

**An Investigation into the Effects of
Cancer of the Breast and Mastectomy
on Black Women in
Former Bophuthatswana**

by

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DECLARATION

I declare that "An Investigation into the Effects of Cancer of the Breast and Mastectomy on Black Women in Former Bophuthatswana" is my own work, and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

MARY KAU

DEDICATION

This study is dedicated to the late Professor Margie Beukes and my late grandmother, Maria Skhosana, who died from cancer of the breast; also to my late brother Abrahm Masotsha Sindane who died from cancer of the lung.

SUMMARY

An Investigation into the Effects of Cancer of the Breast and Mastectomy on Black Women in Former Bophuthatswana

According to the 1991 Annual Report of the Department of Health and Social Services of former Bophuthatswana, there were 364 reported malignant conditions found in women with cancer of the breast and cervix being the most prevalent. What causes great concern is the fact that patients present for the first time at health facilities during advanced stages of these diseases thus making the prognosis poor. Black patients in this study were found to present with cancer of the breast at an earlier age than their white counterparts. In addition to the above named problems, no facility exists for the treatment of cancer in the area of study and patients have to be referred to other areas.

It was on the strength of the above observations that the researcher embarked upon this study to establish the effects of the diagnosis cancer and mastectomy on the victims. The aims of the study therefore were: to explore and describe the psycho-social effects of the diagnosis and treatment on Black women; develop guidelines for oncology nurses and doctors to assist with the adaptation of these patients to the diagnosis and treatment; and provide information that could lead to better training of oncology personnel as well as develop a proper support system to facilitate adjustment of the mastectomised patient to the disease and its treatment.

Data were collected using the qualitative and quantitative approaches with individual in-depth interviews forming the main strategy. The findings revealed that the diagnosis cancer of the breast was equated with death among all respondents.

The mastectomy added more stress for the patient, which was further compounded by chemo- and radiotherapy. The latter was described as causing more pain than the tumour itself.

Problems experienced by the patients were reported to include: financial difficulties; general weakness; fear of recurrence and metastasis; concern for dependent children and fear of unemployment. All respondents in this study expressed the need for the formation of a voluntary care group, which could assist them with adaptation to the disease and its treatment.

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DEFINITION OF TERMINOLOGY USED IN THIS STUDY

The purpose of the following definitions is to clarify concepts used in this study.

Carcinoma: A general term used to describe malignant growths in the body which are characterised by the production of abnormal cells that do not obey the laws of normal tissue. These cells infiltrate surrounding tissues. (Long and Phipps, 1989)

Chemotherapy: The specific treatment of malignant growths. In this study, it is the administration of chemical compounds which possess the quality of decreasing the size of the malignant growth in the breast (Jefferies, 1978).

Mastectomy: Total surgical removal of the breast as part of treatment for the malignant growth in the affected breast.

Metastasis: The spread of cancer cells from the primary source through intramammary (breast) lymphatics to regional nodes leading to distant parts of the body getting involved (Long and Phipps, 1989).

Radiotherapy: The treatment of malignant tumours of the breast using radium x-rays and radioactive isotopes (Wilson, 1971).

KEY CONCEPTS

Key concepts used in this study include breast lump, oozing blood from the nipple, mastectomised women, metastasis, adaptation, voluntary care givers, support group and effects of breast cancer and mastectomy.

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CHAPTER 1

AN INVESTIGATION INTO THE EFFECTS OF CANCER OF THE BREAST AND MASTECTOMY ON BLACK WOMEN IN FORMER BOPHUTHATSWANA

1.1 INTRODUCTION

According to the 1991 Annual Report of the Department of Health and Social Services of the former Republic of Bophuthatswana, there were 1267 reported cases of different types of cancer in the country. Of these 364 were reported to be malignant conditions found among women with cancer of the cervix and breast being the most prevalent. Although accurate statistics on the number of breast cancer patients could not be kept due to client ignorance and their failure to report abnormalities to relevant institutions, the number of patients who reported to the clinics and regional hospitals revealed that cancer of the breast is common in former Bophuthatswana. What causes more concern is the fact that patients presented for the first time at advanced stages of the disease. Winters, Mannell and Esser (1988:69) made similar findings in their study of cancer amongst Black women in South Africa. They reported that the prognosis of breast cancer patients is in most cases poor amongst Black women, because of the late stage during which the patients presented for treatment for the first time. Of more importance is the fact that Black women present with the disease at a younger age than their white counterparts whose mean age at diagnosis was reported to be 58 years, whereas the Black patients' mean age at diagnosis was found to be 51 years (Winters et al 1988:69). The reason for this

difference is unknown, however, Chiedozi (1985:656) in his study of breast cancer in Nigeria, made similar findings and assumed that "the relatively low mean age at discovery of the lump could be ascribed to differences in social status, diet and environmental influences not forgetting genetic differences" between Whites and Blacks.

Walker, Tshabalala, Isaacson and Segal (1984:24) concur with Winters et al. Their study of cancer among Black women in South Africa reported that most patients suffering from cancer of the breast presented for the first time at the hospital during the third stage of the disease, and therefore had a poor survival rate. Hacking, Gudgeon and Lubelwane (1988:57) in their study of breast cancer patients treated at Groote Schuur and Frere hospitals in South Africa made similar findings and reported that 75% of their Black patients suffering from cancer of the breast presented with advanced disease compared with the Coloured and White patients. What compounded the problem was the fact that in addition to presenting at an advanced stage of breast cancer, once the disease was confirmed, these patients often refused hospital treatment and disappeared to the rural areas where they would later surface during the terminal stage or die in the care of a traditional healer. In this study, the average period of delay before reporting changes in the breast was 18 months. Since former Bophuthatswana was 80% rural it was no exception. There was no facility for the treatment of cancer in the country. Although each of the twelve regions which formed the area of study had a community hospital, none of these provided specific treatment for cancer. The patients were therefore always referred to hospitals in the Republic of South Africa such as Ga-Rankuwa,

Kalafong and Pelonomi in Bloemfontein. These hospitals are all not less than 300 kilometres from the research area, a factor which created social as well as emotional problems for the patients who were referred to them for further management. Patients from the above-named area admitted to these hospitals complained about loneliness since their next of kin found it difficult to visit them regularly because of the distance involved. It is on the strength of the above facts that this study was undertaken; the intention being to establish the emotional and social effects cancer of the breast and mastectomy have on Black women in the area where the study was undertaken.

1.2 BACKGROUND INFORMATION ABOUT THE RESEARCH AREA

The former Republic of Bophuthatswana came into existence on 6 December 1977, when the Batswana people of South Africa were granted sovereign independence by the Republic of South Africa. The country was situated between the latitude 24 and 30 South and the longitude 22 and 29 East in the interior of the Republic of South Africa. It consisted of twelve districts found in seven separate blocks of land. It shared common borders with both South Africa and Botswana (see Figure 1).

As reflected in Figure 1, Bophuthatswana consisted of separate land units in a jigsaw formation lying across the eastern corner of the South African plateau.

The total land mass was just over 44,000 square kilometres (27,346 square miles) which made it larger than the Netherlands. The country is flat with



FIGURE 1: FORMER REPUBLIC OF BOPHUTHATSWANA

scattered trees and bushwood. It has warm summers and cool winters. The average midsummer (January) temperature varies between 22.5° and 25° Centigrade (72.5° and 77° Fahrenheit). The midwinter (July) temperature varies between 10° and 12.5° centigrade (50° and 54.5° Fahrenheit). Rainfall is between 399 and 500 millimetres and occurs during summer between October and April. Altitudes vary between 1,000 and 2,000 meters above sea level.

The country had a population of approximately 1,279,000 people (1981 census) of whom 500,000 were attending school (Vermaak and Verwey, 1983:6).

1.3 THE INFRASTRUCTURE

Mining The mining industry formed the most dynamic section of the country's economy. Minerals such as platinum, diamonds and gold provided a fair share of foreign exchange, and the creation of job opportunities for the Batswana people. During the period 1977 to 1994 the government made sure that no constraints existed which affected the development of mineral resources and the extension of mines and quarries. The platinum group metals, cobalt, iron-ore and salt all attracted foreign investment into the country. The government played an important role by providing tarred roads, water and electricity even in the most remote areas of the country.

Broadcasting was launched as a service and a means of communication with the government. The purpose was to educate, inform and entertain; and this service was extended to the entire country.

Primary, Secondary and Tertiary Education The number of these institutions increased substantially during the first ten years of 'independence'. A university was built, secondary schools more than doubled in number from 42 to 104, and 450 early learning centres were established which operated with 1800 teachers who were specifically trained for early learners.

Health Services As far as these are concerned, the country developed a unitary, comprehensive service which concentrated on preventive, promotive, rehabilitative and curative services. Thirty clinics were built, some of which were poly-clinics with doctors living on site. Two hospitals were built in two regions of the country. A large number (209) of health stations were established which were staffed by mobile teams attending to the needs of rural communities.

Tourism also provided an important source of revenue. The Sun Hotels mushroomed in every region, the greatest attraction being the Sun City complex near the Pilanesberg National Park which is very popular in its own right.

Transport was improved and companies such as Bop Air and Bophuthatswana Transport Holdings invested in the country and provided luxury chartered services for passengers.

Agriculture Former Bophuthatswana had the potential to become self-sufficient in basic food production. Maize, sorghum and wheat were cultivated in addition to oil seeds such as sunflower, soya beans and groundnuts. Intensive dairy and

poultry farming were viable in all those areas where 80% of the rural population was concentrated (Strydom, 1987:74). As a result, this sector of former Bophuthatswana contributed substantially towards the country's growing economy. However, the health services did not improve remarkably; the existing mission hospitals were converted into community hospitals, but structure and the quality of services rendered did not change.

1.4 THE RESEARCH PROBLEM

According to Minuchin (1974) in Northouse & Swain (1987:221), when illness occurs in a family the effects thereof are not confined to the patient alone, but rather reverberate throughout the family system. In other words, if one family member suffers from a disease such as cancer, the whole family experiences the cancer crisis, manifested by a variety of emotions. The diagnosis of cancer according to Blumberg, Flaherty and Lewis (1980:308) forces the individual into a series of crises that affect his or her entire well-being. Fear, guilt and powerlessness according to Fredette and Beattie (1986:309) often accompany the diagnosis of cancer. Quint (1964:119), in his study of patients who had a mastectomy, reported that the cancer experience had a disruptive influence on family relationships. This was manifested by tension in the marital relationship accompanied by decreased communication. This was further compounded by separation induced by hospitalisation and physical and psychological withdrawal on the part of the patient. Quint (1963:63) goes further and states that family members had difficulty coping with the emotional ramifications of cancer. The most difficult and crucial time arises when the patient is waiting for the results

of the biopsy and after the mastectomy when the patient takes a look at the scar or incision and when the spouse sees the scar for the first time and responds with support or rejection. Of greater importance is the time when the couple resolve to resume physical intimacy and accept the changes brought about by the surgery.

The researcher found that there is lack of information on cancer of the breast and mastectomy among Black women residing in the research area. Although there is a high incidence of the disease cancer of the breast according to statistics obtained from local hospitals, no previous research has been conducted to determine how these women experience the diagnosis cancer of the breast and subsequently the mastectomy. Of greater importance is the fact that women diagnosed with cancer of the breast reported changes in the affected breast long after the disease had spread to the nearby lymph nodes.

Respondents in this study reported to have delayed for an average period of 18 months before reporting changes in the breast to health professionals. Since the lump was not painful and it did not worry the respondent, it was felt reporting was unnecessary. Chiedozi (1985:653) made similar findings in his study of breast cancer in Nigeria. He reported that breast cancer patients presented with "very advanced breast cancer, 85.3% of the sample of 116 women presented for the first time with stages III and IV of the disease." He describes this aptly when he stated that "patients presented with large unilateral breast masses, usually concurrent with axillary masses." Chiedozi's patients are reported to have covered up like some of the respondents in this study. They would report

"symptoms have been present only for 6 months". In Chiedozi's sample, one third of the participants reported to have been treated by traditional healers before coming to the hospital. Some of the respondents in this study reported to have received treatment from the Zion Christian Church and faith healers. However, only one respondent was encouraged to consult a traditional healer. Chiedozi's sample was reported to have been characterised by "crude attempts at incision and drainage, scarification marks over the breast, with tumour ulceration and fungation through the cuts" (Chiedozi, 1984:654).

It does appear that the problem associated with reporting changes in the breast among Black women goes beyond pain and ignorance. The breast is considered a sexual organ and therefore a certain amount of privacy is attached to its exposure. Changes in the breast may be associated with such exposure, handling and fidgeting by a stranger who is not one's husband. Black women in their traditional set-up hated their breasts to be touched and fondled by strangers. This may be one of the reasons for the delay in reporting the existence of changes in the breast to doctors and nurses. The emotional reasons for the delay in reporting changes need further research in the future if the poor prognosis referred to by Chiedozi (1954:654) is to be controlled.

The researcher met one breast cancer patient who could not be included in the sample because she refused a mastectomy at Baragwanath hospital where she was referred to for treatment. She was a traditional healer and believed that the lump was an abscess (*lethopa*) which required incision by another traditional healer. As the oncology nurses dressed the gaping and slough covered wound

on her breast, she expressed the idea that indeed the abscess is healing since the pus (*boladu*) was escaping (see Appendix C). This patient died from metastasis into the lungs four months later.

It was on the strength of the above observations that the researcher embarked upon this study in order to establish the emotional and social effects the diagnosis and mastectomy have on Black women.

Another motivating factor which prompted the researcher to undertake this study was the fact that she survived cancer of the breast and mastectomy herself and that she experienced this as traumatic, with anger, isolation and depression. The magnitude of these emotional problems in herself further spurred her to determine the effects of such diagnosis in other Black women.

Health personnel taking care of breast cancer patients are concerned only with the disease, its prevention and spread. The emotional aspect has received little attention, if any. From the findings of this study, health professionals could be prepared in a better way to enable them to manage the effects of cancer of the breast and its treatment.

1.5 OBJECTIVES OF THE STUDY

It is assumed that women who have had a mastectomy live with the underlying fear that the cancer can re-occur and possibly become unmanageable. Hinton

(1973:105) concurs with this statement. He reported that variables such as uncertainty, control of the cancer situation and fear of recurrence play an important role in the lives of women who have had this type of surgery. Taking into account the World Health Organisation's definition of health as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity" (Jones, 1991:47), the question may be raised whether women who have had a mastectomy ever consider themselves healthy at any point in life following the operation.

Fodor (1981:1) defines health as being more than physical well-being. She sees it as 'a state involving the interrelatedness of physical, mental, spiritual and social factors'. In this definition, emphasis is placed on the whole individual and his or her interrelationship with society. Dunn (1957:225) aptly captures this interrelationship when he stated that '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 family as well as society' (Dunn, 1957:225-235). In other words, societies are no longer concerned with the cure of illness and prevention of disease but rather with raising levels of wellness through prevention of disease, promotion of health and rehabilitation of those patients who went through a period of illness or recovering from surgery.

Health, therefore, is not merely a continuum of physical, mental, social and spiritual well-being, it should rather be looked upon as a combination of the four facets dynamically interrelated. In other words, the human being functions as

a whole unit with each dimension of health having influence upon the other. A mastectomy, therefore, whether it was performed a day or a number of years back, is bound to have emotional, social and spiritual effects on the victim. Maguire (1976:390) concurs with this statement when he reported that alteration in body image in women who have had a mastectomy may result in reduced social activity and withdrawal. The objectives of this study, therefore, are to:

- determine the experiences of Black women following the confirmation of the diagnosis cancer of the breast and mastectomy;
- determine whether nurses and physicians contributed towards the adjustment of mastectomised women to the cancer and surgery;
- provide a base for appropriate intervention to enable the breast cancer sufferer to adapt to the diagnosis and its treatment;
- assist with the formation of a support group with similar health problems which will assist the mastectomised women with relevant information that will facilitate their adaptation to the cancer and its treatment.

1.6 THE SIGNIFICANCE OF THE STUDY

The research area described on page 3 of this thesis shares the same health problems with other Third World countries. Although the dry climate makes the country less susceptible to tropical diseases such as Malaria and Bilharzia (Kau, 1987:9), global health problems such as hypertension, cancer and sexually transmitted diseases are a public health concern. Over the years the country developed a national health service whose aim is the provision of a

comprehensive service for its people. The philosophy "take health to the people" is made more effective and efficient every year. Communities are encouraged to get more involved in their own health care with the health worker being the guiding mechanism (Mokgethi, 1991:3). The Department of Health and Developmental Social Welfare is committed to provide as well as promote a comprehensive health system which includes cancer detection, treatment and rehabilitation. However, no studies on cancer of the breast and mastectomy per se have been reported in this area, as a result not enough information is available to design programmes that could address the problem. Therefore, this study is intended to provide information that could lead to better training of oncology personnel, and that a proper support system could be developed to successfully deal with problems of Black mastectomised women.

1.7 DELIMITATION OF THE STUDY

This study was delimited as follows:

Respondents were Black women residing in the former homeland called Bophuthatswana. Only Black mastectomised women aged 21 and above and some of their husbands were interviewed to determine the effects of the diagnosis cancer of the breast and mastectomy on them. In addition, only mastectomised women who had their breast removed six months or more were included in the sample; and all interviewees had to be resident in former Bophuthatswana.

1.8 ORGANISATION OF THE STUDY

This study is organised into the following chapters:

Chapter 1 presents an introduction to the study, background of the research area, the research problem, objectives, significance and delimitations of the study.

Chapter 2 presents a review of the relevant literature on the effects of breast cancer and mastectomy. Sister Callista Roy's adaptation model is presented with a framework to assist mastectomised women to cope with their present day-to-day living.

Chapter 3 presents the research design and method; as well as the construction and pretesting of the data collecting instruments, sampling procedures, training of research assistants and the data collection itself.

Chapter 4 presents the findings of the quantitative aspect of the study (stage one of the data collection). Stage two consists of data collected using in-depth individual interviews and focus groups. Findings from data collected from husbands of mastectomised women in the former Bophuthatswana are also presented.

Chapter 5 presents guidelines for supportive action by health professionals to facilitate adaptation to breast cancer and mastectomy.

Chapter 6 presents a suggested support group consisting of breast cancer survivors. The role of this group is presented together with King's theory of goal attainment.

Chapter 7 summarises the study, conclusions are drawn and recommendations are made.

Data in this study were collected in three stages:

Stage 1 used 150 respondents from whom information was tapped using a structured interview schedule.

Stage 2 consisted of in-depth interviews and two focus groups.

Stage 3 comprised data collected from some husbands of mastectomised women in the former Bophuthatswana.

Sister Callista Roy's adaptation theory is presented in Chapter 2; it was found suitable for this study in that its main theme is "adaptation to stimuli" which is relevant for breast cancer and mastectomy. Imogene King's theory of goal attainment is presented in Chapter 4, with emphasis on the nurse-client reciprocal relationship to help set mutual achievable goals.

CHAPTER 2

LITERATURE STUDY

2.1 THE PSYCHOSOCIAL EFFECTS OF THE DIAGNOSIS CANCER

In this chapter selected literature which is relevant to the psychosocial effects of the diagnosis of cancer, breast cancer and finally mastectomy on both the woman and the family, is reviewed. No previous studies on breast cancer nor mastectomy have been undertaken in former Bophuthatswana, therefore, no information exists to form the basis for this study. Information on cancer in general and the effects of breast cancer comes from surveys of varying reliability in developed and developing countries. According to O'Connor, Wicker and Germino (1990:167), the period following the diagnosis of cancer turns out to be the time when life and death predominates, it is a crisis which emphasizes the patient's mortality. Weisman and Worden refer to it as the "existential plight" (1976:480). The struggle and stress that presents when the diagnosis of cancer is confirmed brings awareness of personal mortality. Thus the newly diagnosed patient with cancer is often confronted with his or her own humanity and mortality and this becomes a period of despair. Northouse and Swain (1987:221) concur with Weisman and Worden (1976:480) when they reported that when a member of the family suffers from a life-threatening disease such as cancer, the effects are not only experienced by the patient but rather they reverberate throughout the family system and the patient and family all experience the cancer crisis. Newman (1982:135), in his analysis of the

environment of the cancer patient, stated that the environment consists of a "compilation of stress factors made up of tension, producing stimuli that have the potential to cause disequilibrium." He further maintains that stressors are identified as intrapersonal, which are stressors from within the individual particularly in the case where the patient is concerned about the recurrence of the disease.

Sister Callista Roy in Fitzpatrick and Whall (1983:163) viewed the individual as a system which received the above named internal and external stimuli. To attempt to cope with these stimuli the patient employs coping mechanisms which Fitzpatrick and Whall (1983:163) refer to as the regulator and cognator sub-systems. The regulator sub-system originates from biological, physiological and social sources and contribute to those coping mechanisms or adaptation modes that are of chemical, neural or endocrine origin.

The cognator sub-system responds through cognitive emotional channels such as perception, learning, judgement and relief seeking. In this way coping or adaptation to stimuli is achieved and a state of equilibrium is established. Thus, as stated earlier, adaptation is both the process of coping - in this case with the diagnosis of a life-threatening disease and the end product. Adaptation to the diagnosis will, according to Roy in Fitzpatrick and Whall (1983:166), involve holistic functioning to affect health positively and promote integrity.

Quint (1964:119), in his studies of the general effects of the diagnosis of cancer on patients, revealed patients' reports of the cancer diagnosis' disruptive

influence on family relationships regardless of whether the disease was detected early or whether it was in an advanced stage. This was manifested by tension in the marital relationship caused by the repeated 'assault' caused by the disease leading to decreased communication. This results in the patient's increasing detachment, which eventually leads to physical and psychological withdrawal. Fredette and Beattie (1986:308) concur with Quint (1964:308) when they reported that a diagnosis of cancer can be a threatening experience that evokes a variety of emotions for both the patient and his or her family. The patient goes through a stressful period and a series of crises that affect his or her entire well-being. Feelings of depression, resentment, fear, guilt and powerlessness are a few characteristics enumerated by Fredette and Beattie as revealed in their study of cancer patients. The author, having worked among cancer patients, and having survived cancer for 13 years, agrees with Fredette and Beattie's findings. Cancer patients live with the underlying fear that their disease could recur and possibly become unmanageable. This causes uncertainty which continuously haunts the cancer sufferer. Weisman and Worden (1976:480), agree that the diagnosis cancer carries a certain stigma, which is a salient factor in the withdrawal of support for the cancer patient. Severo (1977) in the New York Times, reported that the stigma attached to the diagnosis of cancer persists even after death. Peters-Golden (1982:483) confirmed this when he stated that it is not uncommon for a cancer patient's obituary to read "died after a long illness". This, according to Peters-Golden above, evokes intense fear of cancer and thus attaches the stigma of cancer as a debilitating disease which protracts and the sufferer dies after long illness. Hence, according to Sontag in Peters-Golden (op.cit.), the word 'cancer' itself is loaded and powerful. He reported that many

diseases with the same effects and prognosis as cancer are accepted with less terror and stigmatization. Peters-Golden (1982:483) cites the following reasons why cancer is feared: The disease is viewed by the man in the street as unerringly fatal, and has a hopeless prognosis, even with early detection and advances in radio- and chemotherapy, it is still greeted with suspicion. What is worse, patients who have survived and are doing well following the diagnosis are regarded as "lucky" and they also consider themselves as "lucky".

Sontag in Peters-Golden (1982:483) maintains that the diagnosis of cancer to a lay person means "death, a spectacularly wretched death which creeps in slowly, invades and eventually devours the host." In the process it causes unbearable pain and mutilates the body before it kills. The stigma is carried further when Hinton (1973:107) states that in many cases of cancer the mutilation is caused by part of the treatment, for instance, radiotherapy is quoted with its possible destruction of superficial layers of the skin if absolute care is not taken. Nausea, vomiting, and lack of appetite accompanied by destruction of the mucous membrane especially in the mouth causing the taste buds to fail to function, are part of the debilitating effects of the treatment for cancer. Harvey (1978:164) reported that cancer is "traitorous" in that it invades the body; in certain instances without the victim being aware of its presence. He describes this "stealthiness" as particularly unfair. Abrahms (1969:881) regards cancer as "unclean" when he reported that cancer patients are repugnant with a singular ability to "evoke physical aversion and disgust in others". This image of contamination is found throughout the literature. Sontag (1977:728) shares the same view about cancer as a disease. He maintains that

some cancer patients share this inner revulsion, and have a feeling of uncleanliness, hence some patients regard it as a punishment for sins committed in the past. In this study, three of the respondents shared similar views about the unclean nature of cancer as a diagnosis. They expressed the feeling that "batho ba yi le go nyonya", meaning "people are going to view me with revulsion."

Kaplan, Cassel and Gore (1977:21) reported that cancer is different from other diseases in that it fails to conform to the model of 'cause and effect'. What compounds issues is the fact that even if the patient co-operates fully with the physician and follows the treatment regimen faithfully, it is difficult to guarantee that therapy will be successful. This is what, in the researcher's opinion, makes cancer a fearful disease. Moreover, even if the physician thinks cancer is 'cured', there is always the lingering likelihood that it may recur and manifest itself in organs of the body where it cannot be operated upon such as in the pancreas or liver.

Moreover, the side-effects of chemotherapy and radiotherapy such as loss of hair, nausea and vomiting, fever, and mouth ulcers make the cancer victim so miserable that Kaotsane (1991:3) described the effects of the treatment as making the patient more sick than the disease itself. The effect this has on the family is aptly described by Mathabe (1993:4) when she stated that the patient suffering from cancer finds himself in an environment within which he must have an interactive relationship. The disease affects the family which forms part of

the environment of the patient. Thus the family also becomes a "patient" and requires attention. Depression in the family following the diagnosis of cancer in a member reigns supreme, denial in both the patient and the family compels both to shop around, moving from one physician to the other with the hope that one physician may negate the diagnosis. At this stage, the family is going through the same crisis as the patient. Among Black patients the crisis often compels them to consult traditional healers. This often results in defaulting and thus valuable time is wasted for effective treatment. Hence, according to Hacking, Gudgeon and Lubelwane (1988:57), who are supported by Walker, Tshabalala, Isaacson and Segal (1984:24), patients with breast cancer were reported to present for the first time at Groote Schuur hospital during the third stage of the disease. Day (1966:884) refers to this as a panic 'response' that includes countryside safaris with the patient in the back seat of the car in response to fly-by-night reports of cancer cures from friends and neighbours, quacks and traditional healers. At times, there is little one can do as a patient, but to accede to the family's insistence on such contacts in a search for health. Day (1966:884) describes this anxiety experience as overwhelming. According to him, the fear on first hearing of the diagnosis of cancer is 'paralysing'. This anxiety occurs even if the chances of death are remote and less threatening. The reasons for this anxiety response may be real or just imaginary. The extensive surgery or treatment by frightfully large and mysterious x-ray machines in a foreign environment which may result in disfigurement and mutilation are probably a factor which creates anxiety on the part of the patient. These, according to Day (1966:884), pose a threat to one's self image and sense of integrity. Hence the very mention of the diagnosis 'cancer' fills the patient with

horror. In this study, all the respondents reported to have been terrified when the diagnosis was confirmed as cancer of the breast. Some reacted by crying, some by denial, fifteen respondents thought of immediate death and all respondents reacted with depression before final acceptance.

2.2 PSYCHOSOCIAL EFFECTS OF BREAST CANCER

According to Morris and Ingham (1988:1257) breast cancer is the most common cancer found among women; because of this it is reported to be the leading cause of death in women between the age of 35 and 55 years. Baum (1981) in Morris and Ingham (1988:1257) stated that approximately one in every twelve women in Great Britain develop the disease and 24,000 new cases are reported yearly resulting in 12,000 deaths annually. Bruning, Bonfrer, Ansink, Russel and de Jong-Bakker (1988:115) concur with Morris and Ingham when they stated that breast cancer is the most frequent malignant tumour in females in the western industrialized world. In the Netherlands there were 32.2 deaths from cancer of the breast reported per 100,000 of the population from 1980 to 1981. This, according to Bruning et al (1988:115) was superseded only by Great Britain, Malta and Gozo. Otherwise, the Netherlands was reported to have the third highest figure of breast cancer patients in the world. Bilbas (1989:527) in his study of cancer patients in Haifa, concurred with Bruning et al (1988:115). He reported that 44.3% of his sample was found to be women suffering from cancer of the breast.

Chiedozi (1985:653) made similar findings among Nigerian women. He reported that not only is breast cancer the most prevalent cancer amongst Nigerian women, but the disease carries a "truly bleak prognosis" since patients report to hospitals for the first time following failure of treatment by traditional healers. These patients, according to Chiedozi (1985:653) report to the hospital because of the malodorous drainage and ulcerated breast lesions which are reported more often than not to have made the patient an outcast. Such patients, reported Chiedozi, present with crude incisions, scarification and fungation from the affected breast. This practice is not exclusive to Nigerian women, the author, during her visits to rural cancer patients in the area of study, made similar findings. Often Black breast cancer patients consult a traditional healer after the diagnosis is made by western doctors. The traditional healer would then advise the patient against surgery. The reason forwarded being "once kwasi (the traditional Setswana name for cancer) is incised, it spreads like wild fire" (Jongani, 1993). This accounts for the defaulting that occurs among cancer patients who surface when the disease is at its third stage and metastasis has already occurred.

Chiedozi (1985:654) reported that breast cancer in Nigeria occurs commonly between the age of 40 and 49 years. In his study of 116 breast cancer patients, 73.3% were reported to be pre-menopausal women. This, to Chiedozi, revealed that breast cancer among Black patients occurs a decade earlier than in their White counterparts. This creates severe psychosocial problems according to Chiedozi (1985:654), since Blacks attach a high value to the breast as a symbol of femininity and sexuality.

Sinsheimer and Holland (1987:76) reported that the age at which breast cancer occurs alters the emotional effect treatment will have on the patient. The younger the woman the more distressful the diagnosis and treatment will be. This, according to Sinsheimer and Holland (1987:77) becomes more problematic if the diagnosis is made at a time when the woman is at the height of her attractiveness, intimacy and childbearing. Older women who have reached menopause were found by Sinsheimer and Holland to react with less distress to the diagnosis especially when the diagnosis is made at a time when other losses have occurred in the past, such as the death of a spouse.

Anxiety about the uncertain outcome of the disease is reported by Sinsheimer and Holland (1987:78) as one of the emotional effects of the diagnosis. Other problems are related to age and developmental tasks that breast cancer threatens the personality and coping strategies employed in life stresses. Social support available from partners, family and friends play an important role in the adjustment of the patient to the diagnosis and treatment (Sinsheimer and Holland, 1987:78).

Eighty percent (80%) of breast lumps are discovered by women themselves. In countries where women are knowledgeable, can read and write, this discovery is fraught with anxiety. The client, after discovery of the lump, consults a physician who may refer her for mammography for confirmation and further management by surgeons. According to Scott (1983:24) the woman at this stage goes through a period of extreme anxiety relating to a threat to life and uncertainty about the spread of the disease to vital organs. The woman's

thinking ability at this stage is impaired and her concentration decreases. Sinsheimer and Holland (1987:77) describe the diagnosis as a symbol of death and an affront to the woman's self-image and social interaction. At this critical stage the only solution to the anxiety and distress state experienced by the woman is the doctor-patient relationship which must build up to a good rapport between the two. Information given to the patient, however, should take into account the following different types of patients (Sinsheimer and Holland, 1987:78):

The traditional older woman who feels that the doctor should take all decisions since he/she is in "charge" of her. Placing the responsibility on this category of patient may provoke more anxiety and distress according to Sinsheimer and Holland (1987:79). Searle (1993:2) concurs with Sinsheimer and Holland when she stated that "rural Black patients diagnosed as having cancer usually have a problem in understanding Western medicine, and therefore they may not know what their rights are relating to treatment and response to the disease. What the diagnosis, treatment and prognosis mean may not be understood by the patient" (Searle, 1993:2). Hence, placing all the trust and decision about the treatment in the surgeon may be the only comforting procedure for the patient.

Another type of patient is the younger woman who approaches the decision for treatment very assertively after gleaning lots of information on the diagnosis, treatment and prognosis. This type of patient, according to Sinsheimer and Holland (1987:80) prefers autonomy in the decision about the disease and treatment, in certain instances, her decision may not be medically appropriate.

However, this category of patient, due to her ability to control her anxiety and depression and to collect information from other sources, integrate it and make decisions about treatment based on personal preferences, is the best client as far as adaptation to the diagnosis is concerned.

The last group of patients a physician must be on the look-out for according to Sinsheimer and Holland (1987:80) is the type that is overwhelmed and horrified by the diagnosis 'cancer of the breast'. Decision-making about treatment for this category of patient may be difficult and counselling by a psychiatrist, psychiatric nurse, clinical psychologist or even the physician is recommended before treatment could be effected. The author has on several occasions been called to talk to such patients in order to help them decide about the treatment. Among Black patients the problem of decision-making about treatment is compounded by cultural values and practices. Not only does surgical intervention on an organ such as the breast and other reproductive organs threaten the sexual life of the woman, but fear that the husband may decide to dump her for a younger, healthy woman reigns supreme in her mind. There is also the perpetual 'minor' position the married woman occupies by virtue of the 'lobola' or bride-price system. The husband, according to this system, has control of the woman's body and has therefore to give consent for any surgical intervention to be undergone by the wife. Legally, this is not the case, but culturally this procedure has to be followed otherwise the woman may be ostracised by her in-laws. Schain (1985:200) confirms this when he reported that women with breast cancer may fear rejection from friends and significant others due to society's value and emphasis on the breast as a symbol of

sexuality and nurture. Peters-Golden (1982:483) reported that having breast cancer and losing the breast can both affect interaction with significant others, however, positive interaction can maintain or improve one's self-concept and sense of control over the illness situation. Social support of breast cancer patients is reported by Feather and Wainstock (1989:294) as the endorsement of another person's behaviour, perceptions and expressed views. They maintain it is the giving of symbolic or material aid to the patient. In this way social support becomes an interpersonal phenomenon that is conveyed through expression of caring, reassurance and validation of personal worth (Hays, 1984:177).

According to Morris, Greer and White (1977:2380) the psychological response of patients following the diagnosis of cancer of the breast was noted to take the following trend:

Denial characterized by responses such as "Oh, no! It can't be true, why me? My children are still so young." Or "I can't believe it, the doctors must have made a mistake." These are some of the immediate reactions patients display when the news about the diagnosis is revealed. The author has intervened on several occasions when patients are unable to accept the diagnosis. Others exhibit a fighting spirit portrayed by a hopeful attitude accompanied by a search for information about the effects of treatment. Many patients ask friends and relatives and consider themselves lucky because the diagnosis was made during, what they consider the first stage of the disease. It is to be noted that some of these patients may show a brave appearance, yet deep down, they are terrified

by the diagnosis. This gets compounded if the patient is unsophisticated and has never attended school. According to Searle (1993:3) "the message about cancer as the diagnosis may not be understood, however, the patient will sense that something is wrong although she is not able to ask the right questions at the time". This inability to question the physician and nurse may compound the patient's anxiety.

Some patients, according to Morris et al (1977:2380) may respond to the diagnosis of cancer of the breast with stoic acceptance. They may acknowledge the diagnosis, carry on normal life without excessive concern about the illness. The author has come across this category of patient among members of a religious sect called "Abazalwane" meaning born-again Christians. Members of this sect display a positive belief system in the healing power of faith. They believe that even if cancer is incurable, with the power of the 'blood of Jesus Christ' that was shed on the cross, cancer can be cursed and cured. This belief system goes further and states that the disease is caused by the power of the devil, therefore, cursing cancer using the name of Jesus Christ is able to bring about healing. Whether this is true or not, the author is not sure. However, what the author has experienced is the faith these people have in their belief system. The members of this sect give one another close support during illness. It is this support which Bloom, Ross and Burnell (1978:295) refer to as "factors able to reduce isolation and temporary disorganisation". In cancer of the breast, social support would influence adjustment and enhance control of the disease. Funch and Marshall (1983:77) found women who had breast cancer survived longer when they were involved in social organisations compared with those

who were not involved socially. He also reported that women who maintained close interpersonal relationships with family and friends were more likely to cope effectively with cancer than those who were not able to maintain such relationships.

2.3 THE EFFECTS OF MASTECTOMY ON THE PATIENT

Breast loss according to Taylor, Lichtman, Wood, Bluming, Dosik and Leibowitz (1985:2506) forms the central emotional crisis of the diagnosis of breast cancer. Pfefferbaum, Pasnau, Jamison and Wellisch (1977:63) equate mastectomy with castration, and consider it a blow to the woman's sexuality, her feelings of motherhood and femininity. Mastectomy causes poor adjustment because of disfigurement and accompanying problems related to self presentation, for instance the scar and the "lopsided" feeling which, according to Taylor (1985:2506) cause more concern than the loss of the breast itself.

The respondents in this study all had total mastectomy and none reported to have been asked to consider reconstructive surgery. In the pilot study, the 15 mastectomised respondents reported a mean waiting period of 45 weeks before reporting the existence of the breast lump. On being asked why they waited so long before seeking medical advice, 9% reported fear that the lump may be cancer. In the cases researched in this study, it was the delay that resulted in total mastectomy. Leis (1974:609) reported similar findings in his study of mastectomised women. He stated that total mastectomy was in most of his respondents the only option because the tumour was already too advanced for

lumpectomy. Hacking, Gudgeon and Lubelwane (1988:57) made similar findings in their study of breast cancer patients in the Cape Province in South Africa.

Another factor which may result in poor adjustment to the surgery may be ongoing disability such as difficulty in the use of the arm on the side of the mastectomy. Pain and swelling may worsen the quality of life and subsequently lead to poor adjustment to the surgery. Chemotherapy and radiotherapy with their unpleasant side effects such as nausea, vomiting, temporary hair loss, skin changes and fatigue may also play a role in the patients' poor adjustment to the mastectomy. Difficulty in concealing the scar, or self-consciousness about it may, according to Leis (1974:609) cause the mastectomised woman to withdraw from social activities or may prompt friends to change their behaviour towards her. Mastectomised patients reported to the researcher that they had problems each time they considered going to bed with their partners. The scar and absence of the breast made them shy away from sexual desire.

Not all men accepted the absence of the breast. According to May (1981:292), one respondent reported that "mastectomy, while performing a gratifying and life-saving service, the mastectomised woman's appreciation of the surgery was muted by the actual loss of the breast, physical disfigurement and accompanying psychological trauma." Fear of recurrence of the disease, concern over sexuality and sexual relationships are all factors that threaten the woman's adjustment to the surgery. Cole (1978:29) maintains that the psychological reaction to mutilation and loss of femininity in mastectomised women was compounded by fears associated with breast loss, emotional disturbance, distress and turmoil.

Weisman (1979:187) is of the opinion that mastectomy often creates problems far beyond those of the tumour itself. He reported that it is unfortunate that these psycho-social problems experienced by the patient are often given the least attention by the health professionals. Although mastectomised patients are supposed to receive care from a multi-disciplinary team during hospitalization and follow-up care, the researcher has never seen this team in operation, not even during the most critical time immediately post operatively. The main actors in the mastectomised patients' treatment are the surgeon and chemotherapist who are also only interested in the cancer and its complications. Both professionals are usually so busy that they never have the time to talk about "peripheral" matters such as depression, sexual problems, general anxiety and domestic issues. Widows and divorcees who live alone appeared to be the most hard hit when they have to visit the hospital or clinic for follow-up care. Amongst Black mastectomised patients who formed the researcher's subjects, unemployment, lack of income, concern about where the next cent will come from to buy food for dependent children and payment of services such as electricity and water appeared to cause major concern.

