

**THE RELATIONSHIP BETWEEN SYMPTOM DISTRESS
AND QUALITY OF LIFE
IN PATIENTS WITH ESOPHAGEAL CANCER**

- A PILOT STUDY

by

WENDY ANN MORGAN-ECKLEY

A THESIS

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ABSTRACT

Esophageal cancer primarily occurs in people over 50 years of age. According to statistics compiled by the Manitoba Cancer Treatment and Research Foundation, the incidence of esophageal cancer has almost doubled in the past twenty years. Often by the time that esophageal cancer is discovered, it is too late to cure the advanced disease. Treatment of the disease includes major surgery, or in the case of advanced disease, palliative treatment. Clinical improvement allows the patients to be able to eat and spend time with their families in relative comfort for their remaining lifetime.

The aim of this study was to describe the relationships among symptom distress, type of treatment, and quality of life in patients with esophageal cancer who experience surgical or palliative treatments for their disease. Five questionnaires were utilized: the Functional Living Index - Cancer (FLIC) (Schipper et al, 1984) as a global measure of quality of life, the Symptom Distress Scale (SDS) (McCorkle & Young, 1981), a demographic questionnaire, and two qualitative questionnaires which provided information about how patients perceived their disease and the treatment. The reliability estimates of the scales were high at time one and time two (FLIC 0.87 and 0.89; SDS 0.90 and 0.83) as measured by Cronbach's alpha.

The study was designed for a sample size of thirty, however, only sixteen patients were able to provide data at time one and fourteen for the final analysis. The mean age of the patients was 70 years and there were more men than women (2.2:1); these statistics are representative of the population identified by Manitoba Cancer Foundation statistics.

The results showed that for the majority of patients (n=7) symptom distress increased and quality of life decreased regardless of the treatment. There was a strong significant negative correlation between symptom distress and quality of life at time one ($r = -0.54$, $p = 0.004$) and time two ($r = -0.80$, $p = 0.001$). There were significant negative correlations for quality of life ($z = -2.26$, $p = 0.01$) and symptom distress ($z = -1.96$, $p = 0.05$) at time one according to treatment. These results showed that palliative patients are likely sicker at time one than are patients undergoing a surgical procedure.

Further study is needed with a larger sample size to validate these results. A qualitative study to identify helpful behaviours by nurses and other health care professionals would also benefit these patients.

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CHAPTER ONE

STATEMENT OF THE PROBLEM

Although technology has helped to provide advanced health care to society, neither the technology itself nor the quality of life for persons receiving this technology have been examined. Specialized treatment protocols are meant to increase longevity and improve the quality of life for patients (Storch, 1982). When it is evident that the patient can no longer be cured, then palliation becomes a viable option.

The most recent data from the Canadian Cancer Society (1987) reported 947 actual cases of esophageal cancer in Canada. According to statistics compiled by the Manitoba Cancer Treatment and Research Foundation, the incidence of esophageal cancer has almost doubled in the past twenty years. In 1991, 42 Manitobans were diagnosed with cancer of the esophagus (Manitoba Cancer Treatment and Research Foundation Annual Report, 1991). Esophageal cancer primarily occurs in people over 50 years of age. The three major symptoms that these patients experience are dysphagia, chest pain, and weight loss. Usually by the time that esophageal cancer is discovered, it is too late to cure the advanced disease. Treatment options include major surgery such as esophagectomy and esophageal resection, and palliative procedures that include laser treatment and insertion of an esophageal prosthesis, radiation, chemotherapy, and radiation and chemotherapy, in combination.

Surgery is appropriate if there is any chance at all for a cure and no medical contraindications exist (Fleischer, 1984). Two surgical procedures that are commonly used in Manitoba to treat carcinoma of the esophagus are esophageal replacement with a segment of the bowel and a pull-through procedure where the stomach is anastomosed to the remaining segment of the esophagus following a resection.

These procedures have a high degree of morbidity and mortality. Fleischer (1990) reported that the results of surgery are poor and survival rates for five years are only about five percent; therefore, the goal of treatment is palliation, that is to provide comfort and improve the quality of life of the patient. Studies show that palliative treatment provides clinical improvement for patients, but none of the studies measured the quality of life and symptom distress for these patients.

Palliative treatment is appropriate if quality of life is improved, if it is performed easily, and if the patient is not harmed (Sander, Poehl, & Spuhler, 1984). One of the first reported studies on palliative treatment of esophageal cancer is by Souttar (1924). He inserted a flexible metal tube into the esophagus to open the stricture caused by the malignant growth. The tube remained in the esophagus indefinitely and the author stated that it appeared to be a satisfactory method for treating strictures due to esophageal cancer. This treatment is similar to one used today, where an endoprosthesis is inserted into the esophagus to relieve the obstruction.

There are two different methods of palliative treatment in common use for patients with esophageal cancer. One involves inserting an endoprosthesis in the esophagus, and the other treats the tumour with the Neodymium: yttrium aluminum garnet (Nd:YAG) laser. There should be minimal risk of morbidity and mortality to justify either the use of the laser or the insertion of an endoprosthesis. Patients with esophageal cancer are usually poor surgical risks due to the disease process, and the purpose of the treatment is to improve the quality of their life, not create more problems for them (Fuchs, Freys, Schaube, & Eckstein, 1990). Based on anecdotal records, both procedures relieve the symptoms of dysphagia in the remaining six to twelve

months of the patient's life (Fleischer, 1990). As the dysphagia is relieved, the patient is able to take in more nourishment and thereby relieve the malnutrition.

Unfortunately, neither of these treatments will alleviate chest pain. Over 30 studies report a 96 percent success rate for obtaining a patent lumen in the esophagus after laser treatment with a functional benefit reported in 75 percent of the cases (Fleischer, 1990). A properly placed endoprosthesis results in a 90 percent improvement in symptoms of dysphagia but patients must make some modifications in their diet (Boyce, 1988). Once the endoprosthesis is inserted, no further treatment is usually necessary. The laser procedure may be staged over several days, or weeks depending on the size of the tumour and the physical condition of the patient. The patient may return for further treatment if the tumour continues to grow and obstruct the esophagus again. The palliative goal for these patients is to attain some clinical improvement allowing the patient to be able to eat and spend time with his/her family in relative comfort for the remaining lifetime.

Purpose of the Study

Palliative treatments for esophageal cancer patients are intended to be less traumatic than surgery and to decrease the hospital stay of the patient and improve the comfort level and quality of remaining life of the patient (Cerne, 1988). Lewis (1982) found that patients experienced increased control over the quality of their lives if symptom management is effective. Lewis also found that late stage cancer patients would have improved quality of life when they experienced greater control as measured by self-esteem ($r = -.33, p = .001$), anxiety ($r = -.30, p = .001$) and perceived meaningfulness ($r = -.45, p = .001$). However, based on the literature and personal clinical observations, quality of

life in patients with esophageal cancer has, in the past, been poor due to their inability to swallow and maintain adequate nutrition. Studies have shown that either palliative treatment or surgery opens the esophagus and permits the patient to resume oral intake; but no studies have been conducted to determine the quality of life for these patients. Without sound empirical work related to quality of life in persons with esophageal carcinoma, nurses and other health care professionals lack the knowledge to assist patients and families to make informed decisions about treatment. Administrators must also consider issues of quality of life because surgical and palliative treatments are expensive technologies that warrant thoughtful and prudent use. If the quality of life is not improved for these patients, then the efficacy of the treatment may be in question.

Given the lack of research related to quality of life of esophageal cancer patients, a descriptive study was judged to be the appropriate level of investigation to pursue. Such studies seek to describe the characteristics of a group by obtaining data from small, representative samples of the population (Kerlinger, 1979). Therefore, the aim of this research was to describe the relationships among symptom distress, type of treatment, and quality of life in patients with esophageal cancer.

Research questions

Three research questions were identified to direct the study:

1. What is the relationship between the type of treatment for esophageal cancer (that is, palliative or surgical) and symptom distress of esophageal cancer patients?
2. What is the relationship between the type of treatment for esophageal cancer and quality of life of esophageal cancer patients as measured by a commonly applied instrument, i.e. the Functional Living Index-Cancer.

3. What is the relationship between quality of life and symptom distress experienced by esophageal cancer patients before and after treatment?

It was hypothesized that either treatment would ease symptom distress and that as symptom distress was alleviated, quality of life would improve for these patients.

Summary

Empirically based studies to evaluate the quality of life and symptom distress of patients undergoing treatment for esophageal cancer are needed. Health care professionals caring for these patients both in hospital and through home care services are continuously faced with the challenges of helping patients cope with changes in quality of life due to the effects of the disease and symptom progression. Until health care professionals have a clearer understanding about the impact that different care and treatment approaches have on patients' lives based on systematic inquiry from the patient's own perspective, approaches to care will be based on little more than trial-and-error efforts. A first step to this understanding is the need for a careful description of the relationships among symptom distress, type of treatment, and quality of life for patients with esophageal cancer.

CHAPTER TWO

LITERATURE REVIEW

The literature reviewed for this study was grouped into several different areas: nursing and palliative care, surgical treatment of esophageal cancer, palliative treatment including palliative laser surgery and insertion of an endoprosthesis for treatment of esophageal cancer, quality of life, and quality of life measures. Each area will be examined separately. The demographic characteristics of the population under study were also reviewed and are described here.

Nursing and Palliative Care

Scanlon (1989) stated that a holistic approach is necessary when caring for a dying patient. This includes understanding how the disease will progress and how to intervene appropriately to ease symptom distress. The emphasis in palliative treatment is symptom control.

There are instances in which a surgical procedure may be helpful in a palliative setting, particularly when providing relief for an obstruction. The goal of the treatment is to relieve symptom distress and thereby improve the quality of life for the patient. The patient needs to understand the risks and benefits of such procedures. The nurse's role in these situations is to provide support and help the patient in decision making (Degner, 1991; Davies, & Oberle, 1990).

