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**AN EVALUATION OF THE FOLLOW-UP NURSING CARE OF
ADULT CANCER PATIENTS IN THE WINDHOEK AREA - A
GENERAL NURSING PERSPECTIVE.**

by

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the degree of**

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**SUPERVISOR: PROFESSOR C SEARLE
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DECLARATION

I declare that "An evaluation of the follow-up nursing care of adult cancer patients in the Windhoek area - a general nursing perspective" is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete reference.

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SUMMARY

Follow-up nursing care has always been part of community health nursing services.

The aim of the study is to evaluate, from a general nursing perspective, the follow-up nursing care of adult cancer patients discharged from the Windhoek Hospital.

The research approach is a descriptive survey. Structured and unstructured interviews and questionnaires were used to collect data.

The findings revealed that cancer patients are not adequately prepared for discharge, that follow-up nursing care of cancer patients is inadequate, and that patients experience difficulty in regard to the financial aspects of self-care particularly in respect of nutritional, medication and surgical dressing needs.

The findings indicate that that there is a need for nurses to be actively involved in the follow-up nursing care of cancer patients, and for a programme of home-care, to be introduced within the parameters of Primary Health Care programmes.

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CHAPTER 1

INTRODUCTION AND STATEMENT OF THE PROBLEM

1. INTRODUCTION

Cancer is a universal health care problem. Throughout the world about 4 million deaths occur each year - all due to cancer (Reed Ash, 1986 : 172). although cancer occurs in children and adolescents it is more prevalent in the aged. Thus, the number of cases has increased by virtue of the increase in the aged population (del Regato et al, 1985 : X). Apart from human misery, the financial burden in terms of drugs, medical care, hospitalization, home care and loss of earnings is staggering. The tragic progression of the disease will continue as long as people do not seek help during the early stages of the disease (Barckley, 1980 : 31).

In the United States of America (USA) the annual incidence rate is about 30 per 100,000 individuals of 20 - 24 years of age but rises to 190 for those of 40 -44 years, 900 for those of 60 - 64 years, 2000 per 100,000 persons of 80 - 84 years old (del Regato et al, 1985 : X). The rates are higher for White than Black men, about 397 and 342 per 100,000 respectively, and for White and Black women, about 270 and 247 respectively (del Regato et al, 1985 : X).

In 1989 T. Green, Vice-President of the American Cancer Society, oncology nurse specialist and current chairman of nursing education at International Union Against Cancer (UICC), said that it was estimated that 3 million people would die of cancer during that year (Report on UICC workshop held at Fort Hare University, 1989).

In 1989 Dr. M.J. Otto, co-ordinator of the South African Cancer Registry stated that the total population of South Africa is 30 million. The top six cancers in South Africa are cancer (Ca) of the oesophagus, mouth, lip and face, prostate, breast, uterus and liver. The rate of Ca oesophagus among Black males is 28,4 per 100,000 and of Ca cervix among Black women is 20,1 per 100,000. (UICC Report, Fort Hare University 1989). In Namibia statistics for cancer mortality and morbidity are not readily available as is the case in many developing countries. Prior to independence the Department of National health and Welfare started to compile a cancer Register for Namibia. The figures for the years 1987, 1988 and 1990 are reflected in Table 1.1. These figures do not reflect the total incidence of cancer for the following reasons:

(i) these figures only include histological provenly diagnoses and exclude clinical diagnoses such as chest X-ray e.g. lung cancer and clinical examination;

(ii) patients seen in outlying areas who only require palliative treatment are not referred to Windhoek;

(iii) a number of patients choose to be treated by traditional healers and never come to the health service;

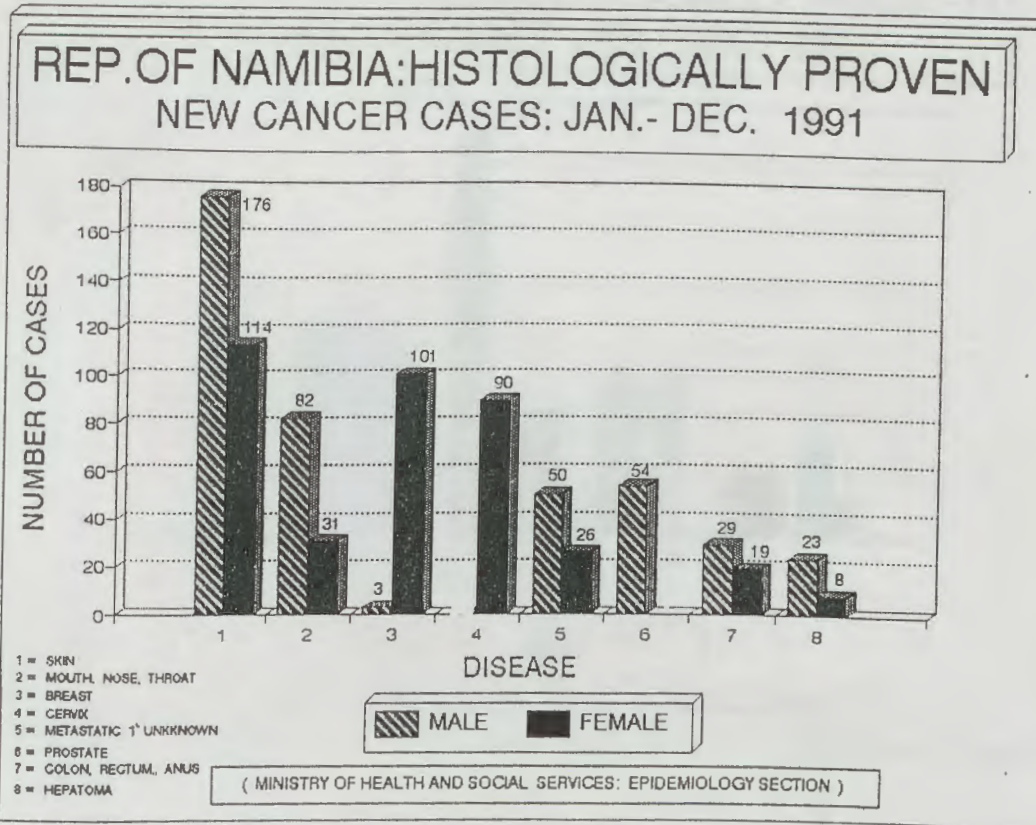
(iv) there are patients who prefer to be referred to the Republic of South Africa (RSA) and thus bypass the Windhoek Oncology Unit.

Cancer of the cervix and breast are the commonest cancers affecting women in Namibia. The number of new cancer cases for the year 1991 is reflected in Graph 1.1. The incidence of new cases of Ca skin for both men and women is relatively high (Graph 1.1.). Cancer of the prostate is also high. Cancer of the mouth, nose and throat is also causing concern as it has a total of 113 new cases of both sexes. Knowledge of the relatively higher or lower incidence of the various forms of cancer age groups is important in clinical practice. Graphs 1.1, 1.2, 1.3, 1.4 and 1.5 reflect the number of new cases of the various types of cancer for the year 1991.

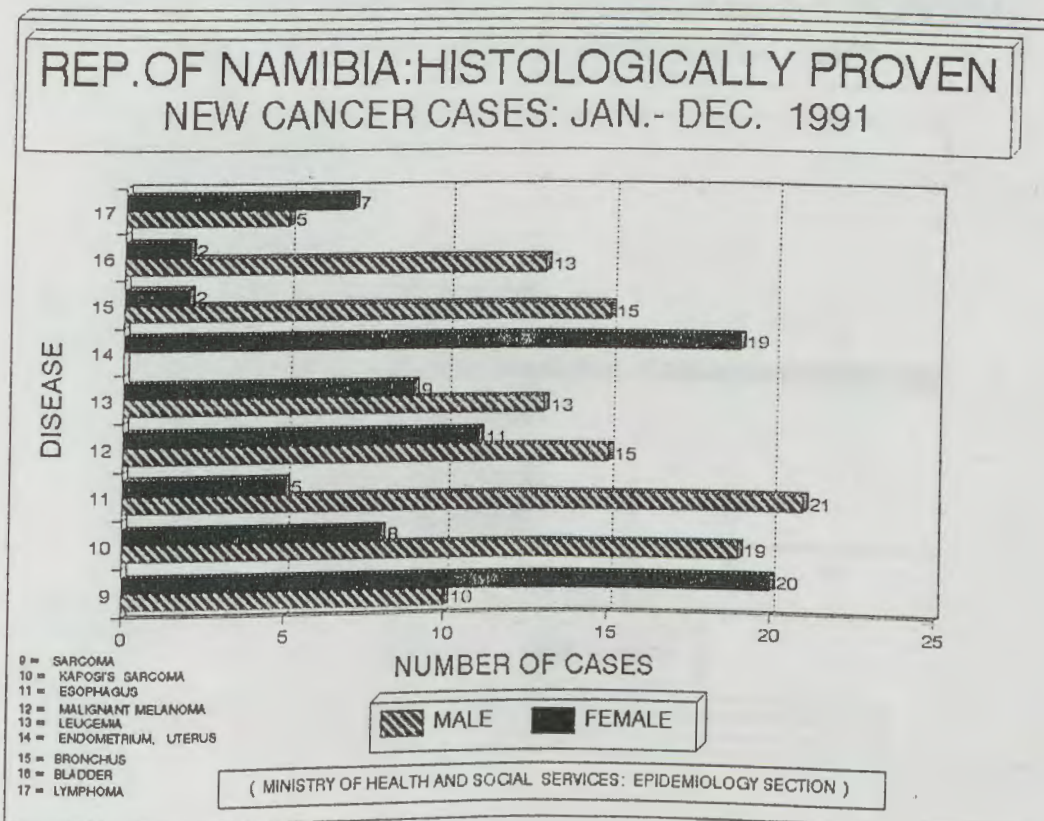
TABLE 1.2 NUMBER OF HISTOLOGICALLY PROVEN CANCER CASES

TYPE OF CANCER	DEC 1986 DEC 1987	JANUARY - DECEMBER 1988	1990
MALIGNANT MELANOMA	-	36	15
SKIN	297	267	279
MOUTH, EAR, NOSE, THROAT	180	179	112
MAMMA	127	97	129
CERVIX	113	78	123
PROSTATE	113	110	45
COLON, RECTUM, ANUS	39	33	34
LIVER	35	42	20
METASTATIC CA - 1 UNKNOWN	56	33	71
LYMPHOMA, HODGKINS	33	19	10
LUNG	34	23	-
LEUKEMIA	32	29	14
ENDOMETRIUM, UTERUS	29	17	17
BLADDER	27	18	24
SARCOMA	27	18	32
OESOPHAGUS	26	20	35
OVARIA	14	13	8
KAPOSI SARCOMA	13	13	28
THYROID	10	7	8
KIDNEY	4	11	9
STOMACH	9	18	11
TESTIS	3	1	-
MYELOMATOSIS	8	11	4
LARYNX	-	-	36
BRONCHUS	-	-	30
DIVERSE	-	-	11
EYE	-	-	10
PENIS	-	-	7
VAGINA	-	-	5
SALIVARY GLANDS	-	-	4
VULVA	-	-	3
PANCREAS	-	-	2
GALL BLADDER	-	-	2

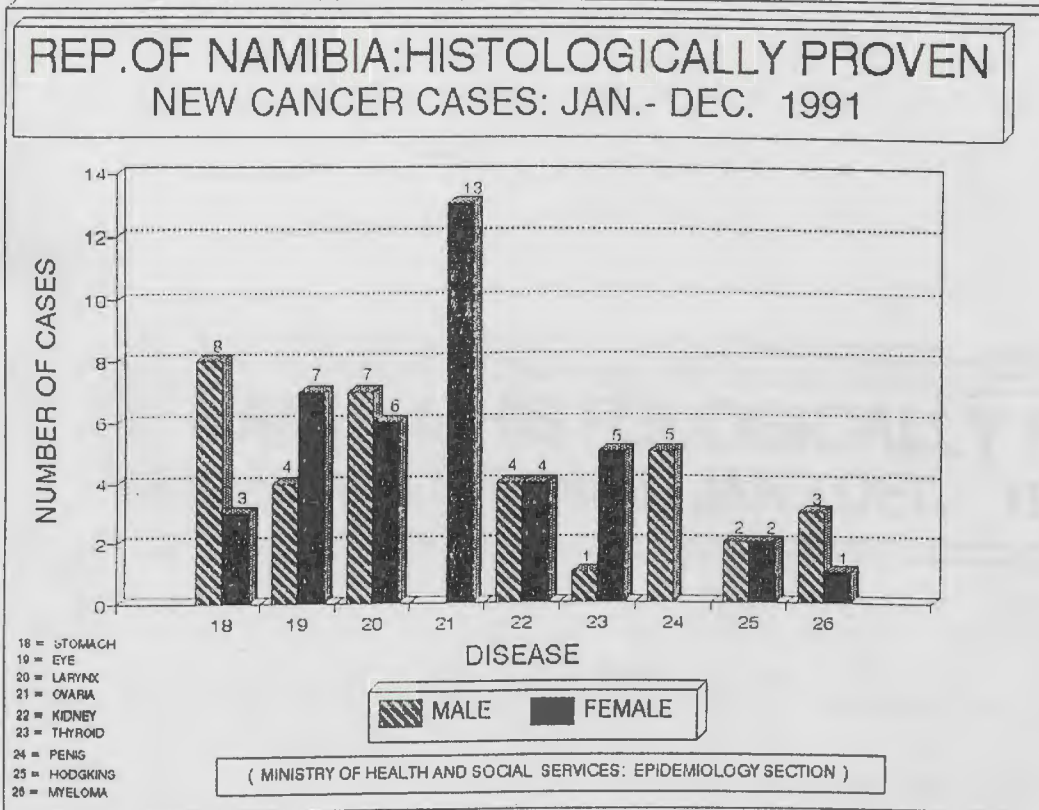
GRAPH 1.1



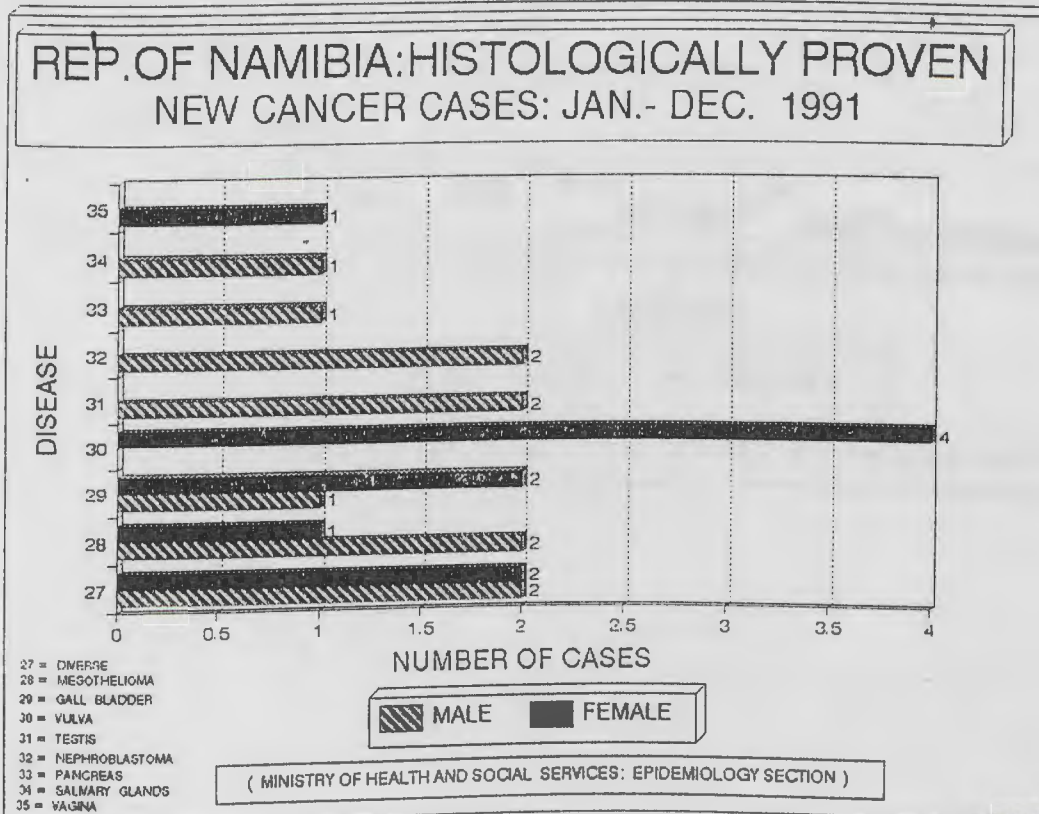
GRAPH 1.2



GRAPH 1.3

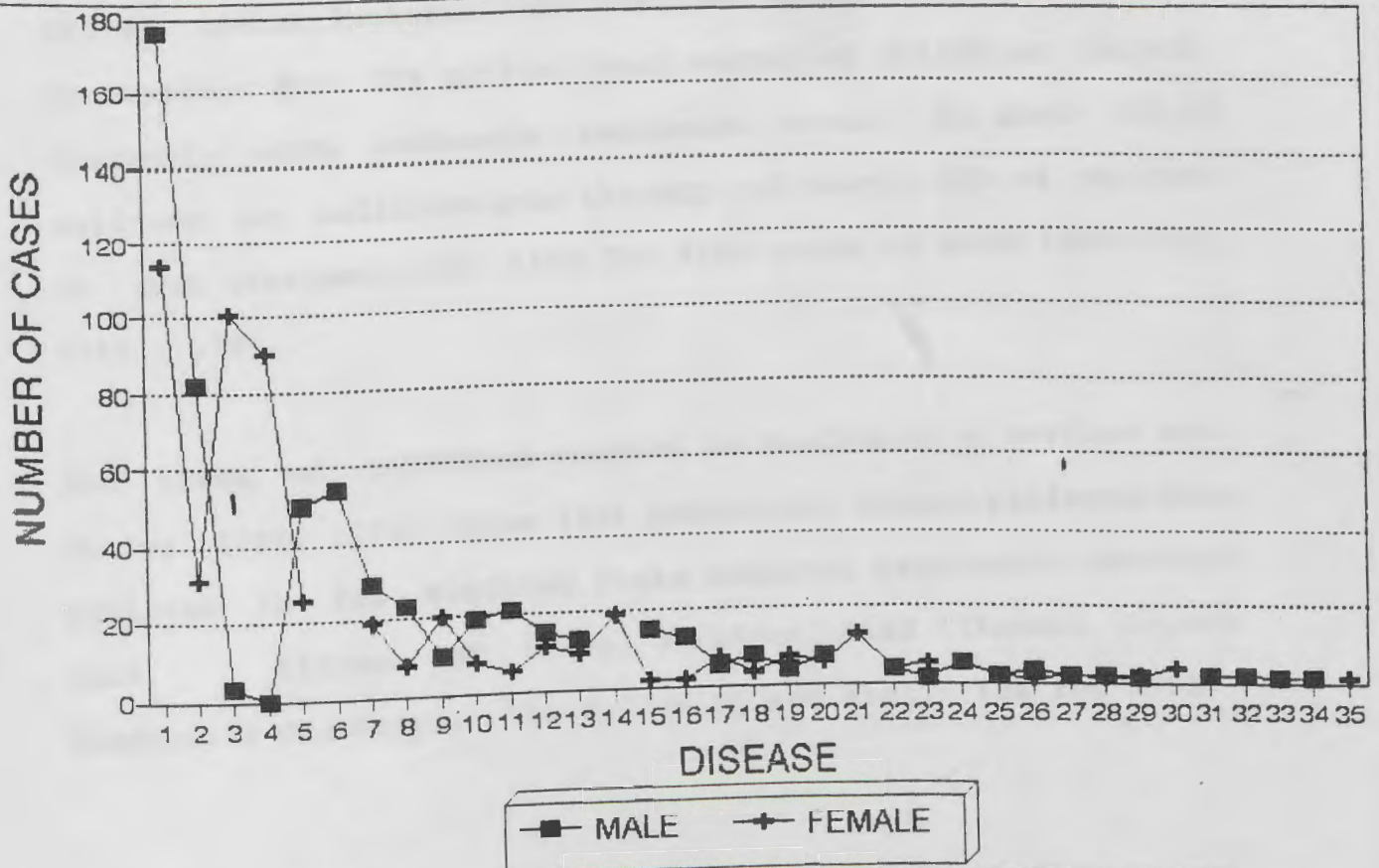


GRAPH 1.4



GRAPH 1.5

REP. OF NAMIBIA: HISTOLOGICALLY PROVEN NEW CANCER CASES: JAN. - DEC. 1991



(MINISTRY OF HEALTH AND SOCIAL SERVICES: EPIDEMIOLOGY SECTION)

In 1989 Colvin from the Johannesburg General Hospital, RSA, stated that 80% of childhood cancer is due to leukaemia. The age group affected by retinoblastoma is 17/12 months. Twenty five percent (25%) of retinoblastoma is bilateral and 2% spread to the brain. Twenty percent (20%) of all childhood cancer is due to nephroblastoma (Report on UICC workshop at Fort Hare, 1989). According to Barckley (1980 : 173) in the United States leukaemia was the most common childhood cancer, accounting for 50% of the total number of childhood cancers. Currently with leukaemia remission occurs in about 85% of children on multiple-drug therapy and nearly 15% of children on such treatment will live for five years or more (Barckley, 1980 : 174).

The issue of childhood cancers in Namibia is a serious one. During 1991, fifty three (53) paediatric cancer patients were admitted to the Windhoek State hospital paediatric oncology unit. Sixteen of these children died (Annual Report Paediatric Oncology). The following are statistics for 1991.

Data from Windhoek Paediatric Oncology Unit 1991.

Table 1.2

TYPE OF CANCER	NO OF PATIENTS	NO OF DEATHS
Acute lymphocytic leukaemia	9	3
Acute mycoblastic leukaemia	2	1
Retinoblastoma	7	2
Neuroblastoma	7	2
Wilhm's Tumour	6	1
Hodgkin's disease	5	-
Brain Tumour	2	1
Rhabdomyosarcoma	5	1
Osteogenic sarcoma	4	2
Burkitt's lymphoma	3	2
Bladder carcinoma	2	1
Ovarian	1	-

1.1 The Problem:

The incidence of childhood cancer in Namibia is such that it warrants a separate study. For this reason the present study is concerned with adults only. It is obvious that even in a developing country like Namibia cancer is a problem. Much is being done about cancer prevention and early detection and cancer treatment such as health education, papsmeas, breast examination sessions, surgery and chemotherapy. Yet according to the Cancer Association it is not enough. The type of education given must go hand

in hand with all forms of cancers and cancer treatment and care.

Recent improvements in diagnostic techniques and treatment modalities have resulted in shorter periods of hospitalization or even treatment on an out-patient basis. As a result, the responsibility of providing care at home for the patient with cancer rests mainly with the family members. This responsibility contributes to stress for family caregivers because of their lack of knowledge in implementing the required skills in managing the daily care of the patient (Cawley & Gerdts, 1988 : 268). Worldwide there appears to be inadequate after-care services (Brink, 1988 : 11, 16). Brink found that patients with advanced cancer in the Republic of South Africa (RSA) do not differ substantially from those in the USA and the United Kingdom. Previous findings by McCorkle that self-care, social and mobility problems are major concerns of patients with advanced cancer were confirmed by Brink's study (Brink, 1988 : 16). There is a need to establish what after-care is provided for adult persons who had cancer treatment in Windhoek. Some questions must be asked: What is the extent of the problem that is faced? What are the health care authorities doing? Are there after-care programmes by health authorities and is there private voluntary assistance? To what extent does this meet the need? Are student nurses taught to do this after-care?

These are some of the questions that need to be looked into. There is doubt among nurses in the Windhoek area as to whether:

- adult cancer patients are adequately prepared for discharge and for coping at home,
- there is adequate follow-up nursing care of adult cancer patients,
- the family is prepared for their involvement in the care process,
- nurses are aware of the need and equipped to follow-up discharged patients and to continue their care,
- health care authorities and voluntary health care associations have any intention to provide after-care for adult persons who have been discharged from an oncology unit or who have undergone treatment for some form of cancer.

1.2 MOTIVATION AND OBJECTIVE OF THE STUDY

For the cancer patient and family, there is nothing of greater importance besides cure itself, than how to cope with difficulties and to understand problems, to understand aberrant behaviour and to tolerate present distress through week, months or even years. Cancer is not just another chronic disease, it brings out many of the deepest fears of human beings.

It is an increasing chronic disease with intermittent acute episodes accompanied by a great deal of psychological and physical suffering. It spreads into emotional and social domains, disrupts families and challenges the values of life. Many patients have, in spite of limitations, the chance of living two or more years with their families. This is of indescribable value to the human being. It is in this context, in particular, that effective home nursing care is so important.

The need for after-care on a home-nursing basis has been identified by cancer authorities. For the state and many patients this is an economic necessity. Family support and proximity is desirable and the clients enjoy the freedom from hospital rules. The nurse is the co-ordinator and a constant source of support.

The study aims:

- to identify and describe what the nature is of home care services provided by the family;
- to ascertain whether there is a need for assistance to families in this regard and how it could be provided;
- to describe the follow-up home-nursing care that is available to cancer patients with cancer in the Windhoek area;

- to identify possible measures that could be put into operation in a developing country to improve the quality of care available.

1.3 ASSUMPTIONS

In consideration of the above-mentioned the study is a descriptive survey. The investigation is therefore, without a hypothesis and is based on the following assumptions.

- Adult cancer patients are not adequately prepared for discharge.
- Family members are not prepared for their involvement in the care process.
- Support services to adult cancer patients need expansion.

1.4 THE ORGANISATION AND PRESENTATION OF THE STUDY

1.4.1 USE AND DESCRIPTION OF KEYWORDS

Certain keywords which are used extensively in this study played a major role in the selection of the literature. For the ease of subsequent usage they are described in this chapter in the sense in which they have been used.

EVALUATION

The Concise Oxford Dictionary defines evaluation as "to ascertain the amount of". According to the Readers Digest Family Word Finder (1978 : 267, 59) to evaluate means "appraise, rate, assess, weigh, judge, estimate, value, assay", and in the same book assay in turn means to "analyse, assess, evaluate".

According to Reilly (1980 : 90) evaluation is " a judgemental process and, as such, it reflects the beliefs, values and attitudes of participants". Reilly further states that evaluation "is a major process in helping the individual to achieve self-actualization".

Self-actualization means "helping a person to develop to the fullest" (Vrey, 1984 : 42). Guinée (1966 : 205) goes further and includes interests, ideals, ways of thinking, work habits and social adaptability.

As standards for measurement are non-existent for oncology nursing in this country, in this study evaluation refers to a judgemental process that reflects the beliefs, values and attitudes of participants.

FOLLOW-UP CARE ON A HOME CARE BASIS

Improvements in cancer diagnostic techniques and various modalities of treatment have resulted in the number of

cancer patients receiving therapy on an out-patient basis. Cancer patients are discharged too soon and the family becomes responsible for providing care to the patient at home.

Blank et al, (1989 : 78) defines home health care as "that component of a continuum of comprehensive health care whereby health services are provided to individuals and families in their places of residence for the purpose of promoting, maintaining or restoring health, or of maximizing the level of independence, while minimizing the effects of disability and illness".

Follow-up care can be seen in the same light as home care for cancer patients.

Follow-up health care in the context of this study is, thus, home health care that is rendered by nurses, social workers, doctors, physiotherapists, speechtherapists and voluntary workers. Follow-up nursing care is also care provided by family members or friends.

NURSING CARE

Fawcett, (1987 : 61) states that Johnson describes nursing "as an external regulatory force which acts to preserve the organization and integration of the patient's behaviour at

an optimal level under those conditions in which the behaviour constitutes a threat to physical or social health, or in which illness is found".

Searle et al, (1983 : 12) state that McManus describes the function of a professional nurse as "The definition or diagnosis of its interrelated aspects deciding upon a course of nursing action to be followed for the solution of the problem in the light of immediate and long-term objectives of nursing, with regard to prevention of illness, direct care, rehabilitation and promotion of highest standards of health possible for the individual". For the purpose of this study the description of Searle et al, will be used including the rehabilitation aspect.

CANCER

Cancer is a large group of diseases characterized by uncontrolled growth and spread of cells (Barckley, 1980 : 7; Luckman & Sorensen, 1980 : 430). Del Regato et al, (1985 : IX) defines cancer as "a generic term for a wide variety of malignant neoplasms that may result in deleterious effects on the host due to their invasive and metastasizing character".

The term malignancy is defined as "a condition that, if

uncorrected, tends to worsen so as to cause serious illness or death" (Luckman & Sorensen, 1980 : 430).

The term neoplasm is derived from the Greek "neos" which means "new" and "plasia" meaning "growth of new tissues" (Luckman & Sorensen, 1980 : 430). A malignant neoplasm is "an abnormal growth that is always harmful to the body and that may spread or metastasize to other tissues far removed from the site of origin" (Luckman & Sorensen, 1980 : 430).

