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## Nutritional problems and information needs of patients receiving chemotherapy and radiation therapy

Margaret Joan Robinson  
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**NUTRITIONAL PROBLEMS AND INFORMATION NEEDS  
OF PATIENTS RECEIVING  
CHEMOTHERAPY AND RADIATION THERAPY**

A thesis submitted in partial fulfilment of the  
requirements for the degree of  
Bachelor of Nursing (Honours)  
at Edith Cowan University, Western Australia  
Faculty of Health and Human Sciences

By

Margaret Joan ROBINSON, R.N.


## USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

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Signature

 Margaret Joan ROBINSON

Date

1st October 1996

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## ABSTRACT

Nutritional status is a major factor in determining the successful outcome of treatment for cancer. The combined effect of cancer, and the treatment for cancer, has the potential to severely impair nutritional status. The purpose of this study was to investigate the incidence and severity of treatment-related side-effects which affect nutritional status in cancer patients and to determine the sources and helpfulness of information about nutrition which had been utilised by patients.

A descriptive study was used to investigate two groups of patients, one group who was receiving chemotherapy, and the other, radiation therapy. A questionnaire developed by the researcher sought information about the occurrence and severity of problems, as rated by patients' self-reports. This study was structured on the theoretical basis of Lazarus and Folkman's theory of stress, appraisal and coping (1984). The diagnosis and treatment for cancer is usually regarded as a stressful event, and this theory posits that patients may use either problem-focussed or emotion-focussed coping styles to cope with the situation.

The results of this study indicate that nutritional depletion is a serious problem for this group of patients. Weight loss, which is the principal marker of nutritional status, was experienced by more than 85% of the patients. Patients showed evidence of using emotion-focussed coping styles, where they often did not seek information about nutrition, and considered they had "no real problems".

Information from this study may assist healthcare teams who care for patients who are receiving treatment for cancer to focus more on nutrition, and develop educational programmes which meet the

needs of these patients more effectively. This information, including patients' self reports and recommendations, may also assist the Cancer Foundation of Western Australia to develop a booklet which is specifically designed for cancer patients who are receiving treatment and who experience nutritional problems.

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## CHAPTER ONE

### Introduction

Cancer is a leading cause of death throughout the world, and it is well documented that response to treatment, length of survival time and the development of complications in patients diagnosed with cancer are associated with nutritional status (Bergstrom, Braden, Laguzza & Holman, 1987; Bistrian, 1986; Blackburn & Thornton, 1979; Grindel, Cahill & Walker, 1989; Heber et al., 1986; Nixon et al., 1980; Smale, Mullen, Buzby & Rosato, 1981 and Waltman, Bergstrom, Armstrong, Norvell & Braden, 1991).

The overall nutritional status of the patient is compromised because cancer cells have high energy needs. Organs not directly affected by cancer can be indirectly affected through the lack of basic carbohydrates, proteins minerals and vitamins which have been usurped by the malignant cells. Moreover, treatment of cancer itself may directly affect the ability of the patient to ingest, digest and/or absorb nutrients (Torosian & Daly, 1986).

Lazarus and Folkman (1984) suggest that seeking information is one of the principle coping strategies which is used during periods of stress. It is essential, therefore, that nutritional information for cancer patients who are receiving treatment is cognisant of the unique problems which this group of patients frequently encounter.

This study has examined the specific problems which impact on nutritional intake in two groups of cancer patients. One group was receiving chemotherapy and the other, radiation therapy. Additionally,

patients were asked to self-rate the severity of these problems as they personally experienced them.

This chapter overviews the relationship between nutrition and cancer and presents the background and the purpose of the study. Chapter two critically reviews the current relevant literature on problems which affect the nutritional status in patients who receive treatment for cancer and incorporates an overview of why patients may seek non-traditional dietary methods. Patient education methods and factors to consider when developing education tools are also reviewed. Finally, chapter two presents and explains the conceptual model underpinning the study. Chapter three describes the method used in this study and chapter four presents the results. Chapter five discusses the results, the implications for nursing practice, and makes recommendations for further research in this area.

### Nutrition

Nutrition is a term given to the range of processes associated with the intake of food and fluids. Included in these processes are the ingestion, digestion and absorption of food and fluids and finally, elimination from the body of waste and by-products of metabolism. This process is essential for proper bodily functioning and maintenance of health. Interference to any one or more of these processes may result in nutritional deficiency leading to malnutrition (Holmes, 1986).

### Malnutrition

Malnutrition is a disorder of nutrition. It may result from poor nutrition associated with an insufficient, unbalanced, or excessive diet, or it may be a consequence of impaired absorption of foods. Serious health problems which lead to eventual death will eventuate should there be an inadequate or inappropriate nutritional intake over a period of time (Curtas, Chapman & Meguid, 1989). Moreover, the development of some cancers has been linked with certain dietary habits (Scrimshaw, 1990).

### Definition of terms

Some terms used in this study may require definition or clarification. In order that the flow of the thesis is not impeded by explanations in the body of the work, such terms are expounded in Appendix A.

### Development of cancer

Some malignancies have been associated with the ingestion of specific foodstuffs, as well as from ingesting foodstuffs containing carcinogenic agents (Scrimshaw, 1990). For example, societies with a high intake of smoked and salted foods have a higher prevalence of cancer of the oesophagus and stomach. Excessive alcohol intake is associated with stomach cancer and perhaps liver cancer. The incidence of breast and colon cancer is low among Japanese consuming a traditional diet, but much higher in ethnic Japanese living in California, implying the consumption of a Western diet to be directly

related to the development of breast and colon cancer (Scrimshaw, 1990).

### Progress of cancer

Rates of growth, and usual sites of metastases vary according to the specific cytology of the tumour. The most usually observed sequelae for patients in whom cancer has developed and who refuse or do not have treatment for some reason is an increasing and unrestrained growth of the primary tumour, with localised invasion into surrounding tissues and organs and widespread metastases throughout the body. This course of events may also occur for many patients who do receive treatment for their cancer.

### Relationship between nutritional status and tumour growth

There has been conflicting evidence regarding the effect of nutritional status upon tumour growth, with some researchers considering that encouraging a high nutritional intake only served to provide more nutrients for the tumour to make use of, thus promoting growth of the tumour itself. Evidence supporting this school of thought is based upon animal studies and was reported by Torosian and Daly (1986). Torosian and Daly further reported that other researchers considered it to be essential that the patient maintain an optimal nutritional state in order to withstand the effects of surgery and adjuvant treatment and thereby overcome the disease.

Smale et al. (1981) studied the efficacy of optimal preoperative nutritional support in reversing protein-calorie malnutrition in

malnourished cancer patients who were undergoing major cancer surgery. Smale et al. demonstrated that malnutrition in cancer patients was closely correlated with morbidity and mortality. Torosian and Daly (1986) reported there was no direct objective evidence of accelerated tumour growth in humans with cancer who receive nutritional support as part of their treatment regimen. Moreover, evidence from their own studies of rats which received continuous parenteral or intrajejunal feeding, suggested an improvement in tumour response to chemotherapy.

Smale et al. (1981) and Torosian and Daly (1986) concluded that nutritional support in the cancer patient whether by the enteral or parenteral route, could reverse the malnourished state without apparent tumour stimulation or unacceptable complications.

### Treatment for cancer

Conventional treatment for cancer commonly consists of surgery, chemotherapy and radiation therapy. Each of these treatments may be given either alone, or in combination (Hill & Price, 1980). The aim of treatment is to destroy malignant cells. However, healthy tissue is often damaged in the process (Holmes, 1986; Torosian & Daly, 1986). (See Appendices B and C for more detailed information concerning chemotherapy and radiation therapy). The incidence of morbid conditions in cancer patients who are receiving treatment has a profound effect upon nutritional status, and ultimately, weight loss, which is universally regarded as the primary marker for nutritional

status (Brown, 1993; Bruera & MacDonald, 1988; D'Agostino, 1989; Dewys et al., 1980; Elmore et al., 1994; Lindsey, Larson, Dodd, Brecht, & Packer, 1994; Sarna, Lindsey, Dean, Brecht & McCorkle, 1993; Wilson, Herman & Chubon, 1991).

#### Specific morbidities related to treatment which affect nutritional status

According to Holmes (1986) nutritional depletion is seen in 33 - 66 % of all patients with cancer, and the effects of treatment may greatly exacerbate this problem. Surgery and radiation therapy which is directed at the head, neck or the gastrointestinal tract may severely affect ingestion, digestion and/or absorption of nutrients (Holmes, 1986; Hunter & Janes, 1989; Pretty & Whelan, 1989 and Wilson, et al., 1991).

Chemotherapy-induced emesis, decreased taste sensation, pain, diarrhoea, constipation and stomatitis, have all been suggested as possible causes of nutritional depletion in cancer patients receiving cytotoxic therapy. Radiation therapy may cause changes in taste sensation, dry mouth, mucositis and/or stomatitis, oesophagitis, dysphagia, oesophageal fibrosis/stricture, acute/chronic intestinal damage, diarrhoea, fluid/electrolyte imbalance, malabsorption, fistula/stenosis of intestine or partial/complete intestinal obstruction, depending upon treatment sites (Holmes, 1991b).

In view of these morbid conditions associated with treatment for cancer which may impact upon nutritional status, it is essential that there is appropriate information on nutrition readily available for

patients receiving treatment. Moreover, it is vital that the information which is given to patients will be effective in promoting maintenance of an optimal nutritional status. The information which is given must be consistent, and have the necessary elements to be of practical help to patients who are experiencing problems which may be detrimental to their nutritional state.

#### Background to this study

In Western Australia, informative literature for cancer patients about nutrition has developed on two fronts and as a result, has been somewhat fragmented. The first approach provided information focussed on health promotion and maintenance, recommending avoidance of foodstuffs that have been identified as possibly carcinogenic. The second focus arose 'ad hoc' and was essentially a response by clinicians who observed problems which resulted in patients' inability to maintain an adequate nutritional intake during treatment. These 'ad hoc' pamphlets and information sheets were devised by dietitians and nurses in order to provide advice for patients who were experiencing problems, and essentially informed patients on ways to increase protein and calorie intake when specific problems were being experienced.

The Cancer Foundation of Western Australia, the peak body for disseminating information on cancer in this State, recently reviewed the published information it had available. Amongst that information was advice concerning diets and cancer. The main booklet, 'Food for thought', (Boulden, 1994) was aimed at providing accurate information

about nutrition and cancer and gave practical advice regarding health promotion, maintenance and well-being. As well, limited supplies of the booklet 'Understanding nutrition' (Queensland Cancer Fund, 1995), produced by the Queensland Cancer Fund, had been made available to Western Australians through the Cancer Foundation of Western Australia.

In response to the clinically observed need for information for patients who are receiving treatment for cancer, it was realised there was a need for more specific detailed information produced locally, and which was aimed at providing information which was more relevant for those patients who were experiencing problems related to nutrition. In order to do that accurately, it was necessary to identify the problems which patients stated they experienced, and to enquire from those patients what information would be of practical help for them.

#### Purpose of study

The purpose of this study was to investigate the occurrence and severity of problems which potentially affected the nutritional status of patients receiving chemotherapy and/or radiation therapy for cancer. To date, there has been limited investigation into the severity of such problems, as described by patients. This study then, sought that specific information from patients. It is anticipated that the information gained will provide a sound background for preparing a booklet on nutrition especially for patients who are receiving treatment for cancer, and who are experiencing nutritional problems associated with that

treatment. Additionally, this study sought information about the nutritional information sources which had been utilised by patients, and how helpful those sources had been.

### Significance of the study

The information from this study will assist healthcare professionals to be more effective in maintaining optimal nutritional states in cancer patients who are receiving treatment. Through the dissemination of the results of this study, nursing staff will be alerted to the serious consequences of impaired nutritional intake, and the ultimate effects that has upon weight loss, and the critical implications that has upon the outcome of treatment. It is hoped that there will be observable improvements in patients' response to treatments, with less incidence of morbidity, less mortality, and reported improvement in over-all quality of life by these patients. As a consequence of involvement in this study, patients became more aware of their problems, were apprised of ways to increase protein and calorie intake, and consequently, maintained a higher nutritional state and experienced improved treatment outcomes.

### Objectives of the study

The objectives of the study were to determine:

- The problems affecting nutritional status which may be experienced by patients receiving chemotherapy and/or radiation therapy for cancer treatment.

- The severity of these problems, as rated by patients.
- The information about nutrition available to and used by patients.
- The effectiveness of available information, as rated by patients.
- The information which patients want which they perceive will assist them.
- The source of that information.
- The use of alternative and/or complementary medications and diets, and the perceived helpfulness of these modalities.

## CHAPTER TWO

### Review of Literature

This chapter will review the literature relevant to this study. Recent information on the common 'outcome measure' of nutritional status, weight loss, is reviewed. This is followed by four separate sections, each presenting an overview of separate topics which are associated with this investigation, and are later integrated into the discussion on this study. Section one examines specific problems which affect nutritional status in patients who receive treatment for cancer. Section two considers the use of complementary and alternative methods of treatment. Section three reviews issues relating to the development of patient education materials, and finally, section four presents the conceptual framework which has guided the development of the conceptual model for this study.

#### Weight loss

It is well established that decrease in weight is regarded as a primary marker in declining nutritional status (Brown, 1993; Bruera & MacDonald, 1988; D'Agostino, 1989; Dewys et al., 1980; Elmore et al., 1994; Larson, Lindsey, Dodd, Brecht & Packer, 1993; Lindsey et al., 1994; Sarna et al., 1993 and Wilson et al., 1991).

Three studies which were presented during the American Cancer Society's Second National Conference on Cancer Nursing Research in 1992 each included weight loss as a variable in their reports. Each paper reported on samples of adults with lung cancer,

and examined the relationships over time of nutritional intake, patterns of weight loss, functional status and age. Brown (1993) described the precancer factors associated with energy intake and expenditure and weight loss in adults ( $n = 60$ ) with non-small cell lung cancer. Larson et al. (1993) investigated whether special problems occurred in older patients compared to middle-aged patients ( $n = 33$ ) with lung cancer during and after radiation treatment. Sarna et al. (1993) conducted a descriptive longitudinal study on nutritional intake and weight changes in adults ( $n = 28$ ) with advanced lung cancer over a six -month time period. Each of these three studies is described in more detail in other sections of this review.

The study by Brown (1993) found a continual decrease in weight from beginning of radiation therapy to the completion of therapy. Larson et al. (1993) found that the under 65 age group lost weight from the commencement of the study (mean weight 76.1 kg.) until the end (mean weight 65.4 kg). The 65-or-older group gained a very small amount of weight over the same time. Sarna et al. (1993) found that weight remained relatively stable during the period of the study, however younger patients, those with small cell lung cancer, and those receiving chemotherapy lost the most weight over time.

When reviewing these three studies, Lindsey (1993) suggested that more information about the relationships over time among food intake, energy expenditure, weight change, functional status, and age was needed in order to provide direction for nursing practice with specific cancer populations.

A descriptive study conducted by Wilson et al. (1991) identified the eating strategies employed by American patients ( $n = 11$ ) who had received radiation therapy to the head and neck. Eating problems had been identified by these authors as a major concern to this patient group. In this patient group weight loss was identified as being the most significant indicator of nutritional compromise. Nine subjects (82%) lost from 2.7 kg. - 16.4 kg. during treatment, and none had returned to their pre-treatment weight level at the interview which was conducted within six months of completion of radiation therapy. Bruera and MacDonald (1988) also considered weight to be the most useful parameter of nutritional status, in the absence of pleural or peritoneal effusions, oedema or lymphangitis.

### Summary

It has been evidenced from these reports that variations in weight serve as a point of reference for nutritional status, and that weight loss in cancer patients receiving treatment is regarded as evidence of a compromised nutritional state. This review will now consider the particular problems which patients who are receiving treatment for cancer may experience, and which impact upon the ability of these patients to maintain nutritional status and consequently weight maintenance.

## Section one - specific problems which affect nutritional status in patients who receive treatment for cancer

Principal conditions which have impact on nutritional status have been identified from the literature. These conditions may be pre-existing, such as age and social support, or may be related to lifestyle factors, such as a history of smoking or alcohol use. The literature review on these factors follows.

### Pre-existing conditions

#### Age

Cancer is a common disease in aging populations. In Western Australia over two thirds of cancer deaths occur in the over-65 age group. (Cancer Foundation of Western Australia, n.d.). Methods of assessment of the nutritional problems in the elderly were reviewed by Mion, McDowell & Heaney (1994) who asserted that nutritional problems were exhibited in the elderly even prior to the incidence of life-threatening illnesses such as cancer. This corroborated the findings of other investigators, such as Brown (1993) and Bruera and MacDonald (1988).

A longitudinal prospective study ( $n = 45$ ), of the elderly (mean age 69.8; range 61-86), who were receiving radiation therapy for breast or lung cancer was conducted by Lindsey et al. (1994). A slight decrease in mean weight was found, however the majority tolerated the course of radiation with less than adequate caloric intake to meet their

usual energy requirements. This study was limited by the high attrition rate, where the number of subjects dropped from 45 who were weighed at Time 1 of the study, to 13 being weighed at Time 4, a loss of 71.7 % of the original sample.

Larson et al. (1993) also examined the relationship between age and problems experienced by patients receiving radiation therapy. The purpose of this prospective, longitudinal study was to determine if patients with lung cancer who are 65 years of age or older experience problems differently than patients younger than age 65 during and following radiation treatment. The outcome variables included in this study were weight, body mass and multi-dimensional functional status. The sample included 33 patients with lung cancer, ranging in age from 48 to 86 years; 13 were younger than 65, and 20 were 65 or older. This study was marred by the high attrition rate. Twenty eight subjects (85%) of the sample remained at Time 2, 20 (61%) at time 3, and 10 (30%) remained at Time 4. Two sample was divided into two groups - one comprised of under age 65 and the other age 65 or older. The 65-or-older group did not experience the therapy-related problems any differently than the under-65 subjects. However, Larson et al. admitted that because of the small sample size, generalising the findings to other groups of patients with lung cancer may not be possible.

Waltman et al. (1991) conducted a prospective study of American institutionalised elderly patients (N = 200) admitted to a long-term care facility. A secondary analysis was conducted on the data obtained from the primary study.

This secondary study investigated differences in nutritional status, incidence of pressure sores, and incidence of mortality between two groups, one composed of elderly institutionalised patients with cancer (  $n = 33$  ), and a matched-group of patients without cancer. Subjects with cancer were matched with subjects without cancer based on age, sex, and pressure sore risk status on admission. Risk status was determined by the Braden Scale for Predicting Pressure Sore Risk (Bergstrom et al. 1987). Subjects with Braden Scale scores of less than 17 were considered to be at risk and were included in the study. Skin breakdown, dietary intake, and blood and serum indices of nutritional status were evaluated weekly throughout a 12 week period.

Each group comprised 13 male and 20 female Caucasian subjects. The mean age was 78.36 (S.D. = 6.22) for the group with cancer and 78.63 (S.D. = 7.43) for the group without cancer. During the 12 week study period, 28 of the 33 subjects with cancer developed pressure sores, compared with 23 of the subjects without cancer. Compared with the subjects with cancer, twice as many of the subjects without cancer remained free of pressure sores. Moreover, 13 of the cancer patients died, and all of them had pressure sores. The results of this study indicated that elderly patients with cancer appeared to be at greater risk of pressure sores, and incidence of pressure sores is related to a compromised nutritional status.

This review of literature has established that age and the incidence of cancer are positively related. Moreover, the relationship between cancer and nutritional problems is also well documented.

Studies which have examined these factors in combination have produced less conclusive reports, and those studies have recommended that further research is indicated in this area.

### Social support

The second pre-existing condition which may impact upon nutritional status is the availability of social support. Social support means having a person or group of people who care about one. Lindsey et al. (1994) regarded multiple factors in their study, including the effect that social support had upon outcomes in older patients who were receiving radiation therapy. Perceived social support was assessed at Time 1 using the Norbeck Social Support Questionnaire, which these authors stated had been assessed for reliability and validity. Three dimensions of social support were measured, these being: the number of persons that subjects listed as being important to them; the total functional support that was provided by these persons, measured in aspects of "affect, affirmation and aid" (p. 117); and the total support given in terms of frequency of contact, and sharing of confidence. Lindsey et al. found that although social support was reported in other literature as a moderating variable in an individual's response to illness, particularly in the elderly, the relationships in their study between the outcome measures of weight, body mass index, and functional status were very weak. Moreover, subjects with lower social support perceived themselves to have better functional status. No studies were identified which examined the effect of social support on patients who were receiving chemotherapy.

## Lifestyle

### Smoking

Brown (1993) examined the relationships between gender, age, usual weight, and tobacco use with cancer-related weight loss. A convenience sample ( $n = 60$ ) of patients who had non-small cell lung cancer, and who were at least one month post-radiation therapy were included in the study. Brown stated that cigarette smoking, specifically nicotine exposure, had been reported to increase energy expenditure by 7 - 35%. Results from the study by Brown indicated that patients who were currently smoking were at high risk for weight loss.