Davies and Oberle (1990) conducted a study to describe the clinical component of the nurse's role in palliative care. The researchers conducted an indepth open ended interview with an expert palliative care nurse, in which the nurse told her story of caring for dying patients. The analysis

identified six dimensions of the supportive role in palliative care: valuing, connecting, empowering, doing for, finding meaning, and preserving own integrity. The doing for role included all the physical care required for the patient. A major aspect of this dimension was pain and symptom control. Their work supports the need for more study on the best methods of symptom control and quality of life for cancer patients.

Degner, Henteleff, and Ringer (1987) conducted a study to assess palliative care services. The sample consisted of 29 patients, three physicians, and 16 primary nurses. They employed three different measures in their study. The Quality of Life Index developed by Spitzer, an objective measure of quality of life, obtained low estimates of reliability (Cronbach's alpha coefficient for nurses = 0.49, 0.40; for physicians = 0.40, 0.36). The Symptom Distress Scale (SDS) developed by McCorkle & Young (1978) was also used. The results showed that scores decreased between admission (mean 33.8) and one week post-admission (mean 25.7) which indicated improved quality of life for patients ($t=4.27$, $p=0.0005$). Reliability of the SDS using Cronbach's alpha at the two testing times was .67 and .72 respectively. The Social Dependency Scale by Benoliel, McCorkle, and Young was reported to be a reliable measure of personal and social competence (alphas = 0.79, 0.82), but did not detect significant improvements in the patients.

The literature shows that symptom distress is an important consideration in a palliative care setting. Relief of symptoms either by nursing measures or palliative treatment may help to improve the quality of life of the patient.

Surgical Treatment

The literature does not reveal any studies related to the quality of life for patients having surgical treatment of esophageal cancer. Surgical treatment of esophageal cancer is an appropriate course if there is any chance of a cure. The two procedures most commonly performed today are esophageal replacement with a segment of bowel and a pull-through procedure where the stomach is anastomosed to the remaining segment of esophagus following a resection (Fleischer, 1984). Either procedure presents a challenge for nurses as the patients are often elderly, are pre-operatively debilitated and frequently experience complications.

Earlam and Cunha-Melo (1980) reviewed the literature during a twenty year period between 1960 and 1979 to determine the incidence, treatment, and prognosis for patients with esophageal cancer. They found that there is no perfect study. Of the studies that were reviewed, they found that the mortality rate after resection was 13% and only 18% survive one year. Most studies concentrated on quantity of life rather than quality and no quality of life measures were reported. The general impression appeared to be that no patient resumed their previous lifestyle following resection. The question that the authors posed after their review was: would patients consent to major surgical procedure if they were properly informed about the outcomes of treatment?

Major surgery poses many risks and complications for the patient with esophageal cancer. The literature points to the need for patients to be properly informed regarding treatment options and risks in order to make informed decisions about their care.

Palliative Laser Surgery

A search of the literature over the past ten years did not reveal any studies related to quality of life for patients undergoing palliative surgical treatment for esophageal cancer. The majority of the literature for this group of patients concerns the treatment process and outcomes with emphasis on survival rates rather than on the quality of life for these patients (Holmes & Dickerson, 1987).

Fleischer, Kessler and Haye (1982) conducted the first reported study on the palliative treatment of esophageal cancer with Nd:YAG laser. They treated five patients who had a history of weight loss and dysphagia with a positive diagnosis of carcinoma of the esophagus. Relief of symptoms in all five patients was shown as indicated by tumour destruction and ability to eat solid foods. The patients received 4 to 13 treatments over a period of 8 to 28 days. Appealing aspects of this treatment were that the laser surgery was technically easy and could be done under local anaesthetic. In a second study by Fleischer and Sivak (1984), fifteen patients with adenocarcinoma of the gastric cardia were treated with Nd:YAG laser. These patients underwent between one to five treatments over a period of one to twelve days. All patients had a poor prognosis and all showed clinical improvement by barium swallow over the course of the treatment. The authors stated that the aim of the treatment was palliative, to allow the patient the opportunity to increase their intake of food and thereby improve the quality of their life.

Riemann, Lux, and Demling (1985) treated seventeen patients diagnosed with esophageal cancer with the Nd:YAG laser. The patients underwent one to five treatments. Fourteen of the patients demonstrated clinical improvement on barium swallow, decreased symptoms of dysphagia, and ability to eat solid food. None of these studies reported findings related to quality of

life for their patients. Functional benefit was reported by clinicians; however, systematic assessment of functional ability as perceived by the patient was not assessed.

In an unrelated study, McGowan, Barr, and Krasner (1989) conducted a prospective study of the quality of life for patients with inoperable rectal cancer. The question posed was whether the Nd:YAG laser treatment improved the quality of life and the dying process experienced by these patients. The subjects included 14 patients treated with Nd:YAG laser for adenocarcinoma of the rectum. The quality of life of the patients was measured before, during, and after the laser treatments using the Quality of Life Index (QLI) developed by Spitzer, Dobson, Hall, Chesterman, Levi, Shepherd, Battista, & Catchlove (1981) and the Linear Analogue Self-Assessment (LASA) developed by Priestman, & Baum (1976). In an interview by the physician the QLI concerned itself with five areas: activity, living, health, support, and outlook on life. The LASA was completed by the patient and included emotional, physical, and social experiences measured by twenty-five visual analogue scales. A correlation coefficient of 0.79 between the QLI and the LASA scores was reported ($p < 0.001$). The test-retest was done by a different physician 24 hours after the first assessment and evidenced stability over time (QLI 0.82, LASA 0.78), although inter rater reliability was not reported and may have had an effect on these results. All patients showed clinical improvement for 5 to 24 weeks post treatment and eight patients were still alive at the time of printing with five showing improved quality of life. The researchers concluded that the quality of life was improved (QLI $p = 0.002$; LASA $p = 0.002$), but if the patients were experiencing a great deal of pain (no measure cited) the therapy was not effective. Therefore, careful selection of patients may be the predominant factor influencing treatment outcomes.

The studies show that laser surgery has been clinically successful in relieving obstruction due to cancer of the esophagus, but no studies have specifically measured quality of life and its relationship to symptom distress in patients with esophageal cancer. This question was addressed in the study reported here.

Insertion of an Endoprosthesis

The purpose of inserting an endoprosthesis is to improve the quality of life of the patients by relieving dysphagia, restoring the pleasure of eating, and possibly improving the physical status of the patients by improving their nutritional intake. Boyce (1988) reports a 90 percent clinical improvement in dysphagia as measured by barium swallow, after insertion of an endoprosthesis to relieve esophageal obstruction due to a cancerous tumour. It is a rapid, safe, and effective method of treatment. The average survival for these patients is three to six months. Complications that may result from this treatment include perforation of the esophagus, displacement of the prosthesis, food obstruction, tumour overgrowth, pain and bleeding.

Den Hartog, et al (1979) conducted a study over five years that included 200 patients who had a plastic prosthesis inserted to relieve obstruction due to esophagogastric cancer. The researchers reported good palliation, but unfortunately did not report how this was measured. The researchers did report that 53 percent of patients survived more than two months and five patients survived more than one year. The results support the conclusion that insertion of a prosthesis to relieve obstruction due to esophageal cancer has satisfactory results for improving length of life; however, quality of life was not measured in this study.

Ogilvie, Dronfield, Ferguson, and Atkinson (1982) conducted a study with 118 patients who experienced palliative intubation of the esophagus. One hundred and twelve of these patients, in response to a five point Likert-type scale, reported satisfactory swallowing after the procedure. The degree of dysphagia was measured prior to intubation and post-intubation. Although specific information about when the scale was completed or by whom are not provided, the researchers stated that the relief of dysphagia resulted in increased feelings of well-being and stopped weight loss, but the measures that were used were not cited. The researchers also stated that the value of the procedure lies in improving quality of life by correcting dysphagia and allowing the patient to be cared for at home.

Insertion of an endoprosthesis to relieve obstruction due to cancer of the esophagus has also shown to be effective clinically (Boyce, 1990; Den Hartog et al, 1979; Ogilvie et al, 1982). A review of the literature indicated that further study was needed to determine if the quality of life for these patients is in fact improved after the treatment.

Quality of life

Germino (1987) stated that quality of life is a relevant outcome measure in cancer nursing particularly when considering symptom distress and management. A diagnosis of cancer, the symptoms associated with the disease, and the treatment may result in changes in health that ultimately affect quality of life. The symptoms are not only problematic for the patient, but also for family and caregivers associated with the patients. The relationships between quality of life and symptom distress have not been clearly defined.

Calman (1984) hypothesized that quality of life measures the difference between the ambitions of an individual, and that individual's present

experience. Quality of life includes all life's experiences and the impact of illness and treatment. Patients may report improved quality of life when facing a life threatening illness because they have adjusted their expectations to a more realistic level.

Graham and Longman (1987) investigated the quality of life in patients with malignant melanoma and its relationship to symptom distress, social dependency, behaviour-morale, and life change. Their initial hypothesis was that quality of life is inversely proportional to symptom distress, and social dependency. They also hypothesized that behaviour-morale which is the subject's perceived morale as measured by the interviewer would be positively associated with quality of life. Graham and Longman used five instruments to measure quality of life in 60 patients with malignant melanoma. The Quality of Life Questionnaire developed by Graham and Longman consisted of two questions which rated the quality of the patient's life and the patient's degree of satisfaction with their current quality of life. There was a strong association between the two questions ($r=0.81$, $p=0.0001$). They also used the Symptom Distress Scale (coefficient alpha 0.82) and the Social Dependency Scale (coefficient alpha 0.90). The behaviour-morale scale developed by MacElveen was completed by the interviewer and consisted of 17 items intended to measure behaviour-morale through observation. The life change scale has 18 items to measure change since the time of diagnosis in the area of daily living. The results supported all three hypotheses: symptom distress and social dependency were inversely proportional to quality of life ($r= -0.34$ and $r= -0.28$ respectively, $p=0.004$) and behaviour-morale was positively associated with quality of life

($r=0.38$, $p=0.001$). The researchers identified that the findings are tentative due to the small sample size, but do support the proposition that persons realign their values when facing a life-threatening disease.

Quality of life is a complex concept that changes over time for an individual. Symptom distress is only one aspect of quality of life. Measuring quality of life and its relationship to symptom distress in patients with cancer who experience different treatments allows the health care professional to assist the patient in making informed decisions about treatments that are appropriate for them.

