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EFFECTS OF STRUCTURED EDUCATION FOR HEAD AND NECK CANCER PATIENTS RECEIVING RADIATION THERAPY

by

Sandra Lynn Gerhart Kreamer

A Thesis Submitted to the Faculty of the COLLEGE OF NURSING
In Partial Fulfillment of the Requirements For the Degree of MASTER OF SCIENCE
In the Graduate College
THE UNIVERSITY OF ARIZONA 1983
STATEMENT BY AUTHOR

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ACKNOWLEDGEMENTS

The author recognizes that without the continual assistance, guidance and support of numerous persons this thesis would not have been completed.

Special appreciation is expressed to Dr. Alice Longman, my thesis chairperson, who willingly gave many hours, much patience and ample encouragement throughout the entire project. Recognition is also given to Dr. Beverly McCord whose encouragement and faith provided motivation and Dr. Joyce Verran whose knowledge of methodologies provided the mechanism to allow it all to fit together.

A special thanks to Sharon Guthrie whose persistence and willingness to help allowed access to the patients. Thanks are also extended to the University of Arizona Radiation Oncology clinic for access to the patients in that facility. Appreciation is also extended to the American Cancer Society for their continued financial assistance.

Lastly, but most importantly, to Will, by husband, who lovingly supported me throughout the "thesis experience"; my children Kate and Matt who allowed me to be a mother and a graduate student; my mother who instilled in me the will to persevere and succeed; and Christine whose emotional support and assurance allowed all the roles to intermix.
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ABSTRACT

Cancer is the second most common cause of death in the United States. Approximately one half of all cancer patients receive radiation therapy at some time in their treatment. Radiation treatment is still one of the most misunderstood of the cancer treatment modalities. The literature clearly supports the many benefits of patient education.

The purpose of this quasi-experimental study was twofold. The first purpose was to confirm the concept that patient education has a positive effect on affective state. The second purpose was to describe what patients with head and neck cancer, receiving external radiation therapy, report in the way of self-care interventions dealing with side-effects which develop. It was postulated that patient education has a positive effect on affective state. At the empirical level this study tested the booklet "Help Yourself Deal With Radiation Therapy" as the patient education source and the instrument Profile of Mood States (POMS) to measure affective state.

Twenty patients with cancer of the head and neck region who were currently undergoing radiation therapy participated in the study. The results of the study did not yield statistically reliable findings, however the subjective analysis suggested pertinent implications for further nursing practice.
CHAPTER 1

INTRODUCTION

Over 700,000 people are diagnosed yearly as having cancer. While cancer of the head and neck accounts for only five percent of all malignancies, the pronounced cosmetic deformities and associated social stigmata heighten their relative importance. Trauma, chronic irritation, prolonged heavy use of alcohol, snuff, tobacco, poor oral hygiene, and syphilis have been identified as definite etiologic factors in the development of cancer of the head and neck (ACS, 1975). Attention is now directed not only to how long these people can survive, but how well they survive within the constraints of their disease and its treatments. In addition, factors such as poor nutritional intake associated with heavy alcohol intake, and compliance difficulties can lead to more intensive side-effects with these patients (Marino, 1981).

The American Nurses' Association and the Oncology Nursing Society have identified 10 standards for providing care within the practice of cancer nursing. One standard states, "The client and family possess knowledge about the disease and therapy in order to attain self-management, participation in therapy, optimal living and a peaceful death" (Outcome Standards for Cancer Nursing Practice, 1979).
Purpose of this Study

The purpose of this study was to confirm the concept that patient education has a positive effect on affective state. The study also described what patients with head and neck cancer, receiving external radiation therapy, report in the way of self-care interventions dealing with side-effects which develop.

Statement of the Problem

Two problems were investigated in this research. The first involved a study of whether differences existed between the affective states in patients with head and neck cancer receiving external radiation therapy who undergo a program of specific patient education, and those patients who do not receive this education.

The second problem involved a descriptive investigation of how both groups of patients deal with side-effects which develop as a result of radiation therapy. The specific research questions were:

1. Is there a difference in affective state, as measured by Profile of Mood States (POMS), between patients receiving external radiation therapy who are given specialized patient education in the form of a booklet entitled, "Help Yourself Deal With Radiation Therapy," and those who do not receive this specialized patient education?

2. How do these two groups of patients deal with side-effects which develop as a result of external radiation therapy as recorded in their side-effects management logs?
Significance of the Problem

Radiation as a treatment modality for cancer can have serious side-effects. Patients need to be taught how to manage these side-effects as they occur to achieve an optimal level of life satisfaction during the course of treatment.

Patient education has become an important part of health care, and therefore, an important nursing responsibility. Patients want the information necessary to make decisions regarding their disease and the different treatment modalities available. If nurses are going to take the time and effort for patient education, then optimal effectiveness is desired. Research has clearly shown that teaching patients about various aspects of their conditions in an organized and systematic manner is an effective method for improving quality of care (Johnson, 1980).

There are many factors which may inhibit patient learning. If the patient does not know about his disease, and does not listen to what is being said to him about his disease, he can then continue to deny its existence (Cassileth, 1980). People have to be receptive to the teaching experience for learning to take place (Shaw, 1981). Adults are motivated to learn subjects or skills which will help overcome a perceived problem (Shaw, 1981). Other studies have demonstrated that if patients are given verbal and written material which both stress the same point, the understanding of the material is improved (Hoffland, 1978 and Visser, 1980).

Numerous booklets, brochures, books, etc., have been written to help cancer patients deal with treatment side-effects. Many times these
are quickly handed to the patient or family without a thorough explanation or review of what is covered in them. Patients may have questions they forget to ask, or are afraid to ask. They may never sit down and read the material because they find it too depressing to think about the impending unknown. With verbal communication, information may quickly be lost in the clutter of new information which accompanies a diagnosis of cancer and its treatments.

If patients are given information in such a way that they understand it and can foresee practical application of the information, then they should be able to effect change in their lives and have more control of their treatment regimen.

Theoretical Framework

There are four separate aspects of the theoretical framework of this study. They are patient education, affective state, a patient education booklet, "Help Yourself Deal With Radiation Therapy," and the Profile of Mood States (POMS) tool. The interrelations of these aspects are pictured in Figure 1.

Figure 1 THEORETICAL FRAMEWORK OF STUDY
Patient Education is the means of providing information to the patient to allow them to make decisions regarding their disease, care and treatment. By allowing involvement in decision making, some control is given back to the patient. Cancer patients are saying, "offer us the TOOLS and let us choose the options. We can feel more in control then" (Marino, 1981, p. 95). They are also stating, "... I need to have control over my body and over my life. Beyond imparting information, offer me options, choices, and specific suggestions for self-care. Then I can decide to not only do something about an aspect of my health, but also have some choice as to how to do it" (Marino, 1981, p. 96).

Not knowing what to expect has been proven to be related to loss of control and fear of death (Lane, 1980). Patient anxieties are often alleviated if they are able to understand what to expect regarding their disease and its different treatment modalities (Johnson, 1980). Cancer, as a chronic disease, requires the development of new coping strategies which facilitate adaptation to the disease. Numerous studies have indicated that when clients receive instructions which help them understand the nature of their illness and the specific role they are expected to play, there is less need for hospitalization, and greater adherence to prescribed programs (Marino, 1981). Studies by Seligman and O'Niell both reported that feelings of helplessness and loss of control were very real for people dealing with a life-threatening disease (Marino, 1981).

"Help Yourself Deal With Radiation Therapy," is a booklet specifically prepared by the author for patients with head and neck cancer receiving radiation therapy. The booklet describes specific
interventions to help decrease the potential severity of, or alleviate, side-effects which may develop as a result of radiation therapy. Suggestions are provided regarding what the patient can do to manage the side-effects which may develop. These suggestions allow for some degree of control on the part of the patient, and thus should lead to a more positive affective state.

Emotions effect how the patient is able to deal with his disease and treatment. Understanding the psychology of emotions requires more than physiological and behavioral data. It requires subjective data relating to feeling, affect and mood (McNair, 1971). Affective state refers to feelings or emotions, especially as they relate to the pleasurable or unpleasurable aspects of the mental process. The cancer patient undergoing radiation therapy is going through an emotionally difficult time. His affective state should be an indicator of how well he is dealing with his disease and its treatments.

Profile of Mood States (POMS) measures six identifiable moods or affective states: Tension-Anxiety; Depression-Dejection; Anger-Hostility; Vigor-Activity; Fatigue-Inertia, and Confusion-Bewilderment. The tool has been shown to be a sensitive measure of the effects of various experimental manipulations on normal subjects and other non-psychiatric populations (McNair, 1971). It was believed that measuring the affective states of patients would allow the investigator to determine if patient education as accomplished by the booklet does indeed allow the patient emotional or psychological support.
**Definitions**

1. **Patient Education** - any combination of learning opportunities designed to affect the knowledge level, skills, attitudes, or other behavior of patients or other persons closely associated with them (Johnson, 1980).

2. **Affective State** - feelings or emotions, especially as they relate to the pleasurable or unpleasurable aspects of the mental process, as measured by POMS.

3. **External Radiation** - therapeutic ionizing radiation delivered by an external source such as a machine, to the surface of the skin or below. In this study, this pertains to the areas of the head, neck, and/or upper abdomen.