Sarna (1995) described the smoking behaviour of women with a recent diagnosis or recurrence of lung cancer. A convenience sample ( $n = 65$ ) American women participated in interviews about their smoking status, and self reports of symptom distress and functional status. Symptom distress was measured by the modified Symptom Distress Scale of McCorkle and later modified by McCorkle and Young (1978). The results from this study were reported using a summed total score, and only items related to respiratory distress were analysed separately. Thus, other individual reasons for distress are not available. However, in the literature reviewed by Sarna, it was stated that increased postoperative surgical morbidity and increased weight loss were associated with continued smoking.

Moreover, Scrimshaw (1990) cited evidence that smoking affected taste, and in view of this, it may be suggested that current smoking may adversely influence nutritional intake.

### Alcohol Consumption

Sarna et al. (1993) included alcohol consumption as a moderator variable in their descriptive longitudinal study of the relationship of nutritional intake to weight change, symptom distress and functional status over a six month period in 28 subjects with lung cancer. Sarna et al. found some variability in the intake of alcohol during the study period and at Time 2 there was a strong correlation between nausea and grams of alcohol consumed ( $r = 0.97$ ) for the small number of subjects ( $n = 4$ ) reporting these data.

### Summary

This section of the review of literature has outlined the pre-existing and lifestyle factors which may possibly affect the nutritional status of cancer patients. The following section will review side-effects which result from treatment for cancer, and which seriously interfere with nutritional states in patients who are receiving those treatments.

### Treatment-related side effects

Side effects which are commonly experienced by patients who receive chemotherapy and/or radiotherapy are initially discussed. The effect of recent hospitalisation, which has occurred from surgery to remove tumour growth, is then outlined.

### Dry mouth

Dryness of the mouth is an observed clinical phenomenon associated with many forms of cancer and cancer treatment. However, there have been few studies elicited in the literature regarding this fact. Wilson, et al. (1991) studied head and neck cancer patients' perceptions

of their eating problems, focussing mainly on the eating strategies employed by this group in order to overcome their problems. In this qualitative, descriptive study (n = 11) conducted at two North American radiation therapy departments, dryness of the mouth was identified by five of the participants as a problem. These subjects were reported to have addressed their problem by drinking more liquids. Holmes (1986, 1991b) emphasised the importance of good oral hygiene for these patients, and suggested the use of artificial saliva to assist keeping the mucous membrane moist. Failure to address this problem may lead to ulceration, dental decay and tooth loss through multiplication of oral bacteria (D'Agostino, 1989).

#### Sore mouth and throat

Mucositis and stomatitis are common side effects of chemotherapy and radiation therapy which result in cancer patients experiencing a sore mouth or throat and can disrupt nutritional patterns (Grindel, et al. 1989; Holmes, 1991(b); Western Consortium for Cancer Research, 1991). Mucositis is an inflammation of the mucous membrane, in this case, of the mouth and throat. Stomatitis is a similar condition of the mucous membrane of the mouth, but more specifically relates to the presence of infection, for example, fungal infection (caused by the yeast fungus, *Candida albicans*). See Appendix A for more detail.

Drugs used in cancer therapy exert profound cytotoxic effects and since they cannot discriminate between normal and malignant cells, may have marked effects on healthy tissue. The mode of action of

chemotherapeutic agents is to interrupt the reproductive ability of cells. Cells, such as malignant cells and also those mucous-secreting cells which line the gastrointestinal tract, rapidly divide. Cells which are dividing more rapidly are therefore more sensitive to the effects of chemotherapy. This lack of selectivity causes mucositis and stomatitis.

Radiation therapy also acts upon the reproductive ability of cells, and therefore results in the side effects mucositis and stomatitis when the radiation therapy is directed at the head and neck. This may severely reduce a patient's oral intake because of the inflammation and ulceration it may cause (Holmes, 1986). Nine of the 11 subjects studied by Wilson et al. (1991) identified mucositis and stomatitis as the most common problem experienced, and equal to the problem of weight loss.

King, Nail, Kreamer, Strohl and Johnson (1985) described a group of North American patients' experiences of receiving radiation therapy. The sample was divided into subjects who received radiation therapy to the chest ( $n = 15$ ), head and neck ( $n = 25$ ) male pelvis ( $n = 26$ ) and female pelvis ( $n = 30$ ). Subjects were interviewed weekly during treatment and monthly for three months after treatment had ended.

Symptoms experienced varied somewhat by the site of treatment and more than 30% of the subjects in each group experienced the persistence of at least one symptom for up to three months after the completion of treatment. The incidence of sore throat reached 86% of patients receiving radiation therapy to the chest at the third week of

treatment, then decreased gradually from that point until the last week of treatment, after which it decreased sharply over the following months. Subjects rated the severity of the sore throat as a "little bad" to "moderately bad". A few subjects whose throats continued to be sore after radiation therapy had ended reported it to be "moderately bad". Subjects reported that the sore throat interfered with eating, especially dry, rough foods such as toast or crackers (King et al., 1985, p.57-58).

Subjects in the study by King et al. (1985) who received radiation therapy to the head and neck also reported the problem of sore throat. This portion of the sample reported the incidence of sore throat to be 72% by the third week of treatment, and rated the severity as moderately bad. After treatment had ended reports of sore throat gradually decreased.

#### Taste change

Change in food appreciation has been consistently identified as one of the causes of poor dietary intake, thereby contributing to a deterioration of the cancer patient's general condition. Taste changes have been associated with food aversion resulting from treatment, whereby patients may complain that food tastes 'metallic' or 'sweet' or 'salty' (Bernstein, 1986; Bruera & MacDonald, 1988; Grindel et al., 1989; Huldij, Giesbers, Klein Poelhuis, Hart, Hulshof & Bruning, 1986; Larson, et al., 1993 and Wilson et al., 1991).

Huldij et al. (1986) prospectively studied the alterations in taste appreciation for five months in Dutch men and women cancer patients

during radiation therapy and/or combined chemotherapy. Diagnoses included endometrial or cervical cancer ( $n = 28$ ), bladder or prostate cancer ( $n = 52$ ), and malignant lymphoma ( $n = 28$ ). The one patient who received radiation therapy for lymphoma of the head and neck lost his sense of taste completely, and was excluded from the study. Huldij et al. found that patients with food aversions developed weight loss, decreased appetite, and early satiety significantly more often than patients without food aversions. Huldij et al. concluded that the cancer patients they studied showed different patterns of food appreciation. They recommended that nutritional advice should be adapted to the individual patient's changing needs.

Bernstein (1986) examined the research aimed at cancer anorexia, focussing on studies of learned food aversions. Bernstein concluded that learned food aversions occurred as a result of the association of foods with symptoms induced by chemotherapy and/or tumour growth. Wilson et al. (1991) found that subjects in their study had 'vivid' descriptions of their changes in taste perception. Such descriptions included "everything tasted like wet cardboard . . . rubber . . . mush" (p. 102 -103).

The longitudinal study of American women ( $n = 19$ ) with breast cancer by Grindel et al. (1989) to assess changes in nutritional patterns whilst these patients received chemotherapy also indicated that patients experienced alterations in taste, but that food aversions did not develop.

It has previously been established that the incidence of cancer rises as age increases. The elderly have predisposing problems related

to taste and smell (Kick, 1989). Kick, who described patient teaching for the elderly, stated that cognitive changes together with decreased oxygenation, cerebral blood flow and haemoglobin have the effect of decreasing sensitivity to variations in taste and smell. It is a logical progression therefore, to assume that a large proportion of patients who are receiving chemotherapy and/or radiation therapy for treatment of cancer have a decreased ability to identify and appreciate taste sensations, and that the treatment they receive will further affect this.

#### Chewing problems

Treatment such as surgery and radiation therapy for tumours of the head and neck often cause problems in the ability of patients to chew effectively (Holmes, 1991a and Wilson et al., 1991).

Additionally, the site of the tumour may directly affect the ability of the patient to chew properly (Holmes 1991a). In the study by Wilson et al. (1991) of eating strategies used by persons with head and neck cancer ( $n = 11$ ) during and after receiving radiation therapy, 27% of the sample described this as a problem for them, although the small sample size makes this difficult to generalise to other patients, and the degree of severity of the problem was not elicited.

#### Pain

The presence of pain has been recognised as a problem affecting nutritional status, particularly when it is in the region of the head and neck (Bruera & MacDonald, 1988 and Wilson et al., 1991). Holmes (1991a), in describing the symptom distress in two cancer patient populations ( $n = 51$ ) found that the presence of pain caused radiation

therapy patients significant concern, although this problem was not elicited in chemotherapy patients. Unfortunately this study does not reveal the diagnoses or treatment areas of the subjects, and it is difficult to make judgement as to whether the sample group for radiotherapy patients had specific problems which may have exacerbated this finding.

### Fatigue

Asthenia, or fatigue, as it is commonly known, is well documented as a distressing symptom of cancer (Brown, 1993; Bruera, Macmillan, Kuehn, Hanson & MacDonald, 1990; Bruera et al 1989; Bruera et al. 1986, Irvine, Vincent, Bubela, Thompson & Graydon, 1991 and Irvine, Vincent, Graydon, Bubela & Thompson, 1994), and was reported by 65% - 95% of patients studied by King et al. (1985).

A report by Irvine et al. (1991) appraised the research literature on fatigue in cancer patients receiving treatment. In the 16 studies which were reviewed by Irvine et al. on cancer patients receiving chemotherapy the prevalence of fatigue was estimated between 80% and 96%. Studies reviewed by Irvine et al. on fatigue in radiation therapy patients, indicated the prevalence of fatigue increased over the course of radiation therapy. The lack of control groups, the failure to control for possible confounding variables and the use of unidimensional scales with limited reliability and validity were regarded as serious flaws in the majority of the studies reviewed by Irvine et al.

In order to overcome these faults, Irvine conducted a study which accounted for these uncontrolled variables. The study conducted by Irvine et al. (1994) utilized a control group when investigating the

prevalence of fatigue among patients receiving treatment with radiotherapy ( $n = 54$ ) and chemotherapy ( $n = 47$ ). The level of fatigue experienced by cancer patients was compared with the level of fatigue experienced by apparently healthy auxiliary staff ( $n = 53$ ) working at three cancer treatment sites. Fatigue was measured using the Pearson Byars Fatigue Feeling Checklist, reported by Irwin et al. to have a reproducibility coefficient of 0.95.

There were no differences in the mean level of fatigue experienced by cancer patients and the mean level experienced by healthy controls before the start of cancer treatment. However, cancer patients experienced a significant increase in fatigue over a 5 or 6 week course of radiotherapy ( $t = 4.69, p = 0.0001$ ) and 14 days after treatment with chemotherapy ( $t = 2.81, p = 0.0074$ ), and these increases were significantly greater than the fatigue reported by healthy control subjects. Fatigue was found by Irvine et al. (1994) to be a covariant with weight, symptom distress, mood disturbance, and alterations in usual functional activities. Symptom distress and fatigue were significant predictors of impairment in functional activities related to illness. Irvine et al. concluded that the results from their study provided evidence that fatigue negatively impacts on the patient's quality of life, and confirmed previous reports of increasing levels of fatigue over the course of treatment.

A study to determine the prevalence of asthenia and its association with nutritional status, lean body mass, anaemia, psychological status, and tumour mass was conducted in consecutive

Canadian women (n = 64) with advanced breast cancer by Bruera et al. (1989). Asthenia was determined by four self-assessment tests. These were: - a rating of energy level using a visual analogue scale; a twenty-seven item questionnaire designed to assess the patient's ability to perform physical tasks in activities of daily living; a combination of six visual analogue scales which asked the patient to rate her ability to perform activities of daily living and a seven item questionnaire designed to assess the percentage of the patient's normal physical activities she was able to perform, compared to her resting time. A control group of sixty-eight healthy females underwent the same assessment. Results revealed 91% of the study group reported a substantial increase in physical fatigue during the previous year, as compared with 34% of the control group ( $p < 0.0001$ ). The evaluative study by Holmes (1991a) of a measurement instrument for symptom distress found that tiredness was the most common complaint in the two English cancer patient populations which were studied.

### Dyspnoea

D'Agostino (1989) referred to dyspnoea as one of the concurrent problems which may affect the ability of the cancer patient to maintain nutritional status, and stated that poor oxygenation associated with shortness of breath may impede the ability of the patient to effectively metabolise nutrients. Larson et al. (1993) stated that patients who have lung cancer experience exacerbated shortness of breath firstly as a result of their underlying disease, and secondly, from the effects of radiation therapy.

### Dysphagia

Dysphagia, or difficult or painful swallowing may result from an obstructing tumour, radiation to the head, neck or chest, and chemotherapy or radiation therapy-induced stomatitis or oesophagitis (D'Agostino, 1989). Wilson et al. (1991) studied patients receiving radiation therapy for head or neck cancer, and stated that dysphagia was a problem for 64% of the subjects in their study ( $n = 11$ ), although a severity rating was not sought. Treatment to the head and neck frequently has a severe impact upon the ability of this group of patients to easily eat and drink. As well, this group of patients frequently experience nutritional changes early in the disease process because the tumours alter chewing and swallowing ability. The side effects of surgery, chemotherapy and radiation therapy further compromise the nutritional status of these patients. Therefore, patients with head and neck cancer are at extreme risk for developing severe and sustained nutritional problems that begin before diagnosis and remain after completion of treatment (Wilson et al.).

### Nausea and vomiting

Nausea and vomiting may result from toxic effects of the tumour, as well as from treatment. Both chemotherapy and radiation therapy can induce nausea in cancer patients (Holmes, 1986, 1991b). Many cytotoxic drugs cause nausea and vomiting which can produce a significant decline in voluntary food intake and well as fluid and electrolyte imbalance (Grindel et al. 1989; Holmes 1991b). Holmes (1991a) found nausea to be a problem for 18% of chemotherapy

patients ( $n = 22$ ), and 10% of radiation therapy patients ( $n = 29$ ). Symptom distress, which included nausea was the subject of a study by Sarna et al. (1993). The purpose of this descriptive longitudinal study ( $n = 28$ ) was to determine the relationship of nutritional intake to weight change, symptom distress and functional status over a six month period in American subjects with progressive lung cancer. In part, the study showed that a low level of nausea persisted throughout the duration of the study, with a wide variation across subjects. This study was limited by the small sample size and the high attrition rate ( $n = 9$  at the end of the study, representing a loss of 68%).

#### Early satiety

One of the many reasons for inadequate nutritional intake of cancer patients is early satiety (Bruera & MacDonald 1988; Holmes 1991(b); Huldij et al. 1986). Bruera and MacDonald, in reviewing the literature on malnutrition, suggested approaches for nutritional management of these patients. Bruera and MacDonald described their findings from a group of six patients who complained of anorexia, chronic nausea and early satiety. After performing barium meals and gastroscopic examinations of the stomachs, no evidence was found of mechanical obstruction or intrinsic abnormality. However, when gastric emptying scans were performed, they were found to be significantly abnormal with the average emptying time of 190 minutes versus 70 minutes for a control population ( $P < 0.01$ ). Bruera and MacDonald concluded that for some patients with advanced cancer, a syndrome which they termed "autonomic insufficiency" developed (p.

136), and this could explain some of the abnormalities in gastric emptying.

#### Indigestion and heartburn

Little was elicited from the literature on this problem in relation to cancer and its treatment modalities, and no studies have been found which have examined this problem solely as an area for study. Holmes (1986) has referred to this as a common problem, brought about in part by mucosal inflammation resultant from radiation therapy. Soffer et al. (1994) conducted a prospective, double-blind randomized trial of naproxen versus a placebo for the prevention of radiation-induced oesophagitis in 28 patients receiving treatment to the thoracic region for lung cancer. In part, they reported heartburn to be associated with this treatment and treatment area for 15 (53.57%) of the subjects.

#### Diarrhoea

Holmes (1991a) described the adverse side effects on intestinal function caused by chemotherapy and radiation therapy. Chemotherapeutic agents may cause diarrhoea by indiscriminately injuring the rapidly-reproducing cells in the intestine. Patients receiving radiotherapy to the abdominal or pelvic regions may experience the onset of diarrhoea one to two weeks after treatment starts, and this may continue for several weeks after treatment is completed. In some cases, Holmes stated, it may persist for prolonged periods, and may lead to dehydration and electrolyte imbalance. King et al. (1985) sought severity recordings from symptoms from radiation therapy subjects whom they studied. Both male (n = 26) and female (n = 30) subjects

receiving radiation therapy to the pelvic region experienced problems from diarrhoea, and recorded the severity as "a little bad" to "moderately bad" (p. 59).

### Constipation

Holmes (1991a) found that in the two hospitalized cancer patient populations studied, constipation accounted for distress in 29.4% of the total sample and affected 13.6% of chemotherapy patients, and 41.4% of radiation therapy patients. This study did not investigate the reasons for the problems, and it is therefore unknown if there was any relationship between drugs, stage of disease and the problem of constipation. Wilson et al. (1991) reported that only one of the eleven head and neck patients identified constipation as a problem.

### Anorexia

Anorexia and appetite changes are well documented as problems which affect the nutritional status of cancer patients (Bernstein, 1986; Brown, 1993; Bruera & MacDonald, 1988; Holmes, 1991a; Larson et al. 1993; Sarna et al. 1993 and Wilson et al. 1991). Bernstein reported on the causes of anorexia, and concluded there were several factors which contributed to this problem. These included intestinal obstruction, treatment side effects and numerous biochemical changes which could feasibly contribute to appetite loss in cancer patients.

Bruera and MacDonald (1988) recognised anorexia to be one of the common causes of malnutrition, and stated that the cause of it was unknown. Bruera and MacDonald stated that studies suggested either

the tumour or the treatment produced abnormalities in neurotransmitters, and brought about food aversions. Moreover, chemotherapy was stated to produce an anorexic state (Bruera & MacDonald, 1988; Wilson et al. 1991). Holmes (1991a) found that appetite changes were amongst the most significant problems which caused distress to patients receiving radiation therapy. Anorexia was amongst the most common problems experienced by patients with lung cancer who were receiving radiation therapy (Brown 1993; Larson et al. 1993; Sarna et al. 1993).

Sarna et al. (1993) reported that there was little change in the perception of hunger over the six month period of their study, however a slight but relatively constant disruption in appetite occurred over the time period. As has been previously identified, this study was somewhat limited by high attrition. D'Agostino (1989) described anorexia as being a major problem for cancer patients, and resulted in poor nutritional status, poor response to therapy and consequently, poor prognosis. D'Agostino identified several contributing factors to the incidence of anorexia. These included, disturbed central control of feeding, gastrointestinal malfunction, diminished ability to taste, and an imbalance in energy expenditure. As well, anorexia may also result from reduced gastric emptying and slow peristalsis, both of which result in early satiety.

#### Recent Hospitalisation

Many patients who are treated with chemotherapy or radiation therapy have had recent hospitalisations for surgical procedures

(Hunter & Janes, 1989 and Smale et al., 1981). The prevalence of protein-calorie malnutrition in hospitalized cancer patients is widely recognised (Elmore et al., 1994; Loogman, 1992 and Torosian & Daly, 1986). The frequency of malnutrition in hospitalized patient populations is approximately 30% to over 50% depending on the criteria used to define the malnourished state. Elmore et al. reported an evaluation of the effectiveness of a nutrition screening tool and stated that 31% of medical and surgical patients are at high risk of malnutrition. Loogman described nutritional status in gastroenterology patients and cited evidence that malnutrition affected approximately 55% of all hospitalised patients. This percentage rose to 69% when patients were hospitalised for more than two weeks.

### Summary

This section of the literature review has provided an overview of the specific problems which affect nutritional status in patients who receive treatment for cancer, and has provided a synopsis of the current literature on the impact of pre-existing conditions, lifestyle factors and treatment-related side-effects on nutritional status. The following section will provide a summary of the literature on the use of non-conventional methods of treatments which are reported to be used with increasing frequency throughout the world.

## Section two - the use of complementary and alternative methods of treatment

The use of alternative methods, which include diets, medications, and physical therapies has received increased interest in recent years from members of the general public, and consequently, from health-care professionals world-wide (Downer et al., 1994; Fisher & Ward, 1994; Montbriand & Laing, 1991). Frequently, methods utilised by patients may be referred to as 'complementary', rather than 'alternative'. Orthodox medicine refers to practices which attempt to adhere to modern scientific practices. Complementary therapies are practices which are used in conjunction with orthodox medicine. The definitions provided by Fulder (1988) and cited in the Australian Nursing Federation (1993) Policy Statement on the use by nurses of these therapies, are set in Appendix D.

In the United Kingdom and Europe complementary therapies are widely used by many doctors, nurses and other therapists. Fisher and Ward (1994) stated that throughout these two world areas public demand is strong and growing. For example, in 1981, over 6% of the Dutch population attended a therapist or doctor who provided complementary medicine. This figure increased to over 9% in 1985, and to almost 16% in 1990. Similar examples are available in the United Kingdom, where the figure of 14% of the population who had attended a practitioner in complementary therapy in 1985 rose to almost 25% in 1991. In the United States of America, large

proportions of the population would appear to use alternative and complementary therapies. Eisenberg, cited in Fawcett, Sidney, Hanson and Riley-Lawless (1994) estimated that 33 per cent of the adult population in the United States were using 'unconventional' therapies in 1990. Figures such as this may explain the Position Statement released by the American Dietetic Association (1995) which warned on what they referred to as 'food faddism', stating that "food and nutrition misinformation has harmful effects on the health and economic status of consumers" (p. 705). Food faddism, this Statement claimed, involves unreasonable and exaggerated beliefs that special attributes of a particular food may cure disease.