Quality of Life Measures

Questionnaires should allow for repeated use, and be comprehensive yet sensitive enough to allow for comparisons between groups (Schipper, 1983). It is difficult to define what is to be measured because quality of life is a continuous variable and the patients serve as their own controls. Any index should be cancer specific, patient self-administered, generally applicable, and sensitive across a range of clinical practice. It should be short, repeatable, and have demonstrated validity and reliability (Schipper & Levitt, 1985). Guyatt, Bombardier and Tugwell (1986) stated that disease specific instruments should be developed to measure quality of life and should be based on what is important to the patient. Aaronson (1988) also supports the notion of supplementing a generic quality of life measure with a disease or treatment specific instrument. Three quality of life measures were examined as well as the Symptom Distress Scale developed by McCorkle and Young (1978).

Linear Analogue Self-Assessment Scale (LASA) was developed by Priestman and Baum (1976) to measure the subjective effects of treatment in women with breast cancer. The patients were asked to mark a point on a ten

centimeter line with descriptive extremes at either end that was appropriate to their feelings at the time. The scores were then summed out of one hundred. The patient completed the questionnaire in the presence of a physician and then alone 24 hours later to determine if the physician's presence had an effect on the scoring. The correlation between the two scores was 0.87 ($n=29$, $p=0.05$). The authors stated that all factors were given equal weighting which may not be an accurate assumption about how individuals evaluate elements of a quality of life assessment. However, the scale was readily comprehensive, and convenient.

Schipper and Levitt (1985) criticized the instrument as not being adequately validated because it was tested with only one disease group using a small sample size. The early work of Priestman and Baum (1976) did demonstrate the viability of measuring quality of life. Selby and Robertson (1987) used the LASA and reported it to be reliable (correlation coefficient for test-retest >0.70) and able to detect differences over time and between groups. McGowan et al (1989) administered the LASA to patients in their quality of life study. Their results showed high reliability with a test-retest of 0.78 and 0.82.

The LASA scales appear to be more difficult to understand, particularly when used with an older population. Although the instrument appears reliable, its utility has not been tested with cancer patients representing a wide range of diagnostic categories.

Quality of Life Index (QLI) is an objective measure developed by Spitzer, Dobson, Hall, Chesterman, Levi, Shepherd, Battista, and Catchlove (1981). It was designed for use by physicians as a global measure of quality of life and consists of five items that are scored on a scale from one to ten. Internal consistency was reported using Cronbach's alpha of 0.78. Reasonable interrater agreements were reported by these authors (Spitzer et al, 1981) in an Australian study ($r=0.61$, $p=0.001$, $n=161$) and in a Canadian study ($r=0.69$, $p=0.001$, $n=51$).

Selby and Robertson (1987) stated that the scale was completed quickly and performed well in validation exercises that involved comparisons with linear analogue scales and that it also distinguished between clinically distinct groups of patients. They confirmed that if it is used alone, the QLI fails to sample many important areas of relevance to clinical studies including symptoms. Mor (1987) also reported that the scale was easily used and could be summed into a single score. Mor used the QLI in three separate populations of cancer patients at different stages of their disease: newly diagnosed, treated for recurrence or progression, and the terminally ill. The samples came from three different studies of cancer patients. Data was collected from personal interviews with primary care givers, patients during an interview, and telephone interviews with patients. The mean QLI for each group was significantly different ($p=0.001$): terminal patients 3.9, active treatment patients 7.5, and newly diagnosed patients 8.1, although not all newly diagnosed patients had the highest scores nor did all terminal patients have the lowest scores. Mor concluded that patients and families are able to provide information on quality of life and that the QLI appears useful in documenting patients declines as death approaches. Degner et al (1987) did not find the QLI to be a reliable measure, but in the McGowan et al (1989) study, the data was collected by physicians which may account for the differences in the findings for the two studies. Degner et al (1987) found poor interrater reliability between nurses and physicians with the QLI ($t=5.73$, $p=0.0001$). Low reliability may be due to the short questionnaire. It may also occur because nurses and physicians view patients differently.

Given that the QLI is purported to be an objective measure of quality of life and quality of life in this study was considered in a subjective view of the patient, the QLI was not selected.

Functional Living Index - Cancer (FLIC) is a subjective measure developed by Schipper, Clinch, McMurray, and Levitt (1984). It is a cancer specific, functionally oriented measure. It is an overall global measure of quality of life structured according to a Likert-type format. A group of eleven people including patients, family members, physicians, registered nurses, psychologists and the clergy developed questions that were judged to measure quality of life. After several trials, the final questionnaire was reduced to twenty-two questions, from an initial 250, that take approximately 10 minutes to complete. The scores may be summed to obtain an overall score for quality of life. Correlation coefficients between the FLIC and other quality of life measures reported in subsequent studies range from -0.441 to -0.724 ($p=0.0005$). A high FLIC score indicates a good quality of life, whereas for other quality of life measures used in this comparison, the reverse is true.

Selby and Robertson (1987) stated that the FLIC is a comprehensive attempt to develop a generally applicable measure of quality of life. It is easily completed by the patient and content validity is inherent in the design. They identified that it is not flexible enough to be used as the only measure in disease specific clinical trials because major symptom areas are not included. Schipper et al (1984) after further validation studies stated that the instrument is sensitive enough to distinguish between patients either in follow up care, hospital care, or palliative care.

The FLIC is a comprehensive measure of quality of life that is easy to understand and can be completed quickly. These are important considerations when dealing with a debilitated group of patients.

Symptom Distress Scale (SDS) was developed by McCorkle and Young in 1978. The measure consists of thirteen symptoms of concern to patients. The concerns are rated on a Likert-type scale from one (least distress)

to five (most distress). The scale takes approximately five minutes to complete. Reliability was assessed using Cronbach's alpha. A standardized item alpha of 0.83 was reported. All the symptoms can be used together or they may be examined individually. Given over time, the scale is sensitive to change.

McCorkle (1981) used the scale to examine symptom distress in 52 subjects, 28 with cancer of the lung and 24 with myocardial infarction. The subjects with cancer reported higher distress in all thirteen symptoms with total symptom distress scores ranging from 13 to 44, with a mean of 27. The scores for the subjects with myocardial infarction ranged from 13 to 28, with a mean of 18. The author advocates the use of scales as they are non-invasive, and the content includes data that is routinely shared with nurses. The items are sensitive to change over time. McCorkle (1981) states that the "goal of clinical nursing research and practice in cancer is to identify and attend to the combination of factors that will decrease the impingements of a person's illness on his/her living" (p.26).

As reported earlier, Degner et al (1987) found the SDS to be reliable when used in a palliative care setting (alpha at T1=0.67, at T2=0.72). The scores for the patients decreased between admission (mean =33.5) and one week post admission (mean =25.7). The decrease was attributed to better pain control and improved bowel patterns. The researchers concluded that improvements were a result of the palliative care service. Graham and Longman (1987) also used the SDS to measure the relationship between symptom distress and quality of life. They hypothesized an inverse relationship which was supported in their study ($r = -0.34$, $p = 0.004$).

The Symptom Distress Scale has been shown in the literature to be a reliable measure to detect differences in symptoms experienced by cancer patients over time. It is easy to understand and may be completed quickly which make it an appropriate measure for this study.

Demographic and Disease Characteristics

Esophageal cancer occurs mainly in males over 50 years of age. Usually by the time that diagnosis is confirmed, it is too late to treat with major surgery and results tend to be poor (Brunetaud, 1988; Fleischer, et al, 1982; Fleischer, & Sivak, 1984; Fuchs, et al, 1990). Previous treatment of the disease was recorded to determine the homogeneity of the sub groups. It was postulated that results of the study could be influenced if the patient was undergoing any adjunct treatment such as an analgesic course, radiotherapy, or chemotherapy; therefore, this information was also obtained. Information about demographic characteristics such as age and gender was obtained in order to provide a description of the sample and allowed the researcher to compare the sample to the population under scrutiny (Polit, & Hungler, 1987).

Conceptual Framework

Graham and Longman's (1987) quality of life model was the conceptual framework used to guide the research. This model was developed as a result of research with cancer patients. Graham and Longman conceptualize quality of life as "a subjective orientation on the part of the person, *influenced* by but *separate* from life circumstances." (p.339). Symptom distress, social dependency, behaviour-morale, and life change are identified as individual variables affecting quality of life. The quality of life model has been tested empirically to some extent, lending support to the decision to select the model. Graham and Longman's (1987) data show that subjects with a poor prognosis identify symptom distress as having the greatest effect on their quality of life. The patients in the study reported here also have poor prognoses; therefore, symptom distress was judged to be an appropriate dependent variable to measure. According to Germino (1987), the focus of nursing is to alleviate

symptom distress; but to date, the relationships between symptom distress and quality of life had not been clearly described. Therefore, Graham and Longman's (1987) conceptual model which specified these two concepts was especially useful.

The quality of life definition was incorporated in the model and operationalized using the four central components of quality of life: physical/occupational status, psychological state, sociability, and somatic discomfort (Calman, 1984; Schipper & Levitt, 1985). According to Schipper (1983), symptom distress may affect all aspects of a patient's life. The impact of treatment on quality of life may influence decisions about its effectiveness; therefore, quality of survival must be considered as well as the quantity of survival. Moinpour et al (1989) stated that the benefits of a treatment regime should outweigh the costs to the patient.

The belief in personal autonomy is in concert with patients being the best judges of their own quality of life at any given moment in time (Calman, 1984; Germino, 1987). The relationship between symptom distress and quality of life is diagrammed in Figure 1. Symptom distress has a direct effect on the quality of life of the patient (Graham & Longman, 1987), and is purported to have a major effect on all four aspects of quality of life. The goal of the treatment is to alleviate the distressing symptoms of the disease and if possible, effect a cure. Nursing care augments the treatment and includes the psychological and daily supportive management of the disease. The nurse's role is one of support not only for the patient, but also the family (Davies & Oberle, 1990). The well being of the patient may be as important or more important than their survival. The treatment should provide patients with symptom relief that will make their remaining days more comfortable (Scanlon, 1989).

