67	0.79	11.40	1	<.01*	0.07	0.01	0.33
Barrier to health	1.75	0.73	5.74	1	0.02*	5.72	1.37	23.84
Knowledge of Cervical cancer	2.36	0.82	8.25	1	<.01*	10.55	2.11	52.66
Constant	-1.04	0.79	1.72	1	0.19	0.35		

As shown in table 4.11, variables that remained significant are listed below:

- Women that made decision to seek health care themselves are more likely to visit other providers rather than a health worker.
- Respondents above 50 years of age are less likely to have had their first pap smear when they are younger, hence presenting in an advanced stage of cervical cancer.
- Respondents who have difficulty in accessing health care are less likely to have been referred for Pap smear.
- Respondents who are less educated are less likely to have been referred for Pap smear.
- Five independent variables, marital status, employment status, decision maker, barrier to healthcare, knowledge of cervical cancer, made a statistical significant contribution to the model. The strongest predictor of ever been diagnosed for cervical cancer through routine Pap smear was knowledge of cervical cancer, recording an odds ratio of 10.55. This indicated that respondents who had has been diagnosed with cervical cancer through routine pap smear were over 10 times more likely to report having knowledge for cervical cancer.

4.7 CONCLUSION

This chapter has presented the findings of the study. Analysis was made using descriptive, bivariate analyses and multivariate analyses.

Descriptive statistics were used to provide an overview of the predisposing, enabling and need characteristics of respondents, as well as of their health seeking choices.

Bivariate analyses were performed, which revealed the variables that most influence health seeking behaviour are age, marital status, employment status,

social support for medical treatment, educational level, knowledge of Pap smear screening and recognition of symptoms of cervical cancer.

In the multivariate analysis, the variables found to remain statistically associated with the outcomes are having social support for medical treatment, age, employment status, marital status, knowledge of cervical cancer and barriers to accessing health care.

5. DISCUSSION AND CONCLUSIONS

5.1 INTRODUCTION

The main aim of the study was to determine the patterns of health seeking behaviour of women being treated for cervical cancer at Grey's Hospital. Women (N=109) being treated for cervical cancer at Grey's Hospital from June to August 2009 were surveyed. Their health seeking behaviours were assessed by describing predisposing factors, need factors and enabling factors associated with health care seeking decisions and choices. The results described in the previous chapter are discussed in this chapter, in the light of the existing literature on health seeking behaviour in women with cervical cancer. Conclusions are drawn from the research process, against the research objectives, and recommendations are proposed that the Department of Health could consider in alleviating the impact of invasive cancer on women and increase cervical screening uptake. Suggestions for further research are also included.

5.2 PREDISPOSING FACTORS ASSOCIATED WITH THE DECISION TO SEEK CARE

Predisposing factors are factors that make respondents susceptible to the outcome of interest in this case, cervical cancer. The descriptive findings on Table 4.1 presents data on age, marital status, educational level, household size, and household decision maker and suggest that the demographic profiles of the respondents are comparable to previous studies in South Africa.

With regard to age, the women being treated for advance stages of cervical cancer are middle aged and mostly older women, single with limited education and from large household. The findings are consistent with other research conducted in the field that has established cervical cancer as primarily a disease

of early and late middle age, of women with lower education, and of poor women (Berer, 2008; Walker, et al., 2002; Waktola, et al., 2005).

The bivariate analyses tested the association between the predisposing factors and the outcome variables. Women in households that have more than six people were 41 times more likely to make use of other providers rather than health workers for their general health care. According to Astin (1998), there are many reasons why users prefer alternative medicines. In his study, it was found that beside being more educated and reporting poorer health status, the majority of alternative medicine users appear to be doing so not so much as a result of being dissatisfied with conventional medicine but largely because they find these health care alternatives to be more congruent with their own values, beliefs, and philosophical orientations toward health and life. This requires further research in the KZN setting. The single, younger users who may have been exposed to social support for medical treatment would prefer health care workers, indicating that provision of accessible health care incentives and facilities would have great impact on the control of cervical cancer.

Women older than 50 years of age are more likely to present with cancer above stage 3 and are less likely to have their first Pap smear at a younger age, confirming that the epidemiological profiles of the demographic in studies (Walker, et al., 2002; Waktola, et al., 2005) done in South Africa are consistent. Also, respondents above 50 years of age are less likely to have had their first Pap smear when they are younger, hence presenting an advance stage of cervical cancer. This is in line with findings by Mandelblatt et al. (1999) that elderly women above 65 years were significantly less likely to have ever had a Pap smear than younger women. The South African screening guideline of 'three in a lifetime over 30' policy is a good target although it may not have achieved its purpose due to the low uptake in routine screening.

The findings also reveal that respondents who are less educated are less likely to have been referred for a Pap smear. Hence, increased educational level would strengthen women's desire to protect themselves and go for regular screening. This is in agreement with Forbes, (1999) study that increasing the uptake of screening, alongside increasing informed choice, is of great importance in controlling cervical cancer through prevention and early detection. Health education is effective in promoting a reduction in behaviours likely to put women at risk.

Multivariate analysis shows that women who make their own decision are more likely to seek healthcare from other providers and are less likely to be diagnosed of cervical cancer through routine Pap smear. More research is needed on this aspect.

5.3 ENABLING FACTORS ASSOCIATED WITH DECISION TO SEEK CARE

Enabling factors provide the means or opportunity for an individual to seek health care. Descriptive findings present data on employment status, barriers to accessing regular health care, and social support for medical treatment. Most women while unemployed experienced no barrier in accessing regular healthcare and reported having social support for medical treatment. This may be as a result of increase in availability of health services and the policy on free health care services.