A rising interest in the use of complementary therapies in Australia has been recognised by several nursing authorities. The Australian Nursing Federation (1993); the Cancer Foundation of Western Australia (1996); the Nurses Board of Western Australia (1996) and McCabe, Ramsay & Taylor (1995) have released literature aimed at the provision of accurate information and guidelines for nurses who wish to use these treatments, and mostly refer to techniques such as relaxation, aromatherapy and other therapies "within the nurse's scope of education" (A.N.F. Policy Statement 1993, p. 2).

#### Why patients may seek and use complementary and alternative diets and medications

The reasons why patients seek and use complementary and alternative methods of treatment is an interesting and complex issue.

Based on Lazarus and Folkman's (1984) theory on stress, appraisal and coping, it has previously been stated that information-seeking is one of the primary means of coping. It is posited that the use by patients of complementary and alternative methods of treatment may be evidence of 'problem-focussed' coping. Problem-focussed coping will be expounded upon later in this chapter.

Downer et al. (1994) studied oncology patients at two London hospitals in order to determine what proportion were using complementary therapies in addition to conventional medical treatment. Respondents to a postal screening questionnaire (n = 406) indicated that 16% were or had used complementary therapies, and that 75% of those used two or more therapies. Respondents to the questionnaire were invited to participate in an interview. A total of 48 (74%) of patients using complementary therapies participated in this interview process. Reasons which respondents gave for using such therapies included; attraction to the perceived holistic nature of the remedies (42%); seeking treatment which allowed more patient participation (25%); and importance which the patient placed upon the supportive relationship which was established between themselves and the practitioner (17%).

Montbriand and Lang (1991) conducted an ethnographic study of patients from a mid-Canadian city hospital (n = 75) and reported that 89% of the sample were using alternative health care methods. The aim of the analysis was to explore the many ways of looking at the

informants' perceptions of alternative care as a control strategy rather than a description of actual health care practices.

Fisher and Ward (1994) examined the major forms of complementary treatments that are used by many doctors and other therapists throughout Europe and the United Kingdom. Fisher and Ward reported that the British Medical Association had recommended that complementary medicine should be incorporated into medical under-graduate programmes and that accredited post-graduate training should be set up.

### Summary

Section two of this review has provided an overview of the increasing world-wide trend towards therapies which may be regarded as outside orthodox medicine. Some reasons why patients may seek these treatment have been outlined. Section three of the review will present current thought which is expressed in the literature regarding patient education.

### Section three - patient education

This section of the literature review will outline the reasons why the provision of information has positive effects upon health outcomes of patients. Methods of patient education will be outlined, and factors which ought to be considered when designing printed educational material for patients will be described.

### Provision of information to patients

Lazarus and Folkman's (1984) theory of stress, appraisal and coping has been used as a theoretical framework in studies which have been conducted in nursing fields. These studies have given strength to the concept that the provision of information has significant benefits for patients. Such benefits to patients have been measured by Poroch (1995) who conducted a study ( $n = 50$ ) on the effects of preparatory information on anxiety and satisfaction with care of radiation therapy patients. Results from this study indicated that the provision of information early in treatment significantly reduced state anxiety and significantly improved satisfaction with care. These results affirmed the findings of a previous study by Derdarian (1989) which indicated that the provision of information to both an experimental and control group of cancer patients and spouses ( $n = 60$ ) resulted in a significant improvement with their satisfaction with care. Moreover, results from other studies indicate that patients prefer to be involved and participate in their care (Cassileth, Zupkis, Sutton-Smith, & March, 1980 and Oberst, 1984) and seek information in order to better cope with stressful situations (Derdarian, 1986, 1987a and 1987b).

Lauer, Murphy and Powers (1982) compared nurses and patients' perceptions of learning needs. Using rating scales, 33 nurses and 27 patients rated the degree of importance of learning 36 informational items, including nutrition, treatment, and diagnostic testing. In addition, nurses and patients ranked six content areas according to how problematic each area was for the patient; how much

knowledge the patient had about each area; and how much the patient wanted information about each area. Results indicated that significant differences existed between nurses' and patients' perceptions of the learning needs of cancer patients. Nurses rated the degree of importance of the 20 general information items significantly higher than did the patients.

Dwyer (1986) who examined the myths and realities of nutrition education stated that nutrition education is an important consideration in the health promotion and management of the cancer patient and his/her family. Dwyer further established that everyone on the health care team, including physician, nurse, pharmacist and dietitian needs to know the basics of nutrition so the information they give is consistent and reinforced during encounters with the patient. These considerations ought to be borne in mind when developing patient educational programmes.

#### Methods of patient education

Fredette (1990) described four theories concerning psychosocial adaptation stages and education, and developed an educational model for the cancer patient. This model suggested nursing approaches, educational topics, and teaching strategies based on the patient's behavioural responses. However, the model was quite complex, and consisted of six separate educational periods. This may be impractical

to co-ordinate and maintain in a busy clinical setting without the support and commitment of the entire healthcare team.

Hiromoto and Dungan (1991) evaluated a contract learning protocol amongst five chemotherapy outpatients in a private oncology/haematology clinic in Hawaii. This learning protocol utilized the principles of adult learning. These principles are firstly, as adults, patients are independent learners; secondly, their past experiences are resources for learning; thirdly, adults are more ready to learn, (compared with children) because of greater development, and finally, adult learning is task or problem-oriented, that is, they will seek out various resources for specific learning.

Hiromoto and Dungan (1991) developed an assessment tool and contract based on literature. The learning needs assessment tool and contract were then completed with each client. The tool elicited demographic information, patient's level of interest of learning on a 4-point scale (1 = total disinterest or defers to a significant other; 4 = desires 'all there is to know'), preferred learning method, assessment or visual or neurosensory impairments, and questions related to self-care requisites whilst receiving chemotherapy. After completing the tool the subjects were asked to read a 5-sentence contract that encouraged participation in health care through self-care measures and to seek further knowledge as questions or problems developed. Upon assessment of the patients' learning needs, the nurse provided material and utilized teaching methods preferred by the patient. Based on the level of expressed interest, the clinical specialist compiled printed

resources to augment the teaching plan. Results of the study were that the most preferred learning method was through printed material.

Luker and Caress (1989) expressed doubts concerning the transferability of theories of adult learning to patient education. Luker and Caress claimed that generalist nurses are not 'good patient teachers', and suggested that patient education should become the responsibility of specialist nurses. As well, Luker and Caress stated that computer-assisted learning could provide a solution to problems faced by patient educators, by assisting patients, particularly those with weak literacy skills, or physical impairment, such as blindness.

The use of computers in patient education was also described by Cartwright (1988). Advantages outlined by Cartwright included allowing the learner to proceed at his/her own pace, permitting review of sections not fully understood; ensuring the learner's active participation by requiring responses to questions; being always available; provision of different routes through the material depending on the individual learners' needs; provision of immediate reinforcement of learner responses when correct, and immediate notification and help when incorrect; provision of instruction in an entertaining manner when the soft-ware is imaginatively designed, and allowing the learner to 'test' ideas in simulated situations, without having to suffer any unfortunate consequences. The growing use of computers in the sphere of patient education was also confirmed by Kruckenberg Schofer and Ward (1990).

However, printed educational material is regarded as an economical method for providing information to most patients (Allensworth & Luther, 1986 and Lange, 1989). Moreover, the advantage of providing information which is consistent is regarded as highly desirable. This method provides an attractive alternative to the more expensive method of computer education. However there are important issues to be considered when writing educational material for patients, and these are set out below.

#### Factors to consider when designing printed educational material

##### Analysis of learning needs

Before embarking on any educational program it is essential to determine what are the learning needs of the target audience. The significance of a needs analysis prior to writing educational material was recognised by Mathis (1989) and Hiromoto and Dungan (1991). The latter authors confirmed that teaching is not effective when the anxiety of crisis is high, and learning needs should be assessed until a state of 'readiness to learn' is apparent.

The importance of determining learning needs was endorsed by Duchin and Brown (1990) who reported from their study that patients should be included when designing educational material. Duchin and Brown stated that it is important for patients to choose the content which is of significance to them as it enabled them to manage symptoms better, and allowed for some control in their lives.

### Evaluation of printed material

When evaluating printed educational material Allensworth and Luther (1986) suggested that "readability, motivational appeal, legibility...and usability" are the most important factors to consider (p. 18). The concept of 'readability' is stated by Allensworth and Luther to include legibility, ease of reading due to interest value and ease of comprehension of the material. 'Legibility' refers to the ease and speed by which each word can be recognised and understood. This is dependent upon such factors as size and style of the type, the colour of ink and paper, and the paper texture. Bernier (1993), Fain (1994), Mathis (1989), and Redman (1988) confirmed that these factors are important.

There are, furthermore, other factors to consider when designing printed educational material for patients, and these are described below.

### Limitations affecting learning

Whilst factors have been described which give guidance in the designing of patient educational material, there are other important factors which require elaboration. These may broadly be classified as factors which 'limit the ability to learn'.

Limitations in the ability to acquire knowledge have been identified by several sources. These include visual impairments (Estey, Jeremy & Jones, 1990), and weak literacy skills (Doak, Doak & Root. 1985; Fain, 1994, and Redman, 1988). Redman reported that only

22% of patients attending a diabetic clinic in 1984 were able to comprehend written material at eighth grade level.

Meade, Diekmann and Thornhill (1992) examined 51 booklets from the American Cancer Society, and found them to have a mean reading level of grade 11.9. They reported that the median reading skill of most Americans is probably between grades 8 - 10. Fain (1994) confirmed these findings, and stated that 33% of Americans eighteen years of age and over are classified as at least marginally illiterate.

Bernier (1995), Redman (1988) and Allensworth and Luther (1986) described a tool for assessing the educational level necessary in order to understand particular text. The SMOG formula is a quick and easy method and requires no complex skills to complete.

The SMOG formula, devised by McLaughlin (cited in Doak, Doak & Root, 1985, p 37-39) is a tool used to assess readability. Based on this formula, 10 consecutive sentences at the beginning, the middle and end of the texts are examined and the number of words with three syllables in these sentences are counted. This computation then is used to convert the patient-education resources to the appropriate grade level. Examples of conversions include 13 - 20 polysyllabic words (ps) = 7th grade, 43 - 56 ps = 10th grade, 57 - 72 ps = 11th grade, and 73 - 90ps = 12th grade; a master's degree equates with 211 - 240 ps (Sarna & Ganley, 1995).

Other factors to be considered when evaluating and designing printed educational material include considerations of patient motivation, presence of high stress, and effects of medications (Mathis,

1989 and Redman, 1988). Fain (1994) further suggested that attention be given to the use of familiar, commonly used words, positive statements rather than negative ones, and variance of sentence length. He advised the use of the active rather than passive style and that important information be highlighted.

### Summary

This section of the literature review has established why the provision of information has positive effects upon health outcomes of patients. Methods of providing educational material for patients have been described, and factors which ought to be considered when designing printed educational material for patients have been summarised.

The following section of the review of literature will describe Lazarus and Folkman's (1984) theory on 'stress, appraisal and coping'. The conceptual model which has been developed from this theory has been used to guide the development and interpretation of this study.

### Section four - Conceptual framework

The conceptual framework which has guided the development of this study and the interpretation of the results is derived from Lazarus and Folkman's (1984) theory of stress appraisal and coping. This theory enables the described phenomenon to be interpreted in clinically meaningful terms and provides direction for future nursing practice.

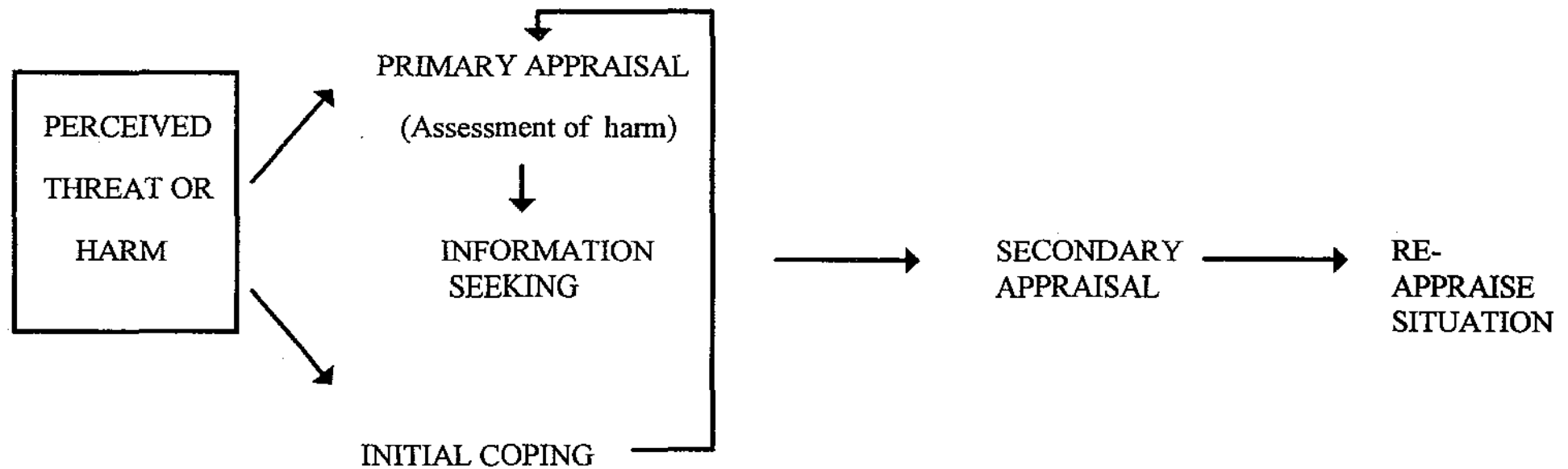
When faced with a potential threat or harm, (that is, stress) Lazarus and Folkman propose that cognitive and behavioural efforts are made by the person in order to cope with the situation. The harmful situation is primarily appraised, information is sought, and secondary appraisal takes place. Reappraisal of the entire situation then follows. This is diagrammatically represented in Figure 1. A more detailed explanation follows.

### Coping

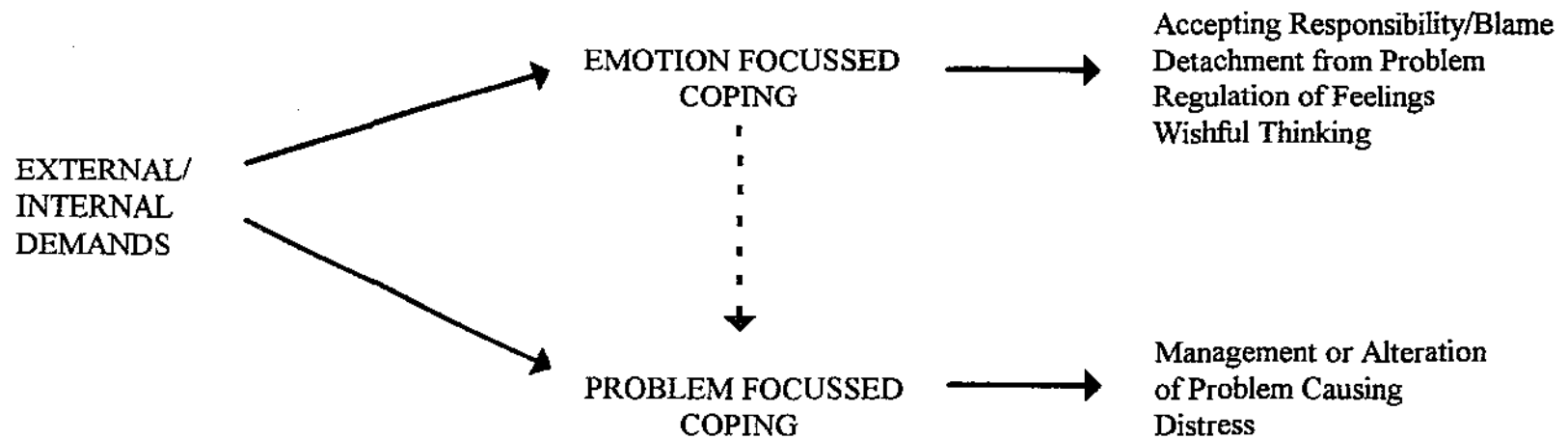
Coping is defined by Lazarus and Folkman (1984) as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Coping functions that are directed at managing or altering the problem causing distress are known as problem-focussed strategies, and those directed at regulating emotional response are known as emotion-focussed strategies (see Figure 2).

Gulick (1995) wrote that problem-focussed coping included efforts to confront the problem and the deliberate use of analytical approaches to problem solving. Emotion-focussed coping included detaching oneself from the problem (distancing), making efforts to regulate one's own feelings (self-control), acknowledging one's own role in the problem and attempting to put things right (accepting responsibility), wishful thinking and behavioural efforts to escape the problem (escape-avoidance).

**FIGURE 1. Conceptual framework - Lazarus & Folkman's (1984) theory of stress, appraisal and coping.**



**FIGURE 2. Conceptual framework - coping strategies (Lazarus & Folkman, 1984).**



Lazarus and Folkman consider that both problem-focussed coping and emotion-focussed coping can be used at any phase of a stressful encounter, and the initial use of emotion-focussed coping may facilitate the subsequent use of problem-focussed coping. Lazarus and Folkman further posit that seeking information is the most primary of the four modes of coping, the other three being direct action, inhibition of action, and cognitive processes (thinking and appraisal). Derdiarian (1989) stated that seeking information enables the individual to assess if the problem does exist, whether it is as potentially harmful as was initially appraised, and what options are available to change or alter the situation. Individuals assess the situation through appraising the nature of the event and the extent of the harm.

### Appraisal

A process of appraisal occurs simultaneously with the initial coping strategies (Derdiarian 1987a). Derdiarian wrote that "appraisal is a cognitive process through which an event is evaluated according to what has been harmed, what is at stake, and what resources are available to cope with the perceived actual or potential harm" (p. 108). Appraisal comprises three stages: primary appraisal, during which an assessment is made of the significance of the harm; secondary appraisal, or an assessment of the resources available to contend with the perceived threat or harm; and reappraisal of the harms, threats, resources, and choice of action and anticipated outcomes (Figure 1).

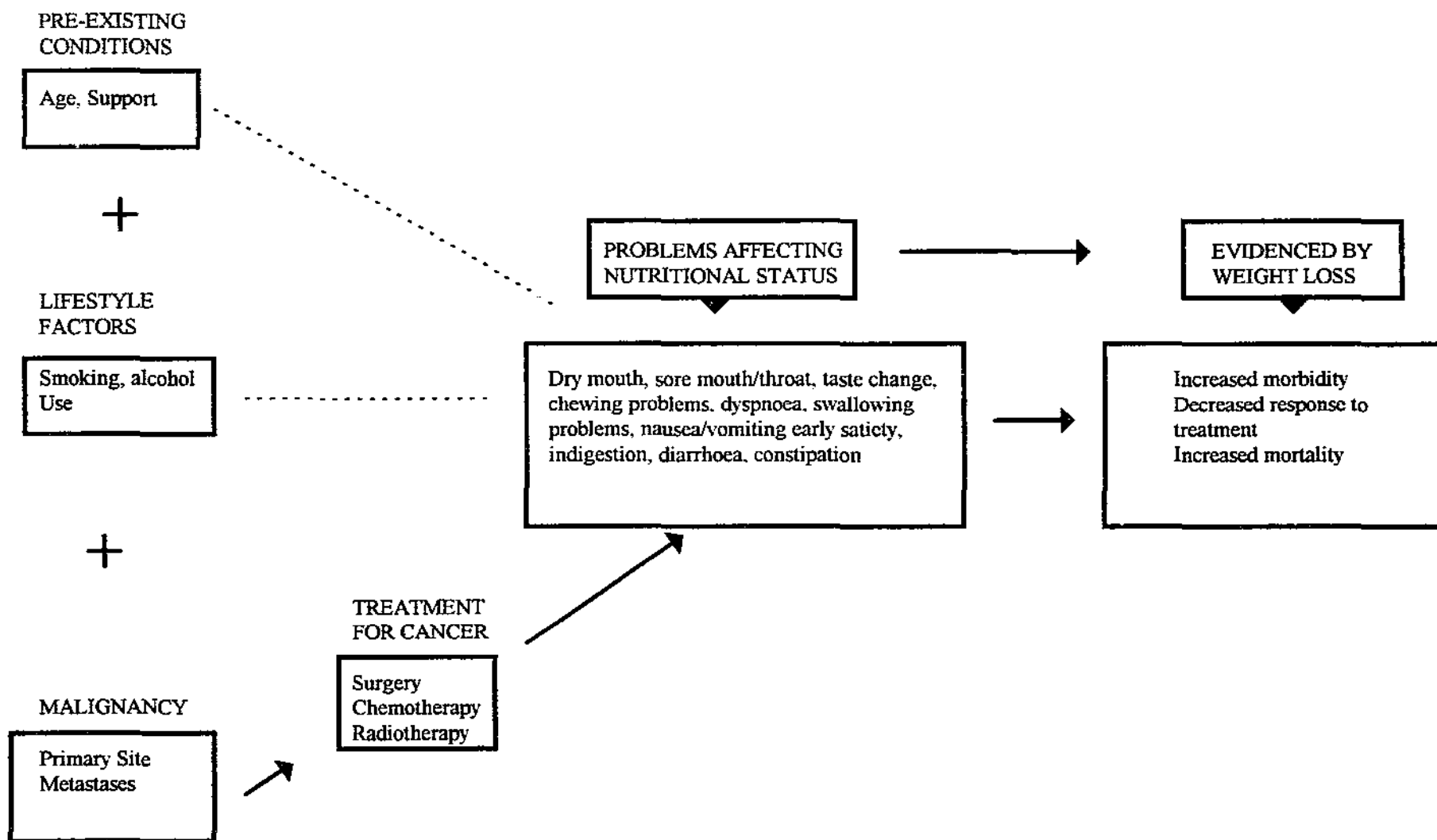
### Conceptual model

The conceptual model for this study integrates Lazarus and Folkman's (1984) theory of stress, appraisal and coping with the factors affecting nutritional status of cancer patients who are receiving chemotherapy and/or radiation therapy. A conceptual model of the impact of lifestyle factors, malignancy and treatment for malignancy on the nutritional status and weight of cancer patients who are receiving treatment for cancer is shown in Figure 3. A conceptual model of the process of primary - secondary - and re-appraisal which occur during the time of diagnosis and treatment for cancer is shown in Figure 4.