Patients with esophageal cancer may report a very poor quality of life due to the symptoms of their disease. This study describes the relationship between quality of life and symptom distress as experienced by patients with esophageal cancer.

Summary

Graham and Longman (1987) provide a subjective definition of the complex and changing concept, quality of life, and present a holistic view of the patient. The symptoms of esophageal cancer are distressing for the patients, and for health care professionals caring for them. Often by the time that a diagnosis of esophageal cancer is made, it is too late to cure the disease. Different surgical procedures have been attempted but the cure rate is less than 5% over a five year period. It has been demonstrated in the literature that palliative procedures improve the clinical picture for these patients, but there is no literature available that considers the quality of life for esophageal cancer patients. There is some evidence that relief of symptoms does improve quality of life in other disease processes. Many quality of life measures are available, but not all of them have a subjective focus. The literature review and critique helped shape the conceptual framework for this study and resulted in selection of the most appropriate measure for quality of life in this patient population.

CHAPTER THREE

METHODOLOGY

Many studies have examined the clinical results of surgical treatment of esophageal cancer, but none have examined the quality of life of these patients; it has been assumed that the quality of life would improve. The design of this pilot study was descriptive and attempted to define if a relationship existed between symptom distress and the quality of life for patients with esophageal cancer. The study was approved by the Ethical Review Committee, Faculty of Nursing at the University of Manitoba.

Population and Sample

The population under scrutiny consisted of patients with esophageal cancer. All patients admitted to the Victoria General Hospital for treatment of carcinoma of the esophagus within a one year period were eligible for the study. It was estimated that during this period of time, 20 patients would be admitted for treatment. This would represent approximately 50 percent of the Manitoba population with this disease (Manitoba Cancer Treatment and Research Foundation, 1991). The study originally was designed to compare patients undergoing two different palliative procedures for relief of symptoms of esophageal cancer. Unfortunately, an apparent change in treatment resulted in a lack of patients; therefore, the study was expanded to include all patients with a diagnosis of esophageal cancer, regardless of their treatment. The patients had been informed of their diagnosis by their physician prior to contact by the researcher. The patients were able to read and understand English. They were well enough to complete the questionnaires. Permission was obtained from the patient's physician prior to contacting any patients. The purpose of the study was explained to the patient prior to obtaining consent to participate (Appendix A).

Table 1
Number of Respondents

	Palliative	Surgical	Total
Male	5	6	11
Female	4	1	5
Total	9	7	16

Measures

Five measures were used in this study (Figure 2). One was a global measure of the quality of life of the patient, the second measured the symptom distress that the patient was experiencing, the third was a short demographic questionnaire. The last two measures were questionnaires that elicited qualitative data from the patients regarding their symptoms and the nursing care.

The Functional Living Index - Cancer (FLIC) (Appendix B) developed by Schipper et al (1984) was given to each patient to complete prior to the treatment and again one week post operatively for palliative patients and one month post operatively for surgical patients. The use of a global measure allows for comparison of results across several trials (Moinpour, Feigl, Metch, Hayden, Meyskins, & Crowley, 1989).

The Symptom Distress Scale (SDS) (Appendix C) developed by McCorkle and Young (1978) was completed by each patient one day prior to their treatment and again one week post operatively for palliative patients and one month post operatively for surgical patients. The thirteen questions in the SDS were augmented with two questions that specifically addressed the major symptoms identified in the literature as being experienced by patients with

esophageal cancer, that is, the sensation of choking and the inability to swallow. The reliability of this instrument had been previously established in several other studies (Standardized item alpha 0.83, Graham & Longman, 1987; Cronbach's alpha 0.78, test-retest reliability 0.78, Degner et al, 1987). The information from a disease specific measure supplements the global measure (Moinpour, et al, 1989).

Both of these instruments were easily completed in under thirty minutes, which was an important consideration when dealing with a population that is older (generally over sixty), debilitated by their disease, and with limited energy.

Demographic and disease data were collected from the patients regarding age, sex, time since diagnosis, type of treatment, previous treatment, and adjunct treatment (Appendix D). This data allowed the researcher to determine the representativeness of the sample.

Two separate qualitative questionnaires (Appendices F and G) were utilized to determine the patients' expectations regarding their treatment and care. This information was used to augment the data from the Symptom Distress Scale, and the Functional Living Index - Cancer, and provided an additional description of the quality of life experienced by the patients in the study.

Procedures for data collection

The researcher attempted to visit each patient the day prior to their scheduled treatment to explain the purpose of the study, invite them to participate (Appendix E), and for those who chose to participate, obtained an informed consent (Appendix A) from them. When the study was expanded to include all patients diagnosed with esophageal cancer within the past year, the

initial contact was made with four patients after their treatment or procedure was complete. After the consent was obtained, the patient was asked to complete the demographic questionnaire, the FLIC and SDS, and answer two qualitative questions. Prior to the patient's discharge from hospital, the researcher set up an appointment to meet with them at home post treatment. The patient was then asked to complete the two questionnaires again at that time, as well as answer six qualitative questions. Consistency was maintained by having the same researcher explain the questionnaires to each patient. Most of the pretreatment interviews were conducted in the patient's hospital room; the post treatment interviews were in the patient's home or their hospital room. Some of the participants lived outside the greater Winnipeg area, and the post treatment questionnaires were mailed out with a self-addressed, stamped envelope and were returned to the researcher.

Analysis

Data analysis included five steps. Descriptive statistics such as frequencies, measures of central tendency, and dispersion were used to describe the overall sample characteristics in terms of demographic and disease variables, quality of life, and symptom distress. It was important to describe these variables as they have not been adequately reported in the literature.

A difference in symptom distress for the whole sample at time one and time two was tested using rank sum test to determine if there was a difference in symptom distress after treatment.

The relationship between quality of life and symptom distress was tested using the nonparametric Spearman's r test for the whole sample to determine if there was an association between symptom distress and quality of life. All tests of significance were preset at $p < 0.05$.

Change scores were calculated for symptom distress in all patients at time one and time two ($S.D.t1 - S.D.t2 = X$). A rank sum was calculated for the two groups to assess the effect of the treatments. The greater the change score in a positive direction, the more effective the treatment had been. A frequency distribution was calculated using the change scores, and the mean, median, and range of change scores were identified. Any negative change scores were identified and an attempt was made to determine why they occurred.

Qualitative data was analyzed for predominant themes. Using content analysis these results were used to support and validate the quantitative data in Chapter 4.

Additional sampling strategies

Data collection began in October of 1991; however, during the first six months of the study only four patients presented for palliative treatment of esophageal cancer. A decision was made to expand the study to include all patients diagnosed with esophageal cancer regardless of the type of treatment that they had. This allowed the researcher to contact patients who had been treated within the past year for esophageal cancer. Four of the sixteen patients were not seen prior to their treatment. These patients were asked to recall how they felt when they first became ill and were diagnosed as having esophageal cancer. The post operative follow-up was done at different times that ranged between one week and one year post treatment.

Ethical considerations

All patients signed an informed consent. It was stressed that the patients could withdraw at any time during the study. They were also assured

that there would be no effect on their care or treatment regardless of whether they choose to participate or not. Current practice indicates that treatment choice is based on size and location of tumour, condition, and age of the patient, convenience, and availability of operating room time (personal communication with Dr. T. Horan, December 5, 1990).

All information was gathered from the patients themselves and the researcher did not access any patient records. Confidentiality of the information was guaranteed by the researcher. All patients were assigned a number and subjects were assured that no names would appear in the written reports of the study. The list connecting patients with code numbers was kept under lock and key. The study was approved by the Ethical Review Committee, Faculty of Nursing at the University of Manitoba prior to implementation.

Summary

The design of the study was descriptive as the purpose was to describe the relationships between quality of life and symptom distress in patients with esophageal cancer. The SDS and the FLIC were utilized to determine the symptom distress and quality of life experienced by patients with esophageal cancer and two qualitative questionnaires were used to enhance the quantitative results. The SDS was augmented with two questions on symptoms specific to patients with esophageal cancer.

Data analysis attempted to determine if there was a relationship between the dependent variables (quality of life, and symptom distress) and the types of treatment, and estimate the representativeness of the sample.

CHAPTER 4

RESULTS OF DATA ANALYSIS

The purpose of the study was to describe quality of life and symptom distress in patients with esophageal cancer. Characteristics of the sample and the participation rate are described. Internal consistency reliability estimations of the scales were obtained using Cronbach's alpha coefficient and are reported here. The results of the hypothesis testing for treatment effects and symptom distress and quality of life are also described. An analysis of unusual cases is also presented.

Description of the participation rate

Sixteen patients were contacted by the researcher and all agreed to participate in the study. Data collection at time one (prior to treatment) was completed for all sixteen patients. Data collection at time two (after treatment) was completed for fourteen patients for a participation rate of 85%. Of the two patients who did not complete questionnaires at time two, one died prior to being able to complete the questionnaires and the other had several post operative complications and chose not to complete the questionnaires.

Description of the sample

Sixteen patients participated in the study initially. The age range of the patients is shown in Table 2.

Table 2
Age and Gender Distribution of Respondents

GENDER

AGE RANGE	MALE	FEMALE	TOTAL
46-59	2	0	2
60-69	5	1	6
70-79	2	3	5
80-89	2	1	3
TOTAL	11	5	16

The average age of the respondents was 70.0 years and males outnumbered females 2.2:1. Statistics from the Manitoba Cancer Treatment and Research Foundation (1991) indicate that the majority of patients with esophageal cancer are over 60 years of age, and it is more prevalent in males (2.6:1). Therefore, the sample was quite representative of the population in terms of age and gender.

Of the sixteen patients, seven underwent a major surgical procedure such as an esophageal resection or replacement, and nine received a palliative treatment, that is, either laser treatment, or insertion of an endoprosthesis. The time since diagnosis ranged between one and twelve months with a mean of 2.56 months. The majority of the patients (n=10) were diagnosed within two months of visiting their physician. Only one of the patients had radiotherapy treatments in conjunction with their surgery.

With the expanded study, data collection post treatment occurred one to 44 weeks after treatment. The mean data collection time was six and one half weeks post treatment. The majority of patients (n=12) were visited within the first four weeks following treatment.