The bivariate associations between the enabling factors and the outcome variables confirm that employment has an impact on the decision to seek health care. Women that are employed are more likely to visit other providers at first symptom than those unemployed; they are also less likely to have been referred for Pap smear and are less likely to have been diagnosed through a routine Pap smear screening. These findings suggest that women that are employed may have difficulty in accessing health care.

The implication of employment on health seeking behaviour is noted in the findings and this could be as a result of working hours and opening hours of the health institution; these women may have difficulty in taking time off work and there might be other reasons.

Additionally, because they were often unable to find work, once they did become employed, they were reluctant to miss days of work to keep medical appointments (Cheatham, et al., 2008). One participant expressed fear that he would lose his job if he was perceived to be sick by his supervisors.

Majority of women reported not having barriers to accessing health care, but most gave cost as the barrier to accessing regular health care. Health care in provincial hospitals is free in South Africa therefore further research needs to be conducted to look at the implication of cost in accessing health care and what kind of cost may be incurred specifically. Pillai et al., (2003) comment that economic status is the primary predictor of health service utilisation. The role of social support for medical treatment was also noted in the bivariate findings. The women who received social support for medical treatment were 20% less likely to consult other providers and more likely to seek health care from clinics and hospitals.

In multivariate analyses, barriers to access increase the likelihood of seeking care from other providers and decrease the likelihood of ever being referred for a Pap smear or being treated through a Pap smear. However, there were some exceptions as it was noted that more than half of the women reported not to have barriers in seeking health care as most women utilise health facility for general health care and services which are free. Since health services are free, it could mean that these women are not aware of the importance of early diagnosis and the impact of the cervical screening policy being implemented in South Africa.

Consequently, this would indicate that apart from economic status being a primary predictor of health service utilisation, since most respondents agree that there is social support for medical treatment, then dissemination of information on policies like the cervical screening should be well emphasised to enable health seekers to have vital and available information on proper healthcare.

5.4 NEED FACTORS ASSOCIATED WITH DECISION TO SEEK CARE

The need factors reflect perceived illness levels that are thought to require the use of health services. The descriptive findings, as illustrated in Table 4.3, show how respondents perceived their general state of health, their reported knowledge of cervical cancer and causes, understanding diagnosis and recognition of cervical cancer symptoms, their disease severity in terms of stage of cancer and HIV prevalence as recorded in the patient's records.

Most women perceived their health status as good and do not have knowledge of cervical cancer, neither do they understand nor recognise the symptoms of cervical cancer. However, the 64.2% that perceived their health status as good did not undergo routine Pap smear for early detection of cervical cancer and never referred for any. They had no knowledge of cervical cancer until later diagnosed. It was deduced that since most do not have knowledge of cervical cancer nor understand or recognise the symptoms of cervical cancer, these could have resulted in their late diagnosis and poor uptake of Pap smear screening. This can also be said to be due to failure on the part of the healthcare giver to disseminate information to the people regarding the reason and value of cervical screening and lack of knowledge.

Women with stage of cancer above 3 are more likely at first symptom to visit other providers instead of health workers. The aforementioned are also in agreement with Kang et al. (2009) findings that there are several reasons for late presentation, namely: ignorance about symptoms; fatalistic attitude; readiness to

attribute to cancerous disease to supernatural causes; and low coverage of the population by health care services especially in rural areas. This was confirmed in this study as respondents who have difficulty in accessing health care are less likely to have been referred for Pap smear. In the view of Walker et al., (2002), not undergoing regular Pap tests is the greatest risk factor for a poor outcome in women who develop cervical cancer.

More than half of the women only undergo Pap smears once the cervical cancer symptoms were present. Almost half the women were HIV positive, while more than half the women interviewed were in advanced stages of cervical cancer. Women who are HIV-infected are also less likely to ever have had Pap smear in relation to other condition. These have a major implication in the protocol of management for women diagnosed as HIV-infected and thus reflect a system failure.

Finally under the multivariate analysis, the study found that respondents who had has been diagnosed with cervical cancer through routine Pap smear were over 10 times more likely to report having knowledge of cervical cancer. This is in agreement with Holoroyd et al., (2004) who suggests that the level of knowledge is an important factor prompting both attendance and re-attendance in a range of cultural groups to attending screening programmes. Lack of knowledge has been shown to limit choice of health seeking behaviour. This need to be properly addressed to enlighten and educate women on cervical cancer and its prevention in order to control the spread of the disease.

5.5 HEALTH SERVICE UTILIZATION CHARACTERISTICS OF PATIENTS BEING TREATED FOR CERVICAL CANCER AND ANALYSIS OF FACTORS ASSOCIATED WITH HEALTH SEEKING BEHAVIOUR IN WOMEN TREATED FOR CERVICAL CANCER

On analysing the preferred health provider in relation with the different factors, where there are more than 6 people in the household respondents were 41 times more likely to make use of other providers for the general health care. Women who had social support for medical treatment were 20% less likely to consult other provider for general health care. Women who are older than 50 years may share values and beliefs that make them prefer other health providers instead of health workers (Holoroyd, et al., 2004).

On analysing age of first Pap smear and ever been referred for Pap smear, women who are older than 50 are more likely to have been referred for Pap smears and likely to have had their first Pap smear above 50 years of age.