4. **Side-Effects** - any reaction of the human body, either physiological or psychological to the ionizing radiation.

5. **Self-Care Interventions** - any intervention the patient, family or significant other is able to perform to alleviate the severity of a side-effect, either as a palliative or preventive action.
CHAPTER 2

REVIEW OF THE LITERATURE

This chapter is divided into three sections. The first section deals with patient education, the second radiation and cancer, and the third side-effects which may develop.

Patient Education

The patient has a right to know about his disease, and an informed patient is better equipped to deal with various stages of that disease. Issues relating to loss of control and fear of death, have been related to "the dark cloud of unknowing" (Lane, 1980). Patient anxieties are often alleviated when they are better able to have knowledge about the disease and its treatments. Within the field of oncology nursing practice, patient education has become a recognizable component of cancer nursing. Patient education is identified as an outcome criteria for the majority of the 10 standards identified in "Outcome Standards for Cancer Nursing Practice," prepared by the Oncology Nursing Society and the American Nurses' Association (1979). In addition, one standard specifically addresses patient education. It states: "The client and family possess knowledge about the disease and therapy in order to attain self-management, participation in therapy, optimal living and peaceful death".
Numerous methods are available in approaching patient education. These include written materials, verbal explanations, audio-visual materials or any combination of these. Research has shown that much of the information given to patients is neither followed or understood. Handing a brochure to a patient can not be considered patient education unless the health care professional has a plan for assessing the patient's level of understanding and application of the material (Johnson, 1980). There are many reasons that the patient may not comprehend educational materials he receives. First, it needs to be determined if there is actually a need. Then, does the patient and/or family want to know? Finally, can education alter outcome? (Richel, 1981). Recent literature supports that education can help in reaching positive treatment outcomes. Carefully planned and executed educational programs have shown increased patient understanding, thus promoting compliance (Richel, 1981). A 1980 study of 50 patients receiving radiation therapy revealed that 88 percent of those surveyed wanted to participate in decisions regarding their treatment (Smith, 1980).

The results of a study conducted by the Chicago Cancer Information Center revealed three specific areas of patient concern. First, the patient welcomes and values written information regarding cancer. Secondly, not enough is being done with the family to include them in illness care. Thirdly, health professionals often fail to recognize the information needs of the patient and family. They also fail to recognize the difficulty of integrating and acting on new material which had been presented in the medical setting (Oleske, 1981).
Another study, reported by Cassileth, explored the degree to which 256 cancer patients preferred to become informed about, and participate in, their medical care. This study showed that younger patients wanted more information to enable them to participate in decision making. Older patients preferred the non-participatory patient role (Cassileth, 1980).

Physicians' attitudes have changed over the past 20 years. In 1950, most physicians preferred not to tell their patients that their diagnosis was cancer. In the 1970's most physicians informed their patients and allowed them to participate in decision making concerning treatment and care. There has been a trend in the last 20 years towards emphasis on the individual's responsibility and the right of the patient to control his own life and dying (Cassileth, 1980).

In 1980, Visser reported that written material can be a good starting point for patient education as it is a quick way to disseminate information to a large group at one time. Written material does not interfere with the organization of the nursing unit and enables patients to obtain and review information during waiting periods. Written materials alone were not always read by patients. People with high anxiety have been shown to become more anxious when given brief, cursory, non-supporting information. Patients who forget that same material, may be utilizing a defense mechanism related to the anxiety producing nature of the material. The study concluded that written information provided a good starting point for doctor and nurse reinforcement and
explanation of material, but, of itself was not enough (Visser, 1980). Hoffland (1978) further substantiated this conclusion in a similar study.

In Shaw (1981), Knowles an expert in adult learning, applies four assumptions to the adult learner. First, a person becomes an adult when he achieves self-direction. Second, experience is a major influence in the quality of new learning. Third, social needs, or the need to fill a social role, are necessary. Fourth, adults are motivated to learn subjects or skills that will help them overcome a perceived problem (Shaw, 1981). If patient education is applied to the adult patient, all of these assumptions need to be considered.

Johnson stated "the literature is clear, teaching people about various aspects of their conditions in an organized and systematic manner is an effective method for improving the quality of care provided by the health care institutions" (Johnson, 1980, p. 63). Cancer is a chronic illness. As such, patients with cancer need to be taught how to modify and adapt their behavior to adjust to the ramifications of cancer, as well as the treatment modalities of the disease (Marino, 1981). Cancer patients are saying that they want to make decisions about their lives. In order to make the appropriate decisions they need information. Cancer patients are saying they want some control (Johnson, 1980). Information which allows patients to make decisions, in turn gives them that control. Oncology patients view educational programs as a commitment on the part of the professional, to the cancer patient. This commitment, to help the patient face cancer and its
treatments, allows the patient self-respect (Johnson, 1980). The patient should be an important participant in decision making concerning his care, and as such, needs valid information on which to base these decisions.

Cancer and Radiation

Cancer is the second most common cause of death in the United States. It kills about 365,000 Americans annually. Forty years ago, fewer than one of every five Americans diagnosed with cancer survived. Today, one out of three survives. While over one million people are under treatment for cancer, more than one person dies of it every two minutes (ACS, 1975). Approximately one half of all cancer patients receive radiation therapy at some time in their treatment (Marino, 1981). Radiation treatment is still one of the most misunderstood of the cancer treatment modalities. Patients express fears of becoming "radioactive," burned, experiencing pain, sexual dysfunction, and dying (Rotman, 1977).

From birth to death the living organism is in a constant state of change; growing and degenerating, sustaining injury and repairing the damage, adapting or failing to adapt to the environment, reproduction and finally death. All of this activity involves the death and orderly replacement of millions of cells everyday. When this process of cell division becomes disorderly and uncontrolled, not responding to the natural feedback system of the body, abnormal growth of cancer cells takes place. Cancer cells multiply beyond the limits established for cells, and do so without organization or proper differentiation.
Multiplication of these diseased cells within the body, if left uncontrolled, will invade normal tissue and lead to the eventual death of the host (ACS, 1975).

Cell reproduction and division takes place during the cell cycle (Figure 2). The cell cycle can be divided into two periods, mitosis and interphase. Mitosis is the time during which actual cell division takes place. It is a relatively brief period in the cell cycle and can be further divided into four stages; prophase, metaphase, anaphase, and telophase.

![Figure 2 Phases of cell cycle and stages of mitosis (Hubbard, 1981).](image)

Interphase encompasses the entire period of cellular growth that occurs between cell divisions. Deoxyribonucleic acid (DNA) replication occurs during interphase, which makes it a vital part of
the cell cycle. Interphase can be further divided into distinct phases; 
$G_1$, $S_1$, and $G_2$. $G_1$ is the phase which begins at completion of cell divi-
sion or mitosis. DNA synthesis ceases during this time, except for 
repair of damaged DNA. However, ribonucleic acid (RNA) and protein 
synthesis continue. Cellular enlargement occurs mainly during this 
phase. At a critical point, late in the $G_1$ period, the cell becomes 
committed to undergo mitosis. A nuclear signal initiates a burst of 
RNA synthesis and the $S$-phase begins. Cellular DNA doubles during the 
$S$-phase. The cell now enters the premitotic phase, $G_2$. During $G_2$
DNA synthesis ceases, but protein and RNA synthesis continues. The 
cell then undergoes mitosis, in which the genetic material is separated 
into two daughter cells (Marino, 1981).

Death of a cell can be obtained in two different ways; inter-
ference with the cell life cycle, or structural degeneration of the 
cell independent of the cell cycle. Interference with the processes 
which occur during the normal cell cycle creates conditions which pre-
vent normal cellular replication required for the cell to sustain life. 
Radiation is one form of interference.

Cell death can only take place if the cells are in the process 
of dividing. The most radiosensitive cells, therefore, are rapidly 
dividing cells (Dietz, 1979). Strand breakage in DNA is one of the most 
important biochemical phenomenon leading to cell death after ionizing 
radiation exposure. Radiation introduces a mitotic delay in the $G_2$
phase of the cell cycle and cells escape from that mitotic delay in a 
partially synchronized state (Kaplan, 1977).
Radiation therapy also affects the extracellular environment. Oxygen is a necessary ingredient to the subsequent damage of the DNA. The center of many large tumors is necrotic, due to the disorganized cellular structure of the tumor which precludes adequate vascularization during the rapid tumor growth period. Radiation destroys the peripheral cells of the tumor which allows for revascularization and reoxygenation of the necrotic center. The greater the vascularization and oxygenation of the tumor, the more radiosensitive it is. Therefore, by allowing the revascularization of the necrotic center, a more complete kill of the tumor cells is achievable (Marino, 1981).

Several factors effect the type of radiation plan to be used. They are:

1) Depth of lesion
2) Size of the area to be treated
3) Radiosensitivity of the tumor
4) Extent of the cancer
5) General physical condition of the patient (Dietz, 1979).