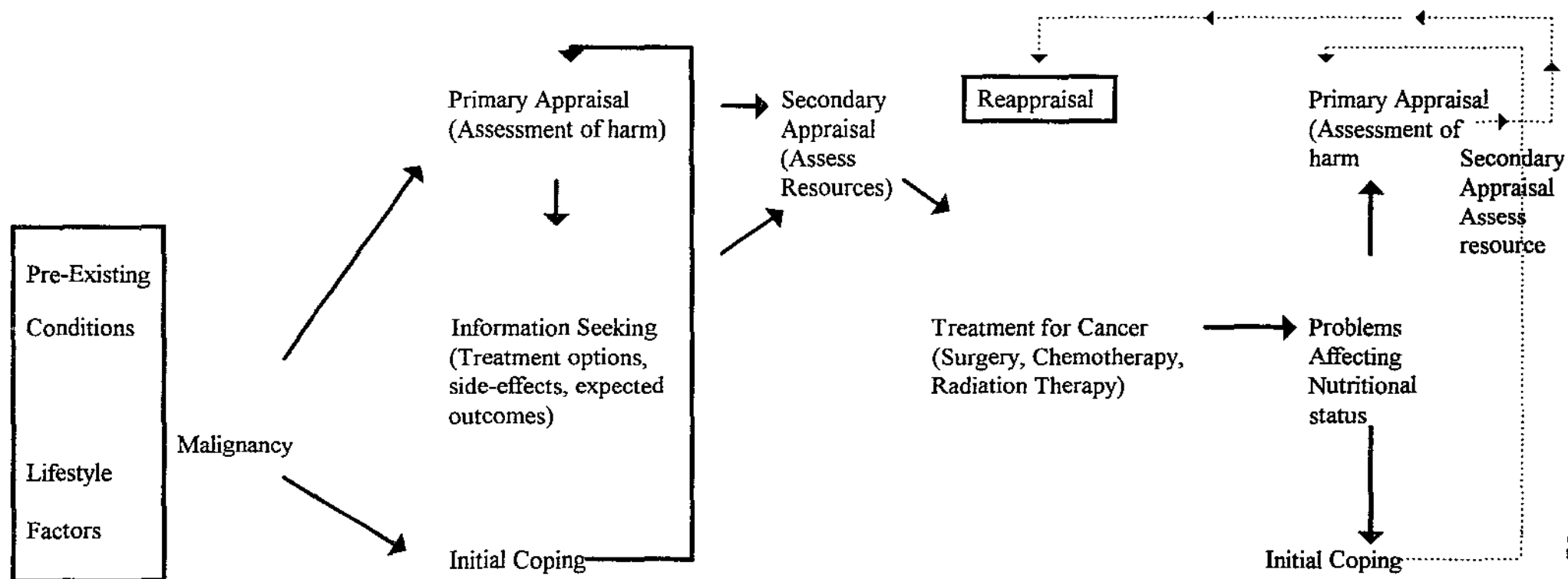
### Summary

The fourth section of this review of literature has focussed on Lazarus and Folkman's (1984) theory of stress, appraisal and coping which was used as a framework for the development of the conceptual model. The following chapter will describe the methods used in this study.

**FIGURE 3.** Conceptual model - impact of lifestyle factors, malignancy and treatment for malignancy on nutritional status and weight of cancer patients who are receiving chemotherapy and/or radiation therapy.



**FIGURE 4. Conceptual model - the process of primary, secondary and re-appraisal occurring during the time of diagnosis and treatment for cancer.**



## CHAPTER THREE

### Method

This Chapter will describe the method used to conduct this study, and outlines the sample, setting, research design, the development and validation of the instrument, the procedure for implementation and analysis of the data. Ethical considerations are discussed at the end of the chapter.

The purpose of this study was to describe the occurrence and severity of problems which potentially affected the nutritional status of patients receiving chemotherapy and/or radiation therapy for cancer. Furthermore, information was sought from these patients about the literature regarding nutrition which they had received, who had provided that information, and how helpful it had been. As well, data was sought on the use of alternative diets and medications. Subjects were asked how much alternative diets and medications had relieved their problems. Subjects were then asked what information would help them most, and from whom they wished that information to come.

#### Sample

A convenience sample of patients from Oncology ( $n = 29$ ), and Radiation Therapy ( $n = 26$ ) was drawn from the population of patients attending these outpatient clinics. Patients who were able to speak and understand English and were identified by nursing staff as having experienced or were experiencing problems related to the ingestion of food and/or fluids were invited to participate in the study. Additional requirements were that patients receiving chemotherapy were to have

completed at least one cycle of treatment, and those receiving radiation therapy to have had at least two weeks of treatment. The reasons for these latter requirements are that chemotherapy patients who have received one full cycle of treatment will have experienced the full range of toxic side-effects which the regimen may possibly produce. Patients receiving radiation therapy may take up to two weeks before experiencing the 'immediate acute response' from the treatment. Therefore, both groups of patients would have been exposed to a wide range of possible side effects of their treatment when approached and interviewed for this study.

### Setting

The setting for this study was the outpatient Oncology department and the outpatient Radiation Therapy department at a major metropolitan teaching hospital.

The Oncology department treats over 11,000 patients each year, of which 91% (10,110) are follow-up patients. There are 10 full-time equivalent Registered Nurses in this department whose duties are to take blood, administer chemotherapy and monitor patients as they are receive chemotherapy.

The Radiation Therapy department treats approximately 1,400 patients each year with an average of 100 patients on treatment at any one time. The overall patient attendance figure is approximately 26,330 per annum. There are two full time Clinical Nurses, one full time Registered Nurse, and one full time Enrolled Nurse in the department caring for patients on treatment and during the follow-up period. The

duties of these nurses include patient education regarding treatment and expected side-effects, assessment and treatment of radiation side-effects and support and counselling of patients and their care-givers.

Treatment for both groups of patients is usually on an outpatient basis with patients living at home or in hostel accommodation adjacent to the hospital provided by the Cancer Foundation of Western Australia. This latter accommodation specifically caters for patients from country areas.

### Research Design

A descriptive survey was chosen to determine the problems affecting nutritional status of patients receiving chemotherapy and radiation therapy. Information was sought about the severity of nutritional problems; the information about nutrition which is available and the perceived effectiveness of this information; use of alternative diets and medications; and the dietary informational needs of these patients. Additionally, participants were asked to describe their experiences in their own words. This broadened the perspective of the problems encountered, and further qualified the results of the study.

### Development and Validation of Instrument

A questionnaire (See Appendix E) was developed after reviewing the current literature and seeking content domain from expert practitioners in cancer treatment and care, including doctors, nurses and allied health workers. After formation of the original set of questions, content validity was sought from five experts who worked in the areas where the study was to take place. These experts included a Clinical

Nurse Specialist in oncology, a senior nurse with eight years experience in chemotherapy, two Registered Nurses who had each worked in radiation oncology for more than five years, and a dietitian who had worked in oncology for five years. This was in accordance with the criteria confirmed by Lynn (1986). Lynn established that determining and quantifying content validity is fundamental to the validation of any instrument. A two stage process was recommended by Lynn which incorporated rigorous instrument development practices and quantified the aspects of content validity. During the first stage, the content domain should be identified and items are generated to reflect the scope of the domain of a 'cognitive variable' or each of the dimensions of an 'affective variable'. Once formulated, the items are assembled in a usable, testable format. The second stage consists of presenting the instrument and domain or dimensions to a panel of experts, the size of which is an '*a priori*' decision, for their judgement of the items, using a 4-point ordinal rating scale.

In the current study, content validity was sought from five of the experts, and amendments made to the questionnaire from their comments as recommended by Lynn (1986). No item was identified by this group as having no validity. Items regarded as requiring modification by any of the five experts were altered in response to their recommendations, thus giving a content validity of 1.00. The questionnaire was further appraised by five lay persons to assure validity for readability and ambiguity. A pilot test of the questionnaire was undertaken by six subjects (10.9% of the final sample) from the

outpatient Oncology clinic, where patients were receiving Chemotherapy. Final adjustments were made to the questionnaire to ensure the flow of questions was smooth, and followed in a logical manner.

A visual analogue scale (VAS), with gradings from one to ten was shown to the subjects in order to identify the severity of the problems (See Appendix F). The value of 'zero' indicated 'no problem', and 'ten' indicated 'the worst problem you can imagine'. These scales are similar to linear analogue scales. The reliability of linear analogue scales was assessed by Revill, Robinson, Rosen and Hogg (1976). These investigators, using lines of varying length, assessed the reliability of this scale in evaluating pain. Significant correlations between each subject's initial score and that at 5 minutes ( $r = 0.994$ ) or 24 hours ( $r = 0.976$ ) were recorded. These writers concluded that there was a good correlation between repeated ratings of a recalled pain distant in time, and that a linear analogue seemed to be a suitable method of recording the patient's opinion of a severe pain.

In this study the VAS was used in a manner similar to the pain analogue scale. The inter-rater reliability in recording and interpreting the severity of the symptoms described by the subject was checked simultaneously during the pilot study by an independent observer ( $r = 0.98$ ).

## Procedures For Implementation

### Recruitment of chemotherapy subjects

Patients who met the criteria were selected after they had been seen by the doctor, had blood taken, or other tests, such as X-Rays, performed, and were either waiting to be called to receive chemotherapy, or were in the process of receiving it. Nursing staff in the clinic approached individual patients, and gave a brief overview of the purpose of the study. The nursing staff then informed the researcher if the patient was willing to participate. If the patient was agreeable, the researcher either took the patient to one of the small rooms vacant at the time within the clinic area, or sat beside the patient whilst they received their treatment. Some of this latter group sat in comfortable chairs, whilst others lay on beds in the outpatient rooms. Many who were in chairs or on beds had intravenous lines running during the course of the questionnaire. Others were waiting for the chemotherapy to arrive from the pharmacy. The prescription for chemotherapy is not written by the doctor until the results of blood tests are available, and there may be a waiting period of an hour or more for these patients. Often there was an accompanying person or persons with the patient, usually family members.

### Recruitment of radiation therapy subjects

Nursing staff identified patients who met the selection criteria. These patients were approached by the nursing staff, or the researcher herself, and the purpose of the study explained to them. If they were willing to participate, the patient and any accompanying person (if they

both wished) went to a small lounge room on the outpatient clinic, where the majority of interviews took place. Occasionally, there was no-one around where the patient was sitting, and they expressed the preference to stay where they were seated in the waiting room. At all times, the patient and their accompanying person was made aware that they could move to a private room if they so wished. Patients were assured that the researcher would inform the staff where they were if they did move, so there was no possibility of missing their appointment. Most of the patients were waiting to be called for treatment, some were waiting to see the doctor after their treatment, and a few were waiting for hospital transport to take them home.

#### Implementation of the questionnaire

Both groups of subjects underwent an identical method for completing the questionnaire. When the researcher met with the subjects, the study was described in full. In addition to the verbal information, the subject was given a copy of the Cover Letter (See Appendix G) which was then kept by the subject. Anonymity and freedom to withdraw from the study were assured. The patient was asked to sign the consent form (See Appendix H), and the questionnaire was read out by the researcher. The researcher then filled out the questionnaire for the patient. Time was allowed for rest during the questioning if the patient indicated this was required. Time taken to answer the questionnaire ranged from twenty minutes to approximately fifty minutes, depending on the involvement and information that the patient and often caregiver wished to give.

### Data Analysis

Data were analysed with the Statistical Package for the Social Sciences (Norusis, 1986), and used descriptive analytical techniques. Qualitative data was extracted, and the reporting of this enabled the descriptions used by the subjects themselves to provide a broadened insight into problems that had been described in quantitative methodological terms.

### Ethical Considerations

The study was reviewed and approved by the Ethics Committee at the teaching hospital where the study was conducted. The Medical Oncologist in the Oncology Department, and the Radiation Oncologist in the Radiation Therapy Department where the study was to be conducted were consulted about the research and their support was gained.

Informed consent was gained after each patient had been given a description of the study. All subjects were made aware of an identification code used by the researcher to allow identification of the group from which the patient came. The list of names from the consent forms was kept separate from the questionnaires in separate locked filing cabinets at two different office locations. Data will be stored in these secure locations for five years, and destroyed by shredding after that time.

Recognition was made of the fact that a study involving diet and nutrition may have caused some patients increased anxiety about their nutritional status. In order to address this potential problem, the

dietetics department at the hospital was approached, informed of the study, and requested to be available for extra support if required. Subjects were made aware of this service, but the need for extra support was not requested.

### Summary

This chapter has outlined the purpose and described the method used to conduct this study. The sample, setting, research design, the development and validation of the instrument, the procedure for implementation and analysis of the data have been detailed. Ethical considerations in conducting this study have been discussed. The following chapter will present the results of the study.

## CHAPTER FOUR

### Results

This chapter will report the results of this study. The sample will be described, together with the prevalence and severity of problems experienced by subjects. Subjects' use of tried remedies in addition to current dietary intake and changes in weight will be outlined. Two important lifestyle factors which affect nutritional status are alcohol and tobacco use, and the use of these by subjects will be described. A study of information sources made available or utilized by subjects will be outlined together with the perceived effectiveness of that information. The use of alternative or complementary diets and medications will be reviewed, and subjects' perceptions about information they require will be presented.

#### Description of sample

Fifty-five subjects ranged in age from 17 to 84 ( $M = 55.43$ ,  $SD = 15.37$ ). The majority (60%) were female. Subjects were receiving either chemotherapy or radiation therapy for their cancer. Two subjects were receiving both treatments concurrently. In addition, a number of subjects ( $n = 10$ ) who were receiving the one treatment when interviewed had received the other treatment in the past. Subjects receiving chemotherapy when interviewed were classified according to their original diagnosis. Subjects who were interviewed whilst receiving radiation therapy had their diagnosis classified according to the area being irradiated. Subjects who were receiving treatment for

systemic malignancies, such as Hodgkin's lymphoma, were classified as 'other'. Treatments and diagnoses are summarized in Table 1.

Table 1. Summary of Treatments.

N = 55

	Head and Neck	Chest and Thorax	Abdomen and Pelvis	Other
	Females = 3 Males = 4	Females = 15 Males = 3	Females = 11 Males = 10	Females = 4 Males = 5
TREATMENTS				
Chemotherapy	0	6	10	8
Radiation therapy	6	4	9	0
Both treatments	1	8	2	1

Forty-six of the subjects (83.6%) had a support person at home, and 37 (63.3%) stated that this person prepared some of the food for the subject. Those subjects who had support at home were provided with this by either spouse (67.3%), child (12.7%), or other relative (3.6%). Only one subject received regular meals from a community service. Twenty-seven subjects (49.1%) had been hospitalized within the previous two months. Demographic data including country of birth, educational level and usual occupation are summarized in Table 2. One subject declined to disclose demographic data.

Table 2. Summary of demographic data

(N = 54)

Country of Birth		Educational Level		Usual Occupation	
Australia	34 (62.96%)	Primary school	5 (9.26%)	Manager	7 (12.96%)
United Kingdom	13 (20.07%)	Year 10	20 (37.04%)	Professional worker	1 (1.85%)
Europe	4 (7.41%)	Year 12	8 (14.81%)	Para-professional	11 (20.37%)
Asia	2 (3.7%)	Apprenticeship/trade cert.	8 (14.81%)	Tradesperson	8 (14.81%)
Other	1 (1.85%)	Certificate/Diploma	10 (18.52%)	Clerk	4 (7.41%)
		Bachelor Degree	3 (5.56%)	Sales person	12 (22.22%)
				Machine operator	3 (5.56%)
				Labourer	5 (9.26%)
				Student	1 (1.85%)
				Home duties	2 (3.7%)

Problems affecting nutritional status which were encountered  
by subjects

Fifty-five subjects were interviewed. Not all problems were experienced by all subjects, and severity was rated by subjects on a range of 1 - 10 for those problems. Each symptom will be described in quantitative terms, with the subjects' own comments about each symptom added to provide further insight and appreciation of the problems encountered by the subjects. Frequencies and severity of nutritional problems are summarized in Table 3. Cross-tabulation of diagnoses/treatment areas, treatment and severity of symptoms is displayed in Table 4 in order to provide information about the severity of each symptom according to the treatment being received. In the presentation of these results, problems have been classified by the researcher as producing 'low', 'medium' and 'high' distress for subjects. Problems with a mean severity of 1 - 3.9 have been classified as causing 'lower' distress for subjects; those with a mean severity of 4 - 6.9 as 'moderate' distress, and those with a mean severity of 7 - 10 as 'high' distress. Problems encountered by subjects, together with a comparison of these results with previous studies follows.

Dry mouth

This problem was the most frequently described and was reported by 74.54% of the total sample. Subjects who were receiving treatment for cancer affecting the chest and thorax and subjects who were receiving treatment to the head and neck, experienced this problem to a moderate degree. Subjects who were or had received

Table 3. Frequencies and severity of problems

N = 55

Dry Mouth n = 41		Sore Mouth n = 29		Taste change n = 39		Chewing Difficulties n = 11		Swallowing Food n = 19		Drinking Fluids n = 16		Nausea n = 39	
M	4.51	M	4.91	M	4.64	M	5.46	M	5.79	M	5.91	M	5.60
S.D.	2.59	S.D.	3.05	S.D.	2.54	S.D.	2.86	S.D.	3.03	S.D.	3.16	S.D.	2.83
Range	1 - 10	Range	1 - 10	Range	1 - 10	Range	2 - 10	Range	1 - 10	Range	1 - 10	Range	2 - 10
Vomiting n = 25		Early Satiety n = 28		Indigestion n = 16		Abdominal Wind n = 26		Diarrhoea n = 26		Constipation n = 31			
M	6.60	M	4.80	M	5.56	M	5.8	M	6.37	M	6.08		
S.D.	3.20	S.D.	2.38	S.D.	2.80	S.D.	2.98	S.D.	3.15	S.D.	2.46		
Range	2 - 10	Range	1.5 - 9	Range	0.5 - 9	Range	1.5 - 10	Range	1.5 - 10	Range	2 - 10		

Table 4. Cross tabulation of diagnoses/treatment area, treatment, and severity of symptoms

DIAGNOSIS/ TREATMENT AREA	TREATMENT	SYMPTOM	
		Dry Mouth	Sore Mouth
Head & Neck	Chemotherapy	0	0
	Radiation therapy	M = 7.8 S.D. = 2.17 n = 5	M = 5.0 S.D. = 3.16 n = 5
	Both treatments	0	0
Chest & Thorax	Chemotherapy	M = 5.75 S.D. = 2.87 n = 4	M = 2.63 S.D. = 1.11 n = 4
		M = 6.75 S.D. = 3.59 n = 4	M = 8 S.D. = 2.83 n = 2
	Radiation therapy	M = 6.75 S.D. = 3.59 n = 4	M = 8 S.D. = 2.83 n = 2
	Both treatments	M = 3.5 S.D. = 2.5 n = 5	M = 5.83 S.D. = 3.87 n = 6
	Chemotherapy	M = 3.29 S.D. = 1.47 n = 7	M = 4.08 S.D. = 2.91 n = 6
		M = 2.79 S.D. = 0.95 n = 7	0
Abdomen & Pelvis	Radiation therapy	M = 2.79 S.D. = 0.95 n = 7	0
	Both treatments	M = 6.5 S.D. = 2.12 n = 2	M = 10 n = 1
	Both treatments	M = 6.5 S.D. = 2.12 n = 2	M = 10 n = 1
Other	Chemotherapy	M = 3.33 S.D. = 0.88 n = 6	M = 4.63 S.D. = 2.06 n = 4
		0	0
	Radiation therapy	0	0
	Both treatments	M = 3 n = 1	M = 3 n = 1

Continued/...