In this study, cancer (Ca) is defined according to del Regato et al, which considers what cancer means to the lay public. The families of cancer patients are members of the lay public.

PATIENT

According to Brown et al, a patient is "the individual experiencing cancer, family members and close associates" (1982 : 14). Hill & Smith (1985 : 2) define a patient as "a typical sick person who has a dependent relationship with a health care provider for the purpose of receiving health care services".

CLIENT

There are several definitions of a client. They are:

- A person who is a recipient of a professional service.
- A person who is "a recipient of health care regardless of the state of health".
- "A recipient of health care who is not ill or hospitalized" (Guidos, 1986 : 251).

PERSPECTIVE

The Oxford Advanced Learner's Dictionary of Current English (1985 : 626) defines perspective as an "apparent relationship between different aspects of a problem". For the purpose of this study the concept - a general nursing perspective - means that nursing care of cancer patients is provided by nurses who are not specialists in cancer nursing, i.e. they are not qualified and registered in oncology nursing but are nurses who provide the type of care that every registered general nurse should be able to provide.

1.4.2 OTHER IMPORTANT TERMS

ONCOLOGY

Burn, and Meyrick, (1977 : 98) define oncology as the science and study of cancer. Oncology is also used "to describe the study of malignant disease and covers all aspects of the disease" (Deeley et al, 1974 : XIII).

ONCOLOGY NURSING CARE

According to de Kleijn, and Muller, (1991 : 24) "oncology nursing care is the nursing care of patients suffering from cancer and may be curative, restorative, palliative or supportive, depending upon the medical diagnosis of the patient". In the terms of registration of nursing specialists the term "oncology nurse" reflects a person who has had a specialised course of training in oncology nursing, as opposed to the nurse who is a general nurse and provides nursing for all conditions of health.

CAREGIVER

According to Hirst & Metcalf, as quoted by Jensen & Given (1991 : 181) a caregiver is "one who attempts to meet the physiological and psychological needs of the individual."

1.4.3 PRESENTATION OF THE REPORT OF THE STUDY

1.4.3.1 Title of the Report

The report is presented under the title "An evaluation of the follow-up nursing care of adult cancer patients in the Windhoek area - a general nursing perspective".

1.4.3.2 Organization of the Report

The report is divided into five chapters.

1. Introduction and statement of the problem

2. Literature Review
3. Methodology
4. Analysis and discussion of data
5. Conclusions and recommendations

1.4.4 SUMMARY

In common with the rest of the world cancer in Namibia is a major health problem. As a result problems in the provision of health care arise. This is the case in respect of the follow-up (home care) which persons suffering from cancer and who are cared for in the family situation may need. Certain assumptions are made. The study is aimed at identifying certain key problems areas, with a view to recommending specific remedial action.

CHAPTER 2**LITERATURE REVIEW****2.1 THE OBJECTIVE AND SCOPE OF THE LITERATURE REVIEW**

A literature review pertinent to the study included an overview of writings related to the home care of cancer patients, palliative treatment, cancer rehabilitation and education and the role of the nurse in cancer nursing. From the literature review it will be possible to:

- select a relevant literature useful for this study;
- integrate literature from several content areas;
- indicate the investigator's knowledge and awareness of research specific to the problem under study (Bush, 1985: 22; Treece & Treece, 1986 : 92; Kovacs, 1987 : 43).

The objective of the literature review for this study is to:

- understand the role of the generalist nurse in cancer nursing;
- obtain an understanding of the follow-up care of cancer patients as a specific function of the nurse;

- identify published material in this regard in order to obtain background information on what to include in the instruments.

There is a great need for community based cancer nursing because of the increased awareness of the public and the increase in the incidence of the disease. Nursing schools/colleges are incorporating cancer prevention care, physical assessment and early detection in their curricula. The South African Nursing Council gives guidelines for the four-year course as a generalist nurse in the preventive, curative and rehabilitative fields.

There are many opportunities today for nurses to use their knowledge, provide competent and appropriate nursing intervention to patients, family members and the public (Reed Ash & Jenkins, 1990 : 2). Cancer nursing is an expanding, demanding and dynamic area for specialisation. The basic education of the nurses should provide the necessary foundation to enable the nurse to meet the challenge for specialisation as well as to enable her to provide basic cancer nursing. A good undergraduate education programme should enable nurses who are concerned with cancer nursing as part of general

non-specialised nursing to provide care to cancer patients in hospital and in the community (Barckley, 1980 : 5)

According to Watson (1990 : 3) Dietz and Rusk pointed out that cancer and its treatment frequently resulted in disabilities that warrant the same considerations given to disabilities arising from other causes, hence the need for generalist nursing knowledge, as well as for the preparation of specialists in this field.

2.1.1 Home Health Care Follow-up Nursing Care

Home health care is "that component of a continuum of comprehensive health care whereby health services are provided to individuals and their families in their places of residence for the purpose of promoting, maintaining, restoring health, or of maximizing the level of independence, while minimizing the effects of disability and illness including terminal illnesses" (Blank, Clark, et al, 1989 : 78 - 79).

The professional nurse is responsible for the specific nursing care of patients at high risk, and in this

case, the cancer patient. The cancer patient needs to change his habits, modify his normative prescribed social life and redefine health and illness needs to be understood by nurses, caregivers and patients (de Kleijn & Muller, 1991 : 23). The nurses objectives are to assist the patient to adjust to different ways of meeting his daily requirements, establishing new techniques of self-care, modifying self-image, developing a new life-style compatible with the effects of any disability and revising his routine of daily living (de Kleijn & Muller, 1991 : 23).

Home care nurses should make contact with the patient as soon as the diagnosis is made. Support for the patient for the trauma of the diagnosis, the fear of the treatment intervention and the fear of not coping creates numerous problems for the patient and family. The nurse who will be involved in the home care situation should make contact with the patient as soon as possible so that he/she can be mentally adjusted to the sequence of activities arising from the treatment and care (Searle, 1993 - personal communication in connection with the philosophy of cancer nursing). Close communication with families, direct patient care

and collegiality with other health care providers are some of the sources of job satisfaction (McKay, RG, 1991: 4). Therefore the nurse needs to be actively involved in home care as she is in a position to act as an advocate, facilitator and co-ordinator attending to the patient's priorities as a total person (McCorckle & Hongladarom, 1986 : 126; Cahoon, 1982 : 31).

2.1.2 The Need for Home Care

According to Oleske, et al (1987 : 191) "the National Centre for Health Statistics in America estimates that currently 3,4 million noninstitutionalized adults of 45 years of age and older need help in order to manage at home because of a chronic health problem". Cancer care is a stress-ridden situation and requires considerable skill in caring for the patient, skill that is far in excess of that needed in basic general nursing in the home care situation. It is estimated that there are many adult patients in need of home care in Windhoek. Previously the statistics of the patients discharged from Windhoek Hospital did not reflect the area from which the patient came. Statistics are only now being compiled to indicate this (Statistics of Oncology Clinic, 1993).

Studies in the USA show that cancer patients needing home care are frequently bed- or chair-bound, suffer from nutritional problems and have financial problems (Oleske, et al 1987 : 195 -196). This is where the importance of the role of the general nurse practitioners concerning follow-up nursing care for effective home care is crucial.

In Bophuthatswana selected cancer care groups are trained by professionals to create cancer awareness and encourage the community to play their role, emphasizing community involvement. The Alma Alta Principles of Primary Health Care are also discussed with the care groups. Functions of the care groups include:

- basic activities such as comprehensive and promotive health and early cancer detection;
- compilation of a village register;
- follow-up care on domicilliary basis including a cancer care group (UICC workshop, Fort Hare, 1989).

There are four participants involved in home care, namely: the patient, the family, the nurse and the physician (Cahoon, 1982 : 31). In many rural areas and even in urban areas in Southern Africa, the traditional

healer is also a member of the home care team. This is a black cultural trait that is predominant despite modern health care facilities. Usually if someone suffers from an illness that is not clearly understood e.g. cancer, the traditional healer is consulted. On the other hand, if the medical practitioners fail to cure a disease the traditional healer is also consulted (personal experience). According to Searle (1986 : 4) the power of the traditional healer arise from the fact that in the view of the family and patient he is able to:

- offer protection to the individual and family;
- diagnose and treat ill-health;
- determine what caused the ill-health;
- interpret the wishes of ancestors;
- understand the deep-rooted cultural nuances of diagnosis, treatment and care;
- understand the patient's and family's need for emotional support, voice their fears and discuss the illness and give assurance that the ancestors have not deserted them.

Whatever the cause of the disease patients and their family still ask for absence from hospital for a week or two and during this time visit the traditional healer (personal experience).

It is, therefore, important to recognize the role of the traditional healer in such societies because of the major psychological effect it has on the people.

Home visits provide families with opportunities to continue to seek new information about the disease, handling new symptoms and appropriate planning of care. According to Thompson (1990 : 147) before embarking on a home visit the nurse must realize that each family has individual needs and some of the factors to be considered are social, cultural, religious and language influences.

Assessment of the home environment, assessment of the family and their coping mechanisms, teaching procedures, health education, patient advocacy and supportive counselling are the kind of services that the home nurse provides (Thompson, 1990 : 147; Blank et al, 1989 : 80 - 81; Woods et al, 1989 : 28 - 29). The nurse is a guest in the family to help them to cope.

Cancer nurses must play an active role in community health care, either as teachers, consultants or as extenders of hospital care (Barckley, 1980 : 201). According to Barckley other cancer centre nurses offer home visits with constant telephonic support. In some countries cancer

care centres have a tremendous amount of input in home care such as helping to update the community nurses knowledge of cancer by offering seminars; referring nurses to short courses offered by universities, health agencies and hospitals; arranging for self-directed study or attendance of self-help groups (Barckley, 1980 : 202). These are just a few of the services rendered by these home care centres.

2.1.3 Home Care Centres and Support Networks

Many nurses realize that help is needed by the patient and his family and do not know where to turn to in order to provide such assistance. They refer the patient to the social worker and therefore tend to have nothing to do with the patient (personal experience). As the role of the social worker is so important, a brief reference to the role she could play in this field is necessary.

The social worker, as a member of the multi-disciplinary team, helps to identify emotional, social and financial needs and provides support in group and family dynamics, interpersonal relationships, knowledge of available resources. She also helps to adjust the cancer patient, whether child or adult, to his situation at work, school

or in the home.

In other countries numerous support services exist for cancer sufferers such as the hospice movement started in 1970, The Cancer Relief MacMillan Fund, the Marie Curie Memorial Foundation, Sue Ryder Foundation, MacMillan Continuing Care Homes. A range of other voluntary movements exist. (Tschudin, 1988 : 455 - 457; Thompson, 1990 : 143; Oleske et al 1987 : 191).

According to Tschudin, cancer care homes are characterized by informality and a relaxed atmosphere. The patients need not be admitted until the late stages of the illness, coming in when the family feels they can no longer cope. The patients may be admitted for pain and symptom control, and go home again when this is achieved, to be supported by home-care teams and district nurses. Patients may also come in regularly to give their caring family members a break, thus avoiding physical and emotional exhaustion.

Bouchard & Owens (1976 : 298 - 300) discusses various services available to cancer patients in the USA.

The American Cancer Society has numerous units which provide these services, e.g. a loan closet to provide sickroom equipment such as wheelchair, basin, transport for patients who need to go to the clinic, oxygen for the patient at home and prosthetic equipment. Volunteers provide transport services. In South Africa the Wits-Vaal Oncology Nursing Society provides a grant to patients for taxi fares to attend Baragwanath Cancer Clinics. (Annual Report: Wits-Vaal Oncology Nursing Society, 1990).

The experience in cancer services in the western world indicates that home care for cancer patients is an essential requirement in a modern health care system. It is essential to explore the need for such a service in Namibia, bearing in mind that the meaning and composition of such a service will vary greatly, depending on the situation where home care is needed. In the cities and towns it could be organized as:

- a full scale home care service organized by a voluntary charitable organization and subsidized by the state (e.g. National Cancer Association, Oncology Nursing Society, a church organization);
- a division of the hospital services;
- a selection of community nursing services provided by a local authority;

- a subsidised service provided by a nurse in private practice who donates part of her service to the cause of cancer, or who provides the services at a reduced fee for a poor community;
- a visiting service by a clinic nurse, or ward nurse, in a small town or rural area;
- a service provided by student nurses for their practical in home care work.

Where there is a perceived need and a will to meet this need, a way can generally be found. In one area in the Republic of South Africa retired nurses provide a voluntary service and the Lions Club' provides transport costs. Much can be done if one knows what has to be done, why, when, where and how it will be done. (Searle, Communication from NONSA Policy, 1989).

The socio-economic circumstances in Namibia, the absence from home for the greater part of the day of the mother and neighbours who are in employment, will raise major problems.

2.1.4 Knowledge Need of the Cancer Patient

Numerous studies have shown that even after being taught

patients are not well informed (Fredette, 1990 : 207). Time must be allowed for learning to take place because it cannot be assumed that learning has occurred because a patient has been taught (Oncology Nursing Society Education Committee, 1982 : 6). Many authors have emphasized the importance of adaptation in response to illness and the impact it has on patient and family learning (Fredette, 1990 : 208; Oncology Nursing Society Education Committee, 1982 : 7; Redman, 1988 : 32 - 37; Weisman, 1979 : 85 - 90; Kubler-Ross, 1975 : 97 - 100).

Effective patient education can be achieved when teaching is properly timed and planned which, in turn, facilitates adaptation. First and foremost, it is important that the nurses, in planning the patient education programme, be able to identify what the patient and family need and want to know rather than what the nurse wants to teach (Oncology Nursing Society Education Committee, 1982 : 9).

According to Derdarian (1987 : 109) Adler et al, state that a need for information refers to that which is lacking, faulty, or distorted, or incomplete in situations needing decision-making.

Fredette (1990 : 208) tabulates knowledge needs of a person living with cancer. The tabulated needs can basically be divided into eight categories namely: Cancer (the illness), specific cancer of the patient (my illness), health care system, feelings, coping responses, resources, modifying life style and remission/recovery. A person living with cancer is not really concerned with how the health care system works or how to manage it but is rather concerned with available resources in the community and hospital. It is also important to note that Fredette includes myths and untruths among the needs which is very relevant in the African context. Derdiarian states that informational needs were expressed in four categories of concerns namely: disease, personal, family and social concerns (1987 : 111 - 112).

Fredette's table would serve as a guideline for nurses to control what educational needs have been met and what is outstanding. Accurate recording and communication with the patient is essential. In a developing country the education must be such that persons with no, or with a low level of literacy are able to comprehend and apply the information. The patient's literacy level and cultural perceptions must be considered.

Health professionals, especially nurses, have the

responsibility to give health information and develop education programmes to inform individuals of their cancer risk. Cancer education is a priority. According to the research findings of Powers, Weinrich & Weinrich as quoted by Reed Ash et al there is a need for nurses to be involved in cancer programmes for less educated, low-income, older black persons. There is still a need to teach the Seven Warning Signals and facts about cancer, including the fact that the risk of cancer increases with age. The differences and similarities between aging changes and cancer symptoms should be emphasized (Reed Ash & Jenkins, 1990 : 231).

2.1.5 The Role of the Nurse in Follow-up Care.

The literature search revealed that many studies have been focused on hospitalized cancer patients and the role of the nurse in the hospital setting. Fewer studies attempt to determine the role of the home health nurse in meeting the needs of the discharged adult cancer patients. There is a dearth of such literature relating to Southern Africa.

To provide meaningful care and support to a cancer patient, irrespective of what happens to him, depends on the knowledge, skills and efforts to understand the patient's

needs, and to respond to them appropriately (Tschudin, 1988 : 409). This is the essence of good nursing care.

Cancer is a serious and complex health problem that presents itself in different ways. The role of the nurse will therefore, also be complex. Many authors agree that the following are some of the roles of the nurse:

- prevention and early detection;
- patient education;
- psychological care;
- palliative care;
- follow-up care;
- rehabilitative care (Bouchard & Owens, 1976; Barckley, 1980; Tschudin, 1988; Bailey, 1992; Thompson, 1990; Tiffany, 1978; Reed Ash & Jenkins, 1990).

In the context of the study prevention and early detection is part of the general health education of the public, and in this case the other members of the family of the patient, friends and community members.

2.1.6 The Assessment Role

A patient should be assessed on admission to hospital for

potential problems on discharge regarding home care. A detailed history of the patient should be taken. Assessment is defined by Boroch (1976 : 144) as "the process of interpreting pertinent relationships between the information about the client's behaviour patterns described in the health history and the knowledge about his basic human needs, life-style, ageing process, physiologic relationships, growth and development, family relationships, community dynamics, nutrition and energy requirements, assets and limitations, effects of medications, client and family learning needs and communication patterns".

The above-mentioned definition is all embracing and it is obvious that nurses involved in home care will have to use a variety of skills and senses to fulfil their assessment role. This is general nursing care exercised in the nursing process.

2.1.6.1 Home Assessment

According to Garon (1991 : 51) the nurse should continue to observe and assess the patient's home as she enters. The nurse should assess the appearance of the home, cleanliness, is the patient alone, clues indicating

cultural influences, e.g. is the patient's room stuffy due to certain herbal sticks burning so that the smoke can "chase away" the evil spirit causing cancer and the type of resources available.

2.1.6.2 Family Assessment

The family is an important source of support for the patient and therefore the family needs to be assessed. It is important to know what the patient's role in the family is, e.g. sole breadwinner. Is communication in the family open or closed? What is the family's perception of their needs? The nurse needs to assess the family's expectations from the cancer treatment and how they feel about the patient's illness so that misconceptions can be clarified. This type of information will enable the nurse to determine what type of support and resources the family needs at home. Home-based care needs refers to "physical, psychological and health service requirements of ambulatory cancer patients necessary to maintain normal functioning at home" (Longman et al, 1992 : 183).

2.1.6.3 Patient Assessment

Garon (1991 : 51) states that when entering the patient's home , the nurse symbolically enters his

system and "can alter the perception of the nurse from a position of self-proclaimed authority, attempting to manipulate client behaviour, to a partner helping the client to make his or her own health care decisions". The nurse needs to see the problems through the patient's eyes (Garon, 1991 : 51). The nurse should ask the patient for his view concerning present needs and problems and has to listen to enable her to establish a therapeutic relationships and mutual interaction. For example, it would be useless for a nurse to teach or interview a patient about a pre-planned subject while the patient is in pain and soiled, as the pressing need at that time will be personal hygiene and alleviation of pain. According to Garon (1991 : 52) and Tschudin (1988 : 450) it is necessary that the nurse also give attention to the strengths of both the patient and family to identify available resources and to enable the patient and family to identify their own strengths. Searle (1986 : 7) in her study on Aspects of Home Care for Cancer Patients in Southern Africa, states that the black cancer patient in rural areas uses his residual powers to move out of his hut to sit in the sun or under a tree, where he is in contact with nature, animal and human activity. His sitting or sleeping mats have animal skins to alleviate pressure on his body. Thus he

remains self-reliant as far as his strength allows.

2.1.6.4 Community Assessment

Cancer patients can be cared for at home successfully if the resources in the community are assessed and properly utilized. Assessment must start when the nurse enters the patient's community. The nurse should look at the type of environment, e.g. clean community, squatter camp, nearby clinic or health centre, Round Table and Red Cross Health Care Centre. Such systems should be utilized to render voluntary services. Garon (1991 : 51) states that the following can be used by the nurse to assess the community:

- type of feeling that the neighbourhood gives;
- open and friendly neighbourhood with many people;
- a closed neighbourhood with closed doors, barred windows and empty streets;
- active volunteer groups or helpful church members.

The nurse should also find out whether there are other groups, e.g. ostomy, laryngectomy, mastectomy groups. In the black communities in Namibia such support groups do not exist at present.

It is usually the nurse in-charge of a unit or primary nurse who should initiate discharge and assess the

probable needs of the patient, taking into account prescribed medication, recommendation of other members of the team and a knowledge of the patient's level of dependence (Tschudin, 1988 : 448).

2.1.6.5 Self Care Assessment

The ability to provide "self care" has to be assessed. According to Orem, self-care is "the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being" (Fawcett, 1987 : 179; Hill & Smith, 1985 : 7). The sick, the aged and the disabled require varying degrees of assistance with self-care activities. Orem describes the ability to care for one's self as self-care agency (Fawcett, 1987 : 179).

Nurses should make time to analyse the patient's present health state, identify his shortcomings or deficits and then discuss realistic goals with the patient and his family to meet the patient's needs. The provision and management of the individual's need for self-care action on a continuous basis in order to sustain life and health and to cope with the effects, is of special concern to nursing (Fawcett, 1987 : 181). It is thus necessary that the nurse sees that

the family and the patient understand what is required of them in facilitating self-care. The family caregiver must not do everything for the patient as this would make the patient totally dependent on the family caregiver. This depends on the stage of the disease, e.g. terminal or real terminal. The nurse must constantly encourage the patient to achieve maximum self-care and also assess the level of self-care achieved and the degree of support and help needed by the patient. Without follow-up nursing care it is impossible for cancer patients to accomplish some of the fundamental needs because of the illness. For example, a cancer patient who experiences difficulty in eating, swallowing and has pain, will lose weight and become dehydrated, and anxious because of the pain and will not have adequate sleep. The pain could also impede his mobility and the ability to keep his body clean. This example indicates the extent of nursing care by others involved in the self-care process.

Self-care relies heavily on the individual's knowledge and skills that he already has, be it home remedies or traditional health practices (McCorkle & Hongladarom, 1986 : 226). The nurse can build on and supplement these practices. The patient needs information to care

for himself, and nurses can provide this information as from admission. This will involve self-observation, recognition of symptoms, assessing and choosing treatment options (McCorkle & Hongladarom, 1986 : 226).

According to Levin and Orem (McCorkle & Hongladarom, 1986 : 226) self-care is the ultimate responsibility of the individual. This, however, does not mean that the nurse should not teach the patient how to care for himself at home, especially where some traditional practices could have a negative effect on the patient. Self-care is part of rehabilitation and should be viewed in a more serious way by the nurse. Self-care deficits result from lack of knowledge about the situation and/or available self-care activities, incompetence in performing self-care activities and inability of the person to function in a physical or emotional sense due to illness (McCorkle & Hongladarom, 1986 : 226).

To be able to meet self-care needs the person must have the essential knowledge, skills and responsibility for health care needs; be well-motivated and have energy to begin and continue until the desired results are obtained; place a high value on health and have a perception that the new health behaviour will reduce

vulnerability to the illness (Hill & Smith, 1985 : 10).

2.1.7 Emotional Support of the Patient

Most nurses care about their patients but they do not have time to tend to the patient's emotional needs as their workload is excessive. This is aggravated by the shortage of staff. During the process of providing care to the sick individuals in an acute care unit, nurses often focus on the patient's disease, its treatment and the prognosis (McCorckle & Hongladarom, 1986 : 125). According to Donovan it is often unclear whether the disease, its treatment or the chronicity of the illness is the primary cause of a given symptom (McCorckle & Hongladarom, 1986 : 125).

When the multiple causation theory of illness (Narrow & Buschle, 1982 : 7) predominates the health team may become so involved in the scientific aspects of the patient's problem that his need for recognition of his individuality and for emotional support is overlooked. In the present health care climate the multiple causation theory of cancer is prevalent and the search for answers is constant and widespread. This theory, if applied to cancer prevention and care, has major implications for nursing in

all cancer care situations. According to Anderson (1989 : 87) nurses may enhance hope and desire for life within and among the patients and their families by providing emotional support, understanding, and by teaching patients about the disease and treatment. A patient with cancer reacts to his disease with feelings, attitudes, fears and concerns. Understanding the patient's emotions is very important, and the nurse should approach the patient with empathy and a positive attitude.

2.1.8 Psychological Support of the Family

The interpretation of the cancer patient's reactions to his situation poses a threat to the family caregiver or spouse. The patient may experience different emotions e.g. anger and withdrawal, and may direct these emotions at those he loves. According to Penson (1984 : 26) and Oberst et al, (1989 : 210) the key family caregiver may show signs of strain, suffer physical manifestations of stress, and have minor illness and discomfort. In Namibia the poverty levels and the need to maintain employment, with resultant absence from the care situation, causes psychological conflict and guilt feelings in the family members.

It is therefore important that the nurse supports and explains the situation to the family caregiver/spouse from the time of diagnosis through all the behavioural stages, as the stages occur. The family caregiver must, therefore, be seen as part of the therapeutic team. Penson (1984 : 26) states that some caregivers "may prefer to share their emotions with a nurse" who knows the patient as the caregivers feel that at home they have to keep up a "brave front". This is very true where a spouse is the caregiver and has to show that the situation is under control. The spouse has actually to give emotional support to the family and the patient while he himself is in an emotional and physical turmoil. Under these circumstances it is not a matter of "expecting too much from the nurse".

Family support affects the adjustment of the cancer patient. Northouse's work (Woods et al, 1989 : 31) with mastectomy patients shows the important influence of the caregiver, especially the spouse. Eighty one percent (81%) of the women could discuss their mastectomy-related concerns with the spouse, while 57% believed that their spouse understood how they felt. Patients evaluate lack of family support very negatively. Information and advice is perceived as helpful when given by health care

providers but unhelpful if given by friends or family (Woods et al, 1989 : 31).

In Germino's study (Woods, et al, 1989 : 29) on patterns of concerns in 90 families of cancer patients, it was found that persons with cancer rated personal, symptom, work and financial concerns as of highest priority. The spouses rated personal, symptom and existential concerns as of highest priority while adult children, 18 years and older rated symptom, existential and social dependency concerns as the highest. From the above-mentioned, it is clear that both personal and symptom concerns are very important and the nurse should pay special attention to these when planning teaching as well as supporting the patients and spouses. Whether the same findings would be valid in the African cultural context is not known. Research in this is necessary. However the nurse has to be aware of these issues and be on the look-out to see whether they manifest in the same form or other.

Germino also found that patients with cancer disclosed their concerns primarily to their spouses and other family members. The spouse of a person with cancer hardly disclosed his/her concern to the children (Woods et al. 1989 : 30). This indicates that the family caregivers

definitely need to be supported to enable them to cope.

In Hinds' study (Oberst et al, 1989 : 210) it is reported that family caregivers were concerned about their ability to manage physical care and provide emotional support. Few of the psycho-social needs of the patients were being met by health care professionals.

With the Namibian black population, because of the closeness of even the extended families, home care in the rural families is characterized by strong family support provided by the extended and immediate family, as well as members of the tribe. Relatives assist financially and participate in the actual patient care.

In most cases the discharged cancer patient is taken to the family members in the rural area ("reserve") for further care, and this makes the patient's illness a "family and community or tribal concern" (personal experience). In the urban areas, however, the cancer patient and family, tend to be isolated due to economic, labour and environmental conditions. Therefore, there is lack of family support.

Nurses need to do a detailed taking of history of cancer

patients, including the ages of their children so as to determine the scope of caregiving that will be needed. One can imagine the psychological trauma such children are exposed to, without such education. Vigorous teaching, guidance and support of the whole family and mobilization of community resources is to be undertaken.

In the Namibian situation child-caregivers, due to the absence of adults who are at work, are encountered. This will be explored in this study.

2.1.9 Rehabilitative Care

According to Kershaw (Tschudin, 1988 : 12) Raven emphasizes that rehabilitation and improved quality of life is important when cure is uncertain. Nurses should be actively involved in rehabilitation of cancer patients where care and not cure is dominant.

Many authors have defined rehabilitation e.g. Madden (1977 : 35), Dietz (Watson, 1990 : 4), Dudas (Watson, 1990 : 4), Barnard (Tschudin, 1988 : 452) and Borocho (1976 : 6 - 7). Dietz is known for the notion of adaptive cancer rehabilitation consisting of the following categories, namely: preventative, restorative, supportive and

palliative (Watson, 1990 : 3). Preventive refers to rehabilitation measures designed to improve physical functioning and reduce morbidity and disability. Restorative refers to the actions used when a cure is likely, the aim being the control, circumvention or elimination of residual cancer disability. Supportive rehabilitation occurs when a patient continues to have cancer and supportive interventions are planned to lessen disability and other problems that occur with remission. Palliative rehabilitation is used when the disease is advanced and the patient is actively sick (Watson, 1990 : 3). The goal of cancer rehabilitation is to improve the quality of life of the patient for maximum productivity with minimum dependence (Anderson, 1989 : 85).

Searle says (Barckley, 1980 : 191) that rehabilitation begins at diagnosis and not on admission. Therefore the advice given at the diagnosis and the attitudes of the medical personnel are crucial. Madden (1977 : 35) says that rehabilitation does not only depend on the skills of health practitioners, but also largely upon their attitudes.