Radiation can be administered either internally or externally. Internal radiation is usually administered through the use of radioactive implants. External radiation is the type of radiation dealt with in this study. External radiation is usually administered by fractionation. Fractionation is the administration of small doses of radiation over long periods of time. This allows the optimum cancer cell destruction with the most tolerable side-effects to the patient (Dietz, 1979).
Henri Coutard, as reported in Kaplan (1977), conducted some of the first clinical trials of radiation on cancer patients with fractionated daily doses of radiation therapy. He treated patients with a variety of cancers in the head and neck area. By 1930, he was able to present data showing a five year survival rate for a variety of primary cancers of the oral cavity, pharynx, and larynx. Permanent cures for a percentage of the cancer arising from that area had been achieved for the first time in history (Kaplan, 1977). Radiation therapy had opened new doors for previously incurable disease. Since that time radiation therapy has become a highly developed specialty used to treat cancer.

The goal of radiation therapy is to kill the malignant cells and render them incapable of further cell division without providing excessive damage to the surrounding normal tissue (Dietz, 1979). One half to two thirds of all patients with cancer are treated with ionizing radiation due to its effectiveness in controlling a variety of malignant tumors. Radiation can be used as the sole source of the treatment for cancer or it may be combined with surgery, chemotherapy or immunotherapy. There is often great fear associated with radiation therapy. Many patients do not know the difference between controlled therapeutic radiation and uncontrolled radiation. Peck (1976) conducted a study with 50 patients receiving radiation therapy which showed that only 39 of these patients were aware they had cancer. They were stunned on their first visit to the radiation department and did not ask questions, or comprehend or remember explanations given. Patients interpreted having to receive radiation as "bad". It eliminated any possibility
of denial that they did have cancer. They viewed radiation after surgery as a final desperate attempt after the first treatment, surgery, had "failed". Patients in this study stated that it was helpful if they were informed of what side-effects to expect. They were then able to grasp and retain the information they were given (Peck, 1977). Those who were not informed of side-effects were disappointed and angry. No one complained of being informed of a side-effect which did not materialize.

Radiation therapy comes at a time in the patient's life when his ability to cope with stress has already been strongly taxed with diagnostic procedures. Anything which the health professional can provide in the way of support or information is greatly appreciated (Peck, 1977).

All cancer can be cured with radiation. There is some dose which will destroy the most resistant tumor. However, in the process of doing so it is likely the surrounding tissue would also be destroyed and the patient would not survive.

The goal of radiation therapy is a delicate balance of enough, but not too much. Enough radiation to sterilize the tumor, but not too much as to cause irreversible damage to the surrounding tissue, thus making the treatment more destructive than the disease (Kruse, 1979).

Side-Effects of Radiation Therapy

The goal of radiation therapy is to destroy tumor cells with minimal injury to the structure and function of the adjacent tissue
It is the injury to the structure and function of the adjacent cells which produces side-effects. The literature clearly supports at least five general areas in which side-effects may develop in patients with cancer of the head and neck region who undergo external radiation therapy. They are:

1) Sore throat and mouth
2) Loss of appetite (anorexia)
3) Nausea and vomiting
4) Weakness (tiredness)
5) Skin problems


There is a strong interrelationship between the first four side-effects. Soreness of the mouth and throat can have a direct effect on nausea and vomiting, anorexia and tiredness-weakness.

Sore Mouth and Throat

The effects of radiation on the oral mucosa appear early in the course of therapy. The mouth and throat are lined with squamous epithelium, which is highly sensitive to radiation. Initially, an erythema appears, which eventually leads to extensive ulceration and desquamation. This sometimes results in severe radiation mucositis which can cause pain and dysphagia, resulting in anorexia and weight loss. The mucositis begins to appear two to three weeks into treatment and reaches a peak at the end of therapy. It is most severe at the tumor site, where
the radiation has been most intense. The mucosa of the oral cavity does not react in the same manner in all locations. The severity of the mucositis is dependent upon the volume, dose and radiation field (Beumer, 1979). Initial radiation induced changes in the oral mucous membrane give rise to the loss of the normal glistening followed by the formation of a thin, whitish film called a false or pseudomembrane. This is associated with various levels of soreness and inability to swallow (Rotman, 1977). It also varies from patient to patient. Patients with compromised oral mucous membranes secondary to alcoholism, exhibit the most severe mucosal changes. Healing is rapid, and is usually complete within two to three weeks after therapy is completed (Beumer, 1979).

The salivary glands are also affected during radiation to the oral cavity. Changes in the saliva's volume and viscosity contribute to impairment of taste acuity, make swallowing difficult, and thus affect appetite. Changes in the saliva's pH predispose the patient to dental caries which can lead to more serious bony infections. Salivary gland epithelium exhibits rather slow turnover which should, theoretically, make it more resistant to radiation. In fact, however, the opposite is true. Available information suggests that these changes are due mainly to compromising of the fine vasculature. The normal salivary excretions are slow to return and, depending upon the specific radiation site, may return to normal in one to two years, or never (Beumer, 1979). Radiation also causes shrinkage of the gums, which leads to exposure of the tooth neck, and an increased incidence of gum disease and dental caries (Thomson, 1980).
These patients are also very susceptible to herpes simplex and thrush (Thomson, 1980). Chronic, post-therapy, moniliasis of the corners of the mouth are often overlooked. These infections present acutely as erythema and a burning sensation of the oral mucous membranes. Chronically, moniliasis is found in the corners of the mouth and beneath dentures (Beumer, 1979).

Management of these symptoms is supportive, and is aimed toward relieving the symptoms and preventing further complications (Donaldson, 1979). These interventions can be categorized into four general categories: aggressive oral hygiene, avoidance of substances irritating to the oral mucosa, soothing measures, and eating patterns. These four categories with specific interventions are repeatedly supported in the literature (Donaldson, 1977; Lang, 1977; Rotman, 1977; Beumer, 1979; Dietz, 1979; Dodd, 1980; Varricchio, 1981).

Aggressive oral hygiene can be accomplished in a number of ways. Teeth and gums should be brushed at least four times a day with a soft toothbrush, which decreases the possibility of trauma to teeth and gums, yet stimulates circulation. A waterpik can be used to reach areas the toothbrush cannot reach, or which may be too sore for brushing. Teeth should be flossed daily, and a fluoride toothpaste used for added protection (Beumer, 1979; Dodd, 1980).

Oral irritants should be avoided. Alcohol, tobacco, highly spiced foods, citrus fruits and acid vegetables are all irritating to any broken surface of the oral mucosa and should be avoided. Commercial mouthwashes should also be avoided. Commercial mouthwashes usually
contain alcohol, and have a drying effect on the mouth. Foods which are extremely hot or cold have also been reported to be irritating (Donaldson, 1977; Lang, 1977; Beumer, 1979; Dodd, 1980).

There are numerous soothing interventions which the patient can undertake to help decrease the severity of the soreness of his mouth and throat. Chewing aspergum is one. It coats the mouth and throat to help decrease the soreness as well as help stimulate salivary secretions to alleviate a dry mouth. If the cold can be tolerated, popsicles or ice chips help numb the mouth. If a patient's home is heated with dry heat, use of a humidifier or steamkettle in the bedroom may be beneficial. If the pain becomes severe, the physician may prescribe medication in an elixir form such as Tylenol with codeine or xylocaine to swish and swallow (Lang, 1977; Dodd, 1980; Varricchio, 1981).

There are several mouthwashes which soothe the sore oral mucosa. One quart of warm water with one teaspoon of salt and one teaspoon of soda is one variation. It is recommended that the patient use this five to ten times a day (Dodd, 1980). Another variation is a mouthwash of half saline and half hydrogen peroxide, used three or four times daily (Varricchio, 1981). Either variation is reported to soothe the irritated oral mucosa.

Eating patterns are also affected by the soreness of the oral cavity. Patients should be reminded to eat a well balanced diet, even though that may be difficult. Choosing foods that are soft in texture, such as mashed potatoes, yogurt, scrambled or poached eggs, custards, ricotta cheese, milk shakes, puddings, gelatins, creamy cereals,
macaroni and cheese makes eating easier. Food should be cut into bite-size pieces and moistened with gravy, salad dressing, mayonnaise, sour cream, yogurt or anything else which enables them to be swallowed more easily (Lange, 1977; Dodd, 1980; Varricchio, 1981).

Anorexia

Anorexia in patients with head and neck cancer has a matrix of physiological components. These include a sore mouth and throat, the catabolic effect of the tumor, the decreased sense of taste and the decrease in the production of and alteration in the consistency of saliva (Rotman, 1977). Psychological components, also play a significant part with anorexia. It may stem from emotional disturbances, especially depression and anxiety (Marino, 1981). Management of this non-specific anorexia is often tedious and frustrating. Any support the family and friends can offer to get the patient to eat is encouraged (Schreier, 1977). Anorexia seems to get worse as the day goes on; therefore, breakfast is a very important meal (Rose, 1978). Recommendations are to make it as attractive as possible, with whatever foods the patient enjoys, preferably those with high caloric value. Studies have shown that patients receiving radiation may develop an overall decrease in the pleasure of taste perception, and some a total aversion to meat. Patients reported that food tasted rancid or spoiled. They complained of a persistent sour, salty, bitter or metallic taste, as well as an overall aversion to protein (Rose, 1978). It is this overall type of
taste alteration that causes many patients to quit eating. Patients also complain of foods that are too spicy or too severe in temperature deviation (Donaldson, 1977).