Reliability of the scales

Although the sample size was small, an estimate of the internal consistency of the scales was obtained. The FLIC achieved internal consistency estimates of 0.87 and 0.89 at time one and time two as measured by Cronbach's alpha coefficient. However, there was some evidence of redundancy as indicated by 6 inter-item correlations >0.70 at time one and 10 inter-item correlations >0.70 at time two. Comments by subjects during the qualitative part of the study confirmed that some redundancies were noted by the subjects. The SDS achieved internal consistency estimates of 0.90 and 0.83 at time one and time two as measured by Cronbach's alpha coefficient. There was also evidence of redundancy in the SDS as indicated by 13 inter-item correlations >0.70 at time one. There was only one inter-item correlation >0.70 at time two. Although the case to item ratio is low, likely exaggerating somewhat the reliability estimates obtained, there is evidence that the tools were reliable.

Hypothesis testing results

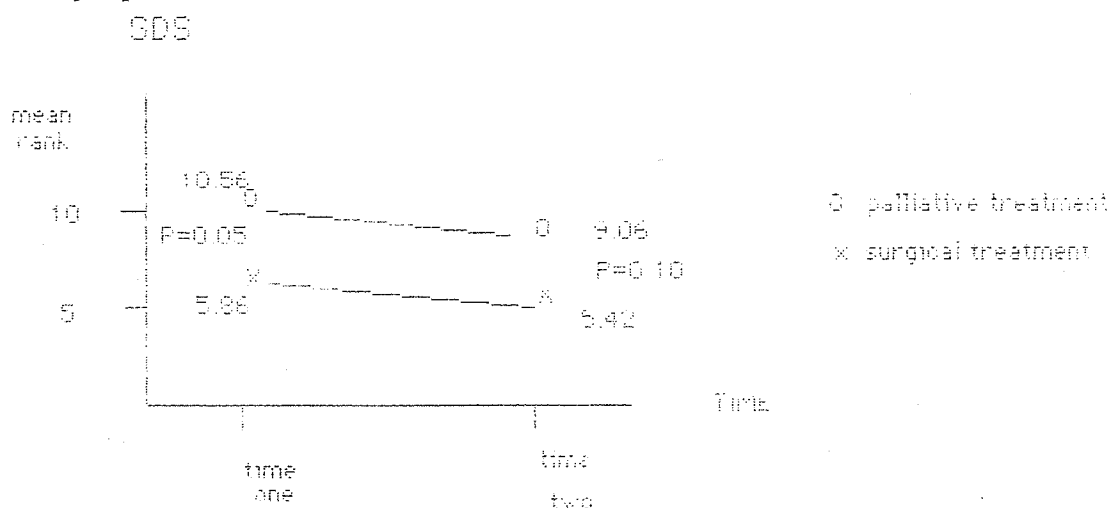
Three research questions were posed: what is the relationship between the type of treatment and symptom distress? What is the relationship between type of treatment and quality of life? And what is the relationship between symptom distress and quality of life before and after treatment?

a) **Treatment effects**

The gender of the patient did not have a significant effect ($p > 0.05$) on either the quality of life symptom distress before or after treatment. The patients who experienced a palliative treatment, reported significantly higher symptom distress scores at time one than did patients who underwent a surgical procedure ($z = -1.96, p = 0.05$). They also reported higher symptom distress scores at time two, but the group difference was not statistically significant. Overall, symptom distress scores increased for both groups between time one and time two. Figure 3 illustrates the mean rank for symptom distress scores at time one and two. Symptom distress scores are significantly higher for palliative patients than for surgical patients at time one ($p = 0.05$). The mean rank is lower at time two indicating greater distress for both groups.

Analysis of qualitative data indicated that prior to treatment, patients reported that they were most distressed by the inability to swallow or eat properly and the weight loss that they had experienced ($n = 3$). After their treatment, patients continued to be bothered by the inability to eat, swallow, and keep their food down ($n = 7$). Other patients reported that they were able to eat better ($n = 5$).

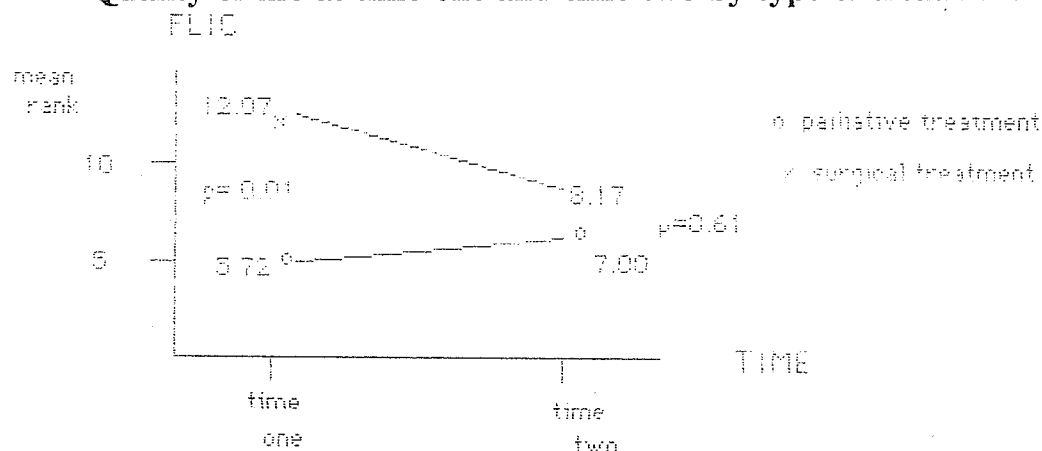
Figure 3
Symptom distress at time one and time two by type of treatment



Quality of life decreased for the majority of patients in the study (n=11). Patients who experienced a palliative procedure had significantly lower FLIC scores at time one than patients who underwent a surgical procedure ($z = -2.66$, $p = -0.01$). Surgical patients reported a decrease in FLIC scores at time two; palliative patients reported a slight increase in FLIC scores at time two ($p > 0.05$) (Figure 4).

Analysis of qualitative data indicated that prior to treatment, patients were hopeful that the discomfort that they were experiencing would be relieved.

Figure 4
Quality of life at time one and time two by type of treatment



b) Symptom distress and quality of life

Table 3 shows the descriptive statistics for the FLIC. The possible range of scores for the FLIC is 22 to 154 with a lower score indicative of poor quality of life. Schipper et al (1984) report mean scores between 84 and 154 for cancer patients in their study. Ganz, Haskel, Figkin, LaSoto, and Siau (1988) reported a mean FLIC score of 107, standard deviation 22.3 in a related study of quality of life for patients with metastatic lung cancer.

Table 3
Functional Living Index - Cancer
Descriptive Statistics at time one and time two

Data Collection	Mean	Mode	Range	s.d.
Time 1	105.88	90	75-153	22.14
Time 2	91.50	80	48-143	22.40

The mean FLIC scores at time 1 and time 2 decreased almost 15 points from 105.88 to 91.50. The result was significant ($z = -2.26$, $p = 0.02$).

Table 4 shows the descriptive statistics for the SDS. The possible range of scores for the 15 question SDS is 15 to 75 with a higher score indicative of greater symptom distress. The scores on the original 13 question SDS have a possible range of 13 to 65. McCorkle (1981) reports scores ranging from 13 to 44 with a mean of 27 for patients with cancer. McCorkle and Young (1978) reported scores ranging from 10 to 41 with a mean of 20 in their study of 45 cancer and 8 non-cancer patients. Degner and Sloan (1992) reports scores ranging from 13 to 50 with a mean of 24.3, standard deviation 7.29 for a general population of ambulatory cancer patients.

Table 4 (a)
Symptom Distress Scale Descriptive Statistics at time one and time two
(15 questions)

Data Collection	Mean	Mode	Range	s.d.
Time 1	28.56	17	16-63	12.09
Time 2	34.36	36	16-58	10.16

The mean symptom distress increased by five points from 28.56 to 34.36, although the results were not significant ($p > 0.05$) using the nonparametric method specified.

Table 4(b) shows the means and standard deviations for the original 13 questions of the SDS at time one and time two for this population. A highly significant negative correlation between symptom distress and quality of life at time one (Spearman's $r = -0.65$, $p = 0.006$) and at time two was noted (Spearman's $r = -0.80$, $p = 0.001$) (Figure 5) which is consistent with the relationship specified in the conceptual framework. There were no other significant correlations.

Table 4 (b)
Symptom Distress Scale Descriptive Statistics at Time One and Time Two
(13 questions)

Data Collection	Mean	Mode	Range	s.d.
Time One	24.94	14.0	13-57	11.22
Time Two	30.21	33.0	14-51	8.82

Figure 5
Plot of symptom distress and quality of life at time two

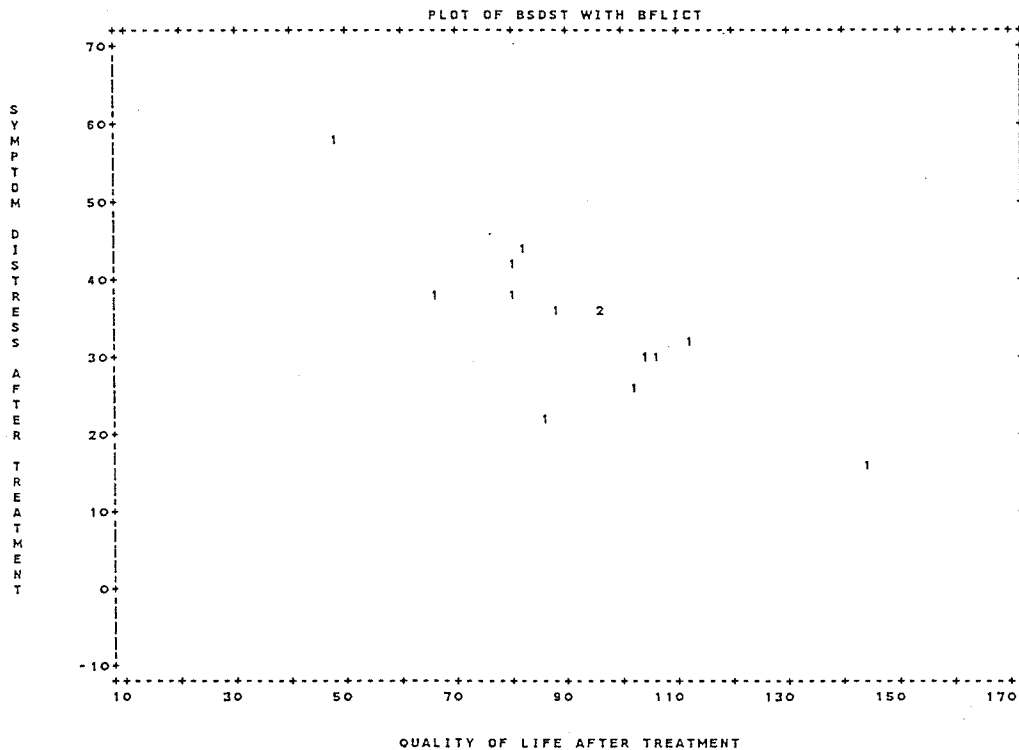


Table 5 shows the means and standard deviations of the individual questions in the FLIC at time one and time two. Figure 6 shows diagrammatically the responses to each question at time one and time two. Only two of the twenty-two questions show a marginal increase in score (#3 and #18) which is not significant.