Rehabilitation is a multidisciplinary concept (Anderson, 1989: 86; Madden, 1977 : 37; Tschudin, 1988 : 452;

Bouchard & Owens, 1976 : 32). Nurses have a major role to play in cancer rehabilitation. In Brown's discussion on ambulatory services, it is stated that outpatient cancer care is a necessity and that nursing must find methods to practice effectively in this setting (Anderson, 1989 : 87). Many cancer patients are able to maintain their jobs, family life, social life and other important activities more successfully in an outpatient setting, e.g. with colostomy and amputation. Optimal nursing care should be given and continuity of care maintained.

It is important that nurses recognize the importance of continuity of care for cancer patients after discharge from hospital. This requires a pattern of systematic co-operation among all facilities and programmes at community level to enable the cancer patient to receive adequate, appropriate and continuous care (Madden, 1977 : 37). This can be achieved through getting acquainted with the patient's diagnosis, medical complications, precautions to be observed, setting realistic goals with the patient, follow-up home visits, accurate documentation and reporting, and referring patients to team members. This is part of the independent function of the nurse.

According to Teich and Raia, independence and mobility

increase when patients participate in their own care and these are consistent with the goals of rehabilitation for cancer patients (Anderson, 1989 : 87). Madden (1977 : 36) states that an environment of liberty, concern, acceptance of people on their own terms and opportunity for patients to make their own decisions is necessary for rehabilitation. In hospital, patients give up their self-concept and accept a submissive role whereas with home care they are allowed to maintain their self-concept. Nurses play a key role in facilitating the rehabilitation environment (Madden, 1977 : 36).

One of the goals of rehabilitation is self-care and begins by allowing the patient to continue to do everything he is capable of. The family supplements that and the nursing personnel fill gaps and help each to learn (Madden, 1977 : 36). The family caregiver must not be excluded from rehabilitative care of the patient. Some family members are eager to help and the help and support that the nurse gives the family aids this process. It lessens the problem of family adjustment, reduces lack of understanding, aids cooperation and reduces the possibility of rejecting the patient. The patient will progress well and improve his self-image if his family is warm and supportive.

"Rehabilitation is a creative, problem-solving process for which resources exist in community settings" (Anderson, 1989 : 88). The nurse should be aware that the patient's problems range from altered anatomy and physiology, recurrences, complications, emotional upsets and prejudices. Therefore, with insight and constructive planning, the nurse will be able to advise, counsel and teach the patient and his family (Bouchard & Owens, 1976 : 38). It is therefore necessary that the nurse assists the patient through the above-mentioned problems.

It is difficult to generalize cancer rehabilitation and the nurse's role because of the diversity of the disease and its consequences. According to the American Cancer Society, the degree of the disease and the subsequent method of correction determines the extent of rehabilitation (American Cancer Society, 1974 : 6). For patients with cancer of the head and neck even slight facial disfigurement can be a source of embarrassment compared to cancer of the prostate or breast. The patient with cancer of the face requires more extensive surgical methods of correction as well as extensive rehabilitation.

It is beyond the scope of this thesis to elaborate on

rehabilitation of the various types of cancers. Therefore, only the pre-operative and post-operative aspects of rehabilitation will be mentioned.

2.1.9.1 Pre-operative and post-operative Aspects of Rehabilitation.

According to the American Cancer Society (1974 : 7) the following pre-operative aspects are important:

- The patient's family should be included in the early stages of rehabilitation, particularly if disfigurement or prosthesis will be permanent and the patient will require continued care at home.
- Nursing staff should encourage the patient and his family to discuss their fears and problems and assure them of their continued support and help.
- The patients should be instructed in the special procedures related to their post-operative care and the reasons for such procedures.
- The climate set soon after admission by the nursing personnel through their efficient care, warmth and understanding will influence the patient's reactions to hospitalization and treatment.
- The patient should be introduced to others who have undergone similar corrective measures and are now

recovering and able to cope.

- Team approach toward rehabilitation, e.g. nurses, doctors physiotherapists, social workers is provided to meet the needs of the patient.

The following post-operative aspects of rehabilitation are worth mentioning:

- The nurse should encourage the patient to participate in their own daily care and in managing their prosthetic devices.
- Families should also be instructed in the particular requirements of the patient and be encouraged to assist in preparation for discharge (American Cancer Society, 1974 : 7 - 8).

Patients who will need long-term follow-up care concerning rehabilitation problems should be identified before discharge and referred.

2.1.10 Palliative Care

To maintain continuity of care at home nurses need to ensure that communication is maintained between the hospital, community health nurses and community resources. Barnard (Tschudin, 1988 : 447) states that

there is evidence that many patients who require support following discharge often do not receive it due to poor communication. One of the ways to ensure that the patient and family gain proper support and care at home is by discharge planning (Tschudin, 1988 : 448). Discharge planning is defined by Jupp and Sims as "the plan involved before a patient is transferred from one environment to another" (Tschudin, 1988 : 448). The patient, his family , the hospital and community teams should be involved in planning discharge. According to Hopkins (1992 : 28) there is confusion about the exact meaning of "palliative care" and to whom it applies. Literature search has revealed that palliative care is used with terminal care, hospice care and continuing care (Reed Ash & Jenkins, 1990 : 272 - 273; Tschudin, 1988 : 450, 455 - 456; Viljoen & Uys, 1988 : 223; Barckley, 1980 : 83 - 84; Bailey, 1992 : 89; Thompson, 1990 : 149 - 150; Grobe et al, 1981 : 371 - 372). Hopkins (1992: 28) states that the Palliative Care Working Group of the Yorkshire Regional Cancer Association compiled a regional philosophy based on the World Health Organization's (WHO) Policy Statement on Palliative Cancer Care. To make this philosophy a reality attention should be given to the following:

- relieving pain and other distressing symptoms;

- providing continuing support to patients through the various stages of their illness.
- offering psychological and spiritual care;
- establishing a system of support to uphold the family of the informal carer during illness and bereavement;
- establishing a support network to enable professionals to maintain effectiveness;
- facilitating the distribution of information to the public;
- offering comprehensive education and training to all professionals (Hopkins, 1992 : 28).

The Cancer Association of Namibia is actively involved in cancer prevention and early detection. This association has a small "interim home" where nine patients receive palliative and supportive care. The majority of the patients are in the general units in the Windhoek Central and Katutura State Hospitals. There is a need for the hospital-based nurses to get involved in cancer palliative nursing care and to be reorientated. In order to develop principles of good palliative care the viability of palliative care working groups should be investigated. Webber (1992: 186) states that "nurses must themselves be empowered" in order to empower patients and families. Palliative care, especially

hospital-based care has been well documented by many authors. As the disease progresses problems caused by physical symptoms increase. Therefore, constant assessment is essential. Palliative care is about enabling patients to live life as fully and actively as possible (Webber, 1992 : 186) and to improve the quality of the life of the patient (Walter, 1977 : 70). Although palliative care consists of chemotherapy, surgery and radiotherapy (Viljoen & Uys, 1988 : 223; Walter, 1977 : 71), it is mainly nursing care (Viljoen & Uys, 1988 : 223). For the purpose of this thesis attention will be given to hygiene, environment, nutrition and symptom control.

2.1.11 Nutritional Aspects

According to Harvey (Tschudin, 1988 : 110) cancer cells compete with the normal cells of the body for the essential nutrients whereby the tumor utilizes the ingested nutrients before the normal cells are able to. Therefore, malnutrition may occur even though the nutritional intake is good. Cancer cells proliferate 24 hours a day and it becomes difficult for cancer patients to meet their nutritional needs with their usual food intake (Tschudin, 1988 : 110). It is, therefore, important to note that not only patients with cancer

of the stomach or oesophagus become malnourished. Harvey (Tschudin, 1988 : 108) states that from a study of 126 cancer patients receiving chemotherapy or radiotherapy, appetite and the ability to eat are the most important factors in their physical well-being. Nausea and vomiting are common side effects of cytotoxic drugs.

Anticipatory nausea and vomiting also referred to as conditioned or psychological nausea is linked to "repeated association of the side effects with environmental stimuli". For example, certain smells, sights, taste sensations or thoughts occur in patients receiving chemotherapy and evoke nausea and vomiting (Pickett, 1991 : 335). This has to be borne in mind when preparing and serving meals.

Malnutrition in cancer patients can be prevented by early identification of patients at risk while still in hospital and continued assessment of their nutritional state at home. Patients having problems such as nausea, vomiting, diarrhoea, constipation, anorexia, depression tend to be malnourished. The patient's nutrition must be planned with the patient and the family according to the available resources at home, such as the cultural food "shikundu" and the patient's preference.

"Shikundu" is a very nutritional drink made by Owambo people with a "filling " effect and is tasty (Personal experience). It is made of "Mahangu". A patient's meal should be planned according to what the family can afford and clearly-written guidelines or careful explanation must be given to the patient on discharge in the case of special diets. At home the patient's weight loss cannot be controlled daily or weekly and no special diets can be ordered per prescription card. The nurse is, however, in a position to evaluate the patient's nutritional and physical state during follow-up care.

2.1.12 Hygienic Aspects

Optimal physical comfort is important when caring for a cancer patient. A neat personal appearance uplifts the patient's morale and puts the patient's family at ease. Personal hygiene is, therefore, an important part of cancer nursing care. For example, a patient will lose his appetite if oral hygiene is not done and will not rest or sleep in a soiled bed. Tschudin (1988 : 13) adds the ability to eliminate body waste to basic needs of care. Thus with a bed-ridden patient this is part of hygiene. The role of the nurse during the provision of physical care and comfort should not be underestimated as an atmosphere of confidence, trust and emotional

support is built during the provision of this care.

2.1.13 Symptom Control

Good symptom control should maximize the potential of the patient. Thus, it is fundamental that the patient and family be seen as a unit and be given adequate teaching and support to facilitate coping with cancer symptom treatment at home. Some of the symptoms associated with cancer that are worth mentioning are nausea, vomiting and pain. Nausea and vomiting influence food intake and needs serious attention before the patient develops cachexia.

The home of the patient should be free from bad odours that can evoke nausea. Therefore, adequate ventilation is important. Deodorant blocks can be used to eliminate odours in the home. Frequent changing of soiled dressings will avoid embarrassment caused by odour. This is costly. Therefore, provision for the supply of dressing must be made.

Patients should be well-informed about the symptoms and the side-effects of their treatment so that they can be

better prepared. Measures to alleviate nausea and vomiting should be explained to the patient. The patient needs to be assured that anti-emetics are always available.

According to the International Society of Nurses in Cancer Care, the nurse should do the following to patients being discharged or receiving out-patient treatment:

- "make sure that patient is informed about the likely pattern of nausea and vomiting;
- explain how and when anti-emetic medication should be taken;
- if anti-emetics are likely to cause sedation warn the patient;
- ensure that carer understands this information;
- outline the methods used to relieve nausea - even if this has been done before;
- help the patient to identify precipitating factors and ways of avoiding these;
- emphasize the need to maintain adequate food and fluid intake;
- provide dietary suggestion leaflets/recipe sheets for light meals;

- during subsequent visits look for signs of dehydration or poor nutrition;
- discuss anticipatory symptom" (Hawthorn et al, 1991 : 154)

2.1.14 Pain

Man's reaction to pain is indeed complex and is influenced by culture, past experience, emotion, anxiety and genetics (Tiffany, 1987 : 172). One cannot know exactly how much pain the patient is suffering as pain cannot be measured directly. Much has been written about cancer pain and its control but there are still discrepancies in the nursing management of cancer pain. In a study by Ferrell et al on Clinical Decision Making and Pain by nurses it is reported that 76% of the nurses indicated that the patients did not get adequate pain relief (Ferrel, et al, 1991 : 294). Only twenty two percent (22%) feared addiction.

Tschudin (1988 : 417) and Ferrel, et al. (1993 : 169) agree that one third of patients with advanced cancer have no pain.

According to Ferrel, et al. (1991 : 289) nurses have an important role in making decision regarding pain and its

management. It is, therefore, important that the nurse has adequate knowledge of different methods of effective pain relief, whether these are pharmacological or non-pharmacological methods. In addition to this the nurse should be able to assess the scope of the pain, e.g. the origin of pain and intensity. This implies that the nurse's assessment of pain will be based on what the patient says and on observations. Ferrell et al, (1991 : 290) state that nurses unconsciously use the clinical decision making process in making decisions about pain when they gather information about the pain by asking the patient if pain is present, observing activity and mobility, relying on the doctor and other nurse's reports and then deciding which method is best to control pain.

According to Paice et al (1991 : 299) Watt-Watson discovered that nurses had difficulty with pain assessment and only 3% of the sample used a systematic approach.

The most frequently used method of assessing and determining pain intensity is to ask the patient, observe patient behaviour, activity and mobility (Ferrell et al, 1991 : 293).

In their study Ferrell et al (1991 : 294) also noted that 81% of the nurses administered analgesics routinely compared to the 19% who administered PRN and only 4% contacted the physician to discuss the side effects of the medication. Literature has cited lack of knowledge among nurses and physicians as a major barrier in effective pain management (Ferrell et al, 1991 : 296; Paice et al, 1991 : 299; Evans Faries et al, 1991 : 307; Diekmann & Wasseem, 1991 : 319).

It is interesting to note that with the lack of knowledge mentioned Evans Faries et al, (1991 : 307) state that health professionals often rely on their own observations and judgements in assessing the amount of pain a patient experiences and determine the amount of medication needed. Lack of knowledge is identified as an obstacle to pain management.

2.1.15 Management of Pain at Home

According to Ferrell et al, (1993 : 170) family members especially spouses, can mould and perpetuate pain behaviour. Pain and discomfort are stated as major issues by family caregivers while provision of

information and comfort were identified as priorities (Ferrel et al, 1993 : 170).

Rowat and Knafl observed that managing pain is a primary source of distress for caregivers of chronic pain patients (Ferrell et al, 1993 : 170). It is also important that the investigation showed that 75% of the caregivers could describe factors that were associated with either a decrease or increase in pain (Ferrell et al, 1993 : 170). It is, therefore, important that the family caregivers and patients be given education on pain management, including treatment and side effects of medication to be able to cope at home.

Discharging a cancer patient on pain medication and a follow-up date is not enough. Follow-up nursing care should be implemented to resolve other problems identified in the literature study that occur at home.

According to Garon (1991 : 54) the following are some helpful nursing interventions:

- support of effective pain management plans.

The nurse should encourage the client and family to follow the medication schedule and the pain relief plan that is working.

- Intervention when there is a change needed.

If the regimen is not working the nurse should inform the physician so that other measures should be implemented.

- Exploration of non-pharmacological therapy.

Nonpharmacological therapies increase the effectiveness of medications and provide the client with feelings of having more control over his circumstances.

- Inclusion of family members in education regarding medication, prescribed doses and schedule.

To manage pain effectively at home co-operation between nurses and physicians is necessary. Cleeland(Diekmann & Wasseem, 1991 : 315) stated that nurses, physicians and other health care personnel have been identified as those most responsible for cancer pain undertreatment.

2.1.16 Dying at Home

The terminally ill patient has many emotional needs; for example, coming to grips with dying, coping with denial anger and fear (Tschudin, 1988 : 411 - 412) and according to Kübler-Ross, bargaining, depression and acceptance

(Weisman, 1979 : 88). Kennedy (1982 : 3) states that feeling secure is a primary need and the patient must know that someone will be there to help him if he feels lonely or has pain.

At the patient's home the nurse can help control almost all aspects of care that can lead patient and family to make decisions in the patient's best interest. Visitors can be scheduled at the patient's best convenience. The terminally ill patients fear dying alone in a strange environment isolated from their families and friends. At home the patient rests in his bedroom surrounded by treasured mementos of happier times and this is of immeasurable value (Barckley, 1980 : 201).

A lot has been said about dying with dignity (Weisman, 1979 : 97; Burn & Meyrick, 1977 : 90; Barckley, 1980 : 205; Kennedy, 1982 : 6). All these authors view this as being treated like a respected and loved person, not just like another case.

There is no way to provide this kind of loving care except at home, or perhaps at a special cancer hospice, provided the family has free access at all times

(Kennedy, 1982 : 6). According to a survey of terminal patients, the most pressing need is not to be abandoned by loved ones (Kennedy, 1982 : VIII). The patient needs to be kept comfortable and helped to avoid depression.

de Villiers (1986 : 17) states that total care of the terminally ill involves constant contact with the patients and their relatives so that effective communication can take place. Tiffany (1987: 51) states that "communication is part of treatment, for it helps the patient to adapt to the conditions imposed by the illness making him aware of his situation".

According to de Villiers (1986 : 18) caregivers fail to listen or to deal with what the patient actually says. Nurses view communication with a cancer patient as a challenge and do not want to become too involved with the person.

When a subject is introduced into a conversation by the patient, it may mean that the patient actually wants to talk about it (de Villiers, 1986 : 18). Tiffany (1987 : 51) says that nurses should be sensitive to and recognize hints that patients throw out.

2.1.17 Conclusion

The literature study provides excellent guidelines on how to cope with home health care for cancer patients and above all indicates the type of preparation that nurses need for this demanding role.

CHAPTER 3

METHODOLOGY

3.1 RESEARCH APPROACH

The research approach is a descriptive survey. Descriptive research has its main objective as the accurate portrayal of the characteristics of situations, persons or groups, and the frequency with which certain phenomena occur (Polit & Hungler, 1991 : 643). Survey research is a type of non-experimental research that focuses on obtaining information regarding the status quo of some situation, often via direct questioning of respondents (Idem : 656).

3.2 LITERATURE STUDY

An intensive literature study was done in accordance with the objectives set out in the introduction of Chapter 2.

3.3 DEMARCATION OF THE STUDY

The research is centred on adult persons who have been discharged from the cancer care wards at the Windhoek Hospital Complex. Some of the patients are resident in the Windhoek area, but others are resident in the various areas of Namibia - in the north, the south, the east and the west. Patients from outside the Windhoek area, are included in the study as they return to the Windhoek Oncology Clinic for follow-up care at 3 - 6 month intervals, and if re-admission to hospital is required for adjusted treatment would report back to the Windhoek Hospital Complex where decisions would be made if referral to Tygerberg Hospital in the Republic of South Africa is necessary. For this reason the demarcation of the study is described as the Windhoek area.

3.4 TIME-SPAN

The study commenced in August 1991 and will be completed by 30 November 1995.

3.5 PERMISSION FOR THE STUDY

Permission to undertake the study on adult patients in the Windhoek Hospital Complex and the Oncology Clinic at Windhoek was obtained from the Department of National Health and Welfare. (See letter of application (Annexure 3.1) and letter of granting permission (Annexure 3.2)).

3.6 REQUEST TO COLLEAGUES FOR COOPERATION

A letter (Annexure 3.3) was sent to nursing colleagues asking for their cooperation in undertaking the study.

3.7 ETHICAL ISSUES

- All patients interviewed were assured of anonymity and confidentiality and free withdrawal (See Annexure 3.4).
- All professional ethics as contained in the professional practice of a nurse will be observed by the researcher.

3.8 TARGET POPULATION

All adult patients discharged from the Oncology unit at the Windhoek Hospital Complex who are still alive and who attended the Oncology Clinic between 8 - 19 July 1994 are included. The number is 326.

3.9 METHOD OF CONDUCTING THE SURVEY

3.9.1 Identification of the Problem

An analysis was done by means of a study of the records of cancer patients discharged from the cancer wards at the Windhoek Hospital Complex to determine the number of adult persons involved and whether follow-up nursing was indicated, according to the cancer patients' condition. Due to the vagueness of the nursing records in this respect it was difficult to decide whether follow-up was needed. However perusal of the medical records gave the necessary lead.

3.9.2 Interpretation of the concept Windhoek Area

The cancer wards of the Windhoek Hospital Complex from which the patients were discharged is the central treatment area in Namibia for cancer. When patients are discharged they return home, or are sent for further treatment outside Namibia but return to their homes in Namibia. Some patients (group 1), remain in the Windhoek area, others (group 2) return to their homes in the distant parts of Namibia. All, however, return to the Windhoek Oncology Clinic for further treatment at prescribed intervals, or to the Cancer Unit in the Windhoek Hospital Complex for re-admission. Both group 1 and group 2 patients are therefore regarded for the purpose of this study as patients of the Windhoek area.

3.9.3 Tracing of Patient Population

This was done by checking the records of the Oncology Clinic to identify addresses and checking whether follow-up nursing care is prescribed.

3.9.4 Investigation of the Patient Problems and Needs with Regard to Follow-up Care

A survey by means of structured interviews utilising questionnaires as instruments was considered the most suitable approach, as many of the patients and caregivers might be illiterate and English as the language medium of the instruments could present major problems. The researcher who speaks English, Afrikaans and one of the indigenous languages would make use of an interpreter to cope with the many indigenous languages. The interpreter was guided in the exact meaning of the questions so as to reduce the errors of interpretation to a minimum.

The questionnaire for use by the professional nurses who during the time-span indicated (3.4 above) nursed in the cancer wards would be completed by the nurses.

3.9.4.1 Design of the Questionnaires

Following on the literature study and in consultation with Dr Zietsman, Oncologist in charge of the Cancer Services of the Ministry of Health and Social Services, the following instruments were prepared:

Structured Questionnaires

- Questionnaire A: Patient - Client (Annexure 3.5, A)
- Questionnaire B: Caregivers (Family or other assistants (Annexure 3.6, B))
- Questionnaire C: Professional nurse (Who works or worked in the unit in the time-span 1991 - 1994) (Annexure 3.7, C)

3.9.4.2 Pilot Study

Draft questionnaires were prepared and then submitted to a pilot study committee consisting of Dr Zietsmann, Oncologist, and five nurses who are members of the Oncology Nursing Society of Namibia or are lecturers in the subject or managers of nursing services. Adjustments were made as required and the instruments were finalised and submitted to Dr Zietsmann for approval.

3.9.4.3 Validity and Reliability of Instruments

Validity, or the degree to which an instrument measures what it is intended to produce, and reliability, or the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure (Polit & Hungler, 1991 : 374 - 375), appear to be met through the results of the pilot study.

Further testing was done, the researcher undertaking 2 pilot study interviews with patients, 2 with caregivers and 2 with nurses who had previously worked in the Cancer Unit. Adjustments were then made to improve validity and reliability of the instruments.

3.9.4.4. Delivery of Questionnaires

The questionnaire C (Annexure 3.7) for completion by professional nurses from the cancer ward was handed personally to the respondents (see 3.9.4.5) for return after 7 days. Questionnaires A and B (Annexure 3.5 and 3.6) for use by the interviewer, did not need delivery.

3.9.4.5 Return of Questionnaire C

A total of 17 questionnaires was handed out and 17 (100 percent) were received back as the researcher personally fetched them.

3.9.4.6 Total Number of Patients Who Were Willing to Participate in the Research. (Respondents)

All adult patients with cancer discharged from wards of the Windhoek Hospital are referred to the Oncology Clinic. The clinic opens a record for each patient. The records at the Oncology Clinic were checked to determine the total number of patients who were still attending the clinic for treatment. A total of 326 patients were still attending the clinic at this time.

The researcher attended the clinic from 8 to 19 July 1994 to contact the patients attending during this time. All 326 attended in this time-span. Each patient had the purpose of the study explained to him/her by the researcher and was asked whether he/she was prepared to participate in the study and to be interviewed. Only 53 patients agreed to do so (16,3% of the target population). These 53 were interviewed utilising the questionnaire (3.5 A). An interpreter had to be used at times. In addition and as a result of statements made by patients, the questionnaire interview was followed by an unstructured interview in regard to the home-remedies used by patients.

3.9.4.7 Total Number of Caregivers Who Could be Identified and Who Were Willing to Participate.

Some of the caregivers accompanied patients to the clinic. In other cases patients provided the name and

address of the caregiver. Some stated they had no caregivers. Others were not able to identify their caregivers or not willing to supply their names and addresses. Only 14 caregivers could be identified. Some of them were visited in their homes. They all agreed to participate by being interviewed. This was done subsequently by the researcher using Annexure 3.6 B.

Caregivers living outside Windhoek could not be interviewed for the following reasons:

- caregivers' lack of finance to pay for private transport facilities to Windhoek to accompany patients;
- some caregivers were working and could not accompany patients;
- caregivers had to look after the children in the absence of the patient.
- child caregivers had to attend school and could not accompany patients;
- caregivers cannot accompany patients using the hospital bus;*
- the researcher's lack of finance to travel over the great distances to interview caregivers in rural areas.

*Only patients are allowed on the bus so caregivers cannot accompany them. The hospital bus, one for the North and one for the South collects patients from Oshakati in the North, collecting at Otjiwarongo, Tsumeb, Okahandja - Windhoek, and from the South, Keetmanshoop, Rehoboth, Mariental - for specialized health care. These journeys are made once a week.

3.9.4.8 Total Number of Professional Nurses Who Were Willing to Participate.

All professional nurses who worked in the cancer wards of the Windhoek Hospital Complex from 1991 to 1994 were asked to participate in the study. There were 17 in all. All agreed (100 percent) to participate.

3.9.4.9 Unstructured Interviews on Policy about Follow-up of Nursing Care

Unstructured interviews were conducted with the Chairman of the Oncology Nursing Society of Namibia and the Director of Primary Health Care in Namibia, Dr N Shivute and Mrs E Barlow, Deputy Director, Nursing Services.

3.10 ORGANISATION AND ANALYSIS OF DATA

Two approaches were required, namely:

- analysis by means of computer using the Statistical Package System for Social Sciences;
- collating of answers to unstructured questions which was done by hand by the researcher.

3.11 DISCUSSION OF FINDINGS

It was envisaged that this would be done directly at the presentation of the data.

3.12 RECOMMENDATIONS ARISING FROM THE FINDINGS

A chapter is devoted to recommendations.

CHAPTER 4**ANALYSIS AND DISCUSSION OF DATA**

Data was analysed by computer using the Statistical Package for Social Sciences (SPSS), except for a couple of items in each annexure and comments in the structured interview which, because of the smallness of the number involved and the wide ranging areas of residence of respondents, were done by hand.

Annexures 3.5 A**Item 0:**

Of the 53 respondents 19 (36%) were adult males and 34 (64%) adult females.

Item 0.0

Patients attending the Oncology Clinic at Windhoek came from all over Namibia. Figure 4.1 shows a map of Namibia showing the residential areas of the respondents. The wide distribution of patients and the long distances to be travelled could indicate the enormity of the problem in providing follow-up nursing care. The nearest hospital/clinic to an area from which a respondent comes is also indicated in Figure 4.1. Most of the smaller areas are not indicated on the map.

The availability of some health care facilities is important to provide much needed dressing and analgesic substances for pain control for terminal patients. This aspect will be addressed further under the recommendations.

Item 1

Table 4.1: Age distribution of respondents. N = 53 (M & F)

Age distribution	Frequency	Percent
18 - 45 years	14	26.4
> 45 years	39	73.6
TOTAL	53	100.0

It is significant that the greater percentage of the respondents fall into the >45 year age group which is consistent with the frequency of cancer in the various age groups. One of the respondents (1.9%) is 18 years old.

Item 2

Table 4.2: Marital status of respondents. N = 53 (M & F)

Marital status	Frequency	Percent
Married	25	47.2
Single	28	52.8
TOTAL	53	100.0

The high percentage (52,8%) of unmarried respondents is significant. Family support affects the adjustment of the cancer patient.

Twenty five of the respondents (47,2%) are married. It is important that family support be strengthened as a single cancer patient will rely heavily on the family for support. Family education, therefore, becomes very important and the family needs to be contacted regularly. Family support groups need to be established. The nurse should be a facilitator in this respect and should act as a resource person.

Item 3

Table 4.3: Number of dependent children of respondents.

N = 53 (M & F)

Number of children	Frequency	Percent
0	15	28.3
1	7	13.2
2	10	18.9
3	6	11.3
4	3	5.7
5	3	5.7
6	5	9.4
7	3	5.7
9	1	1.9
TOTAL	53	100.0

The majority of the respondents 38 (71,7%) have children. This distribution is displayed in Table 4.3.

Item 4**Table 4.4: Ages of dependent children of respondents.****N = 53 (M & F)**

Ages	Frequency	Percent
0 - 6 years	14	26.4
6 - 12 years	23	43.4
12 - 18 years	16	30.2
TOTAL	53	100.0

The majority of the children 39 (73,6%) are of school-going age, 23 (43,4%) being between 6 - 12 years old and 12 - 18 years old respectively.

Child care is necessary when the respondents are hospitalized. It is necessary that the respondents explain their condition to their children so that the children understand the reasons for the periods of absence of the parent. These children need to be emotionally supported.

Some of the respondents who are employed also indicated that they have to employ someone to look after their children as they were still small. This is an additional financial burden for the respondent.

Item 5: Hospitalization of respondents.

All 53 respondents (100,0%) were hospitalized. They indicated they were admitted either for surgery, chemotherapy, radiumtherapy or when they were acutely ill.

Item 6

Table 4.5: Employment of respondents. N = 53 (M & F)

Employment	Frequency	Percent
Employed	9	17.0
Unemployed	44	83.0
TOTAL	53	100.0

Forty four (83,0%) of the respondents are unemployed . This may become a source of social problems and is a major concern of the respondents.