Weisman (1979:189) reported that mastectomised women have returned to work and have discovered that the energy, morale, endurance and the capacity to confront everyday decisions were reduced. What compounded their plight according to Weisman (1979:189) was the constant reminder that the cancer can "reoccur" or that additional chemotherapy or radiotherapy may be necessary. Weisman (1979:191) refers to a stage in the life of a mastectomised patient which he calls "accommodation and mitigation phase". During this

phase a range of adaptive efforts and tactics are employed by the patient to try and come to terms with the breast surgery. In those patients where, despite the surgery, the tumour reoccurs, vulnerability often looms high and disappointment reigns supreme. Coping with mastectomy according to Krause (1991:241) included control, acceptance of the illness, hopefulness, goal setting, social activity, information seeking, positive life changes and expression of feelings. Maguire (1978:3901) reported that when a woman has had a mastectomy following breast cancer, she has to cope with two main tasks:

1. To learn to live with the knowledge that she has a potentially fatal disease and has to overcome fears that the disease may "come back", invade other parts of her body, cause pain, suffering, invalidism and death.
2. She also has to adapt to the loss of a body part which may have been very important to her sense of femininity, self-esteem and attractiveness. She may have to cope with the repeated reminder of the operation and its implication which she may continuously experience when she bathes, dresses, looks in a mirror or makes love.

Maguire (1978:3901) is of the opinion that, although science has made progress in the management of cancer of the breast, most women remain fearful of the disease and this may be responsible for the view held that mastectomy has serious emotional as well as social effects. The degree of emotional distance reported in Maguire's respondents was found to impair the women's ability to cope with domestic chores during the first year following mastectomy. He sums

up the psycho-social effects of mastectomy by stating that "the morbidity following the surgery is substantial, it causes much suffering and impairs the quality of life in the survivor (Maguire, 1976:414).

In conclusion, Maguire (1976:416) is of the opinion that adjustment and adaptation to the mastectomy may be made more difficult if the relationship between the woman and her husband has not been sound prior to the surgery. Adverse experiences such as other members of the family having died from cancer leading to bereavement, may make adjustment to the mastectomy problematic as well as difficult, which may lead to maladaptive behaviour such as tearfulness and depression.

2.4 RECONSTRUCTION SURGERY

Klein (1971:1616) compares mastectomy with the loss of a loved one. He maintains that women post mastectomy as mentioned on previous pages go through stages of denial, anger, depression, despair and finally acceptance of the surgery. These stages are similar to those one goes through in the event of death. Goin and Goin (1982:355) describe the above period as a stage of "pseudo-acceptance" since the mastectomised patient displays massive denial and employs defense mechanisms to protect herself from the feelings experienced post mastectomy. The author concurs with Goin and Goin (1982:355). For six months post mastectomy the researcher experienced severe depression and a feeling of 'sinking into a deep hole' each time she went to bed. No amount of counselling from the surgeon or social workers could relieve the

problem. Asken (1975:56) reported similar findings and recommended that breast reconstruction was the only answer to feelings of disfigurement caused by total mastectomy. Clifford (1979:1) in his study of 65 mastectomised women found that those subjects who received reconstruction surgery post mastectomy reported no negative psychological effects of the breast amputation. Fifty five percent of Clifford's (1979:2) subjects who were interviewed whilst waiting for breast reconstruction surgery were preoccupied with the acceptance of the loss of the breast, complaining of the "lopsided and unbalanced feeling". Thirty two percent (32%) expressed a feeling of diminished self-concept and femininity, and 38% reported decrease in sexual activity (Clifford, 1979:2).

Laurie, McGrath, Richard, Druss, Sven, Kister, Frank, Gump and Kenneth (1984:620) also recommended breast reconstruction. He maintained that following breast reconstruction surgery women described an improvement in their self-concept, better feelings about their contour and being less self-conscious in public. The feeling of "deformity" and "hollowness" which the author still experiences after 13 years following a mastectomy was reported to have disappeared after reconstruction surgery. Laurie et al (1984:622) subjects reported the reconstruction as "restoration" of the lost breast and that it had enabled them to return to normal life of swimming, playing tennis and hiking. The inhibition about their bodies also disappeared. From Laurie et al's (1984:622) study it does seem breast reconstruction attempts to minimize the psycho-social effects experienced by women who have had a mastectomy, although the erotic sensation from the constructed nipple is absent (Schover,

1991:112). However, in the analysis of the results of the pilot study, respondents of this particular research appeared to present at health centres or hospitals during the late stages of the disease, a fact which may have contributed to the surgeon's reluctance to perform reconstruction of the amputated breast. Moreover, according to Tlale (1994) mastectomised Black women who received follow-up care at Pelonomi Hospital in the Orange Free State (this is one of the referral hospitals for cancer patients from erstwhile Bophuthatswana) were reluctant to undergo another type of surgery following mastectomy.

Tlale (1994), in her daily contact with cancer patients, ascribes this unwillingness to the age at discovery of the breast cancer and subsequent mastectomy. She maintained that the younger the patient when the mastectomy was performed, the more willing she was to have another type of surgery. However, the older the woman, the more unwilling and unnecessary she found the reconstruction surgery. Perhaps Black women in this study lacked pre-counselling before the mastectomy. This was confirmed by the lack of knowledge revealed by those women who formed the pilot study. It was not uncommon to hear that respondents did not know about the existence of a prosthesis and where it was obtainable. Nurses and doctors need to be made conscious about the importance of pre-counselling before a mastectomy is performed. Another area that was found to be completely neglected was sexuality and the mastectomised patient. This subject will be discussed in the following pages.

2.5 SEXUALITY AND MASTECTOMY

The development of the breasts has an important role in the psychic as well as physiological maturation of any young woman. Different cultures will therefore place different values and significance on the development of the breasts. Bard and Sutherland (1955:656) pointed out that the female breast has been idolised throughout the world and has become the primary source of a woman's identification with the feminine role. Hence, according to Bard and Sutherland (1955:656), the appearance of the breast constitutes an important criterion of a woman's desirability and acceptance. The thought of amputation, therefore, may precipitate feelings that life is no longer worth living in those women whose breasts play a vital role as erotic zones and stimulation in their sexual gratification. Witkin (1978:20) reported that "sexual self-concept supersedes mortality as the primary concern of most recovering mastectomy patients. Sexual concern dominates the thinking of the patients and becomes of central importance to psychological and emotional functioning" (Witkin, 1978:20). Winkler (1976:80) reported that although concern with sexuality plays such an important role in mastectomised women, it is surprising that it is also the one area that is "often avoided in all discussions with surgeons and nurses. Sexuality is often glossed over and given no attention at all, yet it is one area that has emotional implications in mastectomised patients." Witkin (1975:290) is also of the opinion that many husbands of mastectomised women assume that they should not have sex or indicate a desire for it until the woman suggests it post mastectomy. In Wortman and Dunkel-Schetter's study (1979:148) of husbands of mastectomised women, one client reported that "he did not have

sex with his wife for a long time because he felt she really did not want it after such a major operation, worst still with her breast gone." This assumption according to Wortman et al (1979:148) may have been genuine, however, the wife's feelings may have been the direct opposite. On the contrary, the abstinence could have been misconstrued as a sign of confirmation of her worst fears that her husband may have been disgusted at seeing her a "half woman or can't stand looking and caressing her and not finding the breast" (Wortman et al, 1979:148). The author concurs with Wortman et al (1979:148). As a mastectomised patient she experienced a complete change for the worst following surgical intervention. The scar became an instrument that turned the author's spouse off, each time she was ready to have relations with him. The partner would each time suggest that the sexual act be postponed, and this practice continued for 8 years. Naturally other problems such as diminished communication followed and the marriage became so unbearable that it had to end with a divorce nine years post mastectomy.

Bard and Sutherland (1955:660) reported that some women place self worth and acceptability upon body attractiveness throughout their lives. Mastectomy for such women may generate feelings that their loved ones may reject them. One respondent in Bard and Sutherland's study (1955:660) reported a feeling of disgust in a sense that she felt as if she was sexless after the mastectomy, and she assumed that her husband would be disgusted to go to bed with a sexless woman. Although Bard and Sutherland (1955:660) conducted their study 40 years ago, the information according to the author remains valid in that Black women in this study are not more socially advanced than those studied by Bard

and Sutherland during 1955. Although surgery has advanced and reconstruction surgery in developed countries seems to have alleviated the psycho-social problems following a mastectomy, in this study it does not seem to be the case.

Another psychological effect of mastectomy is the constant fear of recurrence of the disease on the remaining breast. Imagined lumps and painful sensation as well as preoccupation with self-breast examination is, according to Bard and Sutherland (1955:666) an indication of deep-rooted fear of loss of the remaining breast. Besides some women in Bard and Sutherland's study reported that they considered themselves so fragile that they feared having sex with their husbands because "his weight on my chest caused pain on the chest wall the following day." One patient also reported that she thought she had recovered from the effects of the surgery, however, her husband seemed afraid to hurt her, when he caressed her, he would ask "does my handling and fondling hurt you?" These appear to be the problems faced by both the mastectomised women and their husbands. Cobb (1976:305) advocates that it is the duty of health professionals especially the surgeon or even the patient's physician to seize the opportunity post operatively to build a strong rapport with the mastectomised woman to enable successful psychological convalescence. It is during post operative care that the physician becomes the "healing physician, the helper of the wounded, the encourager and the resolver of doubts." The physician needs to seize this opportunity to show his "healing art" and guide the evolution of successful adaptation or adjustment to convalescence (Cobb, 1976:305). Veronesi and Martino (1978:349) corroborate Cobb when they stated that the medical profession has to influence the hospital, the community and society as

a whole to establish structures that will support a more complete rehabilitation of the mastectomised patient so that her physical and psycho-social adjustment to the surgery is enhanced. Rehabilitation should be seen as more than just a useful programme, it should be viewed as a philosophy of care and an attitude of hope and encouragement that each member of the health team should bring to the patient (Veronesi and Martino, 1978:399).

Sexual disruption according to Andersen and Jochimson (1985:25) reduces frequency and brings about specific difficulties with the attainment of orgasm in mastectomised women. Battersby and Armstrong (1978:406) in their study of mastectomised women revealed that 39% of their respondents reported problems with achieving orgasm during coitus with their spouses. This adversely affected marital adjustment after the mastectomy which is described by Andersen and Jochimson (1985:25) as "marital distress" which led to decreased kissing and less body contact such as partners holding one another when kissing. Similarly partners of breast cancer patients may feel some constraints when they wish to embrace and kiss their spouses for fear of possibly reminding them of the change in form. However, further research in this area is recommended in order that concrete evidence relating to the reduction in sexual behaviour is brought to the fore. Sturesteps and Darrach (1986:23) in their study of the adjustment of Australian husbands to total mastectomy undergone by their wives reported that "Sexual activity on the part of the couple following mastectomy decreased in frequency" and one respondent reported that "her husband did not accept her as a total being after she had had a total mastectomy on the one breast" (Sturesteps and Darrach, 1986:23).

Leif (1978:57) made similar findings when he stated that mastectomised women in his study reported a temporary decrease in the desire for sex and this resulted in a decrease in frequency as well as a decline in orgasm. Erotic sensation from the remaining breast in Leif's respondents disappeared in 50% of the subjects. A further decrease in erotic responses was reported in those clients who reported inability to undress in front of their husbands and remain nude during sexual intercourse. To this end it does seem that emotional support from the spouse plays a crucial role in helping the mastectomised patient adapt to the surgery and diagnosis, as well as resume her loss of femininity and sexual desirability. Morris, Greer and White (1977:2381) in their study of mastectomised women found a positive relationship between sexual difficulties and disfigurement from the breast surgery. Body image disruption has received both professional and lay persons' attention as being central to the desires experienced by mastectomised patients; however, Steinberg (1985:38) reported that according to his findings in a study conducted among totally mastectomised women versus patients who had a lumpectomy performed, found that sexually dysfunctional patients in both groups reported marital discord and less intercourse long before surgery. Wellisch, Jameson and Pasnau (1978:543) concur with Steinberg (1985:38) when he stated that pre-surgical marital discord was a great determinant of poor adjustment to the mastectomy and lumpectomy. In other words, if the marital relationship was poor prior to the mastectomy, amputation of the breast simply created a wider gap between the patient and her spouse. However, Schover (1991:112) advises mastectomised women that communication is the only answer to fears and anxieties created by the surgery. Granting that women will react differently to the mastectomy, most

will withdraw into themselves, others will view it positively and will have heightened awareness of the remaining parts of the body which they took for granted in the past. Talking openly about their fears according to Schover (1991:112) may just be the answer, and that alone may hasten adaptation to the surgery. Winkler (1976:172) is of the opinion that to speak of accepting the mastectomy is misleading, however, it is better to talk about: "one gets acclimatized to it." Mastectomy should be looked upon as a turning point in life since it enables the victim to emerge as a more fully developed and integrated human being. Winkler (1976:173) concludes by stating that mastectomised women must change their priorities from attitudes of shame to making others aware of their needs. Mastectomised women need to appreciate the advances science has made in early detection and survivorship, therefore the poor attitude of "I would rather be dead than have a mastectomy should be seen as more deadly than the cancer itself." (Winkler, 1976:173)

2.6 INVOLVEMENT OF THE SPOUSE

One cannot lose sight of the fact that when a psychologically valued organ such as the breast is removed, the patient requires constant reassurance. This is worse in mastectomised patients who cannot rid themselves of the constant feeling that they "will never be the same again." Bard and Sutherland (1955:671) reported that in mastectomised women it does not matter how well they appear to have adjusted to the surgery and its consequences, the physical loss and psychological wound remain for ever. For the older patient the surgery seems to usher in the onset of old age, uselessness and decrepitude. For the

younger woman who is still of childbearing age, mastectomy signals hypochondriacal feelings and manifestations of irremediable injury that will render the patient unable to function as vigorously as before.

To this end, therefore, the husband, according to Maguire (1976:418) has to be involved from the time the diagnosis is confirmed. The husband according to Maguire can play a crucial role in ensuring that the patient achieves full recovery from the disease and surgery. The spouse who is kept in the picture about possible treatment should be able to clarify any misconceptions the patient may have. His involvement may make him feel that his views are valued by the treatment team and his attitude can play a vital role in the wife's recovery (Maguire, 1976:416). Peters-Golden (1982:489) concur with Maguire (1976:416) in his study of husbands of mastectomised women. He found that the husband's inability to offer support to the patient resulted in distress and poor adjustment on the part of the patient. Peters-Golden (1982:489) further reported that mastectomised patients whose disease re-occurred and had to have additional chemotherapy reported inadequate and inconsistent support from their husbands contrary to those whose husbands were totally involved in their treatment and their disease was arrested by the mastectomy. Peters-Golden, (1982:490) maintained that these findings may be a result of increased need for support from the husband and other members of the family. In Peters-Golden's (1982:490) study of patients who reported problems with adjustment to the mastectomy as well as heightened feelings of stigmatization expressed through isolation, avoidance and a general feeling of abnormality were all ascribed to decreased support by the spouse and the family. Wortman and Dunkel-Schetter

(1979:120) are of the opinion that the diminished support mentioned above could be a result of the stigma attached to the disease cancer per se. Mastectomised patients in Peters-Golden's study (1982:490) reported inappropriate assessment of their needs and priorities by family and friends as well as misjudgment of the concern of these patients by well individuals whose focus is on the lost breast. In this way the true problems of the mastectomised patients may be obscured.

2.7 THE MASTECTOMISED PATIENT AND INTERPERSONAL RELATIONSHIPS

In the pilot study of this research, the researcher discovered that 14 of the respondents reported that ever since the diagnosis cancer of the breast was confirmed, they became very close to their children and 10 reported friends to be their only source of support. Wortman and Dunkel-Schetter (1979:124) in their study of mastectomised women discovered the following interpersonal problems:

1. Communication with friends about the surgery was very superficial to a point that in certain instances the mastectomy was kept a deep secret which the patient had to learn to live with.
2. There was lack of open communication with family members.
3. The future was also not discussed with the family.

Wortman and Dunkel-Schetter (1979:124) concluded that from their study a positive relationship was found between the patient's interpersonal relationships

and her ability to cope with the disease and surgery. Carey (1974:433), Jamison, Wellisch and Pasnau (1978:432) concur with Wortman and Dunkel-Schetter when they stated that "individuals who are able to maintain close interpersonal relationships with family and friends despite their illness are more likely to cope effectively with the disease than individuals who are not able to maintain such relationships" (Jamison, Wellisch and Posnau, 1978:432).

According to Wortman and Dunkel-Schetter (1979:124), mastectomised women may be highly fearful and uncertain of the outcome of the surgery. This may lead them to believe that they are coping poorly with the disease. It is at this stage according to Wortman and Dunkel-Schetter (1979:125) that they experience "intense need for social support." Unfortunately this support from family and friends is usually not forthcoming or it may not be what the patient expects from the significant others. Incidentally, Wortman and Dunkel-Schetter (1979:125) reported that the reaction of significant others towards cancer and its treatment is usually ambiguous in that while their feelings towards the cancer is negative they are expected to accord normal behaviour and remain positive as well as optimistic and cheerful in their interaction with the patient. The researcher had similar experiences. It does seem that these significant others believe that there is a special way to behave that is considered appropriate when in the company of the patient. Should the patient display anxiety and fearfulness the significant others emphasize the opposite. Experience has taught the researcher that friends and next of kin avoid and actually block any conversation relating to the cancer and the mastectomy. Doctors and nurses will also answer the patient's questions very businesslike. In other words, only

what is asked will receive attention, nothing beyond that. The patient may, in turn, interpret this as rejection and impatience. This may result in poor communication when in actual fact the patient may be having deep-rooted problems which need immediate solutions. Sinsheimer and Holland (1987:75) found that relationships with surgeons and medical practitioners were important during hospitalization. The client with breast surgery, be it minor or major, perceives the surgeon as competent and concerned about her. The confidence with which questions are answered engender trust in the patient. In many instances the patient is unable to make decisions relating to chemotherapy and radiotherapy post surgery. She may have problems with what to tell colleagues at her place of employment or even her own young children about the outcome of the diagnosis. All these problems according to Kleinman, Mantell and Alexander (1977:403) require the patient to be given an opportunity to discuss them openly with someone who will listen patiently and offer correct information and advice. Bloom, Ross and Burnell (1978:59) in their study of 26 mastectomised women who were provided with comprehensive treatment consisting of information, opportunity for airing their feelings and support from a team of medical and psycho-social personnel, reported that these patients displayed higher self-esteem and self-efficacy scores than a comparative group who did not receive the same treatment. However, it should be noted that although open communication regarding fears and concerns experienced by the mastectomised patients is recommended, this according to Wortman and Dunkel-Schetter (1979:130) is not always the case since mastectomised patients feel inhibited about identifying themselves as such and fear that open discussion of their feelings may upset the significant others especially their dependent

children. Harker and Swarts (1977:305) see the strategy to protect family members as normal since the patient perceives herself more often as a burden on the significant others. The researcher also found open discussion among Black patients very limited. The Coloured and Indian patients were found more open than Black and White patients. Black patients appeared to be embarrassed by any discussion relating to sex and the breast. This area requires further exploration.

2.8 THE REACTION OF OTHER PEOPLE TO THE MASTECTOMISED PATIENT

The behaviour of significant others towards the patient is likely to be affected by two factors, say Wortman and Dunkel-Schetter (1979:131):

1. The feelings the people have with regard to the patient.
2. Assumptions about how the patient would like to be treated.

Because of the strong feeling and belief that cancer is incurable and the belief that the diagnosis has a poor prognosis, significant others come to believe that it is important to be cheerful, optimistic, and encouraging when interacting with these patients. This alone, according to Wortman and Dunkel-Schetter (1979:131) may be discrepant with the patients' true feelings and may cause discomfort on the side of both the patient and the significant others. The said discomfort may precipitate behaviour that causes distress on the part of the patient with resultant poor communication.

In the area where this research was undertaken, terminally ill mastectomised patients are discharged from hospital to go home and spend their last days with

their family and friends. When such patients are visited by the oncology nurses, this includes the researcher, it becomes difficult to tell the truth that indeed death is imminent. Instead the nurse will keep on giving conflicting behavioural cues such as "God will help and will have mercy on you." This may not be what the patient wants to hear. Her problem may be her young dependent children who may not have somebody to see them through school should she die. The difficult situation the nurse finds herself in, may result in her avoiding another visit to this family. The relatives to the patient are often tired and frustrated by the patient's lack of progress, and this according to Kalish (1977:133) may be ascribed to the lack of adequate coping skills on the part of the patient, which may generate aversion and guilt feelings on the part of the significant others. Schwartz (1977:276) reported that open discussion of one's problems relating to the disease and its treatment helps the patient to adjust and cope with the disease. This should be encouraged by the health professionals and significant others. Parker (1979:140) is of the opinion that 'no matter how much the family loves the terminally ill cancer patient, they frequently become drained emotionally from trying to keep pace with the rapid fluctuation in the patient's physical condition, mood and coping strategies' (Parker, 1979:140). Frustration on the part of the family results from efforts to help the patient which seems to have little effect on the course of the disease. In the terminal stage, physical exhaustion is common among care givers and the strain of financial difficulties often increases the burden on the family. The family members' own daily needs, interests and problems are often neglected as they battle to satisfy the needs of the terminally ill patient whose condition does not improve. It is therefore self-explanatory that no matter how supportive the family may be, if the patient's

state of health does not show improvement, patience runs dry and occasional outbursts in interacting with the patient is revealed as the stress of caring increases. These negative outbursts of feelings towards the patient may result in remorse and feelings of guilt which may make family members feel uncomfortable. The researcher, in her care of terminally ill cancer patients, has experienced this on several occasions. This is worse in families where the patient is taken care of by daughters or close relatives. 'Legacy hunters' are often amongst those who rally around the patient until the end of life, hoping that they will be included in the patient's last will as beneficiaries. At this stage of the patient's life, Wortman and Dunkel-Schetter describe it well when they reported that, "Friends, family members and even health professional are likely to voice reassurance on the surface but manifest negative non-verbal behaviours as well as inconsistencies in behaviour" (Wortman and Dunkel-Schetter, 1979:142). The effort to be reassuring on the part of family and health professionals may in certain instances backfire into an "oversolicitous and patronizing attitude" which may be easily detected by the patient and this may cause distress and leave the patient hurt and rejected. On the other hand this is not what the family would like to see.

Wortman and Dunkel-Schetter (1979:143) recommend family therapy which they believe will make both the patient and family members aware of the complicated social environment in which the patient and the family are trapped. Cohen, Goldenberg and Goldenberg (1977:45), Wellisch, Mascher and van Scoy (1978:84) concur with Wortman and Dunkel-Schetter when they reported that cancer patients should be schooled to appreciate the fact that the rejection they

receive from others is not dependent on their own behaviour. Moreover, family members' rejection and feelings of anger and guilt should be viewed as normal. Support groups in the community are encouraged since they can play a role in encouraging open communication between the patient and the family. The researcher in her voluntary work with cancer patients has intervened when patients had assumed an attitude of despair. The idea that the researcher is a cancer survivor enables patients to listen attentively to what she has to say. This has helped patients to accept and come to terms with their conditions and the surgery.

Sanders and Kardinal (1977:952) stated that patients suffering from any disease especially a serious condition often use others who are doing well as a yardstick to measure their own progress. However, this social comparison can be distressful if the patient does not "measure up" favourably. A good example quoted is a patient who is fearful of recurrence of the disease. Should such a patient encounter a similar patient who has had a recurrence, this may upset the patient immensely. The researcher is a constant victim of this. The lingering fear of possible recurrence of the cancer has remained over the past 13 years, despite the fact that doctors have declared the possibility of 100% cure after 10 years of survivorship.

2.9 PROVISION OF INFORMATION

Provision of information and answering the patient's queries, sensations, feelings and possible psycho-social problems likely to accompany breast cancer and the

mastectomy is crucial for satisfactory adjustment to the surgery. It does appear that knowledge and information reduces the stress level. From experience the researcher has witnessed surgeons giving nurses instructions to this effect, "This patient must receive chemotherapy for six weeks, tell her she may experience nausea and vomiting and there may be hair loss, however, the treatment is going to help with the tumour." From there the nurse has to interpret what the surgeon said in the patient's language. No terminology exists for chemotherapy and radiotherapy in Setswana, Xhosa or Zulu, the home languages spoken by respondents. The nurse will battle in vain to try and explain what the above treatment represents. The only words that the patient may grasp are "the big machines" which more often than not scare the patient out of her wits. Peck and Boland (1977:186) in their study of cancer patients receiving radiotherapy reported that they found that patients received superficial information and when the side-effects manifested themselves, these came as a shock to the patient. Mitchell and Glicksman (1977:60), in their study of cancer patients, reported similar findings among patients who received little or no information whatsoever about the chemo- and radiotherapy. Wortman and Dunkel-Schetter (1979:121) reported their experience with cancer support groups; they found that patients who were never given relevant information about the treatment and its side-effects misinterpreted such occurring side-effects as a sign of metastasis. This then resulted in even more distress for them.

Open communication between health professionals and the family of the patient should be encouraged. The researcher was asked to intervene in a case of a

mother who was terminally ill following cancer of the breast and mastectomy. The spouse did not want the young children to see the mother as she was terminal. The three dependent children were also crying to see the mother. Finally, the health professionals, the researcher and the husband of the patient agreed that the children be allowed to see their dying mother. Indeed they cried, screamed but an hour later the mother died peacefully. The children were content at the fact that they saw how their mother suffered and that through death she was now at peace.

In conclusion, according to Veronesi and Martino (1978:349) it is important that society does all in its power to make the cancer patient's life following treatment as normal as possible. This can be done by creating a less terrifying image of cancer and its treatment by modifying the philosophical background of the health professions and to influence the social structures, to establish a more complete physical and psycho-social rehabilitation of the patient. Cancer needs to be undramatized by objectively informing the patients about its possible causes and treatment. Person to person communication and small group discussions are to be encouraged especially about the fears and anxieties brought about by the disease and its treatment. Education about the disease should be introduced in schools so that the image the disease has can be modified. Rehabilitation according to Veronesi and Martino (1978:350) must form the bridge that must lead the patient from the condition of "diversity to a condition of normality" (Veronesi and Martino, 1978:250). The important role played by cancer survivors should be emphasized, since such patients can better than anyone else help the cancer sufferer overcome her ordeal. It must be remembered that

rehabilitation has to be continued for a long time post operatively. When signs of maladaptation appear, close care by clinical psychologists cannot be too strongly emphasized. Veronesi and Martino (1978:250) suggested three challenges for behavioural scientists to consider when dealing with patients associated with the diagnosis of cancer:

1. To determine the spectrum of normal behaviour, and adaptive responses to cancer and its treatment in the patient and the family;
2. to determine the origin and range of maladaptive responses, and
3. to search for early effective and economically feasible psycho-social interventions for the maladaptive responses.

It is, however, to be noted that according to Veronesi and Martino (1978:250) "the response to cancer is a continually changing adaptation that is based on the stresses imposed by the disease and its treatment. Psychological management may enhance better adaptation" (Veronesi and Martino, 1978:250).

2.10 A THEORETICAL FRAMEWORK RELATING TO MASTECTOMISED WOMEN IN ORDER TO HELP THEM COPE WITH THEIR DAY TO DAY LIVING

This theoretical framework is based on Callista Roy's adaptation theory which is intended to assist mastectomised women to adapt to the cancer and its treatment. An overview of this model will be given, and a critical discussion will follow which will indicate the significance of this model for the adjustment of these patients.

The development of Roy's Adaptation Model of Nursing has been influenced by her personal and professional background. According to Fitzpatrick and Whall (1983:157) Roy believed in the "innate capabilities, purpose, and worth of human beings." Basic to the model are four elements, namely:

- 1) the person,
- 2) the environment,
- 3) health, and
- 4) nursing.

2.10.1 The Person

According to Riehl-Sisca (1988:115), Roy's model indicates that it is based on the concept of adaptation as a positive response to a continually changing environment. The person or recipient of nursing care, client or patient is defined as a bio-psycho-social being with innate and acquired coping mechanisms. Nursing's goals will, therefore, be to promote adaptation or a positive response to changes within the internal and external environment. This, according to Riehl-Sisca (1988:115) can be achieved when the nurse intervenes to assist the person in coping effectively with environmental changes. Roy (1991) describes the person as a bio-psycho-social holistic living adaptive system. She sees the person as a system, which is a set of parts connected to function as a whole for some purpose. The person is thus seen as a system whose purpose is survival through growth, reproduction and mastery (Roy, 1991). Successful achievement of these goals will promote the integrity of the person and thereby contribute to health (Riehl-Sisca, 1988:116).

It is, however, to be noted that not only the person is considered the recipient of nursing care, but the family, the group, the community and society may all be recipients of nursing care. The person as a living system is seen by Fitzpatrick and Whall (1983:117) as consisting of parts, which act together to form a unified being which is in constant interaction with the environment, and open to internal and external stress. The mastectomised patient in this study is in continuous interaction with the environment, and is subjected to internal and external stress which requires adaption on her part. To achieve this exchange of information matter and energy occurs with the environment. The person receives input externally from the environment and self. Her adaptation is a function of the stimulus received (Fitzpatrick and Whall, 1983:158).

Roy in Riehl-Sisca (1988:117) identifies six subsystems within a person. She refers to the two internal processor mechanisms as regulator and cognator subsystems and also mentions four effectors or adaptive modes which are physiological, self concept, role function and interdependence. Riehl-Sisca (1988:117) is of the opinion that the regulator is related to the physiological mode and is the automatic response of the neural-chemical-endocrine systems within the body. A good example given is the response of the body to a sudden drop in environmental temperature. This change, according to George (1985:253) triggers neural input to the regulator regarding the decrease in temperature. This is transformed into conscious perception of being cold and is a function of the cognator. In response to the regulator shivering follows, the cognator from experience compels the person to wear a jersey to counteract the cold weather. Wearing a jersey is feedback into the regulator and cognator which are effected through the adaptive modes. Shivering is effected through

the physiologic needs mode. Stimuli to the cognator subsystem can both be external and internal in origin, such as brain function of perception, information processing, judgement and emotions. Information processing according to George (1985:253) is related to selective attention, memory and coding. Learning is related to imitation, reinforcement and insight. Problem-solving and decision-making are related to judgement and emotions to seek relief and attachment. According to George (1985:258), the physiological mode represents physical responses to stimuli to achieve physiologic integrity associated with nutrition, oxygenation, elimination, rest and protection. These are all basic needs which are important for survival of the person.

The Self-Concept Mode

This mode, according to George (1985:260), relates to the basic need for psychic integrity. It focuses on the psychological and spiritual aspects of the person. The physical self has the components of body sensation and body image. The personal self has the components of self-consistency, self-ideal and moral, ethical and spiritual self. Body sensation, according to George (1985:260), is how the person experiences the physical self, and body image is how the person views physical self. Self consistency represents the person's effort to maintain self-organisation and avoid disequilibrium. Self-ideal represents what the person expects to be and to do, and the moral, ethical and spiritual self represent the person's belief system and self-evaluation.

In a person who has a mastectomy as treatment for cancer of the breast, diagnosis and treatment are both unpredictable in terms of the outcome of the disease and surgery. The mastectomised patients in this study continuously

reported fears of metastasis and that doctors and nurses may fail to manage the disease. Body image in some respondents was affected adversely by the loss of a body part which interfered with their appearance. Some respondents reported being haunted by the very idea of a missing body part which they needed to make them complete as women. The goal of nursing intervention in this case would be the promotion of adaptive responses in relation to the four above-mentioned adaptive modes.

Role Function Mode

According to George (1985:260), the role function mode identifies the patterns of social interaction of the person in relation to others reflected by primary, secondary and tertiary roles, with the basic need met being social integrity. The primary role determines the person's behaviour which is also determined by sex, age, and developmental stage. Secondary roles carry out the tasks required by the stage of development and primary role. Tertiary roles are temporary and may include activities related to hobbies. Behaviours in this mode have a long term orientation and often focus on role mastery.

Interdependence Mode

This is where affectual needs are met. This mode, according to George (1985:260), identifies patterns of human value, affection, love and affirmation. These processes occur through interpersonal relationships with both individual and groups. In this study, the mastectomised patient's adaptation is greatly influenced by affection from the husband, his support and understanding will determine adaptation or maladaptation. It was discovered during the interview that those mastectomised women whose husbands gave them support and were

understanding, adapted easily to the disease and its treatment, whereas those women whose husbands adopted a negative attitude towards the mastectomy were tearful and depressed throughout the interviews. Talking about their experiences with the disease and the surgery made them cry all over again. Family support appeared to have advanced adaptation to the disease and its treatment.

2.10.2 Environment

Environment, according to Roy (1991:18), represents "all conditions, circumstances and influences that surround and affect the development and behaviour of persons and groups". A patient suffering from cancer of the breast experiences a number of stimuli when admitted into hospital. The hospital environment may be frightening, and the idea of a total mastectomy may even be more frightening and anxiety provoking. These stimuli impinge upon her, and it becomes the duty of the nurses and doctors to promote the patient's adaptation to her new environment and her diagnosis.

2.10.3 Health

Health, in Roy's adaptation model, is defined as a state and a process of being and becoming an integrated whole person" (Roy & Andrews, 1991:19). The integrity referred to is the ability to meet the goals of survival, growth and mastery. The nurse in Roy's model promotes health by promoting adaptive behaviour. Using the mastectomised patient as the example, this patient may

be depressed by the diagnosis of a non-curable disease and the loss of a vital part of her body. The nurse must help the patient to adapt to the diagnosis and the surgery. She can use a number of ways such as counselling and showing the patient that she is not the first person to suffer from breast cancer and to have a mastectomy and that cancer, with the advances in technology, may be curable if discovered and treated early. Counselling the spouse and children to give the patient the necessary support and encouragement may expedite the patient's adaptation to the disease and its treatment.

2.10.4 Nursing

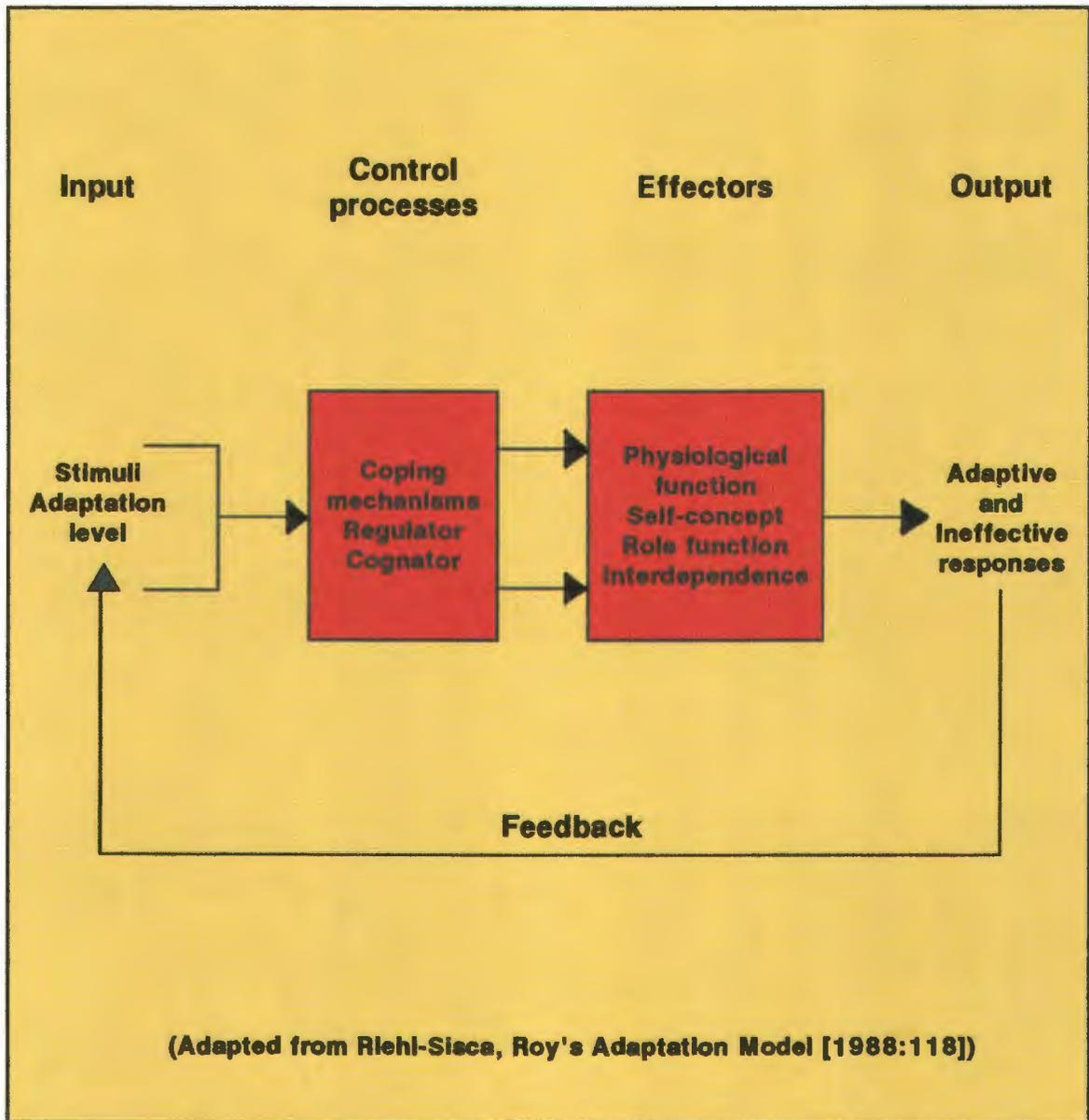
Roy defines the goal of nursing as the promotion of adaptive responses. These are responses that positively influence health. George (1985:261) sees nursing as a way of reducing ineffective responses and promoting adaptive ones by using the nursing process. To cope with the changing environment, the person uses both innate and acquired mechanisms which, according to Fitzpatrick & Whall (1983:164) are biological, psychological and social. Roy (1991:18) is of the opinion that the patient adapts to the environment, and nursing promotes this adaptation in situations of health. It is this adaptation which leads to a higher level of wellness and the adaptive response will be seen to promote the integrity of the individual with regard to general goals of survival, growth, reproduction and mastery.

Nursing is defined by Roy in Riehl-Sisca (1988:117) as a body of knowledge used to positively affect a person's life and health status. This, according to

Roy in Riehl-Sisca (1988:117) is achieved through specific nursing activities which distinguish nursing from other disciplines. These activities are termed the nursing process which consists of six steps. First, the nurse assesses the person receiving care in the four adaptive modes mentioned earlier. This assessment examines behaviour and the factors or stimuli affecting the response or adaptation. The nurse then carries out specific interventions that will manipulate the stimuli affecting these behaviours. A nursing diagnosis is formulated and goals set to promote a positive response to adaptation. The nurse then, finally, carries out specific interventions that manipulate the stimuli to achieve the goals. The effectiveness of the care given in relation to whether or not the goal has been attained is evaluated. It is the nurse who actively selects variables for manipulation in order to bring about a change in the present state of the individual. It is also the nurse who decides which interventions apply in a particular situation and who implements these interventions. It is also the nurse who manipulates the stimuli to promote an effective response. This, according to Riehl-Sisca (1988:118) makes Roy's model fall within the domain of intervention theory.

FIGURE 2

The Person as an Adaptive System



2.11 THE ADAPTATION MODEL AND THE NURSING PROCESS

The Roy adaptation model offers guidelines to the nurse in her application of the nursing process. Roy includes assessment of behaviour, assessment of stimuli, nursing diagnosis, goal setting, intervention and evaluation. These will be discussed in the following pages.

Behavioural Assessment

This, according to George (1985:262) is the gathering of a patient's responses or output behaviour as an adaptive system in relation to each of the adaptive modes: physiological, self-concept, role function and interdependence. It is during the assessment phase that an holistic approach is adopted by the nurses and such assessment clarifies the focus that the nurse will take in caring for the patient. If assessment is skilfully done, behaviour on the part of the patient enables the nurse to evaluate whether such behaviour is adaptive or maladaptive (George, 1985:262).

