

**CULTURAL FACTORS ASSOCIATED WITH MANAGEMENT OF A BREAST
LUMP AMONGST XHOSA WOMEN**

BY

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DECLARATION

I declare that *cultural factors associated with management of a breast lump amongst Xhosa women* is my own original work and that all other sources that I have used or quoted have been indicated and acknowledged by means of complete references; and that this work has not been submitted for any other degree at any other institution.

NOSIPHO MDONDOLO..... NOVEMBER 2001.

Full names

DATE

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ABSTRACT

A qualitative research design and an ethno-nursing research method were used to identify cultural factors influencing Xhosa women's health seeking behaviours associated with breast lumps. Focus group interviews were conducted to obtain data.

The research results revealed that these Xhosa women with breast lumps did not disclose some cultural factors which influenced their health seeking behaviours associated breast lumps. Registered nurses, sharing the same culture and language as the Xhosa women, revealed that Xhosa women with breast lumps sought treatment from traditional healers, prior to seeking medical care from the hospital and/or clinics. When they arrive at the hospital/clinics the breast lumps have often progressed to advanced ulcerated breast cancer, with poor prognoses and poor treatment outcomes.

Xhosa women lacked knowledge about the management of breast lumps. Health promotion efforts should address this issue at Primary Health Care services in the Eastern Cape.

KEY CONCEPTS

Cultural factors; intra-personal factors; management of a breast lump; Xhosa women; health seeking behaviours; advanced breast cancer; Transkei region; explanation of health, sickness and sick role.

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CHAPTER 1

INTRODUCTION TO THE STUDY

1.1 INTRODUCTION

This study looked at the health seeking behaviours among the Xhosa women with breast lumps from the former Transkei region of the Eastern Cape. Late presentation for medical care had been observed amongst these women. This delay results in poor prognosis, despite treatment, due to advanced breast cancer already established when they present for medical care for the first time. Once these behaviours are known and understood, strategies could be taken to ensure that breast lumps are detected in time for effective treatment and good prognosis.

1.2 THE RESEARCH PROBLEM

An in-depth investigation to establish the cultural factors and the health seeking behaviours associated with the management of a breast lump amongst Xhosa women has been undertaken. Once these factors are known, suitable strategies and recommendations could be developed so that early detection and treatment of breast lumps can be achieved, in order to thwart the inevitable progression to advanced breast cancer that is incurable.

1.2.1 The source and background of the research problem

Widespread cancer awareness programmes have been launched by health care professionals by means of health education strategies such as radio talks, and information sessions on early detection and management in the health

care centres, hospitals and in doctors' consulting rooms. Despite these attempts, there is still a notorious delay in seeking diagnosis and medical treatment for breast lumps, especially by the Black African Xhosa women in the former Transkei region, now forming part of the Eastern Cape Province in the Republic of South Africa (RSA).

The researcher observed that patients with breast lumps referred to Umtata General Hospital, following their first visits elsewhere, from the twenty two hospitals of both Regions D and E of the Eastern Cape Province (which form part of the former Transkei Region), present with advanced breast cancer. Some of the women's breasts have already swollen to double the size of the unaffected breast. Others present with breast cancer which has affected both breasts with ulceration, nodules and swollen local and regional lymph glands.

Breast cancer amongst Xhosa women from the former Transkei Region has previously been reported to be less common than that found amongst the White South African women. It is, however, an important health issue in this region. Stepien, Mugwanya, Malgas, Paton and Lucwaba (1998) highlighted breast cancer as the third most frequently occurring malignancy, after cervical and oesophageal cancers, amongst Xhosa females in the former Transkei. The main problem is late presentation for diagnosis and medical treatment for breast lumps, which leads to poor treatment results. Table 1.1 reflects statistics of persons, including women, with breast cancer who were diagnosed at the Umtata General Hospital over an eight (8) year period, that is from 1993 to 2000. The total number of women diagnosed with breast cancer was 432. Seventeen (17) males were also diagnosed with breast cancer over this period, although males do not form part of this study population. The first column of the table represents the eight years during which the observation was done, while the second column represents all those women diagnosed clinically with breast cancer at the Umtata General Hospital. The third column shows

the number of patients whose diagnoses of breast cancer were confirmed by means of histological tests, following on biopsies. The fourth column represents the number of women, while the fifth column shows the number of men who were diagnosed with breast cancer. The last column represents the sum total of patients with breast cancer who were diagnosed at the Umtata General Hospital. This data has not been published, but was obtained by consulting the patients' attendance registers of the hospital, monthly statistical reports and histology reports from the histology laboratory at this hospital.

Table 1: Xhosa women with breast cancer diagnosed at the Umtata general hospital over an eight (8) year period (1993- 2000).

| YEAR | PATIENTS DIAGNOSED CLINICALLY | DIAGNOSIS CONFIRMED BY LABORATORY | FEMALES | MALES | TOTAL |
|--------------|-------------------------------------|---|------------|-----------|------------|
| 1993 | 47 | 13 | 56 | 4 | 60 |
| 1994 | 31 | 22 | 51 | 2 | 53 |
| 1995 | 32 | 20 | 50 | 2 | 52 |
| 1996 | 30 | 21 | 48 | 3 | 51 |
| 1997 | 40 | 14 | 53 | 1 | 54 |
| 1998 | 47 | 7 | 52 | 2 | 54 |
| 1999 | 49 | 9 | 57 | 1 | 58 |
| 2000 | 30 | 27 | 55 | 2 | 57 |
| TOTAL | 306 | 133 | 422 | 17 | 439 |

The figures indicate an initial decrease in the incidence of breast cancer, but an increase leading up to 2000.

Cancer affects women of all race groups worldwide. Passik, Newman, Brennan and Holland (1993:227) observed that breast cancer affects one out of nine women in the industrialised western countries such as the United States of America (USA) and Denmark. Breast cancer in these countries has been found to be the most common form of malignant tumour, with an increasing incidence in the past thirty years. Countries with a traditionally low incidence have been observed to be experiencing the greatest increase in the diagnosis of new cases of breast cancer. However, a comparable situation needs to be investigated and confirmed in the former Transkei region. The possibility exists that the incidence of breast cancer may also rise in the former Transkei region in future. The latest developments in early cancer diagnosis and treatment, make it unnecessary for women to die of breast cancer. It is, however, imperative that breast lumps be investigated, diagnosed as malignant/non-malignant, and treated appropriately as soon as they are detected. The earlier the cancer treatment commences, the better the prognosis. By arriving late at the hospital, and requesting treatment for breast cancer during advanced stages, the patients receive very limited benefits indeed.

Statistics reported to the National Cancer Registry in South Africa in 1997 indicated that 4,084 new breast cancer cases and 1,252 deaths were reported to the Central Statistics Services. In South Africa breast cancer was ranked as the second most common malignancy identified among women in general (16.2%), but was ranked first in Whites (18.9%) and Asians (29.3%), whereas ranked as second in Coloured (20.2%) and Black (12.4%) females. It is the least common among South African Black females with the rate of 12.8/100 000, whereas the standardised rates with their white counterparts is 63.6/100 000 (Sitas 1997:4).

Clients, patients, their families and the society at large usually regard a cancer diagnosis to be a death warrant. The reason is that cancer generates a lot of anxiety for mankind, because of the knowledge that it is generally held to have a high mortality rate. In the minds of the lay public, the word *cancer* conjures up images of mutilation, pain and suffering, dependency on the health care team and friends, loss of sexual attractiveness, loss of potency and death. Although this view has been shared from the old literature by Bouchard-Kurtz and Speese-Owens (1981:57) and Tiffany (1981:30), the same observations have been made by the present day researchers and health care workers in the Eastern Cape Province of South Africa..

Wright (1997:1543) and Levin (1997:2) observed that Black South African women, including Xhosa women, regard breast cancer as being incurable, and believe that it inevitably leads to painful, distressing death with severe emaciation, debilitation and destruction of the person's role through gross disfigurement, loss of function and debility. This finding has been supported by the researcher's observations that the majority of Xhosa women with breast lumps only start seeking medical care once the initially painless lump in the breast begins to interfere with their daily living. For example, if the lump becomes painful, or the partner starts noticing and comments or complains about the breast size, there is pressure from the family or relatives to seek medical care. Studies done as far back as 1970s and 1980s (Hacking, Gudgeon & Lubelwana 1988; Kau 1997; Tiffany 1981; Wright 1997), report late presentation amongst Xhosa women, South African women as well as African American women with breast lumps. The consequences include poor treatment results with low survival and high mortality rates. Women diagnosed with breast cancer often reported changes in the affected breast only long after the disease had spread to the nearby lymph nodes.

Researchers like Searle cited in Tiffany (1981:4) and Ramphele (1986:3) highlighted that the mere thought of being admitted to hospital could be very frustrating to patients from traditional cultures, resulting in the majority doing "*doctor-shopping*" before attending even the nearest hospital. Some of the reasons for this behaviour are that hospitals are unpopular because of their long queues, few and over-worked staff and sometimes over crowded wards. It is even worse to be admitted in teaching hospitals where a patient is subjected to repeated examinations by student nurses and doctors in-training who are acquiring knowledge and skills, and who might maintain an impersonal approach towards patient care. Therefore Black African patients prefer to be cared for at home, where their extended family members can support them in their primitive home situation. During this period they are usually ridden with guilt feelings towards the husband and in-laws because their sickness is depriving them of the essence of their womanhood and of their roles and functions in society.

The problem of late presentation for diagnosis and medical treatment by Xhosa women with breast lumps is not an isolated problem. Hacking et al (1988: 62), in their experience at the Groote Schuur Hospital Breast Cancer Clinic in Cape Town, also encountered similar problems among their Black patients. Kau (1995:2) and (1997:8) also observed the same problem of late presentation for medical diagnosis and treatment of breast lumps amongst Black women from the former Bophuthatswana region, which is presently known as the North West Province. When these women presented for medical treatment for the first time, their breast cancer had already advanced to the third and fourth stages of breast cancer. It was found that the delay in seeking medical treatment was partly due to countrywide safaris in response to fallacious rumours of cancer cures that were spread by friends, neighbours, quacks and traditional healers. Some women reported having consulted fly-by-night care givers. Others responded by saying that, since the lump had not

been painful thus far, they did not associate it with breast cancer and therefore did not see any need to seek medical care.

There is a strong belief among the Xhosas that there is a "*man-made*" cancer, which will never be cured by Western medicine. Some people come to the hospital to seek diagnosis for ulcerated or swollen breasts, and go away for further treatment by the traditional healers, who are very popular among the Xhosa people as the healers of cancer and other "*man-made*" diseases. It is often believed that once the cancer has been punctured with the doctor's biopsy needle, the lump will grow bigger and it will kill its victim faster. Such a belief may explain why Xhosa women with breast lumps prefer to consult traditional healers, sangomas and herbalists. The phenomenon of not consulting any medical practitioner for breast cancer symptoms when the symptoms first appear is very surprising to health care professionals. It is very difficult to understand why a person would stay away from medical treatment until an initially painless lump continues to grow until it ulcerates. However, Williams (1993:10) once mentioned the principle, "*if it does not bother you, do not bother it*". This has been noticed especially among people with terminal illness and those who denied that they might have a serious health problem. This may be another explanation for the failure of women to seek medical diagnosis and treatment promptly after discovery of a breast lump.

1.2.2 Problem statement

Previous researchers have established that Xhosa women with breast lumps seek medical diagnosis and treatment for their breast lumps at a stage when advanced breast cancer is already present. Although more than twelve years have elapsed since the study by Hacking et al (1988:57) on late presentation by Xhosa women with breast lumps, this phenomenon is still being observed

presently among Xhosa women. Late presentation for medical diagnosis and treatment of breast lumps, has also been observed among women from other African countries.

Owor and Kawoya (2000:24) observed late presentation in Ugandan women with breast lumps, whereby the majority of women present for the first time for medical treatment with large inoperable malignant breast tumours. There may be various reasons for delays in seeking medical diagnosis and treatment for breast lumps. According to Chandra (2000:27) cultural factors coupled with personal, social and economic factors, have been observed to contribute to this phenomenon among Indian women. According to Kau (1997:7) when a health problem associated with cancer affects one family member, the whole family experiences a cancer crisis, as manifested by a variety of emotions such as guilt, fear and powerlessness. Various opinions are shared regarding treatment options. Stepien et al (1998:1) and Sitas (1997:4) mention that although cancer of the breast has been found to be the third most common malignancy, following cervical and oesophageal cancers, among Xhosa women in the Transkei region, there is a great need to establish factors leading to delays in seeking medical diagnosis and treatment after discovery of a breast lump. Once the factors associated with late presentation for diagnosis and treatment for breast lumps in Xhosa women have been established, culture congruent health education campaigns on early detection and treatment of breast lumps, aimed at women, families and the community at large, could be developed. With early detection and early treatment of breast lumps, there is a high rate of cure without mastectomy, which destroys a woman's dignity. Whereas if breast cancer is diagnosed late when there are already metastases to other distant areas of the body, there is very little if anything that can be done to treat it successfully.

In this research, the researcher proposed an in-depth qualitative study to determine why Xhosa women present late for medical diagnosis and treatment for breast lumps. The focus was specifically on their health seeking behaviours and the intra-personal and cultural influencing factors. The problem statement for this study was therefore:

What is the nature of the health seeking behaviours of the Xhosa women with breast lumps, and which intra-personal and cultural factors influence those behaviours?

1.2.3 Significance of the problem

This study could potentially contribute towards health professionals' understanding of the intra-personal and cultural factors that contribute towards delayed presentation, by Xhosa women with breast lumps, for medical diagnosis and treatment. The body of nursing knowledge would be enriched and health care professionals could gain insights into the cultural values and practices of the Xhosa patient. This could serve as a foundation for planning and rendering culture congruent care pertaining to breast lumps as well as the prevention and treatment of breast cancer. Culture congruent care could potentially result in Xhosa women being more inclined to seek medical care from hospitals and clinics soon after discovering breast lumps.

1.3 GOAL OF THE RESEARCH

The goal of the research is stated in the form of both the research purpose and research objectives.

1.3.1 Statement of the purpose of the research

The purpose of this research study was to explore the health seeking behaviours of Xhosa women in the former Transkei region of the Eastern Cape Province, and the cultural factors that contribute towards delays in seeking medical diagnosis and treatment for a breast lump. The aim was to develop recommendations that would enable health care professionals to render more effective preventive and promotive breast cancer care.

1.3.2 Statement of the research objectives

The objectives of the study were to:

- *describe the health seeking behaviours of Xhosa women with breast lumps*
- *explore the intra-personal factors that influence health seeking behaviours of Xhosa women with breast lumps*
- *explore the cultural factors that influence health seeking behaviours of Xhosa women with breast lumps.*

1.4 DEFINITIONS OF CONCEPTS

Conceptual definitions are given for the key concepts of the research.

1.4.1 Cultural factors

Culture refers to a totality of learned and transmitted beliefs, values and life experiences of particular human groups essential to generate and establish credible ethical and moral care knowledge (Leininger 1990:49).

For the purpose of this study the term *cultural factors* imply values, beliefs and practices that contribute towards delay in seeking medical care, resulting in advanced breast cancer.

1.4.2 Intra-personal factors

For the purpose of this study the term intra-personal factors imply feelings, knowledge and personal experiences that contribute towards delay in seeking medical care for a breast lump.

1.4.3 Management

Thompson (1992:538) defines management as the ability to cope or succeed in controlling. For the purpose of this study management implies health seeking behaviour associated with the ability to investigate, diagnose and treat breast lumps.

1.4.4 Breast lump

For the purpose of this study breast lump implies any tumour, mass or swelling found in the breast.

1.4.5 Health seeking behaviour

For the purpose of this study health seeking behaviour implies the institutions visited to seek medical care, practitioners consulted and any measures taken to treat breast lumps.

1.4.6 Xhosa

The term Xhosa is derived from Khoisan (Khoi & San) tribe who were occupiers of the Cape Colony when the 1652 Settlers landed. They were also referred to as Kosa meaning angry men, sometimes known as the Black peoples or Bantu speaking peoples with the characteristic click sounds in their language (Elphick & Gilliomee 1989:2-3).

For the purpose of this study Xhosa refers to a group of people with traditional values, beliefs and practices, residing in the former Transkei region of the Eastern Cape in the RSA.

1.5 FOUNDATIONS OF THE STUDY.

The research was based on various assumptions, namely:

- There is insufficient research evidence about the intra-personal factors and cultural values, beliefs and practices that influence the health seeking behaviours of Xhosa women with breast lumps. Therefore, further research on this issue is warranted.
- Valuable information about their knowledge and personal experiences associated with breast lumps, and cultural values, beliefs and practices associated with health seeking behaviours for breast lumps could be obtained from Xhosa women suffering from breast cancer. They are valuable sources of information on both their own inner world and culture, as well as their health seeking behaviours associated with breast lumps.
- Greater insights by the health professionals into the knowledge and experiences of Xhosa women with breast lumps, and the cultural values, beliefs and practices influencing their health seeking

behaviours could be used as a foundation for cultural competent nursing care aimed at early detection and treatment of breast lumps.

1.6 RESEARCH DESIGN AND METHOD

An exploratory, qualitative research design, involving the method of ethnography was utilised in order to achieve the research objectives and to ultimately address the problem statement. A small sample size of the key respondents was used to allow for an in-depth investigation on the topic under study. General respondents were also included in the study for verification of responses given by the key respondents. Semi-structured data collection was done using interview guides through the focus group interviews. Data management was done with the aid of a computer program, after which data was analysed qualitatively.

1.7 STRUCTURE OF THE RESEARCH REPORT

The research design and method, as well as the research findings are reported upon in the form of a dissertation. The structure of the dissertation is as follows:

| CHAPTER | CHAPTER TITLE | CONTENT OVERVIEW |
|---------|---|---|
| 1 | The source and background of the study. | Goal and purpose of the research, objectives, significance, definition of concepts and structure of the research report |
| 2 | Literature review | Review of books, research reports, journal on the topic under study |
| 3 | Research design and method | Method and design used for the study |
| 4 | Data analysis and research findings | Analysis of collected data and findings obtained |
| 5 | Research results, conclusions and recommendations | Final chapter comprising conclusions and recommendations |
| | | |

1.8 CONCLUSION

Chapter 1 presented an overview of Xhosa women's propensity to delay in seeking medical care for breast lumps in the Eastern Cape Province. These behaviours cause delays in diagnosing and treating breast cancers. The significance of researching the reasons for Xhosa women's late health seeking behaviours was addressed.

The goal, purpose and objectives for the research were provided, as well as definitions used throughout this research report. It was indicated that a

qualitative research design, and the method of ethno-nursing would be adopted in a quest to achieve the research objectives.

The next chapter will provide a review of the literature relevant generally to breast cancer and particularly to reasons for delayed health seeking behaviours among women after they have discovered breast lumps.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In chapter 1 an overview of the topic of Xhosa women's delay in seeking medical care for breast lumps in the former Transkei region of the Eastern Cape Province was presented. These behaviours resulted in the breast cancer having already progressed to an advanced stage when the Xhosa women presented for the first time for medical care.

In this chapter, data required for the literature review was identified with the aid of the following computer assisted data base bibliographies namely:

- University of South Africa (UNISA) library literature search which included NISC Discover Report with references to South African (SA) material, periodical articles and books in the UNISA library, and material in SA libraries as well as in international libraries.
- OASIS Library Catalogue, Magnet search and CINAHL (R) Database to Southern African material, periodical articles and books in the UNISA library.
- University of Transkei (UNITRA) Medline Database computer search with references to SA material, research reports, periodical articles as well as international libraries.

The literature search revealed that breast cancer is a multi-focal disease, and so an outline is given about the variety of factors that are responsible for its

development. An overview of cultural perspectives on health, sickness, health seeking behaviour and the significance of the female breast is also presented. The following key words were used to retrieve literature from the computer: breast cancer; cultural factors; Xhosa women and breast cancer; health seeking behaviour, delay in seeking medical treatment and breast lump.

2.2 THE NATURE OF BREAST CANCER

The nature of breast cancer is discussed by referring to its patho-physiology, causes and clinical manifestations.

2.2.1 Pathophysiology

The term cancer covers well over 100 medical conditions, all involving the abnormal and excessive division of cells which threatens the health and life of the affected patients, local tissue invasion and spread to other distant body parts (Barraclough 1994:vi). Breast cancer is a blanket term for about 20 different kinds of malignancy that occur in the breast, whereby malignant cells originating from specialised breast tissues such as ducts, glands and lobules spread both locally and systemically (Faulder 1995:18).

According to Dawson (1995:119) there are various types of breast cancers. The most common type is infiltrating ductal carcinoma arising from the milk-producing glands, whereas other breast cancers occur between the ducts and elsewhere in the mammary tissue. Ireland (1993:28) concurs that of all malignant lumps in the breast, 80-90% are ductal carcinoma, 10% are lobular carcinoma, and the remainder (less than 10%) are some other forms of breast cancers such as papillary carcinomas. Lobular breast carcinoma has been found to be highly curable and is not invasive. Breast cancer types are classified by the pathologists according to the size of the tumour, extent of the lymph node involvement, and evidence of metastasis. Breast cancer is multi-

centric in origin; 41% of these tumours originate in the upper outer quadrant, and 25% originate in the central portion of the breast (Dawson 1995:119).

2.2.2 Incidence of breast cancer

Thompson (1992:445) defines incidence as the rate of occurrence of a disease. In this study incidence is the rate of occurrence of breast cancer. The researcher looked at the incidence of breast cancer from the perspective of different countries, racial and age groups and levels of industrialisation.

2.2.2.1 *Incidence of breast cancer according to country*

The incidence of breast cancer varies from country to country, and according to various race or cultural groups. According to Faulder (1995:18) the incidence of breast cancer is the highest in western countries such as the USA and the United Kingdom (UK).

Nogueira and Appling (2000:663) state that breast cancer remains the most common malignant tumour among USA women, being the second major cause of cancer deaths in women. It accounts for 29% of all cancers, and 18% of all cancer deaths. In 1999, the newly diagnosed cases were estimated to be 175 000. According to the American Cancer Society, 44 500 women are estimated to have died from breast cancer in the year 1996, and there were more than 43 000 deaths. Studies done by Berger and Bostwick (1994:41); Moormeier (1996:897); Amey, Miller and Albrecht (1997:102) as well as Burger (1998:84) found that breast cancer in the USA is the most common cause of death in women between 15-75 years of age. Breast cancer accounts for 32% of all cancers. In the USA there is a relatively low incidence of 95.8/100 000 among Black women as compared to White women with a higher incidence of 112.7/100 000. Differences in breast cancer incidence have also been noted

according to areas. For example in the USA, Hawaii's White women's breast cancer incidence rate was 80.0/100 000; whilst that of Black women from San Fransisco was 57.9/100 000.

Breast cancer is listed in the UK as the most common malignant tumour of women, with a high mortality rate, ranked second only to that of the USA. According to Denton (1996:54), in the UK breast cancer is the most common malignancy among women aged 35-55. There is a rising incidence rate from 10/100 000 among women below 30 years of age to 150/100 000 in women aged 65 or older. Three hundred new cases are diagnosed with breast cancer weekly. A total of 24 5000 women are diagnosed with breast cancer and 15 000 die annually. This mortality of 28.4/100 000 in England and Wales is described as a loss both in human and economic terms.

Japanese and other Far Eastern countries' women have a six times smaller risk of developing breast cancer than their western counterparts. Migration of women from these far Eastern countries to western countries, such as the USA, increases their breast cancer risks. This may be attributable to factors such as changed lifestyles, dietary habits, exposures to radiation and pollution. The situation in Japan and Eastern European countries has been found to be the opposite of the westernised industrialised countries. They have the lowest incidence of breast cancer accounting for 12.1/100 000. However, it has been established that this situation changes once women from Japan migrate to the USA or to the UK; breast cancer incidence increases among these women (Faulder 1995:18-19).

Breast cancer was identified as a leading cause of cancer related deaths among women in Poland in the 1980s, with a mean incidence growth rate of 3.5% per annum. In 1988 the crude breast cancer rate was nearly 40/100 000, indicating that 8000 women developed breast cancer in the total population of Polish

women. A high incidence, reaching its peak of 149.2/100 000, was noticed in the Warsaw urban areas as compared to 86.6/100 000 in the Warsaw rural areas (Faulder 1995:18-19).

Greenberg (1993:19) mentions that third world countries like Saudi Arabia, Morocco and Kenya have been found to have breast cancer as the second most common malignancy, following cervical cancer.

Evaluation of world trends clearly indicates that the incidence of breast cancer in the RSA will probably continue to rise among all population groups, although the breast cancer incidence is to date reportedly relatively low compared to that of the USA and the UK. The head of the National Cancer Registry further explains the African and the South African situations. In his health research, after carrying out some international comparisons, Sitas (1997:4) observed a higher increase in breast cancer incidence in the developed countries than in the developing countries. There is a relatively low breast cancer incidence in African countries. African women of Harare have a breast cancer incidence of 20.4/100 000. The incidence in Kampala, Uganda, is 16.4/100 000. In Gambia the incidence is even lower, namely 3.4/100 000.

The preceding discussions indicate that there is a relatively low incidence of breast cancer among Black women in both the western and underdeveloped African countries. However the trend of the increasing incidence of breast cancer could also affect Xhosa women from the Eastern Cape Province.