The previous table (Table 4.4) reflects that 73,6% of the respondents' children are attending school. This causes financial problems for the unemployed respondents as the school uniforms are costly and school fees are high. Some of the schools are situated far from the respondents' homes and the respondents stated that most of the time there is no money for food. Therefore, the children would attend school on an empty stomach.

The respondents who live in urban areas have to pay rent, and for water and electricity.

The respondents also stated that it is difficult to find work because of the sequela of the illness e.g. Kaposi sarcoma. Absence from work when receiving radiumtherapy or chemotherapy also causes problems with employers.

If 83% of the respondents are unemployed, 52,8% are single (Table 4.2) and the majority of the respondents' children are of school-going age (Table 4.4), social assistance (social grant) is desirable for the children to assist them with schooling.

Item 7

Table 4.6: Source of income of respondents. N = 53 (M & F)

Source of Income	Frequency	Percent
Social assistance (social pensions)	17	32.1
None	34	64.2
Family assistance	2	3.8
TOTAL	53	100.0

The source of income of the 17 (32.1%) respondents is from old age pensions (social pension). The thirty four (64.2%) indicated in Table 4.6 have no income. Two respondents (3.8%) indicated that they did not need income as they are financially supported by their adult children.

The majority of respondents indicated that they do not qualify for social assistance due to their age.

Voluntary organisations could be approached for social assistance for these patients. The nurse needs to initiate the organisation of this type of assistance as part of her community-based nursing care. It is necessary that the nurse be involved in the establishment of such a network.

Item 8

Item 4.7: Respondent's contribution towards living expenses.

N= 53 (M & F)

Contribution	Frequency	Percent
Yes	48	90.6
No	4	7.5
Not applicable	1	1.9
TOTAL	53	100.0

The majority of the respondents (90,6%) indicated that they have to contribute towards living expenses. Table 4.5 indicates that 83% of the respondents are unemployed and 64,2% (Table 4.6) have no other source of income. The financial status of these cancer patients is, thus, serious. This is a common occurrence and financial support has to be prioritized.

One respondent (1,9%) was still attending school and this item was therefore not applicable.

Item 9

Table 4.8: Someone who helps at home. N = 53 (M & F)

Always Someone Present	Frequency	Percent
Yes	35	66.0
No	18	34.0
TOTAL	53	100.0

Table 4.8 indicates that 35 (66%) of the respondents have someone who helps them at home. Most of these respondents are from the rural areas (see Figure 4.1) and this may contribute to the availability of helpers from the extended family system. Eighteen respondents (34%) in the urban area do not always have someone to help at home.

Caregivers are needed by patients especially during the terminal stage of the illness. Voluntary womens' organizations and church organizations could be approached for assistance. The hospital is not always in a position to admit cancer patients just because they are terminally ill. Voluntary caregivers should be able to liaise with the community nurse to ensure appropriate care. This will also instill in the caregiver a feeling that her contribution is purposeful and meaningful. Voluntary community caregivers should be trained for this type of care. This should be the role of the nurse.

Item 10

Table 4.9: Relationship of patient with caregiver.

N = 53 (M & F)

Relationship	Frequency	Percent
Spouse	10	18.9
Family	39	73.6
Friend	4	7.5
TOTAL	53	100.0

The above table indicates that the family (73,6%) is mainly involved as caregivers. This is consistent with previous studies. (Oberst et al, 1989 : 210; Woods et al, 1989 : 30 - 31).

Table 4.9 also indicates that 10 patients (18,9%) have their spouse as caregivers. Four patients (7,5%) have a friend as caregiver. There is no indication that community caregivers are available.

PATIENT KNOWLEDGE

Item 11

Table 4.10: Respondents who were/are on chemotherapy.

N = 53 (M & F)

Responses	Frequency	Percent
Yes	39	73.6
No	14	26.4
TOTAL	53	100.0

Most of the respondents (73,6%) are/were on chemotherapy. Fourteen respondents (26,4%) were/are not on chemotherapy.

It is important that support is given to patients to alleviate the side effects of chemotherapy.

Item 12

Table 4.11: Respondents who were on radiotherapy. N = 53 (M & F)

Responses	Frequency	Percent
Yes	32	60.4
No	21	39.6
TOTAL	53	100.0

Thirty two respondents (60,4%) were on radiotherapy. Twenty one respondents (39,6%) were not on radiotherapy.

Item 13

Table 4.12: Respondents who had undergone surgery.

N = 53 (M & F)

Responses	Frequency	Percent
Yes	34	64.2
No	19	35.8
TOTAL	53	100.0

The findings in the above table indicate 34 respondents (64,2%) had undergone surgery. Nineteen (35,8%) did not undergo surgery.

Item 14

Table 4.13: Respondents who are aware of the side-effects of chemotherapy or radiotherapy. N = 53 (M & F)

Responses	Frequency	Percent
Yes	23	43.4
No	30	56.6
TOTAL	53	100.0

The findings in the above table indicate that thirty (56,6%) respondents are not aware of the side-effects of these treatment modalities.

Twenty three respondents (43,4%) are aware of the side-effects.

The results in the above table indicate that there is a need for support of the patient. Being aware of the side-effects of the treatment modalities helps the patient to cope and prepare himself. This is part of the function of the nurse to prepare the patient for such treatment, and how to cope with side-effects.

Item 15

Table 4.14: Persons who informed respondents about the side-effects of the treatment. N = 53 (M & F)

Responses	Frequency	Percent
Doctor	19	35.8
Nurse	4	7.5
Another patient	0	-
Friend	0	-
Social Worker	0	-
	30 Missing	56.6 Missing
TOTAL	53	100.0

Table 4.14 indicates that nineteen (35,8%) were informed by the doctor and four (7,5%) by nurses. The thirty respondents (56,6%) reflected as missing in this table corresponds with the thirty respondents indicated in Table 4.13 who said they were not informed.

Nurses are neglecting their role of teaching patients how to cope with side-effects.

Item 16

Table 4.15: Were respondents informed how to handle side-effects at home? N = 53 (M & F)

Responses	Frequency	Percent
Yes	15	28.3
No	38	71.7
TOTAL	53	100.0

Table 4.15 shows that fifteen (28,3%) respondents were informed how to handle the side-effects at home. Thirty eight (71,7%) respondents were not informed.

The care that the nurses give is ineffective as the majority (71,7%) of respondents will not know how to handle the side-effects at home. There is thus lack of support to the patients. The nurses are ignoring their responsibility to teach the patient and his family.

Item 17

Table 4.16: Adequate information about home management of the side-effects. N = 53 (M & F)

Responses	Frequency	Percent
Yes	12	22.6
No	38	71.7
	3 Missing	5.7 Missing
TOTAL	53	100.0

This table indicates that the majority 38 (71,7%) of the respondents feel that they were not adequately informed about the home management of side-effects.

This is significant as Bouchard & Owens (1976 : 38) state that the patients' problems range from altered anatomy and physiology, recurrences, complications, emotional upsets and prejudices of others. It is the specific role of the nurse to help the patient live with the disease. To facilitate "living with the disease" the nurse needs to be accessible, willing to inform, explain and support the patient. This is part of the rehabilitation aspect of her role.

Twelve (22,6%) of the respondents feel they were adequately informed about the home management of the side effects. Three respondents (5,7%) reflected as missing were not sure whether the information they were given was adequate or inadequate, which indicates lack of clarity by those who supplied the information.

Item 17.1

Table 4.17: Information that respondents need concerning home management of side-effects. N = 53 (M & F)

Information	Frequency	Percent
Specific	2	3.8
All information	51	96.2
TOTAL	53	100.0

It is significant that 51 (96,2%) respondents need all information concerning home management of side-effects. This would enable the respondents to be better prepared to cope with the effects of the treatment and with the daily living process with the disease.

Although 22,6% of the respondents (Table 4.16) feel they were adequately informed about the home management of side-effects they are among the respondents illustrated in Table 4.17. This

is indicative of the need for proper patient education programmes. Nurses should be adequately prepared for this role.

Item 18

Table 4.18: Informing respondents about home management of physical symptoms. N = 53 (M & F)

Responses	Frequency	Percent
Yes	9	17.0
No	44	83.0
TOTAL	53	100.0

Table 4.18 indicates that the greater percentage (83,0%) of the respondents were not informed about home management of physical symptoms. Only 9 respondents (17.0%) were informed.

These statistics are significant as good symptom control should maximize the potential of the patient and facilitate coping at home.

Item 19.1

Table 4.19: Respondents who were informed on discharge. N = 53 (M & F)

Responses	Frequency	Percent
Yes	2	3.8
No	51	96.2
TOTAL	53	100.0

This table indicates that only 2 respondents (3,8%) were given information on after-care on discharge.

These results depict the seriousness of the need for health information when one considers the results in Table 4.14, Table 4.16 and Table 4.18. It appears that the nurse is neglecting her teaching role.

The patients are not in a position to internalize information given on discharge as there is no time to ask questions, but they will have to listen carefully and try to absorb all the information given.

Item 19.2

Table 4.20: Respondents who were informed during hospitalization. N = 53 (M & F)

Responses	Frequency	Percent
Yes	7	13.2
No	2	3.8
	44 Missing	83.0 Missing
TOTAL	53	100.0

Table 4.20 shows that 7 (13,2%) respondents were given information on after care during hospitalization.

Considering Table 4.18 it appears that from the 9 respondents (17%) who were informed seven (13,2%) were informed during hospitalization and two respondents (3,8%) (Table 4.19) were informed on discharge.

The 44 respondents (83%) reflected missing in Table 4.20 corresponds with the respondents in Table 4.18 who were not informed about home management of physical symptoms.

If cancer after-care is to be effective and if the nurses want the patient's life to be meaningful they will have to give much more attention to health information.

Item 20: Knowledge of any services offered by the Cancer Association of Namibia. N = 53 (M & F)

Twelve (12) respondents (22,6%) know of the services offered by the Cancer Association of Namibia while the majority 41, (77,4%) do not know about these services.

There are no branches of the Cancer Association of Namibia in the country. Members of this association travel throughout the country while providing papsmear services. The services offered by this association must be brought to the notice of the patients at the hospital. Publicity should be given to this association by advertisements and notifying the community authorities. This will enable the patients to visit the association when the need arises without having to be referred to it via the hospital. This will also improve the image of the association in the community.

Item 21

Table 4.21: Respondent's use of services of the Cancer Association of Namibia. N = 53 (M & F)

Responses	Frequency	Percent
Yes	4	7.5
No	49	92.5
TOTAL	53	100.0

Table 4.21 indicates that 49 (92,5%) of the respondents do not use any of the services of the Cancer Association of Namibia; only 4 (7,5%) of the respondents do. This could be because the majority (77,4%) indicated in Item 20 do not know of these services.

Item 21.1

Table 4.22: Specification of the services of the Cancer Association of Namibia used by respondents.

N = 53 (M & F)

Services	Frequency	Percent
Counselling	1	1.9
Equipment	2	3.8
Finance	1	1.9
	49 Missing	92.5 Missing
TOTAL	53	100.0

From the findings in the table above it will be seen that a small number of respondents use the services. The 49 respondents (92,5%) reflected as missing correspond with the respondents in Table 4. 21 who do not use these services.

The services as indicated in Table 4.22 are very important. The Cancer Association has sponsored tickets for patients to the Republic of South Africa for further cancer treatment. This was indicated during an unscheduled interview with the professional nurse working at this association. Equipment is available at the association at a minimum fee. This, however, would be a financial burden for the unemployed cancer patients. Counselling is an important service and needs to be made known to the patients and families.

Personnel working at the association can also be invited by the ward personnel to give information to themselves and to cancer patients who need counselling. There is a need for nurses to communicate with the personnel of the Cancer Association of Namibia to facilitate effective after care.

COMFORT

Item 22: Cleanliness of respondent's home. N = 53 (M & F)

All 53 respondents (100%) claim that their homes are always kept clean. Visits were not done to ascertain this.

Item 23:

Respondent's ability to take care of his/her personal hygiene.

N = 53 (M & F)

Fifty respondents (94,3%) stated that they are still able to take care of their personal hygiene. Only 3 respondents (5,7%) are unable to do so. Provision of personal hygiene is, therefore, a problem for these 3 respondents. Provision of care and support is, thus, necessary.

Item 24

Table 4.23: Respondent's sleep pattern - do you sleep well?

N = 53 (M & F)

Responses	Frequency	Percent
Yes	31	58.5
No	22	41.5
TOTAL	53	100.0

The table above shows that the majority of respondents, 31 (58,5%) sleep well. Twenty two (41,5%) of the respondents do not sleep well.

It is important that the care givers assist with maintaining an environment conducive to sleep, established regular rest and sleeping hours for the patient. They should give pain medication at bedtime to facilitate sleep.

Item 24.1

Table 4.24: Causes for not sleeping well. N = 53 (M & F)

Causes	Frequency	Percent
Pain	12	22.6
Insomnia	10	18.9
	31 Missing	58.5 Missing
TOTAL	53	100.0

The major cause for not sleeping well is pain. Twelve respondents (22,6%) do not sleep well as a result of pain. Ten respondents (18,9%) suffer from insomnia. The 58,5% who are shown or are missing are those who sleep well (see Table 4.23).

The percentages stated above are consistent with other studies. For example Ferrell et al (1991 : 294) reported that 76% of the nurses indicated that patients did not get adequate pain relief.

During follow-up care causes of insomnia should be identified. Means of relief should be instituted as sleep is very important in cancer care. The nurse should teach the patient and family caregivers pain control measures and ensure that the patient has an adequate supply of analgesics.

Item 25

Table 4.25: Respondent's pain experience. N = 53 (M & F)

Responses	Frequency	Percent
Yes	36	67.9
No	17	32.1
TOTAL	53	100.0

It will be seen from the above table that 36 of the respondents (67,9%) experience pain. Seventeen (32,1%) of the respondents do not experience pain. This is consistent with the frequency of cancer pain experience.

Item 25.1

Table 4.26: The nature of pain experienced by respondents.

N = 53 (M & F)

Nature of Pain	Frequency	Percent
Cancer Pain	28	52.8
Other Pain	8	15.1
	17 Missing	32.1 Missing
TOTAL	53	100.0

Table 4.26 indicates that 28 (52,8%) of the respondents experienced cancer pain. Eight of the respondents (15,1%) experienced other pain not related to cancer. The 17 (32,1%) missing did not answer the question as they did not experience pain as yet.

The family caregivers and respondents will have to be supported with pain management at home as the magnitude of the problem is illustrated in Tables 4.25 and 4.26.

Successful management and alleviation of pain requires nurses to do a careful analysis of pain, based on questioning of the patient.

Item 26

Table 4.27: Pain medication. (Are patients on pain medication?)

N = 53 (M & F)

Responses	Frequency	Percent
Yes	28	52.8
No	25	47.2
TOTAL	53	100.0

The table above indicates that 28 (52,8%) of the respondents are on pain medication, while 25 (47,2%) of the respondents are not on pain medication.

It is significant to note that from the 52,8% of the respondents experiencing cancer pain (Table 4.26), 15,1% of the respondents had not yet notified the doctor of the other non-cancerous pain. This was indicated by the respondents during the interview. This, therefore, explains the 25 (47,2%) respondents (Table 4.27) who are not on pain medication.

Item 26.1

Table 4.28: Respondent's knowledge of type of pain medication.

N = 53 (M & F)

Type of pain Medication	Frequency	Percent
Known	11	20.8
Unknown	17	32.1
	25 Missing	47.2 Missing
TOTAL	53	100.0

Eleven (20,8%) out of the 28 respondents who are on pain

medication know the type of pain medication they receive. The majority of the 28 who responded (32,1%) do not know the type of pain medication they receive. This number could describe the colour and size of the pain medication. However out of the total sample of 53, a total of 25 (47,2%) did not respond as they were not on pain medication.

The eleven respondents (20,8%) indicated that they know the name of the medication but do not know how the medication works.

All the respondents who are on pain medication need more information concerning pain medication e.g. whether the pain medication is a mild analgesic, sedative or muscle relaxant.

Item 27

Table 4.29: Respondent's experience of nausea. N = 53 (M & F)

Responses	Frequency	Percent
Yes	18	34.0
No	35	66.0
TOTAL	53	100.0

Table 4.29 indicates that 35 of the respondents (66,0%) do not experience nausea. Thirty four percent (18) of the respondents experience nausea.

It is significant to note that although the majority of the respondents were on radiotherapy (Table 4.11) and were/are on chemotherapy (Table 4.10), the minority are experiencing nausea.

Item 27.1

Table 4.30: Causes of nausea experienced by respondents.

N = 53 (M & F)

Couses	Frequency	Percent
Environment	1	1.9
Medication	13	24.5
Food	4	7.6
	35 Missing	66.0 Missing
TOTAL	53	100.0

The majority of those responding (24,5%) indicated that the medication caused them to become nauseous. Four respondents (7,6%) experienced nausea due to food. One respondent cited the environment as a cause of nausea (1.9%).

All causes of nausea should be eliminated as a proper nourishing diet is very important. The nurse has a particular facilitative role in this respect.

Item 28: Do you experience vomiting? M = 53 (M & F)

Forty three (81,1%) of the respondents do not experience vomiting. Ten (18,9%) of the respondents experience vomiting.

It is encouraging to note that the greater percentage of the respondents do not experience vomiting. The nurse caring for a patient with vomiting must inform the patient about fluid and electrolyte imbalances that may ensue, but if she is not in contact with the caregiver, problems can arise in such cases due to the ignorance of the caregiver.

NUTRITION**Item 29****Table 4.31: Appetite of respondents. N = 53 (M & F)**

Responses	Frequency	Percent
Good	41	77.4
Poor	12	22.6
TOTAL	53	100.0

The above table indicates that 41 (77,4%) of the respondent's appetite is good. Twelve (22,6%) of the respondents' appetite is poor.

The 12 respondents (22,6%) identified who experience anorexia suffer from oropharyngeal cancer. Promotion of good oral hygiene is important. The nurse should stimulate the patient's appetite and offer alternative nutritious fluids. If available a dietician should be consulted, or relatives could be consulted about the available fluids which the patient likes, e.g. "Shikundu".

Item 29.1**Table 4.32: Respondent's reasons for poor appetite.**

N = 53 (M & F)

Reasons	Frequency	Percent
Pain	3	5.7
Therapy	2	3.8
Anorexia	7	13.2
	41 Missing	77.4 Missing
TOTAL	53	100.0

From the twelve respondents with poor appetite 3 (5,7%) cited pain as the cause. Two (3,8%) cited the treatment as the cause and 7 (13,2%) were anorexic. The 41 (77,4%) indicated as missing are those who indicated their appetites were good (Table 4.31).

Further questioning of the anorexic respondents revealed that fear, lack of income and uncertainty about the future were the causes of their anorexia.

Anorexia should be alleviated early as it influences all the systems of the patient. The high percentage of anorexia causes concern as it is a condition that can be controlled. It is important to build up the patient's resistance. It requires a great deal of patience from the relatives and the nurse. The importance of nutrition must be emphasized to the patient and family without it being "a telling what to do", but a further provision of information and encouragement.

Item 30

Table 4.33: Types of food that appear to agree with respondents. N = 53 (M & F)

Type of food	Frequency	Percent
Specific diet	8	15.1
Regular diet	45	84.9
TOTAL	53	100.0

The table above indicates that a regular diet appears to agree with 45 (84,9%) of the respondents. A specific diet appears to agree with 8 (15,1%) of the respondents.

The specific diet mentioned is not prescribed by the doctor but what the respondents can afford and tolerate.

The majority of the respondents are resident in the north of Namibia. "Mahangu" (Millet) is grown in the north on large scale and is the staple food. Food prepared from "Mahangu" flour is very nutritious and tasty and is part of the regular diet (own experience).

Item 31

Table 4.34: Types of fluids that appear to agree with respondents. N = 53 (M & F)

Types of fluids	Frequency	Percent
Specific fluids	6	11.3
Regular fluids	47	88.7
TOTAL	53	100.0

Regular fluids appear to agree with 47 (88,7%) of the respondents. Specific fluids appear to agree with 6 (11,3%) of the respondents. The specific fluids that the 11,3% of the respondents can afford mostly is black coffee or tea. The respondents indicated that they cannot afford special nutritious diets like complan. These special diets, even though sometimes prescribed were not always available at the hospital pharmacy when they are in Windhoek for follow-up treatment.

The nurses can do much to alleviate this situation and prevent dehydration by giving health education on nutrition and getting voluntary support organizations involved. Improving the nutritional state of a patient is part of the treatment particularly when the patient is discharged.

Item 32: Bowel actions of respondents. N = 53 (M & F)

The majority of the respondents (88,7%) have a regular bowel

action. Six of the respondents (11,3%) do not have a regular bowel action.

Item 33

Table 4.35: Elimination problems experienced by respondents.

N = 53 (M & F)

Elimination Problems	Frequency	Percent
Constipation	38	71.7
Diarrhoea	5	9.4
Urinary Incontinence	2	3.8
No problems	8	15.1
TOTAL	53	100.0

Table 4.35 indicates that constipation is experienced by 38 (71,7%) of the respondents. Five of the respondents (9,4%) experience diarrhoea. Two of the respondents (3,8%) experience urinary incontinence. Eight of the respondents (15,1%) do not experience elimination problems. Much can be done by the nurses to alleviate constipation by giving health education on types of food to be consumed e.g. including fibre and fruit in diet and adequate fluid intake.

Item 34

Table 4.36: Do you cope with altered elimination problems?

N = 53 (M & F)

Responses	Frequency	Percent
Yes	48	90.6
No	5	9.4
TOTAL	53	100.0

Table 4.36 indicates that 48 (90,6%) of the respondents are able to cope with elimination problems. Five (9,4%) of the respondents are not able to cope.

Although constipation is experienced by the majority of the respondents (Table 4.35), it is significant that the greater percentage of the respondents are able to cope with elimination problems. The majority of the respondents are resident in the north of Namibia (Owamboland). "Omboka" is a leafy green veld vegetable that grows in Owamboland. It is nutritious and has a very mild laxative effect (own experience). It is a staple food in the north. It has a high vitamin A, Iron and Folic acid content (interview with Dr N Shivute).

SEXUALITY

Item 35

Table 4.37: Does the illness interfere with your sex life?

N = 53 (M & F)

Responses	Frequency	Percent
Yes	7	13.2
No	46	86.8
TOTAL	53	100.0

The greater percentage (86,8) of the respondents indicated that the illness does not interfere with their sex life. Seven (13,2%) of the respondents indicated that the illness interferes with their sex life.

Item 36

Table 4.38: Respondents' response on whether they were informed that chemotherapy/radiation could decrease sexual response or desire. N = 53 (M & F)

Responses	Frequency	Percent
Yes	7	13.2
No	46	86.8
TOTAL	53	100.0

From the table above it can be seen that 7 (13,2%) of the respondents were informed that chemotherapy/radiation could decrease sexual response or desire. Forty six of the respondents (86,8%) were not informed.

The 7 respondents who indicated that the illness interferes with their sex life (Table 4.37) and the 7 respondents (13,2%) indicated in Table 4.38, fall into the 18 - 45 age group.

Although the 13,2% of the respondents were informed, they indicated that they could not handle this situation and it caused emotional problems with their spouse.

Item 37

Table 4.39: Persons who informed respondents that chemotherapy/radiation could decrease sexual response or desire. N = 53 (M & F)

Responses	Frequency	Percent
Doctor	6	11.3
Nurse	1	1.9
Another patient	0	0.0
A friend	0	0.0
	46 Missing	86.8 Missing
TOTAL	53	100.0

The majority (11,3%) of the respondents were informed by the doctor. One respondent (1,9%) was informed by a nurse (professional).

It appears that the nurses are neglecting their role as health educators. Even if the doctors give information to the patients, the nurse needs to re-inforce the information and identify any misunderstanding. The missing 46 (86,8%) are the 46 indicated in 4.38 who were not informed.

MOBILITY

Item 38: Interference of illness with respondent's mobility.

N = 53 (M & F)

Thirty seven (69,8%) of the respondents indicated that the illness does not interfere with their movements. Sixteen (30,2%) of the respondents indicated that the illness interferes with their movements.

The nurse needs to encourage mobility for as long as possible to avoid complications of immobility.

Item 39: Respondents who do active muscle movements or exercises. N = 53 (M & F)

Forty three (81,1%) of the respondents do not do active exercises. Ten (18,9%) of the respondents do exercises.

EMOTIONAL SUPPORT**Item 40****Table 4.40: Do you communicate your feelings about living with cancer? N = 53 (M & F)**

Responses	Frequency	Percent
Yes	48	90.6
No	5	9.4
TOTAL	53	100.0

Table 4.40 indicates that the greater percentage (90,6%) of the respondents communicate their feelings about living with cancer. Five (9.4%) of the respondents do not communicate their feelings about living with cancer.

It is encouraging that the 90,6% respondents are communicating. It indicates the willingness of patients to be advised. The caregivers can also be a source of information to the nurse.

Item 41**Table 4. 41: Persons to whom the respondents mostly communicate their feelings about living with cancer.**

N = 53 (M & F)

Responses	Frequency	Percent
Doctor	0	-
Nurse	0	-
Spouse	18	34.0
Friend	4	7.5
Caregiver	26	49.1
	5 Missing	9.4 Missing
TOTAL	53	100.0

Table 4.41 indicates that the 26 (49,1%) of the respondents communicate their feelings about living with cancer to their caregivers. Eighteen (34,0%) of the respondents communicate their feelings to their spouse and 4 of the respondents (7,5%) communicate their feelings to their friends.

It is important that the family caregivers and the spouse be involved in counselling so that they can understand the feelings of the patients to enable the caregivers to support the patient emotionally. The 5 missing (9,4%) are those reflected in Table 4.40 who do not communicate their feelings.

Item 42

Table 4.42: Respondents' reasons for not communicating their feelings about living with cancer. N = 53 (M & F)

Reasons	Frequency	Percent
Stigmas	4	7.5
Live alone	1	1.9
	48 Missing	90.6 Missing
TOTAL	53	100.0

Table 4.42 indicates that 4 (7,5%) out of the 53 members of the sample do not communicate their feelings about living with cancer because of the stigmas of the illness. One (1,9%) of the respondents lives alone. Forty eight (90,6%) of the respondents indicated as missing are the respondents indicated in Table 4.40 who do communicate their feelings.

The stigmas indicated is often cultural and traditional traits concerning certain beliefs about cancer.

Item 43

Table 4.43: Respondents' need for more personal emotional counselling or support. N = 53 (M & F)

Responses	Frequency	Percent
Yes	41	77.4
No	12	22.6
TOTAL	53	100.0

Forty one (77,4%) of the respondents indicated that they need more personal emotional counselling. Twelve (22,6%) of the respondents indicated that they do not need personal emotional counselling. The above-mentioned 12 respondents indicated that women from their church congregation supported them emotionally. This is not enough considering the variety of emotions involved. There is a need for nurses to be trained in cancer care counselling so that they can be actively involved in emotional counselling.

SOCIAL SUPPORT

Item 44

Table 4.44: Persons who assist the respondents with personal nursing care at home. N = 53 (M & F)

Responses	Frequency	Percent
Children	28	52.8
Family member	14	26.4
Spouse	9	17.0
Nurse	0	-
Friend	2	3.8
TOTAL	53	100.0

The table above indicates that 52,8% of the persons who help the

respondents with personal nursing care are children. Fourteen (26,4%) of the persons who help with personal care are family members. Nine (17,0%) of the persons who help with personal care are the spouses. Two (3,8%) of the persons who help with personal care are friends.

The respondents included all their children even, adult daughters or sons, as their children. Children must, therefore, not be interpreted as child. During the interview the respondents indicated that 19 out of the 28 children who assist the respondents with personal nursing care fall in the 12 - 18 year age group, that is 67,9%. Nine (32,1%) of the children are, in reality, adult sons or daughters.

The issue of child caregivers needs to be looked into to alleviate this problem as it exposes these children to psychological stress. These children also need emotional support. Persons of this age are not equipped to provide the emotional or to a considerable extent, the physical support such a patient needs.

Item 45

Table 4.45: Does the community nurse visit your home as part of your follow-up treatment? N = 53 (M & F)

Responses	Frequency	Percent
Yes	7	13.2
No	43	81.1
	3 Missing	5.7 Missing
TOTAL	53	100.0

The table above indicates that the community nurse visits 7 (13,2%) of the respondents at home as part of the follow-up

treatment. Forty three respondents (81,1%) indicated that the community nurse does not visit their homes as part of follow-up treatment. Three of the respondents (5,7%) indicated as missing stay with their children who are professional nurses and does not need follow-up home visits. The nurses visit them because of their friendship with their daughters, who are nurses. The greater percentage of respondents indicated that they need to be visited at home by the nurse.