For instance, in the event of a newly operated mastectomised patient:

- Increase in heart rate plus an elevated temperature may indicate infection.

- Tension and increase in blood pressure may indicate adaptation difficulty.

- Excitement and loss of appetite and continuous tearfulness a day or two post operatively may all be a reaction to loss of the breast and an indication of adaptation difficulties.

If this happens, the patient's physician may prescribe a sedative to calm the patient, and in this way get her gradually to adapt to the mastectomy.

Signs of Cognator Ineffectiveness may include amongst others:

Faulty perception caused by inadequate information given to the patient following a mastectomy. Some of the problems which may delay adaptation include no information given to the patient regarding when to assume sexual activity with the partner. On the contrary, the partner may also be in doubt as to when he can make advances in this respect. It was evident from the data collected that this created concern. Patients assumed that partners, who did not make advances when expected, rejected them because they had only one breast.

The tingling sensation of the affected arm, if not explained, also caused concern. Respondents misinterpreted this sensation and thought a moving object or 'worm' was present in the arm especially during the first month after the mastectomy. One respondent, who was 26 years old with one child, reported in a depressed state that she experienced pain during sexual intercourse with her husband. This was the effect of radio- and chemotherapy which negatively affected her ovaries resulting in hormonal deficiency and subsequently dryness of the vaginal canal. This physiological change resulted in painful sex and

distasteful intercourse. Complete failure to adapt to the mastectomy and its treatment was the outcome.

George (1995:267) reported that in behavioural assessment the nurse analyses the emerging themes and patient behaviour and identifies in the process ineffective responses which require support. She collects data on the focal, contextual or residual stimuli impacting on the patient and can plan the type of intervention required to assist with effective adaptation. Commonly occurring adaptation problems may be manifested in the physiological mode such as poor oxygenation, interference with nutrition, disturbance of elimination, poor sleep patterns, lack of rest, fluid and electrolyte disturbance, defective cognitive processing and ineffective hormone regulation (George, 1995:267).

Nursing Diagnosis

After the assessment of the patient, a nursing diagnosis is made by stating the observed responses to stimuli.

Goal Setting

These include the behaviour, the change expected and time frame. Reduction of adaptive problems and the availability of energy to meet other goals for survival, growth, reproduction and mastery. Setting adaptation goals will include the patient since respect of privileges and patient's rights is part of nursing.

Implementation

Implementation of the nursing intervention plans will focus on broadening coping ability of the patient so that the total stimuli fall within the patient's ability to adapt.

Evaluation

According to George (1995:271) Roy's nursing process is completed by evaluation and goal behaviours are compared to the person's output responses. In this way, adaptation (according to Roy) is achieved. If, after evaluation, areas of maladaptation are noted, readjustments to goals and interventions are made on the basis of evaluation data.

Roy's adaptation model according to Pearson and Vaughan (1986:87) is based on "the way in which an individual as a whole system responds to stimuli." Rambo (1984) in Pearson and Vaughan (1986:87) sees each person as an integrated whole with biological, psychological and social components. This individual is in constant interaction with his environment. Rambo seems to have omitted the spiritual component of the individual which in this study seems to play a crucial role in the adaptation or adjustment of the respondents to their plight caused by cancer of the breast and subsequent surgery.

Rambo goes further and states that according to Roy to maintain homeostasis or integrity individuals need to respond to changes in the environment using

"innate and acquired mechanisms." Galbreath (1984:30) concurs with Rambo (1984) when she states that individuals, in their attempt to interact with the environment, exchange information and in the process adapt and adjust to the environment. This fact could not have been more appropriate in this study. To quote an example, adjusting to the news that one has cancer of the breast and that the only treatment of choice is a total mastectomy of both breasts will require both innate and acquired mechanisms to adapt effectively to such devastating news. Living with the constant fear of the possibility of metastases into any vital organ in the body requires strong faith and mechanisms to maintain integrity. Focal stimuli such as the scar which acts as a constant reminder that one was or is a cancer victim need mechanisms which the victim must constantly fall back on to maintain a steady state, and integrity. Integrity is viewed by Galbreath (1984:308) as "a state or a process of being or becoming a whole person." The integrity being the ability to meet the goals of survival, growth, reproduction and mastery. Adaptation to changes according to Roy in Galbreath (1984:308) is related to the individual's "adaptation zone" which determines effective or ineffective adjustment to stimuli. This 'zone' according to Pearson and Vaughan (1986:88) is concerned with the capacity to respond to stimuli. Roy (1986:88) maintains that if all stimuli fall within this 'zone', the response the individual makes will maintain integrity and will be considered positive adaptation. However, should stimuli be too great or fall outside the adaptation zone, the response will not maintain integrity and therefore will be maladaptive or negative (Pearson and Vaughan, 1986:88).

Considering a newly diagnosed and confirmed cancer of the breast with total mastectomy, radio- and chemotherapy as treatment of choice, such stimuli, if directed at an illiterate Black woman, one would expect her to respond in a maladaptive manner such as being continuously tearful. Under such pressure sleeplessness, fatigue, poor concentration and loss of appetite may reign supreme. This may affect the entire family and dependent children may manifest stress by showing poor performance at school. The spouse may become equally irritable and show lack of concentration at work. Small wonder then that some of the respondents in the qualitative study for this research reported that prayer was the only adaptive mechanism that kept them going and gave them hope and strength (see Table 1 item 5.2).

The goal of intervention in nursing according to Roy in Pearson and Vaughan (1981:89) is to help subjects adapt in order to respond positively to stimuli. Roy also refers to needs relating to the self-concept which is concerned with the way people perceive themselves. According to Rambo (1984:88) the self-concept is concerned with how people perceive themselves in relation to their feelings, sensation, appearance and body image. Difficulty in this area is well portrayed in totally mastectomised patients. Adaptation to the loss of the breast (or breasts) with subsequent deformity and flat bosom on one side where unilateral mastectomy was performed will depend on a multiplicity of factors such as the emotional support the client will receive from the spouse and significant others. The overriding goal of Roy's adaptation model is therefore to assist the patient to move towards adaptive behaviour.

Talcott Parsons in Savage (1981:221) refers to generalised adaptive capacity when he refers to adaptation as more than "passive" adjustment to the environment. This, according to Savage, involves a process far more than a cause - effect relationship. According to Parsons in Savage (1981:221) "adaptation is the capacity of the living system to cope with the environment and to master it." The organism "copes" with the environment and is actively concerned with "mastery" or the ability to change it to meet the needs of the system which is the achievement of equilibrium. This according to Fitzpatrick and Whall (1983:169) leads to higher levels of well-being or health. Hence the definition of health according to Roy as "a state and a process of being and becoming an integrated whole person." Integrity here implying soundness or unimpaired condition that can lead to completeness or unity and the highest possible fulfilment of human potential. Integration according to Roy is health, whereas the absence of integration is lack of health (Roy, 1984:28). The World Health Organization's (WHO's) definition of health as "more than the absence of disease" places emphasis on this state of well-being (Andrews and Roy, 1986). Health can qualitatively be described on a continuum from maximum to minimum health. In this study it is assumed that adaptation to the diagnosis cancer of the breast and mastectomy signifies mastery of both the internal and external environment and is, therefore, a sign of integration and achievement of equilibrium.

This can be achieved only if the mastectomised patient has a sound psychosocial support system. The husband needs to be supportive and understanding. The children and close relatives need to be equally supportive.

The surgeons, chemotherapist and nurses at local referral hospitals have a similar role to play in assisting the patient to adapt to the disease and surgery. This can be achieved by providing the relevant and required information to alleviate anxiety and fear in respect of all aspects of the tumour. The voluntary support groups in the community, the church and women's groups with similar health problems will all play a vital role in assisting the mastectomised Black patient to adapt successfully to the diagnosis cancer and its treatment.

Support groups are recommended in the event of breast cancer and mastectomised patients whose condition deteriorates because of metastasis and other complications. In former Bophuthatswana, the voluntary health care groups rendered vital services with regards to social and emotional support for these patients. The group visited the home and helped wherever there was a need. They reported to the nurses at the health centre when the patient's condition changed. They fetched sedatives and made sure that these are taken regularly by the patient.

The oncology nurses looked after those patients who were discharged from hospital or those who had to report for further management. They kept Tomoxifen and distributed the drug to patients who were on chemotherapy. They took blood specimens to monitor the patient's full blood count. They arranged transport from the regional to the referral hospital, and ensured that this transport was available as arranged. Oncology nurses also visited patients at home to establish what problems they were experiencing; they washed, dressed and made patients comfortable. In the event of a patient who had

dependent children, the oncology nurses consulted social workers to trace relatives who could look after them if it became necessary.

2.12 PURPOSE OF THE ROY ADAPTATION MODEL

According to Fitzpatrick and Whall (1983:165) the purpose of Roy's adaptation model is to indicate how human beings adapt or cope with stimuli in the form of stressors. Central to this model of nursing is the component of adaptation since nursing is concerned with the person as a total being interacting with the environment and responding to stimuli. Nursing will, therefore, always be necessary when unusual stressors make the person cope ineffectively with the environment.

Roy's adaptation model succeeds to explain how the nursing process promotes adaptation which eventually leads to higher levels of wellness. It indicates the relationship among the concepts person, environment, adaptation and nursing. It shows how the person adapts and how nursing promotes such adaptation in both situations of health and ill-health. The model finally shows how adaptive responses promote integrity in relation to survival, growth, reproduction and mastery (Fitzpatrick and Whall, 1983:173).

In applying Roy's model to mastectomised patients, one cannot lose sight of the painful stimuli caused by the diagnosis cancer of the breast which is compounded by the surgical removal of a body part which is central to a woman's femininity. As if this is not enough trauma, the chemo- and

radiotherapy with their side effects of vomiting and alopecia impinge upon the already traumatized patient making positive adaptation impossible.

The researcher selected the adaptation model to guide this study because every member of this population has been a victim of stressors caused by the diagnosis cancer, the treatment, constant fear of recurrence of the disease and fear of untimely death. Cancer of the breast is a life-threatening disease and requires adaptation strategies which will assist the victim to adapt both to the treatment and the disease. Failure to do this may result in maladaptive behaviour such as continuous tearfulness, stress and loss of weight. Counselling by experts to facilitate adaptation was found to be necessary. What is worse, not only is the patient affected, but the entire family becomes a victim of stress caused by the diagnosis. It is on the strength of the negative effects of the diagnosis and its treatment on the patient and family that a model which would facilitate adaptation was chosen. Roy's adaptation model and the nursing process was found appropriate.

From the data collected, support from the family seemed to be vital in assisting the patient to adapt positively to the diagnosis and its treatment.

Other strategies which seemed to foster positive adaptation were friends and fellow patients with similar problems. Hence, the recommendation was made for the formation of a voluntary care group made up of mastectomised patients who, in turn, can help their fellow breast cancer patients. The researcher is convinced that only a mastectomised patient can appreciate the problems

experienced by another mastectomised patient. Moreover, all members of the second sample (16) expressed the need for the formation of such a voluntary care group.

The Roy Adaptation Model is relevant for this study especially when it is used in relation to the steps of the nursing process. Assessment and identification of the adaptation problems, the use of relevant resources to assist the patient to adapt positively to the diagnosis and treatment, the identification of maladaptive behaviour during assessment are all attempts to eradicate situations which will lead to a disturbance of integrity and thus lead to maladaptation. The nurses' intervention will manipulate stimuli in the environment which will bring about equilibrium.

The literature reviewed and findings of the study (Chapter 4) regarding the experiences of respondents following the diagnosis and mastectomy, show that adaptation problems can arise out of fear of premature death, metastasis into vital organs of the body, deformity caused by the lopsided feeling, fear of what people will think of a one-breasted woman; through problems created by certain designs in clothing that cannot be worn without exposing the mastectomy scar and changes in life-style. All these may hamper positive adaptation if not handled appropriately.

In summary, the themes and categories of this study (expressed by respondents in Table 1), such as the meaning of the diagnosis 'breast cancer', 'mastectomy', 'changes in lifestyle' and 'lack of information from health professionals' can only

be handled accordingly if appropriate adaptation strategies are found. Otherwise, inappropriate mechanisms can be developed such as anger, denial, depression and despair. All these are negative mechanisms which will not benefit the patient but may trigger maladaptive behaviour patterns such as self-pity, poor self-esteem and aggression. Such behaviour patterns, according to Kalish (1977:133), may be ascribed to the lack of adequate coping skills which may generate aversion and guilt feelings on the part of the family.

FIGURE 3

Roy's Nursing Process Chart



(Reproduced from Roy, C. [1976a] Introduction to Nursing, An Adaptation Model. Englewood Cliffs, N.J.: Prentice Hall)

CHAPTER 3

RESEARCH DESIGN AND METHOD

3.1 INTRODUCTION

This chapter describes the research method followed to ensure that the objectives of the study are attained. Included in this chapter are the methods used for the selection of the samples, data gathering, target population and data analysis.

This study was conducted in two phases. The first phase is concerned with the exploration and description of the experiences of a group of selected Black women and some of their husbands concerning breast cancer and mastectomy. Data from these respondents were collected using two separate interview schedules (see Appendices A and B) and individual in-depth interviews.

Phase two of the study is concerned with the formulation of guidelines for oncology nurses to assist them to counsel Black cancer patients, particularly breast cancer patients and their families, to enable them to adjust to their disease and the mastectomy, based on the findings from phase one.

3.2 RESEARCH DESIGN

The study is designed as an ethno-phenomenological, contextual, exploratory, quantitative, qualitative and descriptive study.

3.2.1 ETHNO-PHENOMENOLOGICAL

The study was ethno-phenomenological in that it explores the experiences of a specific group of Black women and some of their husbands regarding cancer of the breast and mastectomy (Wilson 1993:236).

3.2.2 CONTEXTUAL

This study is contextual in that it discusses the experiences of Black women residing in the former Homeland that used to be called Bophuthatswana. These women tell of their specific experiences relating to the diagnosis of cancer of the breast and the surgical removal of the affected breast after confirmation by the doctor or nurse that "indeed the lump in the breast was cancer". The study is contextual in that individuals from a specific area and specific racial and cultural group (Batswana) served as samples in obtaining the data. Their immediate environment, health beliefs and practices are all factors which could have influenced their experiences with the disease and its treatment (Holloway and Wheeler, 1996:192).

3.2.3 EXPLORATORY

This study was exploratory in that it explored the depth, richness and complexity of the practical experiences of Black women who had a mastectomy and were residing in the area of study. Increased insight and understanding of the effects of the disease cancer of the breast and its treatment was sought by listening, observation, discussion and analysis of characteristic attributes and themes expressed by respondents.

3.2.4 QUANTITATIVE

The study was quantitative in that it obtained objective information on the effects of cancer of the breast and mastectomy on Black women and some of their husbands (Burns and Grove 1987:752).

3.2.5 QUALITATIVE

According to Burns and Grove (1987:39), qualitative research is one in which the researcher plans to observe, discover and analyse the characteristics, attributes, themes and underlying dimensions of a particular unit.

This study is concerned with exploring the experiences of women confirmed as suffering from cancer of the breast with subsequent mastectomy, and radio- and chemotherapy as treatment. A qualitative approach allowed the investigator to "gather data by exploring whatever seemed relevant to the problem under

investigation" (Wilson, 1993:224). The researcher strove to promote responses that were spontaneous, self-revealing and personal and an attempt was made to examine the experiences, feelings and perceptions of the informants regarding cancer of the breast and its treatment. In addition, every word uttered by the respondent, action taken and non-verbal move made was noted and recorded in context. It is, however, to be noted that each situation was experienced differently by each respondent although the diagnosis and treatment may have seemed the same. The qualitative design was thus found most suitable for this study since it assumes that "subjectivity is essential for understanding of human experience" (Burns & Grove, 1987:36).

In the qualitative aspect of the study, each respondent was asked the following question in the language in which she felt most comfortable to be interviewed:

"Share with me your experiences from the time the diagnosis cancer of the breast was confirmed to date."

Respondents were encouraged to communicate their experiences freely and in a conversational manner. This was considered the best method to gain insight and understanding of the manner in which individuals experienced an identical situation differently.

3.2.6 DESCRIPTIVE

In this study the experiences of women suffering from cancer of the breast with subsequent mastectomy are described. More information about the variables

cancer of the breast and mastectomy were sought for the purpose of providing a picture of the situation as it is. Based on the results of the interviews, guidelines were formulated to assist health professionals to counsel mastectomised women to enable them to adjust to the disease cancer of the breast and mastectomy.

3.3 CONSTRUCTION OF THE STRUCTURED INTERVIEW SCHEDULES

This was done with effect from January to June 1993. Both schedules for the husbands and their mastectomised wives were meant to elicit information pertaining to the experiences of both husband and wife following the confirmation of the diagnosis of breast cancer and the subsequent mastectomy. The mastectomised women's interview schedule had 135 items and the husbands' had 54 items (see Appendices A and B). These structured interview schedules were presented to colleagues in the Department of Nursing and Psychology of the University of the then Bophuthatswana for comments. Minor corrections were effected on both tools. The schedules were then presented to the promoter in the Department of Advanced Nursing Sciences at the University of South Africa for approval. Approval was granted to pretest the instruments and to continue with data collection.

3.4 PILOT STUDY

The structured interview schedule for the mastectomised women was pretested on 15 women during December 1993 and January 1994. Six of these

mastectomised patients were interviewed at different times at Bophelong Hospital during follow-up care. Nine were interviewed at the Thusong and Gelukspan Hospitals in the Ditsobotla region (see Figure 8:93). In each hospital permission was obtained from the Superintendent and Nursing Service Manager. The respondents were interviewed in the side-wards where they were made as comfortable as possible. Each interview lasted for 45 minutes. No difficulties were experienced in terms of interpretation of the items on the schedule, nor did the respondents have any difficulties in understanding the content.

The second pilot study for the husbands of the mastectomised women mentioned above was not an easy one. The researcher visited the homes of some of the mastectomised women after making an appointment with the husband, and more often than not the husband would not honour the appointment. Those who were visited in the evening after work would refuse to discuss the wife's illness with the researcher. As a result, only 4 of the husbands of the mastectomised women in the pilot study were willing to be interviewed to pretest the interview instrument. The interview for the husbands lasted 30 minutes, and no problems of ambiguity or misunderstanding were noted. The respondents used in the pilot studies were excluded from the main study.

With the qualitative study (formed by 16 respondents) only one case study was used to determine the effectiveness with which the question asked elicited the information required from the respondent. An in-depth interview was arranged and the leading question for this interview was:

"Share with me your experiences from the time the diagnosis cancer of the breast was confirmed and that you had to consider a mastectomy as treatment."

This leading question followed by subsequent questions (see Appendix D) was found suitable and was discussed with the promoter prior to data collection.

Training of Research Assistants

Two research assistants were trained:

- One assistant was, during 1993, a student pursuing a Bachelor of Nursing degree in the University of North West. It was at the end of her studies for a basic degree that she was appointed as a research assistant.
- The second assistant was an experienced registered nurse employed as a part-time research assistant by the Medical University of South Africa (Medunsa) in Ga-Rankuwa.

The following training was given by the researcher to the assistants prior to administering the structured interview schedule:

- Quantitative research methods were fully explained.

- Every question on the interview schedule was discussed and explained to ensure that it was understood and interpreted in the same way by the researcher and her assistants.
- Making patients comfortable and reassuring them was discussed at length with the research assistants.
- Assistants were shown how to complete the interview schedule.
- Assistants were requested to interview patients in hospitals prior to their treatment (chemo- and radiotherapy) which often makes them feel sick and miserable afterwards.

Ethical Considerations

Permission to interview patients in referral hospitals was obtained from the Department of Health and Social Welfare (see Appendix F).

Consent was obtained from hospital superintendents, chief nursing officers and sister in charge of out-patients departments of hospitals.

Consent to interview patients was obtained from all respondents and those not willing to be interviewed were allowed to do so without coercion.

Permission to use side-wards to interview patients coming for follow-up care was also obtained.

The researcher had been involved with cancer sufferers for ten years as chairperson of the former Bophuthatswana Cancer Society. This exposure gave her the opportunity to be in continuous contact with cancer patients during voluntary work. She knew the respondents and had given counselling and guidance to some of them a couple of months prior to the interview. This contact made the in-depth interview easy since the respondents were not total strangers nor was the researcher a complete stranger to the respondents.

3.5 SAMPLING PROCEDURES

3.5.1 TARGET POPULATION

The target population for this study comprised Black women who have had a mastectomy six months or more prior to the interview. These were adults over the age of 21 years residing in the geographical area formerly known as Bophuthatswana. The respondents were diagnosed cancer of the breast and subsequently had a mastectomy. Since the study aimed to investigate the effects of mastectomy, a period of six months post operatively was considered sufficient to enable the patients to have experienced the effects of the diagnosis and surgical intervention.

The second population consisted of Black men whose wives had suffered from breast cancer and who had had a mastectomy six months prior to the interview.

3.5.2 SAMPLES

This study was conducted using 3 groups of respondents, 2 groups of Black women who were 21 years and older who resided in the former homeland Bophuthatswana. Respondents in both groups suffered from cancer of the breast and had a mastectomy six months or more prior to the interview.

The third group of participants was formed by some husbands of mastectomised women who were interviewed using a structured interview schedule.

The first sample mentioned above consisted of 150 mastectomised Black women who were selected using purposive sampling. These women presented at 3 referral hospitals for follow-up care. This sample was purposive in that the women met the criteria, which included a confirmed diagnosis of cancer of the breast and mastectomy. Moreover, these women were available to answer the questions on the structured interview schedule.

Seventy (70) participants were interviewed in Ga-Rankuwa hospital over a period of one year (January to December 1994).

Fifty (50) participants were interviewed at Pelonomi hospital in Thaba 'Nchu. Here, too, the research assistant was given a side room where patients who met

the criteria for inclusion in the sample were interviewed privately. A structured interview schedule was administered to respondents who formed this sample. Consent for the interview was obtained from the Superintendents, chief professional nurses and the respondents.

The remaining 30 participants were interviewed at Kalafong hospital by the researcher over a period of one year. Participants were interviewed monthly as they presented for follow-up care (chemo- and radiotherapy). Interviews took place in a side-ward requested for the purpose a day prior to treatment.

The researcher and assistants visited the relevant referral hospitals a week prior to the interviews. They requested to see the list of prospective patients in the register who would come for follow-up care the following week. In other words, the researcher and her assistants could select those patients who satisfied the criteria for inclusion in the sample a week before they reported at the relevant hospital for follow-up care.

The research assistants followed the same procedure in the other referral hospitals. If a patient did not report on the stipulated date the next patient in the list who satisfied the requirements or criteria for inclusion in the sample was selected. In this way a fair representation of breast cancer patients who had a mastectomy six months or more prior to the interview were included in the sample. Using this method over a period of 12 months enabled the researcher and two assistants to interview 150 patients who were referred from the 12 regional hospitals to the referral hospitals for chemo- or radiotherapy. Of the

150 respondents, 30 came from Kalafong hospital, 70 from Ga-Rankuwa and 50 from Pelonomi hospital in the Bloemfontein area. Patients from the latter hospital came from Thaba N'chu, one of the furthest regions which formed the area of study. (See Figure 4:93).

In February, 1996, the researcher presented the completed 150 interview schedules to the Department of Statistics of the University of South Africa for analysis. It was at this point that the data presented proved not to have sufficiently tapped the experiences of the mastectomised women after the diagnosed breast cancer and its treatment. The researcher, with the assistance of the promoters in the Department of Advanced Nursing Sciences of the University of South Africa decided jointly on a qualitative study which formed the second stage of the data collection.

The second sample consisted of 16 mastectomised women selected using purposive sampling. This was done with effect from February to May 1996, after the promoter, researcher and statistician discovered that the structured interview conducted on 150 respondents above did not satisfactorily elicit the experiences of the respondents with the disease and its treatment. Their emotional experiences in particular were not tapped by the structured tool. A qualitative approach was then decided upon by the researcher with the assistance of the promoter. This approach was found suitable since it allowed the researcher to "gather data on numerous aspects of the patients' experiences with the disease and its treatment (Mouton & Marais, 1988:205).

The 16 respondents above were selected in the following manner:

During February 1996, the researcher visited Ga-Rankuwa, Kalafong and Pelonomi hospitals. These are three referral hospitals for cancer patients from former Bophuthatswana. Registers for follow-up care for breast cancer patients were examined to identify the residential addresses of relevant patients.

Characteristics which qualified patients to be included in the sample were:

- Mastectomy performed 6 months or longer to the month of February 1996;
- Residential address had to be accessible by car;
- Patient had to be resident in the area formerly known as Bophuthatswana; and
- Patient had to be 21 years or older.

Using the above guidelines, every second patient was selected to form the sample. Systematic purposive sampling was used in an attempt to obtain a sample that was as representative of the area of study as possible. In this way, 3 patients were identified in the Thaba N'chu area, another 3 in the Molopo region, 2 were resident in the Ditsobotla area, 2 in Madikwe and Mankwe, 1 in Ganyesa, 2 in Moretele, 2 in Odi and 1 in Kudumane. These patients made up the sample of 16 and were interviewed in-depth by the researcher. Eight were interviewed in their homes and the other 8 were formed into two focus groups which were interviewed in two different hospitals.

The third sample consisted of some husbands of mastectomised women who formed the first sample. A structured interview schedule was also designed for the husbands to determine the effects which the disease and mastectomy had

on them as well as the type of support they gave their mastectomised wives. Fifty structured interview schedules were designed for the husbands of women who formed the first sample of the study. Unfortunately, most husbands were employed in the mines and in Johannesburg and could not be reached by the researcher and her assistants. Some of those who could be approached in their homes simply refused to discuss the wife's illness with the researcher. As a result, only 13 male respondents were cooperative and gave consent to be interviewed.

3.5.3 DATA COLLECTION

Data collection in this study was done in three stages. Stage one consisted of data collected from January to December 1994 after the pilot studies were completed. One hundred and fifty (150) respondents were interviewed by the researcher and two assistants using a structured interview schedule as follows:

Thirty respondents were interviewed over a period of 12 months at Kalafong hospital situated in Atteridgeville near Pretoria. This is one of the referral hospitals which admits cancer of the breast patients for radio- and chemotherapy. These patients receive the above treatment at H.F. Verwoerd hospital at the Radio-Active Isotopes Department. However, for inclusion in the sample the researcher identified the relevant patients from the cancer register a week prior to chemo- or radiotherapy. The relevant arrangements for the interviews were made with the sister in charge of the relevant ward where the patient was to be admitted. In the event where patients were not admitted they

were interviewed in a side-ward at the out-patient department of Kalafong Hospital.

The researcher interviewed 30 respondents using a structured interview tool containing 135 items (see Appendix A). Seventy (70) respondents were interviewed for one hour and thirty minutes each by a research assistant at Ga-Rankuwa Hospital over a period of 12 months. Here, too, a structured interview schedule was used to elicit the relevant information.

The remaining 50 patients were interviewed at Pelonomi Hospital in the Thaba N'chu region in the Orange Free State Province. These respondents were also interviewed using the same structured tool as the two former groups of respondents from Ga Rankuwa and Kalafong hospitals. The researcher arranged a meeting with the assistants at 3-monthly intervals to ensure that the procedure followed in collecting data was the same for the 3 referral hospitals. At end of 12 months, the 150 completed structured interview tools were submitted to the Statistics Department of the University of South Africa for analysis.

The above data was analysed and this will be reflected as part of the findings in Chapter 4 of this study. It was at this point that it was discovered that the structured interview schedule did not succeed to elicit the emotional experiences of the respondents. A qualitative study was then decided upon by the researcher in an attempt to determine the overall effects breast cancer and mastectomy have on the patients.

Second Stage of Data Collection

Pursuant to the decision taken to embark on a qualitative study, a set of data was obtained using in-depth interviews on the second sample of mastectomised women. Sixteen respondents were selected using purposive sampling. Eight of these respondents were interviewed individually in their homes and the remaining 8 were formed into 2 focus groups of 4 respondents each. According to Wood (1992:2821) "valuable insight can be gained into patients' attitudes towards cancer and its treatment by using focus group interviews since this approach encourages participants to relate feelings and their personal experiences on the topics of interest." Focus groups are described as "a structure meeting designed to elicit beliefs and experiences about a particular topic of interest", in this case cancer of the breast and its treatment (Wood, 1992:2821). Each of the two focus groups were willing to talk about their experiences in a group setting. Written consent to participate in the focus group interview was obtained from each participant. Free-flowing interaction between participants was encouraged by the fact that the group suffered from the same disease and had similar treatment - mastectomy, chemo- or radiotherapy.

The Actual In-depth Interview

Of the 16 respondents mentioned above, 4 were interviewed as a focus group in Ga-Rankuwa hospital. These four respondents were selected purposively because they met the criteria for inclusion in the sample and they came from different parts of former Bophuthatswana. Two came from Madikwe and the

other two from Ditsobotla. Both areas were part of the regions that formed the area of study. Three of the respondents reported to the hospital for chemotherapy and one for radiotherapy. The respondents were invited by the researcher into a side-ward which was prepared beforehand. All were already admitted into this hospital to receive treatment the following day. After making them comfortable, the researcher introduced herself and asked each respondent to relax since none were in a hurry to go home. Each respondent introduced herself in the traditional Setswana way. After the introduction the purpose of the meeting was explained by the researcher and the leading question for the in-depth interview was asked. Respondents were given a chance to narrate their experiences with the disease cancer of the breast and its treatment in turns. Each respondent was given a chance to contribute at each level of the discussion; they asked questions where clarity was necessary and required. They were allowed to respond and discuss in the language they felt most comfortable with. All preferred Setswana since it was their mother tongue.

A research assistant was seated at the back of the room. She double-audiotaped the discussions, acted as a key witness to the investigation and made field notes. She also cared for the two respondents who broke down and cried as they related their experiences. The interview lasted for two hours, with the researcher guiding the responses to remain within focus of the leading question. Follow-up questions were asked, probing was done where more information was required. Nodding of the head to indicate agreement was done and interest was stimulated throughout the interview.

A review of each audio-tape was done after the interview to make sure that participants were satisfied with the truthfulness of the information. Tapes were transcribed verbatim and both the researcher and assistant checked the transcriptions against the tapes for omissions or inaccuracies.

Two weeks later, the researcher and her assistant made an appointment with the matron of Taung hospital, to conduct a similar focus group interview with patients who reported for follow-up care in her hospital. Taung hospital serves the Taung region south of Vryburg (see Figure 4). More breast cancer patients were seen in this hospital, however, only 4 met the criteria for inclusion in the sample. One respondent came from Pampierstad, 2 from Hartswater and 1 from Pudumoe. This, according to the researcher, was a fair representation of the region. The same procedure was followed for this focus group as the one interviewed at Ga-Rankuwa hospital. At the end of the interview, the respondents were thanked and given a cup of tea. Here, too, the tapes were replayed for the respondents' satisfaction and cross-checked for accuracy. Tapes were transcribed verbatim, and checked for omissions and inaccuracies.

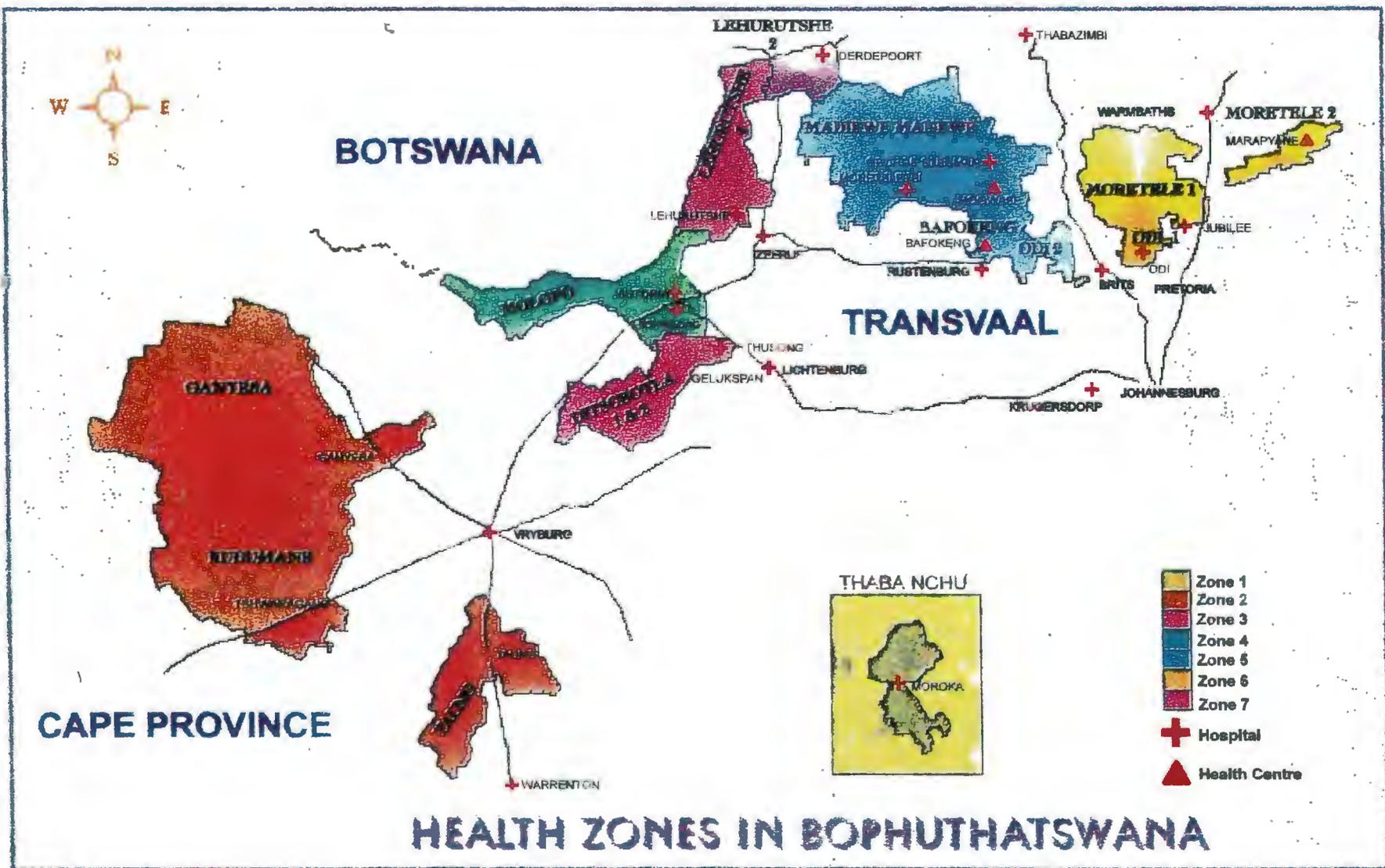
Third Stage of Data Collection from Husbands of Mastectomised Women

A structured interview schedule with 54 items was administered to 13 husbands of mastectomised women who formed the first sample for this study. A purposive sample was planned by the researcher which was administered to husbands of mastectomised women who satisfied the criteria for inclusion in the study. Unfortunately, of the 150 female respondents in the first study, 23 were

widowed, 10 were divorced, 15 were never married. Of the remaining 112 only 13 husbands were willing to be interviewed in their homes. The rest could not be reached because they were migrant labourers who were employed in Johannesburg and the South African mines. Their addresses were unknown thus making it impossible for the researcher and her assistants to interview them. Twenty four husbands refused to talk about their wives' illness and their wishes had to be respected (see Appendix B).

Health Zones in Former Bophuthatswana

FIGURE 4



3.5.4.1 Promoting Trust by Building a Relationship

The researcher worked closely with oncology nurses. Once a participant who met the criteria for the sample was identified, the researcher visited her at her home to make an appointment and to explain the purpose of the visit. Telephone appointments were also made prior to the interview since the area of study was wide and the residential areas of the respondents were scattered. The majority of the respondents came from rural villages where no telephone service was available. In such cases, the assistance of oncology nurses was sought who, as part of their work, followed these patients after they had undergone chemo- and radiotherapy to provide further support. Therefore, they were familiar with the locations of the respondents' homes and worked closely with the researcher to arrange appointments.

On the day of the first appointment, respondents were told the purpose of the visit and the study. They were alerted to possible inconveniences such as time involvement and probing questions relating to their personal life. Permission to record the responses on tape as well as consent to the interview was also obtained. Procedures to safeguard identifying information were described and explained and the issue of people who were likely to have access to the raw data, such as the coders, was discussed with the respondent. This was done to ensure that the respondent was fully informed before she gave her consent to be interviewed. The approximate duration of the actual interview, i.e. one hour, was also mentioned during this initial visit.

3.5.4.2 Anonymity and Confidentiality

Respondents were assured prior to the interview that whatever was discussed between them and the researcher would be kept confidential. Co-coders and supervisors who had access to the raw data would not know whose information they were dealing with since no names and surnames were to be used. In other words, the information source would not be divulged. Informants were told about the voluntary nature of their participation and that they could withdraw at any stage should they wish to do so.

3.5.4.3 The Actual Interview for the Qualitative Study

Eight of the respondents (50%) were interviewed in their own homes during the course of the week when children had gone to school and the rest of the family had gone to work.

The in-depth interview was conducted in the room of the respondent's choice, which was either in her bedroom or the lounge. Once in the interviewing room, the researcher greeted the respondent in the language spoken in the home which was, in most cases, Setswana, although one respondent spoke Zulu and another Xhosa. This did not matter since the researcher understands and speaks these languages fluently. The researcher always waited to be offered a chair. The same procedure was followed when she was in the company of an oncology nurse.

- The researcher then introduced herself to the respondent as a student at the University of South Africa, conducting research into the experiences of Black women regarding the diagnosis cancer of the breast and subsequent mastectomy. A long introduction was unnecessary, because most respondents and the researcher knew each other from previous contact as a voluntary care giver.

- The researcher, although a nurse by profession, was dressed in civilian clothing to avoid identification with the nurses. An avoidance of this was very important because the former pilot study showed that this influenced the respondents' answers - they felt uneasy to reveal some of their personal experiences. Since nurses are, by rural women, generally looked upon as superior to the ordinary man in the street, the researcher feared that the respondents may think certain experiences may not be for the nurse to hear.

- The respondent was then asked to introduce herself using her name and surname and who her parents were. This was done in accordance with Tswana culture where one's roots are considered important in any introduction. During this introduction, respondents very often volunteered information regarding their parents which was valuable to the researcher, for example, that their mother had died from cancer of the breast or their maternal grandmother. This saved the researcher from having to ask this question later in the interview.

- After the introduction, the researcher started the conversation with general social issues; then asked the respondent to share her experiences since she was diagnosed cancer of the breast and had a mastectomy.

- It had been explained to the respondent that the conversation would be audio-taped to ensure accurate recall of the information exchanged during the interview. It was then also explained that the interview would be transcribed verbatim to avoid the loss of meaning of concepts and words as expressed by the respondent.

From the responses, the researcher used communication skills such as probing, reflecting, clarifying, paraphrasing and summarising, silence and minimal verbal responses. In this way, the researcher was able to get a clear picture of the situation. Each interview took about one to two hours on average.

3.6 FIELD NOTES

Notes were made describing the interview and the researcher's impressions immediately after each session with the respondent. This practice also ensured that no collateral information was lost. Each interview was transcribed within 24 hours for the extraction-synthesis process.

According to Burns & Grove (1993:579), extraction - synthesis is a process of "moving the descriptions from the language of the participants up the level of abstraction to the language of science."