.../Continued. Table 4. Cross tabulation of diagnoses/treatment area, treatment and severity of symptoms

DIAGNOSIS/ TREATMENT AREA	TREATMENT	SYMPTOM	
		Taste Change	Chewing Problems
Head & Neck	Chemotherapy	0	0
	Radiation therapy	M = 6.4 S.D. = 3.78 n = 5	M = 6 S.D. = 3.54 n = 2
	Both treatments	0	0
Chest & Thorax	Chemotherapy	M = 3.9 S.D. = 2.68 n = 5	M = 4 n = 1
	Radiation therapy	M = 5.63 S.D. = 1.97 n = 4	M = 6.25 S.D. = 3.89 n = 2
	Both treatments	M = 2.92 S.D. = 1.02 n = 6	M = 6.83 S.D. = 3.88 n = 3
	Chemotherapy	M = 3.79 S.D. = 1.35 n = 7	M = 5 n = 1
	Radiation therapy	M = 6.25 S.D. = 5.3 n = 2	0
	Both treatments	M = 8.25 S.D. = 2.48 n = 2	0
Other	Chemotherapy	M = 3.86 S.D. = 1.31 n = 7	M = 3 S.D. = 1.41 n = 2
	Radiation therapy	0	0
	Both treatments	M = 7 n = 1	0

Continued/...

.../Continued. Table 4. Cross tabulation of diagnoses/treatment area, treatment and severity of symptoms

DIAGNOSIS/ TREATMENT AREA	TREATMENT	SYMPTOM	
		Swallowing Food	Drinking Fluids
Head & Neck	Chemotherapy	0	0
	Radiation therapy	M = 6.5 S.D. = 2.89 n = 4	M = 6.75 S.D. = 4.60 n = 2
	Both treatments	M = 6 n = 1	M = 4 n = 1
Chest & Thorax	Chemotherapy	M = 1.5 n = 1	M = 7 n = 1
	Radiation therapy	M = 6.5 S.D. = 3.54 n = 2	M = 4 n = 1
	Both treatments	M = 4.2 S.D. = 3.51 n = 5	M = 7.2 S.D. = 3.70 N = 5
Abdomen & Pelvis	Chemotherapy	0	0
	Radiation therapy	M = 7.5 n = 1	M = 1.5 n = 1
	Both treatments	M = 6.75 S.D. = 4.60 n = 2	M = 8.25 S.D. = 0.35 n = 2
Other	Chemotherapy	M = 5.75 S.D. = 1.06 n = 2	M = 2.5 S.D. = 0.71 n = 2
	Radiation therapy	0	0
	Both treatments	0	M = 7 n = 1

Continued/...

.../Continued. Table 4. Cross tabulation of diagnoses/treatment area, treatment and severity of symptoms

DIAGNOSIS/ TREATMENT AREA	TREATMENT	SYMPTOM	
		Nausea	Vomiting
Head & Neck	Chemotherapy	0	0
	Radiation therapy	M = 6.5 S.D. = 3.11 n = 4	M = 6.67 S.D. = 4.16 n = 3
	Both treatments	0	0
Chest & Thorax	Chemotherapy	M = 5.1 S.D. = 2.25 n = 5	M = 5.6 S.D. = 3.38 n = 5
		M = 8 S.D. = 1.73 n = 3	M = 8 S.D. = 1.4 n = 2
		M = 4.63 S.D. = 3.11 n = 8	M = 6.75 S.D. = 3.59 n = 4
	Radiation therapy	M = 5.1 S.D. = 2.25 n = 5	M = 5.6 S.D. = 3.38 n = 5
		M = 8 S.D. = 1.73 n = 3	M = 8 S.D. = 1.4 n = 2
		M = 4.63 S.D. = 3.11 n = 8	M = 6.75 S.D. = 3.59 n = 4
Abdomen & Pelvis	Chemotherapy	M = 6.07 S.D. = 3.81 n = 7	M = 9.33 S.D. = 1.15 n = 3
		M = 5.4 S.D. = 1.56 n = 5	M = 6.5 S.D. = 4.95 n = 2
		M = 8 n = 1	m = 8.5 n = 1
	Radiation therapy	M = 6.07 S.D. = 3.81 n = 7	M = 9.33 S.D. = 1.15 n = 3
		M = 5.4 S.D. = 1.56 n = 5	M = 6.5 S.D. = 4.95 n = 2
		M = 8 n = 1	m = 8.5 n = 1
Other	Chemotherapy	M = 3.7 S.D. = 1.61 n = 5	M = 3.63 S.D. = 2.29 n = 4
		0	0
		M = 10 n = 1	M = 10 N = 1
	Radiation therapy	0	0

Continued/...

.../Continued. Table 4. Cross tabulation of diagnoses/treatment area, treatment and severity of symptoms

DIAGNOSIS/ TREATMENT AREA	TREATMENT	SYMPTOM	
		Early Satiety	Indigestion
Head & Neck	Chemotherapy	0	0
	Radiation therapy	M = 7 S.D. = 2.83 n = 2	M = 3 n = 1
	Both treatments	M = 2 n = 1	0
Chest & Thorax	Chemotherapy	M = 5.38 S.D. = 2.29 n = 4	M = 6.67 S.D. = 2.31 n = 3
	Radiation therapy	M = 5.13 S.D. = 2.02 n = 4	M = 8.5 S.D. = 0.71 n = 2
	Both treatments	M = 4.5 S.D. = 3.5 n = 3	M = 2.0 S.D. = 1.08 n = 4
Abdomen & Pelvis	Chemotherapy	M = 7.25 S.D. = 1.19 n = 4	0
	Radiation therapy	M = 3.5 S.D. = 2.32 n = 5	0
	Both treatments	M = 3 n = 1	M = 9 n = 1
Other	Chemotherapy	M = 3.25 S.D. = 0.5 n = 4	M = 6.4 S.D. = 1.52 n = 5
	Radiation therapy	0	0
	Both treatments	0	0

Continued/...

.../Continued. Table 4. Cross tabulation of diagnoses/treatment area, treatment and severity of symptoms

DIAGNOSIS/ TREATMENT AREA	TREATMENT	SYMPTOM	
		Abdominal Wind	Diarrhoea
Head & Neck	Chemotherapy	0	0
	Radiation therapy	M = 3 n = 1	M = 3 n = 1
	Both treatments	0	0
Chest & Thorax	Chemotherapy	M = 6.0 S.D. = 3.67 n = 4	M = 9.13 S.D. = 1.18 n = 4
		M = 7.5 S.D. = 2.12 n = 2	M = 8 n = 1
		M = 2.5 S.D. = 0.5 n = 3	M = 5.75 S.D. = 6.01 n = 2
	Radiation therapy	M = 9.5 S.D. = 0.58 n = 4	M = 5.43 S.D. = 2.86 n = 7
		M = 5.5 S.D. = 3.18 n = 7	M = 6.14 S.D. = 2.95 n = 7
		0	M = 10 n = 1
Abdomen & Pelvis	Chemotherapy	M = 9.5 S.D. = 0.58 n = 4	M = 5.43 S.D. = 2.86 n = 7
	Radiation therapy	M = 5.5 S.D. = 3.18 n = 7	M = 6.14 S.D. = 2.95 n = 7
	Both treatments	0	M = 10 n = 1
Other	Chemotherapy	M = 5.5 S.D. = 1.29 n = 4	M = 5.17 S.D. = 4.25 n = 3
	Radiation therapy	0	0
	Both treatments	0	0

Continued/...

.../Continued. Table 4. Cross tabulation of diagnoses/treatment area, treatment and severity of symptoms

DIAGNOSIS/ TREATMENT AREA	TREATMENT	SYMPTOM
		Constipation
Head & Neck	Chemotherapy	0
	Radiation therapy	M = 5.0 S.D. = 2.83 n = 2
	Both treatments	0
Chest & Thorax	Chemotherapy	M = 8.5 S.D. = 0.89 n = 6
	Radiation therapy	M = 6.75 S.D. = 2.63 n = 4
	Both treatments	M = 3.0 S.D. = 1.0 n = 3
Abdomen & Pelvis	Chemotherapy	M = 5.9 S.D. = 3.13 n = 5
	Radiation therapy	M = 5.4 S.D. = 1.67 n = 5
	Both treatments	0
Other	Chemotherapy	M = 5.83 S.D. = 2.30 n = 6
	Radiation therapy	0
	Both treatments	0

both treatments to the abdomen and pelvis ( $n = 2$ ) also experienced this as a moderate problem.

Subjects in this study reported using two main methods to assist in coping with this problem. These were:

- (a) Increasing fluid intake by drinking extra, including having drinks beside the bed at night, (lemonade and black-currant juice were found to be useful) and sucking ice.
- (b) Strategies aimed at keeping their mouth clean by mouth washes. Salt and water and bi-carbonate of soda were most often used for this. One patient used an Asian dried plum and red ginger mixture to clean the coating from his tongue. Chewing gum was found by some subjects to be helpful, but not by others. One subject recommended using vaseline to help with dryness on lips.

#### Sore mouth and throat

Most subjects who complained of a sore mouth and throat had experienced mouth ulceration. 'Nilstat' drops were found to be very effective, and combined with salt water mouth washes, subjects stated that the problem was usually resolved. One subject eloquently described her problem when her mouth was badly ulcerated, and she rated her distress from this as '10'. This person stated her mouth was 'like a furnace', and she was even unable to suck ice - the edges of the chips "felt too sharp", she stated. The only intake this subject was able to manage during this time was to peel seedless grapes, freeze them, and suck them until they more or less dissolved in her mouth.

One subject described his teeth being sensitive, and he also experienced bleeding from his gums. Another subject who received radiation therapy to his sternum complained of severe oesophagitis during the treatment period. The severity rating given to this problem was '10'.

### Chewing difficulties

Six subjects who reported difficulties with chewing related the cause to a sore mouth. Additionally, three subjects reported that fatigue made chewing more difficult, and three subjects reported that a dry mouth made chewing more troublesome. The problems of pain, dyspnoea and loose dentures had impacted upon the chewing ability of one patient for each symptom.

A previously unreported symptom was found in this study. When describing chewing difficulties, three subjects receiving chemotherapy stated that their teeth felt sore, tender or loose. This sensation in the teeth was also described by one patient when describing a painful mouth or throat. When asked, subjects stated that food and drinks which were very hot or very cold made this problem worse.

### Taste change

Changes in taste were an equal second-most frequently reported problem for 70.90% of the total sample. An indication of the variety of strategies employed in an effort to address this problem is seen when reviewing the questionnaires. Subjects reported that fluids, such as water, tea and coffee tasted 'different' or 'awful'. Some subjects were unable to eat sweet foods, yet others had changed to a more sweet

dietary intake in an effort to overcome their problem. Some added more salt, another subject stated that 'everything' tasted salty. The changes experienced are summarized in Table 5.

Table 5. Taste changes experienced by subjects

N = 39

'Taste'	n (%)	'Taste'	n (%)
Tasteless	17 (44)	Metallic	12 (31)
Chemical	5 (13)	Sweet	2 (5)
Bitter	1 (3)	Salty	1 (3)
Sour	1 (3)	Other	5 (13)

Subjects who reported that everything 'tasted the same' tried various strategies to enhance their food by adding condiments such as salt, or sugar. Several subjects were unable to drink tea or coffee whilst on chemotherapy. One subject who reported that food and drinks had a 'chemical' taste, was receiving radiation therapy and had never received chemotherapy. One subject found that sucking mint-flavoured lollies, such as 'Tic-tacs' helpful, whilst another tried chewing parsley with some relief. Other comments included that "sweet food tasted bitter", "salads tasted acid" and "food and drinks were uninteresting - nothing helped overcome this".

### Swallowing food

Eleven subjects from the total sample (20%) who reported difficulties with swallowing food reported this to be due to a sore mouth or throat. More subjects receiving radiation therapy to the head and neck were affected with swallowing difficulties. Severity rating of this problem was greatest for one subject who was receiving radiation therapy. Other subjects who described this as a severe problem were those who were receiving radiation therapy to the abdomen and pelvis and also the chest and thorax.

Dry mouth and food being too dry were also reported by three subjects for each of these problems, and nausea was reported by two subjects. One subject who received radiation therapy to neck nodes was unable to swallow at all, and had her condition relieved through surgical dilatation. Two subjects reported that meat was the most difficult foodstuff to swallow, and one subject stated that bread rolled into a ball at the back of his throat and he was unable to swallow it with any ease.

### Drinking fluids

Eight subjects (14.54%) of the total sample who reported difficulty in drinking fluids did so because of sore mouth or throat. Other reasons for difficulty in swallowing fluids included nausea, (n = 2) dyspnoea, (n = 1); unable to easily swallow, (n = 3) and other reasons, (n = 3). Several subjects said it was not possible for them to drink hot or fizzy drinks, but warm drinks were tolerated well.

### Nausea

Reasons which were identified by subjects as instigating or exacerbating the nausea they experienced are summarized in Table 6. Several subjects who categorised the reason for nausea as 'other' were unable to identify one specific reason which brought on their nausea. One subject stated that the smell of alcohol wipes made her feel nauseated. Several subjects reported that their nausea abated after they had eaten something, and several subjects also reported that they felt more nauseated during the hot weather. One subject reported that pain brought on her nausea. The smell of meat cooking was found by one subject to be "intolerable".

Table 6. Reasons for nausea

N = 39

REASON	Food		Fluids	
	n	(%)	n	(%)
Treatment for cancer	20	(51)	8	(21)
Smell of food/fluids	18	(46)	1	(3)
Thought of food/fluids	12	(31)	1	(3)
Other	12	(31)	2	(5)
Sight of food/fluids	9	(23)	1	(3)
Taste of food/fluids	5	(13)	1	(3)
Anticipatory (prior to treatment)	4	(11)	1	(3)

### Vomiting

Reasons which subjects identified as instigating or exacerbating their vomiting are summarized in Table 7. This problem recorded the highest average severity score in subjects who experienced it. As was reported in the problem of nausea, many subjects were uncertain what caused them to vomit, with one subject stating that motion brought on her vomiting to a significant degree, but others unable to determine what had brought it about. These subjects were classified as 'other'.

Table 7 Reasons for vomiting.

N = 25

REASON	Food	Fluids
	n (%)	n (%)
Treatment for cancer	12 (46)	3 (12)
Smell	9 (36)	1 (4)
Other	7 (26)	3 (12)
Thought	6 (24)	1 (4)
Sight	6 (24)	0
Taste	2 (8)	1 (4)
Anticipatory (prior to treatment)	1 (4)	0

### Indigestion

Subjects who complained of this problem also related it to having to drink more to flush the chemotherapeutic drugs from their system. Most subjects found that diet modification, particularly cutting out fatty foods, and taking antacids, relieved the problem for them.

### Abdominal wind

Subjects who were receiving chemotherapy to the chest and thorax ( $n = 4$ ,  $M = 6$ ), and those who were receiving radiation therapy to the chest and thorax ( $n = 2$ ,  $M = 7.5$ ) found this to be a moderate to severe problem. However, subjects receiving chemotherapy to the abdomen and pelvis found this to be an even greater problem ( $n = 4$ ,  $M = 9.4$ ). Subjects associated the problem of abdominal wind with the need to drink more. Taking antacids helped some, but most just 'put up' with the problem.

### Diarrhoea

Diarrhoea had the second-highest average severity score in those subjects for whom it was a problem (see Table 3, page 66). One subject required hospitalisation as a result of diarrhoea, but the majority of subjects had the problem well controlled by medication provided by their specialist when interviewed.

### Constipation

This had the third-highest average severity score for those subjects who had this problem (see Table 3). Many of the subjects had the situation controlled by aperient use, and most had come to

understand their own specific needs and stated they knew when to adjust their medications.

#### Current diet

Nine of the total sample (16.36%) stated their current nutritional intake to be more now than it was before developing cancer, 17 (30.9 %) stated their intake to be the same, and 29 (52.72%) stated their intake to be less. Patients receiving radiation therapy were more likely to be eating less at the time of interview than patients receiving chemotherapy. Food supplements such as 'Ensure' were used by 17 (30.9%) of subjects, and 46 (83.63%) stated they had made changes to their diet since developing cancer.

#### Weight changes

Forty-six subjects (21 males and 25 females) experienced weight losses up to 26.2 kgs ( $M. = 5.03$ ,  $S.D. = 8.76$  [ $n = 54$ ]). This figure represents 85.18% of the sample. Nine (19.56%) of these 46 subjects lived alone, 33 (71.73%) prepared their own food, and 22 (47.82%) had been hospitalised during the previous two months. All subjects over 54 years of age ( $n = 33$ ) experienced weight loss.

#### Alcohol Use

Twenty four subjects (43.6%) stated they had previously used alcohol regularly, that is, daily or just about every day, (range 1 - 12 standard drinks,  $M. = 3.5$ ,  $S.D. = 3.39$ ). Six (11.9%) stated they were still taking alcohol regularly, with the range 0.5 and 24 standard drinks, ( $M. = 5.06$ ,  $S.D. = 7.87$ ). The 16 subjects who had taken alcohol

regularly in the past had stopped drinking between 0.08 - 21 years ago, ( $M = 4.6$ ,  $S.D. = 6.44$ ).

### Smoking

Twenty-eight subjects stated they had been regular smokers in the past, and smoked between 3 - 60 ( $M. = 19.5$ ,  $S.D. = 16.08$ ) cigarettes per day. Only 6 (10.9%) stated they still smoked, and at the time of the study, smoked 3 - 50 cigarettes per day ( $M. = 16.67$ ,  $S.D. = 16.98$ ). The 22 subjects who had smoked but now do not, gave up between 0.33 - 49 years ago ( $M = 8.5$ ,  $S.D. = 10.93$ ).

### Dietary advice

This section of the questionnaire investigated the sources of information which subjects had utilized. As well, the use of alternative diets and medications was studied. Subjects were asked to rate the effectiveness of their information sources, and the effectiveness of alternative diets and medications if they had been used. Finally, subjects were asked what information they would find most helpful to them, and from whom they would like that information. The results of this investigation follow.

Forty-six subjects (83.6%) had received some dietary advice about problems related to the intake of nutrients since their present illness. Eleven different origins were identified, and patients rated the helpfulness of the information received on a scale of 0 - 4, where '0' = not applicable, or the patient had not heard of the source; '1' =

extremely unhelpful; '2' = somewhat unhelpful; '3' = somewhat helpful and '4' = extremely helpful. Sources of information are summarized in Table 8.

Results of the investigation into the use of complementary diets and medications

During the administration of this questionnaire, subjects were found to be uncertain about the term 'complementary' therapy or diet, and most often thought of the diet or medication they may have been taking as 'alternative'. However, in keeping with the terminology set out by the Australian Nursing Federation (1993), it is apparent that these diets ought to be classified as 'complementary', as subjects were also receiving conventional medical treatment. The following results are reported as 'complementary' diets and medications in keeping with the suggested definition from the Australian Nursing Federation, despite the fact that subjects were asked about taking any 'alternative or complementary' diets and medications.

Twenty-one subjects (38.2%) stated they had heard of complementary diets, and seven subjects (12.7%) stated they had or were using complementary diets. The purpose of these diets was to 'cure cancer' (n = 1); to "help fight cancer" (n = 1); to "detoxify the body, thereby allowing the chemotherapy to work more effectively", (n = 3); "to support the immune system and enhance healing" (n = 2).

These diets had been suggested by various sources. See Table 9 for a summary of these sources. Subjects were asked to rate the effectiveness they perceived from their use of the complementary diet

Table 8. Sources of information on nutrition utilized by subjects

INFORMATION SOURCE	How helpful source has been					TOTAL
	N/a	Extremely unhelpful	Somewhat unhelpful	Somewhat helpful	Extremely helpful	
Booklet 'Food for Thought'	47	3	1	4	0	8
Booklet 'Understanding Nutrition'	51	0	0	2	2	4
Pamphlets or leaflets	34	0	2	12	7	21
Advice from nurses	32	0	0	12	11	23
Advice from doctors	46	0	0	8	1	9
Advice from dietitians	39	4	3	6	3	16
Advice from relatives and friends	32	5	3	11	4	23
Cancer Information Service	51	1	0	0	3	4
Cancer Support Group	50	1	0	2	2	5
Books and magazines	32	2	4	13	4	23
Alternative health care practitioners	47	0	1	3	4	8

N/a = Patient has not had information from this source.

Table 9. Information sources about complementary diets which had been accessed by subjects.

SOURCE	n	SOURCE	n
Other	2	Friend	1
Homoeopathist	1	Family member	1
Read about it	1	Cancer Support Society	1
Faith healer	0	Naturopath	0
Iridologist	0		

using a linear analogue scale graded from 1 to 5, '1' being extremely unhelpful, '2' - somewhat unhelpful, '3' - no difference, '4' - somewhat helpful, and '5' extremely helpful. Results ranged from 3.0 - 5.0, ( $M = 4.43$ ,  $S.D. = 0.73$ ).

Nine (16.4%) subjects stated they had taken medications or vitamins supplied by an complementary health care practitioner. Subjects rated the effectiveness of these medications from 3.00 - 5.00, ( $M = 4.14$ ,  $S.D. = 0.84$ ).

Twelve (21.8%) subjects had taken vitamins or other medications bought 'over-the-counter'. Effectiveness of these was rated from 2.0 - 5.00, ( $M = 3.78$ ,  $S.D. 1.06$ ).

Subjects taking complementary diets, medications or over-the-counter drugs were asked if they felt they could tell their doctor or nurse about taking these. Table 10 displays these results.

Table 10. Number of subjects who felt comfortable to tell doctor or nurse about taking complementary modality.

MODALITY	YES	NO
	n	n
Over-the-counter medications	7	5
Medications	2	7
Diet	2	5

#### Subject's perceptions of their need for information

Subjects were asked what information would have been helpful to assist them manage their dietary problems better whilst receiving treatment. Results are summarized in Table 11. Eighteen (32.7%) wished there were more support services available to them about diet and nutrition. Table 12 summarises from where subjects preferred that information to come.