Item 46

Table 4.46: How often does the community nurse visit your home as part of your follow-up treatment? N = 53 (M & F)

Responses	Frequency	Percent
Weekly	1	1.9
Twice a month	0	-
Monthly	6	11.3
Seldom	3 Missing	5.7 Missing
	43 Missing	81.1 Missinf
TOTAL	53	100.0

The table above indicates that 1 out of the 7 respondents (1,9%) who are visited is visited weekly. Six (11,3%) of the respondents are visited monthly by the community nurse. The three respondents correspond with the 3 (5,7%) respondents in Table 4.45. They do get visited seldom by the community nurse but they are sure that it is because of the friendship of their children. The 43 respondents depicted as missing in this table corresponds with respondents in Table 4.45 who are not visited at home.

Item 47: Respondent's visit to the hospital or clinic as part of follow-up treatment. N = 53 (M & F)

All 53 of the respondents (100%) visit the Oncology Clinic as

part of follow-up treatment. All respondents have to come to Windhoek Oncology Clinic.

Item 48

Table 4.47: Family members who accompany respondents to the hospital or clinic. N = 53 (M & F)

Responses	Frequency	Percent
Yes	14	26.4
No	39	73.6
TOTAL	53	100.0

The majority of the respondents (73,6%) are not accompanied by family members to hospital or clinic. Fourteen of the respondents (26,4%) are accompanied by family members. The family members need to be visited at home to be given information.

Item 49

Table 4.48: Respondents who have to use private transport to go to the hospital or clinic. N = 53 (M & F)

Responses	Frequency	Percent
Yes	38	71.7
No	15	28.3
TOTAL	53	100.0

The table above indicates that most of the respondents (71,7%) have to use private transport to go to the hospital or clinic. Fifteen (28,3%) of the respondents do not use private transport.

The greater percentage of respondents indicated that they have to use private transport to get to the nearest hospital to be able to get the hospital bus to Windhoek. This is a major problem as some of the respondents use donkey carts to get to the nearest hospital for transport. One respondent mentioned that he had to leave his donkey cart at a farm, walk to the main road which is quite far and then hitch-hike to the nearest hospital. This may take up to 2 days, depending on the availability of the transport.

Item 50: The respondents who make use of community resources.

N = 53 (M & F)

Fifty one (96,2%) of the respondents indicated that they do not make use of community resources. Two of the respondents (3,8%) make use of community resources.

The greater percentage of respondents indicated that there are no resources available in their communities to help with the specific needs of the respondents (cancer patients).

Item 51

Table 4.49: Community resources used by respondents.

N = 53 (M & F)

Resources	Frequency	Percent
Church Organization	1	1.9
Red Cross	0	0
Other NGO's	1	1.9
	51 Missing	96.2 Missing
TOTAL	53	100.0

From the 2 respondents who use community resources, 1 (1,9%) makes use of the church organization. The other respondent

(1,9%) makes use of a Non-Governmental Organization (NGO). The 96,2% respondents indicated as missing do not make use of community resources. They refer to 51 respondents in Item 50 who do not make use of community resources.

Namibia is a country that has many Non-governmental Organizations. According to the above statistics it can be assumed that there is little or no collaboration between the health institutions and the NGO's regarding cancer follow-up care.

RESIDUAL CAPACITIES

Item 52: Respondent's ability to make use of other parts of the body to cope with movement. N = 53 (M & F)

All 53 of the respondents (100,0%) know how to make use of other parts of the body to cope with movement.

Item 53: Respondents who are prepared to undergo training from a speech therapist if they lost their voices. N = 53 (M & F)

All 53 of the respondents (100,0%) are prepared to undergo training from a speech therapist if they lost their voices.

Item 54

Table 4.50: Respondents who feel they need assistance with home nursing care. N = 53 (M & F)

Responses	Frequency	Percent
Yes	21	39.6
No	32	60.4
TOTAL	53	100.0

The majority (60,4%) of the respondents indicated that they do not need assistance with home nursing care. Twenty one (39,6%) of the respondents indicated that they do need assistance with home nursing care.

The majority of the respondents are from the north. Table 4.8 indicates that 66% of the respondents always have someone at home who helps them. This could perhaps influence the "No" responses indicated in the above table. Nevertheless there is a need to assist the respondents with home nursing care.

4.1.1.1. Distance

Most of the patients who live far away from the main hospital located in the Western region of Malawi live in the north. The hospital has three departments that are located in the north and the south. The north department is a "day care unit" in the north and in the south and east of Malawi. Some of the patients travel by train, e.g. from Lilongwe to Mzimba. The train departs during the evening and arrives in Mzimba the following morning. The cost of this is high. Other patients travel from their homes to the hospital and only stay overnight at a nearby hospital to get the treatment and the following day to be transported to Mzimba. The cost of travelling is reduced when going back home. There is a bus service that runs to Mzimba at regular intervals. Some patients especially those staying in the north have to walk long distances from their homes to the nearest health centre to Mzimba. The distance between Mzimba and the hospital is increasing. The road is not paved and it is very difficult to travel. The road is very bad and it is very difficult to travel. The road is very bad and it is very difficult to travel. The road is very bad and it is very difficult to travel.

Arising from the structured interviews patients were encouraged to talk about the difficulties and problems encountered by them and their caregivers. The respondents were from various ethnic groups namely Herero, Damara, Nama, Owambo, Baster, Coloured and White. For the ease of reference the problems were classified under certain headings as the respondents verbalised their concerns. These were distances, need for counselling, treatment and supplies, management of physical symptoms, unemployment, home-made remedies, sedatives and eating and drinking habits. All these issues greatly affect the future planning of an effective cancer care programme. They are reflected as additional material to that elicited from the questionnaire.

4.1.1 Distances

Most of the patients stay far away from the main hospital located in the various regions in Namibia (See fig. 4.1). The hospital bus that departs from Windhoek to fetch patients from the various main hospitals, travels in a "straight line" to the north and to the south and only on specific days. Some of the patients travel by train, e.g. from Walvis Bay to Windhoek. The train departs during the evening and arrives in Windhoek the following morning. The cost of this is high. Other patients travel from their homes a day before and stay overnight at a midway junction to get the hospital bus the following day to be transported to Windhoek. The same way of travelling is followed when going back home. Travel is expensive. They have to do this at 3 monthly intervals. Some patients, especially those staying in the rural areas, have to walk long distances from their home to the nearest health centre or clinic. For a sick person this way of travelling is exhausting. One rural patient mentioned that he uses a sledge drawn by his donkeys to get to the nearest hospital. His children return home with the sledge.

During the interviews it became evident that for these cancer patients much effort was put into travelling.

Some of the patients also indicated that the supply points or clinics are situated far apart (see fig. 4.1) and supplies are not always available or are out of stock. The patients are, therefore, not in a position to travel to the next nearest clinic and they thus go without much needed medical supplies.

4.1.2 Counselling

During the interviews it became evident that the majority of the patients' caregivers were not counselled. It also became evident that children between the age group 12 - 18 years were involved in caregiving (Item 44, Annexure 3.5 A). Counselling of the patient, caregivers and family is very important to facilitate coping. The rural patient in particular needed this. The results reflected in Table 4.40, Annexure 3.5 A justify the need to address this problem.

4.1.3 Management of physical symptoms

The patients also experienced problems with the management of physical symptoms at home as they were not informed about home management of the symptoms (Item 18, Annexure 3.5 A). The patients and caregivers made use of home made remedies, some of which will be discussed in a subsequent paragraph. Some of the patients also experienced other ill-health problems eg. hypertension. Other patients also experienced other pain not related to cancer (Item 25.1, Annexure 3.5 A). There were no clinics close enough to provide relief from these problems.

4.1.4 Treatment supplies

On further questioning during the interviews the patients indicated that pain management was a major problem. Obtaining appropriate pain medication for cancer pain from the clinics was a problem. Panado is always available at the nearest clinic but the number of tablets made available is not sufficient to last from one clinic visit to the next if the patient suffers much pain. Although Panado can be purchased from shops, the small shops in the rural areas, known as Cuca shops, do not stock much medicine. Panado is also an expensive item for the impoverished family who is barely able to supply food. Panado, as an analgesic, is not effective for severe pain in terminal cases. This was a constant complaint. Yet nurses at the clinics are reluctant to give stronger analgesics. It is obvious that in planning a cancer after-care programme for the rural areas, a special "protocol" must be provided to enable the nurse to provide more effective medication.

Diet supplements such as Complan or Ensure are not available at clinics, and the cost of private purchase of such items is beyond the financial resources of all the patients interviewed.

Unemployment is also a problem facing cancer patients. Lack of social assistance caused poverty, loss of housing facilities and affected the children (Items 3,4,6,7 and 8, Annexure 3.5 A). Without an income rapid deterioration of the sufferer is inevitable and much misery and worry has to be endured.

Problems experienced by the patients, e.g. distances from clinics and lack of supplies, prompted the

investigator to find out how the family caregivers coped with problems such as wound care, pain, mouth care, dyspnoea, fatigue, swelling and eating and drinking habits. Due to the lack of medical supplies in the rural areas and in many urban areas, the families resort to home-made remedies to meet the most pressing needs. These measures were revealed in the unstructured interviews which followed structured interview 3.5 A. The information obtained is not scientifically proved and is, therefore, not recommended. However it indicates the extent to which the respondents are prepared to go to alleviate the symptoms. The following are examples of the approaches adopted.

4.1.5 Wound Care

Honey is put on clean wounds and has a soothing effect. The comfrey plant is extensively used on suppurative wounds. It is apparently rich in Vitamins A, C, E, B12, B1, Iron and calcium. Skin cancer and rodent ulcers also respond well to this. The dry leaves are pulverized and the powder is mixed with vaseline or lanoline and applied to the wound. No dressing is necessary.

Ulcerative and other "wet" wounds are also treated with medications made from plants such as the "Onduraturawa" plant, the roots of which are dried, crushed into powder. This powder is applied to any wet, oozing wounds. It has a drying effect on wounds. "See Wiere" ("See derms") Sea Weed is also used. This is "grilled" over an open fire and crushed into powder. The powder is used on ulcerative wounds. Apparently this has an anti-infection effect. "Kriekiebos" is also used for wounds. The leaves are dried and crushed into powder.

The powder is mixed with goat fat and castor oil to keep the mixture soft. The mixture is applied to a piece of flannel material and is used as a poultice on wounds. It apparently has a disinfectant and healing effect. It is used for ulcerative Ca Mamma.

4.1.6 Mouth and throat care

"Rooi poeier" obtained from a chemist is used to clean the mouth when the tongue is coated. It has a refreshing effect. The plant "Omuzema" ("Omudhime") is used extensively. The dried roots are used to clean the mouth and teeth. The dried roots are rubbed against the teeth or chewed but not swallowed. It also refreshes the mouth.

The "Otjihangatene" plant, that looks like a potato is dried and crushed into powder. The powder is either swallowed or sucked like throat lozenges. It is used for cancer of the oesophagus. The "Omundumba" plant grows like a shrub. Its leaves are cooked in water. The cooled water is used for gargling.

4.1.7 Gastro-intestinal problems

The "!Khuxab" plant is used extensively. The roots are cooked in water. The cooled water is used for drinking. This is apparently effective for stomach ache and stopping diarrhoea. The "Otjindombo" ("Alwyn") is crushed and cooked and the mixture drunk when cold. It has a laxative effect.

4.1.8 Respiratory problems

For respiratory problems such as dyspnoea, the pomelo treatment is used. One pomelo is baked in its skin. The pulp is then bottled. To this is added one bottle

each of Turlington, "Borsdruppels", "Geelbalsam" and raw honey. One tablespoonful is taken three times a day. It is said to alleviate dyspnoea.

The "Kloudoring"/"Gammakoe" is also very popular. The root is cut and dried. This is then cooked in water. When cool it is used as a tonic. It is used for Ca lung and said to have an "antibiotic" effect.

4.1.9 Gynaecological problems

The plant "Gammakoe" is prepared as above and used as a tonic. It is said to have an "antibiotic" effect for Ca of the reproductive system.

The "Wynryk" plant is cooked in water and bottled. It is used as a tonic for a person suffering from Ca uterus.

"Pepperboom blare" are cooked in water which is cooled and used as a tonic. This tonic has a cleansing effect. It is used for Ca uterus and for the vaginal odour caused by discharge. The discharge is said to stop.

"Deurmekaar poeier" is a substance made by somebody in Rehoboth. This powder is cooked in water. When cool it is used as a tonic. It is said to have an effect on Ca of the reproductive system.

The comfrey plant is used extensively. The leaves or the root of the Comfrey plant are used as a tea. They are used dried or fresh. This is used for Ca Ovary, has a soothing, healing effect and relieves inflammation.

Vaginal and uterine steamtherapy is also well known. "Swarthbalsam" is poured into a basin/container with hot water. The mixture is used for vaginal steamtherapy in cases of Ca vagina or uterus. It has a soothing and hydroscopic effect.

4.1.10 Swelling

The pips of olives are "grilled" in a pot and then crushed until fine. The mixture is oily and is applied to a swollen area. The swelling apparently subsides.

The vinegar and cold water remedy for oedema is also well known. Vinegar and cold water is mixed in a basin. Swollen legs are bathed with this and legs placed on a cushion or pillow. The swelling apparently subsides. It is probably the "Tender Loving Care" which comforts the patient and the slight elevation of the limb.

4.1.11 Sedatives

"Voëlent" is used as a sedative. This grows on trees. The plant is prepared like tea and used as a tonic. This tonic has a sedative effect. Comfrey tea is also said to have a sedative effect.

4.1.12 Eating and drinking habits

"Shikundu" is a very nutritious drink. "Mahewu" ("Magou") is also a very nutritious drink made of soft porridge. This is extensively used in oral cancers.

4.1.13 Air Freshner

Ashes from coal is scattered in the room. This removes bad smells (odour) from the room.

4.1.14 Conclusion

The above shows that man in great need of health treatment will resort to remedies of their forefathers to obtain some relief. In a study done by Searle the patients and relatives who described the use of medicinal plants for the treatment of cancer all stated that they knew that death was inevitable but the remedies helped to relieve pain, assisted the sufferer to sleep, helped to eliminate noxious odours or assisted elimination. A very important thing that was said by all - the patient knows that we are trying to help him to live with his sickness until death intervenes. He knows that we care so much that we will do anything to bring him some comfort. In the far-off reaches of this vast country such assistance should be valued.

ANNEXURE 3.6 B

QUESTIONNAIRE B - CAREGIVER (family or other assistant)

Item 1

Table 4.1: Age distribution of caregivers N = 14 (M & F).

Age distribution	Frequency	Percent
0 - 12 years	0	-
12 - 18 years	2	14.2
18 - 45 years	6	42.9
> 45 years	6	42.9
TOTAL	14	100.0

The table above indicates that 2 of the caregivers (14,2%) fall in the 12 - 18 years age group. Six (42,9%) of the caregivers are between 18 - 45 year old. Six (42,9%) of the caregivers are more than 45 years old.

Item 2

Table 4.2: Marital status of caregivers N = 14 (M & F).

Marital status	Frequency	Percent
Married	5	35.7
Single	9	64.3
TOTAL	14	100.0

The majority (64,3%) of the caregivers are single. Five of the caregivers (35,7%) are married.

Item 3

Table 4.3: Number of dependent children of the caregivers.

N = 14 (M & F)

Number of children	Frequency	Percent
0	6	42.9
1	3	21.4
2	2	14.3
3	1	7.1
4	1	7.1
5	1	7.1
TOTAL	14	100.0

Six of (42,9%) of the caregivers do not have dependent children. Three (21,4%) of the caregivers have one dependent child. Two (14,3%) of the caregivers have 2 dependent children. One (1,7%) of the caregivers have 3 children, 1 (1,7%) of the caregivers have 4 children and 1 (1,7%) caregiver has 5 children.

The majority of the caregivers (57,1%) have dependent children.

Item 4

Table 4.4: Ages of the dependent children of the caregivers.

N = 14 (M & F).

Ages	Frequency	Percent
0 - 6 years	5	35.7
6 - 12 years	3	21.4
12 - 18 years	6	42.9
TOTAL	14	100.0

The table above indicates that 5 (35,7%) of the caregivers' children fall in the 0 - 6 year age group. Three (21,4%) of the

caregivers' children fall in the 12 - 18 year age group and six (42,9%) of the children fall in the 12 - 18 year age group. The majority (64,3%) of the children fall into the school-going age group, 6 - 12 years and 12 - 18 years old respectively.

Item 5

Table 4. 5: Employment of caregivers. N = 14 (M & F).

Employment	Frequency	Percent
Employed	3	21.4
Unemployed	11	78.6
TOTAL	14	100.0

From the findings reflected in the table above it will be seen that 11 (78,6%) of the caregivers are unemployed. Three (21,4%) of the caregivers are employed.

The high percentage of the unemployed could indicate that the caregivers have to face many difficulties with their dependent children. The majority of the respondents (Table 4.5 Annexure 3.5 A) are also unemployed. To what extent efficient care can be provided under such circumstances is doubtful.

Item 6

Table 4.6: Other source of income of caregivers.

N = 14 (M & F).

Source of Income	Frequency	Percent
Social assistance (social pension)	1	7.1
None	12	85.7
Family assistance	1	7.1
TOTAL	14	100.0

The greater percentage of caregivers (85,7%) have no other source of income. One (7,1%) of the caregivers obtains social pension while (7,1%) of the caregivers is assisted by the family.

The findings in Table 4.4, Table 4.5 and Table 4.6 reflect the magnitude of the financial assistance that both the patients and caregivers need.

Item 7

Table 4.7: Relationship of the caregiver to the patient.

N = 14. (M & F)

Relationship	Frequency	Percent
Spouse	5	35.7
Family	8	57.1
Friend	1	7.1
TOTAL	14	100.0

Table 4.7 shows that 5 (35,7%) of the caregivers are the husbands or wives of the patient. The majority (57,1%) of the caregivers are related to the patients. One (7,1%) of the caregivers is a friend of the patient.

CAREGIVER KNOWLEDGE

Item 8

Table 4.8: Caregiver's knowledge about the patients who were/are on chemotherapy. N = 14. (M & F)

Responses	Frequency	Percent
Yes	11	78.6
No	3	21.4
TOTAL	14	100.0

The table above reflects that 11 (78,6%) of the caregivers know the patients were/are on chemotherapy. Three (21,4%) of the patients' caregivers know that the patients were/are not on chemotherapy.

Item 9

Table 4.9: Caregiver's knowledge about the patients who had radiotherapy. N = 14. (M & F)

Responses	Frequency	Percent
Yes	8	57.1
No	6	42.9
TOTAL	14	100.0

Table 4.9 indicates that 8 (57,1%) of the caregivers know that the patients had radiotherapy. Six (42,9%) of the caregivers know that the patients did not undergo radiotherapy.

Item 10

Table 4.10: Caregiver's knowledge about the patients who had undergone surgery. N = 14. (M & F)

Responses	Frequency	Percent
Yes	12	85.7
No	2	14.3
TOTAL	14	100.0

The table above reflects that 12 (85,7%) of the caregivers know that the patients have undergone surgery. Two (14,3%) of the caregivers know that the patients have not undergone surgery.

Table 4.8, Table 4.9 and Table 4.10 indicate that the caregivers know what type of treatment the patients had. During the interview the majority of the caregivers indicated that the patients informed them about their treatment modality. Some of the caregivers indicated that they asked the doctor for an explanation because they did not understand the explanation given by the patient. When asked why they did not ask the professional nurse they indicated that the nurse was always busy.

Item 11

Table 4.11: Caregivers who are aware of the side-effects of the treatment. N = 14. (M & F)

Responses	Frequency	Percent
Yes	6	42.9
No	8	57.1
TOTAL	14	100.0

From the table above it can be seen that the majority (57,1%) of the caregivers are not aware of the side-effects of the treatment. Six (42,9%) of the caregivers are aware of the side-effects of the treatment.

Although the majority of the patients come to the hospital alone (Table 4.47 Annexure 3.5 A) for follow-up treatment, all the patients (respondents) were hospitalized (Item 5 Annexure 3.5 A). The nurses should inform the caregivers about the side-effects of the treatment during hospitalization.

It appears that 56,6% of the respondents (Table 4.13 Annexure 3.5 A) are not in a position to explain to the caregivers what the side-effects of the treatment modalities are as the respondents (56,6%) are not aware of the side-effects.

Item 12

Table 4.12: Persons who informed the caregivers about the side-effects of the treatment. N = 14. (M & F)

Responses	Frequency	Percent
Doctor	6	42.9
Nurse	0	0
Another patient	0	0
Friend	0	0
Social Worker	0	0
	8 Missing	57.1 Missing
TOTAL	14	100.0

All 6 of the caregivers (42,9%) who are aware of the side-effects of the treatment (Table 4.11) were informed by the doctor (Table 4.12). The 8 (57,1%) caregivers indicated as missing corresponds with those in Table 4.11 who are not aware of the side effects of the treatment.

The nurse should get more involved in health education as it appears that her role is neglected.

Item 13

Table 4.13: Caregivers who were informed on how to handle side-effects at home. N = 14. (M & F)

Responses	Frequency	Percent
Yes	3	21.4
No	11	78.6
TOTAL	14	100.0

The table above indicates that 3 (21,4%) of the caregivers were informed on how to handle the side-effects at home. Eleven

(78,6%) of the caregivers were not informed on how to handle the side-effects of the treatment at home.

There seems to be inadequate support of the caregivers by the nurses.

Item 14

Table 4.14: Do you feel you were adequately informed by the nurses about the following aspects?:

N = 14. (M & F)

Aspects	Frequency	Percent
Disease	8	57.1
Treatment/therapy of patient	3	21.4
Potential emergencies	1	7.1
First-aid treatment of emergencies at home	1	7.1
Home management of emergencies	1	7.1
TOTAL	14	100.0

Table 4.14 reflects the extent to which the caregivers feel they were adequately informed. Eight (57,1%) of the caregivers feel they were adequately informed by the nurses about the disease. Three (21,4%) of the caregivers feel they were adequately informed about the treatment by the nurses. One (7,1%) of the caregivers feels he/she was adequately informed by the nurse about the potential emergencies, first-aid treatment of emergencies at home and the home management of emergencies respectively.

It appears that very little information is given to the caregivers by the nurse to facilitate coping at home.

Item 15.1

Table 4.15: Indication of when the caregivers were informed about the treatment/therapy of the patient.

N = 14. (M & F)

Responses	Frequency	Percent
During hospitalization	10	71.4
On discharge	1	7.1
	13 Missing	21.4 Missing
TOTAL	14	100.0

Table 4.15 indicates that 10 (71.4%) of the caregivers were informed about the patient's treatment during hospitalization. One (7.1%) of the caregivers was informed about the patient's treatment on discharge.

During the interview the caregivers indicated that the nurses always seemed so busy that the caregivers did not want to trouble the nurses with unnecessary questions.

Three (21.4%) of the caregivers indicated as missing in the table reflects those caregivers who were not informed about the chemotherapy (Table 4.8).

Item 15.2

Table 4.16: Indication of when the caregivers were informed about the potential emergencies. N = 14. (M & F)

Responses	Frequency	Percent
During hospitalization	1	7.1
On discharge	1	7.1
	12 Missing	85.7 Missing
TOTAL	14	100.0

Table 4.16 indicates that 1 (7,1%) of the caregivers was informed about the potential emergencies during hospitalization and 1 (7,1%) of the caregivers was informed on discharge. Twelve (85,7%) of the caregivers (missing) were not informed about the potential emergencies.

Item 15.3

Table 4.17: Indication of when the caregivers were informed about the first-aid treatment of emergencies at home. N = 14. (M & F)

Responses	Frequency	Percent
During hospitali- zation	1	7.1
On discharge	1	7.1
	12 Missing	85.7 Missing
TOTAL	14	100.0

Table 4.17 indicates that 1 (7.1%) of the caregivers was informed about the first-aid treatment of emergencies at home. One (7.1%) of the caregivers was informed on discharge. Twelve (85,7%) of the caregivers reflected as missing were not informed.

Item 15.4

Table 4.18: Indication of when the caregivers were informed about the home management of physical symptoms. N = 14. (M & F)

Responses	Frequency	Percent
During hospitali- zation	1	7.1
On discharge	2	14.3
	11 Missing	78.6 Missing
TOTAL	14	100.0

The table above reflects that 1 (7.1%) of the caregivers was

informed about the home management of physical symptoms. Two (2) of the caregivers (14.3%) were informed on discharge. Eleven (78,6%) of the caregivers indicated as missing were not informed about the home management of physical symptoms. Table 4.18 (Annexure 3.5 A) indicates a high percentage (83,0%) of respondents (patients) who were not informed about the home management of physical symptoms. It is significant that 78,6% of the caregivers (Table 4.18 Annexure 3.6 B) were not informed about the physical symptom management. The caregivers will not be able to alleviate these symptoms or support the patient. Alleviating physical symptoms is part of basic nursing care.

Item 16

Table 4.19: Caregivers who feel they need further guidance and family education. N = 14. (M & F)

Responses	Frequency	Percent
Yes	12	85.7
No	2	14.3
TOTAL	14	100.0

The majority 85,7% of the caregivers feel that they need further guidance and family education. Two (14,3%) of the caregivers feel that they do not need further guidance or family education.

The nurses have much to do in guiding and educating the family to promote health. This is important and is incorporated in the Primary Health Care approach. Serious attention needs to be given to health education of the family as well as the patient to alleviate suffering and facilitate coping at home.

Item 17.1

Table 4.20: Specifications of guidance and family education needed by caregivers regarding causes.

N = 14. (M & F)

Responses	Frequency	Percent
Yes	4	28.6
No	10	71.4
TOTAL	53	100.0

Table 4.20 shows that the greater percentage (71,4%) of the caregivers do not need guidance and family education about the causes of the illness. Four (28,6%) of the caregivers feel they need further guidance and family education regarding the causes of the illness.

Item 17.2

Table 4.21: Further guidance and family education needed by caregivers regarding prevention. N = 14. (M & F)

Responses	Frequency	Percent
Yes	10	71.4
No	4	28.6
TOTAL	14	100.0

The table above indicates that 10 (71,4%) of the caregivers need further guidance and family education regarding prevention of the illness. Four (28,6%) of the caregivers do not need further guidance and family education regarding prevention.

Item 17.3

Table 4.22: Further guidance and family education needed by caregivers regarding home care. N =14. (M & F)

Responses	Frequency	Percent
Yes	9	64.3
No	5	35.7
TOTAL	14	100.0

Table 4.22 indicates that 9 (64,3%) of the caregivers need further guidance and family education on home care. Five (35,7%) of the caregivers indicated that they do not need further guidance and family education regarding home care.

Item 17.4

Table 4.23: Further guidance and family education needed by caregivers regarding wound care. N = 14. (M & F)

Responses	Frequency	Percent
Yes	5	35.7
No	9	64.3
TOTAL	14	100.0

The table above indicates that 9 (64,3%) of the caregivers need further guidance and family education regarding wound care.

During the interview some of the respondents indicated that their spouse withdrew (rejected) from their relationship as they could not cope with wound care. Pre-operative and post-operative information as well as demonstrations of wound care are necessary. This is the role of the nurse.

Five (35,7%) of the caregivers do not need further guidance and family education on wound care.

PATIENT COMFORT

Item 18: Caregiver's involvement in the personal care of the patient. N = 14. (M & F)

Thirteen (92,9%) of the caregivers are involved in the personal care of the patients. One (7,1%) of the respondents is not involved in the personal care of the patient.

Item 19.1

Table 4.24: Caregivers who render nursing care to the patients. N = 14. (M & F)

Responses	Frequency	Percent
Yes	13	92.9
No	1	7.1
TOTAL	53	100.0

Thirteen (92,9%) of the caregivers indicated that they render nursing care to the patients. One (7,1%) of the respondents does not render nursing care to the patient.

Item 19.2

Table 4.25: Caregivers who do household chores for the patient. N = 14. (M & F)

Responses	Frequency	Percent
Yes	13	92.9
No	1	7.1
TOTAL	53	100.0

Table 4.25 indicates that 13 (92,9%) of the caregivers do

household chores for the patient. One (7,1%) of the caregivers does not do household chores.

Table 4.25 and Table 4.25 reflect the extent of which the caregiver is involved in caring for the patient.

Item 20

Table 4.26: Do you think the patient feels comfortable most of the time? N = 14. (M & F)

Responses	Frequency	Percent
Yes	6	42.9
No	8	57.1
TOTAL	14	100.0

In the table above it can be seen that 8 (57,1%) of the caregivers think that the patient does not feel comfortable most of the time. Six (42,9%) of the caregivers think that the patient feels comfortable most of the time.

Item 21

Table 4.27: Does the patient experience pain? N = 14. (M & F)

Responses	Frequency	Percent
Yes	10	71.4
No	4	28.6
TOTAL	14	100.0

Table 4.27 indicates that 10 (71,4%) of the caregivers think that the patient experiences pain. Four (28,6%) of the caregivers think that the patient does not experience pain.