3.7 RELIABILITY

Reliability is concerned with "how consistently the measuring instrument or technique measures the concept of interest" (Burns & Grove, 1993:339). In this study, reliability was enforced by specifying and adhering to the following:

- Characteristics of the participants and the decision processes involved in their selection, e.g. all respondents were confirmed breast cancer patients who had a mastectomy and all were residing in the area of research. (See how samples 1 and 2 were selected - pages 83 and 85).
- Capturing all responses on tape ensured accurate recall of the data and follow-up interviews with those respondents within the researcher's reach.
- Data was independently checked by colleagues from the Department of Nursing Science of the University of North-West as well as co-coders who read both Setswana and Zulu and were pursuing doctoral degrees in nursing at the Rand Afrikaans University (RAU).
- Consensus was reached through joint discussions between the researcher and independent coders from the University of North-West who were

knowledgeable in doing qualitative studies and could read and write Setswana.

- Time was spent with respondents to build rapport except for the two focus groups. Fifty percent (50%) of the respondents had more than a second chance to verbalise their experiences since they were within easy reach of the researcher.
- The recorded interviews were transcribed verbatim into English, the language in which the report was written.
- Reliability regarding data analysis was assured by peer examination of the transcripts and field notes at the University of North-West.

Colleagues consulted were able to read and write Setswana, Zulu, Xhosa and English, and had undertaken qualitative research for the Master's degree and were, at the time, working towards doctoral degrees in different fields in nursing. These peers were asked to identify categories and structures within the data. Consensus in coding and categorising themes was also reached.

3.8 VALIDITY

According to Brink (1993:35), validity in qualitative studies is concerned with confirming the truth value of findings, the extent to which data provides insight, knowledge and understanding of the meaning, attributes and characteristics of

people under study. The following measures were employed in this study to ensure the validity of the information obtained from respondents:

- Respondents were selected in accordance with the criteria set to meet the sample requirements.
- Respondents were reminded continuously that they were the experts in the topic under study; they were questioned when using words and concepts which they took for granted.
- Finally, tapes were played back to each respondent to verify the contents. This was also done with the two focus groups. Since the respondents were first-hand witnesses to their experiences, the researcher believed what they related to be the truth.

3.9 DATA ANALYSIS

Analysis of data collected using the structured interview tools, that is, data collected for stages one and three were analysed as follows:

Data was transferred from the interview sheets and was processed at the Statistics Department at the University of South Africa, using the Statistical Analysis System (SAS). This programme generated descriptive statistics which portrayed demographic information and frequency distributions. It was during the analysis of this data that it was revealed that the structured tools did not

satisfactorily elicit the experience of respondents regarding the diagnosis of breast cancer and its treatment. A qualitative study followed and data was analysed in accordance with Tesch (1990) in Creswell (1994:155) and Strauss & Cobin (1990:61). The steps mentioned below were followed:

- All sixteen transcriptions were read individually to get a sense of the whole. Then, in each transcript, ideas were isolated and jotted down. Underlying meaning of words and thoughts were noted and written in the margin.
- Major themes from each transcript were listed and placed into columns.
- Sub-categories were identified from major themes.
- Topics relating to each other were grouped together to form interrelationships.
- Finally, results were quantified according to the number of similar responses identified from the respondents' verbal reports of their experiences with cancer of the breast and mastectomy.

CHAPTER 4

DISCUSSION OF DATA/FINDINGS

4.1 INTRODUCTION

In the previous chapter, the method used to collect data was discussed. In this chapter, the results are analysed and presented.

4.2 THE SAMPLE

Three samples were used to collect data for this study. The first sample consisted of 150 women who were purposively selected and interviewed using a structured interview schedule.

The second sample consisted of 16 women who satisfied the criteria for inclusion in the study and from whom data were collected using individual in-depth interviews. Eight of the interviewees in the second sample were formed into 2 focus groups of 4 respondents each which were interviewed in 2 different hospitals in former Bophuthatswana (see page 93).

The third sample consisted of 13 husbands of mastectomised women some of whom formed the first sample. This sample was also interviewed using a structured interview tool. It was also purposive since only husbands of mastectomised women six months or more post operatively were included in the

study. Here, too, the experiences of the husbands relating to their wives' mastectomy and treatment was sought.

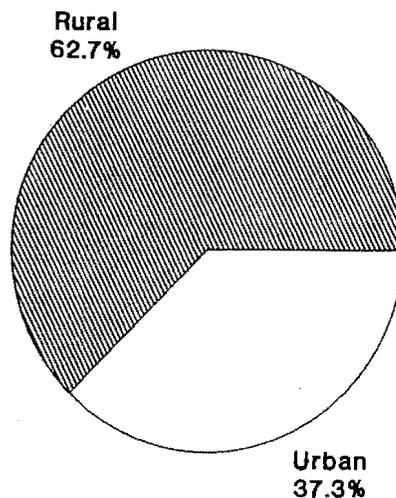
4.3 CHARACTERISTICS OF THE RESPONDENTS

These characteristics belong to the respondents who formed the first sample of 150. All of these were Batswana and spoke Setswana. Ninety three (93) respondents came from rural and 57 from urban areas:

FIGURE 5

Place of Residence

(n = 150)

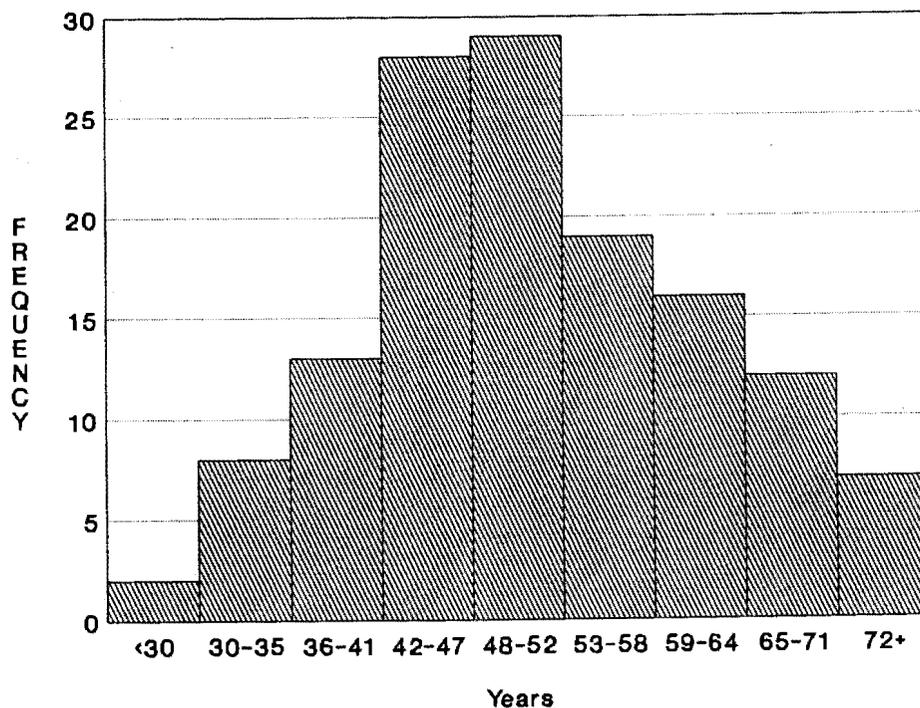


From the above figure it is clear that the majority of the respondents came from the rural areas. This may be due to the fact that former Bophuthatswana was 80% rural.

The respondents were asked how old they were at the time of the interview; less than 5 were below 30 years of age, and the majority of the respondents reported to have been between 42 and 52 years of age. These findings concur with those of Winters, Mannell and Esser (1988:69) who reported that Black women in South Africa present with cancer of the breast at a younger age than their white counterparts. Black patients' mean age at diagnosis of breast cancer was reported to be 51 years. The reason is not known, however, Chiedozi in his study of Nigerian woman made several assumptions (see page 2).

FIGURE 6

Age at Interview
(n = 150)

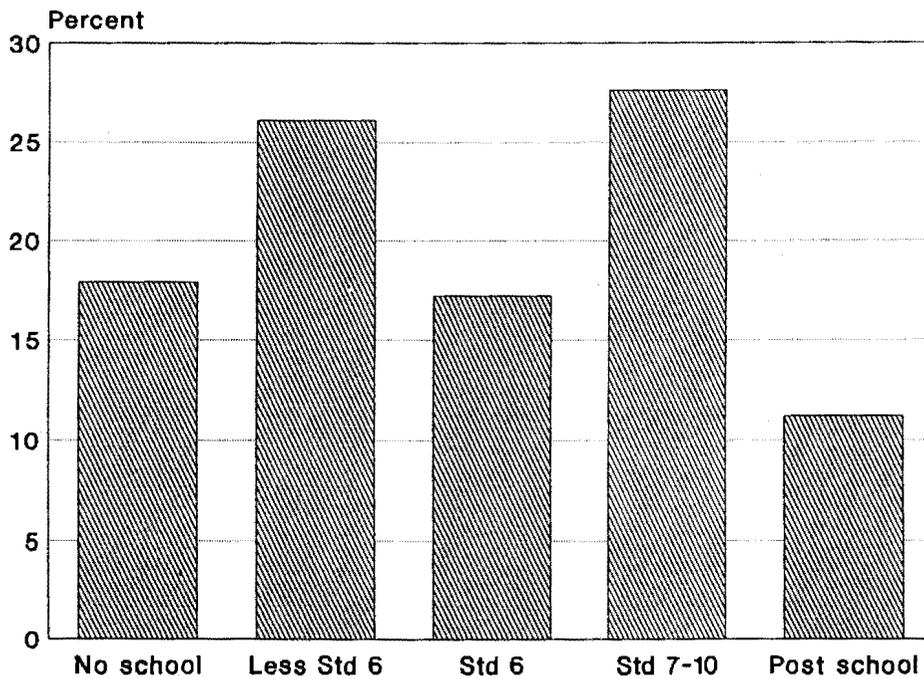


The figure shows that the majority of respondents were between 42 and 52 years of age.

These are important findings in that health professionals, particularly the nurses as well as the physicians, need to be sensitive to the possibility of malignant changes at this particular age. During health education talks at clinics and out-patient departments of hospitals, self-breast examination should be emphasized. In this way, women could be made aware of the importance of reporting changes in the breast to health professionals as early as possible.

FIGURE 7

**Level of Education
(n = 150)**



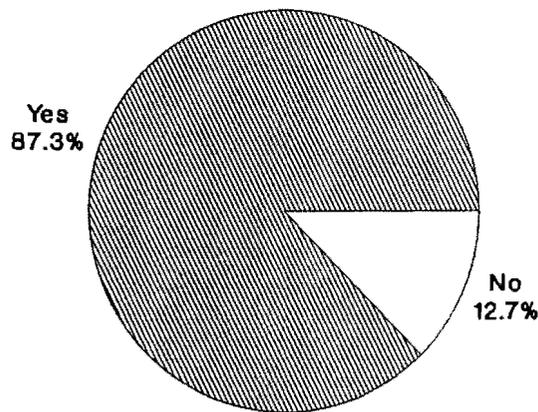
Eighteen percent of the respondents in this sample reported that they had no schooling at all. Twenty five percent had obtained less than standard 6, in other words, they only obtained primary education. It is not surprising, therefore, that Black patients present at health facilities during the late stages of the disease

thus making the prognosis of breast cancer poor. It may be ignorance and the inability to follow and understand written information or health education given in other languages via the media.

There is a general belief in medical circles that a relationship exists between failure to breastfeed long enough and the occurrence of cancer of the breast. In this study, respondents in both samples reported to have breastfed for longer than a year on the average which seems to negate this general belief.

FIGURE 8

**Responses to the Question: Did you Breastfeed your Children?
(n = 150)**



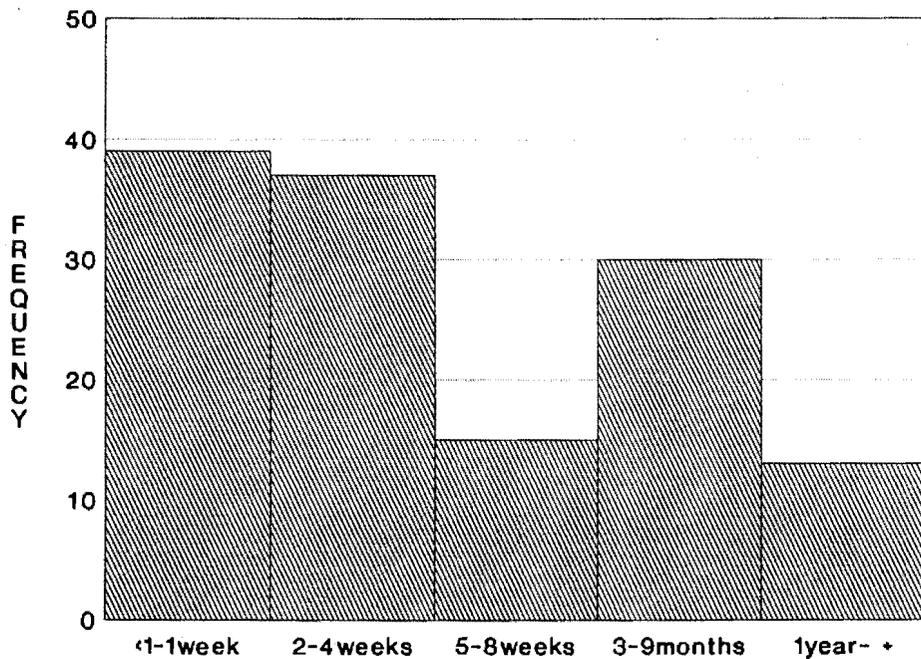
The figure shows that 131 respondents (87.3%) in this sample reported to have breastfed for more than one year.

In an attempt to establish how long respondents waited before reporting changes in the breast, 30 women of the sample waited for 3 to 9 months because the lump was not painful and did not create an immediate problem.

These findings concur with those of Walker, Tshabalala, Isaacson and Segal (1984:24) when they reported that Black women in South Africa presented at hospitals with cancer of the breast during the third stage of the disease. This made the survival rate poor. Chiedozi (1985:6561) made similar findings in Nigeria. He reported that breast cancer patients came to the hospital only after noticing a malodorous drainage and ulceration from the affected breast.

FIGURE 9

**Period Waited Before Reporting Changes in the Breast to Health Professionals
(n = 150)**



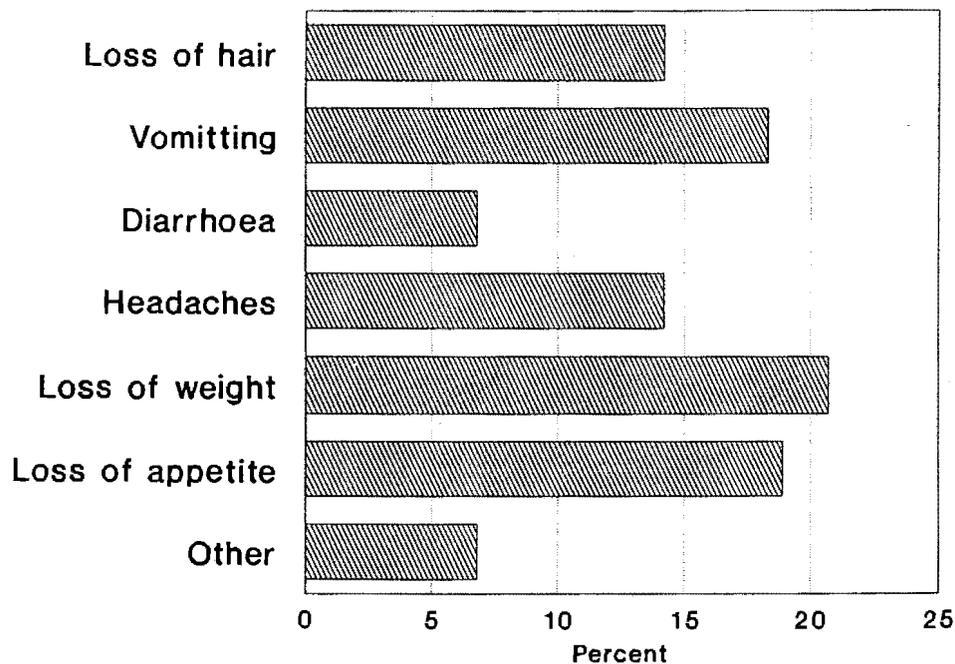
As shown in the figure above, 30 respondents waited for 3-9 months whereas 10 respondents waited for one year or more before reporting changes in the breast.

Finally, respondents in the first sample were asked to list the problems experienced since they had a mastectomy six months or more after surgery. Eight respondents reported loss of hair or baldness as a problem. This was a result of chemotherapy. Twenty seven reported vomiting after chemotherapy which lasted for 2 to 3 days. Nine reported diarrhoea, 2 headache, 32 loss of weight, 45 loss of appetite and 8 did not specify their problems.

It is interesting to note that this sample listed only physical problems experienced after chemotherapy. No emotional experiences were mentioned.

FIGURE 10

**Problems Experienced Six Months or More After Mastectomy
(n = 150)**



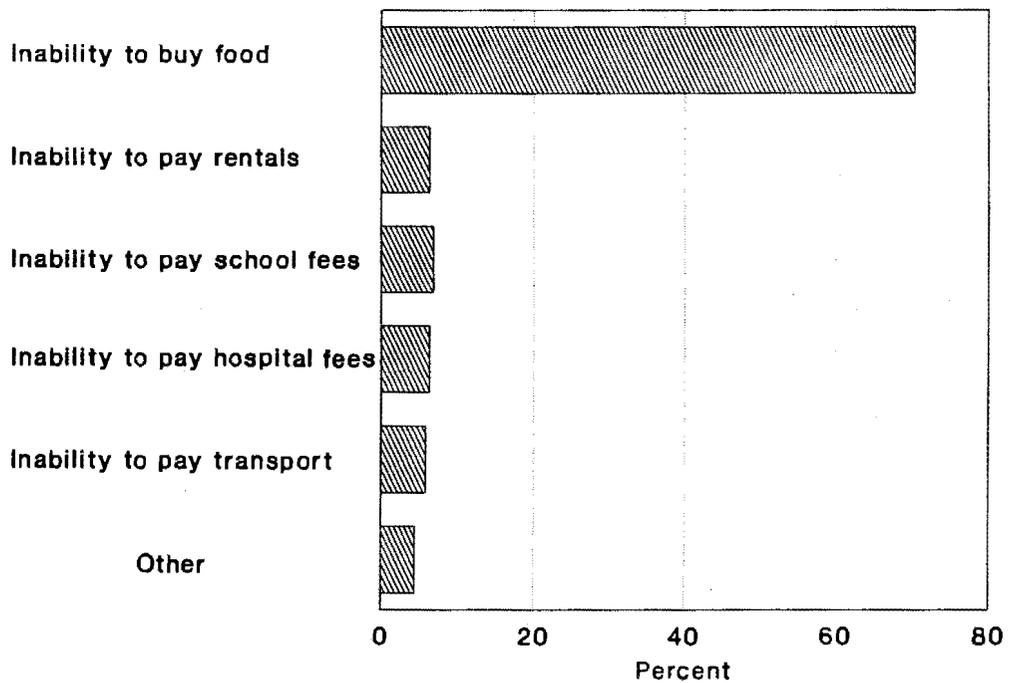
Hence, in an attempt to address this limitation, the researcher selected a second sample of mastectomised women. These were not part of the 150 on whom a

structured interview was conducted. (The second sample was interviewed a year later during the months of February to May 1996.)

Other problems listed by the first sample included financial difficulties experienced by the respondents as reflected in Figure 11 below.

FIGURE 11

**Financial Problems
(n = 150)**



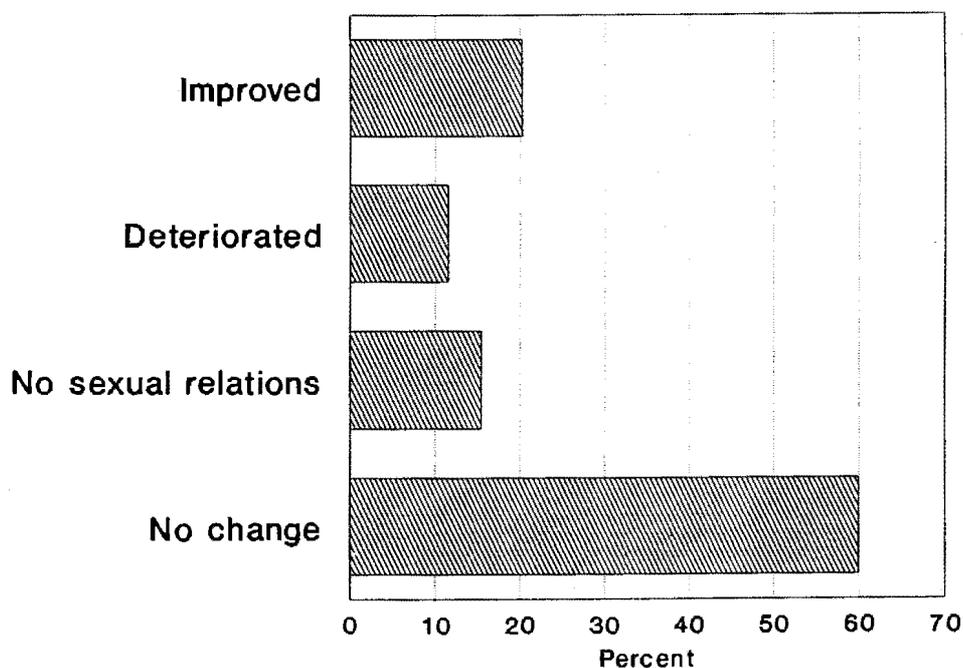
Both samples reported experiencing financial problems because of unemployment. Both had insufficient funds to travel for follow-up care; and lack of funds for the education of their children. Because of the debilitating nature

nature of the disease cancer, respondents could not continue with gainful employment. They reported feeling weak and decrepit.

When they were questioned about changes in their sexual life, the following answers were given:

FIGURE 12

**Respondents' Sexual Reaction to Husbands Six Months After Mastectomy
(n = 150)**



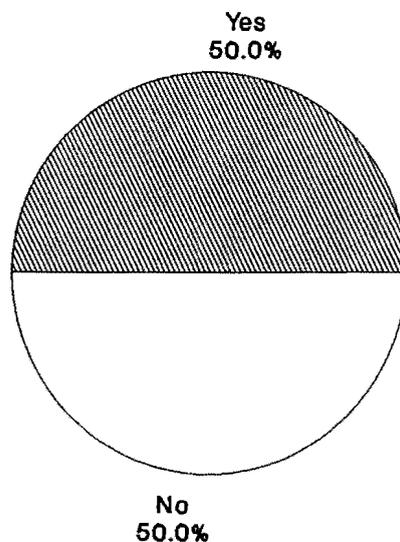
Thirty (30) respondents reported no change in their sexual life after the mastectomy, instead, their relations with their partners improved. Fifteen of the respondents experienced a deterioration in their sexual relations. This concurs with Bard and Sutherland's (1955:660) study of mastectomised women among whom they found those who reported a feeling of disgust at

the fact that they had only one breast and of their fear that their husbands may reject them and look for fully breasted women. Some of Wortman's et al (1979:145) respondents failed to react to their husband's advances because they assumed that the mastectomy turned them into "half women" and, therefore, they considered themselves as sexless. Twenty three of the respondents reported to be sexually inactive probably due to old age, widowhood and illness. Eighty two respondents in this sample reported no change in their sexual relations. The researcher is of the opinion that problems with sexual relations after a mastectomy may be of psychological origin and talking about this with a clinical psychologist may remedy the problem. However, this area requires further research to uncover the root of the problem.

Of the 150 respondents, only half reported using a prosthesis. The remainder either did not know what a prosthesis was or where it could be obtained.

FIGURE 13

**Respondents' Use of Prosthesis
(n = 150)**



The structured interview consisted of 135 items but only the relevant ones are discussed in this study. The rest are not discussed, because they do not depict the effects of cancer and mastectomy on the respondents.

CHARACTERISTICS OF THE SECOND SAMPLE OF 16 RESPONDENTS WHO HAD MASTECTOMIES

4.3.1 Language

- Twelve (12) of the total of 16 informants spoke Setswana which was the language they felt most comfortable to communicate in although one respondent was Xhosa and another Zulu speaking.
- Four (4) preferred the in-depth interview to be conducted in English, a language they felt comfortable with.

4.3.2 Age and Residency

- One (1) respondent was 26 years of age at the time of the interview, and came from the urban area.
- Three (3) were in their early thirties, i.e. 30 to 34 years, and all came from the urban area.

- Seven (7) were in their forties, i.e. 42 to 49 years. Two (2) of these came from rural and five (5) from urban areas.

- Three (3) were fifty years and above, i.e. 50 to 58 years. These were all rural women from the tribal villages of the area where the study was conducted.

- The remaining two (2) women were in their late sixties, i.e. 66 and 69 years respectively. Both resided in remote rural areas of the country.

4.3.3 Results

The following table (Table 1) shows the major themes, categories and sub-categories identified from the informants' descriptions of their experiences following the diagnosis cancer of the breast and its treatment (mastectomy, chemo- and radiotherapy), based on Roy's adaptation theory.

TABLE 1

**Themes and Categories of the Experiences of Mastectomised Women
Six Months Or More Following Surgical Removal of the Breast**

THEMES	CATEGORIES AND SUB-CATEGORIES
1. Changes in the breast (Physiological mode)	1.1 Development of a lump on the breast - who discovers the lump - characteristics of the lump - discharge from the nipple - delay before reporting changes in the breast
2.1 Meaning of the diagnosis 'cancer of the breast' (Focal stimulus)	2.1.1 Cancer of the breast as a stressor - emotional distress - social distress - physical distress - financial distress
2.2 Information received by respondents (Cognator information processing)	2.2.1 Information from: - physicians and nurses - other cancer patients - family members - others members of the health team
3. Treatment for cancer of the breast (Focal stimuli that may affect behaviour)	3.1 Mastectomy as a stressor - effects on the respondents - radiotherapy - chemotherapy - alternative medical care
4. Changes in life style (Role performance)	4.1 Termination of gainful employment - dependence on significant others - follow-up care - sexual life
5. Coping mechanism (Adaptive modes and ineffective responses)	5.1 Denial - anger - depression - despair - acceptance 5.2 Prayer 5.3 Offspring (dependant children)
6. Support systems (Interdependence mode and interpersonal relations)	6.1 Significant others - health professionals - support groups with similar health problems - voluntary care group
7. Myths about the cause of the lump in the breast (Residual stimuli)	7.1 Injury from - the priest's whip - blow with an iron rod inflicted by husband

4.4 DISCUSSION OF FINDINGS

The discussion of findings will be based on the categories and sub-categories set out in Table 1. Relevant scientific data from the literature will be incorporated to support the experiences of the respondents.

4.4.1 Changes in the Breast (The physiological mode according to Roy's adaptation theory)

All sixteen (16) respondents reported changes in the one breast. In the first sample of 150 respondents, too, only one breast was involved. In other words, of the two samples no respondent reported malignancy on both breasts. Hence only the singular will be used throughout the study.

Ten respondents reported that they discovered the lump in the breast on their own. One actually stated that "I was washing, preparing to go to school where I was employed as a teacher. As I washed over the right breast I felt a pea size lump under the face cloth. I immediately touched the affected breast with my bare forefingers. Indeed, it was a hard little lump, not easily felt, neither painful nor problematic. I just ignored it for three months." Another respondent stated that she had consulted a general practitioner as part of follow-up care for hypertension and diabetes mellitus when her son remarked, "Mom, why didn't you show the doctor the lump (knoppie) on your breast?" The mother in response said, "It has not worried me for three years, therefore it is not a priority at the moment." This verbal exchange led to a thorough examination of the

breasts and immediate referral to the nearest hospital for a biopsy, which ended up with total mastectomy and removal of sixteen affected lymph nodes.

Scott (1983:24) concurs with the above findings when he stated that 80% of breast lumps are discovered by women themselves in countries where women are knowledgeable, can read, and write. On discovery of the lump all ten women ignored it since it was not painful or giving them problems.

Four respondents in this study reported to have experienced a blood stained discharge escaping from the nipple. One reported that this occurred 13 years after her last child was breastfed. The bloody fluid oozed continuously night and day even when she did not express the breast. Because of health education received from the community nurses during the cancer awareness week, she knew she must 'run' to the clinic for help. She was immediately referred to Ga-Rankuwa hospital where a biopsy was done and the diagnosis was confirmed. A total mastectomy followed.

Four respondents in this study reported to be suffering from hypertension and diabetes mellitus. One of these also suffered from epileptic fits which she assumed were the cause of her severe headaches. The changes in the breasts of the four respondents were discovered during follow-up care for the above chronic diseases. None of them had accepted the fact that they suffered from cancer in addition to the other chronic diseases. They were tearful throughout the interview, they paused and heaved repeatedly taking deep breaths before talking to the researcher. One reported that she assumed that "the lump was

a result of a scar inflicted on the back of her right shoulder by her husband who beat her on the scapula with an iron rod during a family fight." Another ascribed the blood-stained fluid oozing from her nipple to an old wound inflicted twenty years ago by a minister of religion (a priest) who flogged the congregation during a jumble sale at church. The respondent was affected when the priest's whip (sjambok) missed one member and landed on her back. She believed that the accumulated blood over the years was finding its way out of the body via the nipple. However, she reported the abnormality to the doctors at the clinic who referred her to Bloemfontein hospital for biopsy of the breast and subsequently a mastectomy.

The average period of delay prior to reporting changes in the breast in this study was eighteen months, with the longest period being three years for one respondent. The reasons forwarded for the delay in each case were:

- "The lump was not painful."
- "It did not worry me."
- "I did not know that the lump had to be reported to medical professionals."

These findings concur with those of Walker et al (1984:24), Winters et al (1988:69) and Hacking et al (1988:57), who all reported that Black patients in South Africa present for the first time with advanced disease of the breast compared to their White counterparts. This is probably one of the reasons why the treatment of choice is, in most cases, radical mastectomy with chemo- and radiotherapy, a fact which may militate against immediate reconstruction surgery following the mastectomy.

In conclusion, according to Roy (1980) in Riehl-Sisca (1988:117), the regulator subsystem is related to the physiological mode which responds to changes in the body cells. The breast lump may thus be a response to the neural-chemical-endocrine processes which may be responsible for the malignant changes in the breast.

4.4.2 Meaning of the Diagnosis Cancer of the Breast (Focal Stimulus)

All the sixteen respondents reported that when the diagnosis was confirmed they assumed they were going to die. This was expressed in different ways such as "when my doctor told me the lump was cancerous I concluded I was going to die and leave my dependant children. I cried from that moment until I reached home. I cried even more when I got home. I telephoned all my relatives and told them that I had cancer. I locked myself in my room and cried incessantly for two days. I did not want to be spoken to nor have anything to eat." The respondent heaved and became tearful. She was given a tissue to wipe her tears and water to drink by the oncology nurse who accompanied the researcher. The diagnosis cancer seemed to convey a message of premature death for most of the respondents in this study.

Another respondent said "When the doctor touched my right breast whose nipple had pulled in already, he told me that he was almost 100% sure that I had cancer of the breast. The first thing that came to my mind was my 2 year old son and I knew that I would never see him grow up. I cried bitterly and was

given tissues by the nurse. I was terrified and knew I was going to die." Indeed, this respondent died ten months after the interview.

The third respondent was a cashier at a large supermarket. She was tall and had a big bosom. She discovered the lump whilst dressing up preparing to go to work. She reported "I was very scared. I called my husband to feel the lump. He called the lump a 'knoppie' and urged me to go to the doctor instead of to work. I was cold from fear because my mother had died from cancer of the breast six years ago. I saw the doctor who, without any explanation, just sent me to Ga-Rankuwa hospital. He gave me a sealed letter. At Ga-Rankuwa hospital I saw many breast cancer patients. I cried for the whole day, I did not eat, I only drank water."

Another respondent who delayed for 9 months before reporting changes in her one breast said, "I was afraid I will be told it is cancer. By the time I went to see the doctor the affected breast was hard, red and painful. I lied and said my problem started 3 weeks ago. I was afraid, that is why I lied. The doctor called my husband and, in my presence, told him that I had a fast-growing cancer which had already gone through my body and that there was nothing he could do. I interrupted him by asking whether I was going to die and he told me that 'cutting through that breast will create big trouble'." This respondent recounted how she cried all the way back to her home town.

Another respondent said, "I was referred to Ga-Rankuwa hospital after I felt a lump on my right breast. Many doctors saw me the following day. One old one

told me 'Ma, your breast must be removed, this little lump is cancer'. I burst into tears, questioning how my beautiful breast could be removed. Jo! I got such a shock, I could not understand why my whole breast must be removed because of a little lump (*konopiniana*). My children, who had accompanied me to the hospital, also cried."

These are just a few examples of respondents' responses to the diagnosis cancer of the breast.

Roy's adaptation theory is relevant for the above theme - meaning of the diagnosis cancer of the breast. When respondents were notified that indeed they suffered from cancer, this information acted as both internal and external stimuli which impinged on the patient, triggered fear, shock and confusion. A state of disequilibrium was reported by all respondents. They all reported to have thought of premature death. According to Roy's adaptation model, the regulator and cognator subsystems of the respondents came into the picture on hearing the bad news. The regulator subsystem, being related to physiologic responses such as dryness of the mouth, sweating and a sensation of feeling cold, was the immediate response to the confirmation of the diagnosis. One respondent put it aptly when she reported that "I experienced June, July when I was told the lump was cancer" (in short, she was terrified). According to George (1995:252), the cognator subsystem is related to the adaptive mode in this event, it triggered the tearful response, loss of appetite and actual crying in most respondents. This response, though negative, assisted with the adaptation

process, acceptance and coming to terms with reality. The diagnosis alone was 'shocking'; however, to have been told to consider a mastectomy, amputation and loss of a breast, acted as another stimulus which was transformed into conscious perception and additional fear of what people would think of a one-breasted woman. Married respondents reported that the thought of the spouse made them withdraw and feel ashamed. One respondent reported that she did not want her family nor neighbours to know about the mastectomy. The mere mention of the breast operation (removal) filled her with shame. The response from one husband of a mastectomised woman who said "I do not want a woman with cancer and, above all, one with one breast", made the patient tearful throughout the interview. Although the nurses tried to counsel this patient to accept the diagnosis and treatment, the husband's reaction counteracted the attempt and prevented positive adjustment. Roy and Andrews (1991:258) maintain that the goal of nursing is to encourage and promote positive adaptive responses that will positively influence health. In breast cancer patients, this is not only achieved through nursing, but also the support from next of kin, friends, family and health professionals can bring about positive adaptation.

4.4.3 Cancer of the Breast as a Stressor

4.4.3.1 Emotional Distress

According to O'Connor et al (1990:167), the period following the diagnosis of cancer turns out to be the time when life and death predominates, it is a crisis period which emphasizes the patient's mortality and becomes a period of despair which is manifested in the following different ways:

The patient goes through a stressful period and a series of crises that affect her entire well-being, there may be feelings of depression, resentment, fear, guilt and powerlessness. This is evident from the following account by some of the respondents.

"When Professor told me it was cancer and that sixteen glands were removed because they were infected with cancer, I felt as if all the tall buildings around the hospital could fall on me and bury me alive, I was so depressed that a thick 'lump' in my throat prevented me from speaking. Immediately a psychiatrist was called to come and talk to me. Thereafter I was given anti-depressants for six months. I thought of death all the way through."

Another respondent said, "After I was told I had cancer, I responded by saying, why me?, nobody in my family and in the whole district suffered from this disease, I am the first one. Colleagues at work will shun me, and my neighbours are going to be afraid of me, I am going to be isolated, my colleagues and neighbours are going to be nauseated by my presence (*Ka kopana tlhogo*

katlhaka tlhakana). I cried bitterly, got confused, continued to cry until I was tired. The nurses left me to cry it out, and said. 'now that you have cried satisfactorily, decide what you want to do.' I did not know whether I was coming or going."

Newman (1982:135) reported that the environment of a newly diagnosed cancer patient consists of "a compilation of stress factors made up of tension producing stimuli that have the potential to cause disequilibrium." He maintains that these stressors are identified as intrapersonal especially where fear of a re-occurrence of the disease reigns supreme (Newman, 1982:135).

All the respondents in this study except two seemed to reminisce the trauma they went through as they shared their experiences with the researcher. They all cried all over again, wiped tears and blew their noses incessantly. They made long pauses, and heaved heavily as they related their experiences. This behaviour was noted in fourteen respondents whose average age was 44 years with dependant children and unstable marriages, some reporting actual physical assault by the spouse throughout their married life. The two who did not cry were elderly women who depicted a stoic acceptance of the diagnosis. Both reported that they were widows, and the other reported to have had seven children who were all dead and the only daughter-in-law left, walked out on her. The behaviour of the two respondents is confirmed by Morris et al (1977:2390) when they reported that "some patients with cancer of the breast may respond to the diagnosis with stoic acceptance, carry on with normal life without

excessive concern about the illness." However, psychologists may term this a sign of denial. Sinsheimer and Holland (1987:76) reported that the age at which breast cancer occurs alters the emotional effect it will have on different women. The younger the woman, the more distressful the diagnosis. Older women who have reached menopause react with less distress especially when the diagnosis is made when other losses such as the death of the spouse or children have occurred in the past (Sinsheimer and Holland, 1987:78).

Abrahms (1969:881) regards cancer as 'unclean' when he reported that cancer sufferers are repugnant with a singular ability to "evoke physical aversion and disgust in others." This image of contamination was reported by one respondent who thought, "People are going to dread and fear me, they are going to feel a certain revulsion towards me (nauseated by me); as a result I can't share a room when we go to church conferences." (*Batho ba ele gontsaba, ba nyonye, a ke santse ke tla robala le batho ko dikonferenseng tsa Kereke?**) It is common practice among Black women to share rooms at gatherings such as weddings, funerals or conferences. It is quite acceptable for a group of women to sleep together on the floor; in this way communal life is shared and support given. The above respondent feared that she would be deprived of all communal life and that she might become an outcast and isolated, because she would feel shy to expose her amputation scar to strangers.

Thirteen husbands of mastectomised women were interviewed using a structured interview schedule (see third sample). Those husbands who were at

* People are going to be afraid of me and will feel revulsion towards me.

home when the researcher visited some respondents reported to feel sorry for their wives. One said, "When the doctor said my wife had cancer I felt she is going to die and my children will not have a mother. I was very worried." Another husband said, "I could do nothing to change reality. But I could do all I can to make my wife comfortable and happy. I bought her a BMW car and a van to start a small business of her own."

Some mothers of the respondents of the second sample were more worried than their daughters. One mother urged her daughter to consult a doctor immediately after discovering the lump, and when cancer was confirmed she cried more than the patient because she felt sorry for her. Friends and colleagues of the respondents were not interviewed since the researcher promised confidentiality and never to divulge what the respondents said. May be this area requires further exploration.

The diagnosis cancer of the breast also led to social distress as expressed by one respondent who said, "I hate the word cancer, I fear it and above all the very mention of the word by you health professionals nauseates me." The respondent frowned and twisted her face and lips displaying her disgust at the mention of the word cancer. This same respondent reported that "she did not want her relatives to know of the diagnosis and the mastectomy." On further enquiry she expressed her belief that cancer was infectious. This had caused her deep anxiety, hence the fear of "how other people would react if they learned that she suffered from cancer of the breast."

Another dimension causing emotional distress was the deaths of fellow patients who suffered from the same disease. Respondents were usually informed by relatives who had found their addresses and telephone numbers which were exchanged during follow-up care. It was reported that this caused severe depression and an increased fear of the recurrence of the disease. One respondent covered her eyes with both hands and sobbed as she related her utter distress at the fact that she suffered from cancer.

TABLE 2

**Emotional Distress
(n = 16)**

THEME	NUMBER OF RESPONDENTS
1. The diagnosis paralysed me with fear.	6
2. It was a shock.	7
3. I developed a lump in my throat, I could not talk for a day.	2
4. I cried for two days and refused meals.	1

4.4.3.2 Social Distress

All sixteen respondents experienced social distress in one way or another following the confirmation of the diagnosis and that a mastectomy was the only treatment of choice under the circumstances. One respondent had assumed that "neighbours and friends are going to look upon me in the same way they would view a patient with leprosy. My colleagues at work will be afraid of me and will avoid associating with me."