2.2.2.2 Breast cancer incidence and age

Tefanis and Avent (1998:58) mention that the risk of having breast cancer increases throughout life, with the greatest risk occurring after the age of 65

years. Ellis (1996:445), Guadette, Silberberger, Altmayer and Gao (1996:29) as well as Dolan, Lee and McDermot (1997:413) established that after the age of 30 years the incidence of breast cancer begins to rise, with the highest rates being among women aged 60 years and older. Since 1969, breast cancer incidence among the Canadian women has increased slowly and steadily, rising most rapidly among women over the age of 50 years. El-Thamer and Wait (1999:242) as well as Aziz, Hussain, Sohn, Mediavillo, Saitta, Hussain, Brandys, Homel and Rotman (1999:439) reported that 37.7% Black American women, younger than 50 years of age were found to present with more advanced disease, as compared to 24.7% for Caucasians. This clearly indicates that, although Black women are less at risk for developing breast cancer, they are more likely to present with advanced breast cancer when they seek medical care for their breast lumps. Seeking medical care as soon as a breast lump is discovered would enhance the prognosis.

Kau (1997:7) and Greenberg (1993:13) reported similar findings in South Africa. They reported that the highest breast cancer incidence occurs among White women over 40 years of age, with the highest breast cancer incidence in Black women under the age 40 years. Bezwoda (1998:30) stated that Black women in South Africa presented a decade earlier than their White counterparts. South African Asian women have breast cancer as the most common malignancy, with a mean age of 48 years at diagnosis. The South African Coloured women have a mean age of 54 years at the diagnosis of breast cancer.

The combination of the relatively young age of black women with breast cancer and the phenomenon that they seek medical attention at an advanced stage of the disease process necessitated this research. Both developing breast cancer at an early age and seeking medical care at an advanced stage of the disease, seriously jeopardise the Xhosa women's chances of receiving successful treatment and indeed of survival.

2.2.2.3 Breast cancer incidence according to urban and rural areas

As stated in section 2.2.2.1 the incidence of breast cancer in Poland appears to be higher in urban areas than in rural areas. However, the management of breast lumps and breast cancer in rural areas poses several problems. Ellis (1996:444-5) stated that although rural practitioners have been managing breast cancer for many years, it was difficult to find published material of their experiences. The resources and accompanying infrastructure for prevention and early detection found in the urban settings are mostly absent in rural areas. The management of breast cancer in an uneducated rural patient with traditional beliefs is one of the most difficult challenges for doctors working in cross-cultural health care situations. Patients from the rural areas tend to present late with 3rd and 4th stages of breast cancer, after having been treated by traditional healers, as well as medical doctors. The care provided is usually erratic, and the patient is often given conflicting advice. Furthermore, rural women with breast cancer are very reluctant to undergo surgical treatment, and the patient ends up attending several independent doctors, different hospitals and traditional healers with an ulcerating lesion. Kau (1997:21) referring to the South African context, labels this phenomenon a doctor-shopping panic response. Many factors need to be considered when treating a rural patient with breast cancer. Treatment in a far away hospital may also entail radiotherapy and/or chemotherapy, and possibly dying away from home. Family dislocations and unaffordable costs may ultimately be highly disruptive and unhelpful. Especially transport costs may lead to delays in seeking medical treatment for a breast lump.

The above scenario possibly applies to the Xhosa women with breast cancer, as the majority of these women live in rural areas and maintain traditional lifestyles. The researcher's observations at the Umtata General Hospital (refer

to 1.2.1) revealed that the majority of Black Xhosa women with breast cancer resided in the rural areas. They were referred from the peripheral hospitals for further management with advanced breast cancer, after having been treated for their breast lumps by various healers like doctors, traditional healers, diviners (*sangomas*) or faith healers. The purpose of this research was to determine the cultural factors that contribute towards delayed seeking of medical treatment of breast lumps among Xhosa women.

2.2.2.4 Breast cancer incidence according to racial groups

According to Austin, Cole and Wynder (1992:543) the breast cancer incidence rate was much lower 30 years ago in the USA among Black women than among White women. However, breast cancer incidence rates have since increased among Blacks, especially for younger women. Black women born since 1925 have probably been exposed to all of the causes of breast cancer to which White women had long been exposed. Late presentation by black women remains a problem, as the disease has already progressed to an advanced stage when they eventually appear for medical consultation for the first time. Advanced breast cancer at diagnosis by black women has been related to their poor access to health care, which is common to socio-economically disadvantaged populations. In South Africa, knowledge deficit and socio-economic factors could possibly influence the health seeking behaviour of Xhosa women as well. Chinese women in the USA have been observed to have a substantially lower breast cancer incidence (63/100 000) than their White counterparts (119/100 000) according to Facionne, Giancarlo and Chan (2000:258). However, a world wide increase in the breast cancer incidence rates has been observed, especially among the Chinese women who have lived in the West for a decade or longer, with an overall 80% higher risk than recent immigrants.

Breast cancer has been found to be less common among Black females, with the Age Standardisation Incidence Rate (ASIR) of 12.8/100 000 among Black South African women (Sitas 1997:4). However, the white South African woman has a higher breast cancer incidence of 63.6/100 000, being almost the same as that of Black USA woman of 65/100 000; whereas that of White USA woman is even higher at 89.2/100 000 (Sitas 1997:4).

Bezwoda (1998:27) mentions that breast cancer among Black women in South Africa is the second most frequent malignancy after cervical cancer. Among the white women breast cancer is the most frequently encountered malignancy, excluding basal and squamous cell cancers of the skin. In 1997, according to the National Cancer Registry (Sitas 1997:4), 1 250 new cases of breast cancer were diagnosed in Black South African women, as well as 2 016 cases in White women.

Kau (1997:1); Burger (1998:103) as well as Russell, Langlois, Johnson, Trentham-Dietz and Remington (1999:38) agree that breast cancer is less common among Black women (both locally and abroad), but their mortality is much higher when compared with that of White women. Late presentation with advanced disease results in poor survival rates at five and ten year intervals, poor prognosis and high mortality rates. Yood, Johnson, Blount, Abrahams, Wolman, McCarthy, Raju, Nathanson, Worsham and Wolman (1999:1488), Russell et al (1999:38) as well as Joslyn and West (2000:119) concur that African Americans had the same problem of late presentation, resulting in poor survival and poor prognosis. Five year survival was found to be 77% for Black women as compared to 84% for European American women. Yood et al (1999:1489) further state that White women have been observed to have longer disease free survival and good prognosis, as they present with early breast lumps/lesions for diagnosis and medical care. Therefore, breast cancer mortality rates have declined in White women by 3%, but have increased by 18% among Black women. This again highlights the

importance of this study which could potentially contribute towards the development of strategies to promote early presentation for medical treatment of breast lumps among Xhosa women in the Eastern Cape Province.

2.2.2.5 Breast cancer incidence, prognosis and the Xhosa women

Few studies have been conducted on Xhosa women with breast cancer. Hacking, et al (1988:57) as well as Murray and Gudgeon (1994:116) reported that 34% of Xhosa women with breast cancer presented with 3rd and 4th stages of the disease. Approximately 21% died within the first year, and only 53% completed treatment and survived for longer than a year. The overall five-year mortality rate followed up for five years was 52%. This showed a high death rate in Xhosa women due to late presentation for medical diagnosis and treatment for a breast lump.

2.2.3 Causes of breast cancer

The causes and pathogenesis of breast cancer are poorly understood according to Cameron (1994:417) and Faulder (1995:18). However, there are numerous known risk factors associated with breast cancer.

2.2.3.1 Risk factors

Risk factors are circumstances that result/contribute to exposure to danger/disease (Thompson 1992:310). For this study risk factors are circumstances that contribute to the development of breast cancer.

Age

Breast cancer incidence increases with age. Below the age of 25 years, the incidence is less than 1/100 000, but it rises to 397/100 000 by the age of 80

years. The median age at diagnosis is 57 years. The older one becomes, the higher the risk of having breast cancer. Furthermore, below the age of 30 years one is unlikely to develop breast cancer, although nearly 500 new cases are diagnosed in this age group each year in USA and UK. Therefore, women under the age of 30 years should not accept the brush-off 'you are too young for breast cancer' (Cameron 1994:417; Faulder 1995:19). Hacking et al (1988:57) in the analysis of their study of women with breast cancer highlighted that Black Xhosa women presented for diagnosis at a median age of 50 years, a decade younger than their White counterparts. Although Hacking et al (1988) is a very old study, it is worth mentioning in this research report because it is one of the few done on Xhosa women).

Gender

It has been established by Cameron (1994:417) that females have a higher risk of developing breast cancer than males. In the USA breast cancer risk has been found to be 102/100 000 in females, whereas it is 0.7/100 000 in males; whilst deaths account for 27.4/100 000 and 0.3/100 000 respectively. The above has been confirmed by Hacking et al (1988:58) in their study in the RSA, whereby 5 024 women were diagnosed with breast cancer between 1974 and 1987, of whom 12% were Xhosa.

Race

Mooimeier (1996:898) reported that White women have a higher risk of developing breast cancer than Black women. The incidence is 112.7/100 000 in White women against 95.8/100 000 in Black women.

2.2.3.2 Genetic factors

Genetic factors are circumstances originating from the genes that could lead to the development of abnormalities in a human being (Thompson 1992: 364).

For this study genetic factors are abnormal changes originating from the genes that could contribute to the development of breast cancer.

Family History

A woman who has a family history of breast cancer, has a higher risk of developing breast cancer than a woman with no such history. Familial risk reflects a combination of genetic and environmental influences that are often difficult to separate. For example, mother, sister, daughter as first degree relatives of a person with breast cancer may have it later in their lives. The risk increases also even to second degree relatives, like grand daughter and niece (Cameron 1994:417).

Hereditary Breast Cancer Syndrome

Hereditary Breast Cancer Syndrome (HBCS) is uncommon, and results from an autosomal dominant gene, and it accounts for about 5% of familial breast cancer cases. HBCS is associated with a 50%-80% risk of early pre-menopausal bilateral breast cancer. Bezwoda (1998:28), as well as Jacobs and Gibson (1998:15), explain that the hereditary gene is carried over in the genes in the cell. Two genes have been identified that are associated with breast cancer development. These are the BRCA 1 (Breast Cancer 1) and the BRCA 2 genes. Nogueira and Appling (2000:664) state that women with pre-menopausal breast cancer, and those with a strong family history of breast cancer, are more likely to carry the mutation. It is foreseen that tests will be developed so

that women at risk can be identified and managed before they actually develop breast cancer (Lea & Lawson 2000:418).

History of previous breast cancer

According to Cameron (1994:417), if a woman has had breast cancer in one breast, there is also risk of developing breast cancer in the other breast.

2.2.3.3 Endocrine factors or exposure to ovarian activity

Cameron (1994:417) identified the following factors as increasing breast cancer risks:

- early menarche, with onset of menstruation before the age of 12 years
- nulliparity, namely a woman with no children at all
- late pregnancy after the age of 35-40 years.
- late menopause after the age of 50 years as compared with menopause before the age of 45 years.
- irregular menstrual cycle.

It has been calculated that women who had 40 or more years exposure to ovarian activity have twice the risk of developing breast cancer than those women exposed for 30 years or less of ovarian activity. In addition to the duration of exposure, the levels of oestrogen and progesterone in the plasma and the overall profile of the plasma hormone levels during the reproductive life may be significant factors in the aetiology of breast cancer (Cameron 1994:417).

Exogenous Hormones

According to Faulder (1995:21), ongoing research indicate a correlation between breast cancer and long-term use of oral oestrogen. A woman who takes the contraceptive pills before becoming pregnant, has an increased risk of developing breast cancer prior to menopause. Whether the risk continues after menopause has not yet been established. However, this is not very relevant to the Xhosa women, as the use of oral contraceptives is limited among them. No study has been done yet on the possible association of the long-term use of contraceptives among Xhosa women with breast cancer.

The National Institute of Health (NIH) in the USA has shown concern about the use of intramuscular Depo Provera and breast cancer in South Africa. An amount of R1,3 million was made available for a longitudinal study to be done. South Africa had been found to be an ideal place for such a study since it was found to be one of the few countries where there was wide spread use of Depo Provera for a number of years. The study had been initiated by the growing interest in women's health issues world wide, and the fact that breast cancer is a common cause of death among South African White women, and the third most common cancer found in Black women (Katzenellenbogen & Bailie 1994:60).

2.2.3.4 Lifestyle factors

For the purpose of this study, lifestyle factors are circumstances originating from the way of life of people which result/contribute to the development of breast cancer.

Diet

According to Schlebusch and van Oers (1999:30) there is an association of high fatty dietary intakes, obesity and cholesterol in postmenopausal women with breast cancer. Black South African women who westernise their diet and lifestyle seem to be at particular risk of developing breast cancer. A western lifestyle diet is rich in saturated fatty acids and refined carbohydrates (Burger 1998:84). A western lifestyle is often also characterised by low levels of physical activity, which enhances the risk of obesity, and therefore increases the risk of developing breast cancer.

Jacobs and Gibson (1998:16) as well as Bezwoda (1998:28), agree that excessive alcohol consumption and obesity before the age of 30 years increase the risk of developing breast cancer. In the USA, Jones, Karl, Cumen, Owens and Dubrow (1997:394) as well as Hunter, Redmond, Chen, Austin, Greenberg, Correa and Shapiro (1993:1136), state that Black women (26%) were significantly more likely than White women (7%) to be severely obese at the time of diagnosis with advanced breast cancer. Further research on this aspect is recommended among Xhosa women who are inclined to be obese due to their staple diets of maize.

2.2.3.5 Environmental factors

For the purpose of this study these are circumstances in the surroundings, where people live, that could contribute to breast cancer.

Industrialisation

According to Cameron (1994:418) and Faulder (1995:18) there is no excessive risk that has been reported either in the urban or rural populations who live in industrial areas. However, an increased breast cancer risk occurs with the migration of women from the Far Eastern countries such as Japan to the westernised countries like the USA. This may be attributed to various factors such as changes in lifestyle and exposures to radiation. Within two generations, these Eastern women became as susceptible as their Western counterparts, indicating that an industrialised environment might increase women's chances of developing breast cancers. Austin, Cole and Wynder (1992:534) highlighted that environmental causes have an effect on an increased incidence rate of breast cancer amongst younger Black women in America. For example, Black women who were born since 1925 have been exposed to virtually all the predisposing factors to cancer to which White women had long been exposed. Correlation in the breast cancer incidence among Black women and the extent of their Caucasian genetic admixture was also found among the regions of USA. These findings could indicate that genetic and environmental factors probably interact to increase women's chances of developing breast cancer.

Ionising Radiation

The role of ionising radiation in increasing breast cancer risk has long been recognised. According to Stoll (1995:3) ionising radiation may have acute effects after high levels of exposure. However, prolonged exposure to lower levels of ionising radiation is of wider concern. Its sources include natural background radiation, occupational exposure from nuclear power, consumer products or medical procedures. Everyone is continuously exposed to natural background radiation in radioactive materials in the environment. Internal exposure to ionising radiation has been observed to come from radioactive

materials, which are naturally present in the body, and of those carbon-14 and potassium-40 contribute the greatest input. Radiation is capable of damaging DNA, thus causing chromosomal abnormalities of which only a few might be reversible. Studies of women who received multiple X-ray screening for monitoring pulmonary tuberculosis have shown an increased risk of breast cancer. If a woman with suspected hereditary susceptibility to breast cancer was exposed to mammography every year from the age of 20 years to 70 years, it has been observed that she has a higher risk of developing breast cancer (Stoll 1995:3).

Urbanisation

The South African population has become increasingly urbanised and exposed to many lifestyle-related factors associated with cancer genesis. Such factors include smoking and diets rich in unsaturated fats.

2.2.4 Clinical manifestations of breast cancer

Cameron (1994:418) states that there are early and late clinical signs of breast cancer. The clinical manifestations are subsequently discussed according to local manifestations and systemic manifestations.

2.2.4.1 Local manifestations

Breast cancer usually presents with a palpable lump or thickening, that is generally larger than one centimetre. The lump is usually painless, and is discovered by the patient on breast self-examination, when washing, or by the physician on physical examination. Most clinical signs and symptoms do not appear until the cancer is advanced, and has already invaded the surrounding

tissues or organs. These may include dimpling of the skin over a hard lesion, puckering of the skin due to pull on tissues to which the lump is adhered, alteration of the breast contour, nipple discharge and inversion of the nipple. When the cancer is very advanced, there is enlargement of the axillary and supra-clavicular lymph nodes and/or ulceration of the breast skin over the tumour. Generally the larger the mass the more easily palpable it is. However, such factors as the volume and the texture of the surrounding breast tissue, as well as the training and experience of the person examining the breast, influence its likelihood of palpability and detection.

2.2.4.2 Systemic manifestations

These are late signs which are experienced when breast cancer has spread to the various organs of the body. Cameron (1994:418) states that nearly ten percent (10%) of patients will have metastases at the time of initial diagnosis. Depending on the location of the secondary spread, different systemic manifestations will be observed. For instance, shortness of breath, cough and pleural effusions resulting from pulmonary metastases. There could be bone pains and pathologic fractures due to (bone) metastases; neurologic symptoms due to the central nervous system metastases; hepatomegaly, abdominal pain, and jaundice due to liver involvement. The researcher also noticed these manifestations of advanced breast cancer in Xhosa women presenting for the first time for medical diagnosis and care at the institution where this research was conducted.

2.2.5 Stages of breast cancer

According to Cameron (1994:422), in 1987 the Union Internationale Contre Le Cancer (UICC) and the American Joint Committee on Cancer (AJCC) adopted a uniform tumour, nodal and metastasis status (TNM) staging system.

Clinical staging of breast cancer is based on investigations like tissue sampling or biopsy; physical examination to determine the size of the lump; chest X ray and liver enzymes. In some cases abdominal computerised axial tomography (CAT) and bone scans are done to exclude liver and bone metastases respectively.

2.2.5.1 Tumour stage

This staging is based on the actual size of the tumour as follows:

- TO There is no evidence of a primary tumour present.
- TIS Carcinoma is in situ. Intra-ductal, lobular or Paget's disease of the nipple is present with no obvious tumour mass.
- TI A breast tumour, no larger than 2.0 centimetres in diameter, is present.
- TI a A breast tumour, not larger than 0.5 centimetres in diameter, is present.
- TI b A breast tumour, larger than 0.5 centimetres but smaller than 1.0 cm in diameter, is present.
- T2 A breast tumour, larger than 2 centimetres but not larger than 5 centimetres, is present.
- T3 A breast tumour, larger than 5 centimetres, is present.
- T4 This refers to any size tumour with direct extension to the chest wall, and/or skin ulceration, satellite skin nodules, and inflammatory cancer with diffuse induration.

2.2.5.2 Lymph node stage

In the lymph stage, the breast cancer has spread to the regional, axillary, supra-clavicular and other more distant lymph nodes in the body. Staging is based upon the involvement of various lymph nodes of the body.

- NO There is no regional lymph node metastases present.
- N 1 There are movable axillary lymph nodes present on palpation.
- N 2 There is metastasis to the axillary lymph nodes, which are fixed to one another or to one or other structures, especially the skin and/or muscles or bones.
- N 3 There are metastases to the internal mammary nodes.

2.2.5.3 Metastasis stage

In this stage, breast cancer has spread to the other distant organs/parts of the body through the blood stream.

- MO There is no distant metastasis present.
- M1 Distant metastases are present.

2.2.5.4 Breast cancer stages in relation to Tumour Node Metastasis status (TNM)

This is the most important factor that determines the mode of therapy.

| | | |
|-----------|-------------------------|--|
| Stage 0 | TIS NO MO | There is no tumour mass, no regional lymph node and no evidence of distant metastasis present. |
| Stage I | T1 N0 M0 | Cancer cells are present but they have not spread beyond the breast. |
| Stage IIa | TO-T1 N1 M0 T2 N0 M0 | Cancer has spread to the axillary lymph nodes |
| Stage IIb | T2 N1 M0 T3 N1 M0 | There is more than one lymph node involved under the arm. |

| | | | |
|--------------|---------------------|------|---|
| Stage IIIa-b | T0-T4 M0 | N1-3 | A locally advanced tumour larger than 5 centimetres is present, with extensive cancer in axillary or tissues near the breast. |
| Stage IV | Any T, any N, M1 | | This means metastatic breast cancer involving other distant organs of the body. |

2.2.6 Prognosis

The pocket Oxford Dictionary of Current English (Thompson 1992:715) defines prognosis as the forecast of the course of a disease. For this study prognosis is a prediction of the probable outcome of breast cancer, based on the fact that Xhosa women with breast lumps present late for medical care. Therefore, with advanced breast cancer, there are poor treatment results and short disease free survival periods after treatment.

2.2.6.1 Risk of recurrence

Cameron (1994:432) states that nearly 90% of all recurrence are detected within five years after diagnosis. The risk of local and systemic recurrence at five and ten years is related to the number of lymph nodes involved. Neoplastic cells spread to the local and regional lymph nodes. This is associated with a high risk of the disease recurring even after mastectomy and axillary clearance. The prognosis is very poor in these patients.

2.2.6.2 Five and ten year survival

The overall five year survival for patients with breast cancer is sixty four percent (64%), whereas ten year survival is forty six percent (46%). This is

determined by both the involvement of the lymph nodes and the pathologic stages of the tumour as explained below:

Survival based on nodal status

Bezwoda (1998:31) mentions that lymph node involvement remains the most important prognostic factor in patients with localised breast cancer namely:

- No lymph nodes involved, there is 78% five-year disease-free survival rate.
- One to three lymph nodes involved, there is 62% five 5 year survival rate, and 38% 10-year survival rate.
- More than three lymph nodes involved, 32% 5 year and 13% ten-year disease free survival rate.

This shows that the more lymph nodes that are involved the shorter is the period of survival.

Survival based on pathologic stage

The different stages of breast cancer have got different five and ten-year disease-free survival as explained below:

- Stage I has an 80% five year and a 65% ten year survival.
- Stage II has a 75% five year and a 55% ten year survival.
- Stage II b has a 65% five year and a 45% ten year survival.
- Stage III has a 55% five year and a 40% ten year survival.
- Stage III b has a 35% five year and a 20% ten year survival.
- Stage IV has a 10% five year and a 5% ten year survival.

All of these percentages indicate that the more advanced the tumour is at the time of diagnosis, the shorter the survival period and the poorer the treatment results, if any treatment is ever administered at all (Cameron 1994:432).

Adverse prognostic factors

Prognostic factors such as tumour size, axillary lymph node involvement and other adverse prognostic factors determine the advancement of the disease by the time diagnosis is made, and the prognosis status. For example, the larger the tumour, the greater the incidence of lymph node and distant metastases, thus the poorer the prognosis. Axillary lymph node involvement is the most accurate prognostic factor, as these are the first areas of the spread of breast cancer (Cameron 1994:423-3).

2.2.7 Importance of early detection

It is very important for breast cancer to be diagnosed early before it spreads. Breast screening, awareness education and health promotion should be emphasised so that any lump in the breast could be detected and investigated for malignancy, to reduce mortality and morbidity. Bezwoda (1998:30) maintains that the results of a substantial number of mammographic screening studies prove that early detection of breast cancer results in improved prognosis and survival. There is mounting evidence that screening is beneficial at all ages. In populations with cancer awareness and access to medical care these findings make mammogram screening one of the most important tools for further breast cancer mortality reduction.

Unfortunately, this is not the case for the majority of the population in South Africa, where few or non-existent mammogram facilities prevail. This service is mostly available only in the private health care institutions and in advanced

referral teaching centres. With the escalating costs of the health care services, the majority of the South African population, including most Xhosa women, are not able to pay for such a service. For example, none of the 22 peripheral hospitals in the former Transkei region has any mammogram screening facilities at all. The referral Umtata General Hospital recently acquired one mammogram machine. Owor (2000:24) highlights the fact that practical methods of cancer prevention and screening are often not in place in many African countries owing to their poor socio-economic status. It is therefore advisable for patients and the communities to be educated and taught about thorough breast self-examination for early detection and treatment of all breast lumps. Early detection of breast cancers significantly improve the chances of successful treatment, and it is also cheaper than treating advanced breast cancer. In other words breast self examinations will only succeed in saving women's lives if they seek medical advice as soon as they detect any lumps in their breasts.

Koning, Van Ineveld, De Haas, Van Oormarsen, Klijn and Van der Maas (1992:951) as well as Tsikayi (2000:3-4) emphasise the expense of treating advanced breast cancer, and therefore agree with the cheaper approach of early detection and prevention. They state that a woman with advanced breast cancer is commonly treated with hormonal chemotherapy and pain control analgesics for prolonged periods of time, due to the chronic nature of the disease. Total medical costs for diagnosis and treatment of breast cancer until death amounts to large sums of money. The economic realities faced by many Africans are highlighted by the Zimbabwe experience of an average Mashonaland woman with breast cancer. A woman with breast cancer often has to make a choice as to whether to buy medication or to buy food for her family. It was stated that a bottle of Mist Morphine Sulphate for advanced cancer pain costs the equivalent of one's monthly salary in Zimbabwe (Tsikayi 2000:3-4). This financial reality makes it impossible for many African women

with advanced breast cancer to use Western medicines, or even to control their pain.