Table 11. Nutritional information which would have assisted subjects  
N = 55

TYPE OF INFORMATION	n
More recipes for food	25
Denial by subjects of any problems	23
More recipes for drinks	19
How to increase nutritional value in food/drinks	18
How to make food and drinks more appealing	9
Other information	2

TABLE 12. Sources from which subjects would prefer nutritional  
advice  
N = 18

SOURCE	n
Dietitians	7
Doesn't matter	7
Nurses	3
Doctors	3
Cancer Foundation of Western Australia	0
Alternative health care practitioners	0
Other	0

Qualitative comments which were sought gave further insight into the perceptions of subjects into their problems. These included such remarks as, "People need to know the effect of the food they eat", "There is plenty of information around if you want it", "information ought to be offered", "doctors never talk about nutrition", "doctors need to know that this (nutrition) is a very real problem". I never worried about what I ate in the past, and it's no different now" (this patient had lost 26 kilograms during the period of his treatment), "I need information about the sort of food I can cook for myself, as well as for my family" (meaning that this subject wanted recipes which were suitable for herself, and for it to be suitable also for her family). One subject perceived that information was always available when it was requested, but this subject had lost 18 kilograms during her treatment.

Advice which subjects felt would have helped them, or they consider would help others included: recipes for snacks that can be nibbled whenever one felt hungry; simple, tasty (savoury) recipes; recipes that used the same basic ingredients but served them differently, for example, french toast and omelette or scrambled eggs on toast; dietary advice for people who have other medical conditions such as diabetes; advice appropriate for requirements when experiencing nausea, diarrhoea, or constipation; information on "types of food combination, so that you aren't given just a list of food that you can or cannot eat".

One subject who was staying at the hostel for country patients had advice for the authorities who conduct that establishment. This

included: have local suppliers of foodstuffs call with fruit and vegetables for sale; have laminated coloured charts and pictures, similar to those at child care centres, with dietary advice such as "Try this today" - and a simple recipe attached which could be changed daily.

Two subjects who came from ethnic backgrounds suggested that advice booklets should be written in other languages, and contain recipes that would be normally used in that culture, but which met their special dietary requirements.

Yet another two subjects who had been interviewed whilst receiving chemotherapy advised that there needed to be specialist advice available, and suggested that a support group be set up which chemotherapy patients could attend if they wished, and where talks were given on diets, recipes and nutrition. These subjects suggested that after people attended chemotherapy they could stay and meet for this information-sharing and support session.

One subject who had experienced problems with nausea and who had found cooking meals difficult because the thought, smell and taste of food was very nausea-inducing, stated that a service similar to 'Meals on Wheels', but which met her dietary requirements would have helped her situation.

### Summary

This chapter has reported the results of this study. The sample was described, together with the prevalence and severity of problems which were experienced by subjects. Subjects' use of tried remedies was reported. In addition, current dietary intake and changes in weight

were described. Additionally, the use of cigarette and alcohol was outlined. The use of alternative or complementary diets and medications was reviewed together with the effectiveness of those modalities, and subjects' perceptions about information they require was stated. A study of information sources made available or utilized by subjects was described, together with the perceived effectiveness of that information. Qualitative information gave further understanding of the problems which were experienced, and advice which those subjects gave was stated.

The overwhelming evidence gained from these results is that patients in general do not understand the importance of maintaining an adequate diet during treatment for their cancer. Whilst some of the sample had sought information, it was frequently not forthcoming, and moreover, often was not appropriate to the circumstances of the individual. Consequently, those who had sought information were often disillusioned and angry that their needs were not recognised nor met. Of even greater concern is the evidence that indicates that healthcare professionals often do not give sufficient attention to the dietary intake of their patients during the treatment of cancer.

Chapter five will discuss these findings from the context of the literature and the theoretical framework, and outline the implications of these results for healthcare practitioners.

## CHAPTER FIVE

### Discussion and conclusion

The purpose of this study was to investigate the occurrence and severity of problems affecting the nutritional intake of cancer patients receiving treatment, to ascertain where patients had received information about nutrition and to establish how helpful that information had been. Whilst a certain amount of information about nutritional problems has been reported in the literature, few studies have sought information from cancer patients themselves about problems which affected their nutritional status. In order to more effectively determine the occurrence and severity of these problems, it was necessary to seek information from patients regarding these facts. Information sources which were available and/or utilised by patients were determined, and the usefulness of the information which had been obtained was assessed, using patients' own ratings. In order to design educational material which effectively meets the nutritional needs of patients in these circumstances, patients in the study were asked what information they considered would have helped them and other patients receiving treatment for cancer.

This chapter will examine the results of the study utilising the conceptual model developed for the study and presented in detail in chapter two. This conceptual model considered the impact of lifestyle factors, malignancy, and treatment for malignancy, on the nutritional status and weight of cancer patients who are receiving chemotherapy and radiation therapy (See Figure 3, p. 51). Comparisons are made

with previous literature, and conclusions regarding the problems and need for information of this sample group are made. The results of the study are viewed in light of the conceptual framework, and information needs are identified. Nutritional education methods for cancer patients are reviewed, and recommendations made. The limitations of the study are discussed.

### Pre-existing conditions

#### Age

It has been stated previously in this thesis that cancer is a common disease in aging populations (Cancer Foundation of Western Australia, (n.d.). Seventeen (31%) of patients in this study were aged 65 years or over. Thirty-two (58%) patients were aged over 54 years, and all of this group of patients experienced weight loss. Waltman et al. (1991, who investigated differences in nutritional status, pressure ulcers and incidence of mortality in two groups of elderly subjects, found that subjects who were elderly and who had cancer were twice as likely to develop morbid conditions. Mion et al. (1994) stated that nutritional problems are evident in elderly patients even before serious illnesses such as cancer, are diagnosed. This study has verified that weight loss and increased age do have a positive relationship. It is therefore essential that the special needs of elderly patients must be considered when planning nutritional support and education for elderly patients who are receiving treatment for cancer.

### Social support

This study did not reveal relationships between social support and the outcome measure of weight loss as was also found by Lindsey et al.(1994). However, as was indicated by Lindsey et al. this is an area in which there is conflicting evidence. These authors write that there is widespread evidence in the literature of linkages between social support and health outcomes. When social support is not available to individuals who are experiencing stressful situations, it was proposed by Lindsey et al. that more effective coping strategies would need to be employed, especially amongst the aged who possibly have decreased support resources. In view of this, it is recommended that further research is undertaken which investigates more thoroughly the various dimensions of social support which patients receiving treatment for cancer have available to them. This study only investigated whether there was someone living with the subject, and whether that person helped with cooking and preparation of food. The relationship between support networks, and health outcomes is more complex than just someone who helps with the meals, and research is needed that includes such factors as; the number of persons in the network, the functional support provided by those individuals, and the total support network available to the patient.

The sharing of food and the coming together of family members at mealtimes is a socially bonding time for the family as a unit. Should one of the members of that unit be unable to join in the ritualistic sharing of the meal, the impact is felt by the entire family. Whilst this

was not a domain for investigation in this study, spousal or caregiver's anxiety is an observed phenomenon in clinical practice when a family member is unable to eat the food which has been prepared and this is an area which warrants investigation.

### Lifestyle factors

#### Smoking

Patients in this study who had smoked in the past ( $n = 28$ ) were more likely to have experienced weight loss, whilst those still smoking were no more likely to have lost weight than those who were not smoking. However, given the small number of current smokers ( $n = 6$ ) it was not possible to conduct more inferential statistical analyses into these phenomena. As a result, it is not possible to make objective comparisons with other studies about the influence of smoking on the prevalence and severity of treatment-related side effects. However, the study by Brown (1993) into the relationships of gender, age, usual weight and tobacco use with cancer-related weight loss and food intake, found that current smoking and weight loss were positively related. In view of this it is recommended that further research be conducted to investigate the relationship of past smoking and current smoking with the severity of side effects from treatment.

#### Alcohol use

In this study, there was no difference in the percentages of patients who lost weight and who had or had not used alcohol in the past. The small number of patients who were still using alcohol

regularly (n = 6) all lost weight, but as in the case of smoking, the small number of patients makes it impossible to perform further analyses or draw conclusions.

Previous studies which have investigated alcohol use in relation to nutritional status have similarly experienced problems because of small sample size, (for example Sarna et al. 1993). However, Sarna et al. concluded there was a strong correlation between nausea and grams of alcohol consumed. As with the the other 'lifestyle' factor, smoking, it is recommended that further research be undertaken into the relationship between past and present alcohol use, and severity of symptoms which are experienced by patients who are receiving treatment for cancer.

### Malignancy

#### Primary and metastatic sites, and treatment for cancer

In this study, subjects who were receiving chemotherapy were categorised according to their original diagnosis; subjects receiving radiation therapy were categorised according to the area being irradiated, and those receiving treatment for systemic malignancy, such as Hodgkin's lymphoma, were classified as 'other'. As was already reported, the site of the primary tumour growth as well as metastatic sites may directly affect nutritional status through the pressure of tumour growth upon adjacent intestinal organs, or malignant growths within those organs themselves (Holmes, 1991b). Subjects receiving radiation therapy are at risk for problems affecting nutrition because,

when giving radiation therapy, it is not always possible to protect organs which are close to the malignant site. As well, subjects who receive chemotherapy are at risk because of the lack of selectivity of the chemotherapeutic agents.

In this study, 95% (n = 21) of subjects receiving treatment for abdominal or pelvic cancer, 78% (n = 9) of subjects being treated for non-site specific tumours, such as lymphomas, 61% (n = 18) of subjects receiving treatment for cancer affecting the chest or thorax, and all subjects receiving treatment for head and neck cancer (n = 7) experienced weight loss. Reports of weight changes for patients who receive treatment for abdominal or pelvic cancer, patients receiving treatment for non-specific tumour sites, were not elicited in the literature. Wilson et al. (1991) found that 82% of radiation therapy patients receiving treatment to the head and neck lost weight. However, studies by Brown (1993), Larson et al. (1993) and Sarna et al. (1993) of patients receiving treatment for lung cancer produced more varied results, and it is not possible to determine what has contributed to the weight change in those subjects when considering the site of the tumour and the effect of treatment for that tumour. The assumption is made that the treatment, more than the site, is the reason for weight changes.

### Surgery

One of the recognised factors which may impinge upon nutritional status in cancer patients is the carry-over effect of recent hospitalisation (Hunter & Janes, 1989 and Smale et al., 1981). Whilst

this study did not specifically enquire whether the subjects had undergone surgery, they were asked whether they had been hospitalised within the previous two months. Almost 50% had been hospitalised within this time frame, and more than three quarters of that sub-group lost weight. However, over 85% of subjects who had not been hospitalised during that period also lost weight. Whilst the literature states that malnutrition is common in hospitalised patients (Elmore et al., 1994; Loogman, 1992 and Torosian & Daly, 1986), weight loss, which is indicative of malnutrition, was not found to be significantly different between patients who had been, and those who had not been, hospitalised within the previous two months.

#### Problems affecting nutritional status

A prediction chart for specific problems has been created according to the means of the severity ratings of problems which had been experienced by subjects in this study. This prediction chart can be used as an 'alert' to the possibility that problems may arise, and gives an indication of the severity of problems which may arise as a result of treatment (See Table 13). Levels of severity of problems have been classified in the following manner. As was previously stated, problems with a mean severity of 1 - 3.9 have been classified as causing low (L) distress for subjects; those with a mean severity of 4 - 6.9 as moderate (M) distress, and those with a mean severity of 7 - 10 as high (H) distress. Where there is no predictive letter this does not necessarily indicate there is no likelihood of this problem affecting nutritional status, only that this study did not include a subject which fitted the

Table 13. Prediction chart for specific problems according to treatment and treatment sites.

		Dry Mouth	Sore Mouth	Taste Change	Chewing Problems	Swallowing Problems	Drinking Problems	Nausea	Vomiting	Early Satiety	Indigestion	Abdominal Wind	Diarrhoea	Constipation
HEAD & NECK	Chemotherapy													
	Radiotherapy	H	M	M	M	M	M	M	M	H	L	L	L	M
	Both treatments					M	M			L				
CHEST & THORAX	Chemotherapy	M	L	L	M	L	H	M	M	M	M	M	H	H
	Radiotherapy	M	H	M	M	M	M	H	H	M	H	H	H	M
	Both treatments	L	M	L	M	M	H	M	M	M	L	L	M	L
ABDOMEN & PELVIS	Chemotherapy	L	M	L	M			M	H	H		H	M	M
	Radiotherapy	L		M		H	L	M	M	L		M	M	M
	Both treatments	M	H	H		M	H	H	H	L	H		H	
OTHER	Chemotherapy	L	L	L	L	M	L	L	L	L	M	M	M	M
	Radiotherapy													
	Both treatments	L	M	H			H	H	H					

'H' = high severity rating; 'M' = moderate severity rating; 'L' = low severity rating

category owing to the small sample size. Consequently, this prediction chart may not be generalizable.

When reporting results from this study, the categories described from the prediction chart will be used to describe the severity of problems which were described by subjects. The following describes the results from this study compared with reports in the literature about specific side effects.

#### Dry mouth

The qualitative study by Wilson et al. (1991) of 11 subjects receiving radiation therapy to the head and neck, reported more than 45% of subjects experienced this problem. In this study, 'dry mouth' affected almost 75% of the subjects, with high severity ratings being reported by subjects receiving radiation therapy to the head and neck. Both groups of subjects who received chemotherapy or radiation therapy to the chest and thorax in this study reported moderate severity ratings. Subjects who received both treatments reported low severity ratings from a dry mouth.

#### Sore mouth and throat

This study revealed somewhat similar incidence and severity ratings for sore mouth and throat when compared with other studies, for example, Wilson et al. (1991) and King et al. (1985). The patients studied by King et al., who were receiving radiation therapy to the chest and thorax described the severity of their sore mouths as a "little bad" to "moderately bad". The incidence of sore mouth was less in this present study, being just under 53%, compared with 72% of the

subjects studied by King et al. Subjects in this study receiving radiation therapy to the chest and thorax and both treatments to the abdomen and pelvis described a high severity rating from this problem.

### Taste change

There is much written in the literature about alteration in taste, for example, Bernstein, 1986; Bruera & MacDonald, 1988; Grindel et al., 1989; Huldij et al., 1986; Larson et al., 1993 and Wilson et al., 1991. However, no studies were found which measured the distress caused by taste change. The results of this study indicate that alteration in taste is a problem of moderate severity affecting over 70% of the patients. Given the vivid descriptions given by subjects both in this study, and those reported in the literature, this appears to be a problem which demands some specific attention when planning nutritional support and education. Further research is indicated in this area to assess the effect that taste change has upon nutritional status. Studies which are exploratory, or descriptive would be of significance, as would studies which measured the differences in taste appreciation when different interventions, such as when sweet, sour, bitter or salty/savoury food or fluids, were tested. One subject in this study described the use of chinese medicine to remove the coating on his tongue, and improve his taste. Testing of remedies such as these warrant further investigation particularly given the paucity of treatments available.

### Chewing difficulties

Subjects who were receiving radiation therapy to the head and neck, chemotherapy, radiation therapy or both treatments to chest and thorax, and chemotherapy for abdominal and pelvic cancer all reported a moderate severity rating for chewing difficulties. Literature does not reveal any reports of this problem in relation to treatment areas other than the head and neck, nor has severity been elicited in any of the literature. In this study 11 (20%) of all subjects experienced chewing problems. Of the subjects who were receiving radiation therapy or combined therapies to the head and neck ( $n = 7$ ) only two, (29%) experienced chewing problems. Despite the small sample size of this study, it corresponds with the percentage of 27% found by Wilson et al. (1991) with a sample of eleven subjects.

This study revealed only one subject who was receiving radiation therapy to the head and neck and who stated that pain was the reason he was unable to chew with ease. This contrasts with evidence in the literature which identified pain as a common problem which caused concern for radiation therapy patients, especially in patients receiving treatment for cancer of the head or neck (Bruera & MacDonald, 1988; Wilson et al., 1991 and Holmes, 1991a), although it would be reasonable to expect that pain would cause serious problems for this group of patients. Further investigation into this aspect of nutritional problems is warranted.

Whilst various studies document fatigue as a common problem for cancer patients receiving treatment, (Brown 1993; Irvine et al.

1994), it was not found to be the cause of not being able to chew easily in these subjects; only 3 (5.45%) stating that tiredness or fatigue was the reason they experienced this problem. Studies which examine the effect of fatigue in cancer patients, would be advised to include a section which focussed on the impact of fatigue upon nutritional status.

### Dyspnoea

It is reasonable to expect that, as has been stated by Larson et al. (1993), shortness of breath is a problem especially for patients who have lung cancer, and it would therefore interfere with that patient's ability to eat. Although this problem is often observed in clinical practice, only one subject in this study identified it as being a problem which affected his/her ability to eat.

### Swallowing food

In this study, 19 (35%) patients experienced the swallowing of food to be a problem, with severity ratings ranging from low, for subjects receiving chemotherapy for non specific tumours, to high severity ratings for subjects receiving radiation therapy to the abdomen and pelvis. In the study by Wilson et al. (1991) which studied radiation therapy patients who were receiving treatment for head/neck cancer, 64% (n = 11) experienced problems with swallowing. Severity scores were not investigated in that study. In this study, the two subjects (10.5% of this sub-group) who were receiving radiation therapy to the head and neck experienced swallowing problems and graded the severity of this problem as moderate.

A problem in drinking fluids was not explicitly referred to in the literature. This study found that almost 30% of the sample experienced this as a problem, especially in patients receiving either treatment to the head /neck, and chest/thorax, and was graded by those subjects as either a moderate or high rating. As well, subjects receiving both treatments to the abdomen and pelvis, as well as both treatments for non-specific tumours, all reported high severity ratings for swallowing fluids. This problem needs to be given consideration when providing dietary advice. As well as providing adequate nutritional content, it may be important to consider the fluid thickness. In accordance with common clinical practice, patients who have swallowing problems are fed thickened fluids, and an investigation into whether the provision of thickened fluids would be helpful to cancer patients who are experiencing a sore mouth or throat is suggested.

#### Nausea and vomiting

The problem of nausea is well recognised in the literature, and certainly it was corroborated in this study. Nausea had a moderate severity rating and moreover, it affected more than 70% of patients. Patients receiving radiation therapy to the head and neck, as well as to the chest and thorax experienced nausea more severely than did any other patients. However, chemotherapy patients who were receiving treatment for cancer of the abdomen and pelvis reported a higher severity rating. This study confirms that nausea, together with vomiting, which affected a lesser number of patients, but had a higher mean severity, continue to be significant causes of distress in subjects

receiving treatment, and as a consequence, impact negatively on nutritional status.

It was observed during the data collection period in this study that many subjects receiving chemotherapy had very bad memories of their nausea and vomiting problems, although these symptoms were controlled when interviewed. In view of the ongoing improvements in medications for nausea which now control this problem, it would be reasonable to assume that this problem should rarely arise through anticipating the occurrence of this side effect, particularly as the chemotherapeutic agents which commonly cause nausea and vomiting are well known.

#### Early satiety

This was a problem for just over one half of the subjects in this study, thereby affirming statements made by Bruera and MacDonald (1988) that this as a common problem affecting nutritional intake. In this study, eleven (61%) subjects receiving treatment for cancer of the chest/thorax rated this as a moderate problem.

#### Indigestion

A total of nine subjects (50%) receiving either chemotherapy or radiation therapy for chest and thorax cancer experienced severity ratings of moderate or high proportions, respectively. Additionally, subjects who were receiving combined treatments to the abdomen and pelvis rated this as high. This result is similar to the study by Soffer et al. (1994) into the effect of pre-treatment naproxen versus a placebo as a protection against radiation-induced oesophagitis, and who found that

indigestion was a problem for over half of the radiotherapy subjects they investigated. Subjects receiving chemotherapy in this study identified that the reason for experiencing this problem was the requirement to drink more water. Health team members need to inform these patients that any fluid will flush the chemotherapy from their system not necessarily just water.

#### Abdominal wind

This was a problem which had not been evidenced in the literature. However, in this study some patients expressed surprise at being questioned about this, and revealed that it had indeed been a problem for them. A little less than 50% of patients experienced this problem with abdominal wind. Patients receiving both chemotherapy and radiation therapy to the chest and thorax, and abdomen and pelvis, all experienced this problem, and rated it as having a moderate or high severity. As was the case for indigestion, subjects again reported the reason they experienced this problem to be due to having to drink more water, and this fallacy obviously needs to be addressed by the healthcare team.

#### Diarrhoea

This study found diarrhoea to be a severe problem for subjects receiving both radiotherapy and chemotherapy to the chest and thorax, and a moderate or severe problem for all groups receiving treatment to the abdomen and pelvis. This confirms the findings of King et al. (1985), in relation to patients receiving radiation therapy to the abdomen and pelvis, who described their problem as "a little, to

moderately bad" However, in the study by King et al. subjects who received radiation therapy to the chest and thorax did not report diarrhoea.

Because this is a common problem associated with certain chemotherapeutic agents, as well as for subjects receiving radiation therapy which may affect the intestine, educational material which is written for patients receiving treatment needs to warn of the possibility of this occurrence, and advise about dietary intake during this time.