Means and standard deviations by question
of the FLIC at time one and time two

Question	Time One		Time Two	
	Mean	S.D.	Mean	S.D.
1. Depression	5.18	1.76	4.43	1.87
2. Stress	5.38	1.78	5.07	1.64
3. Thinking about illness	4.31	2.12	4.57	1.79
4. Recreation/leisure	4.75	2.21	2.79	1.63
5. Nausea	5.50	2.22	4.93	1.98
6. Wellness	4.50	1.90	4.00	1.66
7. Make meals/chores	5.00	2.25	4.00	1.80
8. Hardship on family	3.56	1.90	3.29	1.77
9. Discouraged	4.81	1.76	4.64	2.24
10. Satisfaction	4.25	2.05	2.71	1.44
11. Uncomfortable	4.81	1.76	4.36	1.60
12. Disruption	3.56	2.07	3.43	1.87
13. Pain/discomfort	4.44	2.37	3.93	2.34
14. Hardship on you	3.69	2.09	3.14	1.99
15. Do household tasks	5.44	1.75	3.93	2.17
16. Willing to see family	6.31	1.45	5.64	1.69
17. Nausea within 2 weeks	5.69	2.09	4.93	2.13
18. Frightened of future	5.38	1.86	5.50	1.99
19. Willing to see friends	5.45	1.86	4.86	1.96
20. Pain from disease	2.81	2.48	1.71	1.64
21. Confidence in treatment	6.06	1.06	5.57	1.60
22. Appearance today	5.00	1.41	4.07	1.27

Figure 6
Relationship between FLIC questions
at time one and time two

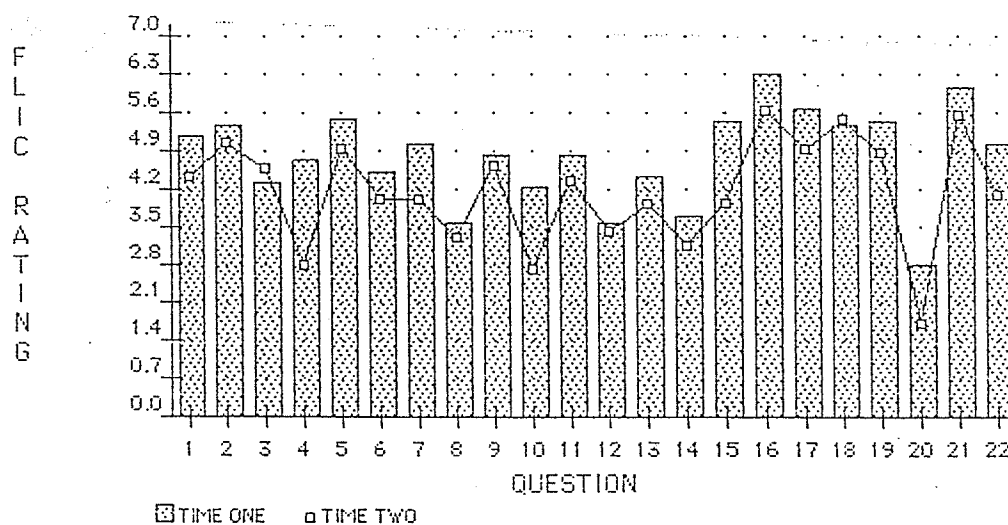


Figure 7 shows the quality of life for each respondent at time one and time two. Patients 2, 3, and 9 had an endoprosthesis inserted, while patients 8, 12, 14, 15, and 16 had palliative laser treatment. Patients 4, 6, 7, 10, 11 and 13 underwent a major esophageal resection. All patients who had an esophageal resection reported lower FLIC scores at time two. Only two of the respondents indicated that their quality of life had shown improvement between time one and time two, both these patients had laser surgery. The qualitative data indicated that only three patients commented that they were worried about the future and the uncertainty of how the disease will progress.

Figure 7
Quality of life
at time one and time two

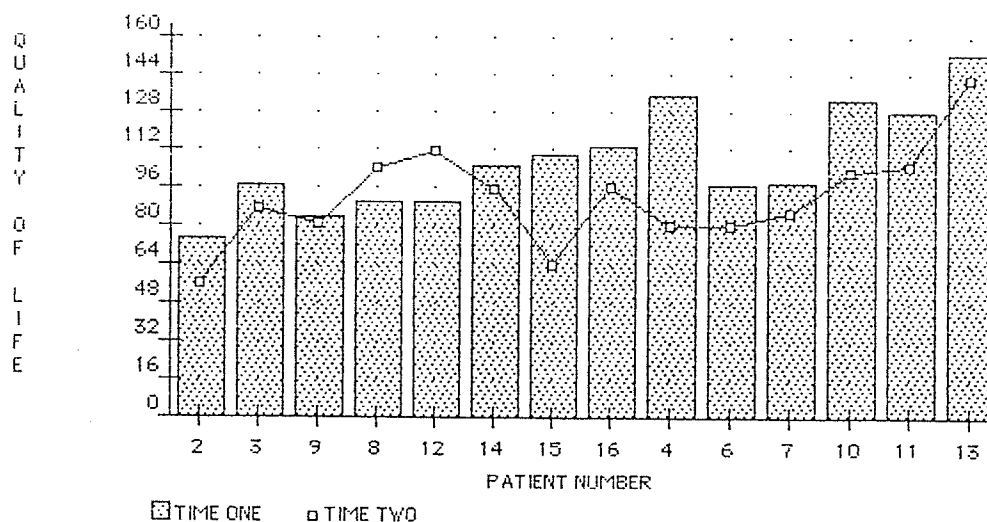


Table 6 lists the means and standard deviations for each question in the Symptom Distress Scale at time one and time two. Figure 8 diagrams the responses to the individual questions by the respondents. Only one of the fifteen questions indicated that respondents had marginally less distress at time two than at time one. Analysis indicated that the concentration for patients was improved at time two as shown by the asterisk (*). Analysis of the qualitative data indicated that some patients (n=4) were relieved once they knew what was wrong with them because it was easier to face the future.

Table 6
Means and standard deviations for the
SDS at time one and time two

Questions	Time One		Time Two	
	Mean	S.D.	Mean	S.D.
1. Insomnia	2.31	1.25	2.50	1.29
2. Fatigue	2.50	1.46	3.36	1.34
3. Bowel	1.69	1.40	2.50	1.51
4. Breathing	1.63	0.96	2.07	1.21
5. Cough	2.13	1.09	2.29	0.99
6. *Concentration	1.88	1.36	1.79	1.12
7. Nausea1	1.63	1.20	2.00	1.24
8. Nausea2	1.56	1.09	1.64	0.75
9. Pain1	2.13	1.41	2.57	1.70
10. Pain2	1.94	1.34	2.36	1.39
11. Outlook	2.13	1.46	2.29	1.38
12. Appetite	1.75	1.18	2.71	1.27
13. Appearance	1.69	1.08	2.29	1.07
14. Swallowing	1.75	0.87	2.00	1.11
15. Choking	1.86	1.31	2.00	0.96

Figure 8
 Relationship between SDS questions
 at time one and time two

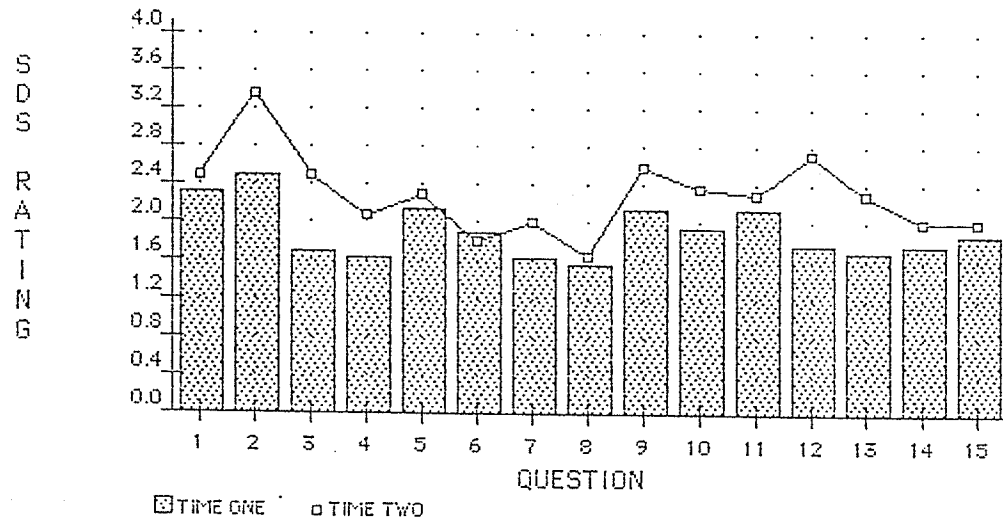
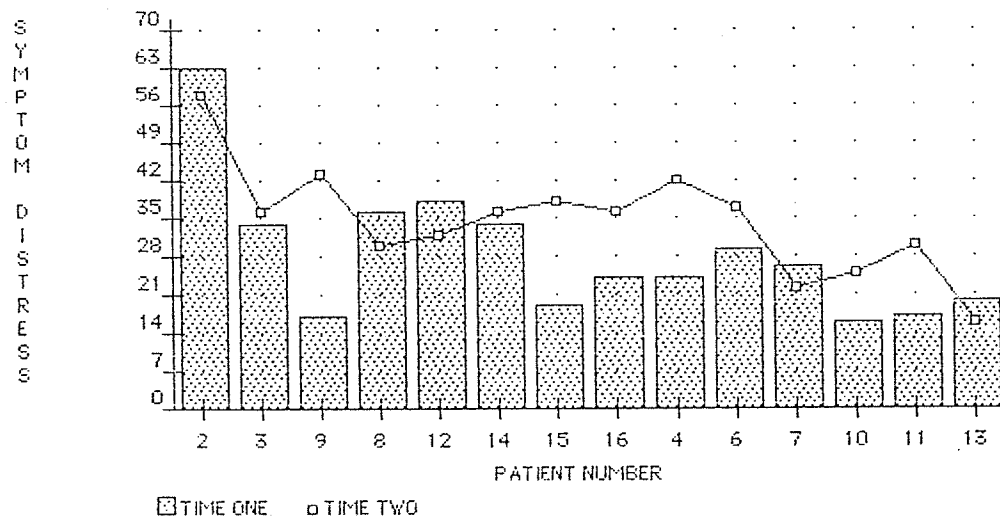