Public awareness of regular periodic breast examination by mammogram, especially those females with big breasts, which are difficult to examine manually, should be emphasised. This should be supplemented with monthly breast examination a week after menstruation in pre-menopausal women, and in the first week of every month in post menopausal women. Women should be encouraged to report a breast lump promptly to ensure early diagnosis and treatment.

2.3 POSSIBLE REASONS FOR DELAYS IN SEEKING MEDICAL CARE FOR A BREAST LUMP

Researchers have identified different reasons for the time delay in seeking health care. As a result when the patient presents for the first time for diagnosis and medical care, the breast lump has become an advanced breast tumour, which is both very difficult to manage and has a very poor prognosis. Some of the possible reasons for the delays in seeking medical diagnosis and treatment are subsequently discussed.

2.3.1 Societal expectations

Society's expectations play a part in the perception about somatic disorders and the labelling of a health problem as worthy of medical care or not. For instance, these expectations may have the effect of making people withstand a lot of pain, because society expects them to do so. This could have disastrous effects as the patient may only seek medical care when a disease has fully established itself, and has possibly progressed to the advanced stages where treatment outcomes are poor.

In traditional African cultures, there has to be primary consensus by the family about the legitimacy of a health problem. Delay in seeking early diagnosis and care for breast cancer may be due to the reluctance of the woman to disclose that she has something wrong with her breast. Usually, disclosure of a health problem affecting a woman's breast leads to long drawn out consultations among the husband's family as to who the guilty person in the situation is, and what must be done within the traditional-cultural boundaries to assist the afflicted victim.

The perceived aetiology of the health problem may affect the nature of medical care sought. For example, if the family views a health problem as being caused by witchcraft, the help of a traditional medicine man (*sangoma*) will be sought. Uys and Middleton (1997:133) state that a *sangoma* is a traditional healer or medicine man who relies to a large extent on divination to discover the cause of discomfort. He/she is a person chosen by the ancestors, and clairvoyant powers are bestowed upon him/her. However, Western medical care will be sought if the health problem is perceived to be caused by unknown aetiology. The end result is often delayed health care seeking behaviour and the patient might present with advanced stages of a disease (Mkumatela 1992:27).

2.3.2 Fear and denial

The discovery of a breast lump links up with the patient's unconscious, pre-conscious and conscious ideas about breast cancer. Cancer in general is associated with severe suffering and death, both consciously and unconsciously. The very thought of possibly having any form of cancer awakens anxiety in most people, arising from its threats to life. In the context of a woman's breast, her integrity, her notions of vulnerability, and above all her identity as a woman, are affected.

Fear and denial have been identified as some of the reasons leading to delay in seeking medical care timeously by patients with breast lumps. The experiences of fear may be further exacerbated by other factors such as family and social pressures, let alone economic hardships which make health care a luxury that cannot be afforded.

Despite widespread cancer awareness programmes and campaigns, delay in seeking diagnosis and health care for breast lumps remains as prominent as it was fifty years ago. This delay might be an attempt to resolve or postpone the crisis brought on an individual by the suspicion of terminal illness. Women with breast lumps, who had been in touch with cancer campaigns, have reported that they were frightened to act on their acquired knowledge about cancer management. Fears of cancer diagnosis, pain, disfigurement, hospitals in general, and of surgery in particular, have been cited as the reasons for delays in seeking medical diagnosis and treatment for a breast lump. These fears may also be accompanied by concern about loneliness and uncertainty about the future. Some women may even demonstrate a fatalistic attitude towards their breast lumps. Fear of disfigurement may be a powerful force among patients about to undergo mastectomies, and it might deter some people from seeking medical advice upon the discovery of a breast lump, especially if the possibility of having breast cancer comes to mind (Brand & Van Keep 1995:58; Jacobs & Gibson 1998:44; Webb & Koch 1997:518). African American women expressed fear as their predominant feeling when they discussed breast cancer, in a study conducted by Phillip, Cohen and Moss (1999:569). All participants in the study stressed that breast cancer is seldomly discussed within the African American community. This secrecy leads to breast cancer being viewed as a white woman's disease. As a result African American women remain silent about breast lumps/lesions until the disease is too advanced for effective curative treatment. Lannin, Mathews, Mitchell, Swanson, Swanson & Edwards (1998:1806) observed that among African

American women, a significant number of them were reluctant to seek medical care for breast lumps because of the possibility that breast cancer might be present and that this disease would impact on their relationships with the men in their lives. They were afraid that their male partners would leave them if a cancer diagnosis became known, and they would no longer be physically attractive. The other fear was that these women might become burdens to their men and/or families both financially and emotionally.

The use of denial-like processes is influenced by a variety of personal, social and physical factors. Denial early in the course of a disease, has been found to be a common means of giving oneself time to adjust to a frightening reality, especially if the condition is unexpected, life threatening, or has important symbolic meaning. Painless lumps do not bother some women, and as a result some wait and hope that the symptoms will go away. Some may even think that the lump is an indication of a health problem other than breast cancer. If the symptoms do not disappear they seek medical care when the third and fourth stages of the breast cancer are already present. At these stages, the prognosis is low (Webb & Koch 1997:517).

2.3.3 Socio-economic reasons

According to Bedel, Wood, Lezotte, Sedlack and Orleans (1995:225) as well as Lannin et al (1998:1803), a delay in seeking early medical care and diagnosis by Black women has been associated with socio-economic reasons such as lack of money or transportation problems. African American women with breast cancer, who lacked private health insurance, also presented with advanced disease.

Mkumatela (1992:35) as well as Vorobiof and Chasen (1998:394), when looking at the South African Black women with breast cancer, reported that a

large number of socio-economically disadvantaged women are unable to consult medical doctors or undergo screening tests like mammograms. For early detection of breast cancer, the only viable resource available to these women is breast self-examination. Presently, there is not enough evidence that small tumours may be detected through breast self-examination. The former Transkei region is characterised by poverty, unemployment, and inaccessibility of health centres due to bad roads, resulting in women with breast lumps from this area presenting only when advanced breast cancer has already developed. Some women are dependent on their husbands and sons for financial support. The men often work in mines in other areas and send money once a month for basic needs like groceries, school uniforms and school fees for their children. The lump in the mother's breast may be neglected because there is no money to pay for health services, or no urgency may be associated with it.

Financial constraints in developing countries hamper access to preventive health care due to a lack of a suitable infrastructure - which is the responsibility of the government. Baider and Cooper (1996:36-37) highlighted that there are few resources devoted to early detection of breast cancer in the under developed countries, resulting in advanced disease at the time of patients' diagnoses. The absence of machines for performing mammograms, bone scans, and even X-rays, contributed to late diagnosis of breast cancer, especially among women with large breasts, as these are very difficult to examine manually during breast self examination procedures. This could be problematic because obesity, associated with large breasts, is associated with an increased incidence of breast cancer (as discussed in section 2.2.3.4).

2.3.4 Ignorance and misinformation

Ignorance from both patients and practitioners has been identified as contributing to advanced breast cancer on diagnosis as established by Piga, Graziano, Zarha and Cellerino (1996:47). For example, an elderly or poorly educated woman who does not realise the potential significance of certain symptoms such as a breast lump, and nipple discharge or retraction may not realise that breast cancer may be present. Stellman (1996:44 & 48) concurred that poor women often fail to take full advantage of screening and early diagnosis programmes. This may partially result from lower levels of knowledge regarding breast cancer and the prevention thereof, although cancer education programmes have been developed to address this problem. A number of studies have noted that women with lower levels of education and income are less likely to practise breast self examination, and are more likely to delay to seek medical care.

Many women from traditional cultures who have breast lumps are poorly informed about the modern cancer treatment modalities that are available. Also, for as long as no pain, ulceration or gross enlargement of the breast is experienced, and ill informed woman may delay her first medical consultation. As a result they fail to seek medical care. There are also myths that cancer can never be cured by Western medicine. For instance, one myth states that once a lump in the breast is 'disturbed' by a biopsy needle or any needle pricks, this intervention causes cancer to spread and kill the victim faster.

Ignorance is often compounded by misinformation. Kau (1997:23) confirms this myth and states that Black Bophuthatswana women with breast cancer often consult traditional healers after Western doctors have made the diagnosis. The traditional healer would then advise the patient against surgery. The reason forwarded was that '*once the cancer is incised, it spreads like*

wild fire'. Lannin et al (1998:1806) observed that African American women with breast cancer shared the same tendency of late presentation as the South African Black women with breast lumps for comparable reasons. African American women with breast cancer presented late for medical care due to the belief that '*letting air get into a cancer*' or '*cutting on*' cancer is to be avoided because it would cause the cancer to spread.

2.3.5 Conscious choice

Barraclough (1994:6) states that a patient may deliberately conceal her lump or tumour when she does not want other people to see it. This happens especially if one is pre-occupied with something which is regarded to be more significant than the painless breast lump. For instance, there may be a more pressing family crisis, requiring the woman's attention. The painless lump may not seem to be important at all.

2.3.6 Embarrassment

The significance of the breast to a female varies from culture to culture. In many cultures it is regarded as a special organ. The woman may experience embarrassment when a breast lump necessitates repeated exposure of the breast for examination and some women might even be reluctant to discuss certain symptoms affecting it. This may be worsened by the likelihood of a breast removal. A woman may not want to expose her breast for examination, especially if one is admitted to a teaching hospital, as there is a likelihood that one becomes subjected to repeated examinations by student nurses and doctors. This exposure might be coupled with indignity, without due consideration for the pain, discomfort and embarrassment caused (Ramphela 1986:4).

Box (1998:8) confirms the above, and states that Black women found it difficult and embarrassing to talk about the pubic area when a cervical cancer screening survey was conducted. This also applies to the breast. The idea of being touched by a strange doctor or a nurse is considered to be disgusting. Some women feel that only their husbands should have access to the private parts of their bodies, including their breasts. Some may even be so embarrassed that they would do nothing about genito-urinary, as well as breast diseases, until symptoms become too troublesome to bear.

Leininger (1991:82) highlights certain problems facing researchers when they are conducting studies among respondents with a traditional cultural background. Respondents are usually guarded against outside intrusions by the researchers whom they regard as strangers. As a result, there is usually reluctance to share cultural secrets, as this is viewed as private knowledge. Protection of local life-ways, beliefs, values and embarrassment in talking about organs like breasts to strangers may result in inaccurate data being presented to research participants. Truths may be modified to protect the self, family, community and cultural life-ways. Unfortunately, the inaccurate data may lead to incorrect findings and solutions. Health professionals may also experience the same as researchers, making timeous detection and treatment of breast lumps very difficult, especially during the early stages of breast cancer. Unless these factors, which were investigated by this research, can be identified and addressed, Xhosa women might continue to present late with signs and symptoms of breast cancer, such as the presence of breast lumps. Late presentation reduces their chances of being treated successfully.

2.4 CULTURAL CHARACTERISTICS OF XHOSAS IN RELATION TO HEALTH, SICKNESS AND HEALTH SEEKING BEHAVIOUR

For the benefit of this study, it is important to and necessary for the reader to understand the origin of the Xhosa women from the former Transkei region of the Eastern Cape Province.

2.4.1 Origin of the Xhosa.

Elphick and Gilliomee (1989:2) explain that Xhosa is derived from Khoisan (that is Khoi and San) meaning Hottentots who were occupiers of the Cape Colony when Jan van Riebeeck landed in 1652. With the collapse of the Khoisan tribe and the colonial expansion, different tribal groups appeared. Khoi or Hottentots were called Black or Bantu speaking peoples, and sometimes referred to as Kosa meaning angry men. Roberts (1995:8-9) explains that the Bantu speaking peoples developed into two main Bantu-speaking language groups, namely the Sotho/Tswana and Nguni. The latter composed of Zulu, Swazi and Xhosa. The main difference between the Nguni and the Sotho/Tswana languages was clicks sounds that remained in the Nguni language group. The clicks in the Nguni language were derived from the Khoisan with whom the Nguni mingled. By 1750 the Xhosa was the most powerful of the Southern Nguni peoples.

2.4.2 The location of the Xhosa

For the benefit of this study it is necessary to know where the Transkei region of the Eastern Cape Province is situated, because it is where Xhosa people who form the study population are located. The Transkei region was formed through the extension of direct colonial rule to certain areas. This colonisation began in 1879, with the incorporation of various territories of Fingoland,

Idutywa and Griqualand East into the Cape Colony and ended with the annexation of Pondoland in 1894. This region is situated in the south-eastern part of Southern Africa. It borders the Indian Ocean in the south-east, the Kingdom of Lesotho in the north, and Northern Cape and the Free State Provinces in the north west. The Western Cape Province is situated in the south-west and the KwaZulu Natal in the north east. This area covers an area of 4 365 263 hectares (South African Population Census Report 1996). The peoples of this region are customarily referred to as the Xhosas, consisting 12 tribes, each with its own kings and chiefs.

2.4.3 Cultural values and beliefs of the Xhosa

Tiffany (1981:30) as well as Hacking et al (1988:58) state that the Xhosa group of people are tradition-bound, and steeped in cultural beliefs and practices relating to the prevention and control of disease. For instance, they have their own way of interpreting symptoms, such as the presence of a breast lump, and breast cancer. Xhosas believe that most of their ailments, except for accidents and trauma, are due to witchcraft. Ancestor worship dominates their lives, and they believe that by offending the ancestors harm will come to them. For example, it is a traumatic experience for a Xhosa woman to undergo a mastectomy. The removal of a breast both completely destroys her role in the Xhosa society, and it displeases the ancestors. Xhosas believe that by seeking the aid of a 'White doctor' they may offend their ancestors. Many of them undergo a purification ceremony when they return home from their visits to the government hospitals or clinics.

Kau (1997:26) further explains that a mastectomy among Black patients threatens the sexual life of a woman. The fear that the husband may decide to leave her for a younger healthy woman dominates the woman's mind. Due to the minor position occupied by women by virtue of the bridal price system

(*lobola*), the husband has control of the woman's body, and therefore has to give consent for any surgical intervention. Paying "*lobola*" gives the Xhosa men the right to possess his wife in the same way that he possesses cattle, a car or a house that he bought and paid for. Legally, this is not the case, but culturally this practice has to be followed otherwise the woman may be ostracised by her in-laws. Black women consider the breast to be a sexual organ, and therefore a certain amount of privacy is attached to its exposure. Handling and prodding by a stranger who is not the woman's husband is viewed in a negative light. This explains Xhosa women's apprehension of having their breasts examined by doctors, who are often White men. This fear is aggravated if the woman's breasts are examined repeatedly by student nurses and/or medical students. Xhosa women, who fear the anger of their husbands if other men handle their breasts, fear breast examinations by male doctors, particularly White male doctors.

2.4.4 Explanation of health

Kau (1997:11) defines health as a '*state involving the inter-relatedness of physical, mental, spiritual and social factors*'. In this definition emphasis is placed on the whole individual and his/her interrelationship with society. The goal of health calls not only for the cure or alleviation of disease, rather it looks beyond and strives for maximum physical, mental and social efficiency for the individual and his/her family, as well as society. However, it is culture that determines which symptoms are legitimate for seeking medical care and which are not.

Health in traditional societies has connotations of good, blessing, beauty and all the positive values in life. It is further explained that health in traditional societies is symptomatic of a correct relationship between a person and his/her natural, supernatural and social environments. It is because of the

latter that, when a member of the family falls sick, the whole family and sometimes the whole society is deemed to be affected, especially if the sick person holds a key role in the environment where he/she resides. Among the Xhosa, while a person may be ill, he may say "*sihamba nako*" which means that one is sick but goes along with it; in other words the symptoms are not severe enough to legitimise seeking medical care (Mkumatela 1992:26).

2.4.5 Explanation of sickness

Sickness can be interpreted in terms of a biomedical perspective (having a disease) or a socio-cultural perspective (being ill).

According to Mkumatela (1992:26), illness to a Xhosa is viewed as being a culmination of all that has fallen out of balance, and the patient together with the family start to ask questions, some of which do not have answers. Traditional beliefs maintain that a spontaneous onset of an illness is caused by an outside person or agency. Kubukeli (1999:3-4) agrees and states that a detailed biomedical explanation, based on germ theory is foreign and irrelevant to a Xhosa. Conceptualisation of sickness is reflected in the manner in which the patient will describe his/her experience of being ill, a manner, which gets lost in the interpretation from Xhosa to English. For example, the patient with congestive cardiac failure will say in Xhosa: *'At night when I go to sleep, something materialises from nowhere, grabs me by the chest and squeezes hard, closing off my breath'*. In the patient's mind, he/she has an image of an external entity literally descending on the chest. The nurse would likely translate this to the doctor: *'At night when I go to bed, I have shortness of breath'*. Subsequently, the doctor would probably start to discuss the symptoms, which in the Xhosa mind are of minor importance, and totally ignore the *'suffocating entity'* which is foremost in the patient's mind. For this reason the Xhosa patient feels it is essential that he/she receives parallel treatment from a traditional healer who can deal with the source of the illness and the fears of the patient while the

Western doctor treats the symptoms. From a biomedical perspective, the Xhosa patient will most likely value laboratory tests and the physician's physical examination, which may reveal pathological evidence that treatment is required.

Kubukeli (1999:4), a qualified practising traditional healer, explains the hierarchy of vital powers beginning with the most powerful divinity followed by lesser entities. These are ancestral spirits, brought about through the agency of living persons, animals and inanimate objects. Any form of ill health is always traceable to some form of imbalance between persons, or between an individual and his environment. A sick person may be the source of this imbalance failing to observe certain rites or possessing undesirable personal attributes, thus incurring the wrath of the ancestors.

Wright (1997:1541) highlights the fact that socio-cultural perspectives play an important part in the way the Xhosa explain sickness. There is a belief that witches and sorcerers (*abathakathi/amagqwira*) representing another misfortune, produce illness. Among the 120 Xhosa patients interviewed by Mkumatela (1992:28), 61% believed that sorcerers could make people sick; 25% believed that evil spirits, who are evil human beings, cause breast lumps and breast cancer. The evil human beings harm others through the use of "*uthikoloshe*" (a small hairy being with the shape of a man) or through the use of substances like herbs. The illnesses that are induced by these evil people are often referred to as the 'illness of the people'. Sorcerers are believed to put poison into the patient's body in the form of cancer during one's sleep. Once the poison enters the body, it moves to a specific area, in this case the breast. Unless the cancer is drawn from the body through special "*imbiza*" (an indigenous African medicine), it eventually kills the patient. This explains why many traditional Xhosa treatments make the patient vomit. Expectorants and purgatives are also used frequently to rid the person of something bad causing his/her illness. To a Xhosa illnesses can result from contamination as

a result of touching a dead body, crossing the trail of specified wild animals, or breathing 'bad air'. Other bad things like "*umeqo*" (stepping over a bewitched path or object) can 'enter' a person to cause illnesses, leading to the concept of illness as a distinct entity operating within the person. Sometimes it is believed that spirits are caused to enter a person (more commonly a female) to control her mind and behaviour. Illness can enter the sick person through some form of deliberate food poisoning (*idliso*). Cocks and Dold (2000:1512) concur that the environment is considered to be riddled with undesirable elements against which one needs protection. Thus it is possible to absorb a multitude of harmful elements from the environment that can cause misfortune and ill health.

Illness could also be attributed to the influence by ancestral spirits. Mkumatela's (1992:28) research results indicate that 41% of women participating in this study indicated causation by ancestral spirits. If a woman had neglected certain customs or taboos, ancestors may become angry and inflict diseases, including breast cancer.

A third explanation of the cause of illness is viewed in terms of disharmony brought about by the actions of other persons because of jealousy or rivalry. Ordinarily, such a rival would employ the services of a medium (witch) capable of controlling and directing evil spirits to inflict diseases on the person (Mkumatela 1992:28).

The Xhosa patient conceives illness as an all-pervasive phenomenon simultaneously affecting the physical, mental and spiritual components of a human being. For this reason vastly different illnesses frequently have the same treatment such as emesis or elimination. When the cause of the illness, in this case breast cancer, has been established the stage of health seeking follows whereby the choice of treatment will vary accordingly.

2.4.6 Health seeking behaviour

Health seeking behaviour occurs in a stage of health care when an individual patient or those around him/her decide to seek expert help for an illness. According to Mkumatela (1992:36) and Kubukeli (1999:8-9) the stage of health care seeking begins when the individual or those around him/her decide to seek expert help. Psycho-social factors play a role in health care seeking behaviour. Traditionally, decisions to seek health care are reached slowly, and this may contribute towards delayed health care seeking behaviour. Usually consensus is sought, through deliberations among the patient's extended family, about the cause of the illness and the appropriate health seeking behaviours. The illness now ceases to be merely a biological disorder suffered by a particular individual, but becomes a social crisis involving a period of adjustment for a group of people, hence the tendency to have 'bridesmaids' accompanying the patient to a doctor. Kau (1997:2) further explains that when a Black woman experiences a breast cancer crisis, which is considered to be life threatening disease, the family members 'shop' around in search of healing and health. These patients only present for the first time for medical care during advanced stages of the disease, after numerous traditional healers' treatments have not cured the breast lumps, or if a traditional healer refers a woman to a Western hospital.

Black African people residing in the urban areas or communities have maximum exposure to Western civilisation, but retain traces of their cultural background. This results in consultation of traditional healers for various health related problems and symptoms, even by the urban Xhosas. While a patient may acknowledge the scientific basis of Western medical practice, there is sometimes a lingering fear that it may not succeed. As a result and safety precaution, the black patient may exploit both systems, that is, both the traditional and western medical care (Kau 1997:2). Kubukeli (1999:4) state that Xhosas seek answers as to what the reasons are for an illness. The cause is

viewed to be the important exposition of the illness itself. The question '*why am I ill?*' is more important than '*what is the nature of my illness?*' From a cultural viewpoint, man has never found the answer to the question '*why do patients fall sick?*'. All the doctors' scientific explanations answer the question 'how'. The causes of illness are often explained by the Western trained persons on the basis of how they happen, but not why they happen. That is why a Xhosa, in search of the answer to this question will consult "*sangomas*" (diviners), prophets, faith healers/spirit media and fortune tellers. The more desperate the person is, the more urgently one goes in search of the answer. Health care seeking behaviour depends on the explanation of an illness, such as breast cancer. Persons belonging to traditional cultures, like the Xhosa, therefore engage in culturally specific behaviours such as consulting traditional healers. This may result in delaying contact with the Western medical doctors. During the period of symptom observation, other factors like fear of hospitalisation, responsibilities around one's home especially if one is a breadwinner, and economic factors like a lack of money, influence the time taken to seek competent help. The choice of the health care provider is often determined by the type of help available, cost to be incurred and perceived cause of the disease. Prayer and repentance, not penicillin, may be seen to cure sickness due to sin, although sometimes both may be used simultaneously.

Perceived aetiology of the disease determines the type of medical care to be sought. Illnesses that are deemed to be of supernatural nature due to sorcery and witchcraft, are treated with traditional medicine. When the aetiology is uncertain, Western medicine is used. When this is not effective, the family may decide to try traditional medicine as well. These two types of treatment may be used simultaneously. If, however, the illness is perceived to be the result of ancestral anger due to neglect of taboos and customs by the sick person, a goat or a cow may be slaughtered to pacify the ancestors. This is done at the instruction of either older members of the family or a traditional

healer (Mkumatela 1992:37). Kau (1997:2) explains that delays occur as patients with breast tumours frequently go on countrywide safaris, on the back of 'bakkies' (vans), in response to fly-by-night reports of cancer cures. These searches exhaust the patients' and their families' financial resources. The patients could also become physically exhausted during all these trips.

Kau (1997:16) concurs that in a rural setting when a family member suffers from a life threatening disease such as breast cancer, the effects are not only experienced by the patient, but rather they reverberate throughout the family system. The patient and the family all experience the cancer crisis. Therefore, the traditional healer ('isangoma') of any kind will frequently move in with the family of the sick person and administer treatment not only to the patient, but also to the rest of the family.

2.4.7 Health practitioners and treatment strategies

The following discussion looks at how people from traditional societies regard health care practitioners and the treatment of illnesses; and the types of traditional healers available in the Black society.

People from the traditional areas have a traditional orientation towards health care in that they:

- pay little attention to initial symptoms, taking 5-7 days or even more before the symptoms are taken seriously
- seek professional help only after they have tried other remedies
- are not likely to be compliant to medical treatment

The presence of an alternative health care system, which at best is different from and at worst in direct conflict with that of the Western health care

system, can influence decisions as to which practitioners to consult for specific health problems. These beliefs may greatly colour the patient-doctor relationship and influence the decision as to whether or not to seek medical treatment (Mkumatela 1992:8-9).