### Constipation

Chemotherapy subjects receiving treatment for cancer of the chest and thorax identified constipation as a severe problem. As well, subjects receiving radiotherapy to the head, neck, chest, thorax, abdomen and pelvis reported this to be a moderate problem. The results of this study indicated that more than 56% of patients experienced a problem from constipation. This figure is higher than previous studies which found the occurrence of constipation to be less than 30% of the chemotherapy subjects, and just over 40% over the radiotherapy subjects studied by Holmes (1991a). Slightly more than 45% of subjects in this study who had experienced constipation problems were taking medications such as morphine for pain relief. As has been previously mentioned, subjects stated they had the problem of constipation controlled when interviewed, and considered they were able to monitor their aperient use appropriately.

### Weight loss

The incidence of weight loss has been well established as the primary indicator of a deterioration in nutritional status (Brown, 1993; Bruera & MacDonald, 1988; D'Agostino, 1989; Dewys et al., 1980; Elmore et al., 1994; Larson et al., 1993; Lindsey et al., 1994; Sarna et al., 1993 and Wilson et al., 1991).

In this study, more than 85% of the sample experienced weight loss, with losses up to more than 26 kilograms being encountered. These results confirm evidence of previous research conducted by Wilson et al. (1991) of weight changes in patients receiving radiation therapy to head and neck, with similar percentages of patients incurring weight loss. However, in this study the weight losses were much more severe, as those patients studied by Wilson et al. incurred weight losses up to only 16.4 kilograms. Weight loss was more likely to be experienced by males than females (95% of males, compared with 73% of females). When current intake compared with previous intake was analysed, 96% who were "eating less", 82% who were eating "the same" and 44% of subjects who stated they were "eating more" experienced weight loss. More than 80% of subjects stated they had made dietary changes since their diagnosis of cancer, and more than 80% of that number had lost weight. Moreover, less than 30% of all subjects were taking any form of nourishing fluid, such as Ensure, and 88% of those had also lost weight.

Larson et al. (1993) investigated problems in older and middle-aged patients receiving radiation treatment for lung cancer and found

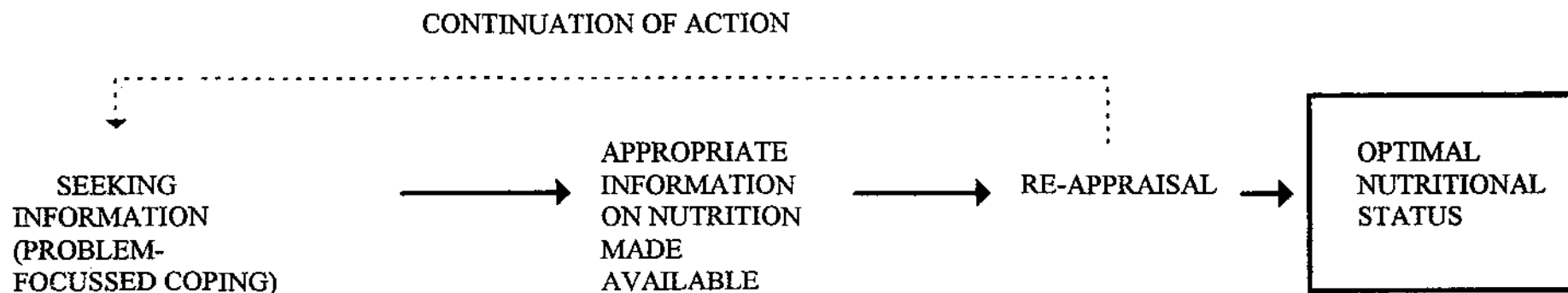
that the group of patients who were under 65 years lost weight, whereas those who were over 65 gained a small amount of weight. In this study all patients over 54 years of age experienced weight loss ( $n = 32$ ).

### Conceptual framework

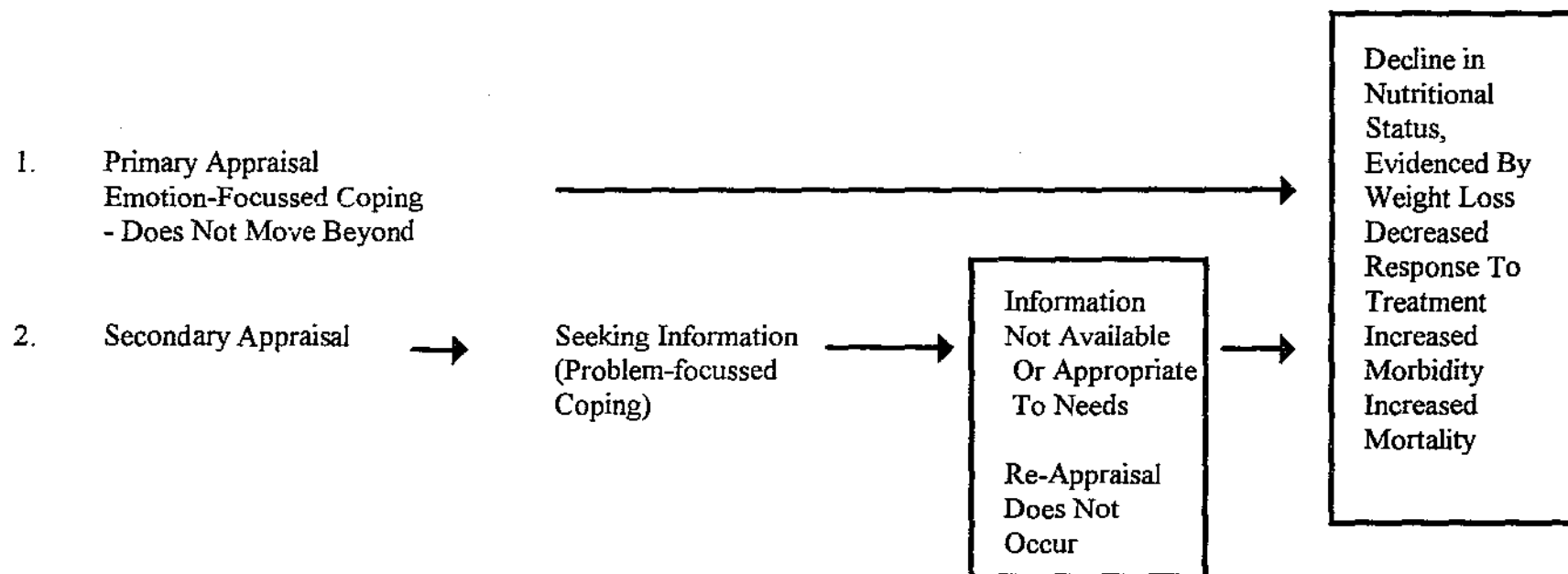
The conceptual framework for this study was provided by Lazarus and Folkman's (1984) theory of stress, appraisal and coping (See Figure 1, p. 47). This theory posits that information-seeking is fundamental to all methods of coping with situations which are appraised as potentially harmful or otherwise threatening. A conceptual framework which diagrammatically represents the coping strategies described by Lazarus and Folkman is depicted in Figure 2, p. 48. A conceptual model of the process of primary, secondary and re-appraisal which occurs during the time of diagnosis and treatment for cancer is depicted in Figure 4 (See p. 52).

The diagnosis and treatment for cancer is usually perceived as a threatening event, and patients are required to address problems as best they can in order to cope with that threat. When problem-focussed coping efforts by the individual to receive information are successful, optimised nutritional outcomes eventuate (See Figure 5). However, when purely emotion-focussed coping strategies are used, or information-seeking efforts are not successful, nutritional status is compromised, and weight loss, with associated morbidity and mortality occurs (See Figure 6). This study will now be interpreted in the light of these conceptual models.

**FIGURE 5. Conceptual model - the use of problem-focussed coping upon the nutritional status of patients who are receiving chemotherapy and/or radiation therapy for cancer.**



**FIGURE 6. Conceptual model - emotion-focussed coping or unsuccessful problem-focussed coping upon nutritional status of cancer patients who are receiving chemotherapy and/or radiation therapy.**



### Problem-focussed coping

It was stated by Lazarus and Folkman (1984) that coping is a cognitive effort to manage or change situations which are perceived as harmful or threatening. Utilising the conceptual model to interpret the effect of problem-focussed coping upon the nutritional status of these subjects, it is shown that seeking information and having appropriate information made available results in the achievement of an optimal nutritional status. It is suggested that subjects who sought alternative forms of diets and medications exhibited this problem-focussed coping. Information that had previously been provided had not been regarded by those subjects as helpful, and they turned to a source which literature has reported as being more supportive, allowed for more patient participation, and was regarded as being more holistic in approach (Downer et al., 1994).

### Emotion-focussed coping, or unsuccessful problem-focussed coping

In this study, there were subjects who had stated that there was plenty of information around if they had wanted it, but no-one had promoted it or shown it to them. This is evidence of emotion-focussed coping, where detachment from the problem is evidence of this occurrence. Moreover, more than half the subjects considered they had 'no real problems'. This lack of recognition, or denial, by these subjects of their need for information is evidence of a lack of information which could have been provided at the outset of their treatment, and had it been provided, would have enabled them to better cope with side effects. When considering this within the framework of Lazarus and

Folkman's theory it is suggested that the lack of information that would have been of assistance to these subjects has resulted in them choosing the only option available to them, that being, accepting the situation as it was, and hoping for the best.

In Australian society today weight loss is regarded as being desirable. Thin, lean bodies are promoted as being 'ideal', and should a few extra kilograms being gained over the 'desirable' weight it is regarded as a reason to diet in order to remove that excess. However, patients who have cancer are in a completely different situation. As was established, weight loss is the most widely accepted indicator of nutritional depletion. Cancer patients who lose weight are at risk for decreased response to treatment, increased incidence of morbidity, and decreased survival time. Therefore, it is important that healthcare team members as well as patients who are receiving treatment are knowledgeable about this.

Ideally, the importance of nutrition and weight maintenance needs recognition by all members of the health-care team, and information that they provide should be consistent and regularly reinforced by all team members. In this study, the perception of many subjects, with a few exceptions, was that nutrition was not a matter which concerned the doctors, nurses and dietitians very much, unless physical problems amenable to medication were encountered. The more slowly developing problems, such as weight loss, were essentially ignored. This may represent an emotion-focussed coping style which the health-care team were using, and could be well worth investigation.

It is possible that members of the health-care team used this form of coping because they did not perceive that they could make any difference to weight outcomes, or that their own lack of knowledge about the effects of weight loss impeded their recognition of this problem.

Subjects who had used complementary or alternative forms of diets or medications were reluctant to tell their doctor or, to a lesser extent, their nurse about this. Comments such as "I know from past experience that my doctor would disapprove", and "the doctors never say anything about nutrition, and it doesn't seem important to them" had the effect of patients with-holding this information. Australian doctors need to be aware of the increasing use in many overseas countries of the use of alternative and complementary forms of therapy by patients and healthcare professionals , and be more enquiring as to why this has occurred. As a result, healthcare practices in this country may alter to meet the needs that patients themselves are identifying.

#### Education needs of patients receiving treatment for cancer

This study has produced outstanding evidence that nutritional needs of patients who are receiving treatment for cancer are not being accurately addressed. The Cancer Foundation of Western Australia had recognised that information was needed by patients who were receiving treatment, and sought data which would be helpful when designing educational material. In addition to providing data about nutritional problems, and the severity of those problems, this study reviewed methods of providing educational material to patients.

Printed educational material was recognised as a cost effective method of providing this information. Issues which need consideration when designing printed educational material include: appropriately-graded reading level, style of writing, sentence length, use of space, style of paper, font style, and font size.

However, other methods of providing education to patients receiving treatment for cancer were identified in the results of this study. Two subjects suggested that a 'specialist' nurse should instigate an education programme. This supports the view expressed by Luker and Caress (1989) who suggested that 'generalist' nurses did not make good educators, and the responsibility of educating patients should be in the domain of 'specialist' nurses.

Another suggestion from subjects in this study was to conduct support group meetings at clinics, and focus on providing information about nutrition, food and cooking, and also include demonstrations on food preparation. As well, the need for special information has been identified as being required by certain groups, such as the elderly, those living alone, those staying in the hostel accommodation which was provided by the hospital for country patients, and possibly also those who have a history of past and/or present smoking and/or alcohol use.

Team members need to be cognisant of the fact that the provision of information on nutrition which is consistent will result in greatly improved outcomes in nutritional status. When the whole team gives consistent information, that information serves to reinforce what has already been stated. However, when information is strongly

promoted by only one section of a team, for example the nursing staff, the impact is lessened and not as effective as if it would be if everyone in the team was promoting the same message.

#### Recommendations for future research

Recommendations for future research have been identified throughout this paper. These include; investigations into the effects of social support, and past and/or present use of alcohol and smoking upon severity of symptoms which are experienced by patients who receive treatment for cancer. Exploratory studies which focus on fatigue, and taste changes in patients receiving treatment for cancer would be significant. An investigation into the special problems experienced by patients receiving radiation therapy to the head and neck, such as chewing and pain, together with examining the effects that different thicknesses of fluids are given to these patients maybe useful in understanding these patients' problems more fully. The testing of alternative diets and remedies upon the severity of symptoms is an also area which warrants investigation, as does a study of the coping styles of health care workers.

#### Limitations of study

The results of this study cannot be generalised to other patient populations principally because of the small sample size. Also, some patients may not have informed the nurses about their problems. Moreover, comparisons could not be made between the two patient groups. Some subjects receiving chemotherapy had been having treatment for several years and were receiving it palliatively to control

the rate of growth of the cancer. Others were receiving aggressive and curative treatment. Some subjects receiving radiation therapy were having it palliatively also (for example, to relieve pain from bone metastases). Others, also, were receiving treatment with the intention to cure. These differences within the groups were not differentiated in this study.

### Conclusion

This study reported on problems affecting the nutritional status of cancer patients who were receiving chemotherapy and/or radiation therapy. The problems encountered by subjects had most usually been described in the literature, although there had been few studies which had sought a severity rating for those problems. However, this study highlighted several areas which were not recognised in the literature. The taboo subject of abdominal wind had not been reported other than in medical texts and almost 50% of subjects had found this to be a significant problem. Taste changes were experienced by more than 70% of subjects, and whilst this has been recognised previously, this study indicated that it is a significant problem for subjects and one which requires further attention. The problem of swallowing fluids has also been previously recognised, but the reports of the subjects this study indicate that this is an area which needs requires further attention and investigation.

Weight loss is regarded as the principal marker of nutritional status, and weight loss was experienced by the majority of subjects:

stark evidence of nutritional depletion. Denial of subjects of the existence of any real problems indicated their lack of knowledge and awareness of the significance of this problem.

Sources utilised by subjects had, for the most part, not provided sufficient information to assist the patients. Health team members need to promote and reinforce nutrition as an important part of the overall treatment, as it has been established that outcomes of medical intervention are bound to nutritional status.

Methods of increasing nutritional knowledge for patients receiving treatment for cancer have been described. This report may provide the Cancer Foundation of Western Australia with meaningful information to assist in preparing educational material for these patients.

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## **APPENDIX A**

### **Definition of terms**

## APPENDIX A

### Definition of Terms

#### Anorexia

Lack or loss of appetite, resulting in the inability to eat. The condition may result from various physical or psychological causes, and frequently accompanies treatment for cancer.

#### *Candida albicans*

A fungal organism which is normally found in the mouth of healthy individuals. However, in certain conditions, such as during a severe systemic illnesses, or whilst receiving antibiotics which interfere with normal flora in the body, this fungus may cause superficial infection, especially throughout the intestinal tract. The mouth and oral cavity are usually affected during these episodes.

#### Carcinogenic

Having the ability to cause cancer.

#### Cytotoxic

A pharmacological compound which has the ability to damage or destroy tissue cells, including cancer cells.

#### Effusion

The escape of body fluid into a body cavity, often into lungs, the peritoneal cavity or into the sac surrounding the heart.

#### Emesis

Vomiting

**Enteral nutrition**

The provision of nutrients via the gastro-intestinal tract when the patient is unable to chew, swallow, but can digest and absorb nutrients. This may be achieved through the use of a tube which is directed into the stomach through the nose, or through a tube which is surgically placed into the stomach or duodenum, and exits through the abdominal wall.

**Dysphagia**

Difficulty in swallowing food, commonly associated with obstructive disorders such as cancer, or muscular disorders of the oesophagus brought about by nerve damage.

**Dyspnoea**

Shortness of breath or a difficulty in breathing.

**Gastroscope**

An instrument which is used to examine the interior of the stomach. (Gastroscopic)

**Hodgkin's disease (lymphoma)**

A malignant disease of the lymph tissue, affecting lymph nodes throughout the body.

**Intra-jejunal**

Via the jejunum - meaning the administration of nutrients into the intestine when patients are unable to chew, swallow or ingest nutrition through the mouth.

**Ionising radiation**

High energy electromagnetic waves, such as X-rays, which are able to cause damage to both normal and malignant cells.

**Jejunum**

The middle part of the small intestine.

**Lymphangitis**

An inflammation of the lymphatic vessels.

**Lymphoma**

A growth of lymphoid tissue which is usually malignant.

**Metastasis**

The process by which cancer spreads throughout the body.

(Plural - 'metastases').

**Morbidity**

An illness or diseased condition. In this study, the term is associated with the occurrence of such illnesses which have occurred as a result of treatment or hospitalisation.

**Mucositis**

Inflammation of the oral cavity and mucous membranes.

Typically the tongue, gums, palate, and insides of the cheeks appear 'beef red' (See stomatitis).

**Parenteral**

The provision of nutrition by methods other than through the digestive system. This may include central venous access or intravenous routes.

### Peritoneal

The potential space between the two layers of the peritoneum. This is often a site where effusions may collect.

### Satiety

The feeling of being full after eating. 'Early satiety' is the term given to the feeling of fullness which occurs after eating only a very small amount of food.

### Stomatitis

Any inflammatory condition of the mouth. It may result from infection by bacteria, viruses, or fungi, from exposure to certain chemicals or drugs, from vitamin deficiency, or from a systemic inflammatory disease. As stomatitis progresses, the oral cavity may become ulcerated and painful and may bleed. Patients most likely to develop stomatitis are those who have had certain chemotherapeutic agents, radiation to the head and neck, and long-term steroid therapy. Stomatitis is associated with a high incidence of oral *Candida albicans* infections, sometimes seen as ulcerated white or yellow patches on the oral mucosa.

## **APPENDIX B**

### **Chemotherapy**

## APPENDIX B

### Chemotherapy

Chemotherapy is a systemic method of treatment of cancer.

This systemic approach is useful for treating systemic cancers, such as leukemia, lymphoma and Hodgkin's disease, which cannot be managed effectively with surgery or radiotherapy. As well, chemotherapy provides a means of treating early, clinically undetectable metastasis.

Chemotherapy may be given either with the intention to totally eradicate tumour cells and to cure, or otherwise it may be given for palliation, when the intended effect is to reduce tumour size, extend life, and improve quality of life (Brown & Hogan, 1990).

Chemotherapy is the use of cytotoxic agents to destroy cancer cells. These agents generally function in the same manner as ionising radiation, they do not kill the cancer cells directly but instead impair their ability to replicate. Chemotherapeutic agents are often used in combination with radiation treatments for their combined effect. A cytotoxic agent, for example, may be used to render a tumour cell more sensitive to the effects of radiation. Thus, by making the cancer cell more vulnerable to the effects of radiation, the cancer can be controlled with smaller doses of radiation than would be possible with radiation alone (Holmes, 1986).

Despite curative surgery and/or radiation therapy, many patients experience a recurrence of their malignant disease. It is thought that the recurrence is due to clinically undetectable metastasis which

developed before the primary tumour was detected. Thus chemotherapy is often used as an adjuvant to surgery and radiation therapy.

Chemotherapeutic agents may be administered in several ways. These are oral, intravenous, subcutaneous and intramuscular routes. The intravenous route is the most common route, and was the method by which all patients in this study received their treatment.

**APPENDIX C**  
**Radiation Therapy**

## APPENDIX C

### Radiation therapy

Radiation therapy (or radiotherapy as it is also known) is a well established and effective method of treating malignant disease, used alone or with other therapies. However, particularly when directed at any portion of the gastrointestinal tract, it may have marked effects on an individual's ability to ingest, digest or absorb nutrients.

Radiation therapy relies on the use of ionising radiation to destroy cancer cells by inhibiting their ability to divide and proliferate. As radiation passes through a tissue some of its energy is transferred to the cells of that tissue, causing ionisation. This results in chemical changes which lead to cellular damage and/or death. The target of radiation-induced damage is deoxyribonucleic acid (DNA), thus the greatest effects are seen during the mitosis (cell division) phase of the cell cycle, when the amount of DNA is doubled.

Damage may be partial, resulting in mutation so that the daughter cells produce abnormal cells, or total, resulting in cell death or an inability to undergo mitosis. Normal cells can repair partial damage but cancer cells lack this ability. Both normal and malignant cells which are totally damaged cannot repair themselves. Cell death occurs in similar ways to normal and malignant cells:

- Immediate death occurs when DNA molecules are irreversibly damaged and cells die within two hours of exposure. This effect is responsible for the immediate side-effects of radiotherapy

- Delayed death follows mutation of the DNA molecule. Limited functions continue until the mitosis phase is reached, when the cell is unable to divide. This may occur within 24 hours or be delayed for day, weeks or months, depending on the generation time of affected cells. Long-term side-effects result from this mechanism
- 'Natural death'. Radiation exposure results in formation of giant (Sterile) cells which continue to function although they cannot divide. Such cells degenerate slowly, dying a 'natural' death.