Wortman and Dunkel-Schetter (1979:124), in their study of mastectomised women in Holland, found that communication with relatives and friends of these patients was superficial and that the mastectomy was kept a deep secret. They reason that this may be a result of deep-seated fear and uncertainty about the outcome of the disease cancer and the surgery.

In this study, some respondents feared that cancer was contagious (could be passed on from one person to the other by direct contact). Some viewed the disease with revulsion. George (1995:258) maintains that although the cognator and regulator subsystems are essential to the adaptive response, these subsystems are not directly observable. Only the responses to the stimuli are observable. In some respondents pain was reported as an ineffective response to infiltration of the body by the tumour or as a result of the effects of radiotherapy which left the skin irritated and raw by superficial burns from the high-energy ionizing radiation. Infiltration of the body by the tumour stimulated pain receptors that transmitted the message along afferent nerve fibres to the central nervous system. This triggered an increase in the heart beat which is a response to pain from the regulator subsystem. In response the cognator subsystem, from past experience, alerts the patient to increase the morphine taken for pain. According to George (1995:256) the patient's action represents the cognator processes of selective action to reduce pain. Pain reduction is an adaptive process to the discomfort caused by the painful stimuli.

Another respondent tearfully reported her social distress when she stated that "after the diagnosis was confirmed and I had a mastectomy, my husband walked

out on me for a younger woman. I knew he was going to do it because he was difficult. He never visited me in hospital, only my children did. After I was discharged from hospital, he came to tell me he did not want a wife who had cancer and no breasts." The respondent's depression was evident through long pauses and deep breaths and heaving. Unfortunately, she had secondary growths on the affected breast and the idea that she had to receive more radiation therapy depressed her even more.

Another respondent was distressed because she believed that the cancer was caused by her stressful life as a regularly battered wife. She reported tearfully that every weekend her husband assaulted her in the presence of their children. These beatings only ceased a year prior to the interview, when her husband was diagnosed with diabetes mellitus. This respondent's distress was intensified by the discolouration of her nails and mucous membranes which were a direct result of the chemotherapy. Her depression was further compounded by other side effects of chemotherapy, i.e. continuous vomiting.

Some respondents were depressed by the radiation therapy which resulted in skin irritation and discomfort; they were upset that they could not take a bath and immerse the radiated area into water.

Fourteen respondents (87.5%) expressed concern about their dependent children. One reported that her youngest child was a first year student at the university, and that her husband had died two years ago. In a very emotional

state, she expressed her worry for this child's future because of the uncertainty of the prognosis of her disease.

All the above respondents were unemployed; some had lost their jobs because of ill-health. One respondent, a nurse, reported that she also was divorced by her husband prior to the diagnosis.

Fourteen respondents reported problems with transport whenever they had to travel for follow-up care because ambulances were rarely available. Six respondents related their difficulties when travelling by car following chemotherapy, which caused nausea and vomiting. They felt that the problem would have been alleviated if they had been allowed to stay at the hospital overnight.

Lack of a reliable financial resource was a major concern among fourteen (87.5%) of the respondents. They reported that they received a pension which was insufficient to meet all their needs. As a result, they were dependent on their children. They came from very poor social backgrounds - even the appearance of their homes revealed poverty (see Appendix C).

TABLE 3

**Social Distress Caused by Lack of Finance
(n = 16)**

THEME	NUMBER OF RESPONDENTS
1. Insufficient funds to travel for follow-up care	12
2. Unemployed, dependent on children	14
3. No funds to educate dependent children	2

4.4.3.3 Physical Distress

Cancer of the breast is a disease and one cannot exclude physical pain; and it was experienced by most respondents. Some reported that the disease was not painful during the early stages. However, in two respondents the disease manifested itself initially by red discolouration of the affected breast, inflammation and excruciating pain which forced them to consult a physician within a week of the onset of pain. The affected breast changed from soft tissue to a "hard pear-like appearance". One respondent reported that she would get up at night because of the pain and rub the breast with petroleum jelly (Vaseline), and apply ice-cubes to cool the pain and heat. At this stage, the pain was unbearable. She reported that the physical distress which was accompanied by fear of cancer was agonizing. When this respondent presented at the hospital and a biopsy was performed, a 'white' offensive discharge was aspirated which also caused her emotional pain. Two weeks later, the results of the biopsy confirmed a "rapid growing tumour" which necessitated immediate mastectomy. She stated, "I felt so bad that I wished I could go right through

the floor and be buried alive." Throughout the interview, the respondent was tearful; she had lost hope of recovering.

This respondent also reported to have been traumatized by the attitude of her physician who bluntly told her that there was little he could do except "to have a mastectomy performed". The respondent did not understand the terminology used by the physician. She was terrified and in extreme pain. The word "mastectomy" was explained by a relative a day later and the patient was 'shattered'. She responded by crying for the whole day and slept very little that night. Her distress was revealed by phrases such as "I could not believe that my dear breast had to be chopped off and thrown away." However, the thought of her minor child and the unbearable pain made her agree to have the operation.

Other respondents reported physical pain post mastectomy, but the accompanying emotional uncertainty about the outcome of the disease was reported to have caused even more pain.

The chemotherapy was reported to have added another dimension to the agony. Thirteen (81.25%) of the respondents complained of nausea and vomiting after receiving chemotherapy and drastic loss of hair. One respondent reported that after the second chemotherapy her hair was falling out in big clumps until she became completely bald. "I could not bear to see my beautiful hair in my hand, on the comb and on my child's hands", she cried.

Another respondent summarised her experiences with chemotherapy as "the total loss of my hair and the thought of facing friends wearing a turban made me more tearful than the diagnosis cancer."

Skin irritation following radiation therapy was reported by some respondents to have caused them physical distress especially if the radiation immediately followed the mastectomy and chemotherapy.

TABLE 4

Physical Distress
(n = 16)

THEME	NUMBER OF RESPONDENTS
1. Pain caused by the mastectomy (surgery)	16
2. Pain on affected breast prior to the surgery	2
3. Pain following radiotherapy, burns and skin irritation	14
4. Pain as a result of chemotherapy (nausea and vomiting)	12

4.4.3.4 Financial Distress

Fourteen (87.5%) respondents reported financial difficulties because they were not gainfully employed. Some reported problems in securing transport to go for follow-up care such as chemotherapy and to fetch their medication from the hospital.

The research area is about 300 kilometres from each of the referral hospitals at which cancer patients are treated. Depending on the stage of advancement of the tumour, respondents were expected to report for follow-up care, which was either chemo- or radiotherapy or a general check-up, at three-monthly or half-yearly intervals.

Respondents reported that they had to hire private transport to the nearest regional hospital, sleep over and be transported by ambulance to the referral hospital. Private transport was reported to be costly and as such out of reach. Patients paid a flat rate of twenty-six Rand each time admission into hospital was necessary. Although these charges appear to be minimal, they are high for chronically ill patients who are unemployed; these costs placed a heavy financial burden on them and their families.

One respondent who did not belong to a medical aid scheme reported to have paid five thousand Rand (R 5,000) for the surgery (mastectomy) because her husband's income placed her in a private patient income bracket. She paid exorbitantly for all her treatment and stated that all of the family's savings have been depleted by medical bills. She did not know where "the next meal would come from".

What compounded the financial problem was the inability of respondents to join medical aid schemes; as cancer sufferers they presented a financial risk and they were not admitted. The researcher had similar experiences with three different medical aid schemes. Each time a claim for treatment was submitted, it was

turned down with comments such as "This medical aid scheme does not cater for cancer sufferers. All treatment relating to cancer is the client's own responsibility." Thus, a heavy financial burden was placed on families of cancer patients in the area where the research was undertaken.

One respondent, whose husband was unemployed, reported to have repeatedly borrowed money from the coffers of her church to go for chemotherapy and hospitalisation. This financial crisis made the patient "more sick than the cancer itself". Three months later it was discovered that she had metastasis into the spine; she died within three months.

Another respondent reported financial problems compounded by the ordeal of having to travel in an ambulance for 300 kilometres because she was terrified by closed spaces and fast moving cars. She dreaded the times of her medical check-ups and eventually decided to travel by car with her son-in-law. This created a new problem of being a burden on her children which also affected her adversely.

Other respondents experienced financial crises because of school fees for dependent children, there was not even money to pay rentals and to buy food in certain instances. One respondent reported that she was dismissed from work after confirmation of the diagnosis cancer.

TABLE 5

**Financial Distress
(n = 16)**

THEME	NUMBER OF RESPONDENTS
1. Refusal of medical aid schemes to cover patients because of the diagnosis (cancer of the breast)	8
2. Inability to pay school fees for dependent children	6
3. Inability to secure transport to go for follow-up care	8
4. Inability to raise money for rentals, food, hospital bills and telephone accounts	4

According to Wortman and Dunkel-Schetter (1979:140), families of cancer sufferers become frustrated when efforts to help the patient seem to have little effect on the course of the disease. It becomes worse if there is already strain caused by financial difficulties which add an extra burden on the family. The majority of the respondents in this study had no source of financial assistance except their pension money and help from their children who had their own financial problems. It is, therefore, self explanatory that, no matter how supportive the family of the cancer patient may be, if the patient's state of health does not show an improvement, patience tends to run out. This can lead to outbursts in the interaction with the cancer patient which may result in remorse and feelings of guilt for both the patient and family members, leaving the cancer patient feeling hurt and rejected. This can lead to self-revulsion and a negative self concept culminating in distress (Wortman and Dunkel-Schetter, 1979:140).

Application of Roy's Adaptation Model

In Chapter 2, Roy's adaptation model was discussed, in this chapter application of the above-named model will be made after the researcher identified the different stressors experienced by respondents following the diagnosis and treatment of cancer of the breast.

Firstly, cancer of the breast as an incurable, unpredictable disease was reported by all 16 respondents to have terrified them to a point where they thought of immediate, premature death. The mastectomy as treatment to this life threatening disease added another dimension to the existing anxiety created by the diagnosis. It was not surprising that 14 respondents (87.5%) of the second sample reported to have thought of death when they were told they suffered from cancer. They responded by crying and were still tearful six months or even more after the mastectomy. During the interview, as the respondents related their experiences from the time the cancer was confirmed to the time of the interview, none reported positive experiences, except for the treatment they received from the nurses at some of the referral hospitals who were reported to have been kind, sympathetic and understanding.

The diagnosis was reported to have been equated with early death, thus making it a focal stimulus according to Roy in Riehl-Sisca (1988:327). The mastectomy was seen as mutilation and loss of a body part which was looked upon as part of the woman's femininity. The chemo-and radiotherapy was reported by those patients who received it as causing more pain than the disease cancer. The loss

of hair, the vomiting, the diarrhoea, the loss of weight and irritation of the skin over the area where the breast was removed, all seemed to cause psychological, social and physical pain. For the few respondents whose husbands were reported to have failed to give their mastectomised wives the required support, the trauma was reported by some of the respondents to have been beyond measure. This was revealed by tearfulness throughout the interview. The respondents, although having had confidence in the nurses and doctors, seemed all to have lost hope, especially those whose condition showed no improvement but revealed metastasis during subsequent visits to the referral hospital.

Roy's adaptation model which was selected for this study, postulates that "nursing's goal is to promote adaptation or positive response to internal and external stimuli which impinge upon the patient" (Riehl-Sisca, 1988:117). The nurse, according to Roy's model, is expected to intervene to assist mastectomised patients with all the above named problems to cope effectively.

The health professionals, also according to this model, have to help the mastectomised patients to grow and master their problems created by the diagnosis and its treatment.

In this study, although the nurses tried to help the patients to adapt positively to their plight, the stimuli both internally and externally were found to be too numerous to enable the patient to adapt positively. To use Roy's terminology, the stimuli were "outside the adaptation zone" (Fitzpatrick and Whall, 1983:168). It seemed difficult to accept and learn to live with a life-threatening

disease, which resulted in such severe financial problems that basic needs such as buying food for survival could no longer be met. Respondents with dependent children reported concern over these children such as inability to pay school and university fees. Some respondents reported lack of funds to go for follow-up care. Put together, all these problems make adaptation to cancer of the breast and its treatment seem impossible. The researcher found interviewing these respondents heart-rendering since most of them had sad stories to tell. The oncology nurses tried but each patient had many problems which made positive adaptation difficult (see Table 10).

However, with counselling from the nursing personnel, support from family and friends and fellow patients with the same diagnosis, 13 respondents in the second sample of this study reported to have accepted the diagnosis and have learned to "take life easy and rest more when they get tired". In some referral hospitals the doctors and nurses were "very nice", some patients reported, and "seeing many women with the same diagnosis" consoled some of the respondents. In this way, tolerance of the diagnosis and treatment was soon achieved. However, the researcher still feels that there is a need for expert counselling for every newly mastectomised patient. The services of a clinical psychologist in the referral hospitals seem to be part of the answer to this problem if augmented by counselling from fully trained oncology nurses who have acquired counselling skills during their preparation for the Diploma in Oncology Nursing. These two health professionals, complementing each other, should be able to counsel the cancer sufferer to successfully adapt to the disease and its treatment.

4.4.3.5 Information on Breast Cancer and its Treatment Received from Health Professionals and Other Sources (Cognator Information Processing)

In this study the information relating to the disease and its treatment should have been received from the patients' physician or the nurses who looked after the patient from the day of consultation to the day of the interview.

□ Information received from the Physician and Nurses as the First Health Professionals Consulted

When respondents discovered the lump in the breast, or blood oozing from the affected breast, the first help they sought was from a doctor or a nurse. Fourteen respondents (87.5%) reported that the lump was confirmed to be malignant (cancerous) by the physician and 2 (12.5%) by the nurses.

All respondents reported to have received the above news with shock followed by severe depression. They all thought they "were going to die soon" and reported to have "cried bitterly and felt devastated".

Prior to confirmation that indeed the abnormality was cancer, 10 (72.5%) of the respondents reported that after the physician had examined the breast, he merely wrote a referral letter to the referral hospital for that geographic area; and only told the patient that she needed to go to a bigger hospital for further management. One respondent went to Ga-Rankuwa hospital, assuming that she was going to be further examined. She had not been told explicitly that she had

cancer and that she was going to have a mastectomy. This she only learnt from the surgeons at the referral hospital. This respondent was depressed not only by the diagnosis, but by the fact that her local doctor had not told her the truth so that she could prepare herself mentally for surgery.

Another respondent was told by her doctor, after waiting for the results of the biopsy for six weeks, that she had cancer and that "she had six weeks to live". She further reported that she was told she was to undergo a 'mastectomy' but that her doctor did not explain the meaning of this word to her. Only the following day did she receive an explanation from her mother-in-law.

According to King in Fitzpatrick and Whall (1983:228) individuals have a right to participate in decisions that influence their life, their health and community services. By participating in decision making, the researcher believes that adaptation to the prevailing situation will be positive. However, if patients who are already terrified and anxious because of the diagnosis are transferred to a strange environment in a referral hospital with no family member accompanying them, and who are treated there shabbily instead of with sympathy, they might never adapt positively to the disease and its treatment.

Indeed, this respondent was very negative; she was tearful and blamed doctors and nurses and expressed her 'hatred' of nurses and doctors at one particular referral hospital. After listening to this patient, the researcher felt ashamed as a nurse; she began to understand why this particular patient did not accept her condition and displayed maladaptive behaviour.

Two respondents reported that they were transferred from the local hospital to Kimberley where they learnt for the first time that a mastectomy would be performed. This was explained by the surgeons who were going to operate the following day.

Only 2 (12.5%) respondents were given the relevant information by the physicians at the local hospital. One reported the physician as having said, "I am almost [100%] sure that this lump is cancerous; I am going to do a biopsy." He continued to explain the biopsy, danger of cancer and the mastectomy to her. This respondent came from a rural village; she was cheerful and knowledgeable about her condition and treatment during the interview.

Two respondents were told about the diagnosis by registered nurses who were assigned to work with cancer sufferers. Both respondents were satisfied with the manner in which they learnt of the diagnosis. One respondent was visited at home by the nurse who had driven to the village to break the news. The nurse informed her of the results of the biopsy and explained that she had to be transferred to Kimberley Hospital for removal of the affected breast. The nurse alleviated her fears by telling her of the many other patients she would meet there with the same diagnosis. This respondent was glad about the nurse's efforts to enlighten her prior to her treatment. During the interview with the researcher, she was cheerful and showed understanding even of the effects of her treatment. This gave the researcher the impression that information is vital for appropriate adaptation to the diagnosis cancer and its treatment.

The last respondent reported to have received "shabby" treatment from her physician. She admitted that she had waited for six months before she reported the changes in her breast. By the time she reported, the affected breast had changed in texture, it was painful and swollen. Her doctor was "very unkind", she said. He referred her to Kimberley Hospital, where the surgeon was also not very sympathetic. She merely looked at the affected breast and said, "what is going on here? How long have you experienced this problem?" The scared respondent tried to 'cover up' and replied "only for one month". The surgeon did not probe any further and informed the respondent that she had to undergo an operation. Neither did she explain the nature nor the reason for the operation, i.e. the biopsy. The respondent was discharged immediately after the biopsy without any explanation. Six weeks later, she was 'instructed' telephonically to report to the hospital, where she was told for the first time that she suffered from cancer, that it was fast growing, that metastasis had occurred and that nothing could be done for her. This respondent was tearful throughout the interview; she felt that she had been poorly treated by both the nurses and the doctors.

□ Information from Fellow Cancer Sufferers

All the 16 respondents (100%) reported to have learned more about the disease from fellow patients who had a similar diagnosis and treatment than from doctors and nurses. Some received encouragement from co-patients, like the one respondent who, after the diagnosis cancer had devastated her, was visited by a neighbour who had been a breast cancer survivor for ten years and who

gave her the courage she needed. This respondent even learnt about the discolouration of the nails and mucous membranes after chemotherapy from other patients.

Another respondent who was very positive reported that "the nurses only told me that "the injections make you vomit a lot, and later your hair is going to break and you will be bald." No other explanations were given.

Roy sees the promotion of adaptive responses which are positively going to influence health as the goal of nursing. These, according to George (1995:261) reduce ineffective responses and promote adaptive behaviour. Adaptation leads to a higher level of wellness. Those patients in this study who received chemotherapy and became bald because of this treatment reported incidents such as "My sister bought me many turbans in different colours and I wore these with different dresses, I was quite happy." One very pretty respondent became bald after chemo- and radiotherapy; she visited the hair salon and cut her hair completely and referred to herself as the "natural Yul Brynner". She appeared pretty with her bald head and accepted herself as such. Her self-concept and image was not negatively affected by her loss of hair.

Another respondent who was referred to a hospital in Pretoria reported that "although the sisters and doctors in this hospital were sympathetic, they had other patients to attend to. My deepest fears and needs were satisfied by fellow patients. We talked about our different experiences and this alone offered me comfort."

The researcher then concluded that there is a need for an organised support group of breast cancer patients in the area where the research was carried out, with similar objectives to those already operating in Europe and America. Such group could, if properly constituted, provide both physical and emotional support to breast cancer sufferers.

□ Information from Family Members

Mathabe (1993:4) discovered during her contacts with cancer patients that if a family member is diagnosed with cancer, the whole family becomes a 'patient' in need of attention. Depression and denial reverberates throughout the family environment, resulting in each family member offering different advice to the increasingly confused patient. One respondent reported that not only were the advices confusing, but also dangerous. She was told by family members "not to agree to have the breast removed, once 'Kwasi' is operated upon, it spreads like wildfire." On the other hand, she had been told by her surgeon that she had to go for radical mastectomy as soon as possible. These conflicting ideas subject the cancer sufferer to severe emotional stress. This becomes worse if the husband is against the surgery. The patient finds herself torn between her loyalty to her husband and medical science. However, if the majority of family members feel that she must listen to the doctors and nurses, treatment for the patient becomes easier because of the forthcoming support.

Two respondents reported that their sisters were nurses, who had urged them to consult a physician immediately after the discovery of the lump in the breast.

After surgery, the sisters assisted with post mastectomy exercises and emotional support.

One of the above-mentioned patients was cheerful during the interview and appeared to have accepted her condition. She was well dressed and well informed. Her sister urged her to take vitamin supplements and extra protein preparations such as Nutrishake. She had totally accepted her condition and handled the interview positively unlike other respondents who were tearful throughout the interview. This respondent reported no particular problems except the fact that she was dependent on her children for financial support. Otherwise, she accepted the disease which caused her no physical or emotional problems at the time of the interview.

Another respondent, who had delayed seeking medical help after the discovery of a growth in her breast, was urged by her mother to immediately consult a doctor to establish the cause of the swollen lymph node in her axilla. The respondent was not aware that this was already a sign of metastasis. The consulted physician vented his anger at the respondent for not having reported earlier. What is important here is the fact that only her mother succeeded to get her to consult a professional. On further questioning the respondent admitted that the reason for the delay in reporting was the underlying fear of cancer.

Family members have a vital role to play in terms of emotional support; however, if they do not consider their advice carefully, it can be detrimental for the patient's future. Such cases were reported by 3 respondents, where the

husbands had been against a mastectomy, but could not offer effective alternative treatment. One of these opposing husbands was a minister of the Dutch Reformed Church who offered 'prayer' to 'heal the cancer'. However, the respondent was adamant to have surgery. Her mother had died from breast cancer because her father had also been opposed to surgery at the time.

Most of the respondents reported that their spouses and children were encouraging them to have the affected breast removed, and to follow treatment as prescribed. One respondent underlined this by saying "my husband visited me in hospital and encouraged me to remove the cancerous breast because he did not want me to die prematurely."

The researcher discovered that knowledgeable families were guiding the patient to make the right decision. Respondents were misguided by ignorant family members in only a few cases.

□ Information from Other Members of the Health Care Team

Social workers, clinical psychologists, physiotherapists, ministers of religion and beauticians are regarded as other members of the health care team. These play an important role in the patients' adjustment to the disease and subsequent mastectomy.

□ Social Workers

All 16 respondents reported how, after the mastectomy, the social worker talked to them about making a prosthesis out of cotton wool or bird seed to replace the lost breast or where to obtain a proper prosthesis and a wig. They also listened to the respondents' concerns about the scar and the possible lopsided appearance. Furthermore, social workers provided meaningful help to patients who had young children in need of care by involving relatives until the mother was discharged from hospital.

□ Clinical Psychologists

None of the respondents reported to have been spoken to by a clinical psychologist; it appears that this important member of the multidisciplinary team did not exist in the cancer referral hospitals. One respondent, who reported to have suffered from post-operative depression, was treated by a psychiatrist, who concentrated only on the depression and failed to establish her other peripheral problems.

□ Physiotherapist

The physiotherapist also had a role to play in the recovery and adjustment of the mastectomised patient. Post-operatively, the affected arm tends to swell, become numb and the patient experiences disturbing tingling sensations. To prevent swelling of the arm, hand and arm exercises have to commence early.

It is the physiotherapist's duty to teach the patient how to do these exercises. During this contact with the physiotherapist, health education is given and certain personal problems can be addressed just by listening to the patient and referring her to the relevant member of the health team.

□ Minister of Religion

The mastectomised woman experiences severe depression due to the loss of a vital organ and the uncertainty about the outcome of the life-threatening disease. One respondent reported that on the day following the surgery, she was more tearful than the day the diagnosis was confirmed. The absence of the breast and the scar with stitches and clips terrified her and drove the point home that indeed she suffered from '*kwasi*'. She immediately called for her church elder to come and pray with her. Another respondent reported that during the worst period of her depression post-operatively, a white lady visiting the hospital presented her with a pamphlet with the inscription "I am standing and knocking at the door, please open". This extract from the Holy Bible gave this patient all the courage she required, she got up, washed the tears from her cheeks and felt better.

All respondents disclosed that prayer was their most important coping strategy. One stated that she "felt closer to her God" after the surgery. Hospital chaplains were reported to have played a significant role in the adjustment to the surgery and the fact that the respondent suffered from an incurable disease.

□ Beauticians

This member of the health team was unfortunately not available in all referral hospitals. However, where present, she played a significant role in helping mastectomised women build their self-esteem after the surgery. She encouraged the respondents to "make-up" their faces, comb and style their hair so that the depression does not show on their faces and appearance. The beautician encouraged patients to adopt a positive attitude, "having lost a breast is not the end of the world, you are still yourself". She also encouraged the use of a prosthesis. Many respondents reported to have gathered a great deal of courage to face life with an amputated breast just by talking to this member of the health team.

In conclusion, Roy in Riehl-Sisca (1988:117) maintains that it is the cognator subsystem that is responsible for information processing, learning, judgement and emotion. Therefore, in this study this subsystem is responsible for information processing which will assist with adaptation or maladaptation to information received on breast cancer and its treatment.

4.4.3.6 Treatment for Cancer of the Breast (Focal Stimuli)

Mastectomy as a Stressor

Taylor, Lichtman, Wood, Bluming, Dosik and Leibowitz (1985:2506) reported that the lopsided feeling following a mastectomy causes more concern than the loss of the breast itself. This was confirmed by several respondents who

narrated that the mastectomy on the one side forces them to stick to certain designs when they purchased dresses. For instance, the scar always showed when they wore dresses with low necklines. The younger respondents complained about the inability to wear evening dresses that expose the back and the top of the breast. The fact that dresses and blouses worn by mastectomised patients must always have bows to cover the uneven bosom caused some of the respondent life-long discomfort and stress. Big-bosomed respondents complained of continuous problems encountered when trying to obtain a well-fitting prosthesis. Similar problems were also experienced by less endowed patients who told of "the shifting of the prosthesis from its position, thus creating an embarrassment in public". One respondent expressed her distress by stating, "I did not want my colleagues to know that I had a mastectomy. I resorted to wearing baggy, loose-hanging dresses which appeared clumsy most of the time. I hated my appearance but I had no choice."

One respondent stated, "I hated the thought that I suffered from cancer but the idea of a mastectomy drove me crazy. I could not stand my beautiful breast to be amputated." She cried, wiped off tears, frowned and twisted her face and lips to express her disgust at the mastectomy.

Another respondent, 28 years old, reported how she could not imagine that her colleagues at work would accept the fact that she had her breast amputated. She was certain of becoming the laughing stock and that the colleagues would most probably wag their tongues for the first two weeks after her return from hospital.

Anxiety was expressed by a patient who dreaded to face her difficult husband after the mastectomy. The idea of showing herself with the scar made her feel down-graded and less feminine. Indeed, this respondent's marriage ended in a divorce two years after the operation.

Weisman (1979:187) reported that mastectomy creates problems far beyond those of the tumour itself. The patient has to adapt to the loss of a body part which may have been very important to her sense of femininity, self-esteem and attractiveness. A mastectomised woman may have to cope with a scar which constantly reminds her of the fatal disease each time she makes love, bathes or looks in a mirror. May (1981:292) put it aptly when she stated that "while mastectomised women appreciate the surgery as life-saving, this was muted by the actual loss of the breast because of the physical disfigurement accompanied by the psychological trauma."

All respondents (100%) reported experiencing constant pain on the affected upper arm or in the axilla. One respondent reported that her surgeon actually told her to "learn to live with the pain because it will always be present." Another respondent reported that the mastectomy has turned her into a 'scrap' because she feels so weak and frail.

Another young respondent expressed distress after the mastectomy by stating that since she was not married yet, and now her one breast had been removed, she has constant fears that her boyfriend may dump her for another young woman with both breasts. She repeatedly said each time she makes love with

her fiancé, the scar reminds her that she has only one breast. However, she consoled herself that, after all, when he met her, she had both her breasts. This respondent was also concerned about her fellow workers. She emphasized the fact that "she would hate to know that some of her colleagues at work were aware that she had only one breast." She referred to this as "*Sepiri sa me*", "my deep seated secret". On being questioned why she wanted the mastectomy to be kept a secret, she replied that "I did not want my co-workers to gossip about my amputated breast."

From 14 (87.5%) respondents forming the sample, it appeared that the mastectomy caused them severe stress. This is confirmed by Parker (1976:215) when he reported that "the loss of a body part is an abnormal event, therefore the reaction to this event should also be abnormal hence amputees suffer from lasting disablement which is in excess of the disablement attributable to the absence of the part itself. The loss is associated with a long-term adjustment related to grief and depression. The amputation is emotionally disturbing and is manifested by tearfulness, anger, insomnia and feelings of insecurity" (Parker, 1976:215).

The youngest respondent in the sample reported that she lost interest in sex all together. This was made worse by the pain on the affected armpit. She reported that each time her spouse touched her scar it reminded her that she is a cancer victim. This turned her off and she rejected her husband's advances.

The husband would try again the following evening, but when she took off her brassière and the prosthesis, she would be reminded again of her mastectomy. At the time of the interview she reported to be worried about the future of her marriage. This respondent died two months prior to the submission of this study for examination.

The registered nurse in the sample also reported to have lost all desire for sex after she had a mastectomy, chemotherapy and radiation. She complained of dryness vaginally resulting in dyspareunia (painful coitus). Her marriage also ended in a divorce two years after the surgery.

From the experiences related by the respondents it appeared that a mastectomy was associated with depression and thus became a stressor for the woman.

One of the two elderly respondents, who were both older than 65 years and widowed, reported that her distress was not caused by the disease or the surgery, but by her fear of the nurses. She expressed this fear like this: "I experienced shivering (*'June-July'*) when I was told I had to be admitted into Bloemfontein hospital." This means she was scared. She reiterated the fact by stating that the nurses are harsh towards patients and that they do not explain procedures clearly to patients. Moreover, some elderly patients are partially deaf and find it difficult to follow what the nurses are saying to them.

The other elderly respondent accepted the diagnosis and surgery with apparent stoicism. She reported to have lost all her seven children at age 21 and above and her only daughter-in-law walked out on her after the son was buried. This respondent was pre-occupied with her traumatic experiences and less bothered about the mastectomy and its treatment. She had no prosthesis, not even a self made one. She appeared to have been traumatized so much in the past, that the diagnosis and treatment of the cancer seemed minor in comparison.

Radiation

Four (25%) of the respondents reported to have been treated with radiation. This treatment entailed high-energy ionizing radiation that destroyed the cancer cells. It was local treatment since cancer cells destroyed only the anatomic area being treated. According to Baird, Donehowe, Stalsbrotten and Ades (1991:63), radiation causes the breakage of one or both strands of the desoxyribo nucleic acid (DNA) molecule inside the cells, thereby preventing their ability to grow and divide. This process then prevents multiplication and growth of the cancer cells. Surrounding tissue may be affected by this procedure. The four respondents who received radiation therapy reported to have experienced the following as a result of this treatment:

One respondent reported that the tumour found in her breast was eight by four centimetres (8x4 cm) in size. She had to be treated with both radiation and chemotherapy. Before she commenced radiation therapy a secondary growth

as big as a five cent coin was discovered on her scalp. She was immediately referred to Bloemfontein Hospital for radiation.

Her major concern was the long distance between her home and the hospital which was more than 500 kilometres. Her first visit to the radiotherapy department evoked a lot of anxiety and the 'big' machines frightened her even more. She reported that the radiographer spoke very little and that she was tearful throughout the procedure. The procedure itself was short and not painful, but she developed blisters and skin-changes three days later. Her whole back was covered with painful blisters and she wore loose, baggy clothing to avoid more pain caused by the moist feeling of her skin. Her white cell count decreased and her haemoglobin dropped to below 6 MM of Mercury. Her general condition changed and she became very weak; the respondent reported that she thought she was going to die. She received nine pints of blood and six pints of compact cells. Two more tumours were discovered on both her thighs for which she received more radiation. She reported to have become depressed to a point where a psychiatrist had to be called to counsel her. She was given anti-depressant drugs for six months. At the time of this report this respondent was in hospital with metastasis into the liver for which she was receiving more radiation and chemotherapy. This respondent was educated, she remembered her treatment and used technical terms when relating her experiences to the researcher.

The other three respondents had a mild reaction to the radiation, developing mild blisters which were soon cured after treatment. However, one respondent

reported that her taste buds were adversely affected leading to inability to taste food. She also experienced weight loss. Respondents who received radiation therapy tolerated the side-effects and could complete the treatment whereas chemotherapy was hated and feared by most respondents.

Chemotherapy

Chemotherapy or the use of chemical agents to destroy cancer cells is, according to Baird et al (1991:73) "the mainstay in the treatment of malignant tumours", especially if widespread or where metastasis has occurred. Radiotherapy and surgery is often supplemented with chemotherapy. In this study, six (37.5%) respondents received chemotherapy which they looked upon as a stressor. All respondents reported that their hair fell out in clumps and that they were bald within three weeks following the intravenously administered chemotherapy. This was accompanied by nausea and vomiting, herpes on the lips and their taste buds became insensitive.

Some respondents experienced discolouration of the nails and of the mucous membrane of the mouth and loss of energy accompanied by general body pains. One respondent reported that the chemotherapy made her so sick and listless that she felt it was more depressing than the disease itself. The loss of hair made respondents lose their self-esteem; as a result they shied away from other people. One reported to have locked herself up in her room each time visitors knocked on the door.

George (1995:260) maintains that Roy's self concept mode relates to the basic need for psychic integrity. Its application in the event of baldness as a result of chemotherapy will be on the psychological aspects of the patient which will include body image. Baldness following sessions of chemotherapy was found to cause both social and psychological maladaptation on the part of respondents in this study. After their hair fell off some neglected their appearance and no longer bothered to appear neat and tidy as most women do. The physical self was neglected. One respondent with metastasis into the spine used a red woollen turban on a hot summer day. This was pulled to cover her ears, too. Her general appearance was unattractive with dry lips without lipstick. Prior to the diagnosis, this lady was very elegant and vivacious. The researcher spoke to her about her appearance and self-esteem. She appeared despondent and having lost hope in life. After a long talk she promised to change her attitude towards the self. Indeed, the next time the researcher visited her she appeared beautiful, bright and full of hope.

Roy's model has strength when applied to the nursing process. Implementation of the nursing intervention often brings about alteration in stimuli and if these were negative, positive responses are usually the result. Thus, positive adaptation usually follows (George, 1995:276). In the above-mentioned case of baldness, the researcher was grateful to see the effects of her intervention and the patient was delighted when told that she looked beautiful.

One respondent expressed her depression by stating that "I cried so much after the mastectomy was performed, but I cried even more when I received the

chemotherapy which made me more sick than the disease itself." Another respondent reported to have vomited three days non-stop following chemotherapy. She lost weight and the smell of food made her vomit more.

The last respondent reported that the combination of chemotherapy and radium therapy as well as tomosifen which is oral chemotherapy dried her vaginal secretions resulting in dyspareunia. She was referred to a gynaecologist for further management. This was solved by a prescription for a vaginal lubricant which helped to eradicate the discomfort. From the respondents' reports, chemotherapy appeared to cause more stress for the patients than the mastectomy itself. It is therefore evident that treatment for breast cancer may generate focal stimuli which may precipitate adaptive or maladaptive behaviour on the part of the patient.

Alternative Medical Treatment

Traditional and folklore medicine is still used as an alternative to western medicine among Blacks in former Bophuthatswana. In a study conducted by Shai-Mahoko (1997:85) among the Batswana in the North West Province, it was found that ancestral worship, herbalists and traditional healers still played an important role in the health care of Black patients.

In this study some of the mastectomised respondents reported to have consulted and used this type of health care. One respondent who suffered from hypertension and epilepsy in addition to the cancer of the breast believed

strongly that she "had an invisible opening at the back of her skull." This resulted in her suffering from incessant headaches, which triggered the epileptic seizures. She reported to the researcher that she abandoned the Methodist Church in search of health and joined the Zion Christian Church (ZCC). There she was treated with sacred tea and had to wash in water containing aloe. She reported not to have consulted traditional healers because she believed they were not trustworthy.

Another respondent maintained that her maternal uncle died from an amputation of the leg, however, she was uncertain of the diagnosis. She only remembered the rumours that he was a victim of witchcraft. The respondent did not personally use traditional medicine because the nurses at Ga Rankuwa Hospital warned her against it.

Another respondent who had also joined the ZCC following the mastectomy and chemotherapy told of the church elders praying for her and treating her with sacred coffee. She was convinced that prayer helped her and she was feeling much better.

Three respondents reported to have used Lennon's drops. One stated that she mixed "rooi-laventel", "pink poeier" and "groen-amara" which, she claimed, gave her strength.

The last respondent reported to use raw garlic and vinegar; she claimed that this mixture gave her strength and made her sleep better during the night.

It was interesting to find that none of the respondents believed that the cancer was a result of witchcraft or sorcery. Some did not understand what cancer was all about, but none ascribed its occurrence to magic or supernatural powers.

4.4.3.7 Changes in Life-Style (Role Performance)

The American Cancer Society's professional education publication (1975:48) reported that the diagnosis cancer may "mean a threat to life, increased expenses, loss of work, changes in body functions and appearance and a shift in body roles." Fourteen respondents in the sample reported in different ways that they "thought they were going to die." One respondent said during the interview, "I know I am going to die prematurely, this is the end of life." She sobbed bitterly and had to be given water and tissue papers to wipe off tears. Another respondent reported that her mother had died from cancer of the breast and when the biopsy results confirmed that the lump in her breast was cancerous, she concluded that she was also going to die and follow her mother.

The 26 year old respondent reacted to the diagnosis by telephoning all her relatives to inform them that she had cancer and was going to die. The lingering fear of imminent death in cancer patients cannot be disputed. The thought that cancer is incurable accompanied by the fact that it can spread to other organs from its source makes it more fearful and unreliable. Harvey (1987:164) describes the disease aptly when he states that it is "traitorous" since it can invade the body and cause death. Because of the above-mentioned characteristics it is bound to bring about changes in the patient's life-style.

Only two respondents in this study were gainfully employed. The remaining fourteen were unemployed and reported to be dependent on their children for survival. One respondent depicted her change in life-style in the following words: "After I had received chemotherapy for the first time I became so ill that I had to terminate employment after three months. My husband had to pay all hospital bills, buy food for the family and pay university fees for two children. My family's life-style changed from living above the breadline to poverty. We had to do without a lot of the luxuries we had enjoyed in the past. This made me feel very inferior especially because I could not work to help my husband."

Another respondent said, "after the chemo- and radiotherapy I was so weak, I could not walk to the door to open it for my seven year old son when he came home from school. He had to get into the house by jumping in through the window. When he found no cooked food I could only tell him to take bread and water because that was the only food in the house."

One respondent told of becoming decrepit after the chemotherapy. She had constant back pains and could not bear sitting or standing as a teller all the time. This pain forced her to resign from her post. Moreover, the affected arm became painful and swollen. She was forced into life of complete dependence on her spouse. The life-style of the entire family had to change because they now all depended on one breadwinner.

Changes in life-style, it was reported, did not only revolve around income. These also included complications due to the need of travelling long distances

to report for follow-up care, visiting the referral hospital at three-monthly intervals for chemo- and radiotherapy, hospital admission, and waiting in long queues for admission or at the dispensary. All these procedures caused the already depressed breast cancer sufferers more depression especially, as one respondent aptly put it, because she was already "frail".

One elderly respondent said that she was forced by ill-health to vacate her own home to join her daughter-in-law because she no longer had the strength to maintain her own home. Her daughter-in-law had to house her to make sure she took her medication and reported for follow-up care. This change in life-style forced the respondent to lead a life of dependence which she felt was dehumanising. She further stated that she had enjoyed living on the farm in her own house because she had made a living by tilling the soil and planting vegetables for sale. Now, after the mastectomy and chemotherapy, this was no longer possible. She reported being depressed and experiencing low spirits (*moya waka o ko tlasika bo pelo bo*) which was evident to the researcher by her apathetic tone of voice.