Uys and Middleton (1997:133) explain that there are different types of practitioners consulted by the Black Africans from the traditional societies. These are traditional healers who are practitioners in Black society, who are responsible for various aspects of illnesses namely: diagnosis, healing, protection of the individual, family and property and supply of herbal medicines or drugs to avenge any misfortunes. Each consultation is commonly referred to as traditional healing, and is said to be effective in solving problems concerning witchcraft, sorcery and ancestral powers as causation of illness in both its mental and its physical manifestations. The types of traditional healers that are found in traditional societies are namely:

- "*isangoma*" or diviner is a traditional healer (usually female) who
- relies on divination to discover the cause of discomfort. She is chosen by ancestors, and her healing power is said to come directly from the ancestors. Usually she is the most highly regarded consultant in black society as a diagnostician and interpreter of the ancestors. When people are faced with unknown and unpredictable situations, they learn the will of the ancestors; through consultation with the "*sangoma*". The client's pertinent questions are answered in a way that they can understand. It is believed that divination provides an answer to ancestral instructions. Consultation is always in full view of the patient's extended family system, thus patients are never treated in isolation.
- "*umthandazeli*" (faith healer) belongs to a mission or an independent Church, and his/her power to heal is believed to come directly from

God, or indirectly through the healer's ancestors. A period of training may/may not be necessary.

- "*umprofeti*" (prophet) is a healer who belongs mainly to the Zionist Church, and has the ability to predict, heal and divine. She/he draws her/his healing powers directly from God or via guiding ancestors. She/he undergoes training, purification and specific initiation by another prophet (Uys & Middleton 1997:134-135).

Traditional healers are usually much more accessible to their patients/clients than medical doctors.

As the traditional healers are found in the same neighbourhood or villages and belong to the same culture as the patients from traditional societies, including Xhosa women, they have a better understanding of the patient's plight. The traditional healer entrenches cultural values and customs, and his/her role in the traditional oriented societies has been emphasised by Mahintsho (1990:60) and Kubukeli (1999:3-4). In many ways the traditional healer is the most important source of health information and care. The traditional healer is accepted in African traditional communities; and his method of divination and manner of dispensing information without touching the patient/client affords comfort and a sense of security to the individual. Xhosa women may therefore prefer to consult traditional healers instead of medical doctors. Many traditionally oriented people never reach the Western health services as they die in their homes under the care of the traditional healer.

Mkumatela (1992:8-9) states that in the former Transkei region the ratio of traditional healers to the population is higher than that of medical doctors. Dlamini (2000:2-3) confirms the higher ratio and accessibility of traditional healers in Swaziland and in South Africa. In Swaziland the ratio of medical doctors to traditional healers is 1:7,5 whereas, in South Africa, the ratio is 1:3

respectively. Seventy percent of traditional African people live in the rural areas, where 90% of patients with health problems consult traditional healers for either diagnosis or treatment. Molebatsi (2001), confirmed, in a television talk show (Two Way on 08/01/2001), that in South Africa there are about 200 000 traditional healers, and 89-90% of the Black population consult traditional healers and rely on them for health care.

Kubukeli (1999:4) state that some traditionally oriented patients consult western medical doctors to be diagnosed, and then return to their traditional healers for cures. This shows the trust and confidence bestowed by the traditionally oriented people on the traditional healers. The approach of the Western medical doctor may also not be compatible with the expectations of the patient. For example, when a mother brings a sick child to the modern medical clinic, the siblings are also brought as well. At the end of the consultation, and if the mother perceives a good relationship with the health care provider, she will frequently ask for the other children to be looked at as well. Usually, the provider will ask the mother in turn 'what is wrong with them?'. This question surprises a Xhosa mother who holds the traditional belief that if one family member is sick, the whole family is probably affected by the spell. She believes that the provider ought to know what is wrong with them. Therefore the confidence in the Western type of care diminishes to a Xhosa, as in traditional healing the whole family is strengthened if one family member is sick. When a traditional healer consults with a traditionally oriented patient, there is no dependence on an interpreter, as communication is conducted in the patient's language. The patient is able to express his/her inner feelings, fears, desires and wishes without the risk of being ridiculed as being superstitious. When communicating with a traditional healer clan names are used, thus allaying anxiety and creating openness and trust between the healer and the patient. Home-made mats (*amakhukho*) are often offered to the patient and the family for sitting, instead of the hard, uncomfortable chairs or benches which are used in the western health care

institutions. The traditional healer never says that he is not sure what is wrong with the client. In cases of doubt he will answer the client's queries and he will name the ailment. The process of naming is therapeutic in itself, and offers a favourable ground for treatment. It gives the client satisfaction that someone understands. The diviner is always a person of considerable status, who can allay clients anxieties, by the perception that their problems are understood, and can therefore be cured. Mbingi (1997:130) further highlights that during the traditional healer's divination there are no painful procedures. Modern medicine has numerous diagnostic procedures, which could be frightening and/or painful such as taking blood samples or performing mammograms. These may take up to weeks to complete before a diagnosis is made. In contrast, through investigations of the patient's social relationships with the significant others, both living people and those who have departed to the world beyond, divination takes place almost immediately.

Traditional treatment strategies are varied and the choice of strategy is dependent upon the perceived cause of the prevailing health problem. When the symptoms are not so severe, the person may treat a health problem such as a breast lump as an ordinary illness by the use of local herbs, home remedies and consultation of '*over the fence physicians*' who are local neighbours, herbalists and local men/women with skills in herbal treatments. Prayer and rituals may be employed to treat health problems that are perceived to be caused by God or the ancestors. Natural remedies are used to treat problems associated with disharmony with the environment. Strategies to lessen the effect of evil forces could also be employed (Mbingi 1997:130). Cocks and Dold (2000:1506) state that many individuals in the Eastern Cape province treat themselves without seeking advice at all, by buying and using medicines from the "*African chemists*". For example, a succulent plant which is purchased commonly to protect the user from the evil spirits, is known as "*intelezi*". Sometimes brightly coloured viscous liquid and salts are also purchased for protection from the evil spirits and for good luck. Even

traditional healers buy some of their medicines from the 'African chemists,' and treat their clients for diseases like cancer, when prior self medication by the clients has failed to achieve cure of a breast lump.

Relationships with the extended family are important in the treatment of an individual family member. The extended family members are sometimes required to contribute financially for the cost of the patient's treatment. Sometimes the family is required to make some social and spiritual contributions by undertaking the necessary spiritual rituals. Traditional healers employ holism in their diagnosis, care and treatment and are therefore able to render culture congruent care. The entire psycho-social milieu is taken into account, as is the patient's total social and spiritual context when diagnosing and treating illnesses. During the healing process the patient is accompanied by his/her family, because of the healer's dependence on ritual and ceremony. The patient and family members are those who initiate and continue certain rites, and the continued well-being of the patient is made his/her own responsibility. Thus the patient is made to feel that he/she has power over his/her health. Sometimes, even if the traditional healer's treatment fails, the patient may even conclude that he/she has not followed the instructions correctly, as the traditional healer is never wrong (Mkumatela 1992:36).

2.5 IMPLICATIONS OF BREAST CANCER

The more objective medical understanding of the most common implications of breast cancer are presented in Section 2.2.6. In this section, the emphasis is broadened to include the holistic view experienced by the sufferer.

2.5.1 Cultural significance of the breast

From early times women have been idealistically portrayed in sculpture, poetry and paintings as symbols of fertility and motherhood. Their breasts have been interpreted as the source of life; and were also associated with feminine beauty. Breasts are important to women because they are outward signs of their femaleness, of their nurturing capabilities and of their erotic potentialities (Schlebusch & Van Oers 1999:30).

According to Ireland (1993:29) as well as Schlebusch and Van Oers (1999:34), the female breast remains a symbol of motherhood and nurturance. The act of feeding young babies on milk secreted from mammary glands in the breast is what makes us mammals, as compared to fish, birds and reptiles. The breasts' ability to produce milk means that it can give life, and is therefore a symbol of fruitfulness and motherhood. The period of lactation for both a mother and her child is mutually satisfying and psychologically important. Maternal-neonate bonding is related to contact leading to mutually reinforcing reflex behaviours with biological breast-feeding. In the earliest developmental stages, the breast is normally experienced by the infant as the source of feelings for warmth, security and nourishment.

However, the female breast has become idealised in society in that it has become a woman's primary identification with her feminine role. Breasts represent a woman's outward signs of femaleness. Breasts represent both part of her conscious and unconscious image of herself. They form an integral part of a female body image thus providing a woman with a symmetrical physique. This contributes to female proportions and the concept of the self as a female, capable of fulfilling the feminine role. Modern cultures, especially western cultures, tend to have loaded the significance of the breast more in the direction of sexuality, desirability and sexual attractiveness, sometimes to

the detriment of the nurturance and motherhood aspects. Breasts have been seen to have erotic and sexual value. Breast size and shape are used as criteria for sexual desirability. The female breast is a greater source of erotic stimulation for men than for women. Most males become aroused when viewing the female breast, while their breasts are tactilely stimulated. For many women the breast may serve as a stimulus to their partners' sexual responses, and may serve to make them feel like desirable women when experiencing their partners' reactions. A female may also derive erotic pleasure from her own breasts. The sight of well-proportioned female breasts may be satisfying for both partners (Denton 1996:16). This shift of emphasis may in part, be linked to the trend, among western women, to forfeit breast-feeding during motherhood in favour of bottle-feeding (Schlebusch & Van Oers 1999:30).

The urbanised younger women from the traditional societies have adopted the same interpretation of the breast as those from the western societies. Breasts have become part of the obsession whereby the services of the plastic surgeon are employed more and more frequently for cosmetic and artistic reasons, rather than for medically essential reasons. After mastectomy, some of these women seek the services of plastic reconstructive surgery to maintain their posture and symmetrical physique. However, the older traditionally oriented women do not bother about the reconstructive surgery. They usually regard the amputated breast as having done its breast-feeding job, and therefore there is no need to pretend that it is still there. Some of the older women do not even use underwear to support their breast prostheses, which tend to be smaller than their remaining breasts. When these women are asked, some of the responses are, *'I am old. I am no longer interested in body appearance. I have had my time; I am just grateful to be alive after the operation'*. (These observations have been made by the researcher from some of the Xhosa women after mastectomy, and are not based on published research findings).

2.5.2 Psychological experiences of breast cancer and the psychosocial significance of the loss of a breast

The question arises as to how a woman may react to the fact that a symbolic organ, like the breast, would be threatened by the diagnosis of cancer. Chandra and Chaturvedi (1998:41) emphasised that breast cancer affects the body part that defines a woman. Her definition of security in feminine and sexual roles is disturbed, and her relationships to intimate and important others is threatened. Breast cancer carries the threat of death as well. Body image is further disturbed if breast removal has been offered as the treatment of choice, thus leading to significant changes in interpersonal relationships. Schomer and Horwitz (1993:296) mentioned that a confirmed diagnosis of breast cancer causes psychological, emotional and social problems besides the potentially life threatening physical aspects of the malignant disease itself. Breast cancer may be extremely traumatic because of the symbolic significance of this organ. The actual loss of the breast could precipitate acute feelings of loss for a body part. Fear, shock and depression are commonly experienced.

According to Ireland (1993:290) as well as Oktay and Walter (1992:33), a woman who has been diagnosed with breast cancer will experience both reactions at a psychological level and disruptions in her social relationships. Breast cancer means loss of key roles, changes in appearance and self-image, loss of control and an uncertain future. Psychological changes may include feelings of anxiety, anger, guilt, helplessness, fear of dying and depression. There may be a major disruption of existing goals, patterns of behaviour and beliefs. Breast cancer poses a major challenge not only to the person's physical well being, but also to her sense of identity and the continuation or maintenance of existing social relationships.

Thorne and Murray (2000:149) highlighted the patient's alienation caused by breast cancer, which can be framed in personal terms. Every woman with breast cancer suffers personal trauma. From the perspective of a patient suffering from breast cancer, the following statements were highlighted namely: *'you are in shock, facing a new situation, terrified to death'*. The emphasis is the reality that a woman with breast cancer has a life threatening disease, while all the other people around her do not have this problem. Everyone encourages her *'to look normal'* and *'to get on with life'*. Admission to hospital is referred to as institutionalisation, *'where they are labelled as patients'*, and *'compliance gains approval'*. She is thrust in a medical system governed by undisclosed rules, while the physicians speak to her in the private jargon of medical science she does not understand. All the above clearly indicates the psychological stresses and frustrations experienced by the women with breast cancer when they are admitted for medical care. These may be the reasons why Xhosa women delay seeking medical diagnosis and care for a breast lump and only reach the medical health care system when other traditional cures have failed.

Mastectomy contributes to poor adjustment, namely psychological upheaval ranging from mild anxiety to major depression. Losing a breast, or the possibility that this may happen, will mean different things to different women, and their reactions will be highly individualistic. It is damaging to the mind, body and emotions, and adjusting to it happening will require courage, will power and positive logical thinking of the highest order. The very word mastectomy tends to strike fear into the bravest of hearts. Such fears often hinder timely diagnosis and results in delays in seeking medical care for a breast lump. O'Hare (1987:43) and Kau (1997:29) concurred that breast loss forms the central emotional crisis of the breast cancer diagnosis. Mastectomy is equated with castration, and is considered to be a blow to the woman's sexuality, her feelings of motherhood and femininity. Breast cancer causes poor adjustment because of disfigurement and accompanying

problems related to self-presentation, like the scar and the 'lopsided' feeling, could cause more concern than the loss of the breast itself. Many women may feel that, because they have lost a breast they will no longer be sexually attractive or acceptable. Some may even feel that they are no longer equipped to play their feminine role because they have been partially stripped of their feminine identity. Some men may even feel sexually inadequate because their wives have only one breast. This situation may be particularly noticed among women who either use, or allow their partners to make use of their breasts as *arousing precursors to sexual intercourse*.

From the above discussion it is clear that breasts are regarded as more than the anatomical organs whose sole function is to produce milk. They are organs that hold psychological, social, sexual and cultural significance in that they are symbols of femininity and motherhood. They play an important role in the psycho-sexual development of women because of this symbolic significance. However, societal attitudes contribute largely to this symbolic importance. Therefore if a breast is regarded as being so important, early diagnosis and early treatment for breast cancer becomes mandatory to prevent unnecessary suffering and stresses caused by this debilitating disease. Kau (1997:19) mentions that the diagnosis of cancer to a lay person means 'death, a spectacular, wretched death which creeps slowly, invades and eventually devours the host'. It is therefore not uncommon for a cancer patient's obituary to read 'died after a long illness'. This long, debilitating illness could be minimised if patients sought medical care while the breast lump is still small, painless and curable. However, given the cultural significance of the female breast and the emotions that women are confronted with when they discover a breast lump, early medical diagnosis and treatment are often not realised.

2.6 CONCLUSION.

Cancer is still regarded by most women, including Xhosa women, as a life threatening disease and a stigma, so they tend to conceal their breast lumps or deny the possibility of having breast cancer. Unfortunately the lump continues to grow until the breast cancer is already advanced when the diagnosis is made. Very few studies have been done on cultural factors resulting in delay by Xhosa women to seek diagnosis and medical care for breast cancer. However, in the available literature of studies done in the Western countries, delay in presentation by Black women with breast cancer has been observed.

This study aims to establish the cultural factors that influence health seeking behaviour of the Xhosa women with breast lumps. Once these cultural factors are understood, culturally suitable strategies can be devised to promote early diagnosis and treatment of breast cancer, thus benefiting Xhosa women from the former Transkei by prolonging the disease free survival rate and prognosis. Therefore the task of the health care providers is to look at their (patients) perceptions related to health, illness and health seeking behaviour. These can then be incorporated into the health care system for early detection and prevention of breast cancer.

Chapter 2 explained the aspects of breast cancer namely: definition, the causes, clinical manifestations, staging and prognosis, incidence according to country, age, rural/urban areas, possible reasons for delay in seeking medical care for a breast lump, health, sickness and health seeking behaviour of the Xhosas with breast lumps and the implications of breast cancer. The following chapter will explain how this research was done. The research design and method are fully discussed.

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

In this chapter the author describes the research design and method that were followed to achieve the research objectives. The methods used for the construction of the data collection instrument, sample selection, data collection and data analysis are explained. Two groups of study populations were used for data collection, namely: key informants and the general informants. Data management was done with the aid of a computer program. Trustworthiness of the study was observed to ensure the integrity of the findings.

3.2 RESEARCH DESIGN

An exploratory, qualitative study was done to achieve the research objectives.

Exploratory research designs allow the researcher to gain the necessary insight to develop new ideas, concepts and theories regarding a problem under review. This study involved an in-depth investigation into the health seeking behaviours of Xhosa women with breast lumps, and the intra-personal and cultural factors associated with their health seeking behaviours. Exploratory research designs are flexible and synonymous with qualitative research, and therefore it is acceptable to use qualitative data collection methods (Brink & Wood 1995:316-317).

A qualitative research paradigm was chosen because of its systematic approach towards gaining an understanding both of the actions of people, and of such actions in terms of the research participants' own beliefs, history and context. It supports a holistic approach towards the research participants as human beings as well as their interactions with various factors within their environment (Babbie & Mouton 2001:271-272). Qualitative research is also effective in investigating emotional responses. Miles and Huberman (1994:10) state that well collected qualitative data focus on naturally occurring ordinary events in natural settings, to enable a researcher to capture real life issues and experiences from the perspective of those who are confronted with it. In this study respondents were expected to explain fully and in-depth, the intra-personal and cultural factors associated with their health seeking behaviours with regard to their breast lumps.

Qualitative research attempts to study human action from an emic perspective (Babbie & Mouton 2001:270) and gives powerless people a voice. This means that even those women who could not fill in questionnaires, because of their illiteracy, had a voice in stating their problems in their own words. It was revealed that the Eastern Cape had a 60% illiteracy rate (1996 Population Census). This allowed people themselves to come forth '*to take control*' of their knowledge and experiences, to share their inner cultural viewpoints, values and life ways.

According to Lemmer (1999:1) qualitative research aspires to capture that which people and their lives are all about, without preconceiving the categories into which information will fit. Babbie and Mouton (2001:270) mention that inductive reasoning is practised during qualitative research. Brink and Wood (1998:309) highlighted that during the data collection period the researcher is able to intuitively re-arrange and make sense of the unknown universe, opening up one or many new

fields in the process. This allows a researcher to discover new phenomena or to gain new insights into known phenomena. In this study, the researcher was able to approach data collection with an open mind to hear, from the respondents' points of view, what their health seeking behaviours were and what intra-personal and cultural factors were associated with their health seeking behaviours.

Brink and Wood (1998:312) state that a researcher must be sufficiently creative to be able to analyse the growing body of unstructured data, and derive new insights or new meanings from the data. During data-analysis the researcher looked for new insights, new understandings and new meanings from the collected data. Complex patterns of health behaviour and associated intra-personal and cultural factors were portrayed in sufficient depth and detail so that the investigator, who had not personally experienced a breast lump, was enabled to better understand this affliction as well as the sufferers' responses to its suspected presence.

3.3 RESEARCH METHOD

The ethno-nursing research method is discussed by referring to its general characteristics and by explaining how the researcher implemented this method.

3.3.1 The ethno-nursing research method

The ethno-nursing research method was used to conduct this study. Ethno-nursing is a qualitative research method, using naturalistic open discovery processes with the diverse strategies, techniques and tools to document, describe, understand and interpret the research participants' meanings, experiences, symbols and other related aspects bearing on actual or potential nursing phenomena. The ethno-nursing research

method is designed to tease out complex, elusive and largely unknown nursing dimensions from the research participants' local viewpoints such as human care, well-being, health and environmental influencers. It is an open discovery and a naturalistic, people-centred research method that permits people, (in this study Xhosa women from the former Transkei region with advanced breast cancer), to share their ideas about care in a spontaneous and informative way with the researcher. The ethno-nurse researcher is involved together with the population under study to discover their past events as well as cultural beliefs, values and ideas about human care meanings and general care experiences as lived (Leininger 1991:79).

When studying care phenomena openness to examining subjective, spiritual or supernatural experiences as well as those experiences lived through human care are required (Leininger 1991:79). This study investigated health seeking behaviours of women with breast lumps and the intra-personal and cultural factors associated with their health seeking behaviours. The ethno-nursing research method was considered suitable for this study because it helped the researcher to systematically document and gain greater understanding of the experiences and meanings of the respondents with regard to discovering a lump in the breast and resultant health seeking behaviours. Therefore, the ethno-nursing research method was suitable to discover, document, preserve and accurately interpret care meanings and experiences of Xhosa women who suffered from advanced breast cancer due to delayed presentation for medical diagnosis and treatment for their breast lumps.

3.3.2 Sampling

Sampling is discussed by referring to the research populations, sampling methods and the selected samples.

3.3.2.1 *The research populations*

Two populations were targeted for this research, namely Xhosa women who suffered from advanced breast cancer due to late presentation for medical diagnosis and treatment of their breast lumps and registered nurses caring for these women. The women who suffered from breast cancer were regarded to be the key informants, while the registered nurses were the general informants.

The target population with regard to the key informants were Xhosa women, hailing from the former Transkei region of the Eastern Cape Province, who had been diagnosed with advanced third (3rd) and fourth (4th) stages of cancer of the breast. The eligibility criteria were that they were adult women from the age of twenty years and above who attended the Umtata General Hospital, as a referral hospital for the 22 hospitals in Regions D and E of the Eastern Cape Province.

The general informants, were the registered nurses (Xhosas themselves) who cared for the Xhosa women both in the surgical outpatient department and in the female surgical ward of the Umtata General Hospital. The eligibility criterion was that they were directly involved with patient care delivery.

In each culture there is a generic (folk) or traditional health care system, in addition to the professional health care system (Figure 3.1). According to Leininger's theory, *Culture Care Diversity and Universality* (Leininger 1991:49), seven cultural and social structural dimensions influence a cultural group's perception of health, illness and care. These cultural universals are technological, religious and philosophical, kinship and social, political and legal, economic and educational factors, as well as cultural values and life ways. These cultural universals are shaped by the broader world view held by a particular culture, and are therefore

also culturally diverse. The Xhosa women who participated in the focus group interviews, represented the generic (lay) health care system. Registered nurses, on the other hand, although hailing from the same cultural background, have been socialised into the professional (biomedical) health care system, representing a scientific approach towards health, disease and health care (Leininger 1991:37-38). Thus including both lay women and registered nurses in the study, the researcher was able to gather data from participants who represented both the professional and the generic health care systems during the focus group interviews.

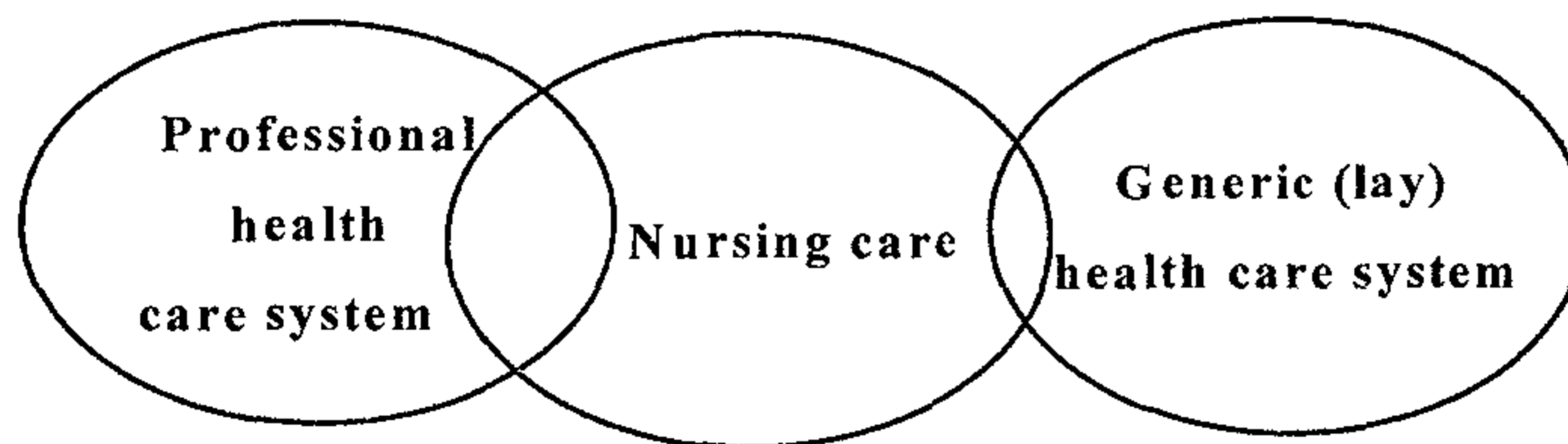


Figure 3.1 Health care systems

The researcher also represented the professional health care system. Although she too shared the same language and culture with the key informants, a measure of distrust was always a possibility, as nurses are sometimes regarded with suspicion. Therefore she also anticipated that the key informants might be reluctant to share information about their breast lumps and health seeking behaviour with her. It is not easy for a researcher to enter the life world of research participants especially when a sensitive research phenomenon, such as breast lumps and

cancer, is being investigated. The researcher also assumed that the respondents might be shy to openly discuss their individual private life experiences in front of each other in a focus group interview setting. To overcome the above potential limitations the researcher involved, not only the key informants, but also general informants in the study.

3.3.2.2 Sampling methods and sample sizes

A non-probability sampling approach, using the method of purposive sampling, was employed to obtain a sample of key informants. The women with advanced breast cancer who had been admitted to the surgical wards, or visited the Surgical Out Patient Department of the Umtata General Hospital for treatment and follow-up care, were included in the research study. This type of sampling approach was used because specific members of the population were required for the purposes of this study, and this approach allows the researcher to hand pick the cases to be included in the sample (Polit & Hungler 1995:235). The researcher was specifically interested in Xhosa women with advanced breast cancer who delayed seeking medical diagnosis and treatment for their breast lumps, and who were residents of the former Transkei region of the Eastern Cape Province. Focused group interviews were held with groups of three to four persons until all the questions were answered and no new data emerged. Therefore it was not possible to decide on a specific sample size as in quantitative research. Sampling was terminated when data saturation was achieved. Thirteen women participated in the study. The aim of the repeated focus group interviews was to gain in-depth contextual knowledge about the research phenomenon rather than generalisation of research findings.