With regards to women ever having Pap smear in relation to another condition, single women, who are primary school leavers, and employed are more likely to have ever had a Pap smear in relation to another condition while women who have a positive HIV status are less likely to ever had Pap smear in relation to another condition.

Further analyses of the outcome variables which are statistically significant confirmed that women that made decision themselves are more likely to visit other providers rather than a health worker once they notice the symptoms of cervical cancer. This is because they find these health care alternatives to be more congruent with their own values, beliefs, and philosophical orientations toward health and life. The variables found to still remain statistically associated with the outcome variables under the multivariate analysis are women having

social support for medical treatment, age, employment status, marital status, knowledge of cervical cancer and barrier to health care.

In South Africa, screening coverage is very low (well below 50%) and adherence to treatment of pre-cancerous and cancerous lesions is also less than 100%, therefore having another preventative measure could be desirable. Most respondents are not educated and are not well informed about cervical cancer. Also, more than half of the women do not have knowledge and understanding of their condition. This calls for need to promote the establishment of Non - governmental organisations (NGO) to embark on awareness campaigns. Such campaigns should be focused in rural areas where it is anticipated that individuals have less education.

Overall finding for late diagnosis of cervical cancer emanates from lack of knowledge of the condition and low uptake of screening programs.

According to the report of the GAVI–UNFPA–WHO meeting on strengthening cervical cancer prevention and control in 2009, two major outcomes was reached; policy commitment and funding strategy for HPV vaccination. HPV vaccination can be an entry point to other adolescent health services, as well as to screening and treatment of precancerous lesions of the cervix in the women of reproductive age (immunize girls, screen their mothers).

In South Africa, 85% of the population of 45 million uses public-sector health services. Private health insurance covers about 15% of the health sector. The country is faced with a weak health system and very serious TB and HIV epidemics. Moodley et al., (2006) in their report state that a planning process to strengthen national cervical cancer prevention should focus on three working groups: (1) HPV vaccine; (2) screening; and (3) treatment and care.

The health department should ensure that bills are to be posted in strategic places like hospitals in local languages to inform women on the need for routine

pap smear' which could lead to early intervention for those already suffering from cervical cancer who may not know or thought it is an act of God.

5.6 FUTURE RESEARCH

Further research should be undertaken in other provinces and health districts in South Africa as to why most women are not aware or do not undergo routine Pap smear' despite the 'three in a lifetime over 30' policy which was developed because cervical cancer is believed to be a slow growing cancer and a Pap smear at the ages of 30, 40 and 50 is regarded as a way to manage this epidemic.

A comprehensive study of the health seeking behaviour of patients presenting with cervical cancer should be undertaken in other provinces and health districts in South Africa to ascertain if there are changes in their pattern of behaviour when stratified in terms of districts or provinces as this will help to seek proper and adequate intervention in promoting cervical cancer screening.

5.7 SUMMARY AND CONCLUSION

As mentioned earlier, this study was designed to determine the patterns of health seeking behavior of women being treated for cervical cancer at Grey's Hospital. The problem that was identified in chapter one was that there is still an increase in the incidence of cervical cancer and many women admitted to oncology wards are at such an advanced stage of disease that palliation is the only treatment option left. Hence, the research tried to describe the underlying factors associated with health seeking behaviors of patients presenting with cervical cancer.

The study found that the majority of respondent did not undergo routine cervical screening and in as much as respondents believed there were healthcare centers available and have no barrier in accessing healthcare, most of them do

not utilize them on time as some still uses other health care providers like the traditional healers and pharmaceutical centers.

Furthermore, the study found that most women are unemployed and have many people in their house hold hence may not be economically buoyant to afford medical care, even when they take decision themselves and has social support for medical care, have not properly utilized them as they are more likely to visit other providers rather than a health worker once they notice the symptoms of cervical cancer.

The variables found to still remain statistically associated with the outcome variables under the multivariate analysis are women having social support for medical treatment, age, employment status, marital status, knowledge of cervical cancer and barrier to health care.

The study further looked on the following problems which may be present:

- There may be inadequacies in the type of health care choices or treatment action sought amongst these women.
- Women may be uninformed about early detection and recognition of the signs and symptoms of the disease, hence presenting in advanced stages.

The study achieved its aim of determining the patterns of health seeking behaviour of women being treated for cervical cancer at Grey's Hospital. The key focus in reducing the incidence of cervical cancer have to be early detection, as the symptomatic stage of cervical cancer is highly unlikely to be at the advanced stage of cancer. It also identified that proper policy of HPV vaccination can be an entry point to address and decrease the incidence of the disease as well as screening and treatment of precancerous lesions of the cervix in the women of reproductive age. The Department of Health need to consider other use of other organizations in South Africa to promote adequate awareness campaign.

REFERENCES

American Cancer Society. 2000. *Cancer facts and figures, 2000*. Atlanta, GA.

Andersen, R.M., 1995. Revisiting the Behavioural Model and Access to Medical Care: Does it Matter? *Journal of Health and Social Behaviour* (e-journal) 36(1) Available through: jstor database. [Accessed 16 June 2007]

Andersen, R. & Neuman, J.F., 1997. Societal and individual determinants of medical care utilization in the United States. *Health and Society*, 51:95-124.

Astin, J.A., 1998. Why patients use alternative medicine: results of a national study. *JAMA*. 279(19):1548-53.

Bailey, S. C., Bourne D., and Bradshaw D.,1996. Trends in cervical cancer mortality in South Africa. *International Journal of Epidemiology*. 25(3):88-493.