The disease and its treatment, especially the chemotherapy, made most respondents in this study lose self-esteem, and this was expressed in several ways such as, "I am now a scrap and am dependent on my children", or "I have to accept that I am frail and I feel frail, I can only do the cooking in the home and most of the time I am tired and resting." The change in role performance as seen by Roy in Tomey (1989:328) is clearly portrayed by respondents in this study.

4.4.3.8 Changes in Sexual Life after Mastectomy and its Treatment

Three (18.75%) of the respondents reported no changes in their sexual life after the mastectomy. Six (37.5%) were widowed and would not discuss their sexual life. Two (12.5%) were divorced post mastectomy and only one of them was prepared to talk about the subject. One respondent was never married and was not keen to discuss her sexual life. Four (25%) experienced the following problems which will be discussed.

TABLE 6

Mastectomy and Sexual Life
(n = 16)

Number of Respondents	Changes Reported
1	Never married - no changes
2	Divorced
3	No sexual problems experienced
4	Experienced sexual problems
6	Widowed

According to a study conducted by Laurie et al (1984:620) in Columbia University, 55% of the respondents who had total mastectomy were concerned about their appearance, 32% expressed a feeling of diminished self-concept and femininity, and 38% reported a decreased desire for sex. In this sample, 4 respondents experienced problems relating to their sexual life following the mastectomy. One expressed it in the following manner: "I have no desire

whatsoever for sex with my husband." On being questioned why that is so, the respondent replied, "I have developed over the past three years dryness of the vaginal canal which makes sex painful and unpleasant." She stated that she last responded normally to her husband's advances about two and a half years ago. This particular respondent was 29 years old with a seven year old son. On being asked for the reason for her 'dryness' she explained that after the radium therapy which involved her spine the doctors had told her that her ovaries were going to be affected and that she may experience menopausal symptoms. Indeed, she experienced hot flushes, dryness of the skin accompanied by dyspareunia (painful coitus) and amenorrhoea (absence of menstruation). All these experiences put together made her feel like an old woman at age 29.

Another respondent who reported a shaky marriage long before the mastectomy, revealed, "After I had the one breast removed, my husband turned away each time after touching the scar, saying 'Ag, let us forget'. He then turned away and faced the opposite direction." This respondent was eventually divorced.

The third respondent also reported a rocky marriage before the cancer was discovered. When she was in hospital for the mastectomy, her husband had never visited her, only her children did. After chemotherapy and the return to her home, her husband told her that "it was not his intention to have a wife with cancer, one who did not even have both breasts." This respondent was also divorced post mastectomy; she was tearful throughout the interview.

The remaining respondent who reported to have had problems sexually was a registered nurse. She revealed that, although she still had the desire for sex after the mastectomy, her husband treated her with such coldness that she eventually developed a revulsion for his advances. She reported to hate sexual relations because these brought back memories of the cancer and mastectomy. Her husband's lack of sympathy and compassion made her generalise her hatred for all men. She reported to have no intimate male friend. "The HIV virus and AIDS have made me wild", she said, "moreover, I may get a friend who is going to exploit me only and never love me." This respondent did not receive any chemo- or radiotherapy and could still conceive. However, she stated that the use of contraceptives might increase her hormones which, in turn, might trigger the recurrence of the cancer. She had numerous fears revolving around cancer.

The rest of the respondents reported no sexual changes following the mastectomy. One reported that she even conceived "I got *'n laat lammetjie* who has become the favourite of the family. This child brought my husband even closer to me than before."

The findings of this study concur with those of Jameson et al (1978:543) when they stated that pre-surgical marital discord was a fore-runner of poor adjustment to the mastectomy. If the marriage was rocky, the mastectomy simply created a wider gap between husband and wife, whereas in a stable marriage the cancer and mastectomy bring the couple closer together and the husband becomes more supportive (Jameson, Wellisch & Pasnau, 1978:543).

4.4.3.9 Coping Mechanisms (Adaptive Modes and Ineffective Responses)

Anger

Baider & Kaplan (1984:265) reported that cancer is a disease which arouses myths, suspicion, fears and anger. Adjustment to this disease will therefore entail adjustment to a number of stressors. Its chronic nature creates ambiguity and anxiety which is often compounded by its unpredictable outcome and its treatment which is always emotionally disturbing. This disturbance, according to Baider & Kaplan (1984:265), is usually accompanied by tearfulness, anger, feelings of insecurity and sleeplessness.

Anger was revealed in 30% of the respondents by remarks such as "why me?" One respondent said, "I was angry with my creator (*Modimo*); I withdrew from public activities and experienced a feeling of despair since I knew life was over." She reported having lost all interest in life, that she was irritable and angry and that this impaired her ability to cope with daily chores. She locked herself up in her room and cried for three days. Then she decided, "I am prepared for whatever happens. If I die, it is okay. However, I pray for recovery for the sake of my two young children."

Fourteen of the respondents in this study reported having cried bitterly after the diagnosis was confirmed. On being questioned why they cried, several answers were given, such as "I knew I was going to die and leave my children" and "nobody in my family or village suffered from this disease, why me?"

One respondent was convinced that the blood oozing from the nipple was a result of a blow inflicted by the husband who used an iron rod during a family fight. This angered the respondent even more. Her anger towards her spouse becomes evident in her language and facial expressions. She repeatedly said, "he is also fixed, now that he also suffers from sugar diabetes. He has stopped assaulting me."

Some respondents directed the anger at their husbands who had ill-treated them for a long time prior to the diagnosis and surgery. One respondent asked whether there was a relationship between a stressful life and cancer. She apparently suffered throughout the twenty years of her marriage. She broke down and cried bitterly during the interview.

Another, unmarried respondent with two dependent children reported anger following the chemotherapy and total loss of her beautiful hair. This young woman attached a lot of value to beauty. The amputation of her breast followed by loss of hair and the lopsided feeling when she wore tight-fitting dresses made her 'sick'. What annoyed her even more was the brown discolouration of her nails and mucous membrane in her mouth. This respondent could not conceal her anger. Another kept saying, "I wish I could just take this cancer out of my system, the thought of it makes me sick." This was the type of anger experienced by some of the respondents in this study.

Depression

According to Kalat (1990:535) depression is a condition in which a person takes little pleasure in life and experiences feelings of worthlessness, powerlessness and guilt. Depressed individuals, according to Kalat (1990:535), experience difficulty in concentrating, a decline in sex life, they feel worthless, fearful and powerless to control what is happening to them. All 16 respondents in this study experienced the above symptoms and signs at one stage or another.

One respondent expressed depression when she stated that, "When my doctor told me that both my femoral bones showed metastasis in addition to the mastectomy I had, I felt cold, helpless and powerless."

Another respondent reported that the night prior to the mastectomy she cried so bitterly that she could not fall asleep, each time she tried to sleep her late mother came in a dream. After the surgery, when she saw the scar for the first time, she reported, "I cried all over again for my lost breast, I felt ashamed and guilty and assumed that God is punishing me for sins committed in the past."

Another respondent reported that when she received the news that she suffered from a fast growing tumour which had manifested itself in the spinal column already, she expressed her anger by snatching the referral note from the doctor who wrote it, tore it up in his presence and threw it into the waste paper bin. After this rage "I felt as if I could go through the floor and be buried alive." When relating this, the respondent sobbed for three minutes, could not talk and

appeared confused. She was consoled by the researcher and was left to rest for the day.

A 28 year old respondent reported that after the diagnosis was confirmed, she left the Out Patients Department of the hospital crying until she reached home. She continued to cry continuously for three days. "I had no appetite for food, I drank only water, slept little and just prayed night and day." After the mastectomy she felt better. However, when she received the first chemotherapy, "I vomited, experienced headache, the world appeared to be going around me, I never felt so bad in my life", she reported. "I felt hopeless and helpless, I became weaker and weaker every day. My doctor told me that I would be given 36 radium therapy sessions of three minutes each." When the respondent recalled this, she burst into tears. She was given the opportunity to compose herself and was ready to continue with the interview. She reported that, although her husband was very supportive, her sisters-in-law were adding more stress to her life. She reported that "one of my sisters-in-law communicates with my husband and ignores me as if I was not there. She had borrowed my wig and lost it .. I am still very upset and angry with her." This respondent was completely bald following the chemotherapy. She reported to have completely lost the desire for sex and was only concerned about her dependent son. She appeared unkempt and spent most of the time in bed. She communicated little with her family and believed that her in-laws talked about her to her husband. This respondent was very depressed, to her, life appeared too cruel, she said. In applying Roy's adaptation model to clients with so many problems (stimuli), one has to fall back on a multi-disciplinary team to try and

address the more urgent problems with the assistance of the patient and her family.

Despair

The Oxford dictionary (1996:108) defines despair as "complete loss of hope". The diagnosis cancer is a threat to life, but its cost in terms of money, loss of production, disrupted lives and human suffering is incalculable, say Burn & Meyrick (1977:1). The most important expenses are the loss of income on the part of the patient and cost of transport to referral hospitals and clinics. All these can result in a state of despair on the part of the cancer patient and the family. This desperation was revealed in the responses of the second sample interviewed for this study.

One desperate respondent said, "I experienced so much pain on my back, and when my doctor reported that the tumour had spread and I had to receive 15 radiotherapy sessions, I completely lost hope and wished for death." At the end of this sentence, the respondent took a deep breath, heaved and cried. Six months later after the radiotherapy, the respondent reported for follow-up care and the bone scan revealed further metastasis on the scalp which required further radiation. When the chemotherapist reported these findings to the respondent, she expressed despair and said, "I have lost all hope and I am shattered." The respondent continued "my hair had grown but now I had to receive radiation on my scalp again, I felt there is no hope but death only." As

the respondent related her experiences to the researcher, she placed both her clasped hands on her reclined bald head, cried, wiped off her tears and blew her nose incessantly. After ten minutes of silence the respondent was given water to drink and she continued and reported that her only hope at that time was the support she received from her husband, prayer and the will to live for the sake of her minor child who was seven years old.

However, not all respondents had despaired. Fourteen reported to have faith in their doctors and the treatment. One reported that her neighbour was diagnosed cancer of the breast and had a mastectomy ten years back. She took her courage from this cancer survivor. Those respondents who could read and write read about the disease and its treatment, followed instructions from the oncology nurses and doctors and were hopeful for the future. From the reports given by the respondents it seemed patients lose hope when the disease progresses rapidly and treatment has little effect. In those patients where the radio-and chemotherapy stops further growth of the tumour and the patient's general condition improves, adjustment is easy and patients easily come to terms with the disease and its treatment.

Acceptance

Thirteen respondents reported to have accepted the diagnosis and had adapted positively to the disease and its treatment. Although at the time the diagnosis was confirmed, the future seemed bleak, one respondent reported, that with

time, encouragement from health professionals, friends and family members, acceptance of the diagnosis and treatment became possible. Another respondent reported, "I have come to accept that I am a weakling. I take things easy, and rest more. I feel tired most of the time, but I rest when I experience this tiredness. I take food supplements sold by the Golden Neo-life Diamite (GNLD) company. This has given me hope for recovery. I feel better and stronger."

All 16 respondents were aware that they suffered from an incurable disease, all accepted the fact that after the mastectomy they will have to live with some kind of physical pain in the body for the rest of their lives. They had accepted that life could not be the same as before but would consist of continuous medical follow-up care, medication and less strenuous work. All 16 respondents had accepted that they suffered from cancer. Even those who sought alternative treatment such as eating raw garlic, Lennon's drops, sacred tea or coffee from the ZCC elders, simply augmented the radio- and chemotherapy received from the referral hospitals. All respondents viewed the cancer as a 'dangerous' disease.

None of the respondents used denial which, according to Kalat (1990:475) is the refusal to believe information that provokes anxiety. However, one respondent used denial when the diagnosis was revealed to her for the first time. She reported that after her doctor told her the bad news, she blurted out, "Me? Cancer of the Breast?!? I don't believe it!" She then burst into tears. This was,

however, the last time she denied that she had cancer. On the researcher's follow-up visit, this respondent stated, "I consider being a cancer patient a noble diagnosis, this has made me grow spiritually and ready for death at any time. I no longer fear death."

This patient had come to terms with the disease cancer. Her husband, a leader in the Dutch Reformed Church, believed strongly that through prayer the wife's condition would improve. This belief influenced the wife's health-seeking strategies. According to Bouwer, Dreyer, Herselman, Lock and Zeelie (1997:51) "Consultation and compliance with treatment depends largely on the individual's perception of his or her condition. This particular patient and her family delayed in seeking treatment because of their belief system. The husband actually verbalised it that "God will cure the cancer through prayer." Although the researcher tried to explain the consequences of non-compliance, the decision to go for follow-up care still remained with the patient and her family. This respondent died a month prior to the completion of this study.

Prayer

Prayer as a coping mechanism was reported to have been used by all respondents. They all belonged to different denominations but all professed to be Christians. One respondent reported to have been told by her physician that there was little that could save her life since the tumour had spread throughout

her body. She bravely faced life and reported that the cancer has brought her closer to her God, she prayed and appreciated the dawn of every day.

Another respondent reported that the only thing that kept her alive was prayer, the belief that God lives and will have mercy on her and her family.

One respondent, the wife of a church elder, said "I cried and prayed so much after the confirmation of the diagnosis that I felt the only thing to do now was to accept God's will."

A respondent from a rural area expressed her faith in the following words: "I am a strong believer in my creator, my faith in Him has helped me travel along this difficult path. Whatever happens to me will be His will. This cancer merely serves to remind me of His might." Although this respondent seemed very brave, she broke down and cried while relating her experiences and her coping strategies.

Two respondents reported to have left their original denomination for the Zion Christian Church (ZCC) after the mastectomy was performed. On being questioned why they took this move both expressed the belief that "they had hope that the ZCC elders would pray for them and their recovery from the cancer." Prayer, for all the respondents, seemed to play a vital role in the adaptation to the disease and its treatment. One respondent whose marriage

consisted of weekly beatings and assault, reported to have prayed for improvement in her family strife.

All 16 respondents expressed in different ways how their faith and prayer helped them to survive the cancer from day to day. They all voiced their appreciation for being alive and ascribed this to the Mercy of God. In this study, prayer was reported to be the greatest adaptation strategy. Even those patients who were dying appeared hopeful and requested sacrament and prayer from the clergy. This alone sustained them during the most difficult time.

Dependent Children

All but one respondent in this study had dependent children. They viewed their children as a source of strength and courage to go on with life. One respondent remarked that when the diagnosis was confirmed "the only thing I was worried about was my four year old son. I knew I was going to die and not see him grow." Another young respondent remarked that she was determined to live, "cancer or no cancer, I must recover and go back home to my children, they need me." The registered nurse in the sample said, "After the diagnosis was confirmed, I cried, thought of death, but at the thought of my two dependent children I consoled myself and felt I have these children to live for."

The one respondent whose husband walked out on her after the diagnosis was confirmed, proudly reported to the researcher that "my children have been so

supportive, they visited me in hospital, brought me all I needed. Moreover, one of my children is employed at Agrichicks, so we have more than enough chicken in the home." This respondent was very satisfied at the manner in which her children treated her. She seemed to care little for her estranged husband. All respondents were enthusiastic to have survived for the sake of their children.

One of the questions in the interview schedule for the first sample was: "What is your major concern now that you suffer from this disease?" This was answered by 52 (43.3%) of the respondents. They all mentioned their dependent children as their main concern. Burn & Meyrick (1977:58) confirmed this when they stated that "it is often the young children who show the signs of the family's distress as an outcome of the diagnosis cancer." The patient may appear to be meeting the illness with calmness, it is the children who may show a change in behaviour such as a return to thumb sucking or bed wetting. In this study, the respondents clearly reported that their children were a source of courage and one objective to want to live. One respondent aptly put it when she said, "My two children have become the reason why I should continue to live after this predicament."

A number of coping mechanisms were mentioned by respondents, some of which promoted adaptation to the disease and its treatment, whereas some were maladaptive, such as changing denominations (to the ZCC) with the hope that the elders would pray and a miracle cure for the cancer would occur.

4.4.3.10 Support Systems (Interdependence Mode and Interpersonal Relations)

According to Barkley (1980:49) family unity is the same throughout the world. This unity is compared with religious beliefs which sustain people in crises. In Russia, according to Barkley (1980:49) it is normal practice for a cancer patient to pour out his or her problems to friends in a way not practised anywhere in the world. Friends in this country will stop at nothing to assist one of their kind in the event of illness, especially an incurable disease such as cancer. This behaviour, according to Barkley, reduces the emotional impact cancer has, such as shame, despair, anxiety, depression, guilt and anger.

Maguire (1976:416) is of the opinion that the spouse of a mastectomised patient has a crucial role to play in assisting the patient to adapt emotionally to the cancer and its treatment. From this study it was found that respondents with supportive husbands accepted and lived positively with the cancer and its treatment, whereas those respondents with unconcerned husbands were tearful throughout the interview and had more physical complaints. Three respondents who were given support from their spouses were cheerful throughout the interview, although two had metastasis into the spine and appeared frail. At some stage the husbands wanted to be interviewed as well and one spouse said, "I know all about my wife's illness. I talk to the doctors and nurses and I allay all fears and misconceptions that she has."

One respondent, whose husband divorced her after the mastectomy, was the most difficult interviewee. She cried incessantly, stopped talking and heaved in

between sentences. Her problems were compounded by a visible secondary tumour over the scar which had to be radiated the following week.

Another respondent, 32 years old, reported to 'hate' men since her husband deserted her, she said "I will never trust men, they are wicked and unsympathetic." She preferred to remain celibate at her age rather than being traumatized by a spouse again.

Dawson (1990:22) reported that some women take a while to adjust to the breast scar after a mastectomy. Most are ashamed and afraid to let their partners see the scar. However, looking at the scar together post operatively whilst in hospital expedites adjustment. As far as other family members are concerned, the mastectomised woman is encouraged to express her feelings and fears openly. The more the woman talks about the cancer and its treatment, the more it helps to discover issues which doctors and nurses take for granted and overlook (Dawson, 1990:22).

In this study, 13 out of 16 respondents (81.25%) reported to have received the expected support from family and friends. This made the anxiety and fear easier to bear. Adjustment to the scar and lost breast was not reported as a major problem compared with the fear of the recurrence of the disease.

Health Professionals

These are physicians and nurses who are supposed to play a major role in helping the mastectomised patient adapt to the disease and surgery. In this

study, the researcher found that 2 of the respondents (12.5% were mismanaged by their family doctors. This number may appear insignificant to the reader, but not when one considers the fact that metastasis had already set in by the time the cancer was confirmed. Had the family doctors exercised the necessary precautions, the respondents and their families would have been saved the unnecessary agony and pain.

Both respondents discovered lumps in their breasts and reported these after two months when their size increased. In both cases, the doctors mistook the lumps for fibrosis (development of excessive fibrous tissue in the breast) and told the patients not to worry. By the time the respondents sought a second opinion, the tumour had grown and nearby lymph nodes were affected. Both respondents were fully aware that their family doctors were negligent, they reported this tearfully throughout the interview.

According to Bouwer, Dreyer, Herselman, Lock and Zeelie (1997:42) a patient who recovers after treatment by a particular practitioner will more often than not consult the same practitioner in future. Perhaps that is why people have family physicians. However, the converse is also true, a poor encounter with a doctor or nurse may influence a patient to consult someone else. Bouwer et al (1997:42) describe it aptly when they report that "western doctors cannot always arrive at a diagnosis immediately, but most wait for the results of diagnostic tests." In cancer of the breast doing a biopsy and waiting for the outcome of the procedure is almost routine with most patients. However, it is important that communication between the patient and the doctor is clear and

no information is misinterpreted. That waiting period for the results seems to be the most traumatic both for the patient and the family. It is during this period that some cancer patients shop around for alternative treatment. The likelihood of consulting a traditional practitioner increases. Hence, some patients disappear at this stage and only reappear when pain manifests itself, and usually at this stage the tumour has grown and has affected nearby organs.

One respondent who delayed to seek medical help reported rude treatment by surgeons and nurses in one referral hospital. She stated, "the doctor was absolutely rude and unfriendly towards me, the nurses were also very harsh." The respondent said that she would never visit that hospital again, even if she was dying.

The remaining 14 respondents (87.5%) reported to have received the necessary care from both doctors and nurses. The doctors in the local hospitals who referred the patients to referral hospitals were reported to be kind and caring although they did not tell the respondents the reasons for the transfer to another hospital. It was only when they arrived at the referral hospital that the registered nurses and the surgeon explained the condition and its treatment. The reasons why local doctors did not reveal the nature of the disease and probable treatment to cancer patients is an area that needs further exploration. The researcher felt it was beyond the scope of this study.

Two respondents were told by nurses that they suffered from cancer and that treatment had to be received either in Bloemfontein or Ga-Rankuwa. However,

none of the nurses mentioned mastectomy. This the respondents learned from the registered nurse at the referral hospitals.

The registered nurses were reported to have been supportive and willing to help with all problems encountered by the respondents. They tried to solve emotional, social and physical problems to the best of their ability. One respondent, who reacted very badly to the chemotherapy, told of the support received from the registered nurses, how they gave her courage and how they fed her sour porridge which helped her to gain strength.

The respondents appeared satisfied with the support received from health professionals especially at referral hospitals.

Support Groups with Similar Health Problems

The researcher discovered that in referral hospitals such as Ga-Rankuwa and Pelonomi in Bloemfontein, special wards were allocated for the care and treatment of cancer of the breast and mastectomised patients. Respondents in this study felt that this arrangement had good therapeutic value. Not only do newly admitted patients come into contact with other patients with a similar diagnosis and treatment, but at the end similar problems are discussed and solutions found. One respondent reported that she was shattered when the diagnosis was confirmed. When she was referred to Ga-Rankuwa hospital, she discovered that many women in the same ward had the same diagnosis and were cheerful as they shared their experiences and problems. This discovery

made her problem easier to bear. Another respondent from a rural area who had never heard of the disease cancer reported her experiences by saying, "I have never heard of this disease, why me? Even in my village nobody suffered from it. I am the first one." But when she arrived in Bloemfontein hospital, she was introduced to "many" patients with a similar diagnosis and treatment. "This comforted me", she said, "I exchanged telephone numbers and addresses with fellow patients, in this way I have managed to keep in touch with friends and keep track of their progress. The idea that I am not alone gives me courage and hope to want to live. The helpful hints received from fellow patients have made me handle personal problems which I was shy to share with health professionals."

The above response gave the researcher insight into the depth of the problems experienced by the respondents. She concluded that unless one has had a mastectomy as a result of cancer one may find it difficult to appreciate the seriousness of the problems experienced by this category of patient.

The Department of Health and Social Services of former Bophuthatswana introduced a concept of organised voluntary care groups (*Bale Kudi*). These were men and women who were appointed by the local community to render voluntary services for the sick in the community. They visited the sick, listened to their complaints and reported these to the clinic nurses. They also helped with domestic chores where necessary, they did the shopping for the chronically ill; they bathed them and made them comfortable. These groups were identified by special uniforms and were known to the local chief. In many instances it was

the Voluntary Care Group members who identified problems in the home and reported these to the clinic nurses for further management. Those respondents who came from rural villages mentioned how they missed the services of these groups which faltered after the reincorporation of Bophuthatswana into South Africa. Respondents spoke openly, without any reservations, during the interviews. Their personal and family problems were aired openly and this gave the researcher the impression that they needed someone to talk to, someone they trusted.

All 16 respondents expressed the view that there was a need for the formation of an organised and well constituted group of mastectomised women in the area where the research was undertaken. This group would extend its services to all cancer sufferers in the area and in this way most of the problems relating to transport, hospitalisation and home care would receive attention. Respondents reiterated that since 1994 when former Bophuthatswana ceased to exist, the Voluntary Care Groups were no longer recognised and ceased to function effectively. As a result, chronic patients discharged from hospitals had only their relatives to care for them, which was difficult in cases where such relatives pursued full-time jobs.

It is on the strength of this information that the researcher also felt the need for the formation of a support group for mastectomised women in the area where the research was done. This group would work hand in hand with the few cancer care nurses and would, jointly, come closer to solving the adaptation problems which these cancer patients experience.

In the following table the source and type of support reported by respondents is reflected.

TABLE 7
Type and Source of Support Received
(n = 16)

Type of Support Received	Number of Respondents	Source of Support	Number of Respondents
1. Financial Aid	16	1.1 Gainfully employed	3
		1.2 Dependent on husband for financial support	5
		1.3 Pension Money	4
		1.4 Dependent on adult children	2
		1.5 Dependent on close relatives - brother or sister	2
2. Health Care	16	2.1 Local clinic (nurses)	16
		2.2 Local hospital	16
		2.3 Family physician	16
		2.4 Referral hospital	16
		2.5 Doctors and nurses and other health professionals	16
		2.6 Zion Christian Church	2
3. Emotional Support	16	3.1 Family and friends	16
		3.2 Oncology nurses, especially at referral hospitals	16

From the table above it does seem cancer of the breast and subsequently mastectomy, radium and chemotherapy render the patient unable to continue with gainful employment. Only three respondents reported to be gainfully employed. One of these was a school teacher who was hypertensive and epileptic and planned to take early retirement because of ill-health.

The other two respondents were in their early thirties and reported to have received neither chemo- nor radiotherapy. They were gainfully employed and appeared fairly well adjusted physically to the mastectomy and its side effects.

The other 13 (81.25%) respondents were unemployed although only two had reached pensionable age. The rest reported to have experienced general tiredness and lack of strength to continue with gainful employment. One respondent who was 26 years old at the time of the interview reported that the continuous interruption caused by repeated chemo- and radiotherapy forced her to give up her job. Another, 43-year old, respondent stated, "I cannot continue working at the till at the supermarket, the work is too strenuous, moreover, my back and hip are painful all the time." The researcher got the impression that all the respondents who received radio- and chemotherapy became invalid after some time. This area requires further investigation to establish whether it is this treatment or the metastasis that makes the cancer patient so weak and complaining of lack of energy and listlessness all the time.

One respondent reported that her employer dismissed her immediately when he received the medical report after the mastectomy. Because of the diagnosis cancer it was difficult for her to secure another job; hence at the time of the interview she was still unemployed and was dependent on her children.

As far as health care was concerned, all 16 respondents were satisfied with the type of medical care received especially at the referral hospitals, both physicians and nurses were reported to have treated them satisfactorily.

The required emotional support came from friends and relatives as well as health professionals in the referral hospitals. The type of support received by the respondents in this study was, on the whole, satisfactory.

According to Tomey (1989:328), the interdependence mode in Roy's adaptation model involves "relations with significant others and support systems". In this way, one can maintain psychic integrity by meeting needs and affection that are so necessary if a patient suffers from an incurable disease.

In breast cancer and mastectomised women, social relations and support from significant others cannot be over-emphasized.

Findings of the Structured Interview Administered to Thirteen Husbands of Mastectomised Women

These findings are a result of the third stage of data collection which was obtained from some husbands of mastectomised women using a structured interview schedule. The purpose of this interview was to determine the effects of mastectomy on some of the husbands of mastectomised women in this study. It was unfortunate that only 13 husbands were willing to participate and answer questions on their wives' illness. Since the number of participants is so small, generalisation of findings to the population of Black men whose wives have had a mastectomy in former Bophuthatswana will not be made. However, the findings from the 13 male respondents will be discussed in the following pages.

Ten respondents reported to reside in the rural villages of the area of research and 3 came from the urban area. Of the 10 above, 9 reported to have obtained lower primary education (standard 5 and lower). The tenth village dweller was a university graduate. The remaining 3 were civil servants employed as clerks in the government service.

The average age of the respondents was 56 years. The researcher found that the educational standard of these respondents played a role in their understanding of their wives' disease and treatment. Those respondents who had a standard 10 certificate and more seemed to adjust much better to their wives' illness and gave them emotional support, thus helping them to adapt to their illness.

The remainder of the respondents who obtained only standard 5 and less were employed in the mines as labourers and could hardly read other languages with understanding. These did not know what cancer (*kwasi*) was all about and its treatment and complications was unknown to them. These respondents reported to have visited their wives only once during hospitalisation because they did not know whether cancer was infectious or not. Two respondents did not know that '*kwasi*' (the Setswana name for cancer) could be fatal if not treated early.

On being asked after confirmation of the diagnosis what their reaction was, 10 respondents reported to have been terrified (*ke ile ka tshoga thata*). Three said they remained neutral, because to them cancer was like all other diseases.

The respondents were asked whether they gave consent for the mastectomy. Twelve reported to have done so. The remaining respondent refused, but his wife went ahead with the mastectomy without his consent. This respondent reported not to care and did not bother to obtain more information about the disease and its treatment.

Respondents expressed their deep worry that their wives may become weaklings after the mastectomy and that their life-spans would be drastically shortened. All 13 reported that they feared the wife may die and leave the children orphaned.

It was interesting to find that only 1 respondent encouraged his wife to seek help from traditional and faith healers. The remaining 12 expressed mistrust in these healers (*Haba tshepagali*).

Respondents were requested to list major changes which occurred in their lives following their wife's mastectomy. The following were recorded:

TABLE 8
Changes in the Lives of Husbands After Wife's Mastectomy
(n = 13)

Response	No of Respondents
1. My wife and I became very close.	6
2. I became very close to my children.	4
3. I became more religious and prayed often for my wife's recovery.	9
4. I was determined to support her emotionally to the end.	5
5. I bought her a car (BMW) for her birthday to prove my love for her.	1

Respondents were asked what gave them hope since the wife's diagnosis was confirmed. Their answers were:

TABLE 9

Factors which Gave Husbands of Mastectomised Women Hope

(n = 13)

Response	No of Respondents
1. Prayer and faith in the Creator (Modimo)	10
2. Trust in the Doctors and Nurses	7
3. Wife's Courage	4
4. Medical Science and Technology	3

Respondents were also asked to list problems encountered ever since the wife had the mastectomy.

TABLE 10

Problems Encountered by Husbands of Mastectomised Women

(n = 13)

Response	No of Respondents
1. Inability to defray hospital costs.	7
2. Lack of sexual desire on the part of the wife (she is cold towards my sexual advances).	5
3. Pain and swelling of my wife's affected arm depressed me.	6
4. Oozing of unpleasant smelling fluid from the wound drove me away from her.	1
5. Her diarrhoea and vomiting after chemotherapy worried me.	5
6. My wife's mood swings and short temper drove me away from home.	2
7. Her loss of weight worried me most.	6

Irrespective of the above named problems, 12 respondents reported to have accepted and adjusted well to their wives' mastectomy. Only 1 respondent, the one who refused to give consent for the mastectomy, failed to adjust. Instead, he tried to encourage his wife to consult traditional and faith healers. His inability to accept the mastectomy may be ascribed to the fact that the wife defied his wishes and went ahead with the mastectomy without his consent. Ten respondents reported that they derived emotional support from friends, relatives, children, doctors and nurses.

Regarding explanations on the illness and treatment, 9 respondents reported to have received satisfactory and relevant information from nurses and doctors. One reported to have read about breast cancer and mastectomy. Only 2 respondents claimed to have been ignorant, they did not seek an explanation about their wife's illness. One of these went further by acknowledging that he did not know the difference between cancer and any other disease, whether cancer was contagious or fatal. The researcher was not surprised by these responses because the respondents, coming from rural areas, did not have access to health education via television or radio.

In conclusion, although this sample was small and the findings could not be generalised to the total population of spouses of mastectomised women, it succeeds to give one an impression about the effects of breast cancer and its treatment on the husbands of affected women.

CHAPTER 5

GUIDELINES FOR SUPPORTIVE ACTION BY HEALTH PROFESSIONALS TO FACILITATE ADAPTATION TO BREAST CANCER AND MASTECTOMY

5.1 INTRODUCTION

In the previous chapter the results of this study were discussed and compared, where possible, with the relevant literature. In this chapter, guidelines for oncology nurses to assist mastectomised patients to adjust to the disease and its treatment will be formulated.

5.2 SUGGESTED GUIDELINES FOR ONCOLOGY NURSES

In the area of study, only two qualified oncology registered nurses were available and practising oncology nursing. These were professional nurses holding a Diploma certificate in cancer nursing. Although all local hospitals and clinics admitted and treated cancer patients, none of the nursing personnel had received training in the care of cancer patients. Normally, a professional nurse was assigned to the Oncology Out-Patient Department of each health facility. Her duty was, amongst others,

- to check whether the treatment prescribed at the referral hospital was taken accordingly by patients.

- to check and arrange transport for follow-up care to the referral hospital.
- to arrange with the social workers for disability grants for cancer patients who are unable to continue with gainful employment.
- together with the physician at the Out Patient Department see new cases, arrange for their relevant treatment and transfer for further management to the referral hospital.
- where possible, do follow-up care and home visits to ensure that patients have no problems.

Other professional nurses assigned to the oncology section of any health facility were exposed to cancer care during their training as student nurses. This training in cancer care was only for one module as required by the registration authority, namely, the Nursing Council. Although these nurses rendered care for cancer patients, their knowledge was too superficial to enable them to render holistic care for the cancer patient and the family. It is thus not surprising that some of the respondents in this study were seen by the health professional in their local hospitals, transferred to referral hospitals, and only then was the diagnosis explained, and counselling about the disease, its effects and treatment given. In some of the local hospitals Staff Nurses who were also exposed for one module in cancer care during their training were assigned to help in the oncology Out-Patient Department. These nurses tried hard to satisfy the needs

of the cancer patients but they, too, had no education preparation to understand the psycho-social needs of these patients.

In the two referral hospitals which the researcher visited, it was discovered that cancer patients are escorted for radium treatment by Enrolled Assistant Nurses who have no idea whatsoever about the emotional and social needs of the cancer patient. The researcher discovered that these nurses merely guided the patients to the relevant section of the hospital where treatment had to be received. Beyond this the nurses knew little if anything about the treatment and side effects or the stage of development of the tumour.

The researcher also discovered that only lip service was given to "holistic care for the patient or caring for the patient in totality". This is taught to the nurses during their training, yet in practice it is not adhered to. The result is a lowered standard of care and dissatisfaction on the part of the patient and his or her family. The knowledge of the nurses assigned to care for the cancer patients especially those undergoing radium- and chemotherapy is an area which requires further investigation. The researcher is of the opinion that only qualified oncology nurses can render satisfactory care for cancer patients.

5.3 SUGGESTED GUIDELINES FOR HEALTH PROFESSIONALS

It was revealed through this study that the diagnosis cancer of the breast was a traumatic experience for Black women. What compounded the trauma was the surgery involving an important part of the woman's femininity plus the side

effects of the radiation and chemotherapy which were not clearly explained to the patients. These were reported to cause more 'pain' than the disease itself.

In the following pages an attempt is made to formulate guidelines for the health professionals to enable them to assist the mastectomised patient to adapt to the diagnosis cancer and its subsequent treatment.

5.3.1 Suggested Guidelines for the Physician

Whether this is the patient's family physician or a practitioner employed at a hospital's Out-Patient Department, the following suggestions could be used to alleviate anxiety and distress at the first contact with a prospective cancer of the breast patient.

THE DOCTOR'S ROLE	THE NURSE'S ROLE
<p>During the initial physical examination and history taking at the local hospital:</p> <ul style="list-style-type: none">- Allay all fears and anxiety experienced by the patient because of the abnormality in her breast.- Prepare the patient for the possible diagnosis by explaining the relevant terminology such as biopsy, cancer and fibrosis.- Explain in the language that the patient understands the possible outcome of the abnormality in her breast following the biopsy.- Explain why the biopsy has to be	<p>First Contact: In the rural areas where the study was conducted the first point of contact between the patient and health professional is at the health centre or village clinic. On examination of the patient and history taking, the nurse should:</p> <ul style="list-style-type: none">- Prepare the patient by explaining that the abnormality requires further management at the local hospital.- Explain the meaning of the word biopsy in the patient's own language.- Refer the patient to the local

THE DOCTOR'S ROLE

THE NURSE'S ROLE

- Commence with counselling of the patient should the results be positive; this will alleviate the shock.
- If the patient is accompanied by a close relative or spouse, obtain permission to include him or her in the brief talk about the possible diagnosis.
- Allow the patient to go home if the biopsy is not going to be done in the Out-Patient Department, to report possible admission to the hospital for a biopsy.
- Once the biopsy is done and the results are positive, the news is going to terrify the patient; the doctor must be prepared to continue with counselling regarding prognosis, treatment, transfer to a referral hospital with radio active facilities, duration of the treatment, radio- and chemotherapy and possible side effects.
- Tell the patient about possible reconstruction surgery.
- Follow-up care for the rest of her life and the importance of adhering to hospital appointments.
- Refer the patient to the registered oncology nurses for further counselling and problem solving.

- At the hospital during examination, the nurse should make sure that the patient understands mastectomy, chemo- and radiotherapy as explained by the doctor.
- The nurse will refer the patient to the oncology nurses who will counsel the patient further, obtain possible problems about dependent children whilst the mother is hospitalized in a referral hospital.
- The oncology nurses should explain the procedure to be followed concerning the transfer of the patient, possible duration of stay at the referral hospital, mastectomy and other treatment dates and means of transport.
- If the patient is gainfully employed, she must be assisted to obtain a letter to the employer regarding possible absenteeism from work, due to treatment and follow-up care.
- Temporary prosthesis construction until a permanent one is obtained should also be explained.
- The stage of the tumour should be explained so that the patient is knowledgeable about her condition, although personnel at the referral hospital will be in a better position to do this after the mastectomy.
- At the referral hospital the role of each member of the multi-disciplinary team should be explained to the patient by the oncology nurses.

THE DOCTOR'S ROLE

THE NURSE'S ROLE

- Complications of radio-and chemotherapy need to be explained to the patient if, post mastectomy, this is going to be the treatment of choice.
- Where ovaries may need radiation to decrease oestrogen secretion, this has to be explained clearly so that menopausal symptoms will not come as a shock.
- Also to be mentioned should be the possible referral to a gynaecologist if menopausal symptoms are problematic.
- In case of a married patient, the husband should be included in the counselling.

- The nurse should arrange for visits by the chaplain either at the local or referral hospital - he has an important role to play in terms of giving spiritual support and encouragement.

5.3.2 The Role of the Social Workers

Where the patient is a married woman and the spouse is still alive, the need for counselling of the couple by the social worker cannot be emphasized strongly enough. In this study, only two respondents were counselled together with their husbands after the biopsy results. In both instances the respondents reported cooperation and understanding from their spouses. One of these respondents had her ovaries radiated and this resulted in serious dryness of the vagina which made sexual intercourse very painful. She reported to 'hate' and 'fear' sex with her husband. This respondent was only 26 years old with only one child. The surgeon, the social workers and oncology nurses had to work continuously as a team to support this couple.

The other respondent was 40 years old, she had radio- and chemotherapy because of metastasis into her spine. she complained of complete lack of libido (desire for sex). Since most hospitals do not have clinical psychologists, the social worker had to counsel the patient and her spouse about the disturbance in their sexual lives. This caused severe emotional trauma, reported the respondent. She said, "I feel so sorry for my husband, because he is young and healthy, and yet I can't satisfy him." At this juncture the respondent burst into tears.

In cases of unmarried couples, the researcher is of the opinion that the patient should be asked if she wishes her fiancé to be counselled with her. This need crystallized clearly during the interview when a respondent reported that one of her major concerns post mastectomy was the fear that her fiancé may 'dump her' for another woman who has both breasts. The fear that she may never have another love relationship because of a missing breast was there all the time. Therefore, the researcher felt there is a need for counselling of fiancées after their partners have had a mastectomy.

Another area of concern which appeared to need the attention of the social worker in this study was transport and finance to enable patients to attend follow-up care clinics. These facilities in the area of study were situated in Bloemfontein and Pretoria. In each case the patients had to travel approximately 600 kilometres to receive treatment, either in the form of radio- or chemotherapy or routine follow-up care.

Respondents reported having serious problems with transport. Since former Bophuthatswana was 80% rural, the only means of transport was by bus to the nearest local hospital. If the patient's condition was poor, travelling by bus was an ordeal. Hiring a car was beyond the means of all patients.