With respect to the general informants, professional nurses working in the Surgical Out Patient's Department and the female surgical ward were selected conveniently to form the sample. A group of four (4)

professional nurses was sufficient because they were not key informants. Their descriptions during data collection were used to substantiate the data gathered from the key informants or to elicit data that did not emerge from the focus group interviews involving the key informants.

3.3.3 Data collection

Data collection is discussed by referring to the methods, processes and instruments utilised.

3.3.3.1 Data collection approach and method

The data collection approach used for this study was the semi-structured self-report approach, which allowed for rich and thoughtful responses from the respondents, while ensuring that the research participants remained within the focus of the research in their discussions (Polit & Hungler 1995:272).

Self-reports were used whereby the research participants were questioned directly to obtain a good deal of information about the health behaviour of these key informants and the intra-personal and cultural factors associated with their health seeking behaviours. Polit and Hungler (1995:255) state that to know what the respondents feel, think or believe, the most direct means of gathering data is to ask them about it.

The focus group interview was used to obtain data. The use of focus group interviews allowed for semi-structured data collection (Polit & Hungler 1995:272). Open-ended questions were asked to enable the key informants to explain and fully discuss their experiences, interpretations and actions. Repeated focus group interviews were conducted with the key informants until data saturation occurred. Only one focus group

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interview was conducted thereafter with the general informants. Roos (2000:18) highlights that this method of data collection allows the respondents to talk freely about their experiences, feelings, attitudes and perceptions. In this way behaviours of the respondents are observed directly by the researcher. Therefore, in this phase of the data collection exercise, respondents were allowed flexible opportunities for revealing relevant data with the proviso that these opportunities fell within the boundaries of research objectives. Probing for more information was possible, and it was based on the information that was revealed by the respondents.

Focus group interviews stressed the interviewee's definition of the situation under study (Lincoln & Guba 1985:268). The research participants were encouraged to structure the account of the situation by focusing on the questions being asked. Questions were asked, re-phrased and further explained to that the participants understood what was asked. This enabled the researcher to elicit data that were directly relevant to the questions asked.

3.3.3.2 Data collection process

The interview environment was arranged to accommodate the respondents and to ensure that they would be comfortable and enjoy privacy. The chairs were arranged in a circle, so that none of them sat behind the other. The researcher sat in the circle during the interviews.

Informed consent was requested from all the respondents to participate in the study (annexures III and IV). The purpose of the study was explained to the respondents before participation. The purpose of the tape recordings was explained to the respondents. The duration of the actual interview was discussed so that respondents were not rushed for time. The length of the interviews was kept to an hour so that

This whole process of knowing each other helped considerably in improving and encouraging trust and confidence in each other.

When the actual data collection period arrived, the researcher participated in the process, with reduced feelings of being an outsider to the key informants. During the initial stages of each interview, the researcher adopted a role of primary observation with limited participation. She introduced the key informants to one another, established a therapeutic environment and collected biographical data. Then the role of primary participation with continued observation was adopted by asking questions and probing further as the need arose. This communication between the researcher and the key informants enabled the researcher to establish some rapport. It enabled the researcher to strengthen their trust to some extent. This made it possible for the researcher to become a participant during the focus group interviews.

During the focus group interviews with the key informants, the researcher listened, observed and reflected. She realised that, although she belongs to the same culture as the informants and speaks the same language, the informants did not speak openly about two sensitive issues, namely neither their breasts nor their health seeking behaviours, especially during the first interview. For instance, the key informants did not reveal any visits to other practitioners, like traditional healers, before seeking medical care from the Western medical institutions. This posed a potential limitation to the research. However, this limitation was overcome by also having interviews with the general informants, namely registered nurses. They were sources of the data that were difficult to obtain from the key informants.

The role of primary reflections and reconfirmation of findings with the respondents was adopted during data analysis. Reflecting on all collected data was done at the conclusion of the study. The respondents

were also given the opportunity to confirm the researcher's interpretations.

3.3.3.3 The data collection instrument

Data collection was done by means of a semi-structured interview guide (Annexure VI), which mainly consisted of open-ended questions to allow the respondents to expand fully on the study phenomenon. Research questions and additional probing questions were asked during the interviews. The study phenomenon was the health behaviours of Xhosa women, and the intra-personal and cultural factors that were associated with their health seeking behaviours for their breast lumps.

A pilot study was conducted to determine face validity. The questions were asked to four women with advanced breast cancer and one registered nurse. These persons were subsequently not included in the sample. The questions that were vague for the respondents were re-phrased by the researcher. The instrument was submitted to the supervisors to assess its content validity prior to data collection.

3.4 DATA ANALYSIS

Data-analysis was done by means of four phases of data reduction. In qualitative research, data analysis is done in words which are assembled, sub-clustered and broken into semiotic segments. These words can then be organised to permit the researcher to contrast, compare, analyse and bestow patterns upon them (Miles & Huberman 1994:10-11).

Leininger (1991:95) describes phases of an ethno-nursing Data Analysis Guide which was used to guide the researcher during data collection and analysis. This enabler is subsequently discussed. A coding system

was developed as the researcher read through the transcriptions of the focus group interviews. Codes were allocated to data as one of the steps taken to reduce the massive data so that it became reasonable and manageable. Data reduction continued until the final report was completed.

3.4.1 Phase I: Collecting, describing and documenting raw data

This phase entails data collection, management and interpretation (Leininger 1991:95). In this study, data was collected and recorded as discussed in paragraph 3.3. Data that emerged from the interviews with the key and general informants were recorded on audiotape. Observations were made and contextual meanings were identified. The researcher then transcribed the recordings from the tapes. The transcriptions were translated into English and typed in ASCII-Text format to enable the researcher to import the file into the QSR NUD*IST4.0 computer program.

Thereafter the researcher read and reread the transcriptions to familiarise herself with similar phrases, relationships between subgroups and common sequences.

3.4.2 Phase II: Identification and categorisation of descriptors and components

During this phase, the initial actions of data reduction are performed by means of coding and categorising (Leininger 1991:95). The researcher utilised the process of inductive reasoning. Data were coded and classified as represented in table 4.1. Similarities and differences were isolated. Recurrent components were studied for their meanings.

3.4.3 Phase III: Pattern and contextual analysis

This phase entails scrutinising of data to discover saturation of ideas and elicit similar or different meanings and interpretations. Data are also examined for meaning-in-context. Credibility is enhanced by allowing confirmation of interpretations by the research participants (Leininger 1991:95). In this study, the researcher interpreted the coded and categorised data to elicit the meanings that emerged from the data. The meanings were then described.

3.4.4 Phase IV: Data synthesis

During this final phase of data analysis findings are interpreted and displayed in a visual format. This results in an organised compressed assembly of data in a thematic format so that conclusions can be reached and decisions could be made about needed actions (Leininger 1991:95). In this research, the researcher reduced the categorised data and underlying meanings into major themes (refer to section 5.3). The themes explicated the underlying relationships that emerged from the data. Final conclusions were reached and recommendations were formulated (refer to sections 5.4 and 5.5).

3.5 TRUSTWORTHINESS OF THE RESEARCH

Qualitative research is concerned with trustworthiness of the research study rather than reliability and validity as applied to quantitative research. Trustworthiness refers to ensuring and persuasion of the reader and audience by the researcher that the research study is worth paying attention to, worth taking account of, and that the findings are to be trusted. For a research study to be trustworthy, four characteristics of credibility, transferability, dependability and confirmability are important to be observed (Babbie & Mouton 2001:276; Lincoln & Guba

1985:290-300). Leininger (1991:113) added additional criteria, namely meaning in context and data saturation.

3.5.1 Credibility

Credibility refers to the extent to which those who read a research report can believe and accept the research findings to be true (Lincoln & Guba 1995:290).

To enhance credibility, the data for this study was collected and analysed in such a way that the findings reflected the exact state of affairs regarding the research phenomenon. The interviews were recorded on audio-tapes and transcribed.

Data triangulation (Streubert & Carpenter 1999:299) was applied by involving two sets of participants, namely women with breast cancer and registered nurses who render health care to women with breast cancer. Data obtained from the general informants, namely nurses, were used to validate data obtained from the Xhosa women with advanced breast cancer. The result was a broad and holistic description of the health behaviours of the key informants and the intra-personal and cultural factors associated with their health seeking behaviours.

The fact that the Xhosa women and the researcher shared the same culture and language also contributed towards credibility of the research findings. No interpreter was needed during data collection. This ensured that all questions and responses were understood as they were intended, without any changes, which might have distorted the actual meaning of the whole study. Cultural perspectives can influence the direction of the research. Researchers are often bound by their own cultures and are frequently unaware of their own biases (Brink & Wood 1998:313). Although the researcher shared the same culture with the key

informants, she also represented the professional health care system. It was therefore important for her to display the attitude and willingness to learn and to discover as much as possible from their beliefs, experiences and actions. The researcher therefore bracketed preconceived ideas and especially personal views about suitable health seeking behaviours for breast lumps. Because she shared the same culture with the key informants, she also had to refrain from thinking that she knew all the cultural factors affecting the health seeking behaviours of the key informants. She maintained an open mind and a genuine willingness to learn from the key informants. In instances where the key informants' viewpoints about breast lumps and health seeking options were different from that of the researcher, she took care to continue to display respect and a non-judgemental attitude. Bracketing was also employed during data-analysis. The researcher continued to maintain an open mind to minimise any biases that may have influenced interpretation of the research results.

Continuous contact had been established between the key informants and the researcher during the years of working with patients with breast lumps and breast cancer. The knowledge that the researcher gained about the research topic and the rapport that had been established with patients enabled her to conduct the research proficiently and effectively. Furthermore, a thorough literature review was conducted on breast lumps, breast cancer and the cultural factors associated with health and illness. All those inputs provided the researcher with the additional knowledge necessary to approach the research with insight.

3.5.2 Confirmability

Confirmability refers to the extent to which the research results are a product of the focus of the study and not the biases of the researcher (Babbie & Mouton 2001:278).

To enhance confirmability, the researcher established an audit trail, by importing the transcribed interviews and field notes into a qualitative data-analysis programme, namely QSR NUD*IST 4.0. The coding system was printed out and has been included in the research report (table 4.1). The data that were classified into the different codes were also printed out. A sample of this is attached as an annexure (refer to annexure VIII). The raw data, the coded data and the researcher's interpretations were scrutinised by the supervisor who acted as an independent coder. The categories identified by the researcher were contrasted with those identified by the supervisor. No major discrepancies were identified between these two persons' analyses of the data.

After interpretations of the research findings were completed, the researcher checked to ensure that the research findings had the same meaning as the collected data. The researcher's interpretations were also submitted to the research participants to confirm that it reflected their responses.

3.5.3 Meaning In Context

Meaning in context refers to extent to which the meaning of the research study is maintained within the context of the study.

During the focus group interviews a facilitator was asked to be present both for observation purposes, and to enable the description of the research context to be carried out. The context in which the interviews were conducted was described. This included the group dynamics and non-verbal behaviours. Based on this, the researcher realised that she was not able to gain full entry into the life-world of the key informants since they were reluctant to discuss issues directly related to the breast as an organ and their traditional health seeking behaviours with the

researcher. The researcher was then able to ensure that the required data were obtained from the general informants.

3.5.4 Data Saturation

The researcher conducted focus group interviews with four different groups of Xhosa women with advanced breast cancer. This was done repeatedly until no new data emerged. Furthermore, interviews were also held with registered nurses to obtain additional data that were required to understand the health seeking behaviours of the key informants and all associated intra-personal and cultural factors. At the completion of the interviews the researcher was satisfied that no new insights would emerge, and that saturation of data has been achieved.

3.5.5 Transferability

Transferability refers to the extent to which the research findings can be applied in other contexts or with other respondents (Babbie & Mouton 2001:277). In qualitative research, generalisations of findings and study conclusions are not made. However, to enable the reader to judge transferability, the researcher provided in-depth discussions of the data obtained, data analysis and interpretation of the research findings. These should enable readers to judge whether these findings can be applied to their contexts and to their health care situations.

3.5.6 Dependability

Dependability refers to which similar findings would be obtained through repeated research (Babbie & Mouton 2001:278). The fact that the researcher complied with the criteria of triangulation and the establishment of an audit trail, enhanced the dependability of this study.

3.6 ETHICAL CONSIDERATIONS

The study involves human subjects who suffer from a disease that affects a sensitive organ, namely the female breast. This necessitated that the researcher complied with a number of ethical considerations pertaining to this research.

3.6.1 Protection of the well being of the respondents

As issues related to self-esteem and dying come into play when a person has been diagnosed with breast cancer, the researcher had to pay special attention to protecting the well being of the key informants. Care was taken to ensure that the key informants were not harmed psychologically, spiritually and/or emotionally. Neither group of respondents were subjected to victimisation. Permission to record the respondents' responses on tapes or cassettes was requested.

Although there were illiterate, poor persons who did not understand what the meaning of the study was all about, among the key informants, they were not victimised in any way whatsoever. The researcher gave more attention to them when she explained the nature of the study to these research participants to enhance their understanding.

The researcher ensured that the general informants were also treated as valued human beings, and protected their well-being. Their participation in the research was confirmed after they indicated their willingness to participate. The general informants were not victimised if they refused to participate or if they chose to withdraw their participation even during the focus group interviews.

3.6.2 Right to full disclosure

All relevant factors about the nature of the study, the participants' rights regarding the study, the researcher's responsibilities and the benefits and risks involved were fully explained to the respondents. Because of the nature of breast cancer, the key informants especially were assured that they could refuse further participation at any point during the research.

Next the researcher explained the nature of focus group interviews to the respondents. She also told them about the inconveniences such as time duration of the focus group interviews. They were also informed that probing questions would be asked during the interviews. Permission to record their responses on tapes or cassettes was requested.

Finally, sharing of the preliminary findings was done with the respondents, and comments were invited before the research report was written up.

3.6.3 Right to fair treatment

No discrimination was practised at all when selecting respondents for the study. The selection was on research requirements, and not on the researcher's likes or dislikes of individual respondents. For example, the researcher did not select those key informants who were more educated than others, with clean non-smelling wounds and staying in clean environments. Non-tiring information gathering sessions were maintained interspersed with breaks whenever the respondents wanted them. The language which was understood by both the respondents and the researcher was used, namely Xhosa.

3.6.4 Right to privacy, confidentiality and anonymity

Maintaining privacy and anonymity in qualitative research is problematic as the researcher typically becomes involved with the lives of those being studied. Moreover, because of the in-depth nature of qualitative studies, there may be greater invasion of privacy than is true in quantitative research (Polit & Hungler 1995:125).

The small sample used and the detailed data gathered during interviews made it difficult to disguise the identities of the respondents. However, assurance was made that all collected data would be kept in the strictest confidence. Culturally, Xhosa women are very secretive, and sometimes they find it very sensitive to talk about organs like breasts. The researcher assured the respondents that confidentiality and anonymity would be maintained even after completion of the study. Any data related to the respondents' identities was kept in a locked cabinet and used for the purpose of this research only. No access to data was possible to any other people except those who were involved in the research project. After the completion of the research study, all data with respondents' identities was destroyed completely.

3.6.5 Protection of the rights of the institution

Permission was asked to undertake the research study from the Medical Superintendent and the Senior Nursing Service Manager in charge of the Umtata General Hospital (Annexure I). Persons-in-charge of the departments where the key informants were either admitted or attended for treatment during the data collection period were approached for permission to conduct focus group interviews (Annexure II). These departments are the female surgical ward and the Surgical Out Patient's Departments (SOPD). Data collection proceeded only after permission had been granted.

3.6.6 Scientific honesty

The researcher acknowledged all those who contributed to the research study. Credit was given to all the authors whose work had been consulted. Reports on data collected were compiled accurately. There was no distortion of any data to support the researcher's viewpoints and/or assumptions.

3.7 CONCLUSION

The research design and method used in this study were described in this chapter. The in depth exploration of the experiences and perceptions of the population under study enabled the respondents to explain their own situation in their own words and language. The sampling procedures, data collection approach and method, data collection instrument and data analysis were also discussed fully. The general informants played a very important role by verifying what the key informants had said and by providing the researcher with data that did not emerge from the interviews with the key informants.

CHAPTER 4

DATA ANALYSIS AND RESEARCH FINDINGS

4.1 INTRODUCTION

In the previous chapter, the research design and method were discussed. This chapter is focussed the data analysis strategy and the research results. Data were classified into categories, codes and sub-codes so that the massive data could be reduced to more manageable levels.

4.2 DATA ANALYSIS STRATEGY

Leininger's data analysis enabler was used as the data analysis strategy for this study (refer to section 3.4).

4.2.1 Collecting, describing and documenting of raw data

The first phase of Leininger's data analysis enabler, namely collecting, describing and documenting raw data, was fully discussed in chapter 3 (refer to section 3.4.1).

4.2.2 Coding and classification of data

This represents phase 2 of Leininger's data analysis enabler as discussed in section 3.4.2 of chapter 3. Data from the interviews held with both the key and general informants were transcribed from the tape recordings. The researcher

then translated the interviews' contents from Xhosa into English. The translated transcriptions of the interviews were then imported into a qualitative data analysis computer program. The computer software used for coding of the data was QSR NUD*IST 4.0. The coding system and data categories are presented in table 4.1.

Table 4.1 Categories and coding system

| CATEGORY | CODES AND SUB CODES | DEFINITIONS |
|--------------------|-------------------------------------|---|
| /Biographical data | | Personal particulars of informants |
| | /Patients | Personal characteristics of women who delayed seeking medical care for a breast lump, who participated in the study |
| | /Nurses | Personal characteristics of nurses providing health care to women with a breast lump, who participated in the study |
| /Discovery | | Acquiring knowledge or sight, by effort or chance, of a breast lump |
| | /How discovered | Method through which knowledge or sight of a breast lump was obtained |
| | /Meaning attached | The significance awarded to the presence of a breast lump |
| | /Explanatory model | Reasons, related to cultural perceptions, about the cause of a breast lump |
| | /Explanatory model /Supernatural | Causation of a breast lump expressed in terms of forces such as God, the gods or ancestors |
| | Explanatory model /Equilibrium | Causation expressed in terms of disturbed relations within the body, with the physical or the social environment |
| | /Explanatory model /Sorcery | Explanation of causation in terms of witchcraft or magic |

| CATEGORY | CODES AND SUB CODES | DEFINITIONS |
|---------------------------|------------------------------|---|
| | Significance of the breast | Meaning attached to the female breast |
| | /Experience upon discovery | Feelings that the informant was aware of upon discovery of a breast lump |
| | /Actions taken | Steps taken by the informant upon discovery of a breast lump |
| /Health seeking behaviour | | Steps taken by the informant to seek health care for a breast lump |
| | /Practitioners | Persons consulted by the informants to obtain treatment for a breast lump |
| | /Remedies | Treatment received by informants for the breast lump |
| | /Institutions | Organised bodies rendering health care visited by informants to seek health care for the breast lump |
| | /Role of significant other | Influence exercised by immediate family or friends with regard to health seeking behaviour of the informants with a breast lump |
| | /Length of delay | Extent of postponement of seeking treatment for a breast lump, and its consequences |
| /Reasons for delay | | Motive for postponement to seek medical care for a breast lump |
| | /Fear | Unpleasant emotion of being afraid upon discovery of a breast lump |
| | /Fear /Death | Fear of dying after discovering a breast lump resulting in delaying to seek medical care for a breast lump |
| | /Fear /Loss of femininity | Fear of losing qualities of being a woman as a consequence of having a breast lump |

| CATEGORY | CODES AND SUB CODES | DEFINITIONS |
|--------------------------|------------------------------|---|
| | /Knowledge | Having or lacking information about the significance of a breast lump and importance of seeking medical care without delay |
| | /Significant other pressures | Exertion of continuous force by immediate family or friends resulting in seeking / delay to seek health care for a breast lump, by the informants |
| | /Embarrassment | Feelings of being ashamed of having a breast lump, experienced by informants |
| /Advice | | Information that informants expressed that they would wish to give to other women about appropriate actions after discovering a breast lump |
| /Views on best treatment | | Opinions expressed by informants about most desirable health care options for a breast lump |

The categories are visually portrayed in figure 4.1. The categories; biographical data, discovery, health seeking behaviour, and reasons for delay, were subdivided into codes and sub-codes. The subdivision of each category into codes and subcodes is represented in figures 4.2, 4.3, 4.4, 4.5, 4.6, 4.7 and 4.8.

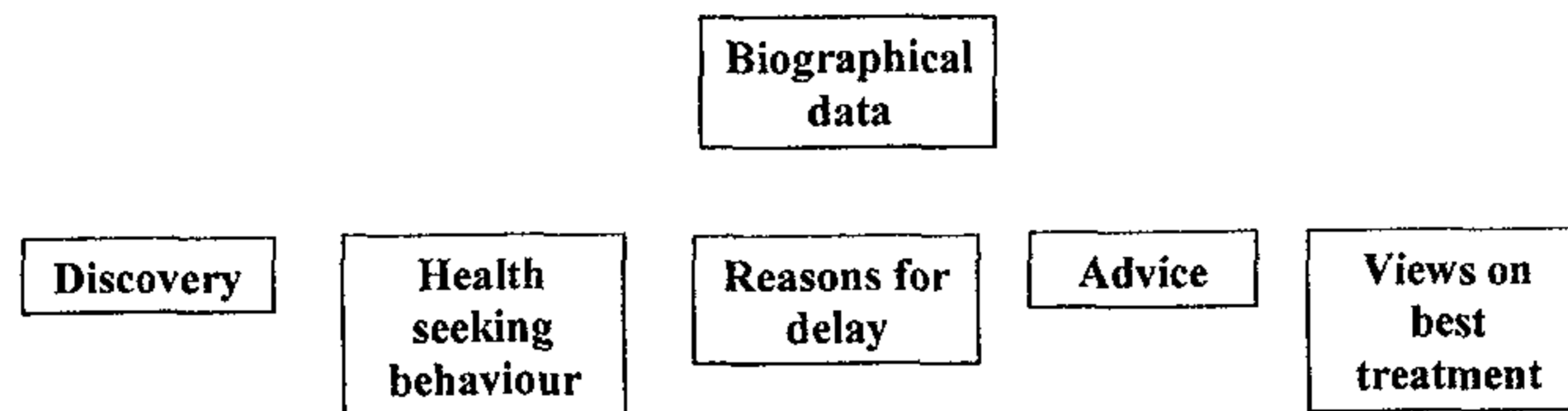


Figure 4.1 Visual presentation of the categories

4.2.3 Pattern and contextual analysis

This represents phase 3 of Leininger's data analysis enabler as seen in section 3.4.3. The research findings are discussed per category and code.

4.2.3.1 Biographical data

This category contains data pertaining to the personal particulars of those who participated in the study. The coding system for biographical data is visually portrayed in figure 4.2.

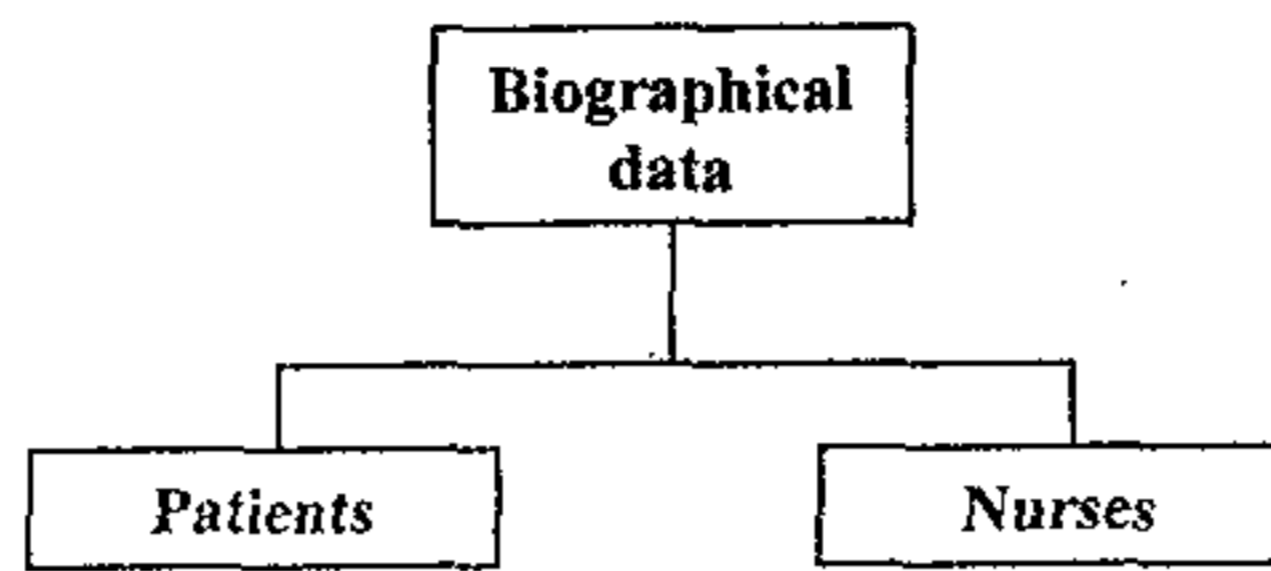


Figure 4.2 Coding system for biographical data

There were two main types of informants from whom data were collected, namely:

- patients
- nurses

Patients

This code refers to data about the personal characteristics of women who delayed seeking medical care for a breast lump, who participated in the study. There were thirteen key informants. Their ages ranged from 31 years to 81 years. The mean age was 52,6 years. Kau (1997:7) and Greenberg (1993:13) both indicated that South African black women had the highest breast cancer incidence under the age of 40 years. However, the research participants in this study were found

to have a higher mean age. They are therefore not necessarily representative of the population.