Batra, P., Kuhn, L., and Denny, L. 2010. Utilisation and outcomes of cervical cancer prevention services among HIV-infected women in Cape Town. *South African Medical Journal*. 100(1):39-44.

Berer, M., 2008. Reproductive cancers: high burden of disease, low level of priority. *Reproductive Health Matters*. 16(32):4-8.

Bosch, F.X., 2005. Risk factors for cervical cancer in Colombia and Spain. *International Journal of Cancer*. 52(5):750 – 758. [Accessed 18 Jul 2006]

Bish, A., Ramirez, A., Burgess, C., & Hunter, M., 2005. Understanding why women delay in seeking help for breast cancer symptoms. *Journal of Psychosomatic Research*. 58(4):321–326.

Campo, J., Comber, H., & Gavin, A. 2004. All-Ireland cancer statistics 1998–2000, second report. Cork, Ireland: National Cancer Registry.

Conner, M. & Sparks, P. 1995. The Theory of Planned Behaviour and Health Behaviours, in Predicting Health Behaviour. Buckingham: Open University Press.

Cheatham C.T., Barksdale, D.J., Rodgers, S.G., 2008 Barriers to health care and health-seeking behaviors faced by Black men. *Journal of the American Academy of Nurse Practitioners*. 20(11): 555–562.

Chirenje, Z. M., 2005. HIV and cancer of the cervix. *Best Practice & Research Clinical Obstetrics and Gynaecology*. 19(2):269–276.

Chiu, M. M., Olaitan, A., 2005. Delayed diagnosis of cervical cancer in young women. *Journal of Obstetrics & Gynaecology*. 25(4):367-370.

Denny, L., 2005. Prevention of cervical cancer. *Reproductive Health Matters*. 16(32):18-31

De Nooijer, J., Lechner, L., and De Vries, H., 2001. A qualitative study on detecting cancer symptoms and seeking medical help; an application of Andersen's model of total patient delay. *Patient Education Counselling*. 42(2):145-57.

Department of Health., 2000. National guidelines for cervical cancer screening programme, South Africa.

Department of Health, *Statistical Notes*, 2000. Vol 2. No. 15.

Duerr A, Kieke B, Warren D, Shah K, Burk R, Peipert JF., 2001. Human Papillomavirus-associated cervical cytologic abnormalities among women with or at risk of infection with human immunodeficiency virus. *American Journal of Obstetrics Gynaecology*. 184(4):584-90.

Engels, E. A., Biggar, R.J., and Hall, H.I., 2008. Cancer risk in people infected with human immunodeficiency virus in the United States. *International Journal of Cancer*.123(1):187–194.

Fayed, L., 2008. Cervical cancer prevention: mandating the hpv vaccine as a condition of school attendance family court review. Volume 46(4):637–653, [Accessed 21 Aug 2008]

Ferlay, J P., Autier, M., Heanue, M., 2006. Estimates of the cancer incidence and mortality in Europe in 2006. *Annual Oncology*

Fonn, S., Bloch, B., 2002. Prevalence of pre-cancerous lesions and cervical cancer in South Africa - a multicentre Study. *South African Medical Journal*. 92(2):148-156. [Accessed 22 October 2009].

Freedman, D A., 2005. *Statistical Models: Theory and Practice*. Cambridge University Press. New York.

Holoroyd, E., Twinn, S., and Adap, P., 2004. Socio-cultural influences on Chinese women's attendance for cervical screening. *Journal of Advanced Nursing*. 46(1):42–52.

Hopkinson, J., Corner, J., and Roffe, L., 2006. Experience of health changes and reasons for delay in seeking care: A UK study of the months prior to the diagnosis of lung cancer. *Social Science & Medicine*. 62(6):1381-1391.

International federation of gynaecology and obstetrics., 2005. Cervical and vulva cancer: changes in figo definitions of staging. *An International Journal of Obstetrics & Gynaecology*. Volume 103(5):405–406.

Isaac N 2005. Health-seeking behaviour and health system response. *American Journal of Tropical Medicine and Hygiene*. 46(3):248-260.

Jemal, A., Siegel, R., Ward, E., Hao, Y., Xu, J., Murray, T., et al. (2008). Cancer statistics, 2008. *CA: Cancer Journal for Clinicians*. 58(2):71–96.

Kang, Y. and Kim, S.S. (2009), Help-seeking among Korean American women with urinary incontinence. *International Journal of Urological Nursing*. 10(3):50-56.

Kroeger, A. (1993) Anthropological and socio-medical health care research in developing countries. *Social Science & Medicine*, 17:147-161.

Lee, M.C. (2000). Knowledge, barriers, and motivators related to cervical cancer screening among Korean-American women: A focus group approach. *Cancer Nursing*, 23(3):168-172.

Leedy, P. D. and Ormond, J. E. (2005) *Practical Research Planning and Design* (8th Ed.): New Jersey, Pearson Education.

Mandelblatt, J.S., Yabroff, K.R., Kerner, J.F., 1999. Equitable access to cancer services. A review of barriers to quality care. *Cancer*. 86 (11): 2378–2390.

Massad, L.S., Seaberg, E.C., Wright, R.L. 2008. Squamous cervical lesions in women with human immunodeficiency virus: long-term follow-up. *Obstetrics and Gynecology*. 111(6):1388–1393.