Figure 9 shows that nine of the fourteen respondents had greater symptom distress at time two than at time one (5 palliative patients 3, 9, 14, 15, 16 and 4 surgical patients 4, 6, 10, and 11). Two questions that were added to the Symptom Distress Scale to assess the patient's distress due to the symptoms of swallowing and choking. These symptoms were identified in the literature as distressing for patients with esophageal cancer. The mean scores for both these questions were low indicating that they were not a major problem for the patients, although they reported slightly worse symptoms after treatment (swallowing 1.75 and 2.00; choking 1.86 and 2.00).

Figure 9
Symptom Distress at time one and time two



Analysis of the qualitative data indicated that patients were concerned that they did not have enough information about their disease and the symptoms.

Analysis of unusual cases

Four cases were notable. The first was of interest because the scores were so different from the rest of the sample suggesting that this subject was an outlier. This respondent reported very high symptom distress at time one (63) and time two (58) compared with the other respondents. The quality of life for this patient was within the same range as the other respondents, but it decreased from time one to time two. It is difficult to determine, due to the small sample size, whether this respondent is an atypical patient or represents a segment of the population that was under scrutiny in the data collection. At the time of participation, she was 77 years old. She was a diabetic and on intravenous therapy. She appeared somewhat confused and did have difficulty answering some of the questions. At both times she did appear to be very distressed by her symptoms, particularly the inability to eat and drink normally. Although the quality of data for this case is uncertain, the case did not create spurious results as evidenced by the consistent findings when repeat hypothesis testing was done excluding this case. The hypothesis found to be significant, that is, a significant inverse relationship between quality of life and symptom distress remained so when the data was analyzed without this patient's data (Spearman's $r = -0.75$, $p = 0.003$, $n = 13$).

Three other cases were of interest because their results deviated from expected hypotheses. Two patients reported decreased symptom distress and decreased quality of life from time one to time two. Both of these patients had major surgical procedures and have since died. One patient reported increased symptom distress and increased quality of life between time one and time two. This patient had an endoprosthesis inserted and died within three weeks of treatment. Interpretation and recommendations for future studies regarding these findings will be discussed in Chapter Five.

Summary

The findings from the data analysis strongly support the hypothesized negative relationship between symptom distress and quality of life. The other results, although not significant, indicate that the majority of patients in this sample experienced high symptom distress and low quality of life. Regardless of the treatment the subjects experienced, symptoms worsened and quality of life was rated lower at time two. Analysis of qualitative data prior to treatment indicated that patients found the symptoms of esophageal cancer extremely distressing and their expectations of treatment were to relieve these symptoms. After treatment patients reported that some symptoms seemed to have been alleviated, but this was not evident in the overall SDS scores.

CHAPTER FIVE

INTERPRETATION, IMPLICATIONS AND RECOMMENDATIONS

The purpose of this study was to describe the symptom distress and quality of life for patients with esophageal cancer pre and post treatment. Treatment for these patients was either surgical resection of the tumour or palliative treatment with the Nd:YAG laser or insertion of an endoprosthesis. Graham and Longman's (1977) conceptual framework provided the theoretical basis of the study describing relationships among nursing care, treatment, symptom distress and quality of life.

This chapter includes a discussion of the findings of the study, study limitations, implications of the findings for clinical practice, and recommendations for further research.

Interpretation of the Findings

Interpretation of the findings will be discussed in terms of design and measurement issues and theoretical issues.

a) Design and measurement issues

A change in treatment protocol that was beyond the control of the researcher resulted in a smaller sample size than was originally estimated. Originally the study was designed to describe the symptom distress and quality of life for patients with esophageal cancer undergoing palliative treatment. A lack of participants during the first six months of data collection resulted in a need to expand the study to include all patients with esophageal cancer regardless of treatment. However, despite the small sample size, the age and gender characteristics were comparable to the Manitoba Cancer Foundation (1991) statistics indicating that the sample was representative of the population in terms of these demographic variables.

The Symptom Distress Scale (McCorkle and Young, 1978) was easy for the participants to understand and complete. The reliability estimates for the scales were high at both time one and time two as measured by Cronbach's alpha (0.90 and 0.83, respectively) providing evidence of the tool's internal consistency.

One limitation of the scale for use in this population may be the lack of response option indicating that the symptom is not present. For example, at time one, several patients were not experiencing any nausea or pain making it difficult for them to answer these questions. A second limitation of the scale may be that some symptoms reported by patients in the qualitative phase of the study were not present in the SDS, for example, heartburn, bloating, and gas. Thirdly, the SDS may be more useful if some symptoms are

weighted for this population such as the symptoms of choking and swallowing as identified in the qualitative analysis. Inter-item correlations between questions 9 and 10 (both addressing the issue of pain) are high at time one and two (0.92, 0.85), suggestive of some redundancy.

Two questions were added to the SDS based on symptoms identified in the literature as distressing to this population. However, the means for these questions at time one and time two indicated that the symptoms of swallowing (1.75, 2.00) and choking (1.86, 2.00) were not a major problem for this group of patients. As this was an unexpected finding, these items might require further testing and refinement to provide more meaningful responses to elicit levels of distress related to these problems. Analysis of the qualitative data indicated that patients could swallow most foods and liquids but had to increase their fluid intake to assist their swallowing. The patients were very willing to discuss their symptom distress with the researcher. This qualitative data provided insight to the disease process for this population but further qualitative exploration would be beneficial.

The Functional Living Index - Cancer (Schipper et al, 1984) demonstrated good reliability results at time one and time two as measured by Cronbach's alpha (0.87 and 0.89). However, it was more difficult for participants to complete. They preferred to have the questions read to them and wanted to circle the response rather than marking the appropriate place on the scale with a straight line. Ganz et al (1988) identified the same difficulty in a study with metastatic lung cancer patients (n=189) which may have been due to inadequate instruction. There is a potential for measurement error when subjects respond differently to the questions. The patients found some of the questions very similar which was confirmed by inter-item correlations at time one and time two. For example, question 16 asks subjects to rate how willing they were to spend time with those closest to them during the past two weeks; and

question 19 asks subjects to rate how willing they were to spend time with friends during the past two weeks (0.71 and 0.82). It is acknowledged that if the FLIC is truly a multidimensional scale, future research with a larger sample size would use a different reliability measure (e.g. coefficient theta). According to Kim and Mueller (1978), use of Cronbach's alpha with a multidimensional scale will give lower estimates of scale, therefore, the reliability results reported here may be conservative. Further reliability testing of the questions with a larger sample size would be appropriate to determine if there is redundancy in the questionnaire for this population.

Based on factor analysis, Schipper et al (1984) identified questions 8, 12, 16 and 19 as dealing with hardship and sociability issues; while questions 4, 6, 7, 10, 11, 13, 15, 20 and 22 deal with issues of physical well being. Because of the small sample size, factor analysis was not possible using this study's data. The two questions that were rated to indicate an improvement in quality of life (#3 and #18) were not classified by Schipper et al (1984).

This scale did not measure the spiritual aspects of quality of life that palliative patients may experience. This deficit may account for the unexpected results obtained by the subjects who reported either increased symptom distress and increased quality of life or decreased symptom distress and decreased quality of life. Quality of life in the terminally ill may be perceived more as an existential/spiritual state making the FLIC less sensitive for this population, or patients may readjust their expectations when faced with a life threatening illness (Calman, 1984). In summary, the FLIC was designed for use with cancer patients in an outpatient setting and may not be the most appropriate measure for esophageal cancer patients, most of whom are terminally ill, because it may not capture the spiritual and psychological states of the terminally ill. In reviewing the literature, there is no quality of life

measure that is specific for terminally ill patients. The FLIC is now regarded as a global measure for quality of life and there is a need to increase its specificity by applying a disease specific module.

b) Theoretical issues

Quality of life is affected by many factors. Graham and Longman (1987) considered variables within the realm of nursing care for their model. In this population, a multidisciplinary approach is more appropriate. The model should be expanded to include a spiritual component as well as the somatic discomfort, physical, and psycho-social components.

Graham and Longman's (1987) data also showed that patients with poor prognosis identified symptom distress as having an association with their quality of life ($r = -0.34$, $p = 0.004$). The results of the present study showed that there was a strong negative correlation between quality of life and symptom distress at time one ($r = -0.54$, $p = 0.004$, $n = 16$) and time two ($r = -0.80$, $p = 0.001$, $n = 14$); that is, patients reported increased symptom distress and decreased quality of life before and after treatment. Palliative patients reported lower quality of life ($z = -2.66$, $p = 0.01$) and higher symptom distress ($z = -1.96$, $p = 0.05$) than surgical patients at time one, but the type of treatment did not make a difference to the symptom distress and quality of life of the patients at time two. This finding is clinically understandable because physicians are less likely to subject a very ill patient to a major esophageal resection while this does present a selection bias. Despite the differences between the two groups at time one, they both felt sicker at time two that is, one week post treatment for the palliative group and one month post treatment for the surgical group.