Five key informants were married, five were single, two were widowed and one informant had been separated from her husband a long time ago.

Twelve key informants had children and one had never had children. The number of children varied between two and ten. The mean number of children was 4,5.

Nurses

This code refers to data about the personal characteristics of registered nurses providing health care to women with a breast lump, who participated in the study. The registered nurses were the general informants.

There were four general informants. The age groups of the nurses ranged between 40 to 59 years. Their mean age was 49,5 years

Their period of employment ranged between 4 to 12 years. The mean was 8.5 years. All of them were registered as general nurses and midwives. In addition, two were registered community health nurses and one was a registered psychiatric nurse. Two were registered oncology nurses.

4.2.3.2 Discovery of the breast lump

This category pertains to data related to how the key informants acquired knowledge or sight, by effort or chance, of a breast lump. The category and its coding system are visually portrayed in figure 4.3.

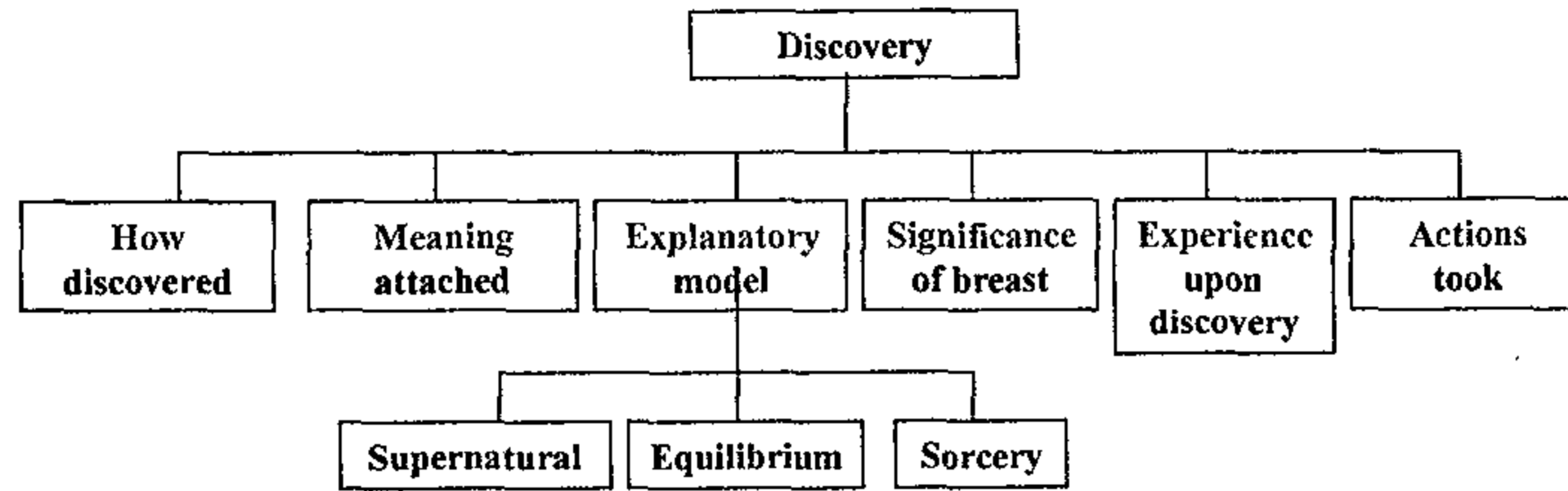


Figure 4.3 Coding system for discovery

Ways of discovery

This code refers to the method through which knowledge or sight of a breast lump was obtained, indicating how it was discovered. Two main explanations of meanings attached to how the breast lump was discovered emerged from the data namely:

- self-discovery of the breast lump
- discovery of the breast lump by a medical doctor

Self-discovery of the breast lump

The responses by the key informants indicated that their breast lumps were discovered in various ways. The key informants mostly indicated that they themselves discovered their breast lumps. An informant explained that she first noticed a discharge from the affected breast's nipple before she became aware of the breast lump.

None of the explanations by the informants indicated that they had any knowledge about breast examination and that their breast lumps were discovered by means of self-examination. They did not receive any health education about the clinical signs of breast cancer prior to the discovery of their breast lumps.

Discovery of the breast lump by a medical doctor

The key informants' responses also brought to light the fact that the doctor was the person who first discovered the breast lump. An informant explained that she had consulted the doctor for sharp pains above the affected breast. She had not felt the breast lump as it was very small when the doctor discovered it.

Meaning attached to the breast lump

This code refers to the significance awarded to the presence of a breast lump.

Five main areas of meanings attached to the discovery of a breast lump emerged from the data, namely:

- did not know what the breast lump meant
- breast cancer could possibly be present

- a health problem other than breast cancer could possibly be present
- the breast lump may result in death
- denial of the personal possibility of having breast cancer although a breast lump has been associated with cancer in general terms.

Lack of knowledge of what the breast lump meant

The key informants who said that they did not know what the breast lump meant did not elaborate further on the significance of their discovery. Some informants said that they did not understand what was happening.

None of the key informants indicated that they had a family history of breast cancer.

The possibility that breast cancer could be present

The key informants who suspected that the breast lump could be an indication of breast cancer based their interpretations on their personal observations of other women. An informant mentioned that she knew somebody with a breast lump that later turned out to be cancerous. Another informant indicated that she thought about the symptoms that her neighbour was having. It seems as if personal encounters with persons with breast lumps and breast cancer influenced the interpretation process, and not previous health education by health professionals.

A health problem other than breast cancer could possibly be present

The key informants, who indicated that they considered the possibility that a health problem other than breast cancer may be present, indicated that they

considered the lump to be "ithumba" (an abscess), an "ilifa" (lipoma) or a swollen lymph gland. Descriptions that were given included the presence of an abscess that would burst open and discharge pus, and would then heal. It was also mentioned that the breast lump was considered to be an abscess that was not ready to drain pus. An informant who was breast feeding indicated that she thought that the breast abscess was due to her baby breaking a wind on her breast.

The possibility that the breast lump may result in death

Various key informants indicated that they did not relate the breast lump to either breast cancer or another health problem, but rather thought in terms of the possibility of death. Some informants elaborated further by saying that they thought that their lives had come to an end and that they would die.

The above responses were supported by the general informants, namely the registered nurses. The general informants indicated that Xhosa women often associated breast lumps with normal breast tissue, a swelling that would subside on its own after time. Breast lumps were often associated with abscesses/boils or lipoma by the Xhosa women. The general informants also mentioned that some women who associated a breast lump with breast cancer thought that it could only be treated with traditional medicine.

It is interesting to note that only the general informants (nurses) mentioned traditional medicine during the discussions about the discovery of breast lumps.

Denial of the personal possibility of having breast cancer although a breast lump has been associated with cancer in general terms

An interesting idea that emerged from the responses of the general informants related to the issue of denial, by Xhosa women, that breast cancer might be present. Some women who associated a breast lump with cancer did not necessarily seek medical treatment "*because they usually say this cannot be cancer at all*". This meant that even if cancer was suspected, it did not necessarily lead to seeking prompt medical treatment.

Explanatory model

The code explanatory model refers to reasons, given by informants, which related to cultural perceptions about the causes of a breast lump. The code was subdivided into several sub-codes, as portrayed in figure 4.4.

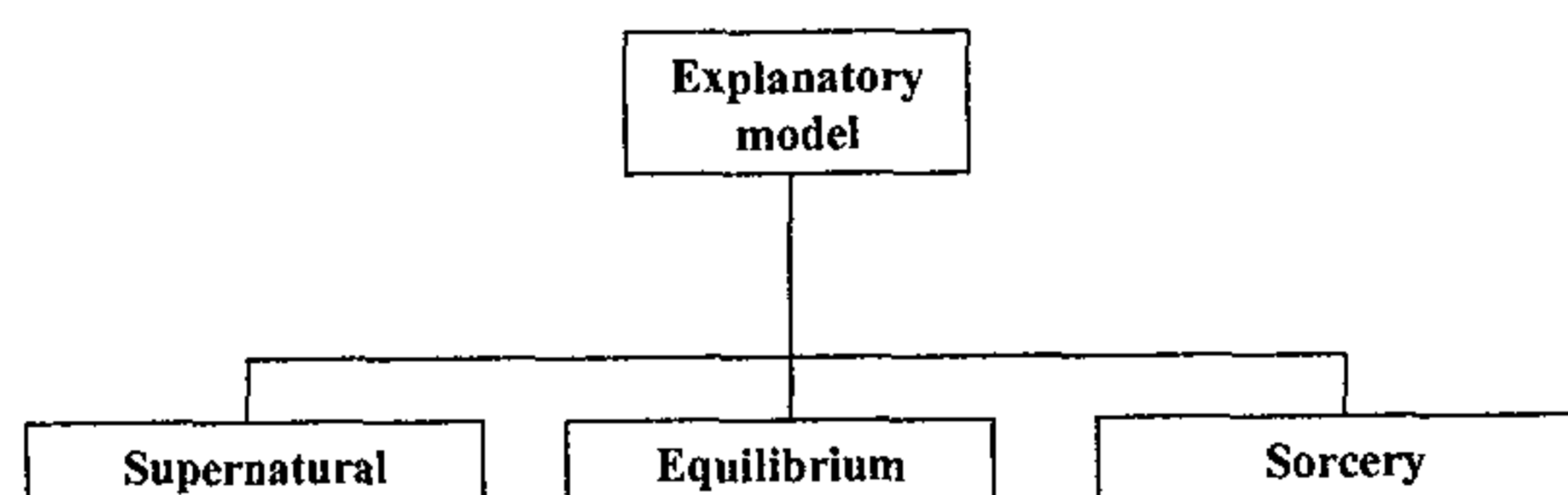


Figure 4.4 Coding system for explanatory model

Explanations in terms of supernatural phenomena

This code deals with informants' explanations about causation of a breast lump expressed in terms of forces such as God, the gods or the ancestors.

Two types of explanations for the cause of breast lump related to supernatural phenomena emerged from the data, namely that:

- there is a link between a breast lump and the ancestors.
- there is no link between a breast lump and the ancestors

There is a link between a breast lump and the ancestors

A key informant explained that family members sometimes believed that a breast lump was caused by complaints from the ancestors. This informant did not explain what the ancestors might be complaining about. Another informant explained that she was not sure about the role of the ancestors in causing a breast lump.

In a previous study, Mkumatela (1992:28) found that 41% of the Xhosa informants believed that the ancestral spirits played a role in causing illnesses, including cancer. This happened when a woman neglected certain customs or taboos.

There is no link between breast lump and the ancestors

Some key informants indicated they did not believe that there was a link between the breast lump and the ancestors.

Explanation in terms of equilibrium

Equilibrium refers to causation expressed in terms of disturbed relations within the body, with the physical environment or with the social environment.

One main explanation of the causation of the breast lump, expressed in terms of disturbed equilibrium, emerged namely that:

- the breast lump was caused by jealousy.

The breast lump was caused by jealousy

An explanation given about the cause of the breast lump, was that of jealousy by others. A key informant explained that her breast lump might be related to jealousy from the people around her because she was working very hard to solve her own problems ever since her husband died. Another informant elaborated by explaining that her breast lump could have resulted from jealousy by people in her neighbourhood, because she had built her own hut without anybody's help, and she was still prepared to do a lot of things until the breast problem set in. A third informant simply indicated her suspicion that jealousy might be the cause of a breast lump. None of these informants gave full explanations about how jealousy caused breast lumps.

Explanations in terms of sorcery

This code deals with explanation of the causation of breast lumps in terms of witchcraft or magic.

Two types of explanation about the causation of the breast lump in terms of sorcery emerged from the data, namely that:

- there is a link between a breast lump and witchcraft
- there is no link between a breast lump and witchcraft

There is a link between a breast lump and witchcraft

Some key informants indicated that their breast lumps could have been caused by witchcraft. However, these informants did not fully explain the details of this perception or belief. What is surprising is that none of these informants revealed that they sought any treatment from the traditional healers, as it has been indicated that Xhosa women believed that witchcraft was best treated with traditional medicines as stated by Mkumatela (1992:27). This author found that 41% of the Xhosa informants believed that their ancestral spirits played a role in causing illnesses, including cancer.

Data obtained from the general informants supported this stance. They explained that Xhosa women regarded a breast lump as a "put for " (*ibekelo*). This meant that a breast lump had been put in the breast through witchcraft, and it was therefore best treated with traditional medicines. This was why Xhosa women sought Western medicine only after traditional medicine had failed to cure their disease. The result was that they presented with advanced breast cancer when they ultimately sought medical treatment. The fact that the key informants did not reveal this information to the researcher may be an indication that they did not want to share their own secrets with a stranger (the researcher). Leininger (1991:82) highlighted the problems facing the researchers conducting studies with informants with a traditional cultural background, where informants guard against outside intrusions by the researchers.

There is no link between a breast lump and witchcraft

Other key informants explained that they did not believe that their breast lumps were caused by witchcraft.

Significance of the breast

This code refers to responses about the meaning attached to the female breast. The informants gave three main explanations about the significance of the breast, namely:

- the breast as a symbol of femininity
- the breast as a symbol of love and intimacy
- the breast is an important organ for breast feeding.

The breast as a symbol of femininity

A key informant indicated that the appearance of breasts when a girl reaches puberty indicated that the girl was no longer a child, but a young woman. Some of the informants stated that the breast is a symbol of femininity to each and every female. It is a shape that represents a woman. In their study Schlebusch and Van Oers (1999:30) confirmed that the breasts are important to women because they are outward signs of femininity.

The breast as a symbol of love and intimacy

The breast was also stated to be of importance to the love making process, as the male partners may fondle and suckle the breasts playfully while both partners enjoy the love making process. Some key informants further indicated that a

breast acts as a "pillow" or a "cushion" for male partners during love making. This important role played by the breasts explained the pressures experienced by the Xhosa women when a lump had developed in the breast. This has resulted in an informant refraining from her partner after the discovery of the breast lump.

The breast is an important organ for breast feeding

The key informants regarded the breast as an important organ for feeding the baby. The breast is always available for the mother and the baby. An informant further stated that engorgement of breasts during pregnancy indicated preparation of the breasts for this important breast feeding role.

The responses from the general informants supported the importance of the breast, and losing a breast was regarded as a devastating experience. It emerged that Xhosa women regarded a female with one breast as no female at all. Xhosa women also experienced feelings of embarrassment when exposing their breasts to or being touched by a stranger. It was mentioned that Xhosa women thought that a female could not survive with one breast, or could not have any children with one breast.

Kau (1997:29) concurred that the loss of a breast for a black woman forms the central emotional crisis of the breast cancer diagnosis, as described in paragraph 2.5.1. What is surprising is the fact that, although Xhosa women attached such great significance to the breast, they did not seek treatment immediately when a lump developed in this important organ.

Experience upon discovery

This code refers to responses with regard to feelings that the informant was aware of upon discovery of a breast lump

Five types of experiences emerged from the data, namely:

- worry
- unhappiness
- frustration
- fear
- shame
- undefined experience

Worry

A key informant indicated that she became worried after noticing a lump in her breast. She explained that her neighbour had cancer of the breast. She therefore related her breast lump with the symptoms of that lady, and this made her worried. It emerged that, although this informant became worried about the breast lump, she did not seek medical treatment when the breast lump was still small.

Unhappiness

A key informant indicated that she did not feel happy at all after she noticed a breast lump. This informant did not give any specific explanation for her unhappiness after the discovery of the breast lump.

Frustration

Some of the key informants indicated that they felt frustrated after they noticed a breast lump.

Fear

A key informant said that she was surprised and frightened after she had noticed a lump in her breast.

Shame

One key informant indicated that after she discovered a lump in her breast, she stopped seeing her boyfriend. She felt so ashamed that she did not want her boyfriend to notice the breast lump.

Undefined experience

Some key informants indicated that they did not have any special feelings after they noticed a lump in the breast. This resulted in these informants staying away from seeking medical treatment. An informant said that she just felt bad.

Actions taken

This code refers to steps taken by the informant upon discovery of the breast lump. The actions of the key informants after discovering a breast lump were twofold, namely:

- seeking medical help
- keeping quiet

Seeking medical help

Some key informants indicated that they went to seek medical help after they noticed a breast lump. It emerged that the lump was already an advanced breast disease when treatment was ultimately sought. An informant thought that the lump would disappear or burst open and drain pus. She stayed away from any treatment as she was waiting for the lump to burst open. Another informant mentioned that the breast lump had been removed from her breast twenty years ago, but it continued to grow. She reported that she did not know what else to do.

Although medical assistance was obtained, but this was not done immediately after discovery of the breast lump. The informants failed to disclose any other assistance sought during these discussions.

Keeping quiet

The responses from the general informants brought to light that Xhosa women often kept quiet and did not report a breast lump to anybody, until it was too late for any effective treatment.

4.2.3.3 Health seeking behaviour

This category refers to steps taken by the informant to seek health care for a breast lump. The coding system for this category is visually portrayed in figure 4.5.

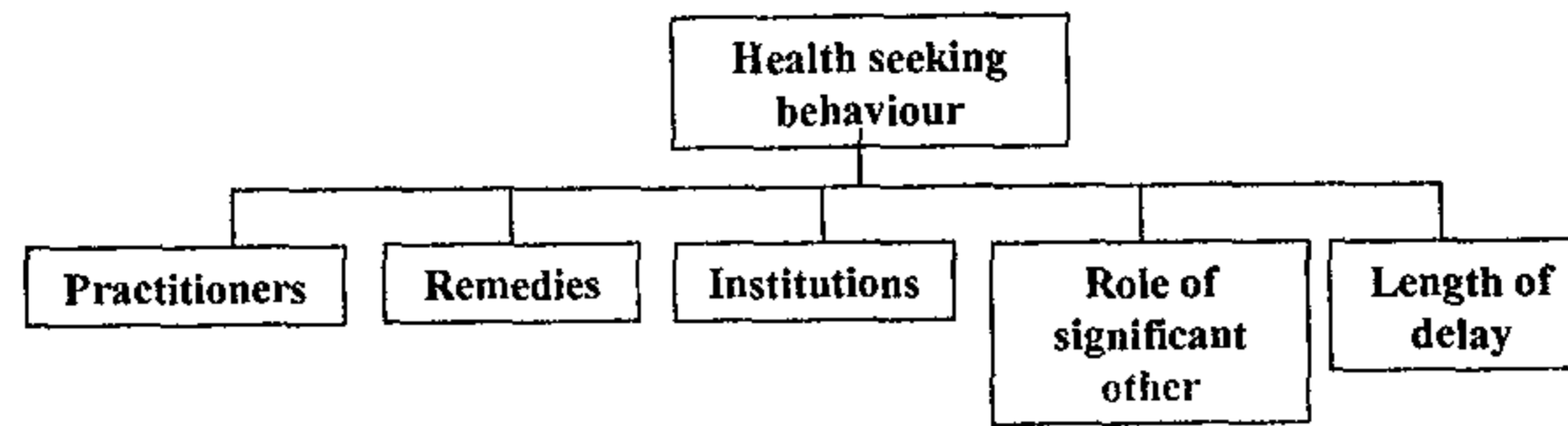


Figure 4.5 Coding system for health seeking behaviour

It emerged that some steps had been taken by the informants to seek health care for a breast lump. It was, however, observed that some of the informants presented for medical treatment when the breast lump had become advanced breast cancer.

Practitioners

This code refers to persons consulted by the informants to obtain treatment for a breast lump.

Informants consulted different groups of practitioners for the cure of a breast lump, namely:

- medical doctors
- traditional healers

Medical doctors

Most of the key informants indicated that they trusted medical doctors for the cure of a breast lump. This trust resulted in these informants consulting a doctor for the treatment of their breast lumps. An informant emphasised that doctors knew everything, and they (doctors) were able to help even if a breast lump had turned out to be breast cancer. While some informants went to the hospital and saw a hospital doctor, others consulted general practitioners in private practice. It emerged that those informants who consulted general practitioners were in turn referred to the hospital doctors for further investigations and treatment.

Traditional healers

A key informant indicated that she trusted traditional healers, and had consulted one for the cure of a breast lump. She then stated that "*nangona engakhange andincede ngoku kulengxaki endinayo*", which means *although the traditional healer did not help me with my problem this time*. She further explained that there were certain traditional healers who were able to cure a breast lump successfully, whereas some traditional healers did not treat it. This informant said that she did not know the role that is played by the medical doctor with regard to the treatment of a breast lump.

Data from the discussions by the general informants indicated that Xhosa women tended to seek treatment for a breast lump from the traditional healers because

they did not operate at all. It also emerged that traditional healers maintained that, once a cancerous breast lump was punctured with biopsy needles or opened with any sharp objects, cancer spread quickly and killed its victim faster. Xhosa women also consulted traditional healers due to their availability, as they stayed in the same neighbourhood as the women. The traditional healers also projected confidence that they were able to cure breast cancer. The general informants explained that they had observed that Xhosa women only presented for western medicine when their breast lumps have advanced to fungated, ulcerated, foul smelling breast cancer lesions.

Remedies

Remedies referred to treatment received by informants for the breast lump.

Two types of treatment were received by the informants, namely:

- medical treatment
- traditional remedies

Medical treatment

Some of the key informants indicated that they received medical treatment for their breast lumps. Investigations were done to confirm the actual diagnosis. These investigations were specified as blood taking (blood tests), a small piece of tissue was taken from the breast (biopsy), chest X Ray and the X Ray of the breast (mammogram).

Not all of the key informants received any curative treatment, as the breast lump was very big and not suitable for any effective treatment by the time they consulted medical doctors. Those who did receive treatment said that treatment

was started after the diagnosis of breast cancer was confirmed. They specified that an operation to remove the affected breast (mastectomy) was done, followed by special injections (chemotherapy) and sometimes radiotherapy or "*layini* " as they usually refer to it.

Traditional remedies

The key informants generally did not indicate that they used traditional remedies for the breast lump. However, an informant specifically indicated that she used traditional medicines before coming to the hospital.

It appears from the responses that the informants generally did not expand on any role played by the Xhosa customs, beliefs, rituals, values and practices in the treatment of a breast lump. However, an informant indicated that there were people who thought that this role existed. The informant did not provide any further explanations about this issue.

The responses from the general informants did not support what had been said by the key informants. The general informants indicated that since Western medicine treated breast lumps commonly by surgery, Xhosa women preferred to seek traditional non-invasive remedies. It emerged that Xhosa women consulted the traditional healers, before seeking treatment from the western health care system. Common remedies used by Xhosa women were hot fomentations to hasten the progression of the "*ithumba*"(abscess) in readiness for excision and drainage. Stomach washouts or "*ukugabha*" (self induced vomiting), self induced diarrhoea or enemas and "*ukufutha*" (steaming) were also used to cleanse one's system of the effects of witchcraft. These remedies were found to have complications. For instance, informants would come to the hospital with dehydration due to excessive diarrhoea and self induced vomiting, or scalds and burns due to hot fomentations to the breast and steaming. The general

informants said that they were not aware of anybody who had been cured of a breast lump by traditional medicines.

The general informants also indicated that they had observed that Xhosa women sought help from faith healers. The faith healer's role was to give hope of cure by means of prayers, lighting of candles while praying for the patient, sprinkling of holy water and Jeyes fluid mixed with milk. All these remedies were administered to the sick person to treat a breast lump and breast cancer. The general informants had seen no evidence that these remedies have cured a breast lump.

Institutions

Institution refers to organised bodies rendering Westernised health care visited by informants to seek health care for the breast lump.

It emerged that the key informants visited one of two organised health care bodies to seek medical care, namely:

- clinic
- hospital

Some key informants indicated that they went to seek medical care for a breast lump from the clinic. These informants were in turn referred to the hospital, whereas other informants directly went to the hospital to seek medical care for a breast lump.

The responses from the general informants supported the data obtained from the key informants. The general informants indicated that key informants only

turned to western medicine in advanced stages of breast cancer, when the traditional medicine had failed to cure the breast lump.

Role of significant others

The role of significant others referred to the influence exercised by the immediate family or friends with regard to health seeking behaviour of the informants with a breast lump.

It emerged from the data that various persons influenced the women after discovery of the breast lump. These included:

- persons who influenced the actions of the women who discovered a breast lump.