Meyer-Weitz, A., Reddy, P., Van Den Borne, H.W., Kok, G. & Pietersen, J., 2000. The determinants of health care seeking behaviour of adolescents attending STD clinics in South Africa. *Journal of Adolescence*. 23(4):741-752

Miller B R., Eisner M, Kosary C, Hankey B, Clegg L., 2006. *Seer cancer statistics review*. 107(8):1711–1742.

Moodley, J., Hoffman, M., Kawonga, M., and Bradley J., 2006. Challenges in implementing a cervical screening programme in South Africa. *Cancer Detection and Prevention*. 30(4):361–68.

O'Malley, C.D., Shema, S.J., Clarke, L.S., and Perkins, C.I., 2006. Medical aid Status and Stage at Diagnosis of Cervical Cancer. *American Journal of Public Health*. 96 (12):2179-2185.

Omigbodun, A., Ayinde, O., 2005. The management of abnormal cervical smears by Nigerian gynaecologists. *International Journal of Gynaecology & Obstetrics*. 88(3):340-41.

Parkin, DM, Bray, F, Ferlay, J, Pisani, P., 2002. Global cancer statistics. *CA Cancer Journal of Clinicians*. 55:74-108.

Peltzer, K, 2001. Psychosocial correlates of healthy lifestyles in black and white South Africans. *Social Behaviour and Personality: An International Journal*. 29(3):249-255.

Pillai, R.K., Williams, S.V., Glick, H.A., and Lowe, R.A., 2003. Factors affecting decisions to seek treatment for sick children in Kerala. *India Social Science & Medicine*. 57(5):783-790.

Pillay, A. L., 2002. Rural and urban South African women's awareness of cancers of the breast and cervix. *Ethnicity Health*. 7(2):103-14.

Robin Y; Meissner, H I; Haggstrom, D A; Wideroff, I., 2007. Specialty differences in primary care physician reports of Papanicolaou test screening practices: A National Survey, 2006 to 2007. *Annals of Internal Medicine*. 151(9):602-611.

Sheeran, P. & Abraham, C., 1995. *The Health Belief Model, in Predicting Health Behaviour*. Buckingham: Open University Press.

Silverberg, M.J, Abrams, D.I. 2007. AIDS-defining and non-AIDS-defining malignancies: cancer occurrence in the antiretroviral therapy era. *Current Opinion in Oncology*. 19(5):446–451.

Sirois, F.M; Gick, M.L., 2002. An investigation of the health beliefs and motivations of complementary medicine clients. *Social Science & Medicine*. 55(6):1025-1037.

Stevens, M., 2008. From HIV prevention to reproductive health choices: HIV/AIDS treatment guidelines for women of reproductive age. *African Journal of AIDS Research*. 7(3):353-359.

Waktola, E.A., Mihret, W., Bekele, L., 2005. HPV and burden of cervical cancer in East Africa. *Gynaecologic Oncology*. 99(3):201-202.

Walker, A.R.P., Michelow, P.M., and Walker, B.F., 2002. Cervix cancer in African women in Durban, South Africa. *International Journal of Gynaecology Obstetric*. 79(3):45-46.

WHO/ICO Information Centre on HPV and Cervical Cancer. 2009. Human Papillomavirus and Related Cancers in South Africa. Summary Report 2009. [Accessed 7 October 2009]

APPENDICES

1. Letters of approval and permission.

Appendix 1. 1 Postgraduate Education Committee Approval.



05 June 2009

Dr A Voce
Public Health Medicine
Nelson R Mandela School of Medicine

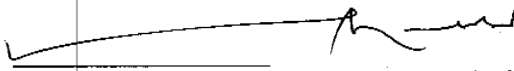
Dear Dr Voce

PROTOCOL: A descriptive study of the health seeking behaviour and health care provision of women treated for cervical cancer in Inkosi Albert Luthuli Central Hospital. O Adejumo, MPH, Public Health, student number 201504626.

The Postgraduate Education Committee ratified the approval of the protocol amendment for the above study on 02 June 2009. The title of the study will now reflect as follows:

A descriptive study of the health seeking behaviour and health care provision of women treated for cervical cancer in Grey's Hospital

Yours sincerely


PROFESSOR T MADIBA
Chairperson: Postgraduate Education Committee

CC. Ms OT Adejumo

Ms D Ramnarain
Biomedical Research Ethics Committee
Westville Campus

**Postgraduate Education Administration
Medical School Campus**

Postal Address: Private Bag 7, Congella, 4013, South Africa

Telephone: +27 (0)31 260 4327

Facsimile: +27 (0)31 4401

Email: hesiopd@ukzn.ac.za

Website: www.ukzn.ac.za

Founding Campuses:

■ Edgewood

■ Howard College

■ Medical School

■ Pietermaritzburg

■ Westville

Appendix 1. 2 Biomedical Research Ethics Approval.

PAGE: 1



UNIVERSITY OF
KWAZULU-NATAL

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION
Research Office, Westville Campus
Govan Mbeki Building
Private Bag X 54001
Durban
4000

KwaZulu-Natal, SOUTH AFRICA
Tel: 27 31 2604769 - Fax: 27 31 2604609
Email: BREC@ukzn.ac.za

Website: <http://research.ukzn.ac.za/ResearchEthics11415.aspx>

14 May 2009

Ms. OT Adejumo
PO Box 38279
South Beach
Durban
4069

Dear Ms Adejumo

PROTOCOL: A Study of the Health seeking behaviour of women on treatment for cervical cancer at Grey's Hospital, Pietermaritzburg. Ms O.T. Adejumo. Department of Public Health Medicine. Ref No: BF080/08.