As generation times vary between the different cell types, some cells are more vulnerable to radiation than others; cells dividing rapidly are more sensitive than those dividing slowly. Thus the greater the number of cells in active replication the greater the cytotoxic effect of radiation. This, combined with the knowledge that poorly differentiated and immature malignant cells are particularly radiosensitive, is used to good effect when the radiation dose necessary to eradicate a tumour is calculated.

It is usually necessary to divide the calculated tumour lethal dose into smaller doses (fractionation) to prevent acute radiation exposure. The fractionated dose is normally delivered over a period ranging from two - eight weeks; this allows both normal and cancer cells to attempt repair between consecutive treatments. As normal cells have a greater capacity for repair than cancer cells, and can also achieve this more rapidly and effectively, fractionation helps to minimise damage to normal tissue.

Damage is also reduced by careful control of the size of the treatment field so that it includes only the tumour and the smallest possible amount of normal tissue. The dose of radiation is carefully calculated so that it is high enough to destroy malignant cells while having minimal effects on the normal tissue present in the treatment field. However, despite these precautions, some damage to normal tissues is almost inevitable; this will occur only if the tissue is included in the treatment field.

Tissue response to such damage is usually described in terms of three categories:

1. Acute responses occurring within the first six months of exposure; these may be immediate or delayed. When normal tissues are affected they are described as the side-effects of radiotherapy.
2. Subacute response occurring six - twelve months after exposure.
3. Late or chronic responses occurring one - five years (or longer) after exposure.

Tissues undergoing rapid or active replication, such as those of the gastrointestinal (GI) tract are the most sensitive to irradiation so that areas of an otherwise normal GI tract are vulnerable and responsible for many unpleasant side-effects. Many of the GI side-effects may significantly affect the patient's nutritional status by limiting his desire or ability to eat, or through induced alterations in his absorptive capacity.

**APPENDIX D**  
**A.N.F. Policy Statement**

# Australian Nursing Federation

## POLICY STATEMENT

The Australian Nursing Federation, 373-375 St. Georges Rd., North Fitzroy  
Vic. Australia 3068  
Tel. (03) 482 2722

### COMPLEMENTARY AND ALTERNATIVE THERAPIES

*Adopted by Federal Executive December 1993*

ANF adopts the policy that:

The Federation supports the use by nurses of complementary and alternative therapies which are deemed appropriate by the client, the client's condition/situation and the nurse.

These forms of therapy may be provided to clients across the life-span, within the continuum of wellness/illness, and for psychological, physiological and physical comfort and wellbeing.

ANF believes that the nurse provides a service which embraces the concept of total health care. The nurse has knowledge and an ability to function in a role which encompasses:

1. the promotion of health and the prevention of disease.
2. the restoration and maintenance of optimal health and health education.
3. empowering individuals to take responsibility for their own health care needs.
4. the assistance of individuals to achieve a dignified death.

The effectiveness of these roles may be enhanced through the use of complementary and alternative therapies, in addition to, or in place of, orthodox medicine (see attached glossary)

### CONSENT

Consent (verbal or implied) should be obtained before any intervention or therapy is given by a nurse. An explanation must be given to the patient/client before any therapy is commenced. If the patient/client is unable to consent, then relatives may give consent.

The nurse should also check the appropriate institutional policies relating to client consent. Consent/refusal may need to be documented in the case notes. The entry must be signed and dated by the nurse giving the therapy.

Consent requirements apply to all nursing interventions or therapies whether labelled orthodox, complementary or alternative.

## SPECIALISED FIELDS

The therapies which have come to be known as complementary or alternative to orthodox medicine vary greatly in complexity, and thus in the education and training required to undertake them safely and effectively.

Some therapies are within the nurse's scope of education and some require additional appropriate preparation. The use of dietary adjustment as an alternative to laxatives; the use of gentle body massage complementary to pain control medication; or the use of warm drinks and music as an alternative to sedation medication are examples of choices of therapy within the nurse's scope of educational preparation.

Specialised techniques and modalities such as acupuncture, acupressure, aromatherapy, hypnotherapy, and reflexology should only be practised to the extent of the nurse's specific education in the field.

\*\*\*\*\*

ANF Policies are reviewed regularly. Comments from members are welcome.
--

## GLOSSARY

Orthodox medicine:	the aggregate of diagnostic and therapeutic concepts and practices which attempt to adhere to modern scientific principles.
Complementary medicine/therapies:	diagnostic and therapeutic practices which are separate from, and in contrast to, conventional scientific medicine. The term complementary infers use of these therapies in conjunction with orthodox medicine.
Alternative medicine/therapies:	diagnostic and therapeutic practices which are separate from, and in contrast to, conventional scientific medicine. The term alternative infers use of these therapies rather than orthodox medicine.
Acupuncture:	Techniques whereby needles are inserted into specific sites on the body surface to improve the flow of energy around the body, thus preventing and treating disease and disability.
Acupressure:	Techniques whereby finger massage is applied to these same points, combined, in shiatzu, with general massage.
Massage:	Any technique in which pressure and touch are applied to the body to stimulate the circulation and relax the tissues.
Hypnotherapy:	The use of hypnotic suggestion to treat illness and destructive behavioural patterns.
Reflexology:	Massage of areas of the feet to treat organ systems with which they are in developmental relationship.
Aromatherapy:	A sense therapy using specific patterns of sense impressions to heal imbalances and assist in cure; with oils, vapours and essences as the therapeutic agents.
Reference:	The Handbook of Complementary Medicine: Stephen Fulder. Oxford University Press. Second Edition. 1988.

## **APPENDIX E**

### **Questionnaire**

# **Nutritional Problems and Information Needs Of Cancer Patients Who Are Receiving Radiation Therapy and Chemotherapy**

(Office Use Only)

Questionnaire No.

Primary Diagnosis. ....

Area of Treatment (if appropriate). ....

Regime/Week of Treatment (if appropriate).....

**Section A**

Q. 1. Are you?	Male	1
	Female	2

Q. 2. How old are you?	<input type="text"/>	<input type="text"/>
------------------------	----------------------	----------------------

Q. 3. Have you been a patient in hospital within the past two months?	YES	1
	NO	2

Q. 4. Do you have a supportive person at home helping to look after you?	YES	1
	NO	2

Q. 5. If 'YES', please state relationship.	Spouse	1
	Child/Children	2
	Other relative	3
	Friend	4
	Neighbour	5

Q. 6. Does this person prepare any food for you?	YES	1
	NO	2

Q. 7. Do you prepare any of your own food?	YES	1
	NO	2

Q. 8. Do you get food from any other source or person?	YES	1
	NO	2

Comment.....

.....

Section B

The questions in this section relate to different problems that some cancer patients **MAY** experience

Answers to these questions will be taken from the visual analogue scale, as indicated by you. All the questions are in relation to the **Present Illness** you are experiencing, **and you will be reminded of this at regular intervals during the answering of the questions.**

Q. 1 Have you had a **dry** mouth or throat since your present illness? ☐

Comment.....

.....

Q. 2 Have you had a **sore** mouth or throat? ☐

Comment.....

.....

Q. 3 (a) Have you experienced **a change in taste** of food and/or drinks? ☐

- (b) Overall, what do food/drinks taste like?
- |                 |   |
|-----------------|---|
| No taste        | 1 |
| Metallic        | 2 |
| Salty           | 3 |
| Sweet           | 4 |
| Sour            | 5 |
| Bitter          | 6 |
| Chemical        | 7 |
| Other (specify) | 8 |

Comment.....

.....

Q. 4 (a) Do you have a problem chewing food since your present illness?



(b) Are you able to tell me if any of the following are reasons for this problem?

(Circle as many as necessary)

- |                     |   |
|---------------------|---|
| Pain                | 1 |
| No energy           | 2 |
| Shortness of Breath | 3 |
| Loose dentures      | 4 |
| Dry mouth           | 5 |
| Sore mouth          | 6 |
| Don't know          | 7 |
| Other               | 8 |

Comment.....

.....

Q. 5. (a) Do you have a problem swallowing food?



(b) Are you able to tell me if any of the following are reasons for this problem?

(Circle as many as necessary)

- |                                |   |
|--------------------------------|---|
| Sore or painful throat         | 1 |
| Can't get food down            | 2 |
| Mouth and throat dry/no saliva | 3 |
| Too nauseated                  | 4 |
| Don't know                     | 5 |
| Food too dry                   | 6 |
| Other                          | 7 |

Q. 6. (a) Do you have a problem drinking any fluids?



(b) Are you able to tell me if any of the following are reasons for this problem?

(Circle as many as necessary)

- |                              |   |
|------------------------------|---|
| Sore or painful throat       | 1 |
| Too nauseated                | 2 |
| Can't get fluids down easily | 3 |
| Can't get fluids down at all | 4 |
| Don't know                   | 5 |
| Drinks too sweet             | 6 |
| Other (specify)              | 7 |

Comment.....

.....

Q. 7. (a) Have you experienced any nausea since your present illness?



(b) What things bring on or make your nausea worse? (Circle as many as necessary)

	<u>Food</u>	<u>Fluids</u>
The treatment for your illness	1	1
The smell	2	2
The thought	3	3
The sight	4	4
The taste	5	5
Feel nauseated when due for treatments or doctor's visits	6	6
Other	7	7

Comment.....

.....

Q. 8 (a) Have you experienced any vomiting?



(b) What things bring on or make your vomiting worse? (Circle as many as necessary)

	<u>Food</u>	<u>Fluids</u>
The treatment for your illness	1	1
The smell	2	2
The thought	3	3
The sight	4	4
The taste	5	5
Vomit when due for treatments or doctor's visits	6	6
Other	7	7

Comment.....

.....

Q. 9. Do you **feel full** after eating or drinking only a small amount, more than you have experienced before your present illness?

☐

Comment.....  
.....

Q. 10. Do you have a problem with indigestion or heartburn?

☐

Comment.....  
.....

Q. 11. Have you felt uncomfortable due to abdominal 'wind'?

☐

Comment.....  
.....

Q. 12. Have you had any problem with diarrhoea?

☐

Comment.....  
.....

Q. 13. Have you had any problem with constipation?

☐

Q. 13 (a). Have you reduced your fluid intake?      YES                      NO

Q. 13 (b). Are you taking pain relief medications?      YES                      NO

Q. 13 (c). If YES, please state what medication you are taking for your pain.

Comment.....  
.....

Q. 14. Have you been having nourishing fluid supplements such as  
Sustagen or Ensure, or another? YES NO

Q. 15. Have you made any dietary changes since your present illness?  
YES NO

Comment.....

.....

Q. 16. Please describe a typical day's food and fluid intake before your present illness.

Breakfast.....Morning Tea.....

Lunch.....Afternoon Tea.....

Evening Meal.....Supper.....

Comment.....

.....

Q. 17. Please describe a typical day's food and fluid intake now.

Breakfast.....Morning Tea.....

Lunch.....Afternoon Tea.....

Evening Meal.....Supper.....

Comment.....

.....

Q. 18. What do you estimate your food intake to be now, compared with what you ate before your  
present illness?

- Eat more ☐
- Eat about the same ☐
- Eat about 1/2 ☐
- Eat about 1/4 ☐

Q. 19. What other things/strategies that you haven't mentioned that you have found helps with the problems you've described?

Oral hygiene ☐

Distraction techniques ☐

Relaxation strategies ☐

Other ☐

Comment.....  
.....

Q. 20 (a). Do you ever feel that you just don't want to eat or drink since your present illness?

Almost always ☐

Often ☐

Sometimes ☐

Almost never ☐

(b). Why do you feel this way?

Too Sleepy ☐

Not hungry ☐

Not interested in eating ☐

Depressed ☐

Other ☐

Comment.....  
.....

Q. 21. What was your usual weight before your present illness? .....

Q. 22. What has been your lowest weight since this present illness? .....

Q. 23. What is your weight now? .....

Q. 24 What is your height? .....

Q. 25. Do, or have you ever drunk alcohol regularly, that is, daily or just about every day?

YES	1
NO	2

If YES to Q 25, would you mind answering the following questions about this?

Q. 26. Do you still drink alcohol regularly?      YES      NO

**IF YES**      How many standard drinks per day?

**IF NO**      How long since you have stopped?

months

How many standard drinks per day did you drink then?

Q. 27. Have you ever been a regular smoker?      YES      NO

Q. 28. **IF YES to Q 27**

Do you smoke now?      YES      NO

**IF YES to Q. 28** how much do you smoke now?

Cigarettes per day

Q. 29. **IF NO to Q 28**

How long ago did you give up smoking?

.....

How many cigarettes a day did you smoke then?

Cigarettes per day

**Section C.**

**Q. 1. Have you had any dietary advice about problems you have experienced related to taking food and drink, since your present illness?**

YES	1
NO	2

**Q. 2. I am going to mention a few different sources of information about diet and nutrition. Can you tell me how if you have heard of them and if so, how helpful they've been?**

**HOW HELPFUL**

**(0 = N/a; (or patient has not heard of it)      1 = extremely unhelpful; 2 = somewhat unhelpful; 3 = somewhat helpful; 4 = extremely helpful).**

Booklet ' Food for Thought' available from the Cancer Foundation of Western Australia	0	1	2	3	4
Booklet 'Understanding Nutrition' available from the Cancer Foundation of Western Australia	0	1	2	3	4
Pamphlets or leaflets handed out by nursing staff at clinics	0	1	2	3	4
Advice by nurses	0	1	2	3	4
Advice by doctors	0	1	2	3	4
Advice by dietitians	0	1	2	3	4
Relatives and friends	0	1	2	3	4
Cancer Information Service, Cancer Foundation of Western Australia	0	1	2	3	4
Cancer Support Group	0	1	2	3	4
Books and magazines	0	1	2	3	4
Alternative health practitioners	0	1	2	3	4

**Q. 3. Have you heard of any alternative diets?**

YES	NO
-----	----

Q. 4. Have you tried any alternative diets since your present illness?

YES

NO

**If YES, please continue with question 5**

**If NO, please go to question 6.**

Q. 5(a). Who told you about this diet?

Naturopath

☐

Iridologist

☐

Healer

☐

Cancer Support Society

☐

Family member

☐

Friend

☐

Read about it

☐

Homoeopathist

☐

Other

☐

Q. 5 (b). What was the name of that diet?

.....

Q. 5 (c). What was the diet for?

.....

Q. 5 (d). Are you still on that diet?

YES

NO

Q. 5 (e). Do you think that diet is/was helpful?

1

2

3

4

5

I \_\_\_\_\_ I

Extremely  
unhelpful

Somewhat  
unhelpful

No  
difference

Somewhat  
helpful

Extremely  
helpful

Q. 6. Do you take any vitamins or other medications supplied by an alternative health care practitioner?

YES

NO

If YES to Q. 6. please continue, if NO please go to Q. 8

Q. 7 (a). Who suggested these medications?

Naturopath	<input type="checkbox"/>	Iridologist	<input type="checkbox"/>
Healer	<input type="checkbox"/>	Cancer Support Society	<input type="checkbox"/>
Family member	<input type="checkbox"/>	Friend	<input type="checkbox"/>
Other	<input type="checkbox"/>	Read about it	<input type="checkbox"/>
Homoeopathist	<input type="checkbox"/>		

Q. 7 (b) What are the names of these medications?

.....

.....

Q. 7 (c) What are these medications for?

.....

.....

Q. 7 (d) Are you still taking these medications?      YES                      NO

Q. 7 (e) Do you think these medications are/were helpful?

1	2	3	4	5
I-----I				
Extremely unhelpful	Somewhat unhelpful	No difference	Somewhat helpful	Extremely helpful

Q. 8. Have you tried any vitamins or medications which have been bought  
'over-the-counter', since your present illness?

YES                      NO

If YES to Q. 8, please continue, if NO, go to Q. 10.

Q. 9 (a).       What are the names of these medications?

.....

.....

Q. 9 (b) What are these medications for?

.....

.....

Q. 9 (c) Are you still taking these medications?       **YES**                               **NO**

Q. 9 (d). Do you think these medications are/were helpful?

1	2	3	4	5
I-----I				
Extremely unhelpful	Somewhat unhelpful	No difference	Somewhat helpful	Extremely helpful

**If YES to these questions about alternative diets or medications:**

Q.10. Have you felt comfortable enough to tell your doctor or nurse about:

- |     |   |     |    |
|-----|---|-----|----|
| (a) | Your alternative diet                             | YES | NO |
| (b) | Your alternative medications                      | YES | NO |
| (c) | Your over-the-counter vitamins and/or medications | YES | NO |

Q.11 (a). In order for you to have managed the dietary problems that you have mentioned, what information would most help? (Circle as many as necessary)

- I haven't any real problems 0
- How to increase the nutritional value in food and drinks 1
- How to make food and drinks more appealing 2
- More recipes on foods I can try 3
- More recipes on drinks I can try 4
- Other 5

Comment.....

I.....

Q. 11.(b) Do you wish that more supportive services about diet and nutritional problems were available to you?

YES NO

Q. 11 (c) If YES, Who do you want that advice from?

- Doctors 1
- Nurses 2
- Cancer Foundation of W.A. 3
- Dietitians 4
- Alternative health care practitioners 5
- It doesn't matter 6
- Other (Please specify)..... 7

Comment.....

.....

**The following questions are optional, and will be used to  
assist analysis only.**

**Q. 1. In which country were you born?**

Australia	1
U.K., Nth. America, N.Z.	2
Asia	3
Europe	4
Other	5

**Q. 2. What is the highest level of education you have completed,  
or closest equivalent?**

Primary School	1
Year 10	2
Year 12	3
Apprenticeship/Trade Cert.	4
Certificate/Diploma non-trade	5
Bachelor Degree	6
Higher Qualifications (post grad)	7
Other (please specify)	8

**Q. 3. What type of work do/did you most frequently perform?  
(Circle One number)**

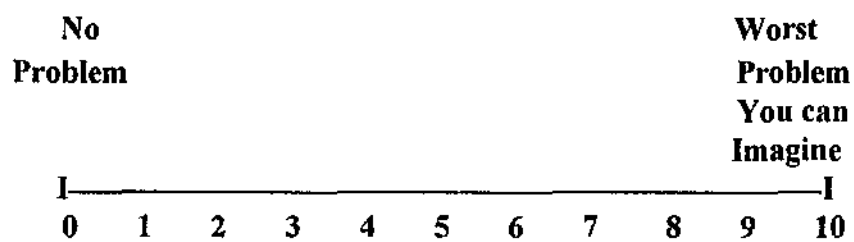
Manager or Administrator	1
Professional worker, e.g. scientist	2
Para-professional, e.g. registered nurse, technician	3
Tradesman	4
Clerk	5
Sales person or personal service worker	6
Plant and machine operator or driver	7
Labourer or related worker	8
Student	9
Home Duties	10
Other	11

**Thank you for your help in completing this questionnaire.**

## **APPENDIX F**

### **Visual Analogue Scale**

Visual Analogue Scale to be Used in  
Conjunction With Questionnaire



## **APPENDIX G**

### **Cover Letter**

Margaret Robinson,

[REDACTED]

6th February, 1996.

Dear Sir/Madam,

I am a post-graduate nursing student at Edith Cowan University, and studying towards my Bachelor of Nursing (Honours) degree. Part of my studies involve research.

The Cancer Foundation of Western Australia has asked me to assist them to identify the nutritional problems that cancer patients have. The purpose of this is to produce a booklet which meets the needs of patients, and provides sound nutritional advice. You may help in this study by completing the accompanying questionnaire about problems related to the intake of food and fluids. The research involves taking some information about your treatment details from your medical records. Your help in this study will be of benefit to other patients like you, who are in a similar situation.

If you have queries at any time, my phone number is. [REDACTED] If you have any other questions, you may wish to contact my supervisor at Edith Cowan University. This person is:-

Ms. Davina Porocho, R.N., M.Sc.  
Edith Cowan University,  
C/- School of Nursing.  
Pearson Street,  
CHURCHLANDS, W.A. 6108.  
Phone 273-8534.

Yours sincerely,

Margaret Robinson, R.N.

Thank you for taking the time to read this. If you wish to join in this study, please fill out the attached form.

## **APPENDIX H**

### **Consent Form**

**CONSENT FORM**

I am a post-graduate nursing student at Edith Cowan University, and studying the nutritional problems of cancer patients who are having radiotherapy or chemotherapy. I wish to determine what nutritional problems patients have so that a dietary booklet can be produced which will be of practical help.

Your responses to the questionnaire and the information obtained from your treatment details will be confidential and any identifiable information will not be revealed as part of the results to any person other than the researcher. An identification code will be used to indicate from which group of patients you come. Information will be kept in a locked filing system, and all data will be destroyed after five years.

You are under no obligation to participate and you are free to withdraw from the study at any time.

Thank you for taking the time to consider this.

Margaret Robinson, R.N.  
Researcher

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I have read the cover letter and this consent form. I have been given the opportunity to ask questions and I am aware that I can withdraw from this study at any time.

Signed.....Date.....

Please print your name.....