From the table above and Table 4.25 (Annexure 3.5 A) which indicates that the majority of respondents experience pain, it is clear that pain appears to be a problem. Nurses should assess pain thoroughly so that proper measures can be taken to alleviate pain.

Item 22

Table 4.28: Is the patient on pain medication?

N = 14. (M & F)

Responses	Frequency	Percent
Yes	7	50.0
No	7	50.0
TOTAL	14	100.0

Seven (50,0%) of the caregivers indicated that the patient is on pain medication. Seven (50,0%) of the caregivers indicated that the patient is not on pain medication.

Item 23

Table 4.29: Reasons why the patient is not having pain medication. N = 14. (M & F)

Reasons	Frequency	Percent
Doctor is not informed	3	21.4
Medications used up	4	28.6
	7 Missing	50.0 Missing
TOTAL	14	100.0

The table above indicates that 3 (21,4%) of the caregivers indicated that the doctor has not yet been informed about the

pain. Four (28,6%) of the caregivers indicated that the medicine is used up before the time for the next follow-up visit. Fifty percent (7) of the caregivers (missing) indicated that patients are not on pain medication.

During the interview the caregivers indicated that the patients got mild pain tablets at the clinic which is ineffective for the pain.

Item 24

Table 4.30: The type of pain medication that the patient uses.
N = 14. (M & F)

Type of pain medication	Frequency	Percent
Known	3	21.4
Unknown	4	28.6
	7 Missing	50.0 Missing
TOTAL	14	100.0

The table above indicates that 3 of the caregivers (21,4%) know the type of pain medication that the patient receives. The caregivers indicated that they know the name of the medication and that it is for pain.

Four of the caregivers (28,6%) do not know what type of pain medication the patient receives. These caregivers do not know the name of the medication but know that the patient gets pain medication.

The patient and caregivers need to be told how the medication works and the duration of the effects of pain medication so they understand the doses.

Item 25

Table 4.31: Ability of the caregiver to manage the patient's pain effectively. N = 14. (M & F)

Responses	Frequency	Percent
Yes	2	14.3
No	12	85.7
TOTAL	14	100.0

From the table above it can be seen that 12 (85,7%) of the caregivers cannot manage the patient's pain effectively. Two (14,3%) of the respondents can manage the patient's pain effectively.

Item 26.1

Table 4.32: Ignorance about pain as a reason for being unable to manage the patient's pain effectively.

N = 14. (M & F)

Responses	Frequency	Percent
Yes	10	71.4
No	4	28.6
TOTAL	14	100.0

The greater percentage (71,4%) of the caregivers indicated they are ignorant about pain. Four (28,6%) of the caregivers are not ignorant about pain.

The results indicate that more information about pain in cancer needs to be given to caregivers. This will enable the caregiver to understand how the patient feels and facilitate coping with pain at home.

Item 26.2

Table 4.33: Ignorance about the medication as a reason for being unable to manage the patient's pain effectively.

N = 14. (M & F)

Responses	Frequency	Percent
Yes	10	71.4
No	4	28.6
TOTAL	14	100.0

The table above shows that 10 (71.4%) of the caregivers are ignorant about the medication that the patient receives. Four (28,6%) of the caregivers are not ignorant about the medication. Ten (71,4%) of the caregivers indicated that the medication mentioned above includes cancer medicine.

Item 26.3

Table 4.34: Silence of the patient as a reason why the caregiver is not able to manage the patient's pain effectively. N = 14. (M & F)

Responses	Frequency	Percent
Yes	7	50.0
No	7	50.0
TOTAL	14	100.0

Table 4.34 shows that 7 (50%) of the caregivers indicated the silence of the patient as a reason why the caregivers are not able to manage the patient's pain effectively. Fifty percent (7) of the caregivers indicated that the patients are not silent.

Some of the caregivers indicated that although the patients are silent the caregivers could see when the patient suffered pain.

This is important as the community nurses need to be alert to such signs.

Item 27

Table 4.35: Does the patient experience nausea?

N = 14. (M & F)

Responses	Frequency	Percent
Yes	6	42.9
No	8	57.1
TOTAL	14	100.0

Six of the caregivers (42,9%) indicated that te patients experience nausea. Eight of the caregivers (57,1%) indicated that the patients do not experience nausea.

Item 28

Table 4.36: Causes of nausea experienced by the patient.

N = 14. (M & F)

Couses	Frequency	Percent
Environment	1	7.1
Medication	4	28.6
Food	9	64.3
TOTAL	14	100.0

Table 4.36 shows that 9 (64,3%) of the caregivers indicated that the patient experiences nausea due to the food. Four (28,6%) of the caregivers indicated that the nausea is due to the medication that the patient uses. One (7,1%) of the caregivers indicated that the environment causes the patient to become nauseous.

NUTRITION

Item 30

Table 4.38: Caregiver's feeling about managing the patient's dietary needs effectively. N = 14. (M & F)

Responses	Frequency	Percent
Yes	11	78.6
No	3	21.4
TOTAL	14	100.0

It is encouraging to see that the greater percentage (78,6%) of the caregivers indicate that they feel they are managing the patient's dietary needs effectively. Three (21,4%) of the caregivers feel that they are not managing the patients' dietary needs effectively.

The nurse needs to give advice in such cases and refer the caregivers to the dietician.

Item 31.1

Table 4.39: Lack of finance as a reason why caregivers feel they are not managing the patient's dietary needs effectively.

N = 14 (M & F)

Responses	Frequency	Percent
Yes	3	21.4
No	0	0
	11 Missing	78.6 Missing
TOTAL	14	100.0

Table 4.39 shows that all the 3 caregivers (21,4%) indicated

lack of finance as a reason for not managing the patient's dietary needs. Eleven of the caregivers (78,6%) indicated as missing are those caregivers in Table 4.38 who feel they are managing the patient's dietary needs effectively.

Item 31.2

Table 4.40: Anorexia as a reason why caregivers feel they are not managing the patient's dietary needs effectively.

N = 14 (M & F)

Responses	Frequency	Percent
Yes	3	21.4
No	0	0
	11 Missing	78.6 Missing
TOTAL	14	100.0

Table 4.40 shows that all the 3 caregivers (21,4%) indicated anorexia as a reason for not managing the patient's dietary needs efficiently.

Item 31.3

table 4.41: Ignorance about diet as a reason why caregivers feel they are not managing the patient's dietary needs effectively.

N = 14 (M & F)

Responses	Frequency	Percent
Yes	1	7.1
No	2	14.3
	11 Missing	78.6 Missing
TOTAL	14	100.0

The table above shows that 1 (7,1%) of the caregivers indicated

that ignorance about diet is a reason why the patient's needs are not managed efficiently. Two of the caregivers (14,3%) indicated that ignorance about diet is not a reason for not managing the patient's dietary needs efficiently.

ELIMINATION

Item 32

Table 4.42: Does the patient experience any altered elimination problems? N = 14 (M & F)

Responses	Frequency	Percent
Yes	10	71.4
No	4	28.6
TOTAL	14	100.0

Ten (71,4%) of the caregivers indicated that the patients experience altered elimination problems. Four (28,6%) of the caregivers indicated that the patients do not experience any elimination problems.

Item 33.1

Table 4.43: Patients experiencing constipation. N = 14 (M & F)

Responses	Frequency	Percent
Yes	10	71.4
No	4	28.6
TOTAL	14	100.0

Ten of the caregivers (71,4%) indicated that the patients experience constipation. Four of the caregivers (28,6%) indicated that the patients do not experience constipation.

The results are consistent with the results shown in Item 33, Table 4.35 (Annexure 3.5 A).

Item 33.2

Table 4.44: Patients who experience diarrhoea. N = 14 (M & F)

Responses	Frequency	Percent
Yes	1	7.1
No	13	92.9
TOTAL	14	100.0

The results show that 13 (92,9%) of the caregivers indicated that the patients do not experience diarrhoea. One of the caregivers (7,1%) indicated that the patients experience diarrhoea.

The results indicated above are consistent with the results of Item 33 (Annexure 3.5 A)

Item 33.3: Patients who experience urinary incontinence.

N = 14 (M & F)

All the 14 caregivers (100%) indicated that the patients do not experience urinary incontinence.

Item 34

Table 4.45: Caregiver's ability to cope with patients altered elimination problems? N = 14 (M & F)

Responses	Frequency	Percent
Yes	13	92.9
No	1	7.1
TOTAL	14	100.0

The results above indicate that 13 (92,9%) of the caregivers are

able to cope with the patient's altered elimination problems. One of the caregivers (7,1%) indicated that he/she cannot cope with the patient's altered elimination problems. The results appear to be consistent with the results indicated in Item 34 (Annexure 3.5 A).

Item 35

Table 4.46: Does the illness interfere with the patient's movements? N = 14 (M & F)

Responses	Frequency	Percent
Yes	3	21.4
No	11	78.6
TOTAL	14	100.0

From these results it can be seen that 3 of the caregivers (21,4%) indicated that the illness interferes with the patient's mobility. Eleven of the caregivers (78,6%) indicated that the illness does not interfere with the patient's movements.

Item 36

Table 4.47: Caregivers who assist the patient with mobility. N = 14 (M & F)

Responses	Frequency	Percent
Yes	3	21.4
No	11	78.6
TOTAL	14	100.0

The table above indicates that 3 of the caregivers (21,4%) indicated that they assist the patient with mobility. Eleven of the caregivers (78,6%) indicated that they do not assist the patients with mobility.

PSYCHO-SOCIAL NEEDS OF THE CAREGIVER

Item 37

Table 4.48: Children who have to help with the caring of the patient. N = 14 (M & F)

Responses	Frequency	Percent
Yes	8	57.1
No	6	42.9
TOTAL	14	100.0

Table 4.48 shows that 8 of the caregivers (57,1%) indicated that the children have to help with the caring of the patient. Six of the caregivers (42,9%) indicated that the children do not have to help with patient care.

The results are consistent with the results in Item 44 (Annexure 3.5 A). The caregivers and the respondents indicated that children are used to help with patient care.

The nurse needs to prepare child caregivers for this task which is stressful for children and can cause much psychological harm to the child.

Item 38

Table 4.49: Caregiver's reasons why children have to help with the care of the patient. N = 14 (M & F)

Responses	Frequency	Percent
Adult members working	8	57.1
	6 Missing	42.9 Missing
TOTAL	14	100.0

Table 4.49 shows that 8 of the caregivers (57,1%) indicated

that the children have to help with the care of the patients because adult members of the family are working. Six of the caregivers (42,9%) reflected as "missing" are those indicated in Table 4.48. The caregivers stated that the schoolgoing children usually arrive home early afternoon and, therefore, have to help with caring until adults arrive, which is usually during the evening.

Item 39

Table 4.50: How do other family members react? N = 14 (M & F)

Reactions	Frequency	Percent
Helpful	12	85.7
Unhelpful	1	7.1
Moved from home	1	7.1
TOTAL	14	100.0

It is encouraging to see that the greater percentage (85,7%) of caregivers indicated that the family members are helpful. The family has an important supportive role to play.

Item 40: Visits by the community nurse as part of follow-up treatment? N = 14 (M & F)

All the 14 caregivers (100%) indicated that the community nurse does not visit the home as part of follow-up treatment.

The nurses are neglecting their role of follow-up care.

Item 41.1: How often does the community nurse visit the home as part of follow-up treatment. N = 14 (M & F)

This item is not applicable as all the caregivers (100%) indicated that the community nurse does not visit the home as part of follow-up treatment.

Item 42

Table 4.51: Caregivers or other family members who accompany the patient to hospital or clinic. N = 14 (M & F)

Responses	Frequency	Percent
Yes	6	42.9
No	8	57.1
TOTAL	14	100.0

The table above shows that 8 (57,1%) of the caregivers do not accompany the patient to the hospital or clinic.

Item 48 (Annexure 3.5 A) indicates that 73,6% of the respondents (patients) are not accompanied by caregivers to the clinic or hospital.

Item 43

**Table 4.52: Caregiver's use of community resources.
N = 14 (M & F)**

Responses	Frequency	Percent
Yes	2	14.3
No	12	85.7
TOTAL	14	100.0

The results show that 12 of the caregivers (85,7%) indicated that they do not use community resources. Two of the caregivers (14,3%) have to make use of community resources.

These results are consistent with the results indicated in Item 50 (Annexure 3.5 A).

Item 44

Table 4.53: Specification of community resources used by the caregivers. N = 14 (M & F)

Community Resources	Frequency	Percent
Church Organization	2 12 Missing	14.3 85.7 Missing
TOTAL	14	100.0

The two caregivers (14,3%) who do use community resources make use of church organizations. Twelve of the caregivers (85,7%) indicated as missing are the caregivers who do not use community resources.

The community needs to be made aware of the resources available in the community and what the objectives are of the NGO's and Community-based Organizations (CBO's). The CBO's that deal with health care have to be identified (Totemeyer et al, 1994 : 99).

Item 45

Table 4.54: Caregivers who need professional emotional support. N = 14 (M & F)

Responses	Frequency	Percent
Yes	11	78.6
No	3	21.4
TOTAL	14	100.0

The results show that 11 of the caregivers (78,6%) indicated that they need professional emotional support. Three of the caregivers (21,4%) indicated that they do not need professional emotional support.

Item 46

Table 4.55 Caregivers who feel they need to be assisted by a nurse with the patient's nursing care at home.

N = 14 (M & F)

Responses	Frequency	Percent
Yes	5	35.7
No	9	64.3
TOTAL	14	100.0

Table 4.55 shows that 9 (64,3%) of the caregivers indicated that they do not need to be assisted with the patient's nursing care at home by a nurse . Five of the caregivers (35,7%) indicated that they need to be helped by a nurse with the patient's nursing care at home.

During the interview some of the caregivers indicated that they need to be taught about wound care as this causes embarrassment due to ignorance and rejection by the patient. Child caregivers, in particular, experienced problems with bedridden patients.

Item 47

Table 4.56: Caregivers who feel they need financial assistance.

N = 14 (M & F)

Responses	Frequency	Percent
Yes	13	92.9
No	1	7.1
TOTAL	14	100.0

Table 4.56 shows that the greater percentage (92,9%) of the caregivers indicated that they need financial assistance. One of the respondents (7,1%) indicated that he/she does not need financial assistance.

Item 46

Table 4.55 Caregivers who feel they need to be assisted by a nurse with the patient's nursing care at home.

N = 14 (M & F)

Responses	Frequency	Percent
Yes	5	35.7
No	9	64.3
TOTAL	14	100.0

Table 4.55 shows that 9 (64,3%) of the caregivers indicated that they do not need to be assisted with the patient's nursing care at home by a nurse . Five of the caregivers (35,7%) indicated that they need to be helped by a nurse with the patient's nursing care at home.

During the interview some of the caregivers indicated that they need to be taught about wound care as this causes embarrassment due to ignorance and rejection by the patient. Child caregivers, in particular, experienced problems with bedridden patients.

Item 47

Table 4.56: Caregivers who feel they need financial assistance.

N = 14 (M & F)

Responses	Frequency	Percent
Yes	13	92.9
No	1	7.1
TOTAL	14	100.0

Table 4.56 shows that the greater percentage (92,9%) of the caregivers indicated that they need financial assistance. One of the respondents (7,1%) indicated that he/she does not need financial assistance.

The caregivers who need financial assistance indicated that they experienced financial problems concerning lack of income due to the illness of the patient, schooling of children that the caregiver or patient cannot afford, and housing problems. The caregivers felt that children of cancer patients should obtain some form of social support from the state.

Item 48.1: Is guidance necessary for school teachers?
N = 14 (M & F)

All the 14 caregivers (100%) indicated that guidance for school teachers is necessary.

Item 48.2: Is guidance necessary for employers? N = 14 (M & F)

All the 14 caregivers (100%) indicated that guidance for employers is necessary.

Item 48.3: Is guidance necessary for other family members?
N = 14 (M & F)

All the 14 caregivers (100%) indicated that it is necessary to give guidance to other members of the family.

Item 49: Social workers who visit the family as part of follow-up care. N = 14 (M & F)

All the 14 caregivers (100%) indicated that the social worker does not visit the family as part of follow-up treatment.

ANNEXURE 3.7 C

QUESTIONNAIRE C - PROFESSIONAL NURSE

(Who works or worked in the cancer unit in the time span 1991 - 1994)

Item I

Table 4.1: Age distribution of professional nurses.

N = 17.

Age distribution	Frequency	Percent
22 - 25 years	1	5.9
26 - 29 years	4	23.5
30 - 35 years	3	17.6
36 - 40 years	3	17.6
> 40 years	6	35.3
TOTAL	17	100.0

The table above indicates that 1 professional nurse (5,9%) falls in the 22 - 25 year age group, 4 (23,5%) of the professional nurses are between 26 - 29 years old. Three (17,6%) of the professional nurses are between 36 - 40 years old. The majority (35,3%) of the professional nurses are above the age of 40 years.

Item 2

Table 4.2: Basic professional qualifications. N = 17.

General Nurse	Frequency	Percent
Yes	17	100.0
No	-	-
TOTAL	17	100.0

Table 4.2 indicates that all 17 (100%) of the professional nurses are registered general nurses.

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The table above indicates that 1 professional nurse (5,9%) falls in the 22 - 25 year age group, 4 (23,5%) of the professional nurses are between 26 - 29 years old. Three (17,6%) of the professional nurses are between 36 - 40 years old. The majority (35,3%) of the professional nurses are above the age of 40 years.

Item 2

Table 4.2: Basic professional qualifications. N = 17.

General Nurse	Frequency	Percent
Yes	17	100.0
No	-	-
TOTAL	17	100.0

Table 4.2 indicates that all 17 (100%) of the professional nurses are registered general nurses.

Item 3

Table 4.2.1: Number of registered midwives. N = 17.

Responses	Frequency	Percent
Yes	13	76.5
No	4	26.5
TOTAL	17	100.0

From the table above it can be seen that 13 professional nurses (76,6%) are registered midwives. Four professional nurses (23,5%) are not registered as midwives.

Item 2

Table 4.2.2: Number of registered psychiatric nurses. N = 17.

Responses	Frequency	Percent
Yes	4	23.5
No	13	76.5
TOTAL	17	100.0

The table above indicates that 13 professional nurses (76,5%) are not registered as psychiatric nurses. Four professional nurses (23,5%) are registered psychiatric nurses.

Item 2

Table 4.2.3: Number of registered community nurses. N = 17.

Responses	Frequency	Percent
Yes	4	23.5
No	13	76.5
TOTAL	17	100.0

The table above shows that 13 professional nurses (76,5%) are not registered as community nurses. Four professional nurses (23,5%) are registered community nurses.

Only four of the professional nurses are registered as general midwifery, psychiatric and community health nurses, that is, they have undergone a comprehensive basic nursing programme.

Item 3

Table 4.3: Number of registered oncology nurses. N = 17.

Responses	Frequency	Percent
Yes	1	5.9
No	16	94.1
TOTAL	17	100.0

Table 4.3 indicates that the majority of the professional nurses (94,1%) are not registered as oncology nurses. One (5,9%) professional nurse is a registered oncology nurse.

There is a need for registered oncology nurses. None of the professional nurses in Namibia working with cancer patients are registered oncology nurses. The only registered oncology nurse is working in the intensive care unit.

The Ministry of Health and Social Services will however be sending professional nurses to be trained as oncology nurses during 1995.

Item 4

Table 4.4: Number of years of experience as a professional nurse. N = 17.

Years	Frequency	Percent
0 - 1 year	-	-
2 - 4 years	10	58.8
5 - 7 years	-	-
> 8 years	7	41.2
TOTAL	17	100.0

Table 4.4 indicates that 10 (58,8%) professional nurses have between 2 - 4 years of experience as a professional nurse. Seven (41,2%) have more than 8 years of experience.

Item 5

Table 4.5: For how long have you worked in the cancer unit?
N = 17.

Responses	Frequency	Percent
0 - 1 months	7	41.2
7 - 11 months	2	11.8
1 - 2 years	2	11.8
3 - 5 years	3	17.6
> 5 years	3	17.6
TOTAL	17	100.0

Table 4.5 indicates that 7 (41,2%) of the professional nurses have worked in the cancer unit between 0 - 6 months. Two (11,8%) of the professional nurses have worked in the cancer unit for 7 - 11 months. Two (11,8%) of the professional nurses have worked in the cancer unit for 1 - 2 years. Three (17,6%) of the professional nurses have worked in the cancer unit for 3 - 5 years and the other 3 (17,6%) for more than 5 years.

From the table above it appears that the majority of professional nurses still need a lot of experience in cancer nursing. It is necessary to allow professional nurses to work in cancer units either permanently or for very long periods so that they can acquire the necessary skill, knowledge and concern needed for this specialized field.

KNOWLEDGE

Item 6

Table 4.6: Availability of any guidelines in the unit regarding cancer pain relief. N = 17.

Responses	Frequency	Percent
Yes	7	41.2
No	10	58.8
TOTAL	17	100.0

Table 4.6 shows that 10 of the professional nurses (58,8%) indicated that there are no guidelines available in the unit regarding cancer pain relief. Seven professional nurses (41,2%) indicated that there are guidelines in the unit.

The chairman of the Oncology Nursing Society of Namibia indicated during an interview that guidelines on cancer nursing practice standards in the form of reference books and articles on cancer nursing were given to the Oncology Unit before independence. Some of these books are missing. International newsletters on cancer nursing are provided regularly to all hospitals in Namibia.

Item 7

Table 4.7: Do you feel comfortable in providing palliative care to a cancer patient?. N = 17.

Responses	Frequency	Percent
Very comfortable	8	47.1
Fairly comfortable	6	35.3
Slightly uncomfortable	1	5.9
Very uncomfortable	2	11.8
TOTAL	17	100.0

Table 4.7 indicates that 8 (47,1%) of the professional nurses feel very comfortable in providing palliative care to cancer patients. Six professional nurses (35,3%) feel fairly comfortable. One professional nurse (5,9%) feels slightly uncomfortable. Two professional nurses (11,8%) feel very uncomfortable.

The majority of the professional nurses (47,1% and 35,3%) are comfortable. This could be due to their experience as professional nurses (Table 4.4).

Item 8.1

Item 4.8: Do you feel there is lack of knowledge among nurses regarding assessment of pain severity. N = 17.

Responses	Frequency	Percent
Yes	11	64.7
No	6	35.3
TOTAL	53	100.0

Table 4.8 indicates that 11 (64,7%) of the professional nurses feel that there is lack of knowledge among nurses regarding

assessment of pain severity. Six (35,3%) of the professional nurses feel that there is no lack of knowledge regarding assessment of pain severity by professional nurses.

This is consistent with previous findings (Ferrell et al, 1991; Paice et al, 1991; Evans Faries et al, 1991; Diekmann & Wassem, 1991). This lack of knowledge regarding assessment of pain is also evident in the patients' records as the type, intensity and the origin of the pain is not recorded.

Item 8.2

Table 4.9: Do you feel there is lack of knowledge among nurses regarding accurate documentation of pain?. N = 17.

Responses	Frequency	Percent
Yes	12	70.6
No	5	29.4
TOTAL	17	100.0

Twelve of the professional nurses (70,6%) feels there is lack of knowledge among nurses regarding accurate documentation of pain. Five of the professional nurses (29,4%) do not feel that this is so.

Item 8.3

Table 4.10: Do you feel there is lack of knowledge among nurses regarding effective pain management? N = 17.

Responses	Frequency	Percent
Yes	10	58.8
No	7	41.2
TOTAL	17	100.0

Ten of the professional nurses (58,8%) feel that there is

lack of knowledge among nurses regarding effective pain management. Seven of the professional nurses (41,2%) that there is no lack of knowledge among nurses regarding effective pain management. When one looks at the responses of the majority in Table 4.8, 4.9 and Table 4.10 it can be seen that there is a need for more information concerning pain management.

Item 8.4

Table 4.11: Do you feel there is lack of knowledge among nurses regarding actions of prescribed medication? N = 17.

Responses	Frequency	Percent
Yes	7	41.2
No	10	58.8
TOTAL	17	100.0

Table 4.11 indicates that 7 (41,2%) of the professional nurses feel there is lack of knowledge among nurses regarding actions of prescribed medication. The majority (58,8%) feel that there is no lack of knowledge regarding actions of prescribed medication.

Item 8.5

Table 4.12: Do you feel there is lack of knowledge among nurses regarding side-effects of prescribed medication?

N = 17.

Responses	Frequency	Percent
Yes	9	52.9
No	8	47.1
TOTAL	17	100.0

The table above indicates that 9 (52,9%) of the professional

nurses feel that there is lack of knowledge among nurses regarding side-effects of prescribed medication. Eight (47,1%) of the professional nurses feel there is no lack of knowledge among nurses regarding side-effects of prescribed medication.

Item 9.1

Table 4.13: Do you feel you are equipped to give information to a cancer patient regarding actions of prescribed medication? N =17.

Responses	Frequency	Percent
Never	-	-
Sometimes	10	58.8
Always	7	41.2
TOTAL	17	100.0

Table 4.9 shows that 10 of the professional nurses (58,8%) sometimes feel equipped to give adequate health information to a cancer patient regarding actions of prescribed medication. Seven (41,2%) of the professional nurses always feel equipped to give such health information.

There are guidelines available in the cancer unit and oncology clinic on prescribed medication.

Item 9.2

Table 4.14: Do you feel you are equipped to give adequate health information to a cancer patient regarding side-effects of prescribed medication? N = 17.

Responses	Frequency	Percent
Never	1	5.9
Sometimes	10	58.8
Always	6	35.3
TOTAL	17	100.0

From Table 4.14 it will be seen that 10 (58,8%) of the professional nurses sometimes feel equipped to give adequate health information to a cancer patient regarding side-effects of prescribed medication. Six (35,3%) of the professional nurses always feel equipped to do so. It could be that the 6 (35,3%) professional nurses are the ones who have worked in a cancer unit for 3 - 5 years and more than 5 years (Table 4.5).

According to Table 4.16 (Questionnaire A) 71,7% of the respondents felt that they were not adequately informed about the home management of side-effects.

Considering the results reflected in Table 4.12, Table 4.13, Table 4.14 and Table 4.17 (Questionnaire A), it appears there is a need for proper patient education programmes to empower nurses to meet the patients' needs.

Item 9.3

Table 4.15: Do you feel you are equipped to give adequate health information to a cancer patient regarding management of symptoms at home? N = 17.

Responses	Frequency	Percent
Never	5	29.4
Sometimes	5	29.4
Always	7	41.2
TOTAL	17	100.0

From the table above it can be seen that 5 (29,4%) of the professional nurses never feel equipped to give adequate health information regarding management of symptoms at home. Five professional nurses (29,4%) sometimes feel equipped to do so and 7 professional nurses (41,2%) always feel equipped to do so.

Although the majority (41,2%) of the professional nurses always feel equipped to give adequate health information 83% of the respondents (Table 4.18, Questionnaire A) were not informed about home management of physical symptoms.

Item 9.4

Table 4.16: Do you feel you are equipped to give adequate health information to a cancer patient regarding medication management of pain at home? N = 17.

Responses	Frequency	Percent
Never	3	17.6
Sometimes	7	41.2
Always	7	41.2
TOTAL	17	100.0

Seven (41,2%) of the professional nurses always feel equipped to give adequate health information to a cancer patient regarding medication management of pain at home. Seven (41,2%) of the professional nurses sometimes feel equipped to do so and 3 (17,6%) professional nurses never feel equipped to do so. Although the majority of the professional nurses (41,2%) always feel equipped to give health information regarding medication management of pain at home, Table 4.28 (Questionnaire A) indicates that 32,1% of the respondents do not know the type of pain medication they receive and 20,8% of the respondents know the name of the medication but do not know how the medication works.

It appears that the nurses do not give adequate health information to the patients although they are in a position to do so. This could pose a barrier to effective pain management.

Item 9.5

Table 4.17: Do you feel you are equipped to give adequate health information to a cancer patient regarding management of pain at home by means other than prescribed medication ? N = 17.

Responses	Frequency	Percent
Never	3	17.6
Sometimes	9	52.9
Always	5	29.4
TOTAL	17	100.0

From the table above it can be seen that 5 professional nurses (29,4%) always feel equipped to give adequate health information to a cancer patient regarding management of pain at home by means other than medications. Nine (52,9%) of the professional nurses sometimes feel equipped to do so and 3 (17,6%) of the professional nurses never feel equipped to do so.

Nurses should give attention to non pharmacological management of pain at home. This could help the patient to cope with pain if the patient's pain medication gets finished before his date for a follow-up visit, especially in remote areas.

Proper patient education programmes to meet the patient's needs is necessary. The nurse has an important role to play in this aspect of cancer pain management.

Item 9.6

Table 4.18: Do you feel you are equipped to give adequate health information to a cancer patient regarding management of dietary needs at home? N = 17.