The Biomedical Research Ethics Committee (BREC) has considered the abovementioned application.

The study was approved by a quorate meeting of BREC on 08 July 2008 pending appropriate responses to queries raised. Your responses dated 01 April 2009 to queries raised on 03 October 2008 have been noted by a sub-committee of the Biomedical Research Ethics Committee. The conditions have now been met and the study is given full ethics approval and may begin as from today; 14 May 2009.

The related study documents have been reviewed and approved:

This approval is valid for one year from (today's date, 14 May). To ensure uninterrupted approval of this study beyond the approval expiry date, an application for recertification must be submitted to BREC on the appropriate BREC form 2-3 months before the expiry date.

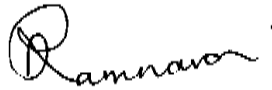
Any amendments to this study, unless urgently required to ensure safety of participants, must be approved by BREC prior to implementation.

Your acceptance of this approval denotes your compliance with South African National Research Ethics Guidelines (2004), South African National Good Clinical Practice Guidelines (2006) (if applicable) and with UKZN BREC ethics requirements as contained in the UKZN BREC Terms of Reference and Standard Operating Procedures, all available at <http://research.ukzn.ac.za/ResearchEthics11415.aspx>.

BREC is registered with the South African National Health Research Ethics Council (REC-290408-009). BREC has US Office for Human Research Protections (OHRP) Federal-wide Assurance (FWA 678).

We wish you well with this study. We would appreciate receiving copies of all publications arising out of this study.

Yours sincerely



PP

PROFESSOR D R WASSENAAR
Chair: Biomedical Research Ethics Committee

Appendix 1. 3 Chief Executive Officer of Grey's Hospital Approval.



GREY'S HOSPITAL

OFFICE OF THE CHIEF EXECUTIVE OFFICER

Private Bag X 9001, PIETERMARITZBURG, 3200

Townbush Road, Chase Valley, PIETERMARITZBURG, 3201

Tel.: 033 – 897 3321, Fax: 033 – 342 2324

email.:sandy.sivrathan@kznhealth.gov.za

Reference: Research

Enquiries: Dr K B Bilenge

2 April 2009

O. Adejumo

Email: bukky_adejumo@yahoo.com

Dear Ms Adejumo,

RE: PERMISSION TO CONDUCT RESEARCH AT GREY'S HOSPITAL

I have pleasure in informing you that permission has been granted to you by the Hospital CEO to conduct research in a Study of Health seeking behaviour of women on treatment for Cervical Cancer (B Adejumo)

Please note the following:

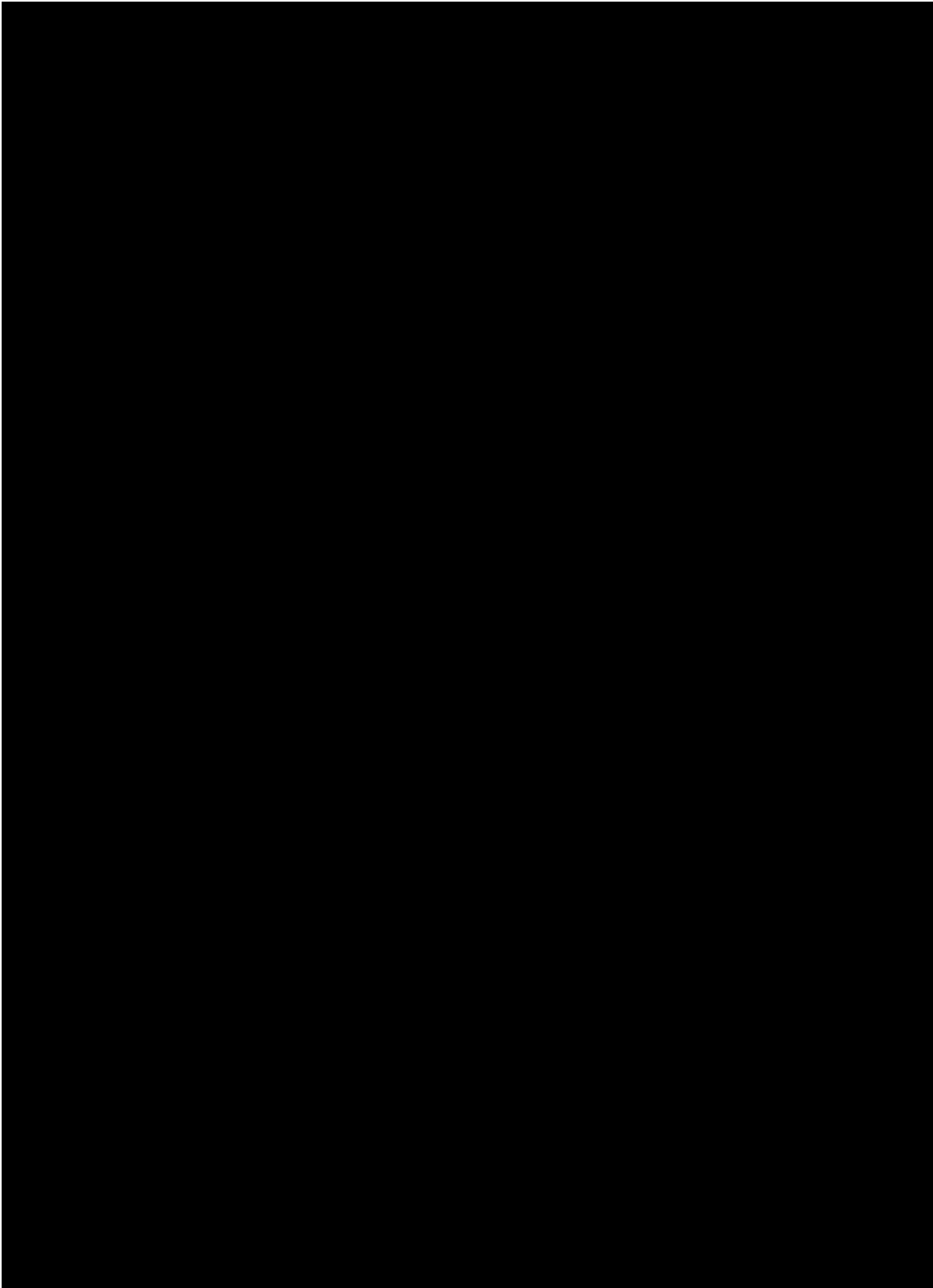
1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. **This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.**
3. Please ensure this office is informed before you commence your research.
4. The Hospital will not provide any resources for this research.
5. You will be expected to provide feedback on your findings to the Hospital CEO.