Anorexia may also be increased by the effects of radiation on the salivary glands. Radiation effects a marked reduction in the quantity of secretions, and an increase in the viscosity and acidity of the secretions. The thick acid saliva potentiates the anorexia. The patient cannot moisten his food adequately when eating. The increase in the acid concentration of the saliva leads to further complications of an increased incidence of dental caries (Rotman, 1977). These patients are encouraged to drink increased amounts of fluids with their meals and to try sucking hard candy such as sugarless lemon drops or chewing sugarless gum (Lang, 1977).

The literature supports numerous interventions to help the patient deal with anorexia. Eating small frequent snacks which include the foods best tolerated by the patient, even though he may not be hungry, is one such intervention. Eating when hunger occurs, even though it is not mealtime, and eating high caloric, high protein foods are some other suggestions. Keep snacks handy and encourage the patient to eat before he goes to bed. Varying the odors and textures of food from one meal to the next, and exercising a few minutes, about one half hour before meals, have been reported to produce an increase in appetite (Lang, 1977; Rotman, 1977; Schreier, 1977; Dietz, 1979; Dodd, 1980; Marino, 1981; Varricchio, 1981).
Nausea and Vomiting

Nausea and vomiting are other possible severe side-effects of radiation therapy. Nausea and vomiting have both emotional and physiological components to be considered. Emotionally, it can significantly impair the patient's coping resources. Physiologically, it can cause a metabolic disturbance and a subsequent nutritional compromise. This nutritional compromise may lead to weight loss and weakness in an already debilitated patient. Some previous studies have shown that anticipation of nausea and vomiting, or of radiation itself, may lead to nausea and vomiting. In some cases when a placebo was given, it decreased the incidence of nausea and vomiting. Whether the cause for nausea and vomiting be physiological or not, the effects are the same (Welch, 1979). Nausea and vomiting usually present shortly after the treatment is given, last a few hours, then go away. Nausea and vomiting usually disappear completely within one week after treatment is stopped (Dodd, 1980).

The literature supports numerous interventions to help control nausea and vomiting. The use of anti-emetics either on an as necessary basis or around the clock, is a major intervention noted (Welch, 1979; Dodd, 1980). Patients should avoid greasy foods. They take longer to leave the stomach than do starch or carbohydrates. Drinking ginger ale, or eating small snacks five to six times daily, have also been suggested. Resting after meals with the patient's head slightly elevated has proven effective with some patients. If the possibility exists that anxiety is playing a part in the patient's nausea and vomiting, the nurse, or significant other, should try and reduce that anxiety. If the patient
consistently feels nauseated after treatment, have him eat before he
goes for therapy. If the patient does not feel well before treatment,
have him try eating lightly before being treated; such as toast, crack­
ers, and juice. If the smell of food cooking promotes nausea, have
someone other than the patient prepare the meals (Lang, 1977; Rotman,
1977; Schreier, 1977; Dietz, 1979; Welch, 1979; Dodd, 1980; Marino,

Fatigue

The fourth side-effect is fatigue. The prevailing theory of the
physiological mechanism of fatigue is that the body is unable to main­
tain a state of equilibrium when faced with a stressor and taxes the
homeostatic mechanism. This could be due to the continual cell destruc­
tion which expends all the body's energy on self-preservation. Another
possible reason is the accumulation of cell destruction end products and
toxic metabolites inhibiting normal cell functions. A final possible
cause is radiation induced anemia, even in the early stages (Haylock,
1979). The best treatment for fatigue is to rest when one is tired,
do not overdo, and take frequent planned rest periods. Eat well and
have the blood count monitored. Finally, allow other people to help
with the daily tasks such as cooking and cleaning (Dietz, 1979; Haylock,
1979; Dodd, 1980).

Skin Reactions

The final side effect to be considered is a skin reaction. The
area to be irradiated will be marked. The irradiated area may be more
sensitive to the sun (Varricchio, 1981).
Skin reactions have three possible stages. The first, erythema, is a redness of the area and a dry itchy feeling. If treatment is interrupted here, the skin damage will repair itself and the treatment may proceed. Dry desquamation is the second stage which is a blistering and sloughing off of the skin surface similar to that of a burn. Moist desquamation, the third stage, is when there is verication and denudation of the epidermis, accompanied by serous oozing (Lang, 1977; Dietz, 1979).

The type of skin complications which develop depend on the dose of radiation, the number of treatments, the overall time in which the treatment was given and the area of the body being treated. Areas where there are skin creases are more susceptible, as are fair skinned people (Lang, 1977).

Treatment for skin reactions should be primarily preventive. Patients should wear loose fitting cotton clothing. They should avoid shaving lotions or perfumes which might irritate the skin. An electric razor, rather than a sharp blade, helps prevent nicks. Lotions and creams should not be applied to the area. The area should be protected from the sunlight, as it may be more sensitive than normal skin. The area should be observed closely. If signs of moist drainage, stickiness, blisters or infection are noted, the physician should be notified right away. If second and third stage skin reactions occur, nursing care should consist of keeping the area clean and soothing the discomfort (Lang, 1977; Varricchio, 1981; Dodd, 1980; Marino, 1981).
CHAPTER 3

METHODOLOGY

This chapter includes the design of the study, the setting and the sample criteria, human subjects approval, method of data collection, the tools used, the method of data analysis, and the limitations of the study. The purpose of this study was to confirm the concept that patient education has a positive effect on affective state. A secondary purpose was to describe what patients with head and neck cancer, receiving radiation therapy, report in the way of self-care interventions dealing with side-effects which develop.

Design

The study used a quasi-experimental design to test the following hypotheses: If head and neck cancer patients, receiving external radiation therapy are given specialized patient education, they will demonstrate a better affective state as indicated by a lower score on POMS than will head and neck cancer patients receiving external radiation therapy who are not given specialized instruction.

One half of the sample (10) received patient education via the booklet, "Help Yourself Deal With Radiation Therapy." The other half of the sample (10) did not receive this booklet, but were given the opportunity to ask any question they had. They were given the general
information booklets available through the radiation-oncology department. All 20 of the patients were given the POMS twice during their therapy.

**Setting and Sample Criteria**

This study was conducted in the radiation-oncology department of a large southwestern medical center and in the office of a group of three private radiation oncologists. The medical center sees approximately 1,869 patients a year, 315 of whom are receiving treatment for head and neck cancer. The private practice sees 863 patients a year, 71 of whom are receiving treatment for head and neck cancer. The sample consisted of 20 patients with the diagnosis of cancer of the head and neck region. Subjects were receiving radiation therapy at the time of the study. Contact with these patients was made through the radiation-oncology nurses in each institution. Permission for this study was obtained from the department head, physicians, and the head nurse.

Subjects were selected on a convenience basis, and met the following criteria:

1. Males or females over the age of 20, who read, wrote and spoke English.
2. Presently receiving radiation therapy for cancer of the head and neck region.
3. Willing to participate in the study throughout the course of their radiation therapy.

Subjects were randomly assigned into either the experimental group, or the control group. The assignment numbers were obtained from a standard table of random numbers.
Human Subjects Approval

The proposal for this study was reviewed by the Ethical Review Committee of the College of Nursing, University of Arizona and deemed exempt (Appendix A). The purpose of the study was explained to each patient verbally and in a disclaimer form each patient read prior to participation in the study (Appendix B). Any questions the participants had concerning the study were answered by the investigator.

Tools

Four tools were used in this study: Profile of Mood States (POMS), the Self-Care Behavior Log, a booklet "Help Yourself Deal With Radiation Therapy," and a demographic data sheet (Appendices C, D, E, and F). Each of these is discussed in detail.

Profile of Mood States

Profile of Mood States (POMS) identifies and assesses transient, fluctuating affective mood states (Appendix C). POMS measures identifiable mood or affective states: Tension-Anxiety, Depression-Dejection, Anger-Hostility, Vigor-Activity, Fatigue-Inertia, and Confusion-Bewilderment, therefore, it is a multidimensional tool. It consists of 65 5-point adjective rating scales: 0 - not at all, 1 - a little, 2 - moderately, 3 - quite a bit, and 4 - extremely. One hundred different adjective scales were defined by repeated factor analysis to produce the final POMS product. Reliability has been established by both internal consistency, and test-retest reliability. The individual items within the same mood scale, measure the same factor at an internal consistency of .90 or better.
Factorial validity of the six mood factors was established by the six factor analytic replications in development of POMS. Congruent results for different patient populations and normal samples for different rating periods have been established. Face and content validity have been established by an examination of the individual items defining each mood scale (McNair, 1971).

Predictive and construct validity of POMS has been established by four areas of research. These four areas are: 1) brief psychotherapy studies, 2) controlled outpatient drug trials, 3) studies of response to emotion-inducing condition, and 4) studies of concurrent validity coefficients and other POMS correlations.

POMS is a self-administered test. Printed directly on the form are simple, explicit directions for usage:

"Below is a list of words that describe feelings people have. Please read each one carefully. Then fill in the ONE space under the answer to the right which best describes HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY." (McNair, 1971).

Persons with at least a seventh grade education have little or no difficulty understanding POMS. It takes approximately three to five minutes to answer the 65 items and the forms may then be hand or computer scored.

To obtain a score for each mood factor, the sum of the responses is obtained by adding all of the adjectives defining each of the mood factors. The grouping of these adjectives is clearly defined in the manual (McNair, 1971). All items are keyed positively except two which receive negative weights in calculating the factor scores.
A Total Mood Score may be obtained by summing the scores with Vigor weighted negatively. Each of the six factors is explained in detail as to its loading in each of the six separate studies.