The researcher explored the possibility of hospital transport to collect patients from their homes, but this proved to be impossible due to the long distances involved. Moreover, the emergency services have been transferred from the hospital to a private company; a factor which compounded the problems relating to the transport of patients to and from the hospital.

Another dimension of the transport problem was created by insufficient funds as only 3 of the 16 respondents were employed. Intervention from the social worker to solve the transport problem for patients seems important. Moreover, speeding up social relief and processing pensions for cancer patients seems the only solution to financial difficulties. This could be solved exclusively by the social worker.

Financial problems also affected the education of dependent children. Twelve (75%) of the respondents had children at university, high- and primary schools, and lack of funds for their education caused them great concern. A social worker could alleviate such additional anxieties by assisting in obtaining a bursary or a loan, which could be paid off on completion of the study programme.

Further, the social worker could be of assistance in obtaining prostheses and wigs for needy patients. If these are obtained through social welfare and the Cancer Association, prices are reduced thus making them affordable to the patients.

Finally, the social workers' role should include counselling of dependent children in cases of rapid deterioration in the mother's condition. Children very often are the most traumatized, yet they are usually ignored and never even told what is happening to their mother. Usually, the effect of the mother's illness reveals itself in their school performance, but nobody cares to heed this warning signal and help the affected child.

In conclusion, it does seem that successful adaptation to breast cancer and its treatment requires cooperation from all members of the health care team mentioned above. The hospital nurses, community oncology nurses, social workers, ministers of religion, voluntary care group members, the family and the patient need to work together if positive adaptation to the diagnosis cancer of the breast is to be achieved. Support in the form of physical, social, emotional and spiritual care should be the goal. In this way, the burden on the patient and family caused by cancer and its treatment can be made easier to bear and positive adaptation facilitated.

King in George (1995:222) refers to nursing "as a process of action, reaction and interaction whereby nurses and clientele share information about their perceptions in the nursing situation". Later King (in George, 1995:222) changes

her view of what she considers as nursing. she reports that "it is that which is done by nurses, lawyers (legal situations), therapists and other practitioners including ministers of religion who interact with clientele". In the care of mastectomised clients all the above-named practitioners are, according to King, rendering nursing in order to achieve the required goal. This goal will be to assist with the patient's adaptation to internal and external stimuli impinging on the patient (King in George, 1995:254).

CHAPTER 6

SUGGESTED SUPPORT GROUP

6.1 INTRODUCTION

In the previous chapter guidelines for oncology nurses, doctors and other health professionals who have a role to play in the adjustment and rehabilitation of the mastectomised breast cancer patient have been discussed. In this chapter, a suggested support group which will help the mastectomised patient adjust to the cancer and mastectomy will be discussed.

6.2 FORMATION OF A SUPPORT GROUP

The present reforms in the health services in South Africa demand a closer look at community participation and involvement through liaison with community organisations, non-governmental organisations and other stakeholders in the provision of health care (National Health Plan for South Africa, 1994:66). The identified health problems that are socio-economic in nature were partly responsible for motivating the researcher to embark on this study. It also became clear that the health professionals in this study were concerned only with the disease cancer and its treatment and all other problems which may be equally important for the patient were ignored or were looked upon as secondary. The family of the patient, dependent children who suffered most during the mother's illness, were found to be completely ignored, yet they

formed one of the major concerns of the breast cancer patient. The patient's financial position which determines the ability to return or not return for follow-up care was another area that was ignored by the health professionals. This included the means of transport from the patient's home to the local hospital. This was discovered by the researcher to be the responsibility of the patient's family. In rural villages where no other means of transport is available, follow-up care for radio- and chemotherapy can be a real problem. It is against this background that the researcher felt there is need for the formation of a support group for mastectomised patients in the area where the study was conducted. This support group would consist of mastectomised women whose role would be to assist fellow patients to adapt to the disease cancer and its treatment.

6.3 PHILOSOPHY

During this study, the researcher considered the philosophical foundation based on King's (1981:23) theory of goal attainment which postulates that "man is capable of learning and changing his behaviour." On the strength of this, "man has a right to participate in decisions that influence his life, health and community service; to that end man has a right to health information that is usable at the time when it is needed and can be used" (George, 1995:220).

King, in discussing her conceptual framework in her introduction to the theory of goal attainment, indicates that "the abstract concepts of the framework are human beings, health, environment and society" (George, 1995:220).

She describes human beings as "social, rational, reacting, perceiving, controlling purposeful action and time oriented". From the above description of human beings, King derived the following assumptions that she considered specific to nurse-client interaction. Interaction, according to King (George, 1995:217) is a process of perception and communication between person and environment and person and person, represented by verbal and non-verbal behaviours that are goal directed. King maintains that each individual involved in the interaction brings ideas, attitudes, perceptions to this interaction. These individuals come together for a purpose and perceive each other, make judgements and decisions to act. From these beliefs about human beings, King derived the following assumptions that are specific to nurse-client interaction:

- Perceptions of nurse and of client influence the interaction process;
- Goals, needs and values of nurse and client influence the interaction process;
- Individuals have a right to knowledge about themselves;
- Individuals have a right to participate in decisions that influence their life, their health and community service; and, finally
- Health professionals have a responsibility to share information that helps individuals make informed decisions about their health care.

In discussing the above-mentioned assumptions, King believes that human beings have three fundamental health needs:

- (1) the need for health information that is usable at the time when it is needed and can be used,
- (2) the need for care that seeks to prevent illness, and
- (3) the need for care when human beings are unable to help themselves.

King concludes by stating that "nurses are in a position to assess what people know about their health, what they think, how they feel about it and how they act to maintain it" (George, 1995:221).

King defines health as "dynamic life experiences of a human being which implies continuous adjustment to stressors in the internal and external environment through optimum use of one's resources to achieve maximum potential for daily living". She sees health as a functional state and illness as an interference with that functional state. She then defines illness as "a deviation from normal, and an imbalance in a person's biological structure or in his psychological make-up even a conflict in a person's social relationships. In a patient suffering from breast cancer with metastasis into the spine or any other vital organ, King's definition of illness could not be more appropriate. She goes further and extends the ability to interact in goal-setting and the selection of means to achieve the goal to include mutual goal-setting with family members in relation to clients and families.

Action is defined by King as a sequence of behaviour involving mental and physical action. Firstly, there is the mental action that recognises the presenting condition. This is then followed by physical action which may be an effort to exert control over a situation. A combination of both mental and physical action may seek the achievement of a goal. According to George (1995:219), King defines transaction by using elements in interaction such as action, reaction, disturbance (problem), mutual goal setting, exploration of means to achieve a goal and goal attainment. Goal attainment will then lead to satisfaction and to effective nursing care. The goal of nursing, therefore, according to King (George, 1995:222) is "to help individuals maintain their health so that they can function accordingly". King concludes that one of the functions of the professional nurse is, therefore, to interpret information for clients as she/he ministers to them using the nursing process.

In this study only a small section of King's theory of goal attainment has been found relevant; hence, a very brief discussion has been undertaken in relation to those concepts that are relevant.

In this study, the need for health information that is usable at the time when it was needed was found lacking in 14 (87.5%) of the respondents. These respondents did not know that an abnormal growth in the breast or oozing of blood from the nipple required immediate medical attention. If this was not the case, none of the 14 respondents would have delayed for an average period of 45 weeks before reporting perceived abnormality in the affected breast. The time wasted before reporting changes in the breast cost two respondents, one

28 years and the other 34 years, their lives. Both reported changes to the medical practitioner after metastasis had occurred and both patients died eighteen months after the mastectomy. Ignorance was responsible for the excessive delay before reporting changes in the breast in most respondents.

Ignorance concerning one's health is ascribed to poor health education both from the media and health professionals. Granting that in the area where the research was done, television and the radio services are not accessible to all rural villagers but health education offered in schools should have included women's health issues which covered breast and cervical cancer. The health education given by community nurses on Cancer Awareness Days makes one wonder whether it is effective if 14 respondents from a sample of 16 delayed in seeking immediate medical attention for abnormalities detected.

The researcher is of the opinion that a more comprehensive, all inclusive education model is desirable for the schools and the communities to effectively prevent cancer. A type of health education model is needed that will include all stakeholders such as community nurses, chiefs, headmen, students, teachers and community members. Extensive use of the media to educate the public should be adopted. Communities should be the ones to identify their needs as far as health education is concerned. It should not be left to community nurses to decide what is relevant for communities to know. A health education model to prevent the occurrence of breast cancer in the area of study is recommended for further research in the future.

The need for the formation of a support group for mastectomised patients in the area of study was voiced by all 16 respondents in this study. It was reported that in referral hospitals respondents were privileged to have psycho-social support from health professionals and fellow cancer and mastectomised patients. On discharge from hospital, 14 respondents reported loneliness and anxiety about the outcome of the disease cancer. These respondents all expressed a need for someone they could talk to, someone who understood their problem. Many of these respondents were still tearful at this stage. On being questioned why they were tearful, all reported fear of recurrence of the cancer.

The researcher, during her voluntary work as a care giver, could give a listening ear to some of the women within her reach, but could certainly not reach all the mastectomised women in all the rural villages in former Bophuthatswana. It is against this background that the researcher feels the formation of a support group in Mafikeng, which is more accessible and central and has the backing of the Department of Health, could be duplicated in other rural villages depending on the number of cases of mastectomised women in the area. Where a village has one or two mastectomised women, these could join the next village to form a sizeable number to be able to render the services required.

In former Bophuthatswana, voluntary health care givers existed in conjunction with clinic committees. These groups rendered non-nursing services such as visiting the sick in the village, washing them where necessary and reporting to the clinic nurses if the patient's condition deteriorated. Unfortunately, this concept diminished when Bophuthatswana as a country collapsed. The support

group for mastectomised patients, the researcher believes, will function along the same lines as the Voluntary Care Givers.

6.4 THE ROLE OF SUPPORT GROUPS

- 6.4.1 To give psycho-social support to newly diagnosed and operated fellow breast cancer patients. The researcher discovered that these patients need someone to talk to about their condition after discharge from the hospital. A cancer survivor is often the person to satisfy this need.
- 6.4.2 The support group members would assist the newly discharged, lonely and devastated patient with arm and hand exercises. This would be required mostly for rural women who lack encouragement and support.
- 6.4.3 Assist with domestic chores where the patient is not strong enough to carry these out. Group members could assist with caring for minor children, cooking and cleaning the home.
- 6.4.4 Help prepare the mastectomised woman for her first follow-up care. This can be a traumatic experience if the patient does not know what it entails. Briefing and advice on what to expect after chemo- or radiotherapy would render the experience less traumatic. One respondent, who only knew that she had to report to the referral hospital for three monthly injections, was mortified following the intravenous chemotherapy. She had to use public transport and vomited all the way from Ga-Rankuwa hospital to

Mmabatho, an ordeal which made her fear and hate follow-up care. This could have been avoided had someone taken the trouble to explain to her what intravenous chemotherapy entailed. This will be part of the information that the support group will share with the newly diagnosed patient.

6.4.5 Assist those patients whose condition does not improve because of the advancement of the tumour. Such patients require continuous assistance especially if they have minor children. The group could assist with shopping, preparation of meals and other domestic chores.

6.4.6 Ensure that patients take their prescribed medication. In many instances these patients are too weak to help themselves; support group members would be valuable at this stage.

6.4.7 Since no hospice care exists in former Bophuthatswana, support group members would help with the care for terminally ill patients nursed at home. They would help to improve patients' moods and solve practical problems which always exist in such circumstances. They would assist family members who are often exhausted from nursing.

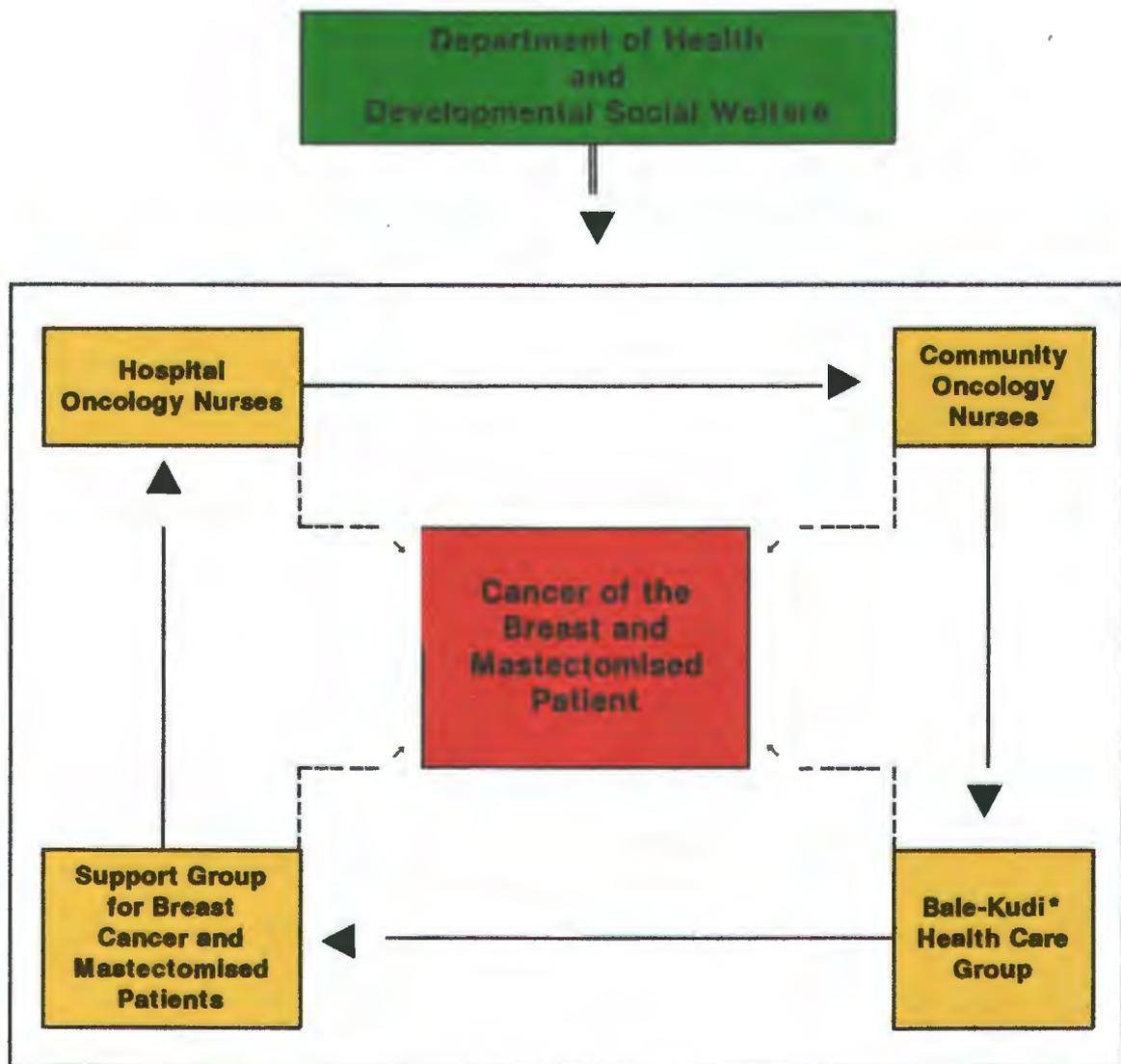
6.4.8 The non-availability of resources to assist family care givers of terminally ill cancer patients makes the need for the formation of the above support group even more urgent. Transport of terminally ill patients from home to hospital only for the patient to die a day or two after admission places

an extra burden on the already financially drained family. If these patients could receive care at home until the end, the family would be relieved of an extra burden. Personal care of the terminally ill cancer patient, housework, cooking, social support of the minor children are areas that can be attended by support group members.

The community cancer care nurses are few and cannot render satisfactory health care for all villages in former Bophuthatswana. The formation of support groups for cancer and mastectomised patients would go a long way to improve the care the patient and their families require especially during the terminal stage. Moreover, health education on self-breast examination cannot be effectively done on one day during the Cancer Awareness Week. This type of health education for women needs to be continuous throughout the year. This can only be done effectively if carried out by the villagers themselves in the form of song and dance at social occasions and during mother and child health days. Finally, placing the responsibility for health education on nurses alone has proven to be a failure because of lack of manpower in rural health facilities. Therefore, training villagers, health care groups and school children to impart this type of health education will be more effective than if it is expected to be delivered by the handful of community nurses in health facilities of former Bophuthatswana.

FIGURE 14

**Graphic Presentation of the Support Group
for Cancer of the Breast and Mastectomised Patients**



* Bale-Kudi = Voluntary health care givers in the community selected by the chief, headmen and the community.

Hospital oncology nurses work hand in hand with the community clinic nurses who, in turn, will work with Bale-Kudi and the proposed support group for cancer of the breast and mastectomised women.

CHAPTER 7

SUMMARY, CONCLUSION AND RECOMMENDATIONS

7.1 INTRODUCTION

In Chapter 1 of this study the problem which forms the basis of the study is presented. It was reported that the diagnosis cancer of the breast was fraught with danger accompanied by fear, guilt and powerlessness. The respondents reported that what makes the experience more fearful was the disruptive effect the disease has on the Black family's relationships. The researcher discovered that there was a gross lack of information on the disease and its treatment among the respondents. What compounded the problem was the delay in reporting changes in the breast so that treatment could commence early and increase the chances of cure. Some respondents waited for an average period of 18 months before consulting a medical professional. Once the diagnosis was confirmed the women became traumatized and anxious. It was on the strength of these findings that the researcher embarked upon this study in order to establish the emotional and social effects the diagnosis and treatment have on the Black women.

Another motivating factor which prompted the researcher was the fact that she is a cancer of the breast survivor for 13 years and the traumatic effect the diagnosis had on her with subsequent anger, isolation and depression.

Health professionals taking care of breast cancer patients were found to concentrate only on the disease and the prevention of metastasis. Other social and emotional problems which caused concern for the patient were ignored.

In the light of these problems the following objectives were formulated:

- to determine the experiences of Black women following confirmation of the diagnosis cancer of the breast and mastectomy;
- to determine whether nurses and physicians contributed towards the adjustment of mastectomised women;
- to provide a base for appropriate intervention to enable the breast cancer patient adapt to the diagnosis and treatment;
- formation of a support group with similar health problems which will assist the mastectomised patient with relevant information to facilitate adaptation.

Pursuant to these objectives, the researcher undertook, in Chapter 2, a literature search to establish the emotional and social effects the diagnosis cancer of the breast has and subsequently what emotional effects total removal of the breast has on the women. It was discovered that in all respondents fear of premature death from metastasis reigned supreme. Most respondents said the diagnosis spelt premature death. Another discovery was the fact that respondents delayed to report changes in the breast. Most of them consulted a health professional only during the late stages when pain was one of the presenting symptoms. Hence none of the respondents had reconstruction surgery.

Chapter 3 presents the research design and method used to conduct the study; both qualitative and quantitative approaches were used to collect data. The method used for sampling, data collection and ethical considerations are described. Data analysis was done in accordance with Tesch (1990) in Creswell (1994:155) and Strauss & Cobin (1990:61).

Data analysis is presented in Chapter 4 which revealed that respondents delayed to report the tumour, hence 14 of them were weak and responded poorly to chemotherapy. Lack of relevant information from doctors and nurses created more problems relating to anxiety on the part of the patient. Most respondents reported to have received the required information from fellow patients in referral hospitals. The disease was regarded disruptive probably because of the stigma that it is incurable and fearful. Some patients held certain myths about the cause of the tumour such as a family life consisting of weekly assaults and abuse from the spouse and punishment for sins committed in the past.

On the strength of the findings of this study, the researcher presented Chapter 5 in which guidelines for physicians and nurses were formulated to assist the patient to adapt to the diagnosis and treatment. In Chapter 6 a support group consisting of mastectomised patients is suggested as the only means to assist the mastectomised patient with her problems. The formation of this group was suggested by all the respondents who formed the second sample for this study. It was felt that a group with similar health problems will be more sensitive to the deep rooted emotional problems of their co-patients than nurses and physicians.

In this chapter, the objectives of the study will also be evaluated to establish whether they were achieved.

7.2 OBJECTIVES

Objective 1 determined the experiences of Black women following the diagnosis and its treatment. It was reported that the diagnosis caused emotional, social and physical stress. This stress was compounded by financial difficulties. Fear of recurrence of the tumour and death was reported by 14 respondents. Anger, depression and despair was also experienced. The major sustaining mechanism used by all 16 respondents was prayer.

Objective 2 determined whether physicians and nurses contributed towards the patient's adjustment to the diagnosis and treatment. Respondents stated that both physicians and nurses were only interested in the tumour and prevention of metastasis. All other problems were not considered. Responses to the chemo- and radiotherapy were considered normal reactions and did not receive attention. Menopausal symptoms, dyspareunia and other emotional problems were looked upon as secondary and had to be tolerated. Nurses from the local hospitals in the area of study were reported to have failed to impart relevant information on the disease and its treatment. The physicians and nurses were reported to have failed in helping the patients adjust to the disease and its treatment.

Objectives 3 and 4 both aimed to provide a base for appropriate intervention to enable the breast cancer sufferer to adapt to the diagnosis and its treatment.

All 16 respondents expressed a need for intervening helping mechanisms that would first impart needed information, then help with the anxiety caused by the diagnosis, give support when the patient goes for surgery, be available to offer advice when the patient returns from the hospital emotionally devastated. It was felt that only a voluntary cancer of the breast support group could appreciate the problems experienced by this category of patient. It was also expressed that a complicated nursing model would not meet the basic needs of these patients. Therefore, the cancer survivors themselves need to come together with the assistance of the researcher to organise and constitute the support group. The role of the group is discussed at length in Chapter 6.

The guidelines formulated for physicians and nurses in Chapter 5 should serve as a base for appropriate intervention from the time the cancer of the breast is discovered through hospitalization, follow-up care and the rest of the patient's life post diagnosis. These guidelines, if followed, should assist the patient to adapt to the fact that she has been diagnosed with cancer and has had a mastectomy but can learn to live with it like with any other chronic disease.

7.3 LIMITATIONS OF THE STUDY

The structured interview schedules used to obtain data from samples 1 and 3 (see Appendices A and B) did not succeed to tap the emotional experiences of the respondents. Therefore, the possibility that not all information was obtained from the mastectomised women and their husbands cannot be excluded.

The number of male respondents who were willing to be interviewed was too small (13) to allow generalisation of findings to the entire population of husbands of mastectomised Black women.

The second sample of Black mastectomised women was equally small; however, Polit and Hungler (1987:350) guided the researcher when they stated that "qualitative research yields vast amounts of data, it is therefore not practical to use large samples that will yield a lot of data which will make analysis cumbersome". Because of the size of this sample (16 women), generalisation of findings can only be made to former Bophuthatswana and not to all mastectomised Black women in South Africa.

The distance involved between the different regions of former Bophuthatswana was too great and some areas were not accessible by car. Hence, some of the respondents were interviewed at referral hospitals and not at home.

The male respondents could not all be reached because some were employed in the mines and their addresses could not be obtained. Some husbands, whose homes were within reach, simply refused to talk to the researcher about their wives' illness; and their wishes had to be respected.

7.4 CONCLUSION

From the findings of this study it was revealed that the diagnosis cancer of the breast with its subsequent treatment mastectomy among Blacks in the former Bophuthatswana causes stress, depression and dependence. Fourteen

respondents (87.5%) reported to have become weaklings following the mastectomy and chemotherapy. All 14 respondents could not cope with gainful employment because of ill-health. One hundred percent of the sample reported emotional and social distress manifested by tearfulness and fear of premature death. Fourteen respondents experienced problems with transport for follow-up care. All respondents complained that information from nurses and physicians to enable them to understand the disease and its treatment was insufficient and did not facilitate adjustment. Based on the findings of this study the researcher believes that health professionals could improve their attitude towards the Black breast cancer patient thus helping her to accept the diagnosis and to be positive about the treatment.

7.5 RECOMMENDATIONS

The following recommendations are made as a result of this study:

7.5.1 Need for Free Medical Services for Cancer Sufferers

Confirmed breast cancer patients who are not gainfully employed should receive free medical care both in local as well as referral hospitals. It is the policy of the Department of Health in South Africa to allow free medical services for pregnant mothers and children - cancer patients, by virtue of the chronic nature of the disease and its debilitating effects, should enjoy the same privilege. All 16 respondents reported to pay R 26.00 at each visit to the hospital. This fee should be scrapped on the strength that this has to be paid for the rest of the patient's life. Although the amount of the fee appears to be low, it is not

affordable by rural villagers who, firstly, receive their meagre pensions on an irregular basis and, secondly, have to meet all other financial needs including the schooling of dependent children. The Department of Health at national level is urged to reconsider these tariffs for cancer patients.

7.5.2 Transport

Fourteen respondents, being rural villagers from former Bophuthatswana, reported that transport facilities were very poor. In certain villages, bus services are scheduled once only in the morning and evening, whereas in other villages a more frequent service exists. However, where such service does not exist at all, patients have to pay more than R 100 for private transport to the nearest hospital. From the hospital, patients are then transported to referral hospitals. The ambulance service used for this purpose has been privatized and is difficult to secure. Patients come to local hospitals for transport to referral hospitals but, if an ambulance is not available, they have to sleep over on benches in the out-patient department until transport for follow-up care is available. This uncertainty adds an extra burden on the already traumatized cancer sufferer. Therefore, transport for follow-up care needs to be improved.

7.5.3 Lack of Information

All 16 respondents complained about insufficient information given by physicians and nurses to patients. Six respondents in this study were told that they were supposed to have a biopsy and none of them knew what 'biopsy' meant. One respondent reported that the physician simply said "You are booked for

mastectomy" without explaining any further. She only learnt the meaning of this term from her mother the night prior to the surgery.

Breast cancer patients in this study appeared to be anxious all the time, but it could not be established whether the cause was the uncertainty of the outcome of the prognosis. However, this behaviour requires further investigation. To alleviate this anxiety, physicians and nurses are urged to explain procedures to patients in the language the patient understands. This need is repeatedly stressed during training at nursing colleges and universities, yet students do not put it into practice. The Department of Health at national level is urged to expedite the translation of health information into the Black official languages, so that patients can read about relevant health issues from pamphlets and brochures distributed freely in the Out-Patient Departments of hospitals and doctors' consulting rooms. This information would enlighten literate patients about health conditions and enable them to share their newly found knowledge with their illiterate co-sufferers.

7.5.4 Clinical Psychologists in Hospitals

The Department of Health at national level is very strongly urged to consider creating posts for this category of health worker both at regional and referral hospitals. The researcher, throughout her experience as a nursing sister in hospitals and as a cancer survivor, has never come across a clinical psychologist who was employed in any of the hospitals mentioned. In the treatment of all cancers, the input of a clinical psychologist is recommended to enable adjustment to the diagnosis. Yet, when it comes to practice, this important

member of the team is not available. In this study, where depression was reported to be extreme in patients, psychiatrists were consulted instead. This shows a great flaw in the health care system in South Africa. Cancer patients require appropriate counselling relating to the disease and its complications - they are not psychiatrically ill and do not need psychiatric care. One respondent, who had been referred to a psychiatrist because of depression, reported to have been very upset at the suggestion.

7.5.5 Ill-Mannered Conduct of Health Professionals

The researcher, herself a member of the health profession team, was aghast and made to feel very small when respondents reported the bad manners of nurses and physicians. However, these are facts and have to be revealed. Some respondents in this study did not mince their words when they spoke of doctors' and nurses' rudeness and how shabbily they were treated. One respondent was so angered by her physician's manner that she tore up his letter of reference in his presence and threw it into the waste paper basket. When she reported this incident, she burst into tears, explaining that her behaviour was prompted by the physician's rude attitude.

Two hospitals in the area of study, one being a referral hospital for cancer sufferers, were identified as having 'rude' nurses and doctors. One does not expect a professional person to be rude to a point which warrants reporting. Such attitude is unethical and makes matters worse for patients who require all the compassion to enable them to adjust to the incurable disease. All hospital

superintendents should make a ruling that ill-mannered professionals should be reported instantly and dealt with accordingly.

The social welfare section of hospitals in the area of study must be involved immediately after a patient's diagnosis has been confirmed. This will facilitate processing of disability grants and thus avoid undue financial stress before the patient's death.

7.5.6 Health Education regarding Cancer Awareness and Early Detection

From the findings of this study it is clear that the health education given by hospital and community nurses regarding cancer awareness and early detection is not effective. Only 2 (12.5%) of the sample reported to have learned from the Cancer Awareness Week that changes in the breast have to be reported immediately to health professionals. The remaining 14 (87.5%) respondents waited for an average period of 18 months before consulting a doctor or clinic nurse. From these, three died prior to the completion of this report.

The Primary Health Care Unit of the Department of National Health is urged to change its strategy regarding cancer prevention and awareness. Strategies for health education that can be evaluated for effectiveness have to be put in place for rural villagers. Where television and radios can be used, health professionals should give talks which should be followed up at meetings in tribal villages with recommendations of the chief and headmen. Health education should be stepped up by voluntary care givers and the proposed support group for breast cancer patients.

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QUESTIONNAIRE

An Investigation into the Effects of Cancer of the Breast and Mastectomy on Black Women in Former Bophuthatswana

(Please record the answer by writing the correct number in the box)

	Quest Nr.				
					1-3
					4
1. Place of Residence	[1] Rural				
	[2] Urban				5
2. Occupation	[1] Nurse				
	[2] Teacher				
	[3] Housewife				
	[4] Typist/Secretary				
	[5] Labourer/Domestic				
	[6] Other (specify)				6
.....					
3. Age at Interview	[1] Less than 30 years				
	[2] 30-35 years				
	[3] 36-41 years				
	[4] 42-47 years				
	[5] 48-52 years				
	[6] 53-58 years				
	[7] 59-64 years				
	[8] 65-71 years				
	[9] 72 years and above				7
4. Age at Menarche	[1] 11 years				
	[2] 12 years				
	[3] 13 years				
	[4] 14 years				
	[5] 15 years				
	[6] 16 years				
	[7] 17 years and above				
	[8] Unknown				8

5. Marital Status
- [1] Married
 - [2] Divorced
 - [3] Widowed
 - [4] Never married 9
6. Have you reached Menopause?
- [1] Yes
 - [2] No 10
- 6.1 If yes, at what age?
- [1] 44 years
 - [2] 45 years
 - [3] 46 years
 - [4] 47 years
 - [5] 48 years
 - [6] 49 years
 - [7] 50 years 11
7. How many children do you have?
- [1] One
 - [2] Two
 - [3] Three
 - [4] Four
 - [5] Five
 - [6] Six
 - [7] Seven
 - [8] Eight
 - [9] Nine
 - [10] Ten and more
 - [11] Never had children 12
- 7.1 How old were you when you had your first child?
- [1] 15 years
 - [2] 16 years
 - [3] 17 years
 - [4] 18 years
 - [5] 19 years
 - [6] 20 years
 - [7] 21 and above 13

8. Did you breast feed your children on both breasts? [1] Yes [2] No 14
- 8.1 If yes, for how long? [1] Less than 3 months [2] 3 months [3] 4 months [4] 5 months [5] 6 months [6] 9 months [7] 1 years [8] 2 years and more [9] Did not breast feed at all 15
- 8.2 If no, give reasons:
.....
.....
- 8.3 Did you have breast dysfunction? [1] Yes [2] No 16
- 8.4 If yes, on how many breasts? [1] On one breast 17 [2] On both breasts 18
9. What is your highest standard of education? [1] Below standard 6 [2] Standard 6 [3] Standard 7 [4] Standard 8 [5] Standard 9 [6] Standard 10 [7] University [8] Technikon [9] Did not attend school 19
10. Who discovered the lump in your breast? [1] Self [2] Nurse [3] Doctor [4] Husband [5] Other (specify) 20
-

11. Age when lump was discovered 21
If unknown, please mark here with "x"

12. After discovering the lump in your breast, how long did you wait before reporting it to a physician or clinic? 22

- [1] Less than a week
- [2] One week
- [3] Two weeks
- [4] Three weeks
- [5] Four weeks
- [6] Five weeks
- [7] Six weeks
- [8] Seven weeks
- [9] Eight weeks
- [10] Three months
- [11] Four months
- [12] Five months
- [13] Six months
- [14] Nine months
- [15] One year
- [16] Two years and more

13. If there was a delay, what was the reason? 23

- [1] Lump was not painful
- [2] Fear that it may be cancer
- [3] Did not know that I had to report the lump to a doctor or nurse
- [4] Did not delay

14. Is there a history of cancer in your family? 24

- [1] Yes
- [2] No
- [3] I don't know

15. If yes to the above question, who in your family suffered from this disease? 25

- [1] Grandmother
- [2] Mother
- [3] Father
- [4] Grandfather
- [5] Sister 26
- [6] Other (specify)

15.1 Specify the type of cancer,
e.g. *cancer of the lung*

.....

16. At what stage was the cancer when you reported the lump or when it was discovered?
(Please check bedletter)
- [1] First stage
 - [2] Second stage
 - [3] Third stage
 - [4] Fourth stage
 - [5] Don't know
 - [6] Other (specify) 27
-

- 16.1 When you were told for the first time by your doctor/nurse that you suffered from cancer of the breast, what was your reaction? (Tick ✓ in the relevant box)
- [1] I cried 28
 - [2] I was terrified 29
 - [3] I did not believe what I heard 30
 - [4] I thought the whole world was coming to an end 31
 - [5] I thought of premature death 32
 - [6] Any other feeling you experienced (specify):
-
-
-
-

17. After the results of the biopsy (specimen) revealed that indeed the lump was cancer, how did you react?
(Tick ✓ in the relevant box)
- [1] I thought a mistake had occurred 33
 - [2] I still believed the biopsy results belonged to someone else 34
 - [3] I said Oh! no! Why me? 35
 - [4] Other (specify):
-
-
-

18. The first few days following confirmation of the diagnosis:

18.1 I could not sleep [1] True
[2] False
[3] I don't know 36

18.2 I suffered from the pain of knowing that I had an incurable disease [1] True
[2] False
[3] I don't know 37

18.3 I was worried about my children [1] True
[2] False
[3] I don't know 38

18.4 I was worried that the cancer would spread to other parts of the body [1] True
[2] False
[3] I don't know 39

19. List other factors that worried you most in their order of importance:
[1]
[2]
[3]
[4]
[5]

20. After coming to terms with the truth (that you suffered from cancer), did you experience anger? [1] Yes
[2] No
[3] I am not sure 40

20.1 If yes, to whom was the anger directed? Specify at length.
.....
.....
.....
.....

- 20.2 Not only was I angry but I was also bitter. [1] True
[2] False
[3] I am not sure 41

20.3 If true, to whom was the bitterness directed?
Specify at length.
.....
.....
.....
.....

21. I also experienced a degree of hatred [1] True
[2] False
[3] I am not sure 42

21.1 If true, towards what or whom was the hatred directed? Specify at length.
.....
.....
.....
.....

22. I am convinced that cancer is a killer. [1] Agree
[2] Strongly agree
[3] Not sure
[4] Disagree
[5] Strongly disagree 43

- 22.1 Cancer of the breast is incurable. [1] Agree
[2] Strongly agree
[3] Not sure
[4] Disagree
[5] Strongly disagree 44

23. After I was told the lump was cancer I was:
- [1] Not depressed at all
 - [2] A little depressed
 - [3] Moderately depressed 45
 - [4] Very depressed
 - [5] I wanted to commit suicide 46
24. After the diagnosis was confirmed I felt guilty and kept asking why it happened to me.
- [1] Agree
 - [2] Strongly agree
 - [3] Neutral
 - [4] Disagree
 - [5] Strongly disagree 47
25. After I was told I had cancer I was so terrified that for a number of days I spoke very little, and I wanted just to be alone.
- [1] Agree
 - [2] Strongly agree
 - [3] Neutral
 - [4] Disagree
 - [5] Strongly disagree 48
26. There is something about suffering from cancer that makes you feel ashamed to tell friends and relatives that you are a victim of the disease.
- [1] Agree
 - [2] Strongly agree
 - [3] Neutral
 - [4] Disagree
 - [5] Strongly disagree 49
27. I felt so ashamed to say I suffered from cancer that I lied about the diagnosis to most of my friends and neighbours.
- [1] Agree
 - [2] Strongly agree
 - [3] Neutral
 - [4] Disagree
 - [5] Strongly disagree 50
28. I felt sinful after I was told I had cancer.
- [1] True
 - [2] False
 - [3] I am not sure 51

29. I felt this was punishment from God. [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 52
30. I felt dirty and wanted to be alone. [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 53
31. The public needs more information to relieve deep seated anguish about cancer of the breast. [1] True
[2] False
[3] I am not sure 54
32. My greatest fear of cancer is dying from uncontrollable pain. [1] True
[2] False
[3] I am not sure 55
33. Sometimes I blamed myself for having forgotten to fulfill the wishes of my ancestors. [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 56
34. I also felt guilty that may be I have sinned in the past, hence this punishment from God. [1] True
[2] False
[3] Unsure 57
35. After the diagnosis was confirmed I worried about the hospital bills - how I was going to pay. [1] True
[2] False
[3] Neutral 58

36. Transport to the nearest hospital for check-ups was a problem. [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 59
37. This illness has affected me at work and, as a result, I am no longer employed. [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 60
38. My income has been affected because of chronic illness and I struggle to buy the bare necessities. [1] True
[2] False
[3] Unsure 61
39. After the mastectomy I became an invalid (a weakling) to a point where I had to leave work. [1] True
[2] False
[3] Unsure 62
40. Following the mastectomy I was forced to stop work because of ill-health. [1] True
[2] False
[3] Other (specify) 63
-
41. After the mastectomy my services were terminated permanently by my employer. [1] True
[2] False
[3] Other (specify) 64
-
42. If you have dependent children, who maintains them financially at school? [1] Husband/Boyfriend
[2] Mother
[3] Brother
[4] Sister
[5] I am gainfully employed
[6] Other (specify) 65
-

43. With my present source of income I cope comfortably. [1] Yes 66
 [2] No

43.1 If "no" to the above question, tick ✓ the relevant box to your situation.

[1]	I am unable to buy sufficient food	<input type="checkbox"/>	67
[2]	Unable to pay rental for the house	<input type="checkbox"/>	68
[3]	Unable to pay school fees and books for my children	<input type="checkbox"/>	69
[4]	Unable to foot bills for hospital treatment	<input type="checkbox"/>	70
[5]	Don't have money for transport to undergo hospital follow-up care	<input type="checkbox"/>	71
[6]	Other economic problems (specify)		

.....

Tick ✓ the relevant box or boxes:

44. After the mastectomy, what were your main concerns?

[1]	Survival	<input type="checkbox"/>	72
[2]	My children	<input type="checkbox"/>	73
[3]	Disfigurement	<input type="checkbox"/>	74
[4]	Loss of the breast	<input type="checkbox"/>	75
[5]	Recurrence of the disease	<input type="checkbox"/>	76
[6]	Spread of the disease	<input type="checkbox"/>	77
[7]	Other (specify)	<input type="checkbox"/>	78

.....