Yours faithfully,

DR K. B. BILENGE

ACTING CEO: GREY'S HOSPITAL

Appendix 1. 4 Department of Health's Research Approval.



Appendix 1. 5 Letter of permission

For attention:

Dr KB Bilenge
Medical Manager
Grey's Hospital

Letter of permission to conduct Master of Public Health (MPH) research study.

Dear Sir,

I am Olubukola Adejumo, a registered student and a professional nurse engaged in the Master of Public Health programme at the Department of Public Health Medicine, Nelson R Mandela School of Medicine, University of KwaZulu-Natal.

I am seeking permission to conduct a study entitled: A study of the health seeking behavior of women on treatment for cervical cancer. The overall aim of this research is to determine the patterns of health seeking behaviour of women on treatment for cervical cancer – their health service utilization and the need, enabling and the predisposing factors associated with the decision to seek care.

The findings of the study will be presented as part of the dissertation component of the Master of Public Health.

The research protocol has been approved by the Postgraduate Education Committee and provisionally approved (pending permission from the health authority to conduct the study) by the Biomedical Research Ethics Committee (BREC) of the University of KwaZulu-Natal. Please see the attached detailed research protocol and approvals.

I attach a letter of permission which I request you to complete and sign, should you give permission for the study to be conducted at your institution.

Thank you for your consideration and look forward to hearing from you on the above matter.

Yours Sincerely,

Researcher: O. Adejumo

Cell: 083 218 2002. Email, Bukky_adejumo@yahoo.com

For further enquiries: Please contact my Supervisor: Dr Anna Voce at 0312604493 or voceas@ukzn.ac.za. Department of Public Health Medicine, Nelson R Mandela School of Medicine, University of Kwa-Zulu-Natal.

Appendix 1. 6 Information document

Study Title: The study of the health seeking behaviour of women treated for cervical cancer in Grey's hospital.

Greetings,

I am Olubukola Adejumo, a registered student and a registered nurse engaged in research study for the completion of Master of Public Health, at the Department of Public Health Medicine in the University of KwaZulu-Natal Medical School.

Invitation to participate: I am inviting you to participate in this research study.

What is the study about? The study is about describing the patterns of health seeking behavior of women being treated for cervical cancer i.e., what you do and where you went when you suspect that you have a symptom of cervical cancer.

Who is conducting the study? I will be conducting this study, and with the assistant of few nursing colleagues, will help collect some data in the Zulu language.

What will I be asked to do? Provided you give consent to involve in the study, you will be interviewed according to a structured questionnaire and your file will be reviewed for other relevant clinical details.

Confidentiality and anonymity: Efforts will be made to keep personal information confidential and you will not be identified in any way.

What are the risks and benefits of participation? There are no risks involved in being in this study. One of the benefits is that, the study will make public health educators understands the health seeking behaviour of women with cervical cancer and will promote adequate planning and educative initiatives.

Your Right as a participant: Your participation in this study is entirely voluntary. If any discomfort arises as a result of the question being asked, you as a participant are free to discontinue with the study with no repercussions. You have the right to withdraw from the study at any point.

For reporting of complaints, problem or further enquiries regarding this research please contact: biomedical research ethics, private bag x540001. Durban 4000. Tel: (031) 260 4769; 031 240 1074; Fax: (031) 260 4609; e-mail: ngwenyap@ukzn.ac.za **Contact details of researcher: O.**

Adejumo <<Cell: 083 218 2002>>

Thank you for your participation.

Appendix 1. 7 Informed Consent

Title of research project: The study of the health seeking behaviour of women treated for cervical cancer in Greys Hospital.

Name of supervisor: Dr Anna Voce

Name of research student: Ms O. Adejumo

Please circle the appropriate answer.

	YES	NO
1. Has the information document been read to you?	YES	NO
2. Have you had the opportunity to ask questions about this study?	YES	NO
3. Have you received enough information about this study?	YES	NO
4. Do you agree voluntarily to participate in this study?	YES	NO
5. Permission to access clinical record	YES	NO

Please ensure that the researcher completes each section with you. If you have answered NO to any of the above, please obtain the necessary information before consenting.