Responses	Frequency	Percent
Never	4	23.5
Sometimes	3	17.6
Always	10	58.8
TOTAL	17	100.0

It is significant that 10 (58,8%) of the professional nurses

always feel equipped to give adequate health information to a cancer patient regarding management of dietary needs at home. Three (17,6%) of the professional nurses sometimes feel equipped and 4 (23,5%) never feel equipped to do so.

Item 9.7

Table 4.19: Do you feel you are equipped to give adequate health information to a cancer patient regarding influence of chemotherapy on sexual response or desire?

N = 17.

Responses	Frequency	Percent
Never	5	29.4
Sometimes	9	52.9
Always	3	17.6
TOTAL	17	100.0

Table 4.19 shows that 9 (52,9%) of the professional nurses sometimes feel equipped to give adequate health information to a cancer patient regarding influence of chemotherapy on sexual response or desire. Three (17,6%) of the professional nurses always feel equipped and 5 (29,4%) never feel equipped to do so.

Table 4.38 (Questionnaire A) showed 86,8% were not informed that chemotherapy/radiation could decrease sexual response or desire.

It is necessary to inform the married and single patients of this aspect of sexual response or desire, considering the age distribution of the patients (Tables 4.2 and 4.1, Questionnaire A).

Item 9.8

Table 4.20: Do you feel you are equipped to give adequate health information to a cancer patient regarding influence of radiation on sexual response or desire?

N = 17.

Responses	Frequency	Percent
Never	6	35.3
Sometimes	8	47.1
Always	3	17.6
TOTAL	17	100.0

The table above shows that 8 (47,1%) of the professional nurses sometimes feel equipped to give adequate health information to a cancer patient regarding influence of radiation on sexual response or desire. Three (17,6%) of the professional nurses always feel equipped and 6 (35,3%) never feel equipped to do so.

Item 9.9

Table 4.21: Ability of the professional nurse to identify the different stages of emotional responses to illness (Kublër-Ross) when presented by the patient.

N = 17.

Responses	Frequency	Percent
Never	3	17.6
Sometimes	7	41.2
Always	7	41.2
TOTAL	17	100.0

Seven (41,2%) of the professional nurses are always able to identify the different stages of emotional response to illness when presented by the patient and the other 41,2% are sometimes able to do so. Three (17,6%) are never able to identify the above-mentioned emotional stages.

SOCIAL SUPPORT FOR PATIENT

Item 10: Professional nurse's knowledge of resources available in the community.

Eleven (64,7%) of the professional nurses know the resources which are available in the community to help support the patient and family when their resources are insufficient. Six (35,3%) of the professional nurses do not know which resources are available.

Item 10.1: List of community resources known by professional nurse.

From the 11 (64,7%) professional nurses reflected in Item 10, seven (63,6%) listed only the Cancer Association of Namibia. four (36,4%) listed both the Cancer Association of Namibia and social workers as resources available in the community.

Nurses working in the hospital should be informed about the resources available in the community in order to be able to give proper guidance and support to the patient.

Item 11: Do you feel that adequate information on social support is given to the patient?

The majority 11 (64,7%) of the professional nurses feel that information on social support given to the patient is not adequate. Six (35,3%) of the professional nurses feel that information given is adequate.

Item 12: Reasons for lack of adequate information on social support

The majority of professional nurses stated in Item 11 gave

various reasons why they feel that information on social support given to the patient is inadequate.

Two (18,2%) of the professional nurses feel that sources for social support are scarce as finance is involved. One (9,1%) professional nurse feels that there are no resources in the remote areas. Therefore there is nothing to refer the patient to. Five (45,5%), which is a majority of the professional nurses, feel that there is lack of knowledge by the nursing personnel. Three (27,3%) of the professional nurses feel that the family is reluctant to enquire about social support.

The nurse ought to inform the family and the patient about available social support and give advice on the best solution. The patient and family could be ignorant of what is available (Item 50, Questionnaire A).

The nurse needs to take the initiative and make inquiries on what is available and liaise with organizations and community leaders.

Item 13

Table 4.22: Do you feel you are able to give adequate emotional support to the patient to facilitate emotional adaptation. N = 17.

Responses	Frequency	Percent
Yes	13	76.5
No	4	23.5
TOTAL	17	100.0

Table 4.22 shows that 13 (76,5%) of the professional nurses feel they are able to give adequate emotional support to the patient to facilitate emotional support. Four (23,5%) of the professional nurses feel they are not able to do so.

Although 76,5% of the professional nurses feel they are able to give adequate emotional support, 77,4% of the respondents (Questionnaire A, Item 43) indicated that they need more personal, emotional counselling or support.

Forty three (81,1%) of the respondents indicated that the community nurse does not visit them at home for follow-up treatment (Table 4.45, Questionnaire A). It, therefore, appears that the nurse is neglecting her role to give emotional support to the patient.

Item 14

Table 4.23: Do you feel the family is actively involved in the treatment plan to care for the patient at home?

N = 17.

Responses	Frequency	Percent
Yes	5	29.4
No	12	70.6
TOTAL	17	100.0

The greater percentage (70,6%) of the professional nurses feel that the family is not actively involved in the treatment plan to care for the patient at home. Five (29,4%) of the professional nurses feel the family is actively involved in the treatment plan.

Item 15: Reasons for lack of active involvement of family in patient's treatment plan.

Two (16,7%) out of the 12 professional nurses indicated in Table 4.23 did not state reasons why they feel the family is not actively involved in the treatment plan to care for the patient at home.

Seven (70%) out of the 10 professional nurses who gave reasons stated that the family lacked knowledge about the disease. Four (40%) professional nurses stated that poverty caused family not to visit the patient while in hospital due to lack of finance and housing facilities. The family stayed in shacks and were unwilling to accommodate the sick patient on discharge.

There is a need for the family to be actively involved in the treatment plan. From the results it can be seen that 70% of the family is ignorant and cannot help the patient at home.

Item 16

Table 4.24: When do you give health information to the patient to facilitate coping at home? N = 17.

Reasons	Frequency	Percent
On admission	-	-
During hospitalization	12	70.6
On discharge	5	29.4
TOTAL	17	100.0

The table above shows that 12 (70,6%) of the professional nurses give health information to the patient to facilitate coping at home during hospitalization. Five (29,4%) of the professional nurses give health information on discharge. It is significant to note that health information is not given on admission.

From the results reflected in Questionnaire A in Table 4.16, Table 4.18 and Table 4.20, there seems to be a discrepancy when a comparison is made with the results reflected in the above table. More attention should be given to this aspect by the nurses to ensure that patients get enough time to consolidate the information given and to ask questions.

Health information should be given from admission of a patient.

Item 17

Table 4.25: Do you encourage the family caregivers to discuss their problems and expectations concerning the cancer patient with you? N = 17.

Responses	Frequency	Percent
Yes	15	88.2
No	2	11.8
TOTAL	17	100.0

Table 4.25 indicates that 15 (88,2%) of the professional nurses encourage the family caregivers to discuss their problems and expectations concerning the cancer patient. Two (11,8%) do not encourage the family caregivers.

Item 18

Table 4.26: How often do you encourage the family caregivers to discuss their problems and expectations concerning the cancer patient with you? N = 17.

Reasons	Frequency	Percent
Seldom	-	-
Sometimes	6	35.3
Always	9	52.9
	2 Missing	11.8 Missing
TOTAL	17	100.0

The table above shows that 9 (52,9%) of the professional nurses always encourage the family caregivers to discuss their problems and expectations concerning the cancer patient with them. Six (6) of the professional nurses (35,3%) sometimes encourage the family caregivers to discuss their problems and expectations.

The 2 professional nurses indicated as missing are reflected in Table 4.25.

Considering the results in Item 40 (Questionnaire B) which indicates that the community nurses do not visit the caregivers at home and Table 4.23 which indicates that the majority of the professional nurses feel that the family is not actively involved, it is doubted whether the results in Table 4.26 indicated by the 52,9% is a true reflection.

On the other hand, it could be that the "Always" reflected in Table 4.26 occurs when the family members visit the patient while hospitalized or when accompanying the patient for follow-up clinic visits.

Item 19: Necessity for a professional to do home visits of patients discharged on palliative care.

All the 17 professional nurses (100,0%) feel that it is necessary for a professional nurse to do home visits of patients discharged on palliative care.

Item 20

Table 4.27: How often should a nurse visit a patient discharged on palliative care? N = 17.

Responses	Frequency	Percent
Once a month	6	35.3
Twice a month	3	17.6
Once a week	3	17.6
Twice a week	5	29.4
TOTAL	17	100.0

The table above shows that 6 (35,3%) of the professional nurses

indicated that the nurse should visit the discharged cancer patient monthly. Three (17,6%) of the professional nurses indicated that the visits should be twice a month, 3 professional nurses (17,6%) indicated that the home visits should be weekly and 5 professional nurses (29,4%) indicated that a nurse should visit the patient twice a week.

The seriousness of the patient's condition will probably determine how often the home visits should be. The needs of the patient and family should be assessed.

It is significant to note that although 100% of the professional nurses feel patients should be visited at home, 81,1% of the respondents (Table 4.45, Questionnaire A) indicated that the community nurse does not do home visits. The community nurses have an enormous task to implement home care visits of cancer patients if they claim to deliver comprehensive health care. Comprehensive health care is provided to individuals and families in their places of residence (Blank, Clark et al, 1987 : 78 - 79).

Item 21: Do you inform the community nurse when a patient is discharged on palliative care?

The majority, 10 (58,8%), of the professional nurses do not inform the community nurses when a patient is discharged on palliative care and 7 (41,2%) do inform the community nurse.

Item 22

Table 4.28: How often do you inform the community nurse when a patient is discharged on palliative care? N = 17.

Reasons	Frequency	Percent
Seldom	1	5.9
Sometimes	6	35.3
	10 Missing	58.8 Missing
TOTAL	17	100.0

It can be seen from the table above that 6 (35,3%) of the professional nurses sometimes inform the community nurse when a patient is discharged on palliative care. One (5,9%) professional nurse seldom informs the community nurse. The majority (58,8%) do not inform the community nurse (Item 21).

It is necessary that the community nurse be actively involved in the follow-up nursing care of the cancer patient, therefore regular contact or communication between the community and hospital nurse is important to enable the cancer patient to receive appropriate and continuous care.

Item 23: Reasons for not informing community nurse.

Eight (80%) of the professional nurses indicated that they do not inform the community nurse when a patient is discharged on palliative care due to lack of communication between the hospital and community nurses. Two (20%) of the professional nurses indicated that the patients are given follow-up dates for the oncology clinic.

Nurses should take the initiative to communicate with the community nurse and not wait for a specific channel to be prescribed. This is part of the nurses' independent function.

Item 24

Table 4.29: Do you feel it is necessary that nursing care be co-ordinated between the wards, oncology out-patient clinic and the patient's home? N = 17.

Responses	Frequency	Percent
Yes	17	100.0
No		-
TOTAL	17	100.0

All the professional nurses (100%) responded affirmatively.

There is a need for better discharge planning by the hospital nurses. Feasible restructuring of community-based clinic services is a necessity to assure that the needs of the patients are met, through proper referrals and collaboration with the oncology clinic physician.

SOCIAL SUPPORT FOR NURSES

Item 25

Table 4.30: Are you aware that there are cancer nursing journals available in the library of UNAM? N = 17.

Responses	Frequency	Percent
Yes	13	76.5
No	4	23.5
TOTAL	17	100.0

The above table indicates that 13 (76,5%) of the professional nurses are aware that there are cancer nursing journals available in the University of Namibia (UNAM) library and 4 (23,5%) of the professional nurses are not aware.

Item 26

Table 4.31: Do you make use of these journals to update yourself on cancer nursing issues? N = 17.

Responses	Frequency	Percent
Yes	8	47.1
No	9	52.9
TOTAL	17	100.0

Nine of the professional nurses (52,9%) do not make use of these journals to update themselves on cancer nursing issues. Eight professional nurses make use of the journals to update themselves.

This means that from the 76,5% (Table 4.30) of the professional nurses who are aware of these journals 61,5% use them.

It is significant to note that the greater percentage (52,9%) of the professional nurses do not use these journals. This could be one of the problems that impedes professional growth of the professional nurse working in the oncology unit. The journal Cancer Nursing is published regularly and is a practical guide to help keep the professional nurse at pace with advances in cancer nursing care.

Item 27

The professional nurses who do not use the journals available in the library make use of the following sources.

One professional nurse (5,9%), who is a registered oncology nurse, is subscribing to the cancer nursing journal. Five professional nurses (29,4%) do not use any other sources to keep themselves up-to-date. Four professional nurses (23,5%) ask

the doctor when they need information. Six professional nurses (35,3%) read their textbooks. One professional nurse (5,9%) reads the quarterly newsletter on cancer nursing.

The textbooks mentioned above are the textbooks that were prescribed during the training of these nurses.

The chairman of the Oncology Nursing Society of Namibia indicated that International Cancer Nursing newsletters are provided regularly to all hospitals in Namibia. It is, therefore, interesting to note that only one professional out of the 17 reads the newsletter.

Item 28

Table 4.32: How often do you attend seminars on oncology nursing? N = 17.

Reasons	Frequency	Percent
Never	11	64.7
Seldom	1	5.9
Sometimes	3	17.6
Always	2	11.8
TOTAL	17	100.0

The majority (11) of the professional nurses (64,7%) never attend seminars on oncology nursing. One of the professional nurses (5,9%) seldom attends seminars on oncology nursing. Three of the professional nurses (17,6%) sometimes attend seminars and 2 of the professional nurses (11,8%) always attend such seminars.

Although this item did not specify whether the seminars were held locally or internationally, the professional nurses who responded "never" indicated that they refer to international seminars.

Usually when local oncology seminars are held the attendance is good (personal experience).

It appears that the nurses working in the cancer unit need to be exposed to international seminars to share their opinions, experiences and problems with the "experts" and obtain knowledge that could be used in the Namibian context.

According to the chairman of the Oncology Nursing Society of Namibia nurses are positive while participating in workshops or seminars. Everyone understands the importance and supports the ideas raised but then lack commitment and/or initiative and drive to introduce their own ideas and put these into practice. The feeling is that they wait for the management to come up with ideas every time.

Item 29: Do you feel it is necessary to have cancer nursing in-service education programmes?

All the (17) professional nurses (100%) feel that it is necessary to have cancer nursing in-service education programmes. From the majority of the responses in Item 26, Item 27 and Item 28 it appears that there is a need to empower the nurses with the necessary knowledge and skills.

According to the chairman of the Oncology Nursing Society of Namibia a "crash course" in cancer nursing for sub-professional and professional nurses is in the planning phase. It is envisaged that this course will be arranged in consultation and cooperation with the relevant medical specialists and the National Cancer Association. The target group consists of all nurses dealing with patients in institutions and communities.

Item 30

Table 4.33: Professional nurses' membership of the Oncology Nursing Society of Namibia. N = 17.

Responses	Frequency	Percent
Yes	7	41.2
No	10	58.8
TOTAL	17	100.0

Table 4.33 shows that the majority (10) of the professional nurses (58,8%) are not members of the Oncology Nursing Society of Namibia. Seven (41,2%) are members.

It appears that the nurses do not realize the important contribution of this society towards cancer nursing. This society has a major role to play in the advancement of cancer nursing.

Further research should be undertaken to investigate the causes of lack of membership of nurses.

Item 31: Reasons for not being a member of the Oncology Nursing Society of Namibia.

Ten professional nurses (58,8%) cited the following as reasons for not being members of the Oncology Nursing Society of Namibia:

Two professional nurses (11,8%) cited that nurses have a negative attitude towards the Oncology Nursing Society. Four of the professional nurses (23,5%) cited that there is lack of interest among the nursing personnel.

One professional nurse (5,9%) does not know that the Oncology Nursing Society exists. Three of the professional nurses (17,6%) gave no specific reasons for not being members of the Oncology Nursing Society. One (5,9%) professional nurses indicated that it is not known what the criteria are for joining the society or who the members of management are.

From these results it is evident that the society has to make the nurses aware of its functions, objectives and membership. This could change the negative attitude of the nurses, increase membership and improve the image of the society.

Item 32

Table 4.34: How often do cancer nursing lecturers visit the ward to enquire about new clinical developments? N = 17.

Reasons	Frequency	Percent
Never	12	70.6
Seldom	2	11.8
Sometimes	3	17.6
Always	-	-
TOTAL	17	100.0

The greater percent (70,6%) of the professional nurses indicated that the cancer nursing lecturers never visit the ward to enquire about new clinical developments. Two of the professional nurses indicated that the cancer nursing lecturers seldom visit the ward and 3 (17,6%) professional nurses indicated that the lecturers sometimes visit the ward.

The cancer nursing lecturer has to be aware of the new treatment modalities in the clinical situation to enable her to correlate theory and practice. It is, therefore, important that she visits the ward regularly.

Item 33

Table 4.35: How often does the professional nurse contact the nursing lecturers to enquire about curriculum content (Cancer nursing)? N = 17.

Reasons	Frequency	Percent
Never	8	47.1
Seldom	6	35.3
Sometimes	2	11.8
Always	1	5.9
TOTAL	17	100.0

The above table indicates that 8 of the professional nurses (47,1) never contact the nursing lecturers to enquire about the curriculum content (cancer nursing). Six of the professional nurses (35,3%) seldom contact the nursing lecturers, 2 professional nurses (11,8%) sometimes and 1 professional nurse (5,9%) always contacts the nursing lecturers to enquire about the cancer nursing curriculum content.

From the results of Table 4.34 and Table 4.35 it is evident that there is a need for more cooperation and contact between the nursing lecturers and ward professional nurses. This could enhance the teaching of cancer nursing.

Item 34

Table 4.36: How often does the Oncology Nursing society of Namibia contact you to keep you up-to-date on cancer nursing issues? N = 17.

Reasons	Frequency	Percent
Never	9	52.9
Seldom	3	17.6
Sometimes	4	23.5
Always	1	5.9
TOTAL	17	100.0

Table 4.36 shows that 9 of the professional nurses (52,9%) indicated that the Oncology Nursing Society of Namibia never contacts them (the ward nurses) to keep them up-to-date on cancer nursing issues. Three of the professional nurses (17,6%) indicated they are seldom contacted, 4 professional nurses (23,5%) indicated "sometimes" and one (5,9%) indicated "always".

From the results it is evident that there is a need for more contact or communication between the ward professional nurses and the Oncology Nursing Society.

Item 35

In this item the professional nurses were asked if there was anything else they could tell the investigator that would help the investigator understand better what problems the professional nurses have, so that better cancer nursing services could be planned.

Seven professional nurses (41,2%) indicated that in-service education regarding cancer nursing issues is needed. Three professional nurses (17,6%) indicated that communication between the hospital and community nurses is needed to ensure continuity of care.

Three professional nurses (17,6%) indicated that family involvement is necessary. Some family members do not visit the patients after admission and cannot be traced due to social problems resulting in lack of health education to the family.

Two professional nurses (11,8%) indicated that there is a need to involve the social workers to help support the patient at home.

Eight professional nurses (47,1%) indicated that trained oncology nurses are needed. When they are allocated to the ward

there is no trained oncology nurse to give proper guidance. The professional nurses do what their colleagues tell them to do. No explanation or rationale is given when asked for. Three professional nurses (17,6%) indicated that more oncology wards/units are needed as other patients are still admitted in the general wards as there is no hospice available in Namibia.

Four professional nurses (23,5%) indicated that more cancer workshops should be planned. Three (17,6%) professional nurses indicated that workshops are needed in which the community is involved. This could make the community aware of the plight of the cancer patient. It would also help with community voluntary work.

Two (11,8%) professional nurses indicated that there is a need for cancer nursing literature in the ward.

Three (17,6%) professional nurses indicated that the Oncology Nursing Society should get more involved at ward level. One (5,9%) professional nurse indicated that pain relief policy should be made in the ward.

Four (23,5%) professional nurses indicated that there is a need to establish counselling for the patients as they are not trained to do so.

According to the Chairman of the Oncology Nursing Society of Namibia, the Society has not yet started to promote community awareness of the need for support for aftercare for patients.

CHAPTER 5**CONCLUSIONS AND RECOMMENDATIONS****5.1 LIMITATIONS OF THE STUDY**

During the investigation the researcher collected all the data. The researcher also made use of an interpreter when necessary. As use was made of the same interpreter for all the interviews and as this interpreter has functioned in this capacity in the Oncology Unit for many years, she is thoroughly conversant with the terminology and concepts used for patient interviews in regard to cancer aspects. The use of an interpreter was not a limiting factor. Perhaps the only limitation was that the researcher could not travel over the great distances to interview caregivers in the rural areas.

5.2 CONCLUSIONS OF THE STUDY

The conclusions of the study will be discussed as follows:

- General conclusions
- Conclusions regarding the assumptions stated in Chapter I.

5.2.1 General Conclusions

The ability to provide general selfcare was satisfactory. The physical conditions of the patients were such that this was possible (Items 23, 24, 27, 28, 29, 34 and 38, Annexure 3.5 A).

The majority of the patients are still able to take care of their personal hygiene, are sleeping well, do not experience nausea and vomiting and still have a good appetite. The illness did not yet interfere with their movements.

- It was also found that the majority of the patients were unemployed (Item 6, Annexure 3.5 A), have no source of income (Item 7, Annexure 3.5 A) and have children of school-going age (Item 4, Annexure 3.5 A). This can be regarded as having a negative impact on the patient's and child's emotional well-being. The above-mentioned indicates a shortcoming in social support.
- From Item 10 (Annexure 3.5 A) and items 7 and 18 (Annexure 3.6 B) it can be concluded that the family is mainly involved as the caregiver.
- From the data analysis it was found that children are involved with the personal care of the patient (Item 44, Annexure 3.6 B). It can, therefore, be concluded that children are actively involved with the personal care of the patient.
- The findings further indicate that the majority of the patients do not know of the services offered by the Cancer Association of Namibia (Item 20 and 21, Annexure 3.5 A). This may have a negative impact on the image of this association, and it limits the assistance which the patient could obtain if he/she was aware of it.
- The majority of the patients experience pain and do not know the type of medication they receive (Items 25 and 26, Annexure 3.5 A respectively). Most of the caregivers cannot manage the patient's pain effectively (Item 25, Annexure 3.6 B).

- From the data analysis it can be concluded that nurses are unable to assess, record and manage pain effectively (Items 8.1, 8.2 and 8.3, Annexure 3.7 C).
- With regards to home visits by the community nurse, the findings show that the majority of the patients and all the caregivers indicated that they are not visited by the nurse for follow-up treatment or guidance (Item 45, Annexure 3.5 A; Item 40, Annexure 3.6 B).
- Items 19, 20, 21, 22 and 23 (Annexure 3.7 C) show that there is a serious shortcoming in the follow-up nursing care.
- Although the professional nurses are aware of the available resources e.g. Cancer Nursing Journals, UNAM library, Oncology Nursing Society and the Cancer Association of Namibia, they do not use these resources for professional growth.
- There is a gulf between the teaching by cancer nursing lecturers and the application of the cancer nursing process by the professional nurses in the cancer wards. The correlation of theory and practice appears to be non-existent. Student nurse teaching is defective in that the lecturers do not do bedside teaching. Neither do the ward professional nurses appear to do so.

5.2.2 Conclusions Regarding the Assumptions

The following three assumptions were made at the beginning of the study.

Assumption 1

Cancer patients are not adequately prepared for discharge.

- * This is reflected under "Patient Knowledge" in Annexure 3.5 A.
- * Fifty one (51) respondents (96,2%) needed all information regarding home management of side-effects (Item 17.1, Annexure 3.5 A).
- * Forty four (44) respondents (83,0%) of the patients were not informed about home management of physical symptoms (Item 18, Annexure 3.5 A). Home management of ulcers, pain, and other physical symptoms is most important. Although this aspect is dealt with in theory it appears that it is not applied in practice.
- * The majority (52,8%) of the patients experience cancer pain (Item 25.1) and yet 32,1% do not know the type of medication they receive (Item 26.1).
- * The majority (58,8%) of the professional nurses do not inform the community nurses when a patient is discharged on palliative care (Item 21, Annexure 3.7 C). This assumption has been proved.

Assumption 2

- **Family members are not prepared for their involvement in the care process.**
- * The majority (57,1%) of the caregivers are not aware of the side-effects of the treatment (Item 11, Annexure 3.6 B).
- * Eleven (11) of the caregivers (78,6%) were not informed how to handle side-effects at home (Item 13, Annexure 3.6 B).
- * One caregiver (7,1%) was informed about home management of emergencies (Item 14, Annexure 3.6 B).

- * Twelve (12) of the caregivers (85,7%) feel they need further guidance and family education (Item 16, Annexure 3.6 B).
- * Four caregivers (28,6%) do not know what type of pain medication the patient receives (Item 24, Annexure 3.6 B).
- * The greater percentage (85,7%) of the caregivers are unable to manage the patient's pain effectively (Item 25, Annexure 3.6 B).
- * According to the professional nurses (70,6%) the family is not actively involved in the treatment plan to care for the patient at home (Item 14, Annexure 3.7 C).

This assumption has been proved.

Assumption 3

Support services to cancer patients need expansion.

- * The Cancer Association of Namibia need to do more to make community, patients and caregivers aware of its activities (Items 20 and 21, Annexure 3.5 A).
- * The majority of professional nurses (64,7%) feel that information on social support given to patients is not adequate (Item 11, Annexure 3.7 C).
- * The community nurse needs to support the patient and family by doing home visits to ensure continuity of care.
- * In Item 50 (Annexure 3.5 A) the majority of patients indicated that there are no resources available in the community to help with their specific needs.
- * Forty one (41) patients (77,4%) indicated that they need more personal emotional counselling or support (Item 43, Annexure 3.5A).

* Social support in the form of social pensions is necessary for those patients who are unemployed and do not have a source of income (Item 7, Annexure 3.5A) and have dependent children (Item 3, Annexure 3.5 A).

* The organization of the services at present is such that patients have to experience great problems to return to the Oncology Clinic at 3 monthly intervals, and to obtain supplies particularly in the rural areas (unstructured interviews).

This assumption has been proved.

5.3 RECOMMENDATIONS

As a result of the findings from this study the following recommendations are made:

- Regular in-service education on cancer care be given to nurses in cancer wards.
- Nurses should be selected in the clinics and health centres who will specifically care for follow-up cancer patients at clinics so that these patients are not exposed to different nurses all the time. Cancer patients will feel at ease if they are helped by nurses who know them, know their conditions and thus facilitate immediate treatment. This will also improve the nurse-patient relationship.
- Nurses should be selected and prepared thoroughly at each central point in a region who will teach or give in-service education or short talks at health institutions and clinics to the nurses regarding cancer care.

- The basic nursing curriculum needs to be revised to ensure that cancer nursing care is given as a "special" field. The importance of the management of side-effects, physical symptoms (home management), pain and emotional support and counselling of the patient and family need to be emphasized. There is a need for more curriculum content for cancer pain assessment and management so that the nurse would be able to manage side-effects of medication and pain control.
- The clinics and health centres in the rural areas should be equipped to provide for the treatment, counselling, nutritional, medication and medical supply needs of the cancer patients. This also means special preparation of the nurse.
- The Oncology Nursing Society of Namibia should be actively involved in continuing education of nurses and cancer education at community level.
- Communication between the hospital and clinic nursing personnel should be addressed. Items 21, 22, 23 and 24 (Annexure 3.7 C) revealed that there is a communication gap between the wards, Oncology Clinic and the clinic in the community. Currently a proper referral system is non-existent.
- An organized system of rendering home health care be developed to facilitate self-care.
- The health authorities should prepare a Blue Print for the implementation of a nation-wide process of cancer education, treatment and follow-up care with specific reference to the type of problems encountered by the patients in meeting the self-care situation.

- Community education for providing support to cancer patients should be a priority. This could be done within the parameters of the Primary Health Care programmes. This needs policy direction as well as special preparation of the nursing personnel.

- The financial aspects of self-care, particularly in respect of nutritional, medication and surgical dressings needs, could be brought to the notice of some of the NGO's in the specific region to ask for assistance and to such community organizations in a district as farmers' associations, church associations, womens' organizations, sports clubs, school clubs and similar organizations, to sponsor specific aspects of the care situation in the region.

- Standards of cancer nursing care that are attainable and affordable should be developed so that a baseline exists for the development of the many dimensions of home care in cancer nursing and its supportive and educational roles.

- A post-basic nursing course in oncology nursing be instituted in Namibia to provide a cadre of expert cancer nurses who could be the resource personnel for in-service and continuing education and for the additional education nursing lecturers require for the cancer nursing component of the basic nursing course.

5.4 RECOMMENDATIONS FOR FURTHER RESEARCH

The issue on child caregivers needs to be researched further. The nature of the preparation of child caregivers and of their support which a community nurse must provide, must be researched and implemented as soon as possible.