POMS has been previously used with the same type of patient population. Dodd (1982) conducted a study to measure the affective state of patients receiving chemotherapy; and to determine if patient education concerning drugs and the management of side-effects altered affective mood states. Dodd thought the instrument was appropriate for her population. The current study is closely related in design and methodology to Dodd's. POMS has previously been used to measure affective states in emotion-inducing conditions. Cancer as a disease process, and radiation as a treatment modality, can be considered emotion-inducing. On the basis of Dodd's study, and cancer and radiation as emotion-inducing conditions, POMS was therefore chosen to measure the affective state of the patients involved in this study.

POMS was given to each patient to complete twice during the course of his radiation treatment. The first was within 10 days of the onset of his treatment, and the second POMS was given at the completion of therapy.

Self-Care Behavior Log

This tool was developed by Dodd and utilized in a 1980 study of oncology patients receiving chemotherapy (Appendix D). The log is divided into four sections; 1) a description of the side-effects, 2) what actions were taken to relieve it, 3) effectiveness of the action, and 4) the source for the suggestion of the action.
Patients kept this log during the course of their radiation therapy. These subjective data were categorized by the investigator. A content analysis was undertaken and the results are presented.

"Help Yourself Deal With Radiation Therapy"

The specific patient education material used in the study was a booklet "Help Yourself Deal With Radiation Therapy" (Appendix E). The booklet was written specifically for patients receiving radiation to the head and neck region. It is concise (10 pages) and consists of a brief description of cancer and radiation therapy. The five most common side-effects which develop with radiation to the head and neck (sore mouth and throat, anorexia, nausea and vomiting, fatigue and skin reactions) are also discussed. The booklet also gives the patient some simple self-help suggestions on how to deal with these side-effects as they occur.

The booklet has face validity and has been reviewed by a panel of experts for content validity. The panel of experts consisted of two graduate students with clinical expertise in oncology nursing, the head nurse of a radiation oncology department, and an oncology nursing specialist. The booklet was written by the investigator of the study.

Demographic Data

The information was obtained from both the patient and the patient record. The information obtained from the patient consisted of previous and concurrent alternate cancer treatment modalities, purpose of radiation therapy (curative versus palliative), marital status,
educational level, occupation, and history of alcohol and smoking habits. The information obtained from the patient record consisted of the identification number, age, sex, race and physician's name. Other information obtained from the patient record was medical diagnosis other than cancer, type of cancer, date of first radiation treatment, expected number of treatments, cancer prognosis, validation of concurrent cancer treatment and types of cancer treatment previously received by the patient (Appendix F).

Data Collection

Contact with the patients involved in this study was made through the radiation-oncology department of a large southwestern hospital and the private radiation oncology practice of a group of three physicians. The initial interview took place within 10 days of the onset of radiation therapy. This interview consisted of reviewing the disclaimer and answering any questions the patient had. Patient permission for participation in the study was also obtained at this time. Patients who consented to participate were randomly assigned to either the control group or the experimental group, and given the appropriate patient education.

During the initial interview the self-care behavior logs were explained. The patients used these logs to record any side-effects they experienced during their treatment and what they did to manage the side-effects. Demographic data were also obtained at this time. All
20 patients were given the Profile of Mood States (POMS) questionnaire twice during the study; upon initial interview, and upon completion of their treatment.

Data Analysis

Two separate types of analysis were conducted with the data collected from this study. An analysis of covariance was conducted with the results of the POMS. The pre-radiation POMS was used as a covariant for each of the five subcategories as well as the total and then compared to the post-radiation scores. It was hypothesized that the difference between the pre-radiation and post-radiation scores for each subcategory (excluding Vigor) and the total score, would be less for the patient education group than for the control group. It was also hypothesized that the analysis of covariance would reveal that the scores for each subcategory (excluding Vigor) and the total score of the post-radiation POMS would be lower for the experimental group than the control group.

The subjective data obtained from the self-care behavior logs were categorized by each side-effect reported and the content analysis of the logs is presented.

Limitations of the Study

This study was limited by a number of factors. The lack of control over information subjects may have received from other health care givers concerning treatment, disease and side-effects was one factor. Another was the use of two separate radiation-oncology centers,
which added an additional variable to the study. Thirdly, the length of time these patients underwent radiation therapy (4-8 weeks) presents difficulty in follow up. Finally, the study was limited by the settings and the findings cannot be generalized to a larger population.
CHAPTER 4

PRESENTATION OF THE DATA

This chapter presents the findings of the data collected in the study. The results reported include the description of the sample characteristics, the analysis of covariance of the POMS between Group I (experimental group) and Group II (control group), and a descriptive analysis of the results of the side-effects management logs.

Description of the Sample Characteristics

Twenty-five patients agreed to participate in the study, and 20 completed the study. The data discussed in this chapter are concerned only with the 20 patients who were able to complete the study. Of the five patients who did not complete the study, one died and four were lost to follow-up. The sample characteristics are discussed for the total sample of 20 subjects.

Table 1 presents demographic data for the total sample and for Group I and II, the two sub-groups. Group I represents the experimental group and Group II, the control group. In general, the two groups were homogeneous, represented by a relatively equal distribution of the variables.

The 20 patients who completed the study were equally divided into Group I and Group II. The sample consisted of 17 males and three females. The ethnic mix of the sample was 19 anglos and one black. The mean age of the total sample was 64.8 years. Sixteen of the
TABLE 1 Characteristics of Sample: Group I (Experimental Group)  
Group II (Control Group)

<table>
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<th>GROUP II N = 10</th>
<th>TOTAL N = 20</th>
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</table>
patients were married, two single, one divorced and one separated. The educational level of the sample was divided into five categories. The patients indicated the highest educational level achieved and these results are presented in Table 1. The patients were further categorized by occupation with 13 blue collar workers (manual labor), and seven white collar workers (professional or semi-professional) (Table 1).

Two patient populations were accessed for this study. Nine of the patients were from a private radiation oncology practice and 11 from the radiation oncology department of a large southwestern teaching hospital. Ten (50 percent) of the patients reported the presence of another disease process in addition to cancer. Squamous cell carcinoma was identified as the type of cancer in 17 (85 percent) of the patients and other malignancies in the three remaining patients. Seventeen (85 percent) of the patients perceived their radiation therapy as a cure for their cancer.

Fifteen (75 percent) of the patients reported other previous treatment modalities for their cancer. Twelve patients reported they had previous surgery, two previous chemotherapy and one patient surgery and chemotherapy prior to radiation therapy.

Eighteen (90 percent) of the patients reported alcohol intake. These 18 patients were further divided into "social drinkers" (seven patients), moderate alcohol intake (seven patients), and heavy alcohol intake (four patients).

Eighteen (90 percent) of the patients reported a smoking history with 12 of the 18 patients currently smoking. Cigarette smoking was further classified by pack year histories; two patients reported
histories of 21-30 pack-years, four patients 31-40 pack-years, and seven patients greater than a 60 pack-year smoking history.

**Analysis of Covariance of the POMS Between Group I and Group II**

The purpose of this study was to determine if the booklet "Help Yourself Deal With Radiation Therapy" had a positive effect on affective state as measured by POMS. The analysis of the POMS was calculated for the score of each of the six subscales, Tension-Anxiety, Anger-Hostility, Fatigue-Inertia, Confusion-Bewilderment, Depression-Dejection, and Vigor, as well as the total score (Table 2).

Within the first 10 days of radiation therapy, prior to the development of any side-effects, the first POMS was administered to the patients. The first POMS was utilized as the covariant to compensate for individual differences, thus allowing a true value of the post-radiation POMS. The total score and two of the subscale scores were significant, using .05 or less as a significance level. Tension-Anxiety had a significance level of .017, Anger-Hostility .002 and the total post-radiation POMS score was .029 (Table 2). A trend was identified in two other subscales; Fatigue-Inertia (.066), and Confusion-Bewilderment (.069). Two of the subscales, Depression-Dejection (.261) and Vigor (.344) yielded non-significant results.

**Descriptive Analysis of the Side-effects Management Logs**

The patients were asked to keep a side-effects log during the course of their therapy. Fifteen of the 20 patients participating in
### TABLE 2  Mean, Standard Deviation and Significance Level of Profile of Mood States subscales and total (n = 20).