By continuing with the questionnaire can the researcher assume that this means that you are consenting to participate in this interview? YES NO

Signature

Date

Signature of Witness
(Where applicable)

Date

Signature of Translator
(Where applicable)

Date

Appendix 1. 8 Questionnaire to patient

Study Title: The study of the health seeking behaviour of women treated for cervical cancer in Grey's Hospital.

Code number:

Date:.....

A. Personal information

1. Age: Please tick appropriate box

1. ≤ 20 years	
2. 21 – 30	
3. 31 – 40	
4. 41-50	
5. ≥ 51	

2. Racial group: Please tick appropriate box

1.African	
2.White	
3.Asian	
4. Coloured	
5.other	

3. Religion: Please tick appropriate box

1. Christianity	
2. Muslim	
3. Hindi	
4. Traditional	
5. Other	

4. Marital Status: Please tick appropriate box

1. Single	
2. Divorced	
3. Widowed	
4. Married	
5. Other	

5. Educational level Please tick appropriate box

1. None	
2. primary	
3. Secondary	
4. graduate	
5. Post graduate	

B. Measure of socio-economic status

6. Employment status: Please tick appropriate box

1. Full time	
2. Part time	
3. Casual	
4. Not employed	
5. Self employed	

7. Household income categories: Please tick appropriate box

1. less than 60 000 per annum	
2. 60 000 – 100 000	
3. 101000 – 150 000	
4. 151 000 – 200 000	
5. 201 000 and above	

C. Household

8. Number of other people in household

1. 1-2	
2. 3-4	
3. 5-6	
4. 7-8	
5. 9 and above	

9. Who makes decision to seek health care in the family?

1. Self	
2. Husband	
3. parent	
4. Parent in law	
5. Other	

D. General use of health care facilities

10. Do you have access health care?

1. No	
2. Yes	
3 If yes: Clinic/ Hospital	
4. Pharmacy/home remedy	
5.Traditional healer	

11. What is/are the barrier(s) in accessing health care?

1. Cost	
2. Distance	
3. Transport	
4. Attitude of health worker	
5.Other	

E. Cervical cancer

12. What is cervical cancer?

1. A sexually transmitted infection	
2. Just a cancer like any other	
3. Disease from other medical condition	
4. I don't know	
5. other	

13. What do you believe about causes of cervical cancer?

1. Disease caused by virus/aids	
2. Punishment or Act of God	
3. Bewitched	
4. I don't know	
5.From previous pregnancy	

Φ. Knowledge about Pap smear

14. Have you ever had a routine pap smear?

Please tick appropriate box

1. Yes	
2. No	

15. Have you ever been referred for Pap smear?

Please tick appropriate box

1. Yes	
2. No	

16. Ever offered Pap smear in relation to other condition?

1. STI screening	
2. Family planning	
3. Antenatal screening	
4. other	
5. Symptoms of cervical cancer	

17) At what age was your first pap smear done?

1. ≤ 20 years	
2. 21 – 30	
3. 31 – 40	
4. 41-50	
5. ≥ 51	

18. Was your diagnosis made through the routine cervical screening?

1. Yes	
2. No	

19. Do you understand the diagnosis?

1. Yes	
2. No	

Γ. Recognition

20. Did you recognise the symptoms you had as cancer?

1. Associate symptoms with cancer	
2. Did not associate symptom with cancer	

21). Describe your general state of health.

1. Excellent	
2. Good	
3. Fair	
4. Poor	

H. Help seeking and health service utilization.

22. When you first noticed the symptoms, what did you do?

1. Home remedies	
2.Over the counter	
3.Traditional healer	
4.Health worker	
5.religious leader	

23. Do you have a support system since your diagnosis?

1. Yes	
2. No	

Appendix 1. 9 Checklists

CHECKLIST ON PERTINENT PATIENT'S DISEASE INFORMATION

24. Stage Characteristics

- 0 Carcinoma in situ, intraepithelial neoplasia.
- I Carcinoma strictly confined to the cervix.
- Ia Invasive cancer identified only microscopically. All gross lesions, even with superficial invasion, are stage Ib cancers. Invasion is limited to measured invasion of stroma ≤ 5 mm in depth and ≤ 7 mm in width.
- Ia1 Measured invasion of stroma ≤ 3 mm in depth and ≤ 7 mm in width.
- Ia2 Measured invasion of stroma > 3 mm and ≤ 5 mm in depth and ≤ 7 mm in width.
- Ib Clinical lesions confined to the cervix or preclinical lesions greater than Ia.
- Ib1 Clinical lesions ≤ 4 cm in size.
- Ib2 Clinical lesions > 4 cm in size.
- II Carcinoma extends beyond the cervix but not to the pelvic wall; carcinoma involves the vagina but not as far as the lower one third.
- IIa No obvious parametrical involvement.
- IIb Obvious parametrical involvement.
- III Carcinoma has extended to the pelvic wall; on rectal examination no cancer-free space is found between the tumour and the pelvic wall; the tumour involves the lower one third of the vagina; all cases with a hydronephrosis or non-functioning kidney should be included, unless they are known to be related to another cause.
- IIIa No extension to the pelvic wall, but involvement of the lower one third of the vagina.
- IIIb Extension to the pelvic wall and hydronephrosis or non-functioning kidney, or both.
- IV Carcinoma has extended beyond the true pelvis or has clinically involved the mucosa of the bladder or rectum.
- IVa Spread to adjacent organs.
- IVb Spread to distant organs.

25. HIV Status

1. Positive	
2. Negative	
3. Unknown	