The role of significant others in deciding what actions to take after discovery of the breast lump was twofold, namely:

- advice to seek medical care
- advice to seek health care from a traditional healer

Persons who supported and influenced the actions of the women who discovered a breast lump

Some key informants indicated that their partners influenced their actions after discovery of the breast lump. One informant indicated that after she discovered a lump in her breast, she stopped seeing her boyfriend. She felt ashamed, and she did not want her boyfriend to see the breast lump.

The key informants who did not have partners indicated that they were getting support from their family members. An informant indicated that her best friend

was supporting her, as she stayed away from her partner since she had noticed a breast lump. Another informant indicated that her neighbour, who was a traditional healer, advised her to seek medical care. This informant did not state whether she sought any help from this neighbour in his capacity as a traditional healer.

The general informants confirmed the importance of the role played by the family members and the significant others when a Xhosa woman had a breast lump. This would be noticed when family members accompanied the sick member to places where health care was sought. The family members would help in the preparation and administration of the prescribed treatment.

It emerged that the opposite would also be observed in other families, where the sick family member would be neglected as the prevailing belief would be that she was being punished for her evil deeds. This became an unfortunate situation, as the sick woman suffering from pain and discomfort during the advanced stages of the disease, might be left without care, due to cultural beliefs that the sick woman was being punished. (Nobody specified for what deeds a woman might have been perceived to be punished by the presence of a breast lump).

Advice to seek medical care

The key informants generally indicated that they were advised by family members to seek medical care from the doctor. They stated that the advice was very helpful, as further investigations were performed to confirm the diagnosis of breast cancer, and treatment was initiated. An informant explained that the advice never helped her, as the breast lump, which turned out to be breast cancer, did not disappear.

It emerged that partners of some of the key informants were concerned and worried about their illness. This resulted in the partners encouraging them to seek medical care.

Some key informants indicated that their husbands were very concerned after their breast lumps were discovered. The husband of one of the informants wanted treatment to be started soon, as he had seen one of the community members in their neighbourhood with advanced breast cancer. The husband of another informant, who worked in Cape Town, phoned regularly to check on the wife's condition, and to monitor the progress of the treatment she was receiving. What was observed was that the breast lumps of these informants were already big when they presented for medical care, although they had seen people with advanced breast cancer due to late presentation. However, they did not explain the reasons why they themselves did not come for medical care while the breast lump was still small.

Advice to seek health care from a traditional healer

A key informant was advised to seek health care from a specific traditional healer, who was regarded to be very good at curing cancer. She indicated that she was never helped, as the breast lump did not disappear. This informant said that she related her breast lump with breast cancer and went to a traditional healer for help. She ultimately went to seek health care from the hospital. It was, however, already too late so she was offered only symptomatic treatment.

The responses of the general informants supported what was said by the key informants. They stated that Xhosa women did consult traditional healers but did not find cures for their breast lumps.

Duration of delay

Length of delay refers to the extent of postponement of seeking treatment for a breast lump, and its consequences.

Two types of data related to the length of the time taken by the informants to seek medical care for a breast lump emerged from the data, namely:

- period of delay in seeking medical care for a breast lump
- the size of the breast lump when the informant sought medical treatment

Period of delay to seek medical care for a breast lump

It emerged that some key informants delayed seeking medical care for a breast lump for a period of two months, whereas other informants indicated that they had delayed for periods exceeding two to three years, after they had first noticed a breast lump. Although some of these informants had thought that the lump in the breast might be associated with breast cancer, they did not seek medical treatment because the lump was not painful at that stage. The informants stated that they also did not consult any other health care person after they had noticed a breast lump.

The general informants confirmed that the Xhosa women delayed seeking medical care after discovery of breast lumps. They explained that the key informants tended to delay seeking medical treatment for periods extending from two months to three or four years or even more. This delay in seeking medical treatment probably contributed towards progression of the breast cancer to an advanced stage when they came to the hospital for the first time. By that stage the breast lump often presented with fungation and ulceration. The general informants stressed that breast cancer was not fatal if detected and treated early,

but that the majority of Xhosa women ended up dying due to late presentation, resulting in consequences such as poor treatment results, poor prognosis and only brief recessions in the severity of cancer.

The size of the breast lump when the informant sought medical treatment

It emerged that the key informants generally presented for medical care for a breast lump when the lump was quite big. The researcher asked the informants to explain and show how big the breast lump was when they sought treatment for the first time. Some key informants indicated that they had a very small breast lump, which only measured about two centimetres when they sought medical treatment for the first time. From the responses of other informants, it appeared that the sizes of the breast lumps could have been between five and ten centimetres. The informants showed the size by bringing the index finger and the thumb together, or both thumbs and index fingers of both hands brought together, for the breast lump that was too large to be measured with one hand.

4.2.3.4. Reasons for delay

This category refers to motive for postponement to seek medical care for a breast lump.

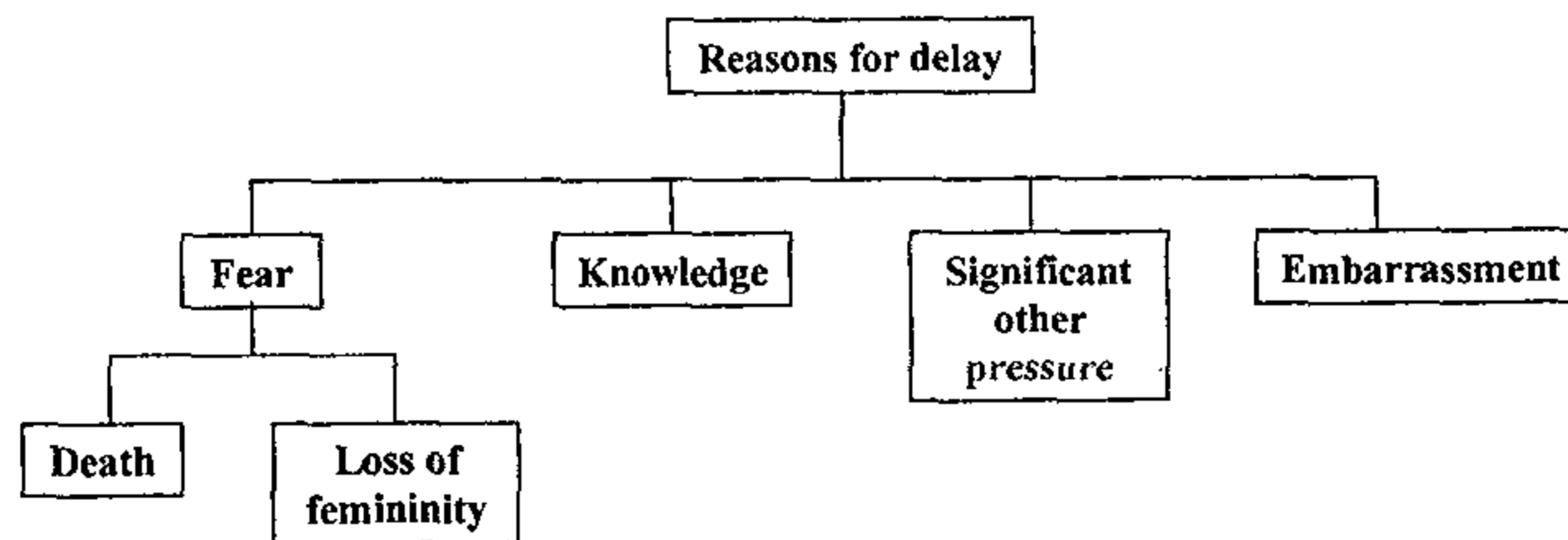


Figure 4.6 Coding system for reasons for delay

It emerged that five types of reasons contributed to the delay by the informants to seek medical treatment for breast lump namely:

- fear of a possibility of death
- fear of loss of femininity
- lack of knowledge/information about the significance of a breast lump
- pressure from the significant others, resulting in delay to seek health care for a breast lump
- embarrassment

Fear of death

Some key informants experienced fear after they discovered a lump in the breast because they associated the breast lump with death. Nevertheless, even these

informants associated a breast lump with death, they did not seek health care from the doctors while the breast lump was still small and more likely to respond to treatment.

Fear of loss of femininity

It was mentioned in section 2.5.1 that the key informants regarded the breast as a symbol of femininity. Some of them feared that the affected breast would be removed as part of treatment. They feared that a breast removal would lead to loss of femininity, as they felt that they would no longer be sexually appealing to their partners.

The general informants confirmed the perception of the breast as a symbol of femininity amongst Xhosa women by stating that key informants regarded a female with one breast to be no female at all, and that she would be ostracised by her husband and in-laws due to her loss of femininity. It emerged that since western health care was perceived to use operations for treating breast lumps, Xhosa women tried to avoid this method of health care by consulting traditional healers who used traditional remedies for treatment of breast lumps. This might explain why medical care was only sought at a late stage when the breast lump could no longer be cured.

Lack of information/knowledge about the significance of a breast lump

The responses by the key informants indicated that they did not possess sufficient information about breast lumps. Some informants reported that they ignored the lump because they never associated the painless lump with breast cancer. They only realised that they needed medical treatment when there were changes in the breast lump, such as ulceration, bleeding and pain. It was

emphasised that it seemed that "the *ithumba*" (abscess) failed to rupture, drain pus and heal." An informant indicated that she was still busy with her home chores, as she wanted to hoe her garden first before consulting the doctor for her breast lump. Another informant stated that the lump started in the axilla and not in the breast, therefore, she did not think that this was a breast lump. It emerged that these informants did not possess any knowledge about the breast lump and breast cancer.

None of the key informants knew anything about prevention, early detection and early treatment of breast cancer. However, an informant indicated that doctors knew everything regarding prevention, whereas another informant said traditional healers were knowledgeable people on this aspect.

The general informants confirmed that the health promotion information shared with clients in the primary health care setting was insufficient, as it did not include cancer prevention. The general informants regarded this to be a serious omission, as nurses emphasised breast-feeding. Health promotion/education given at the primary health care clinics was not enough, as staff in those clinics did not know much about cancer care. This resulted in the omission of stressing the importance of cancer prevention, early detection and early treatment of breast cancer in the health education programme. The general informants also confirmed that the radio was commonly used to disseminate health information in the rural areas. It was an important medium, as health professionals could never gain access to all the widespread places. However, not all households had radios, and some of those who owned radios tended to listen to selected radio programmes like news, short stories and death announcements. They switched the radio off most of the time, in order to spare the batteries. Sometimes illiterate women just listened to radios and did not take any actions even after health educational talks, because they did not really understand the meaning of the

contents of the health talks. This implied that the objective for utilising the radio for health promotion was not being achieved. Xhosa women continued to present late with advanced breast cancer, irrespective of health promotion programmes on the radio.

Pressures from the significant others

This code referred to the exertion of continuous negative persuasion by immediate family or friends resulting in seeking/delay in seeking health care for a breast lump, by the informants. The significant others pressurised the key informants not to seek medical treatment for fear of death. An informant indicated that her boyfriend did not want her breast to be removed because he feared that she might not wake up after the operation. He was afraid that she might die. He preferred that the informant would remain with her breast lump as it was still very small, and was not painful. He pressurised her not to seek medical treatment. It emerged that the informant did not agree with her partner, and her breast was removed. She stated that she felt very happy after the operation because she knew she was going to be healthy.

Embarrassment

This code referred to feelings of being ashamed of having a breast lump, experienced by informants. The key informants indicated that there were people who were ashamed of having a breast lump and did not want anybody to know about it. These people would hide their breast lumps due to the embarrassment that they might have breast cancer. This often happened in the community. Some informants explained that their neighbours died while they were hiding their lumps in their breasts. This meant that there were people who still regarded breast cancer as a stigma. An informant even remarked that it was wrong to

delay for a breast lump treatment, because if the breast lump was cancerous, it (cancer) would kill if it was diagnosed late. This meant that at least some of the informants had some ideas about the importance of early diagnosis and treatment of breast lumps.

4.2.3.5 Advice

Advice implied information that informants expressed that they would wish to share with other women about appropriate actions after discovering a breast lump. Two main types or responses on advice that they wished to share with other women emerged, namely:

- to seek medical treatment for a breast lump
- did not know what to say to other women with a breast lump.

To seek medical treatment for a breast lump

Some key informants specified that they gained some knowledge about early detection of breast cancer through their personal experiences. They stated that a small piece of tissue from the breast lump was taken and sent for tests to confirm the actual cause of the lump in the breast. The informants explained that they had learned through their experiences and would like to advise other women with a breast lump to seek medical treatment in time. An informant stated that "*ndinqwenela ukuba ndiwaxelele amanye amakhosikazi lukhulu ngeqhuma elisebeleni xa sele ndiphilile*" (I wish I could give other women more information about a breast lump when I am well). Another informant specified that she would advise other women to report any unusual findings in the breast. The informants generally indicated that they would advise other women with breast lumps to seek medical care from the hospital before the lump became cancerous, or before

cancer spread to other organs of the body. Some informants confirmed that early diagnosis and prevention of breast cancer was good, as this contributed to longer life. It was indicated that these tests should be done while the lump was still small.

The general informants confirmed the importance of early educating the key informants on how, when, who and why they should do breast examinations for early detection purposes. This strategy was identified as promoting health, thus reducing mortality rates among the Xhosa women.

Did not know what to say to other women with a breast lump

Only one key informant indicated that she did not know what advice to give to other women with breast lumps.

4.2.3.6 Views on best treatment

Views on best treatment referred to opinions, expressed by informants, about most desirable health care options for breast lumps. Three main categories of responses on the best treatment for a breast lump emerged from the data namely:

- removal of the breast lump
- combination treatment
- did not know which treatment was best

Removal of the breast

Some key informants indicated that the best treatment for a breast lump was the removal of the lump. They further indicated that removal of the whole breast was the best treatment if the lump had been found to be cancer. It emerged that

an informant had a breast lump removed twenty years ago, but the lump had recurred. This made her to be in favour of a breast removal, to prevent any further recurrence as she thought that the cancer affected the entire breast.

Combination treatment

Some key informants indicated that the best treatment for the breast lump, if it was found to be cancer, was combination treatment composed of *breast removal* (mastectomy) followed by *special injections* (chemotherapy) and the "iron" (radiotherapy). An informant stated that she was feeling very well because of this treatment combination.

Did not know which treatment was best

Some key informants did not have any ideas about the best treatment for a breast lump. An informant indicated that she had never heard of anything like breast removal before. It appeared that Xhosa women in this region required more effective health education and promotion on conditions affecting them, especially lumps of the breast.

4.3 CONCLUSION

The responses from both the key and general informants have been discussed under the codes and sub-codes, which resulted from the data analysis. The research findings were elaborated by further explanation of the codes and sub-codes, and by references to relevant literature sources.

In the following chapter, the aims achieved by this research are presented. Conclusions are reached, limitations identified and recommendations made that could benefit the population under study.

CHAPTER 5

RESEARCH RESULTS, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In Chapter 1 the nature of the problem, which forms the basis of the study, was presented. Despite widespread cancer awareness programmes, launched by the health care professionals, Xhosa women tend to delay seeking medical diagnosis and treatment for breast lumps. When they eventually seek medical treatment, they often have advanced breast cancer with poor prognoses. The question that arose was: *What are the reasons for such delays?* This researcher investigated the health seeking behaviours of Xhosa women in the former Transkei region with breast lumps, and explored the intra-personal factors, and the cultural values, beliefs and practices that influence their health seeking behaviours.

In Chapter 2, studies on breast lumps and breast cancer, which were conducted in different cultures in different countries, were reviewed. From the findings of these studies, differences and similarities were identified. The literature review brought to light that late presentation for medical treatment of breast lumps was also observed in African American women, resulting in advanced breast cancer by the time they sought medical treatment. However, White women, from South Africa and other countries, tended to seek medical treatment while the breast lump was small or during the early stages of breast cancer. The results of early treatment are good, with longer disease free survival periods after treatment. This is an indication of the importance of early detection and treatment of breast lumps. The literature review also highlighted the fact that breast cancer is an

emerging health problem in developing countries and communities. Late diagnosis and treatment of breast lumps may contribute to a rise in the incidence of breast cancer in those communities. Possible personal, socio-economic and cultural reasons for delays in seeking medical diagnosis and treatment were explored. The literature review guided the researcher through the process of planning for the data collection process.

5.2 RESEARCH DESIGN AND METHOD

In Chapter 3 the research design and method used to conduct this study were presented. An exploratory, qualitative research design, using the ethno-nursing method, was used to address the research problem. The problem statement for this study was

What is the nature of the health seeking behaviours of the Xhosa women with breast lumps, and which intra-personal and cultural factors influence those behaviours?

The research objectives were to:

- *describe the health seeking behaviour of Xhosa women with breast lumps*
- *explore the intra-personal factors that influence health seeking behaviour of Xhosa women with breast lumps*
- *explore the cultural factors that influence health seeking behaviour of Xhosa women with breast lumps*

5.3 SUMMARY OF THE RESEARCH FINDINGS: MAJOR THEMES

Three themes emerged from the research findings and these themes are consequently discussed.

5.3.1 Health seeking behaviour

5.3.1.1 *Intra-personal factors influencing health seeking behaviour*

The data obtained through data collection indicated that, not only cultural factors influenced health seeking behaviour of the key informants, but also a lack of knowledge and personal experiences of the informants once they realised that they have a breast lump.

Lack of knowledge

The key informants mostly discovered their breast lumps themselves. This occurred by chance, as none of them reported any knowledge of breast self-examination procedures.

The key informants attached different meanings to the breast lumps that they had discovered. While some key informants considered the possibility that breast cancer might be present, others thought that this was an indication of a health problem other than breast cancer. Some key informants simply did not know what the presence of a breast lump meant. It could therefore be concluded that the key informants lacked sufficient knowledge about the significance of breast lumps.

The key informants did not know that medical diagnosis and treatment were necessary for painless breast lumps. They only sought medical treatment once it became clear that traditional remedies were not effective. The key informants would leave a breast lump alone to grow from a small painless lump until the

whole breast was affected by the lump, with all the complications of advanced breast cancer, prior to seeking medical help.

Sources of information are personal observations and the radio. Some key informants based their interpretations about their breast lumps on personal observations about what happened to someone else who had a breast lump. The radio did not appear to be an effective medium of communication because not all households had radios, and some of the informants switched the radio off most of the time in order to spare the batteries, whereas those illiterate key informants just listened to radios and did not take any actions even after educational health talks. Likewise, the general informants (registered nurses) are not effective sources of information on breast lumps and breast cancer due to lack of knowledge on their part, as they did not possess enough knowledge on cancer prevention and care. It emerged that the general informants only emphasised breast feeding of mothers, and did not provide the key informants with information about breast lumps and breast cancer.

It is concluded that the key informants did not possess knowledge about breast self-examination, the significance of the presence of a breast lump, and the importance of early diagnosis and early medical treatment. The registered nurses' role performance with regard to health education on breast lumps and breast cancer was ineffective. The effectiveness of the radio as a health education communication medium was also limited.

Personal experiences

The key informants reported negative experiences such as frustration, surprise, and fear of death upon discovery of their breast lumps. Fear of death could be the reason why some key informants denied that breast cancer might be present.

It emerged that fear of death was based on previous personal observations of other women dying from breast cancer.

Experiences such as shame and embarrassment were reported. These experiences could be related to the fact that breast cancer is stigmatised and regarded as resulting in a loss of femininity. This, together with cultural values about the significance of the breast (refer to par. 2.5.1), might have resulted in keeping quiet about the breast lumps.

The presence of the lump in the breast brought negative experiences to the key informants. It is concluded that the key informants stayed away from diagnosis and medical treatment for a breast lump due to fear of death and the stigma that is attached to breast cancer.

5.3.1.2 Cultural factors influencing health seeking behaviour

Cultural factors are beliefs, values and practices that play a part in the health seeking behaviours of the Xhosa women with breast lumps.

Cultural beliefs about the causes of breast lumps

A breast lump was explained by the key informants in terms of the supernatural, witchcraft and holistic explanatory models of sickness. The possible causes are complaints by the ancestors, witchcraft and jealousy. The latter indicated a lack of equilibrium between the woman and the social environment. Traditional and faith healers were perceived to be appropriate sources of health care for ailments caused by supernatural forces, sorcery or disequilibrium with the social environment. Medical treatment was generally sought once it became clear that the remedies prescribed by traditional and faith healers were not effective.

It is concluded that the explanatory model for sickness influenced some key informants in their decisions to consult traditional health practitioners first, while others consulted medical practitioners first. Those who consulted traditional health practitioners first, only turned to medical practitioners once it became clear that traditional remedies were ineffective.

Cultural values about the significance of the breast

The breast is regarded as a significant symbol of femininity, lovemaking, nurturance, fertility, motherhood and outward signs of femaleness. The breast represents part of a female body image, thus providing a woman with symmetrical physique.

A breast lump was associated by the key informants with fears of loss of their femininity and of their appearance. Experiences of embarrassment also occurred and this resulted in the key informants keeping quiet until too late, when the breast lump had already become very big.

Cultural beliefs about the consequences of medical treatment

The general informants explained that beliefs that cancer would spread if the lump was punctured, often result in Xhosa women staying away from medical treatment while seeking other treatment options. This was due to the perception that western health care used needles and blades to puncture the breast lump during diagnosis and treatment.

It is concluded that cultural values about the significance of the breast and fears that diagnostic tests would aggravate breast cancer contributed towards delays in seeking diagnosis and medical treatment for a breast lump.

Significant others

The key informants generally received support from their family members, husbands, friends and significant others by accompanying them to seek medical treatment for breasts lumps. Their advice included seeking medical treatment from the clinic, general practitioner and traditional healer. However, it was also found that it is possible that a woman's partner could pressurise her not to seek medical treatment for a breast lump for fear that a mastectomy might be performed.

It is concluded that the key informants were supported by their significant others upon discovery of their breast lumps and during the health seeking period. However, instances of pressure not to seek medical treatment also occurred.

5.3.1.3 Health seeking practices

These are tendencies to seek medical treatment by the key informants for breast lumps.

Health practitioners and institutions utilised

It emerged that some key informants would first seek health care from a traditional healer or faith healer, due to the belief that breast cancer should never be treated with western medicine. Other reasons are that during a traditional healer's divination, there are no painful procedures whereas the opposite can be

said of modern medical treatment where diagnostic procedures are many, varied and take up to weeks to complete. The traditional healer is accessible and renders culturally congruent care. Other key informants directly consulted a medical practitioner.

The key informants who first consulted a traditional healer finally sought medical treatment where medical diagnostic tests were done and medical treatment were provided for the breast lump, which had by then developed into advanced breast cancer.

It is concluded that the medical and the traditional health care system are utilised complementarily by the key informants, but that medical treatment is sought only once a treatable breast lump has developed into advanced breast cancer.

Remedies and treatment received

Remedies by the traditional healer included hot fomentations, stomach washouts, and steaming. Faith healers provided hope of cure through candle lighting while praying for the patient, using holy water and Jeyes fluid mixed with milk.

It became clear that only when the traditional remedies had failed to cure the breast lump, medical treatment was sought in advanced stages of breast cancer. The occurrence of visible breast changes namely, ulceration, bleeding, fungation and pain prompted the key informants to ultimately seek medical treatment. Another reason was also complications of traditional remedies such as diarrhoea, dehydration and burns resulting from traditional remedies.

The types of medical treatment included mastectomy, chemotherapy and radiotherapy.

It is concluded that the key informants only turned to western medicines when the traditional and faith healers' remedies had failed to cure the breast cancer and complications had already occurred.

Length of delay in seeking medical diagnosis and care for a breast lump.

The length of the delay varied between two months and three years. The consequences of the delay were that the breast lump had grown so big that the whole breast was affected, with oedema, skin puckering, nipple retraction, ulceration, bleeding, and pain.

It is therefore concluded that the key informants waited too long before seeking medical treatment for their breast lumps. This delay had dire consequences, namely advanced breast cancer, poor treatment results and poor prognosis.

5.3.2 Support systems during treatment for breast cancer

The role of the significant others presents two possibilities. While some key informants were accompanied to the health care institutions and assisted during the treatment process, others were neglected and ostracised.

It can therefore be concluded that the role of significant others was very important in supporting the key informants during their treatment period for advanced breast cancer. On the other hand when neglect is deliberately imposed on the sick person by the significant others for cultural reasons, this becomes an unfortunate situation, impacting negatively on the prognosis of the patient.

5.3.3 Insights gained by the key informants that they could share with other women.

The experiences of the key informants resulted in insights that could be used to help others with the early detection of, and seeking medical treatment for breast lumps. They indicated that they would advise other women with breast lumps to seek medical treatment while the lump was still small and curable, before it became cancerous. In hindsight, the key informants regarded mastectomy, chemotherapy and radiotherapy to be the best treatments.

It can therefore be concluded that the key informants gained insights into the importance of medical treatment for breast lumps and breast cancer.

5.4 CONCLUSION

From the findings of this study, it emerged that the key informants used the traditional and professional health care systems, and traditional remedies and medical treatments, in a complementary manner. Denial that a serious health problem may be present and a tendency to keep quiet about the breast lump contributed towards delays in seeking health care. When health care is sought, a traditional healer, faith healer or a medical practitioner is consulted. When the first consultant is a traditional healer or faith healer, additional help is sought from a medical practitioner only once symptoms of breast cancer appear or complications of traditional remedies develop.