<table>
<thead>
<tr>
<th>Scale</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Significance Level</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Tension-Anxiety:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-test</td>
<td>11.85</td>
<td>7.68</td>
<td>--</td>
</tr>
<tr>
<td>Post-test</td>
<td>11.90</td>
<td>6.81</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>--</td>
<td>--</td>
<td>.017</td>
</tr>
<tr>
<td><strong>Depression-Dejection:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-test</td>
<td>7.85</td>
<td>7.17</td>
<td>--</td>
</tr>
<tr>
<td>Post-test</td>
<td>8.55</td>
<td>9.60</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>--</td>
<td>--</td>
<td>.265</td>
</tr>
<tr>
<td><strong>Anger-Hostility:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-test</td>
<td>5.50</td>
<td>6.84</td>
<td>--</td>
</tr>
<tr>
<td>Post-test</td>
<td>5.95</td>
<td>7.61</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>--</td>
<td>--</td>
<td>.002</td>
</tr>
<tr>
<td><strong>Vigor:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-test</td>
<td>15.20</td>
<td>6.22</td>
<td>--</td>
</tr>
<tr>
<td>Post-test</td>
<td>11.65</td>
<td>7.58</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>--</td>
<td>--</td>
<td>.344</td>
</tr>
<tr>
<td><strong>Fatigue-Inertia:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-test</td>
<td>9.95</td>
<td>7.08</td>
<td>--</td>
</tr>
<tr>
<td>Post-test</td>
<td>13.75</td>
<td>8.81</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>--</td>
<td>--</td>
<td>.066</td>
</tr>
<tr>
<td><strong>Confusion-Bewilderment:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-test</td>
<td>7.50</td>
<td>5.29</td>
<td>--</td>
</tr>
<tr>
<td>Post-test</td>
<td>7.50</td>
<td>4.97</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>--</td>
<td>--</td>
<td>.069</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pre-test</td>
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<td>30.02</td>
<td>--</td>
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<tr>
<td>Post-test</td>
<td>59.80</td>
<td>27.73</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>--</td>
<td>--</td>
<td>.029</td>
</tr>
</tbody>
</table>
the study submitted some type of the side-effects management log. In two cases, the wife kept the log for the patient and in two cases the patient made weekly contact with the investigator to report side-effects and their management. The 11 remaining patients inconsistently used the side-effects logs provided.

Seventy-six specific side-effects were reported by the patients. The side-effects were organized into: dry and/or sore mouth and/or throat - 38, weakness and fatigue - 11, nausea - 10, loss of appetite - nine, and skin reactions - eight.

Dry and/or sore mouth and/or throat

In every log submitted, the patients reported dry and/or sore mouth and/or throat at least once. The information in this general category was further divided into four subcategories; changes in saliva, cough, dry mouth and/or throat, and sore mouth and/or throat.

Changes were reported in the saliva's consistency, amount and acidity. The saliva was reported to become "so thick that it caused gagging and choking" and even emesis from uncontrolled "coughing fits". The thick saliva woke patients up during the night "coughing and choking". Swallowing was reported to "no longer be an involuntary action". Some interventions were utilized but with little reported effectiveness. In one case, the acidity of the saliva was neutralized by slowly dissolving an anti-acid in the mouth. The patient reported this to be especially helpful at night when falling asleep. Another patient reported that a water pik and soft toothbrush helped cut through the thick saliva and allowed some bed-time relief. Patients reported that
moist swabs were ineffective and that they caused gagging and vomiting. Swishing with Xylocaine and rinsing with water reportedly gave no relief.

The cough caused by the thick saliva and dry mouth in turn caused a sore throat. Coughing spells were reported as "severe and uncontrollable", occasionally leading to emesis or "dry heaves". Nothing specific was reported that helped relieve the cough.

Dry mouth and throat were directly related to the salivary changes. Many patients reported that drinking liquids was not effective. Gargling with "salt and soda" or just "soda" was reported to give the most effective relief. A salivant prescribed by the physician was reported as not relieving a dry mouth.

Another side-effect reported was a sore throat and/or mouth. One patient reported his throat was so sore he had to "put mineral oil on my pain pill to get it down my throat". Three patients reported pain significant enough that narcotic analgesics were required for relief. Vicks Formula 44, chewing asper-gum, gargling with two Tylenol tabs dissolved in water, and gargling with salt and soda were also reported as interventions which provided some relief. A number of patients reported the only way they could tolerate the pain was to stop treatment a few days and let the area heal itself. Two patients reported bouts with moniliasis, however, mycostatin provided adequate relief.

Weakness and Fatigue

Weakness and fatigue were reported 11 times. The severity of this side-effect ranged from needing to cut down on physical exercise to "being too weak to eat or even carry on conversation". The
interventions utilized by the patients were basically common sense: rest when tired, take naps daily or more often as needed, no extra activity, stay home, go to bed earlier and wake up later. The patients reported that the interventions did not really seem to make a difference. They still remained "tired" or "worn-out" during the course of their radiation therapy.

Nausea

Nausea was reported 10 times. The severity of nausea ranged from an upset stomach, to "not eating in over a week and drinking only 7-up". Most of the patients stated that the nausea was severe and caused them a great deal of distress. Interventions utilized by patients included taking Milk of Magnesia and mylanta, eating very little, not eating at all, changing their diet, thinking more positively and "taking a nausea pill and going back to bed".

Loss of Appetite

Loss of appetite was reported nine times. Multiple factors were reported as causative agents including changes in appetite and weakness. Abnormal taste perceptions were described as "all food tastes the same", "gravy tastes like grease", and "turkey tastes like sawdust". Most patients rated loss of appetite to be moderately distressful. Interventions employed by the patients were "eat small meals more often", "force themself to eat", "try and eat the same amount of food as prior to radiation", must sweat it out", "look for food which they could endure", and "do nothing" as there is "nothing to do".
In many cases the combined effects of the side-effects impaired the patients' ability to eat, thus resulting in weight loss. The exact amount of this weight loss is not known, however five patients reported a 30 pound weight loss during the course of their radiation therapy.

Field Problems

A number of problems were encountered during the course of this study. Eleven (55 percent) of the patients experienced side-effects so severe that discontinuation of radiation therapy for a short period of time became necessary. Follow up was difficult due to the length of the treatment time involved. Eighteen (90 percent) of the patients underwent therapy for five to seven weeks. This time span did not include any "rest periods" required.

Summary

Twenty patients participated in this study. They were divided into two groups: Group I, the experimental group and Group II, the control group. Review of the demographic data distribution reveals two homogeneous groups. The POMS scores indicate significance for two of the subscales, Tension-Anxiety (.017) and Anger-Hostility (.002), as well as the total post-radiation score (.029).

Analysis of the logs revealed 76 reports of specific side-effects. Interventions described by the patients reveal that there is very little that actually helps relieve the side-effects which result from radiation therapy to the head and neck region.
CHAPTER 5

DISCUSSION OF THE FINDINGS AND RECOMMENDATIONS

In this chapter the findings from this study are examined. Issues related to clinical practice and further clinical research are also discussed.

Findings

The purpose of this study was to confirm the concept that patient education has a positive effect on affective state. In support of this, the post-radiation total POMS score as well as two of the subscales (Tension-Anxiety and Anger-Hostility) were statistically significant. A possible trend was identified for two of the other subscales; Fatigue-Inertia and Confusion-Bewilderment.

"Help Yourself Deal With Radiation Therapy" was the specific patient education material evaluated in this study. Evidence for substantiation of benefits achieved through the use of this material was also to have been gained through analysis of the content of the side-effects management logs. Due to inherent problems with the log and the patient population, the evidence was not secured.

The study also sought to describe what patients with cancer of the head and neck region who undergo radiation therapy report regarding self-care interventions dealing with wide effects which develop. Analysis of the logs revealed some information concerning realistic
self-care expectations for this patient population. Inherent problems with the sophistication of log and the health status of the patient population did not allow for the scope of information originally hoped to have been gained by this study.

Demographic Data

Distribution of the demographic variables between Group I and Group II was remarkably even, resulting in two homogeneous groups. In order to access an adequate number of patients in a timely fashion, it was necessary to use two different radiation treatment facilities. The use of a single facility would have allowed more control over the type of patient and information flow, thus a stronger study with fewer variations.

Valuable information concerning the health status of patients at the start of therapy was also obtained from the analysis of the demographic data. Ten (50 percent) of the patients reported previous and/or concurrent major disease processes. Fifteen (75 percent) of the patients reported previous surgery or chemotherapy for treatment of their cancer. These two factors substantiate that this patient population may be entering their radiation therapy in a less than optimal state of health. The manner in which they are able to deal with their therapy, therefore, becomes even more important. Nursing's goal is to assist this same patient population to withstand the effects of radiation therapy to the head and neck region as comfortably as possible.

The present health status of the patient proved to be an important factor relating to the collection of the data needed for this study.
Many of the patients became acutely ill during radiation therapy as a result of the side-effects which developed. It was unrealistic to expect the patients to write down what they were experiencing in their logs. Their primary concern was completion of radiation therapy. The amount of information recorded in the logs was therefore not a realistic representation of all side-effects which developed. This conclusion was substantiated verbally by patients at the termination of their therapy as well as by those patients who had weekly verbal communication with the investigator.

Eighteen (90 percent) of this patient population responded affirmatively in regards to alcohol intake. An affirmative response in regards to cigarette smoking was received from 18(90 percent) of the sample. Alcohol and cigarette smoke are considered causative agents in the carcinogenesis of the head and neck region, and these numbers support that theory.

**Profile of Mood States**

POMS was the instrument used to measure the patients' affective state and was easy to administer and complete. Due to the sample size (n = 20), the reliability of the significance levels must be questioned. However, the trend identified allows for interesting speculation. The significance levels of four of the subscales, Tension-Anxiety (.017), Anger-hostility (.002), Fatigue-inertia (.066) and Confusion-Bewilderment (.069) are the basis for this speculation. On of the major questions dealt with in this study concerned the effects of structured education for this specific patient population. The emotions
represented by these four subscales all lend themselves to molding with appropriate information; patient education. The literature clearly supports that patient education can lead to a decrease in patient's anxiety related to fear of the unknown. Understanding can alleviate the anger which accompanies not understanding the lack of control. Patient education helps sort out the confusion of a new disease, a new treatment and new side-effects. Although fatigue was reported by the patients in their logs, it was reported as only moderately stressful.