5.5 SUMMARY

From the analysis of data, conclusions were made to obtain answers to the problems stated in Chapter One namely:

"There is doubt among nurses in the Windhoek area as to whether:

- cancer patients are adequately prepared for discharge and for coping at home;
- there is adequate follow-up nursing care of cancer patients;
- the family is prepared for their involvement in the care process;
- nurses are aware of the need and are equipped to follow-up discharged patients and to continue their care;
- health care authorities and voluntary health care associations have any intentions to provide after-care for persons who have been discharged from an oncology unit or who have undergone treatment for some form of cancer".

From the investigation it is evident that:

- cancer patients are not adequately prepared for discharge and coping at home;
 - follow-up nursing care of cancer patients is inadequate;
 - the family is not involved in the care process;
 - nurses are aware of the need but are not equipped to follow-up discharged patients and to continue their care;
 - health care authorities and voluntary health care associations intend to provide after-care for cancer patients.
- * A "crash-course" in cancer nursing for sub-professional and professional nurses is in the planning phase (item 29, Annexure 3.7 C).
 - * Training of community-based voluntary health workers have started (Interview with Dr N Shivute).

- * The Cancer Association of Namibia is currently providing after-care to cancer patients although it is on a very small scale.

The aim of the study was:

- to identify and describe what the nature is of home care services provided by the family;
- to ascertain whether there is a need for assistance to families in this regard and how it could be provided;
- to describe the follow-up home nursing care that is available to patients with cancer in the Windhoek area;
- to identify possible measures that could be put into operation in a developing country to improve the quality of the care available.

The aim of the study was realized as reflected in the discussions.

- The data in Chapter one indicates that, as yet, home care for the patients with cancer is not a special national programme. The question arises whether this is to be left to voluntary organizations. There should be an active programme by the state to deal with the question of cancer care at all levels namely preventive, promotive, curative, rehabilitative and palliative. No aftercare programmes exist and private volunteers are few. Therefore, they cannot meet the needs of the patients and families.

- There is no assistance to the family. The data in Chapter four (Questionnaire B) indicates that there is a need for assistance to families.

- * A special study is necessary to identify possible measures so as to have an affordable, assessable, acceptable and equitable measures of care in a health service that is chronically short of funds.

- More community based nursing must be done to meet the health care needs of the patients and families.
- Home care programmes need to be developed to facilitate follow-up nursing care of cancer patients.
 - * Provision should be made to prepare the family to enable them to do the job as well as to give cancer education. The family should, therefore, be actively involved in the care process.
- The extent of the problem is enormous but surmountable. Close collaboration with the various parties involved is important.
- Health authorities must ensure that nursing schools incorporate physical assessment of cancer patients, assessment of home environment, supportive care, pain assessment and management and psychological care in the curriculum at a sufficient level to ensure that the general nurse copes.
 - * Students must be taught/prepared in such a way that they also get experience in home care regarding cancer nursing.
 - * Nutritional education is very important within the limits that a patient can afford.

The evaluation of the follow-up nursing care of cancer patients is not easy, considering the great travelling distances and the difficulties and problems that patients are experiencing.

Follow-up nursing care remains the responsibility of the nurse and it is one major challenge that can never be overlooked.

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DEPARTMENT OF NATIONAL HEALTH AND WELFARE

APPLICATION TO CARRY OUT RESEARCH

1.1 Personal details regarding researcher:

Name: MARJERIE KATJIRE

Address: P.O. BOX 29899 WINDHOEK

Employer: ACADEMY Official title: LECTURER

Academic/Professional qualifications: BA CUR (UNISA),
B. CUR PROG PRAX HONS.

1.2 Personal details regarding officials supervising the project

Name: PROF. C. SEARLE

Address: WOOD ROAD 17, RONDEBOSCH

Rank: PROFESSOR

Station: UNIVERSITY OF SOUTH AFRICA

1.3 Details regarding the research if it is for study purposes.

Present course followed: DEGREE: M. CUR.

Educational Authority: UNIVERSITY OF
..... NAMIBIA (ACADEMY)

Name of study leader: PROF. C. SEARLE

Address of study leader:

2. DETAILS REGARDING RESEARCH PROJECT

2.1 Research design attached YES YES " NO

2.2 Facilities required:

2.2.1 Institutional/Extra-institutional services:

2.2.2 Personnel (Specify)

DOCTORS INVOLVED IN
CANCER THERAPY

2.2.3 Patients (Specify)

DISCHARGED CANCER
PATIENTS

2.2.3.1 Laboratory investigation required and arrangements
in this regard:

NONE

2.2.4 Records (Specify)

RECORDS OF DISCHARGED
CANCER PATIENTS

3. Estimated period for research: 4 YEARS

3.1 Commencing date: AUGUST 1991

3.2 Completion date: NOVEMBER 1995

4. Additional information in cases concerning clinical tests with medications.

4.1 Name and Address of firm executing the test/evaluation: ...

NOT APPLICABLE

4.2 State name/names, rank and qualifications of officials representing the firm in regard to the test/evaluation requested:

N/A

4.3 Pharmaceutical products or equipment which will be used and tested and method to be used.

(i) N/A NONE

(ii)

5. Is the pharmaceutical product:

5.1 Registered with the Medicine Control Council?

YES/NO N/A

If YES give registration number

5.2 Approved only for the test?

YES/NO N/A

If YES, a copy of the approval, or the number thereof must be provided.

6.1 Has a previous test/evaluation been carried out?

If so, where and when. Give details: N/A

6.2 Is a test being carried out at present?

If so where? Give details: N/A

7. I,MARJERIE KATJIRE..... agree to

undertake the above project in accordance with the requirements mentioned in the application form.

I agree to carry out the project without incurring any expenses not budgeted for by the Department, and to bear the full responsibility for the project. Should it be necessary to deviate from any procedure or to terminate the project, I shall notify the Secretary for National Health and Welfare and obtain his approval.

I undertake to obtain full consent from patients who are legally in a position to give this or to obtain consent from their legal guardians.

I agree to submit preliminary results of the project to the Secretary for National Health and Welfare, within a period of 3 months after completion of said project.

I agree to submit all results of the project to the Secretary of the Department of National Health and Welfare.

I understand that the Department in granting permission for the execution of the project places itself under no obligation and will not necessarily grant permission for publication.

25/7/91
.....
DATE

M Katjire
.....
SIGNATURE OF RESEARCHER

WITNESSES:

- 1. H. L. M. M.
- 2. M. Voruis

FOR OFFICIAL USE ONLY

REFERENCE NUMBER: 7/3/34/2

RECOMMENDED/~~NOT RECOMMENDED~~

COMMENTS: Strongly recommended as a potentially
very worthwhile project.

E. Suqer. 30.11.1991
CHAIRMAN: CO-ORDINATING RESEARCH COMMITTEE DATE

COMMENTS:

CONDITIONS:

~~APPROVED/NOT APPROVED~~
M. Madhavi 18/05/92
PERMANENT SECRETARY DATE
MINISTRY OF HEALTH AND SOCIAL SERVICES

ANNEXURE 3.3

Dear Colleague

AN EVALUATION OF THE FOLLOW-UP NURSING CARE OF ADULT CANCER PATIENTS IN THE WINDHOEK AREA - A GENERAL NURSING PERSPECTIVE.

I am busy with the above-mentioned thesis for the purpose of continuing education.

You are requested to fill in the attached questionnaire as accurately as possible. This will enable me to evaluate whether nurses are equipped to follow-up discharged patients and to continue their care.

All information will be handled confidentially. Anonymity will be ensured, therefore your name and unit will not appear on the questionnaires.

Thank you in anticipation.

Yours faithfully

.....
M Katjire

CONSENT TO ACT AS A SUBJECT IN A DESCRIPTIVE RESEARCH STUDY

TITLE: "AN EVALUATION OF THE FOLLOW-UP NURSING CARE OF ADULT CANCER PATIENTS IN THE WINDHOEK AREA - A GENERAL NURSING PERSPECTIVE".

INVESTIGATOR: MARJORIE M KATJIRE
LECTURER, FACULTY OF MEDICAL AND HEALTH SCIENCES

PROMOTER: PROF CHARLOTTE SEARLE
EXTRA-ORDINARY PROFESSOR: FACULTY OF MEDICAL AND HEALTH SCIENCES

DESCRIPTION OF THE STUDY

Many cancer patients experience, in spite of limitations, that after diagnosis and initial treatment they have some more years to life with their families. This is of underscribable value to the individual and the family.

The need for home care has been identified by care authorities. For the state and for patients this is an economic necessity. Family support is desirable and the clients enjoy the freedom from hospital rules. The nurse is the co-ordinator of care and

a constant source of support.

This study will evaluate the follow-up nursing care that a sample of cancer patients in Windhoek received. A questionnaire will be used for the family members and an interview for the patient.

COST:

There is no cost to subjects. Completion of the questionnaire will require about twenty minutes of the subject's time.

CONFIDENTIALITY:

I understand that any information about me obtained from this research and from the hospital chart, will be kept strictly confidential and it will never be identified in any report or publication.

I consent to the publication of study results as long as the information is anonymous.

FREE WITHDRAWAL:

I understand that I am free to refuse to participate in this

study or to withdraw at any time and that my decision will not adversely affect my care at this institution.

VOLUNTARY CONSENT:

I certify that I have read the preceding, or it has been read and explained to me, that I understand its contents, and that any questions that I have pertaining to research will be answered by Marjorie M Katjire, and that my permission is freely given.

DATE:.....

SUBJECT'S SIGNATURE:.....

DATE:.....

INTERVIEWER'S SIGNATURE:.....

QUESTIONNAIRE A - PATIENT/CLIENT

NAME:

SEX:

MALE	FEMALE
------	--------

RESIDENTIAL AREA:

DIAGNOSIS:

1. AGE (IN YEARS):

0 - 12	1
--------	---

12 - 18	2
---------	---

18 - 45	3
---------	---

>45	4
-----	---

2. MARITAL STATUS:

1	2
MARRIED	SINGLE

3. NUMBER OF DEPENDENT CHILDREN:

--

4. AGES OF DEPENDENT CHILDREN:

0 - 6	1
-------	---

6 - 12	2
--------	---

12 - 18	3
---------	---

5. WERE YOU HOSPITALIZED?

1	2
YES	NO

15. Who informed you about the side-effects?
 6. ARE YOU CURRENTLY EMPLOYED? 1 2

YES	NO
-----	----

15.1 The doctor
 7. DO YOU HAVE ANOTHER SOURCE OF INCOME? 1 2

YES	NO
-----	----

15.2 The nurse
 8. DO YOU HAVE TO CONTRIBUTE TOWARDS LIVING COSTS? 1 2

YES	NO
-----	----

15.3 Another patient
 9. IS THERE ALWAYS SOMEONE WHO HELPS YOU AT HOME? 1 2

YES	NO
-----	----

15.4 A friend
 10. WHAT IS YOUR RELATIONSHIP WITH THE CAREGIVER? 1 2 3

SPOUSE	FAMILY	FRIEND
--------	--------	--------

15.5 The social worker
 YES NO

PATIENT KNOWLEDGE

16. Were you informed on how to handle
 11. Were/are you on chemotherapy? 1 2

YES	NO
-----	----

17. Do you feel you were adequately
 12. Were you on radiotherapy? 1 2

YES	NO
-----	----

18. If answer is "yes" to question 11
 13. Did you undergo surgery? 1 2

YES	NO
-----	----

17.1 What information do you need?
 14. If "yes" on question 11 or 12:
 Are you aware of the side effects of the treatment? 1 2

YES	NO
-----	----

15. Who informed you about the side-effects?

15.1 The doctor

1	2
YES	NO

15.2 The nurse

1	2
YES	NO

15.3 Another patient

1	2
YES	NO

15.4 A friend

1	2
YES	NO

15.5 The social worker

1	2
YES	NO

16. Were you informed on how to handle the side-effects at home?

1	2
YES	NO

17. Do you feel you were adequately informed about the home management of the side-effects?

1	2
YES	NO

If answer is "no" to question 17:

17.1 What information do you need?

1	2
YES	NO

18. Were you informed about home management of physical symptoms?

1	2
YES	NO

If "yes" to question 18:

19. When were you informed?

19.1 On discharge?

1	2
YES	NO

19.2 During hospitalization?

1	2
YES	NO

20. Do you know of any services that are offered by the Cancer Association of Namibia?

1	2
YES	NO

21. Do you use any of the services mentioned in question 20?

1	2
YES	NO

If "yes" to question 20:

21.1 Specify service used?

COMFORT

22. Is your home always kept clean?

1	2
YES	NO

23. Are you able to take care of your personal hygiene?

1	2
YES	NO

24. Do you sleep well?

1	2
YES	NO

If "no" to question 24:

24.1 What is the cause?

25. Do you experience pain?

1	2
YES	NO

If "yes" to question 25:

25.1 What is the nature of the pain?

26. Are you on pain medication?

1	2
YES	NO

If "yes" to question 26:

26.1 What type of medication?

27. Do you experience nausea?

1	2
YES	NO

27. If yes to question 27: do you experience?

27.1 What is the cause?

1	2
YES	NO

28. Do you experience vomiting?

1	2
YES	NO

NUTRITION

29. Is your appetite good?

1	2
YES	NO

If "no" to question 29:

29.1 Why not?

30. What types of food appear to agree with you?

31. What types of fluids appear to agree with you?

ELIMINATION

32. Do you have regular bowel action?

1	2
YES	NO

33. Which of the following do you experience?

33.1 Constipation

1	2
YES	NO

33.2 Diarrhea

1	2
YES	NO

33.3 Urinary incontinence

1	2
YES	NO

34. Do you cope with any altered elimination problems?

1	2
YES	NO

SEXUALITY

35. Does the illness interfere with your sex life?

1	2
YES	NO

36. Were you informed that chemotherapy/radiation could decrease sexual response or desire? (See question 1.1. & 1.2 whether applicable)

1	2
YES	NO

If "yes" to question 36:

37. Who informed you?

37.1 The doctor

1	2
YES	NO

37.2 The nurse

1	2
YES	NO

37.3 Another patient

1	2
YES	NO

37.4 A friend

1	2
YES	NO

MOBILITY

38. Does the illness interfere with your movements?

1	2
YES	NO

39. Do you do active muscle movements or exercise?

1	2
YES	NO

EMOTIONAL SUPPORT

40. Do you communicate your feelings about living with cancer?

1	2
YES	NO

If "yes" to question 40:

41. Mostly to whom?

41.1 The doctor

1	2
YES	NO

41.2 The nurse

1	2
YES	NO

41.3 Spouse

1	2
YES	NO

41.4 A friend

1	2
YES	NO

41.5 Caregiver

1	2
YES	NO

If "no" to question 40:

42. Why not?

43. Do you feel you need more personal emotional counselling or support?

1	2
YES	NO

44.2 SOCIAL SUPPORT

44. Who assists you with personal nursing care at home?

44.1 Your children

1	2
YES	NO

44.2 Family member visit the hospital or clinic as part of follow-up treatment

1	2
YES	NO

44.3 Spouse

1	2
YES	NO

44. Does a family member accompany you to the hospital or clinic?

1	2
---	---

44.4 Nurse

1	2
YES	NO

44. Do you have or use private transport to the hospital or clinic?

1	2
---	---

44.5 A friend

1	2
YES	NO

45. Does the community nurse visit your home as part of your follow-up treatment?

1	2
YES	NO

If "yes" to question 45:

46. How often?

46.1 Weekly

1	2
YES	NO

46.2 Twice a month

1	2
YES	NO

46.3 Monthly

1	2
YES	NO

46.4 Seldom

1	2
YES	NO

47. Do you have to visit the hospital or clinic as part of follow-up treatment
- | 1 | 2 |
|-----|----|
| YES | NO |

If "yes" to question 47:

48. Does a family member accompany you to the hospital or clinic?
- | 1 | 2 |
|-----|----|
| YES | NO |

49. Do you have to use private transport to the hospital or clinic?
- | 1 | 2 |
|-----|----|
| YES | NO |

50. Do you have to make use of community resources?
- | 1 | 2 |
|-----|----|
| YES | NO |

If "yes" to question 50:

51. Specify.

RESIDUAL CAPACITIES

52. If you have lost a limb do you know how to make use of other parts of the body to cope with movement?
- | 1 | 2 |
|-----|----|
| YES | NO |

53. If you have lost your voice are you prepared to undergo training from a speech therapist to teach you communication?
- | 1 | 2 |
|-----|----|
| YES | NO |

54. Do you feel you need assistance with home nursing care?

	1	2
	YES	NO

NAME:

AGE:

MALE	FEMALE
------	--------

RESIDENTIAL HOME:

DIAGNOSIS OF DISEASE:

1. AGE (IN YEARS):

18 - 45	3
---------	---

>45	4
-----	---

2. MARITAL STATUS:

1	2
MARRIED	SINGLE

3. NUMBER OF DEPENDENT CHILDREN:

--

4. AGE OF DEPENDENT CHILDREN (AGE RANGE):

0 - 6	1
-------	---

7 - 12	2
--------	---

13 - 20	3
---------	---

5. ARE YOU CURRENTLY EMPLOYED?

1	2
YES	NO

QUESTIONNAIRE B - CAREGIVER

(Family or other assistant)

NAME:

SEX:

MALE	FEMALE
------	--------

RESIDENTIAL AREA:

DIAGNOSIS OF PATIENT:

1. AGE (IN YEARS):

18 - 45	3
---------	---

>45	4
-----	---

2. MARITAL STATUS:

1 2

MARRIED	SINGLE
---------	--------

3. NUMBER OF DEPENDENT CHILDREN:

--

4. AGES OF DEPENDENT CHILDREN (IN YEARS):

0 - 6	1
-------	---

6 - 12	2
--------	---

12 - 18	3
---------	---

5. ARE YOU CURRENTLY EMPLOYED?

1 2

YES	NO
-----	----

6. DO YOU HAVE ANOTHER SOURCE OF INCOME? 1 2

YES	NO
-----	----

7. WHAT IS YOUR RELATIONSHIP WITH THE PATIENT? 1 2 3

SPOUSE	FAMILY	FRIEND
--------	--------	--------

CAREGIVER KNOWLEDGE

8. Was/is the patient on chemotherapy? 1 2

YES	NO
-----	----

9. Did the patient receive radiotherapy? 1 2

YES	NO
-----	----

10. Did the patient undergo surgery? 1 2

YES	NO
-----	----

If "yes" on question 8 or 9:

11. Are you aware of the side-effects of the treatment? 1 2

YES	NO
-----	----

If "yes" to question 11:

12. Who informed you about the side-effects? 1 2

YES	NO
-----	----

12.1 The doctor: 1 2

YES	NO
-----	----

12.2 The nurse

1	2
YES	NO

12.3 Another patient

1	2
YES	NO

12.4 A friend

1	2
YES	NO

12.5 The social worker

1	2
YES	NO

13. Were you informed how to handle the side-effects at home?

1	2
YES	NO

14. Do you feel you were adequately informed by the nurses about the following?

14.1 The disease.

1	2
YES	NO

14.2 The treatment/therapy of the patient.

1	2
YES	NO

14.3 Potential emergencies.

1	2
YES	NO

14.4 First-aid treatment of cancer emergencies at home.

1	2
YES	NO

14.5 Home management of emergencies.

1	2
YES	NO

15. When were you informed about the following?

- * H - During hospitalization
D - During discharge

15.1 The treatment/therapy of the patient.

1	2
H	D

15.2 Potential emergencies.

1	2
H	D

15.3 First-aid treatment of cancer emergencies at home.

1	2
H	D

15.4 Home management of physical symptoms.

1	2
H	D

16. Do you feel you need further guidance and family education?

1	2
YES	NO

If "yes" to question 16:

17. Specify:

22. Why do you provide with family care assistance?

PATIENT COMFORT

18. Are you involved in the personal care of the patient?

1	2
YES	NO

If "yes" to question 18:

Specify care given:

19.1 Nursing care

1	2
YES	NO

19.2 Household chores

1	2
YES	NO

20. Do you think the patient feels comfortable most of the time?

1	2
YES	NO

21. Does the patient experience pain?

1	2
YES	NO

If "yes" to question 21:

22. Is the patient on pain medication?

1	2
YES	NO

If "no" to question 22:

23. Why is the patient not having pain medication?

If "yes" to question 22:

24. What type of pain medication is provided?

25. Are you able to manage the patient's pain effectively?

1	2
YES	NO

If "no" to question 25:

26. Why not?

27. Does the patient experience nausea?

1	2
YES	NO

If "yes" to question 27:

28. What is the cause?

29. Does the patient experience vomiting?

1	2
YES	NO

NUTRITION

30. Do you feel that you are managing the patient's dietary needs effectively?

1	2
YES	NO

If "no" to question 30:

31. Why not?

ELIMINATION

32. Does the patient experience any altered elimination problems?

1	2
YES	NO

If "no" disregard question 33.

If "yes" to question 32:

33. Specify.

33.1 Constipation

1	2
YES	NO

33.2 Diarrhoea

1	2
YES	NO

33.3 Urinary incontinence

1	2
YES	NO

34. Are you able to cope with the altered elimination problems?

1	2
YES	NO

MOBILITY

35. Does the illness interfere with the patient's movements?

1	2
YES	NO

If "yes" to question 35:

36. Do you assist the patient with mobility?

1	2
YES	NO

PSYCHOSOCIAL NEEDS OF THE CAREGIVER

37. Does the child/children have to help with the caring of the patient?

1	2
YES	NO

If "yes" to question 37:

38. Why?

39. How do the other family members react?

39.1 Helpful

1	2
YES	NO

39.2 Unhelpful

1	2
YES	NO

39.3 Moved from home

1	2
YES	NO

40. Does the community nurse visit your home as part of follow-up treatment?

1	2
YES	NO

If "no" to question 40, disregard question 41.

If "yes" to question 40:

41. How often?

41.1 Weekly

1	2
YES	NO

41.2 Twice a month

1	2
YES	NO

41.3 Once a month

1	2
YES	NO

41.4 Seldom

1	2
YES	NO

42. Do you or other family members have to accompany the patient to hospital or clinic?

1	2
YES	NO

43. Do you have to make use of community resources?

1	2
YES	NO

If "yes" to question 43:

44. Specify. (Who works or worked in Community Unit)
(In the time span 1991 - 1994)

1. AGE (OR RANGE):

1	2
---	---

45. Do you feel you need professional emotional support?

1	2
YES	NO

46. Do you feel you need to be assisted by a nurse with patient's nursing care at home?

1	2
YES	NO

47. Do you feel you need financial assistance? (for housing, transport, equipment)

1	2
YES	NO

48. Is guidance necessary to the following?

48.1 School teachers

1	2
YES	NO

48.2 Employers

1	2
YES	NO

48.3 Other family members

1	2
YES	NO

49. Does the social worker visit the family as part of follow-up care?

1	2
YES	NO

ANNEXURE 3.7. C

QUESTIONNAIRE C - PROFESSIONAL NURSE

(Who works or worked in Oncology Unit)
(In the time span 1991 - 1994)

1. AGE (IN YEARS):

22 - 25	1
---------	---

26 - 29	2
---------	---

30 - 35	3
---------	---

36 - 40	4
---------	---

>40	5
-----	---

2. BASIC PROFESSIONAL QUALIFICATIONS

Registered General Nurse

	1
--	---

Registered Midwife

	2
--	---

Registered Psychiatric Nurse

	3
--	---

Registered Community Nurse

	4
--	---

1 2

3. ARE YOU REGISTERED AS AN ONCOLOGY NURSE?

YES	NO
-----	----

4. YEARS OF EXPERIENCE AS A PROFESSIONAL

0 - 1	1
-------	---

2 - 4	2
-------	---

5 - 7	3
-------	---

>8	4
----	---

5. FOR HOW LONG HAVE YOU WORKED IN THE CANCER UNIT?

0 - 6 Months	1
--------------	---

7 - 11 Months	2
---------------	---

1 - 2 Years	3
-------------	---

3 - 5 Years	4
-------------	---

> 5 Years	5
-----------	---

KNOWLEDGE

6. Are there any guidelines available in the unit regarding cancer pain relief?

1	2
YES	NO

7. Do you feel comfortable in providing palliative care to a cancer patient?

7.1 Very comfortable

	1
--	---

7.2 Fairly comfortable

	2
--	---

7.3 Slightly uncomfortable

	3
--	---

7.4 Very uncomfortable

	4
--	---

Previous studies have shown that one of the barriers to optimum pain relief was inadequate knowledge.

8. Do you feel there is a lack of knowledge among nurses regarding the following?

8.1 Assessment of pain severity.

1	2
YES	NO

8.2 Accurate documentation of pain.

1	2
YES	NO

8.3 Effective pain management.

1	2
YES	NO

8.4 Actions of prescribed medication.

1	2
YES	NO

8.5 Side-effects of prescribed medication.

1	2
YES	NO

9. Do you feel you are equipped to give adequate health information to a cancer patient regarding the following?

9.1 Actions of prescribed medication.

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

9.2 Side-effects of prescribed medication. *What has prescribed*

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

9.3 Management of symptoms at home.

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

9.4 Medical management of pain at home.

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

9.5 Management of pain at home by means other than prescribed medications.

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

9.6 Management of dietary needs at home.

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

9.7 Influence of chemotherapy on sexual response or desire.

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

9.8 Influence of radiation on sexual response or desire.

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

9.9 Are you able to identify the different stages of emotional response to illness (Kubler-Ross) when presented by the patient?

Never

	1
--	---

Sometimes

	2
--	---

Always

	3
--	---

SOCIAL SUPPORT FOR THE PATIENT

10. Do you know the resources which are available in the community to help support the patient and family when their resources are insufficient?

1 2

YES	NO
-----	----

10.1 List these resources.

11. Do you feel that adequate information on social support is given to the patient?

1 2

YES	NO
-----	----

If "no" to question 11:

12. Why not?

1	2
YES	NO

13. Do you feel you are able to give adequate emotional support to the patient to facilitate emotional adaptation?

1	2
YES	NO

14. Do you feel that the family is actively involved in the treatment plan to care for the patient at home?

1	2
YES	NO

If "no" to question 14:

15. Why not?

1	2
YES	NO

16. When do you give health information to the patient to facilitate coping at home?

16.1 On admission.

1	2
YES	NO

16.2 During hospitalization.

1	2
YES	NO

16.3 On discharge.

1	2
YES	NO

20.3

17. Do you encourage the family care-givers to discuss their problems and expectations concerning the cancer patient?

	1	2
	YES	NO

20.4

If "yes" to question 17:

18. How often?

18.1 Seldom

	1
--	---

18.2 Sometimes

	2
--	---

18.3 Always

	3
--	---

22.2

19. Do you feel it is necessary for a professional nurse to do home visits of patients discharged on palliative care?

	1	2
	YES	NO

22.3

If "yes" to question 19:

20. How often should a nurse visit a patient discharged on palliative care?

20.1 Once a month.

	1
--	---

20.2 Twice a month.

	2
--	---

20.3 Once a week.

	3
--	---

20.4 Twice a week.

	4
--	---

21. Do you inform the community nurse when a patient is discharged on palliative care?

1	2
YES	NO

If "yes" to question 21:

22. How often?

22.1 Seldom.

	1
--	---

22.2 Sometimes.

	2
--	---

22.3 Always.

	3
--	---

If "no" to question 21:

23. Why not?

23.4 Always.

--	--

24. Do you feel it is necessary that nursing care be co-ordinated between the wards, oncology out-patient clinic and the patient's home?

1	2
YES	NO

SOCIAL SUPPORT FOR NURSES

25. Are you aware that there are cancer nursing journals available in the library of UNAM?

1	2
YES	NO

26. Do you make use of these journals to update yourself with cancer nursing issues?

1	2
YES	NO

If "no" to question 26:

27. What other sources do you use to keep you up to date?

28. How often do you attend seminars in oncology nursing?

- 28.1 Never.

	1
--	---

- 28.2 Seldom.

	2
--	---

- 28.3 Sometimes.

	3
--	---

- 28.4 Always.

	4
--	---

29. Do you feel it is necessary to have cancer nursing in-service education programmes?

1	2
YES	NO

30. Are you a member of the Oncology Nursing Society of Namibia?
- | 1 | 2 |
|------------|-----------|
| YES | NO |

If "no" to question 30:

31. Why not

32. How often do cancer nursing lecturers visit the ward to enquire about new clinical development?

- 32.1 Never.

	1
--	---

- 32.2 Seldom.

	2
--	---

- 32.3 Sometimes.

	3
--	---

- 32.4 Always.

	4
--	---

33. How often do you contact the nursing lecturers to enquire about curriculum content (Cancer nursing)?

- 33.1 Never.

	1
--	---

- 33.2 Seldom.

	2
--	---

33.3 Sometimes.

	3
--	---

33.4 Always.

	4
--	---

34. How often does the Oncology Nursing Society of Namibia contact you to keep you up to date on cancer nursing issues?

34.1 Never.

	1
--	---

34.2 Seldom.

	2
--	---

34.3 Sometimes.

	3
--	---

34.4 Always.

	4
--	---

35. Is there anything else you could tell me that would help me to understand better what problems you have, so that better cancer nursing services could be planned?