The intra-personal factors that are associated with the health seeking behaviours of the key informants are lack of knowledge about breast lumps and breast cancer, and personal experiences such as fear and embarrassment. The key

informants lacked knowledge about the significance of a breast lump, and the importance of early medical diagnosis and treatment. They feared the possibility of death, loss of femininity and impaired interpersonal relationships. They also experienced embarrassment and went through a period of denial that breast cancer may be possible.

Cultural factors are also associated with the health seeking behaviours of the key informants. The female breast is valued in terms of representing the female physique, femininity and motherhood, and breast cancer is believed to threaten these values. Cultural beliefs about the cause of sickness, and certain myths that medical interventions could aggravate breast cancer, are reasons for the delay, by some key informants, in seeking medical diagnosis and treatment for their breast lumps. Furthermore, the fact that traditional healers are accessible and render culture congruent care, also contributed to this phenomenon.

5.5 CONTRIBUTION OF THE STUDY

This study contributed to the body of nursing knowledge based on the information about the health seeking behaviours of the key informants and the factors that influenced their health seeking behaviour. The study also highlighted the reasons why the key informants delayed seeking medical treatment for their breast lumps. This knowledge could be used by registered nurses to better understand how their clients perceive breast lumps, and how they react to the discovery of breast lumps.

The researcher communicated the research findings to the health care institution's management. This enabled them to revise their health promotion programme, by including information about breast cancer prevention, and the early detection and early treatment of breast lumps.

It was established that women who suffered from breast cancer as a result of their delays in seeking diagnosis and medical treatment have gained certain insights that they could share with healthy women. They could be educated and utilised in awareness campaigns to teach healthy women about breast lumps.

The findings that the general informants lacked information on breast cancer prevention were welcomed with appreciation by the hospital management. It was therefore resolved that once a month, primary health care nurses should have in-service education on cancer prevention, and an oncology nurse was allocated to be involved in this programme. The health promotion section of the Cancer Association of South Africa was also approached to participate by providing pamphlets, which are written in both English and Xhosa, for the benefit of both nurses and the community members.

As a result of this research study, a Breast Clinic was commenced in April 2001 at the Umtata General Hospital. Women with breast lumps are referred, consulted and managed. Fine needle aspirations cytology (FNAC) tests are taken from the breast lumps and sent to the laboratory. The results are received after 30 minutes to 1 hour, while the patients are still waiting in the clinic. Treatment decisions are then taken as to the best way to manage the breast lumps.

5.6 LIMITATIONS OF THE STUDY.

The limitations of the study are two fold.

Only Xhosa women from the former Transkei region formed part of the population, and a non-random sampling method was used to select the sample. The sample was not representative of the population. Therefore, the findings

cannot be generalised. However, the researcher did not intend generalising the findings. The in-depth knowledge gained through this research benefited health care delivery as explained in section 5.5.

The inability of the researcher to gain sufficient trust from the key informants to enable them to fully share information about their health seeking behaviours with the researcher, might have been another limitation. However, the researcher addressed this limitation by also interviewing registered nurses, who served as general informants.

5.7 RECOMMENDATIONS

Based on the findings of this study, the following recommendations were made to ensure that the problem of delayed presentation for medical treatment by the Xhosa women with a breast lump was addressed.

5.7.1 Recommendations for clinical practice

It is recommended that registered nurses should receive in-service education on health promotion, prevention, early detection and early treatment of breast cancer. The content should include predisposing causes, clinical signs and symptoms, diagnostic procedures, prevention and early detection of breast cancer. The content should also cover cultural values, beliefs and practices related to health and sickness, with specific reference to reproduction, the reproductive organs, breast lumps and breast cancer. Another important topic is the principles of culture congruent care.

A cultural congruent health education campaign on breast lumps and breast cancer should be planned. The target groups must be traditional/faith healers,

Xhosa women and their significant others. Health education must be taken to the communities as face-to-face communication, as media such as the radio may not be effective. Women who suffer or have suffered from breast cancer because they delayed in seeking diagnosis and medical treatment could also be trained and used as health educators.

Traditional/faith healers should be involved in the health care delivery, especially in the primary health care setting. There should be collaboration between traditional/faith healers and health professionals in the health care delivery, whereby traditional/faith healers could be encouraged to refer women with breast lumps for medical treatment. Xhosa women with breast lumps could be encouraged to receive traditional remedies that do not negatively impede upon medical treatment.

5.7.2 Recommendations for education

It is recommended that a course in Anthropology be included in the curriculum for training health professionals. This course must include information about the cultural values, beliefs and practices specific to the different cultures affecting health seeking behaviours in the RSA.

A course in Transcultural Nursing should be included in the nursing curriculum, to enable nurses to know and understand the cultures of the different groups of clients in health care institutions. This must include cultural values, beliefs and practices related to human reproduction, health and sickness. Such knowledge should be used to provide culture congruent preventive health care to clients in specific areas by means of tailor made educational programmes. In-service education programmes should reinforce registered nurses' abilities in effectively managing patients/clients from different cultures.

5.7.3 Recommendations for further research

More in-depth research should investigate the cultural values, beliefs, and practices related to health and sickness and how these factors could influence health seeking behaviours by Xhosas. It is recommended that participant observation data collection methods should be utilised to enable the researcher to gain lay informants' trust and willingness to share their practices. Alternatively, community members could conduct the interviews, provided that they receive training in interview skills. In future, women with breast cancer could conduct such interviews. Ideally, these interviewers should simultaneously supply information needed by the informants. The focus of further research could be to gain in-depth information about the experiences that women have upon discovery of a breast lump.

Stoll (1995:xvi) stated that breast cancer is a long process, and much of the damage may well have occurred in teenagers and young adults. It may not be what we are eating now but what we ate when we were eighteen that precipitated its later development. When one looks at what the composition of the cultural diet of the Xhosa, the above predisposing causes do not seem to affect young women, but other underlying causes of breast cancer may be present in the environment. Therefore, it is time for more research on this topic.

5.8 CONCLUSION

In view of the findings of this study, there is a belief that late presentation for diagnosis and medical treatment by the Xhosa women with breast lumps could be counteracted if the above recommendations were to be implemented. With the implementation and strengthening of cancer prevention campaigns, Xhosa

women could realise that the painless, small breast lump could be very dangerous if one does not seek prompt diagnosis and medical before it is too late. "Ekugqibeleni sizakuwohlula umhlaza webele" (in the end we will conquer breast cancer).

The Oncology Nursing Society maintains that "... every patient with cancer has the right to the best available treatment, care and support... and that ... educational opportunities equip nurses to act as a resource to patients and their families. Informed nurses also have the responsibility to provide information to the public about cancer, its prevention and treatment" (David 1995:392).

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ANNEXURE I

PO Box 164,
Umtata. 5099.
30th October
2000.

The Chief Medical Superintendent,
Umtata General Hospital,
Umtata.

Attention : Senior Nursing Service Manager.

I am doing Masters Degree in Nursing (MA Cur) at the University of South Africa; and I am expected to conduct a research study as a requirement for the degree. May I, therefore, request your permission to conduct this study in Umtata General Hospital. The topic for my research study is:

"Cultural factors associated with management of a breast lump amongst Xhosa women".

This is a qualitative, exploratory research study as it involves an in-depth investigation of the cultural factors and health seeking behaviour of the Xhosa women with breast lumps. The areas where this study will focus are the female surgical ward and the Surgical Out Patient's Department (SOPD), where Xhosa women with advanced breast cancer are being admitted and treated.

Thanking you in anticipation.

Yours Sincerely,

Nosipho Mdongolo. Chief Professional Nurse.

ANNEXURE II

PO Box 164,
Umtata. 5099.
30th October
2000.

Person In Charge,
Female Surgical Ward/Surgical Out Patient's Department,
Umtata General Hospital,
Umtata.

Re: Application to conduct a research study.

I am doing Degree in Nursing (MA Cur) at the University of South Africa; and I am expected to conduct a research study as a requirement for the degree. May I therefore, request your permission to conduct this study in your department.

The topic of my study is: *'Cultural factors associated with the management of a breast lump amongst Xhosa women'*

This is a qualitative, exploratory research study, as it involves an in-depth investigation of the cultural factors associated with the health seeking behaviour of the Xhosa women with breast lumps. The areas where this study will be focused are the female surgical ward and the Surgical Out Patient's Department, where the Xhosa women with advanced breast cancer are being treated.

Thank You.

Your Sincerely,

.....

N. Mdongolo Chief Professional Nurse.

ANNEXURE III

P. O. Box 164,

Umtata.

30th October 2000.

Dear Madam,

Re: Application for consent to conduct a research study.

I am a student for Masters Degree in Nursing Science (MA Cur.) at the University of South Africa. I am undertaking a research study on "*cultural factors associated with the management of a breast lump amongst Xhosa women*".

To complete this study, focus group interviews should be conducted with the Xhosa women who have been diagnosed with breast lumps to establish their cultural values, beliefs and practices regarding late presentation for diagnosis and medical care. Tape recordings of the interviews will be done, so that findings could be verified.

Confidentiality and privacy will be ensured by observing the following:

- your name will not be used anywhere on the interview guide
- strict privacy and confidentiality will be maintained on all collected data
- should you feel you no longer wish to continue with the interview, it will be terminated immediately.

Your participation in this study will be very important.

Thank you.

Yours Sincerely,

N. Mdondolo. Chief Professional Nurse.

ANNEXURE IV

PO Box 164,
Umtata. 5099.
30th October
2000.

Dear Colleague,

Re: Request for a consent to conduct a research study.

I am currently registered with the University of South Africa for the Masters Degree in Nursing Science (MA Cur). I am undertaking a research study on: *"Cultural factors associated with the management of a breast lump amongst Xhosa women"*.

Focus group interviews of professional nurses dealing with the Xhosa women with advanced breast cancer will be conducted. You have been selected to participate in this study. Anonymity will be maintained, and all collected data will be held in strict confidentiality.

Should you feel that you no longer wish to continue with the interview, it will be terminated with immediate effect.

Thank you very much for your co-operation.

Yours Sincerely,

N. Mdongolo. Chief Professional Nurse.

ANNEXURE V

**INTERVIEW GUIDE FOR XHOSA WOMEN WITH ADVANCED BREAST
CANCER DUE TO LATE PRESENTATION FOR DIAGNOSIS AND
MEDICAL CARE IN THE FORMER TRANSKEI REGION**

SECTION A: BIOGRAPHICAL DATA

- 1 How old are you?

- 2 What is your marital status?

- 3 How many children do you have?

- 4 What is your highest level of education?

**INTERVIEW GUIDE FOR XHOSA WOMEN WITH ADVANCED BREAST
CANCER DUE TO LATE PRESENTATION FOR DIAGNOSIS AND
MEDICAL CARE IN THE FORMER TRANSKEI REGION**

SECTION B: INTERVIEW QUESTIONS

- 1 Tell me how the lump in your breast was discovered
- 2 What did you think the lump in your breast meant?
- 3 How did you feel when you discovered the breast lump?
- 4 What actions did you take after the lump in your breast was discovered?
- 5 What advice did your family or community give you after the lump in your breast was discovered?
- 6 What type of health care did you seek first after the lump in your breast was discovered?
- 7 For how long did you wait before you sought medical care from the hospital?
- 8 What health education did you receive regarding breast lump?
- 9 What advice would you give to other women who discover a lump in her breast?

PROBING QUESTIONS FOR THE INTERVIEW WITH XHOSA WOMEN

These questions were asked only if necessary, for instance if the respondents failed to keep to the point or if insufficient information was forthcoming

PROBING QUESTIONS FOR QUESTION 1

Who discovered the lump in your breast?

PROBING QUESTIONS FOR QUESTION 2

What are your views about the relationship between witchcraft and a breast lump?

What are your views about the relationship between the ancestors and a breast lump?

According to your culture what is the significance of a female breast?

PROBING QUESTIONS FOR QUESTION 3

What are your views about the relationship between the breast lump and breast cancer?

Tell me about family members who suffered from breast cancer?

What happened to the family member who had breast cancer?

PROBING QUESTIONS FOR QUESTION 4

What are your views about the helpfulness of going from doctor to doctor for treatment of a breast lump?

Whom do you trust for the treatment of the lump in your breast?

PROBING QUESTIONS FOR QUESTION 5

How relevant was the advice that you received from your family or community?

PROBING QUESTIONS FOR QUESTION 6

What are your views about the role of traditional healers regarding treatment for a breast lump?

What do you think is the role of spiritual/faith healers regarding treatment of breast lump?

PROBING QUESTIONS FOR QUESTION 7

Why did you stay at home when you had noticed already that there was a lump in your breast?

When you ultimately went to the hospital for treatment, how big was the lump in your breast?

What do you think is the role of cultural beliefs, values and practices of the Xhosa in treatment of breast lump?

PROBING QUESTIONS FOR QUESTION 8

What knowledge did you have about breast lumps?

What did you know about the consequences of delay in seeking medical care for a breast lump?

What has been the reaction of your partner throughout your illness?

PROBING QUESTIONS FOR QUESTION 9

What do you know about breast cancer screening and prevention procedures?

What are your views about breast removal for breast cancer?

What do you think is the best treatment for a breast lump?

ANNEXURE VI

IMIBUZO YOPHANDO KUMAKHOSIKAZI AMAXHOSA ANOMHLAZA
WEBELE NGENXA YOKULIBAZISA UKUFUNA UNYANGO
ESIBHEDLELE KWINDOWO EYAYISAKWAZIWA NGOKUBA
YITRANSKEI.

ICANDELO A: IINKCUKACHA ZESIQU.

1. Ubudala bakho bungakanani ?
2. Buyintoni ubume bomtshato bakho?
3. Ingaba unabantwana abangaphi?
4. Leliphi ibanga lemfundo ephakamileyo onalo?

IMIBUZO YOPHANDO KUMAKHOSIKAZI AMAXHOSA ANOMHLAZA
 WEBELE NGENXA YOKULIBAZISA UKUFUNA UNYANGO
 ESIBHEDLELE KWINDAWO EYAYISAKWAZIWA NGOKUBA
 YITRANSKEI.

ICANDELO B : IMIBUZO YOPHANDO.

1. Kha undixelele ukuba iqhuma elisebeleni lakho lafumaneka njani?
2. Wacinga ukuba iqhuma elisebeleni lakho lithetha ntoni?
3. Waya waziva njani emva kokuba ufumanise iqhuma ebeleni lakho?
4. Ngawaphi amanyathelo owaye wawathatha emva kokuba ufumanise iqhuma elisebeleni lakho?
5. Ngawaphi amacebiso owawafumanayo kusapho lwakho okanye kubahlali bendawo yakho emva kokufumanisa kwakho iqhuma elisebeleni?
6. Loluphi uhlobo lonyango owalufuna kuqala emva kokufumanisa iqhuma ebeleni lakho?
7. Walinda ixesha elingakanani phambi kokuba uye kufuna unyango esibhedlela?
8. Yeyiphi imfundiso yezempilo owathi wayifumana ngokunxulumene neqhuma elisebeleni?
9. Ungawacebisa ntoni amanye amakhosikazi azifumanise eneqhuma ebeleni?

IMIBUZO EPHANDA NZULU KUMAKHOSIKAZI AMAXHOSA.

Lemibuzo yabuzwa kuphela xa kwakufanelekile; mhlawumbi xa babengaphenduli ngokuthe ngqo, okanye xa inkcazo yabo yayingonelanga.

UMBUZO OPHANDA NZULU UMBUZO WOKUQALA

Lafunyaniswa ngubani iqhuma elisebeleni lakho?

IMIBUZO EPHANDA NZULU UMBUZO WESIBINI

Zithini izimvo zakho ngozalwano phakathi kobugqwira neqhuma elisebeleni?

Zithini izimvo zakho ngozalwano phakathi kwezinyanya neqhuma elisebeleni?

Ngokwenkcubeko yohlanga lwakho libaluleke ngantoni ibele kumntu ongumfazi?

IMIBUZO EPHANDA NZULU UMBUZO WESITHATHU

Zithini izimvo zakho ngozalwano phakathi kweqhuma elisebeleni nomhlaza webele?

Kha undixelele ngamalungu osapho lwakho awayenomhlaza webele.

Kwenzeka ntoni kuloomalungu osapho lwakho ayenomhlaza webele?

IMIBUZO EPHANDA NZULU UMBUZO WESINE

Zithini izimvo zakho ngoncedo olufumanekayo koogqira abohlukeneyo ngonyango lweqhuma elisebeleni?

Ngubani omthembayo ukuba angakunyanga iqhuma elisebeni lakho?

IMIBUZO EPHANDA NZULU UMBUZO WESIHLANU

Zaba luncedo kangakanani iingcebiso owazifumanayo kumalungu osapho

lwakho okanye kubahlali bendawo yakho?

IMIBUZO EPHANDA NZULU UMBUZO WESITHANDATHU

Zithini izimvo zakho ngendima edlalwa ngamaggira kunyango lweqhuma elisebeleni?

Ucinga ukuba yintoni indima edlalwa ngabathandazeli kunyango lweqhuma elisebeleni?

IMIBUZO EPHANDA NZULU UMBUZO WESIXHENXE

Kwakutheni ukuze uhlale ekhaya xa wawusele ubonile ukuba uneqhuma ebeleni lakho?

Lalikhulu kangakanani iqhuma ebeleni lakho ngexesha owade waya kufuna unyango ngalo esibhedlela?

Ucinga ukuba yintoni indima yamasiko nezithethe zamaXhosa kunyango lweqhuma elisebeleni?

IMIBUZO EPHANDA NZULU UMBUZO WESIBHOZO

Luthini ulwazi owawunalo ngeqhuma elisebeleni?

Wawusazi ntoni ngeziphumo zokulibazisa ukufuna unyango lweqhuma elisebeleni?

Umlingane wakho waya waphatheka njani ngalo lonke ixesha lokugula lakho?

IMIBUZO EPHANDA NZULU UMBUZO WESITHOBA

Yintoni oyaziyo ngokufumanisa umhlaza webele kwangoko nokuwuthintela kanjalo?

Zithini izimvo zakho ngokususwa kwebele xa linomhlaza webele?

Ucinga ukuba loluphi olona nyango olululo lweqhuma elisebeleni?

ANNEXURE VII

**INTERVIEW GUIDE FOR REGISTERED NURSES WORKING IN THE
UMTATA GENERAL HOSPITAL**

SECTION A: BIOGRAPHICAL DATA

1 How old are you?

2 What are your South African Nursing Council Registrations?

| | |
|------------------------|--|
| General nursing | |
| Psychiatric nursing | |
| Community health | |
| Midwifery | |
| Nursing education | |
| Nursing administration | |
| Other | |
| <hr/> | |

3 In which health care unit do you work?

4 For how long have you worked in the unit that you indicated?

**INTERVIEW GUIDE FOR REGISTERED NURSES WORKING IN THE
UMTATA GENERAL HOSPITAL**

SECTION B: INTERVIEW QUESTIONS

- 1 What are your views about the reasons for late presentation by Xhosa women with a breast lump?

- 2 According to you, why do Xhosa women seek help for a breast lump from traditional healers?

- 3 What do you think motivates Xhosa women to eventually seek medical treatment for a breast lump?

- 4 Apart from medical treatment, what remedies do Xhosa women use for a breast lump?

- 5 How do family members influence the health seeking behaviour of Xhosa women with a breast lump?

- 6 What are your views about health promotion / education which is being given in the primary health care setting on early detection and prevention of breast cancer?

- 7 What advice would you give to Xhosa women regarding early detection and prevention of breast cancer?

PROBING QUESTIONS FOR THE INTERVIEW WITH REGISTERED NURSES

These questions were asked only if necessary, for instance if the respondents failed to keep to the point or if insufficient information was forthcoming

PROBING QUESTIONS FOR QUESTION 1

What are the cultural views of Xhosa women with a breast lump about western medicine?

What is the longest period of delay in seeking medical treatment that you have observed in Xhosa women with a breast lump?

What are the most common reasons of late presentation for medical care by Xhosa women?

PROBING QUESTIONS FOR QUESTION 2

What are your views about breast cancer treatment in Xhosa women?

What are the cultural views of Xhosa women with a breast lump about traditional health care?

What is the cultural significance of a female breast for the Xhosa?

PROBING QUESTIONS FOR QUESTION 3

What are your views about late presentation for medical treatment of a breast lump and prognosis?

What are your views about the successes of traditional medicine for a breast lump?

PROBING QUESTIONS FOR QUESTION 4

According to you, how successful are these remedies in treating breast lump?
What do you think is the role of spiritual / faith healers in the treatment of breast lump?

PROBING QUESTIONS FOR QUESTION 5

What are your views about the role that is played by the sick Xhosa woman when confronted with a breast lump?

PROBING QUESTIONS FOR QUESTION 6

What is the role of the media in health promotion, early detection and prevention of breast cancer?

What do you think is the value of media health talks about breast lump?

ANNEXURE VIII

CODING SYSTEM

(1) /Questions

*** Definition:

Interview questions asked by researcher during interviews with respondents

(1 1) /Questions/Key respondents

*** Definition:

Interview questions posed to women who delayed seeking medical care for a breast lump

(1 2) /Questions/General informants

*** Definition:

Questions posed to registered nurses providing health care to patients seeking treatment for a breast lump

(2) /Biographical data

*** Definition:

Personal particulars of respondents

(2 1) /Biographical data/Patients

*** Definition:

Personal characteristics of women who delayed seeking medical care for a breast lump, who participated in the study

(2 2) /Biographical data/Nurses

*** Definition:

Personal characteristics of nurses providing health care to women with a breast lump, who participated in the study

(3) /Discovery

*** Definition:

Acquiring knowledge or sight of by effort or chance, of a breast lump

(3 1) /Discovery/How discovered

*** Definition:

Method through which knowledge or sight of a breast lump was obtained

(3 2) /Discovery/Meaning attached

*** Definition:

The significance awarded to the discovery of a breast lump

(3 3) /Discovery/Explanatory model

*** Definition:

Reasons, related to cultural perceptions, about the cause of a breast lump

(3 3 1) /Discovery/Explanatory model/Supernatural

*** Definition:

Causation of a breast lump expressed in terms of forces such as God, the gods or ancestors

(3 3 2) /Discovery/Explanatory model/Equilibrium

*** Definition:

Causation expressed in terms of disturbed relations within the body, with the physical or the social environment

(3 3 3) /Discovery/Explanatory model/Sorcery

*** Definition:

Explanation of causation in terms of witchcraft or magic

(3 4) /Discovery/Significance of breast

*** Definition:

Meaning attached to the female breast

(3 5) /Discovery/Experience upon discovery

*** Definition:

Feelings that the respondent was aware of upon discovery of a breast lump

(3 6) /Discovery/Actions took

*** Definition:

Steps taken by the respondent upon discovery of a breast lump

(4) /Health seeking behaviour

*** Definition:

Steps taken by the respondent to seek health care for a breast lump

(4 1) /Health seeking behaviour/Practitioners

*** Definition:

Persons consulted by the respondents to obtain treatment for a breast lump

(4 2) /Health seeking behaviour/Remedies

*** Definition:

Treatment received by respondents for the breast lump

(4 3) /Health seeking behaviour/Institutions

*** Definition:

Organised bodies rendering health care visited by respondents to seek health care for the breast lump

(4 4) /Health seeking behaviour/Role of significant other

*** Definition:

Influence exercised by immediate family or friends with regard to health seeking behaviour of the respondents with a breast lump

(4 5) /Health seeking behaviour/Length of delay

*** Definition:

Extent of postponement of seeking treatment for a breast lump, and its consequences

(5) /Reasons for delay

*** Definition:

Motive for postponement to seek health care for a breast lump by respondents

(5 1) /Reasons for delay/Fear

*** Definition:

Unpleasant emotion of being afraid upon discovery of a breast lump

(5 1 1) /Reasons for delay/Fear/Death

*** Definition:

Fear of dying after discovering a breast lump resulting in delaying to seek health care for a breast lump

(5 1 2) /Reasons for delay/Fear/Loss of femininity

*** Definition:

Fear of losing qualities of being a woman as a consequence of having a breast lump

(5 2) /Reasons for delay/Knowledge

*** Definition:

Having or lacking information about the significance of a breast lump and importance of seeking health care without delay

(5 3) /Reasons for delay/Significant other pressures

*** Definition:

Exertion of continuous force by immediate family or friends resulting in seeking / delay to seek health care for a breast lump, by the resp

(5 4) /Reasons for delay/Embarrassment

*** Definition:

Feelings of being ashamed of having a breast lump, experienced by respondents

(6) /Advice

*** Definition:

Information that respondents expressed that they would wish to give to other women about appropriate actions after discovering a breast

(7) /Views on best treatment

*** Definition:

Opinions expressed by respondents about most desirable health care options for a breast lump

(D) //Document Annotations

*** No Definition

(F) //Free Nodes

*** No Definition

(T) //Text Searches

*** No Definition

(T 1) //Text Searches/TextSearch

Nodes.txt page: 3 4/19/ 1 15:06:51

*** Definition:
Search for 'die', No restriction

(T 2) //Text Searches/TextSearch194

*** Definition:
Search for 'death', No restriction

(T 3) //Text Searches/TextSearch195

*** Definition:
Search for 'dying', No restriction

(I) //Index Searches

*** No Definition

(C) //Node Clipboard - 'Embarrassment'

*** Definition:
Feelings of being ashamed of having a breast lump, experienced by respondents