One purpose of this study was to assess the effects of patient education on affective state. The total score of the POMS had a significance level of .029, thus experimentally the hypothesis was substantiated. However, with a sample size of 20, the statistical results may not be reliable.

**Side-Effects Logs**

The original intent for analysis of the logs used in this study was to compare the self-care interventions reported by Group I (the experimental group) to those reported by Group II (the Control group), and analyze for differences. Due to inconsistent use of the logs by the patient population, this was not achieved. Analysis of the logs allowed for the retrieval of some important information concerning which interventions were successful and which were not for this patient population. Two inherent difficulties with this study were the health status of the patient population and the complexity in completing the logs. As discussed previously, this patient population entered radiation therapy in a less than optimal state of health. Many of the
patients became acutely ill during the course of their therapy. It then became unrealistic for them to accurately keep a written log concerning their side-effects.

The log itself was also a problem. Although it appeared simple and self-explanatory to the investigator, it was too complex for the patient population. Only one patient totally completed the log. The remaining patients kept the log to a varying degree, or simply kept a written account of side-effects on a separate paper. If the log was filled out completely and appropriately, it would lend itself to a more complete analysis of the information obtained. It appears the most appropriate method to collect the data required would be a weekly appointment with the patient to assist them in completing the log for that week, as well as obtaining the additional information which can be gained from verbal encounters. The investigator could then put the information into the log format. Nurses could then give the patient feedback concerning alternate methods of dealing with side-effects which may be developing. Equally as important however, would be the personal assurance to the patient that another person cares about what is happening to them during their therapy.

The literature and the results of the analysis of the logs support that many times the severe side-effects which develop from radiation therapy have no magic cure; they must simply be endured. However, many of the patients mentioned either verbally or in their logs, that attempting to stay optimistic and "deal with the problems" were all they could hope for at times. The few interventions which patients
identified as effective need to be refined. More effective interventions need to be identified so that nurses working with these patients have an empirical base of knowledge to share with the patient.

**Issues Related to Clinical Practice and Further Research**

This study substantiated that patients with head and neck cancer who undergo radiation therapy are subject to the development of side-effects. This same patient population has usually undergone prior treatments for their cancer and are not in optimal health when they begin their radiation therapy. The Oncology Nursing Society has established a specific outcome standard concerning patient education (Outcome Standards for Cancer Nursing Practice, 1979). This specific patient population needs close personal support from a knowledgeable source throughout their therapy to assist them as necessary in making choices concerning how to deal with the side-effects as they develop. This is especially important when there is no known intervention which provides adequate relief.

Collection and refinement of the type of information obtained from the analysis of the logs needs to continue. This information can then be incorporated with the creativity of the patient and the nurse to establish a basis of knowledge at the empirical level. This, in turn, can benefit the patient. The information can then be shared with other nurses and patients to broaden the knowledge base of both.

Questions remain as to the specific type and amount of information necessary for patients to acquire knowledge and to use what they
learn effectively. Individual needs can only be assessed by close interaction with the patient throughout therapy.

It is evident from this study that the primary need of these patients is close nursing support to assist them in coping with the effects of their therapy. This study and the booklet, "Help Yourself Deal With Radiation Therapy," were initial attempts toward that long range goal.

**Recommendations for Further Research**

The specific problems concerning the patient population with head and neck cancer who undergo radiation therapy and the use of the log have now been identified. Elimination of those variables through weekly meetings with the patient should allow for the development of further information on self-care behaviors. Through continued accurate use of the logs the information gained could then lend itself to a more complete analysis as well as empirical relevance. Repetition of this study with elimination of those variables and a larger population could prove a useful study.

A second area for further study is assessments of actual weight loss which occurs during radiation therapy. Analysis of body fat stores at the onset of radiation therapy could be compared with fat stores upon completion of therapy. Further, blood and urine could be monitored for protein catabolism occurring during radiation therapy. A study of this type would allow for definition of the nutritional states of the patient throughout therapy. Appropriate interventions could be initiated early enough to maintain the nutritional status of the body at the pre-radiation therapy level.
APPENDIX A

Human Subjects Approval

THE UNIVERSITY OF ARIZONA COLLEGE OF NURSING
MEMORANDUM

TO: Sandra G. Kreamer

3816 Sunny Shadows Place, Tucson 85741

FROM: Ada Sue Hinshaw, R.N., Ph.D. - Jan R. Atwood, R.N., Ph.D.
Director of Research Chair, Research Committee

DATE: July 23, 1982

RE: Human Subjects Review: "Effects of Structured Education for
Head and Neck Cancer Patients Receiving Radiation Therapy"

Your project has been reviewed and approved as exempt from University
review by the College of Nursing Ethical Review Sub-committee of the
Research Committee, and the Director of Research. A consent form with
subject signature is not required for projects exempt from full
University review. Please use only a disclaimer format for subjects
to read before giving their oral consent to the research. The Human
Subjects Project Approval Form is filed in the office of the Director
of Research, if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH/ss
1982

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APPENDIX B

Disclaimer

Effects of Structured Education for
Head and Neck Cancer Patients
Receiving Radiation Therapy

The purpose of this study is to see what patients with head and neck cancer do to care for themselves concerning any side-effects which may develop as a result of their radiation therapy. The purpose is also to assess the affective state (Moods) of these same patients. You will be asked to fill out a questionnaire called POMS, which will take five minutes. This questionnaire will give me information about how you are feeling.

You will also be asked to keep a log or diary during your radiation therapy. You will be asked to write down any side-effects which you may experience, rate its severity, describe what you did to alleviate the side-effect, rate the effectiveness of the action and identify the source of information for that action. You will keep this log throughout the full course of radiation therapy. The results of this log may be used to help future patients deal with their side-effects.

I will also look at your chart to obtain some information about your general health and your cancer. Your name will not appear on any of these forms, only your patient identification number. This number will help me identify your chart. All information will remain confidential.

There will be no cost to you nor any potential risks. You are free to ask any questions or withdraw from the study at any time. Your decision to participate, to not participate, or to change your mind about participation, will not in any way influence the care which you are receiving.

Your voluntary participation, indicated by filling out the form, is requested. By doing so, you will be giving your consent to participate in the study.

Sandra Lynn Gerhart Kreamer, R.N., B.S.N.
APPENDIX C
Profile of Mood States

Below is a list of words that describe feelings people have. Please read each one carefully. Then fill in ONE space under the answer to the right which best describes HOW YOU HAVE BEEN FEELING DURING THE PAST WEEK INCLUDING TODAY.

| The numbers refer to these grades: 1 Not at all 2 A little 3 = Moderate 4 = Quite a bit 5 = Extremely |
| 21. Hopeless | 22. Reassured |
| 25. Sym pathetic | 26. Unhappy |
| 27. Restless | 28. Unmotivated |
| 29. At ease | 30. Unhelpful |
| 31. Depressed | 32. Unhappy |
| 33. Lonely | 34. Unsympathetic |
| 35. Disheartened | 36. Unkind |
| 37. Troubled | 38. Unfriendly |
| 39. Ashamed | 40. Unattractive |
| 41. Frail |

NAME ___________________________________________ DATE _______________________

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## Self-Care Behaviors Log

<table>
<thead>
<tr>
<th>Experienced Side Effect(s) Due to Radiation Therapy</th>
<th>Actions Taken</th>
<th>Effectiveness of Actions</th>
<th>Sources of Suggestions for Actions</th>
</tr>
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<td>a) Severity of Side Effect, i.e. how intense is it?</td>
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<td>1 2 3 4 5</td>
<td>a. __________________________</td>
</tr>
<tr>
<td>Date of onset: ______________________</td>
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</tr>
<tr>
<td>barely noticeable</td>
<td>most severe</td>
<td></td>
<td></td>
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<tr>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Distress of Side Effect, i.e. how much does it bother you?</td>
<td>b. __________________________</td>
<td>1 2 3 4 5</td>
<td>b. __________________________</td>
</tr>
<tr>
<td>Date of onset: ______________________</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>minor</td>
<td>extremely annoying distressing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date of onset: ______________________</td>
<td></td>
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</table>

**Code:** __________

Self-Care Behavior Log

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**APPENDIX D**
APPENDIX E

Help Yourself Deal With Radiation Therapy
Cancer... What Is It

-The entire human body is made up of cells which continually divide to reproduce themselves. When cells divide they go through a "cell cycle."

-Cells divide to repair damage done to the body, and to replace dead cells with new ones.
-When normal cells divide, they stop at a certain level when their task is completed.
-Cancer cells do not react to this signal to stop dividing. They continue to grow with no control.
-This results in lumps or masses of cells called tumors.
-These cells invade and destroy nearby tissue and organs. They may spread to other parts of the body if their growth is not stopped.
-Radiation therapy is one way to stop this uncontrolled growth.
Radiation Therapy

- The latest information states that 41% of all patients with cancer can now be cured by one of the treatment methods available.

- Radiation is one of these methods.

- Radiation is the use of high energy rays to kill cancer cells and stop them from growing and dividing.

- The goal of radiation therapy is to destroy the cancer cells, while doing as little damage to the surrounding normal tissue as possible.