45. If married, how did your husband react to the loss of your breast?

[1]	Was sympathetic and supportive	<input type="checkbox"/>	79
[2]	Was neutral and said nothing	<input type="checkbox"/>	80
[3]	Was negative and made negative remarks	<input type="checkbox"/>	81

- | | | | | |
|--|-----|--|--------------------------|----|
| 46. What are your feelings about showing yourself with your amputated breast exposed to your family and close friends? | [1] | Resent to show the scar | <input type="checkbox"/> | 82 |
| | [2] | Resent to expose amputated breast | <input type="checkbox"/> | 83 |
| | [3] | I move around naked as I used to prior to the mastectomy | <input type="checkbox"/> | 84 |
| | [4] | Makes no difference at all | <input type="checkbox"/> | 85 |

Write only the relevant number against which you agree or disagree:

- | | | | | |
|--|-----|-------------------|--------------------------|----|
| 47. Transport to the nearest hospital for check-ups is a problem. | [1] | Agree | | |
| | [2] | Strongly agree | | |
| | [3] | Neutral | | |
| | [4] | Disagree | | |
| | [5] | Strongly disagree | <input type="checkbox"/> | 86 |
| 48. Ever since I had my breast removed, I feel I am no good at all as a wife to my husband in bed. | [1] | Agree | | |
| | [2] | Strongly agree | | |
| | [3] | Neutral | | |
| | [4] | Disagree | | |
| | [5] | Strongly disagree | <input type="checkbox"/> | 87 |
| 49. Ever since I had my breast removed, I feel I no longer have much to be proud of as a woman. | [1] | Agree | | |
| | [2] | Strongly agree | | |
| | [3] | Neutral | | |
| | [4] | Disagree | | |
| | [5] | Strongly disagree | <input type="checkbox"/> | 88 |
| 50. I wish I could have a better image of myself as a woman. | [1] | Agree | | |
| | [2] | Strongly agree | | |
| | [3] | Neutral | | |
| | [4] | Disagree | | |
| | [5] | Strongly disagree | <input type="checkbox"/> | 89 |

51. All in all, I am inclined to feel that I am unable to cope with life ever since I had this operation (mastectomy). [1] Agree [2] Strongly agree [3] Neutral [4] Disagree [5] Strongly disagree 90

52. I am dissatisfied with myself as a woman because of the lost breast/s. [1] Agree [2] Strongly agree [3] Neutral [4] Disagree [5] Strongly disagree 91

53. What helps you cope with the idea that you suffer from cancer? [1] I don't worry about it 92 [2] I pray about it 93 [3] I have faith in my doctors and nurses 94 [4] My husband is supportive 95 [5] My children are supportive 96 [6] I have confidence in the treatment given 97 [7] Other (specify) 98

54. Has anybody ever talked about surgical reconstruction of the breast to you? [1] Yes [2] No 99

54.1 If 'yes', who did? [1] Doctor [2] Nurse [3] Other (specify) 100

55. Have you had reconstruction surgery to the amputated breast? [1] Yes [2] No 101

55.1 If 'no', why not?

.....
.....
.....

- 55.2 Would you like to have reconstruction of the lost breast? [1] Yes
[2] No 102

SEXUAL LIFE

56. Are you still sexually active? [1] Yes
[2] No 103

- 56.1 If 'yes' to the above question, how did your husband react to the mastectomy?
- [1] No change 104
 - [2] He became indifferent 105
 - [3] Our sexual life changed altogether for the worst 106
 - [4] He was afraid to hurt me 107
 - [5] We had sexual relations less than before 108
 - [6] We stopped having sex regularly 109

57. If you stopped having sex what do you think is the reason? Explain at length.

.....
.....
.....
.....

58. If you are still sexually active, is your reaction to your husband's/boyfriend's advances the same as before the mastectomy? [1] Yes
[2] No
[3] I don't know 110

- 58.1 If 'no' to the above question, explain what you mean by saying that your reaction is no longer the same:

.....
.....
.....
.....

59. My reaction to my husband's/
boyfriend's advances in bed has
become cold and frigid ever
since I had the mastectomy. [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 111

60. My husband divorced me after I
had the one breast amputated. [1] True
[2] False 112

61. I am convinced the mastectomy
made our marriage relationship
with my husband worse. [1] True
[2] False
[3] I am not sure
[4] Other (specify) 113

62. After the mastectomy my
husband had nothing to do with
me as a sexual partner. [1] True
[2] False
[3] I am not sure 114

63. After the mastectomy my
husband/boyfriend changed. He
became very close and loving
towards me. [1] True
[2] False
[3] I don't know 115

RELIGION

64. Since I was diagnosed to be
having cancer, my faith in my
creator strengthened. [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 116

65. I am terrified of the disease
cancer but prayer gives me hope. [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 117

66. The church has been a pillar of strength ever since I was told I had cancer.
- [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 118
67. In addition to prayer, appeal to my ancestors has also given me strength and courage.
- [1] True
[2] False
[3] Neutral 119
68. I know that cancer can spread to other parts of the body, but this does not worry me because I pray and ask for God's mercy.
- [1] Agree
[2] Strongly agree
[3] Neutral
[4] Disagree
[5] Strongly disagree 120
69. Suffering from cancer has a stigma (a feeling of shame), it is thus important that the patient's close relatives receive counselling to give them understanding.
- [1] True
[2] False
[3] I don't know 121
70. The patient suffering from breast cancer and subsequently mastectomy requires continuous counselling to enable her to adapt to her problem of living with one breast.
- [1] True
[2] False
[3] I don't know 122
71. Has any one spoken to you about the use of a prosthesis?
- [1] Yes
[2] No 123
- 71.1 If 'yes' to the above question, who was it?
- [1] Nurse
[2] Doctor
[3] Social worker
[4] Relative
[5] Other (specify) 124

71.2 If 'no', give reasons why you think you were not advised about the use of prosthesis.

.....
.....
.....

72. Did you construct a prosthesis on your own? [1] Yes [2] No 125

73. Are you using a prosthesis? [1] Yes [2] No 126

73.1 If 'no', please give reasons for non-use.

.....
.....
.....

74. When the cancer was diagnosed, who explained the disease, its treatment and implications to you? [1] Nurse 127 [2] Doctor 128 [3] Relatives 129 [4] I read about it 130 [5] Other (specify) 131

.....

75. Do you examine the remaining breast regularly? [1] Yes [2] No 132

75.1 If 'yes', how often? [1] Monthly [2] Occasionally [3] When I remember 133

75.2 If not, why not? Elaborate.

.....
.....
.....

76. Have you heard of the procedure called a Pap smear? [1] Yes
[2] No 134

76.1 If yes, when last did you have a Pap smear done? [1] This year
[2] Last year
[3] Two years ago
[4] Many years ago
[5] Never 135

76.2 If you have never had a Pap smear done, give reasons why not:

.....
.....
.....

QUESTIONNAIRE For Husbands

The Effects of Breast Cancer and Mastectomy on the Husbands of Mastectomised Black Women in Former Bophuthatswana

(Please record the answer by writing the correct number in the box)

	Quest Nr.	<input type="text"/>	<input type="text"/>	<input type="text"/>	
					1-3
		Male	1		4
<hr/>					
1. Place of Residence	[1]	Rural			
	[2]	Urban	<input type="checkbox"/>		5
2. Occupation	[1]	School Teacher			
	[2]	Lecturer			
	[3]	Administrator			
	[4]	Businessman			
	[5]	Clerk			
	[6]	Labourer			
	[7]	Other (specify)	<input type="checkbox"/>		6
.....					
3. Age at Interview	[1]	Less than 30 years			
	[2]	30-35 years			
	[3]	36-41 years			
	[4]	42-47 years			
	[5]	48-52 years			
	[6]	53-58 years			
	[7]	59-64 years			
	[8]	65-71 years			
	[9]	72 years and above			
	[10]	Unknown	<input type="checkbox"/>		7

4. What is your highest standard of education? [1] Below Standard 6
[2] Standard 6
[3] Standard 7
[4] Standard 8
[5] Standard 9
[6] Standard 10
[7] University
[8] Technikon 8
[9] Did not attend school
5. Were you aware that your wife had a breast problem before the diagnosis was made?
- [1] Yes
[2] No 9
- 5.1 After your wife was confirmed to be suffering from cancer of the breast, how did you react to the diagnosis?
.....
.....
..... 10
- 5.2 Which was the most trying and difficult time of your wife's illness?
- [1] Immediately after the discovery of the lump in her breast. 11
[2] Waiting for the biopsy results.
[3] During her stay in hospital after the mastectomy. 12
6. Were you concerned (worried) after the diagnosis was made?
- [1] Yes
[2] No 13
- 6.1 If YES, what concerned you most?
- [1] The hospital charges
[2] Her survival 14
[3] Our children
[4] Other (specify) 15
.....

7. Did you give consent that the affected breast be removed?

[1] Yes

[2] No

16

7.1 If NO, please give your reasons:

.....
.....

17

7.2 Was the breast removed without your permission?

[1] Yes

[2] No

18

7.3 Was the breast removed without permission from other family members?

[1] Yes

[2] No

19

8. Were you aware of the implications of the diagnosis of breast cancer?

[1] Yes

[2] No

20

8.1 Did you bother about the extent of the cancer (stage at discovery)?

[1] Yes

[2] No

[3] It did not worry me

[4] I was ignorant and did not know that cancer had stages

21

9. When your wife was hospitalised, how often did you visit her?

[1] Once only

[2] Every day

[3] Morning and evening

[4] Other (specify)

22

.....

9.1 Was it practical for you to visit her?

[1] Yes

[2] No

23

If NO, please give the reason:

.....
.....
.....

24

10. How did you cope with the idea that your wife had cancer?

[1] It did not worry me at all

[2] I forgot about it most of the time

[3] It did not worry me very much

[4] I kept myself busy and forgot about the disease

[5] Other (specify)

.....
.....

25

26

11. After removal of her breast, what worried you most?

[1] Failure to return to her usual lifestyle

[2] Failure to react to my sexual advances

[3] Her appearance without the one breast

[4] That she may stop working

[5] Our children who may lose a mother

[6] Recurrence of the disease

[7] Change in sex life

[8] Other (specify)

.....
.....

27

28

12. When your wife was in hospital, what worried you most?

- [1] Worry about shortened life span
- [2] Anaesthesia
- [3] Care by the nurses 29
- [4] Her being away from home
- [5] Fear that she was going to be a weakling 30
- [6] Other (specify)
.....
.....

13. Emotionally, how did you cope with your wife's illness? List mechanisms:

-
..... 31
.....

14. How long after the mastectomy was performed did you see the scar? Specify.

- 32
.....
..... 33

15. How did you react to the incision the first time you saw it?

- [1] Did not make any difference
- [2] I was scared
- [3] It annoyed me
- [4] I told her to cover it 34
- [5] I felt sorry for her
- [6] She appeared disfigured and I hated her appearance
- [7] I was neutral and passive

16. Did you encourage her to visit a traditional healer after the discovery of her illness?

- [1] Yes
- [2] No 35

If NOT, why not? Please specify:

.....
.....
.....

17. Did you encourage her to consult faith healers?

[1] Yes

[2] No

36

If NOT, why not? Please specify:

.....
.....
.....

18. What major changes have occurred in your life ever since your wife suffered from cancer?

[1] I have become more religious

[2] She no longer appeals to me sexually

[3] She has lost interest in our sex life

[4] I have become very close to her and the children

[5] I have become very close to the children

[6] I want to support her emotionally as much as I can

[7] I have just drifted away from her emotionally

[8] Other (specify)

37

38

.....
.....

19. What gives you hope ever since your wife was found to be suffering from cancer?

[1] Prayer

[2] Treatment received from doctors/nurses

[3] My wife is very courageous

[4] Support from the family

[5] Other (specify)

39

.....
.....

20. How have you adjusted ever since the surgery was done?

- [1] Not so well
- [2] Fairly well
- [3] Actually, it never made any difference
- [4] Well
- [5] Very well
- [6] Other (specify)

40

.....
.....

21. What problems have you encountered ever since your wife had the operation and chemotherapy/radiotherapy?

.....
.....
.....
.....

41

22. List methods you have used to solve the problems:

.....
.....
.....
.....

42

23. Do you receive emotional support?

- [1] Yes
- [2] No

43

23.1 If YES, who gives you emotional support?

- [1] Nurses
- [2] Doctors
- [3] The minister of religion
- [4] My children
- [5] Other (specify)

44

45

.....
.....

24. Has your wife's disease ever been explained to you?

[1] Yes

[2] No

46

24.1 If NOT, why not? Please specify:

.....
.....
.....

47

24.2 If NO, have you tried to get information about the disease?

[1] Yes

[2] No

48

24.3 If YES, from whom did you receive information? Please specify:

.....

24.4 Have the complications of your wife's disease ever been explained to you?

[1] Yes

[2] No

49

24.5 If NO, have you taken the trouble to find out? Specify.

.....
.....

25. Specify what you have done to support your wife ever since she became ill and also after the mastectomy:

.....
.....
.....

50

26. Have all your questions about your wife's illness been answered?

[1] Yes

[2] No

51

26.1 If YES, by whom? Please specify:

.....

52

26.2 If NO, why not? Please specify:

.....

53

26.3 Is your wife still alive?

[1] Yes

[2] No

54

PHOTOGRAPHS OF BREAST CANCER PATIENT'S:



METASTASIS



AFFLICTED BREAST



DWELLING

TRANSCRIBED INTERVIEW NUMBER 10 TO DEMONSTRATE THE METHOD OF CONTENT ANALYSIS THROUGH UNDERLINING WORDS AND PHRASES, THEMES IN SETSWANA AND ENGLISH

INT = Interviewer
RESP = Respondent

RESEARCH QUESTION

"Please share with me your experiences from the time the nurse/doctor told you that the lump in your breast was cancer and that you were to have a mastectomy (removal of the affected breast)."

RESP: I was going to school one morning, as I was washing I felt a small lump the size of a small pea under my face cloth. I felt uneasy but decided to touch the lump with my forefingers to get a good feel of it. Indeed, it was small and hard under my fingers.

INT: And then what happened?

RESP: I waited for a month, though I touched it now and again it did not worry me and it was not painful. I showed it to one of my friends two weeks later who also touched it and said, "it feels bean-shaped". She asked whether it was painful, I said no.

INT: Mmh.

RESP: Two weeks later my sister who is a nurse came from Johannesburg to visit me. I showed her my breast and she also felt the bean-shaped lump. She immediately said, "Go see a doctor tomorrow, the breasts are not supposed to grow little lumps like this one."

INT: And - did you go to see a doctor?

RESP: No! I suddenly remembered that I was due for medical check-up, I thought I could then show the doctor the lump.

INT: Okay, and then?

RESP: Indeed, after a fortnight I went to the local hospital for my diabetes and blood pressure.

INT: How often do you visit the doctor for a check-up?

RESP: After every two months.

INT: Ah.

RESP: I went to the diabetic clinic two weeks later but dodged and did not show the doctor the lump because it did not worry me, it was painless.

INT: Why?

RESP: Because it was not painful and it did not worry me, I did not think it necessary to worry the doctor.

INT: And then?

RESP: I went back home and I forgot about the lump except in the morning when I washed to go to school.

INT: Mmh.

RESP: Two months later I went to the hospital again, this time I was not going to forget.

INT: How long was it now since you discovered the lump?

RESP: Three months.

INT: Alright, go ahead Ma.

RESP: When the time came I went to the clinic and after all the tests I showed my doctor the lump. He searched for it with his fingers and he found it.

INT: And then?

RESP: I told him it feels a little bigger than last month.

INT: And then?

RESP: Doctor immediately said to me, follow me. We went into another clinic called the surgical clinic. Here the doctor also felt the lump. He then said you must immediately go to Ga-Rankuwa hospital where this lump is going to be examined. It was during November 1993. He wrote a letter and gave it to me. I was planning to visit my children in Ga-Rankuwa so I thought this will give me a chance to go there. I told doctor this and he urged me not to delay but report immediately on my arrival.

INT: What followed then?

RESP: I reported at Ga-Rankuwa hospital on my second day after my arrival. I found many doctors, gave one the note from my doctor. An elderly doctor just said, "Ma, this breast must be removed, it has cancer." A long pause followed. Then I said, "My breast must be cut off? Jo! I got such a fright." I burst into tears. I cried. I could not understand why a little lump could lead to total removal of my beautiful breast. My two children who had accompanied me to the hospital tried to comfort me,

and we eventually agreed that I must have the operation. On December 28th, 1993, I had my left breast removed. For six weeks I went to H.F. Verwoerd Hospital for radiotherapy.

INT: Tell me, how did the radiotherapy treat you?

RESP: I had no major problems during the first week following radiotherapy treatment. My skin colour changed, became red and a little bit uncomfortable. My fellow patients got real serious burns, I didn't.

INT: How old are your children?

RESP: They are all adults and independent. I have tried to give them all a good education. I am also a strong believer in God, He will help.

INT: What are your immediate problems?

RESP: Numbness and tingling sensation on the affected arm. I experience a nasty feeling like a worm moving inside my arm. I am also very tired. I don't walk for long distances. I also had problems when I was in hospital, I worried over what other people are going to say. I thought I am going to be a laughing stock amongst women. My flat bosom on one side embarrassed me a lot. I kept saying, how am I going to undress in the presence of other people at conferences? I asked myself whether I am going to be a loner. I hated the cancer when spoken about. I also hated when it was mentioned by health professionals.

I was under the impression that I am the first person in my area to be a victim of cancer. To this end I thought I am going to nauseate (ba yi le gonyonya) people as soon as they know that I suffer from this disease. I feared that my colleagues at school are going to be afraid to associate with me.

I asked myself the question, "what am I going to tell my family when they ask me about this disease? What about my children if they want to know what they must tell those who are interested to know, what I suffer from?" I experienced problems with the word "kanker". I said to my children, tell relatives I had a breast operation, don't tell them I had the breast removed. I don't want any person to know my secret.

INT: Mmh, I understand, you don't want people to know that you suffer from cancer?

RESP: "I don't want!" [Her facial expression emphasized her anger.]

My secret did not work whilst I was in hospital, my brother visited me and he reported to me that he is aware that I have had a mastectomy. I thought, "my goodness, the cat is out of the bag!" However, because I was feeling better after the surgery, I accepted the fact that now people knew that my breast is removed. In the ward many women had the same

operation. This consoled me, now that I was having fellow patients who shared my plight. The sisters in the ward called us together to talk to us about this disease, what it does and what can happen.

INT: Were they nice to you?

RESP: Very nice and kind. I then realised that a lot of women had cancer of the breast, and that it is not what I thought - contagious. I was relieved because I thought people were going to shun me.

INT: Ma, where do you come from?

RESP: Verdwaal, a village a few kilometres from Lichtenburg in the Ditsobotla area. My husband died many years ago.

INT: What is your source of income?

RESP: My children look after me and I receive pension money. Actually I baby-sit for my youngest daughter and I am paid for that.

INT: Is there anybody in your family who suffered from cancer?

RESP: Yes, my uncle had an amputated leg when he died many years ago, and it was rumoured that he suffered from "kwasi", although witchcraft cannot be ruled out. It was believed he trampled on witchcraft that is how he lost his leg.

INT: Tell me how often do you go for medical check-up at Ga-Rankuwa hospital?

RESP: Six monthly. Although I hate travelling by car, I hate travelling by these fast moving ambulances even more. I fear close spaces so travelling by ambulance gives me a feeling of suffocating. I was once involved in a car accident, so going by car for medical check-up is a real ordeal for me. Now my son-in-law drives me to Ga-Rankuwa which I don't like because I am now a burden on him.

INT: Have you had chemotherapy?

RESP: No! Thank God! I am told it makes you vomit a lot and have your tummy running for days.

INT: Have you got any other problems?

RESP: Yes, fear of spread of the disease and loss of weight which I notice in fellow patients at Ga-Rankuwa. My children are big but I am not yet ready to die, especially from "kwasi".

INT: Thank you for your time and for allowing me to ask you questions in your home.

DIPOTSOPATLISISO

Thuto eno e rotloeditswe ke polelo: Tsweetswee, ananya le. nna maitemogelo a gago go tloga ka nako ya fa go lemogiwa gore o na le. kankere ya sehuba go sena go totobadiwa go fitlha gompieno.

P: Ke na le mengwaga e le 63. Bolwetse bono bo tlhomamisitswe ngwaga o o fetileng. E rile ka letsatsi lengwe ke sa ntse ke le mo tirong, fa ke tsoga ke tlhapa go ipaakanyetsa go ya sekolong, fa ke tsamaisa lesela jaana (molwetse o kaya ka fa go tlhapa go amileng letsele) mo letseleng ke gatelela, ka bo ke utlwa konopi. Ka e tshwaratshwara ka letshogo, ke tlosa lesela la go tlhapa.

Ka bona gore ke sesonyana se se sa bonaleng. Ka se tshwarela ka mo gare, ka se ka ka isa tlhogong. Ka tlhapa, ka tsamaya go ya sekolong. Ka ya jalo ka bo ka fetsa nako e e kana ka kgwedi ke ntse ke se utlwa.

R: Mm! Jaanong?

P: Ka simolola go tshwenngwa ke gore tlang se sa thubege.

Ka bo ke bolelela tsala ya me. A bo a se tshwara le ena a se utlwa. Ka simolola go tshoga.

R: Se ne se lekana le eng?

P: Nawana.

R: A mme se ne se le botlhoko?

P: Nnya, ga se botlhoko, ga se ope, ga se reng. Ke fela fa ke se utlwang.

R: Mm! Jaanong?

P: Fa kgwedi eo e fela, ausi wa me a bo a tla go tswa Johannesburg (Gouteng). Ke mooki yo o kwadisitsweng. Le ena ka bo ke mmontsha re le mo gae. A bo a re mo go nna: "Mma, e ya fela kwa ngakeng, letsele ga le a tshwanela gore le nne le mathatanyana a gore le tswe selo sengwe."

R: Mogolo ke mooki?

P: Ee, ke mooki.

R: Jaanong?

P: A re e ya fela kwa ngakeng. Ka ya fela ka mafega. A nkemela a re ke ye. Ka ya go tihotlhomisiwa lwa ntlha.

R: O ne a dira ditlhotlhomiso tsa eng mma?

P: Sukiri le madigodimo. Ka bo ke boela ngakeng Ke lebala go mmontsha seso sele. A ke re ga se ntshweney! Fa ke tsena mo gae ka re: "Le batho ga ke a ba bontsha selo sele. Kana ga se ntshwenye, ga se ope, go didimetse fela. Se ntshwenya fela ka gore fa ke tlhapa ke thulana le konopi e."

Ka bo ke dula ke re gongwe ke tla boela ngakeng gape.
Ke ne ke ipoleletse gore fa ke ya nka se ka ka ba ka lebala.
Ka bo ke ya, mme ka bontsha ngaka .

R: Morago ga nako e kana kang?

P: Jaanong e ne e le kgwedi morago ga go lemoga letlhole.

R: Ka mafoko a mangwe o ntse dikgwedi tse pedi ka letlhole le pele o le bontsha ngaka?

P: Ee! Jaanong ka se bontsha ngaka. Ngaka a se phopholetsa a bo a se bona.

R: Mm!

P: "Jaanong ke a tlhomamisa." Mooki a bo a setse a golaganya. Ngaka ya bo e re: "Fa o tswa mo o ye go bona ngaka ya marapo." Ka bo ke tsena kwa go ena. Le ena a bo a se tswara ke sena go mmolelela gore ke rometswe ke mang. Fa a sena go tshwara 'konopi' are: "Ke batla gore o ye go e tlhatlhoba kwa bookelong ba Ga-Rankuwa.

E ne e le Ngwanatsele jaanong, ka 1993.

A bo a re o nkeletsa gore ke ye yona beke eo kwa bookelong ba Ga-Rankwa. A kwala. Ka bo ke re: Iketle pele ngaka. Ke tshwanetse gore ke ye kwa Ga-Rankuwa ka Sedimonthole ke ye go bona bana. A bo a re "go siame"! Fela fa o fitlha teng, o se ke wa boa koo o sa ya ngakeng. A mpotsa gore a ga se ntshwenye.

Ka re nnyaa, ke selo fela se dutse fela. Ngaka ya botsa gore ke tlile go ya neng Ga Rankuwa ba ye go bona gore ke eng. Ke dirile fela jalo fa ke tsena kwa bookelong ba GaRankuwa. Ke ne ke tshwere lekwalo le le tswang kwa ngakeng go tswa kwa bookelong ba Thusong. Kwa Ga-Rankuwa dingaka tsa mekamekana le nna, mme ba bo ba re: "Mma, selo se ke kankere. Go tshwanetse gore letsele lê, le tloswe."

Ka kopana tlhogo, ka tlhakatlhakana. Ka lela. Ka utlwa gore ga go ntsee sentle. Ka re nnyaa, mme fela go sa kgonege gore ke gane.

Dingaka tsa mpolelela ka ga kotsi ya bolwetse bo, le gore nka bo ke tlile ka nako. A ke re jaanong nna ke ne ke makaletse gore konopinyana e e seng botlhoko, a e ka tlosa letsele la me.

Ba mpha nako, ka lela ka ba ka siama. Fa ke fetsa moo, ba re selo seo se tshwanetse se tloge ka bonako. Ka dumela. Ke ne ke na le banake ka bobedi. Le bona ba bolelelwa. Jaanong le bona ba bua le nna. Ka buisana le bona, mme ka ineela. Ka robala mo bookelong go tloga ka la 28 Sedimonthole 1993.

Ka tshwanelwa ke gore go tloga motsing oo, ke nne dibeke tse thataro (6) ke tsamaya "Radio therapy" ko bookelong jwa H.F. Verwoerd.

R: Go ne go ile go dirwa eng koo?

P: Le ne le fisiwa. Ba le fisitse. Go fetile dibeke tse thataro (6) ke ntse ke ya letsatsi le letsatsi. Fa ke fetsa beke ya borataro, ka bo ke ya gae.

R: Motšhini wa Radio Therapy o ne o go tshwere jang?

P: Sentle fela. Go ne go se na mathata. Ke ne ke bona ba bangwe ba ke tsamayang le bone ba na le mathata. Gone, ba ne ba re boleletse gore fa go nna e ke te re tšhwele, re ba bolelele. Nna ke feditse ke bona go siame fela.

Fela, morago ga ke sena go fetsa beke mo gae ke fa go nna o ka re go a tleboga (Go phanyega letlalo), mme e seng thata, go sa tshwane le ba bangwe kwa bookelong.

R: Mm.

P: Ga ke ise ke nne le bothata bo bo tshwanang le gore ke nne ke sa robale, kgotsa eng. Ke ne ke utlwa fela goswa bogatsu ga lebogo go sa ntse go le teng.

Ka nna ka alafiwa kwa bookelong ba H.F. Verwoerd morago ga kgweditharo nngwe le nngwe.

R: O alafiwa eng mma?

P: Ba ne ba ntlhatlhoba, ba mpha dipilise, mme fela ba sa ntlhabe lomao le di X-rays. Mme ba ne ba re ga go na mathata.

R: Go raya gore o filwe phekolo ya matlhasedi (Radio therapy) fela? Ko motšhining ga ba a go fa chemotherapy?

P: Ee.

R: Mrna, Rre o teng?

P: Nnyaa, Rre ke kgale a tlhokafetse.

R: Mma, o na le selo se se esi se se go tshwenyang.

P: Ka gore ga ke sa tlhole ke na le bana ba bannye, ke gopola gore ka mokgwa o mongwe ke ne ke lekile gore wa gofejane a kgone go ikemela, gore a se tshwenyege fa go ka diragala gore ke tsamae ka ke tla bo ke itse gore ga go na sepe se se tla bong se setse, se se tshwanetseng gore ke se mo direle. Ke boitumelo le kgotso fela.

Mme, fa nako ya me e tla gore ke kgaogane le bona, ke tla bo ke kgotsofetse ka se ke ba diretseng sona. Ke ba godisitse, mme ba a itirela, ba na lemetse ya bona.

R: Ke eng se se dirang gore o itshwarelele mo botshelong?

P: Ke fiwa matla ke Modimo. Mmele o siame ga ke na maitšhuitšhu. Ke na fela le letsapa le le ntshwenyang le le sa feleng. Mangole a a lapa, le fa ke tsamaya. Go a gana gore ke tsamae sebaka se ke se tlwaetseng ka maoto.

R: Ke diphetogo dife tse kankere le kgaolo ya letsele di e tlisitseng mo botshelong jwa gago?

P: Ke nna le mathata fela fa ke sa dirise melemo.

R: Le eng gape?

P: Ke ne ke tshogetse gore batho ba tile go ntshega. Go ne go se bonolo fa le sena gi fisiwa le kgaolwa (letsele).

Ke ne ke tshogetse gore batho ba tlile go ntshega . Ba kwa gae le bona ba tlile go mmakalela. Jaanong, se setona, ke re, fa ke se na letsele mme ke bona ba bangwe, go nna maswe. Ke ipotsa gore a fa ke ile dikhosong le ba bangwe, a ke tla tlhola ke kgona go apola mo pele ga bona. Go tla utlwala jang? A batho ba tlile go ntshaba ba nnyonye? Kwa dikhonfereseng tsa Kereke? A ke tla kgona go apola mo pele ga batho?

Ke ila leina la kankere, ke a le tshaba. Ka re ga ke ise ke bone bolwetse jo bo jaana kwa gae. Jaanong ke nna wa ntlha fela kwa gae mo kgaolong ya Ditsobotla (Lichtenburg) yo o tlositsweng letsele. Ke ipotsa gore a ke tla dira jang gone gore batho ba se ka ba itse.

Jaanong fa ke le koo, bonnake ba ne ba tshwanetse gore ba itsise ba kwa gae gore ke kwa bookelong, ba se ka ba bolelela ba kwa gae gore ke dirile karo, mme ba se ke ba ba itsise gore ke karo ya eng. Kana ke ne ke batla go ba itsise morago ka kgang ya go ntshiwa ga letsele.

Go ne go tla ba kwa gae ba ba nnang kwa Ga-Rankuwa go tla go ntlhola, mme ka bona gore oo! Sephiri sa me se ya go tswela mo pepeneneng. Go ne ga diragala fela jalo. Ba bolelela ba bangwe, mme fa ba tla ba bua gore ba utlwile gore ke dirile karo mme letsele le kgaotswe.

Ka nako eo, malatsi a ne a ntse a atamela gore ke tle gae, mme jaanong ka bona go le botoka gore ke lwale thata. Ka bolelela bana gore ba ba bolelele

nnete yotlhe, kooteng ke ne ke bona gore ga ke lwale thata jalo. Ka bona gore bosigo bo a sa, mme bo seswa ke gore ke a bona re bantsi ba re tshwereng ke bolwetse jwa mabele a a kgaotsweng. Ka botsa lza bangwe gore ba tswa kae, mme ka tshwenngwa ke gore botlhe ba tswa kgakala kwa, mme ka bona yo o tswang fano e le nna fela.

Re ne ra bolelelwa gore ga se bolwetse bo bo tshelanwang. A ke re nna ke ne ke tshogetse sona seo gore batho ba tlile go ntshaba. Re ne re bolelelwa ke mooki kwa bookelong. Lotseno mo ntlong lo tla ka madi a bagodi le bana.

Kgwedi e nngwe le enngwe ke ya kwa Mafikeng go bana, e nngwe ke ya kwa Mafikeng go bona bana, e nngwe ke ya kwa Ditsobotla (Lichtenburg). Mme kenna kgakalanyana, gona mo ntlong e. Ntlo ya me yona e kwa motseng wa Verdwaal. Ke tihola ke ntse le ngwana wa ngwanake.

R: Mo losikeng lwa lona o teng yo o kileng a tshwara ke yona kankere?

P: Fa re ntse re gola, ke fitlhetse rremogolo wa me. E ne e le kgale. Re ne re sa itse gore o ne a tshwere ke eng. Fela, ke itse gore o n e a feleletsa a kgaotswe leoto. Ke ne ke sa itse ka bolwetse ba kankere. Ka gore batho ba ne ba ithaya ba re o loilwe. Fela, o ne a kgaolwa leoto.

A mangwe mathata ga a yo mme. Ke a leboga.

Bokhutlo.

R: RESEARCHER
P: RESPONDENT



University^{of} Bophuthatswana

Department of Nursing Science

Private Bag X2046 MMABATHO 8681
Republic of Bophuthatswana
Telephone (0140) 21171/5
Telex : 3072 BP
Fax Machine No.: (0140) 25775
Telegram : UNIBO

Date 21 February 1991

Your reference

Our reference MK/emn

Dr P K Mokgethi
The Secretary for Health and Social Services
Private Bag X2068
MAFIKENG
8670

Dear Dr Mokgethi

Re: APPLICATION FOR CONSENT TO CONDUCT RESEARCH IN BOPHUTHATSWANA

I hereby apply for permission to undertake a study in the Bophuthatswana health facilities. The study is based on "Cancer" as reflected on the proposal. I intend collecting data with effect from June 1991 to December 1992. This is a longitudinal study since one is unsure of the number of respondents who will satisfy the criteria.

Find enclosed a copy of the proposal.

Thank you.



Prof M Kau
ACTING: HEALTH AND SOCIAL SCIENCES

Enc.

REF. NO. : 7/2/7 (2/91)
ENQ. : M.J. MOLEMA
TEL. NO.: (0140)29x2837

DEPARTMENT OF HEALTH
AND SOCIAL SERVICES
PRIVATE BAG X2068
M M A B A T H O
8681

07 MAR 1991

(Prof) Mrs. Mary Kau.
Dept of Nursing Sciences
Univ. of Bophuthatswana
Private Bag X2046
M M A B A T H O
8681

Dear Sir/Madam

RE : PERMISSION TO CONDUCT RESEARCH IN BOPHUTHATSWANA

1. After a careful consideration of your proposal to embark on a research project, the Departmental Research Committee resolved that your application be approved subject to the following conditions :

- 1.1 that you supply the undersigned with progress report on a regular basis,
- 1.2 that on completion of the research project, a copy of your findings and or recommendations (research report, dissertation or thesis), be submitted to the undersigned,
- 1.3 that the use of manpower in institutions, organisations and or establishments to be visited, is the prerogative of the undersigned and,
- 1.4 that permission to publish findings is subject to the approval of the undersigned.

2. You are advised to use the reference No.7/2/7(^{2/91}) for easier reference and or enquiries on this matter. Please read with my 7/2/7(M/F) dated

3. Your usual co-operation is highly appreciated.

SECRETARY FOR HEALTH AND SOCIAL SERVICES

Sekretaris van Gesondheid en Volkswelsyn
Secretary for Health and Social Welfare

/cbn

Tirelopuso ya Bophuthatswana
Ranbuthatswana

THE UNIVERSITY OF THE ORANGE FREE STATE



Department of Internal Medicine
Faculty of Medicine

☒ 339 (G73) BLOEMFONTEIN 9300 REPUBLIC OF SOUTH AFRICA
☎ (051) 405-3154 FAX (051) 481284 SA

Enquiries:

1993-11-10

Prof M Kau
Head: Department of Nursing Science
University of Bophuthatswana
Private Bag X2046
MMABATHO 8681

Dear Professor Kau

Thank you for your letter of 3 November 1993 requesting permission to obtain data on Post-Mastectomy patients.

Your letter has also been referred to professor E J Theron (Head of the Department of Surgery) as well as dr J S van Zyl (Head of the Department of Plastic Surgery).

They will be in a position to provide you with the information you want.

In the meantime preliminary approval is granted to proceed with this study. I will asked the ethics committee at it's next meeting of the 7th of December 1993 to condone my decision.

With best wishes.

A handwritten signature in black ink, appearing to read 'W F Mollettze'.

PROF W F MOLLENTZE
CHAIRMAN ETHICS COMMITTEE

T.P.H. 49

TRANSVAALSE PROVINSIALE HOSPITALE

TRANSVAAL PROVINCIAL HOSPITALS

Telegrafiese Adres
Telegraphic Address

GA-RANKUWA - HOSPITAAL
HOSPITAL

Telefoon Nr.
Telephone No. 5293201./Dr. J. J. Crous

PRIVATE BAG X422

IN ANTWOORD VERMELD ASB.
IN REPLY PLEASE QUOTE
No. 1/5/1

PRETORIA

0001

Alle korrespondensie moet aan die
Superintendent gerig word.
All communications to be addressed to
the Superintendent.

12 November 1991

The Head
Department of Nursing Science
University of Bophuthatswana
Private Bag X2046
Mmabatho
8681

Dear Prof Kau

re: PERMISSION TO UNDERTAKE RESEARCH IN OUR HOSPITAL

Thank you for your letter dated 23 October 1991 in the abovementioned regard. Your previous letter did unfortunately not reach my desk.

I have discussed your proposed project with my Nursing Administration. They have intimated that they do recommend your project and would offer you every possible support in your venture.

You are hereby being given permission to proceed with your plans. You are also advised to communicate in future directly with our Chief Nursing Services Manager, Miss D C Moll.

Yours faithfully


DR J J CROUS
CHIEF MEDICAL SUPERINTENDENT /bf

TRANSVAALSE PROVINSIALE HOSPITALE

Telegrafiese Adres
Telegraphic Address

Telefoon Nr. 373 8011 X 3003/8
Telephone No. DR J A KUNZMANN/db



TRANSVAAL PROVINCIAL HOSPITALS

KALAFONG..... HOSPITAAL HOSPITAL

PRIVATE BAG X 396

PRETORIA

0001

IN ANTWOORD VERMELD ASB.
IN REPLY PLEASE QUOTE
1.5.1
No.....

Alle korrespondensie moet aan die
Superintendent gerig word.
All communications to be addressed to
the Superintendent.



MRS. M KAU
P O BOX 4152
MMABATHO
REPUBLIC OF BOPHUTHATSWANA
8681

RESEARCH PROJECT

Your telefax request of 22 January 1991 refers.

The Superintendent has no objection to the proposed study. However, permission for any research purpose must be obtained from The Deputy Director-general, Branch Health Services, Private Bag x 221, Pretoria,0001.

Your request should contain the following information:

- a. The draft of the proposed study protocol if it has not been finalised.
- b. An undertaking that hospital staff will not be utilized in data acquisition.

It is also customary and highly appreciated if a copy of the final report is made available to the Branch Health Services.

Yours sincerely


SUPERINTENDENT

PROTOCOL FOR CO-CODERS

CONTENT ANALYSIS OF DATA OBTAINED DURING IN-DEPTH INTERVIEWS

Dear Colleague,

As discussed during our meeting on Thursday, please follow the steps below to analyse the data of the transcribed interviews in accordance with Tesch (1990) in Creswell (1994:155) and Strauss & Cobin (1990:61).

1. Read all 16 transcriptions to obtain a sense of the whole, then from each transcript, isolate the relevant ideas, meaning of words and thoughts.
2. Isolate the major themes from each transcript and place these in columns.
3. From (2) above, please identify sub-categories.
4. Topics which you consider relate to each other should be grouped to form interrelationships.
5. Compare all transcriptions and indicate from each category how many respondents used the same words and phrases.
6. Finally, identify relationships between major and sub-categories.

Thank you for your co-operation.

Mary Kau
D.Litt et Phil (Nursing Science) Student

APPENDIX L

**P.O. BOX 4152
MMABATHO
2735**

25 FEBRUARY 1996

Dear Madam

I am a doctoral student at UNISA. I am undertaking research to establish "the effects of cancer of the breast and mastectomy on Black women in former Bophuthatswana". My supervisors are Professor J.M. Dreyer and Professor M. de Jongh of UNISA.

The purpose of this study is to establish what psycho-social effects the diagnosis cancer of the breast and its treatment have on the Black woman in former Bophuthatswana.

To successfully complete this study, I need to undertake interviews with mastectomised women to find out their experiences with the disease and its treatment. The interviews are going to be audiotaped for verification of findings by independent nurses and, if need be, by promoters if so desired. To protect you, the following steps will be followed:

- Your name shall not be used anywhere.
- Data obtained shall be kept under lock and key when not in use.
- No other person will have access to the data except the researcher, co-coders and promoters.
- My forwarding address and telephone number will be made available just in case you need to contact me.
- I shall provide you with a summary of the findings if you so desire.
- Should you feel you no longer wish to continue with the interview, then it will be terminated forthwith according to your request.

Participation in this study, however, will benefit mastectomised women in future by enabling them to adjust and adapt to the disease and its treatment. Moreover, information from this study will improve oncology nurse training to assist with the adaptation of mastectomised women to the diagnosis and treatment.

**M. KAU
D.Litt et Phil (Nursing Science) Student**