- Cancer cells are more sensitive to radiation than are normal cells.

- Healthy cells are more resistant to radiation and have a better ability to heal themselves.

- Radiation treatments are usually given Monday through Friday with Saturday and Sunday as rest days for the normal cells to recuperate.

- Radiation is delivered by a large machine which may make noise similar to a large vacuum cleaner.

- The actual treatment takes only a few minutes, and you will not feel anything.

- You WILL NOT become radioactive.

- Your skin will be marked with a marking pen to allow the technician to deliver the treatment beams to the same spot with every treatment.

- Radiation kills only cells within the beam of its rays. This is the reason the area is carefully calculated and marked for each individual.
Side Effects

-Radiation therapy also affects normal cells it may come into contact with.
-Because of this, there may be some side effects.
-Patients who receive radiation therapy to the head and neck area may experience one or more of these side effects:
  - Dry and/or sore mouth & throat
  - Nausea
  - Loss of appetite
  - Weakness and fatigue
  - Skin reactions

-On the next few pages you will find some suggestions to help you deal with these side effects IF and when they do occur.
-These side effects usually do not develop until you have received treatment for at least three weeks.
Dry and/or Sore Mouth & Throat

-Many times tumors in the head and neck region are underneath the tissue of the throat and mouth.

-The radiation has to pass through the throat and mouth tissue to reach the tumor.

-Because of this, your throat and mouth may need some special attention.

-Some suggestions are:

-Drink plenty of liquids to keep your mouth moist. Liquids could include water, non-citrus fruit juices, milk, and high protein, high calorie diet supplements such as Ensure or Sustacal.

-Clean your teeth and gums at least four times a day.

-Use a SOFT bristle toothbrush. It cleans effectively, yet irritates as little as possible.

-Using a fluoride toothpaste will also help protect your teeth.

-If your mouth and gums become too sore to brush, use a mouthwash made up of one quart warm water, with one teaspoon of salt added. Rinse your mouth at least after every meal.

-Avoid Commercial mouthwashes. They usually contain alcohol, which has a drying effect on the mouth.
-If you wear dentures, be sure they fit properly. Loose dentures can cause trauma to the gums and mouth.

-If your dentures do not fit properly, have your dentist check them. If this is not possible, wear your dentures only when necessary.

-Avoid foods which are very hot or very cold.

-Avoid citrus fruits and acid vegetables such as oranges, grapefruit, tomatoes or lemons. They may irritate your mouth. In place of these substitute other less irritating fruits and vegetables such as apricots, pears, apples and peaches.

-Highly spiced foods such as those containing pepper, chili powder or nutmeg may also irritate your sore mouth and throat. Try and avoid those foods.

-Choose soft foods such as mashed potatoes, yogurt, scrambled or poached eggs, custards, ricotta cheese, milkshakes, pudding, gelatins, creamy cereals, macaroni and cheese.

-Cut food into small pieces and moisten them with gravy, salad dressing, mayonnaise, sour cream, yogurt, or anything else that makes them go down more smoothly. These same substances also help add calories to your diet.

-In spite of these restrictions, it is very important that you eat well during radiation therapy.

-The National Cancer Institute has published a very good booklet, Eating Hints, which has further information on diet, menus and food substitutes. You may obtain this book free by asking the nurse for one of these in the radiation-oncology department.
-Avoid smoking and alcoholic beverages during the course of your treatment. Both are very irritating substances to the mucous membranes of the mouth and throat.

-A humidifier or steamkettle in the bedroom may help, if your house is heated with dry heat.

-Your doctor may prescribe medications such as Tylenol with Codiene elixir or Xylocaine liquid to swish and swallow, if the pain in your mouth gets too bad.

Nausea

-Nausea may or may not occur during your radiation therapy.

-The reason for the nausea may vary from one episode to the next.

-The best way to deal with nausea is to try and determine what has caused it, and get rid of that cause.

-Your saliva may get thicker during radiation, making it more difficult for you to swallow. The thickness of the saliva may cause nausea.

-Drinking fluids may make your saliva less thick and easier to swallow.

-Your taste for foods may change. Meats may taste bitter, or other foods sour or rancid. This may cause nausea. Try and substitute another food in the place of any which have an undesirable taste during therapy.

-Usually this taste change will go back to normal a few weeks after the end of your treatment.
Sometimes, you will not be able to determine what is causing the nausea. Here are some good general principles to follow if that occurs:

- If you do not feel well after radiation therapy, try not eating for several hours before your next treatment.
- If you do not feel well before your treatment, try eating lightly before your treatment (toast, crackers, juice).
- Eat and drink slowly.
- Rest after meals. Activity can aggravate the nausea. If you recline after meals, make sure your head is 4 inches higher than your feet.
- If nausea and vomiting persists, ask your doctor for an anti-nausea medication, and take it ½ to 1 hour before eating or before treatment, whichever is producing the nausea.

Loss Of Appetite

- The presence of a sore and/or dry mouth and throat or nausea may lead to the loss of your appetite.
- In order to help your body fight off the cancer, repair injured cells, and restore its strength, you must supply nutrients through what you eat.
- To supply the proper nutrients you must eat a well balanced diet. A well balanced diet should include at least one serving from each of these groups: 1) meat, fish and poultry, 2) fruits and vegetables, 3) breads and cereals, 4) milk and milk products.
- It may be difficult to eat a well balanced diet, but here are some tips to help accomplish the task.

- Eat small frequent snacks, which include your best tolerated foods, even though you are not hungry.

- Eat when you are hungry, even though it is not mealtime.

- Exercise a few minutes, about one half hour before a meal, to make yourself hungrier.

- Eat foods high in protein. Some examples are meat, milk, eggs, peanut butter, cream cheese and nuts.

- Meat may taste bitter, so you may want to avoid it as your main source of protein. (Page 18 of Eating Hints has some good examples).

- Try adding extra calories into your diet by adding mayonnaise, peanut butter, honey, cream, yogurt and sour cream into your foods (page 19 & 20 of Eating Hints has some good suggestions).

- Some days you may feel more like eating than others. Take advantage of those days.

- Vary odors and textures of food from one meal to the next, to increase your appetite.

- Keep snacks handy for nibbling: popsicles, ice cream, cheese, and dried fruits are some suggestions.

- Eat a snack before you go to bed, in addition to your other meals.
Tiredness Or Fatigue

- This is common with radiation. Your body is working hard to fight the cancer and build new cells.
- Rest when you are tired.
- Take frequent planned rest periods, don't push yourself.
- Take advantage of pre-made and frozen meals.
- Allow people to help you with daily tasks such as cleaning or cooking.

Skin Reactions

- Sometimes the skin of the treatment area may begin to look reddened, irritated, tanned or sunburned. This should be expected and should clear up after the treatments are finished.
- In the meantime:
  - Be gentle with the skin in the treated area. Try not to irritate it.
  - Try wearing only loose fitting, 100% cotton clothing.
  - Use only warm water on the area, never hot.
  - Avoid using perfumes, soaps, cosmetics, ointments, heat lamps or hot water bottles on the treated area. They tend to further irritate the skin.
  - If you must shave the area, use only an electric razor.
- Protect the area from sunlight or extremely cold weather.
- Do not scratch the treated area. If it begins to itch, apply a small amount of cornstarch.
- Observe the area closely everyday. If you note signs of moist drainage, stickiness, blisters or infection, report it to the doctor or nurse immediately.
APPENDIX F

Demographic Data Sheet

CHART INFORMATION
1) Patient ID# __________ 2) Age ________ 3) Sex ________ 4) Race ________  
5) Physician's name ____________________________  
6) Medical diagnosis other than cancer ____________________________  
7) Type of cancer ____________________________  
8) Date of 1st radiation treatment ____________________________  
9) Expected total number of treatments ____________________________  
10) Cancer prognosis: a) adjuvant ________ b) advanced ________  
11) Other cancer treatment patient is receiving concurrent with radiotherapy:  
    ________ a) Surgery  
    ________ b) Chemotherapy  
    ________ c) Immunotherapy  
12) Other cancer treatments patient received previous to initiation of current radiotherapy:  
    ________ a) Surgery  
    ________ b) Radiation  
    ________ c) Chemotherapy  
    ________ d) Immunotherapy  

PATIENT INFORMATION
13) Date of first interview ____________________________  
14) Validate number 11 and 12 with patient ____________________________  
15) Is the purpose of your radiation therapy to cure the disease?  
    Yes ________ No ________
Demographic data sheet
Page Two

Patient Information (Continued)

16) Marital Status: ________________________________
   _____ a) Married
   _____ b) Single
   _____ c) Divorced
   _____ d) Separated

17) Educational level: (highest level achieved)
   _____ a) Less than high school
   _____ b) High school
   _____ c) Some college or advanced training
   _____ d) College degree
   _____ e) More than a college degree

18) What did/do you do for a living? ________________________________

19) Do you drink alcohol? ________________________________
    If yes, how much, how often? ________________________________

20) Do you smoke cigarettes? ________ yes ________ no
    If yes, how many, how long? ________________________________
    Do you smoke pipes? ________yes ________no
    Do you smoke cigars? ________yes ________no
LIST OF REFERENCES


*Outcome Standards for Cancer Nursing Practice*. American Nurses Association and Oncology Nursing Society, Kansas City, 1979.