The demographic characteristics of age and gender were collected to determine representativeness of the sample. When interviewing the patients, some stated that they were smokers, and/or had a history of high intakes of alcohol. Many studies have been done that identify populations at risk for

esophageal cancer (Frank-Stromborg, 1989; Lucas, 1990). Further study of populations at risk to determine if earlier diagnosis would improve symptom distress, quality of life, and survival rates may be beneficial.

Evidence from this study suggests that the disease and interventions have a negative effect on the quality of life and symptom distress for patients with esophageal cancer. However, it is unclear whether or not these individuals experience a worse quality of life and more symptom distress than they would have without any treatment. Despite this uncertainty, the results indicate that claims about the palliative effects of these treatments cannot be assumed or guaranteed. Further study is warranted to determine the effects of these procedures.

The qualitative findings related to this issue point to the importance of health care professional - patient communication related to information and treatment decisions. Patients reported that nurses and other health care professionals did not appear to have much knowledge about esophageal cancer, treatment approaches, and disease progression. They reported that care givers did as much as they could for them but they did not know how best to help them deal with their disease. These comments reinforce the need for more systematic study to examine treatment approaches for this population.

Northouse and Northouse's (1988) review of two hundred papers and studies dealing with communication in cancer patients support these comments. Patients identified seeking information is one of the areas that is a concern. Information decreases uncertainty. The authors concluded that patients have a strong need for illness related information, but the literature is unclear as to how much information or the type of information they prefer. The authors also concluded that imparting information to the patient is a major responsibility of health care professionals. Degner and Gow (1988), in their

studies of care of the dying identified that this should be a required course in the nursing curriculum. All the patients in this study were being cared for on acute surgical units, not in palliative settings. The focus on acute care is to make every effort to cure the patient and the nurses may not be comfortable dealing with the terminally ill patient if they have not had instruction and previous experience in care of the dying.

Limitations

Several study limitations were identified. The sample size was small and although it was quite typical of the Manitoba population based on age and gender distribution, the sample may be atypical in other respects.

Data collection occurred at different points in time for the patients due to changes in subject recruitment criteria which may have affected the findings. Some patients had to recall how they felt when they first became ill prior to their treatment and their recollections may have been blunted by time.

There is no control group for the study, making comparisons about the relationship between quality of life and symptom distress for patients who do not have any treatment for esophageal cancer versus those who are treated unknown, although each patient acts as their own control. There was a selection bias as physicians were less likely to subject a very ill patient to a major surgical procedure; these patients underwent a palliative procedure.

Implications for Clinical Practice

Concerns expressed by the patients related to two major areas. Patients were concerned that health care providers did not have enough qualitative information about their disease to adequately answer their questions; secondly, they were concerned about how they would die. They did not express

fear of dying, but they were concerned about symptom control for pain, and choking sensations. In-depth questions about type of diet and amount of food intake would assist health care professionals with helping patients maintain adequate nutrition. These results point to the need for nurses to know how best to alleviate or reduce the distress associated with the symptoms, such as adequate pain relief and techniques to ease the symptoms of choking. Palliative care should be involved at the outset regardless of the treatment regime for the patient. These experienced caregivers can provide support to the patient, significant others, and the health care team.

Nurses can provide information about treatment options and involve the physicians in ensuring that patients have the necessary information to make a decision regarding treatment. If patients have all the information about the different treatments and the prognosis, they may choose not to have treatment. The length of survival reported in the literature for the two groups is six months to a year. The major implications for nurses and other health care professionals therefore, seems to be in the areas of education and support.

As esophageal cancer is rare and health care professionals are often not familiar with the disease, it is usually too late to help these patients once the diagnosis is made. Identifying populations at risk and concentrating on earlier diagnosis may lead to different outcomes for the current treatments. For example, using the laser at an early stage versus late stage cancer may improve quality and quantity of life for this population. A cost analysis of the different treatments would be beneficial when deciding on treatment options. Quality and quantity of life could be discussed with patients to give a more complete picture when determining treatment options.

Recommendations for Future Research

Further study is indicated with a larger sample to confirm or refute these findings. More specifically, the following studies are recommended:

1. Replication of this study with a larger sample size using a longitudinal design to follow patients from time of diagnosis through death,
2. Further study of quality of life for esophageal cancer patients using a different quality of life measure that encompasses the spiritual aspects of quality of life,
3. A qualitative study to identify nursing interventions helpful for alleviating symptom distress of esophageal cancer, and
4. Further study of populations at risk to determine if earlier diagnosis improves symptom distress, quality of life, and survival rates.

Summary

Esophageal cancer is difficult to diagnose and often by the time that diagnosis is made, it is too late to cure the disease. The goals of treatment, therefore, include the relief of symptoms and patient comfort for the remaining lifetime. Many studies report the clinical results of treatment of esophageal cancer, but there is no literature reporting the quality of life and symptom distress of these patients.

One of the current issues in health care is the quality of life for patients with terminal disease. As there was no nursing literature available on quality of life and symptom distress for this population, this study attempted to describe the symptom distress and quality of life for patients with esophageal cancer prior to and post treatment. The initial results indicate a strong negative correlation between symptom distress and quality of life after treatment regardless of the type of treatment. Further study is required to confirm or refute these results.

REFERENCES

- Aaronson, N.K. (1988). Quality of life: what is it? How should it be measured? Oncology, 2(5), 69-76.
- Arzouman, J.M.R., Dudas, S., Ferrans, C.E., & Holm, K. (1991). Quality of life of patients with sarcoma postchemotherapy. Oncology Nursing Forum, 18(5), 889-894.
- Ball, K.A. (1986). The evolution of surgical lasers. Today's OR Nurse, 8(6), 8-15.
- Boyce, H.W. (1988). Esophageal dilation as a primary method. Paper presented at the Gastroenterology Update, Cleveland Clinic.
- Boyce, H.W. (1988). The endoprosthesis: complications and results. Paper presented at the Gastroenterology Update, Cleveland Clinic.
- Brunetaud, J.M. (1988). Laser treatment. Paper presented at the Gastroenterology Update, Cleveland Clinic.
- Calman, K.C. (1984). Quality of life in cancer patients - an hypothesis. Journal of Medical Ethics, 10, 124-127.
- Davies, B., & Oberle, K. (1990). Dimensions of the supportive role of the nurse in palliative care. Oncology Nursing Forum, 17(1), 87-94.
- Degner, L.F. (1990). Palliative support. In S.B. Baird, R. McCorkle, & M. Grant (Eds.), Cancer Nursing: A Comprehensive Textbook, W.B. Saunders, 407-414.
- Degner, L.F., & Gow, C.M. (1988). Preparing nurses for care of the dying: a longitudinal study. Cancer Nursing, 11(3), 160-169.

- Degner, L.F., & Gow, C.M. (1988). Evaluation of death education in nursing: a critical review. Cancer Nursing, 11(3), 151-159.
- Degner, L.F., Gow, C.M., & Thompson, L.A. (1991). Critical nursing behaviors in care of the dying. Cancer Nursing, 14(5), 246-253.
- Degner, L.F., Henteleff, P.D., & Ringer, C. (1987). The relationship between theory and measurement in evaluations of palliative care services. Journal of Palliative Care, 3(2), 8-13.
- Degner, L.F., & Sloan, J.A. (1992). Decision making during serious illness: what role do patients really want to play. Journal of Clinical Epidemiology, 45(9), 941-950.
- DeHaes, J.C., & van Knippenberg, F.C.E. (1985). The quality of life of cancer patients: a review of the literature. Social Science Medicine, 20(8), 809-817.
- den Hartog Jager, F.C.A., Bartelsman, J.F.W.M., Tytgat, G.N.J. (1979). Palliative treatment of obstructing esophagogastric malignancy by endoscopic positioning of a plastic prosthesis. Gastroenterology, 77(5), 1008-1014.
- Earlam, R., & Cunha-Melo, J.R. (1980). Oesophageal squamous cell carcinoma: 1. A critical review of surgery. The British Journal of Surgery, 67(6), 381-390.
- Edlund, M., & Tancredi, L.R. (1985). Quality of life: an ideological critique. Perspectives in Biology and Medicine, 28(4), 591-607.
- Ferrans, C.E., & Powers, M.J. (1985). Quality of life index: development and psychometric properties. Advances in Nursing Science, 8(1), 15-24.
- Flanagan, J.C. (1982). Measurement of quality of life: current state of the art. Archives of Physical Medicine and Rehabilitation, 63, 56-59.

- Fleischer, D.E. (1984). Endoscopic laser therapy for carcinoma of the esophagus. Endoscopy Review, 37-49.
- Fleischer, D.E. (1984). Endoscopic laser therapy for gastrointestinal disease. Archives of Internal Medicine, 144, 1225-1230.
- Fleischer, D.E. (1990). Endoscopic laser therapy improves life for esophageal cancer patients. Clinical Laser Monthly, 23-25.
- Fleischer, D.E., & Kessler, F., & Haye, O. (1982). Endoscopic Nd:YAG laser therapy for carcinoma of the esophagus: a new palliative approach. The American Journal of Surgery, 4(3), 226-234.
- Fleischer, D.E., & Spivak, M.V. (1984). Endoscopic Nd:YAG laser therapy as palliative treatment for advanced adenocarcinoma of the gastric cardia. Gastroenterology, 87, 815-820.
- Frank Stromborg, M. (1989). The Epidemiology and primary prevention of gastric and esophageal cancer. Cancer Nursing, 12(2), 53-64.
- Fuchs, K-H., Freys, S., Schaube, H., & Eckstein, A.K. (1990). Randomized comparison of endoscopic palliation of a malignant esophageal stenosis. In M.K. Ferguson, A.G. Little, & D.B. Skinner (Eds.), Diseases of the Esophagus: Vol.I: Malignant Diseases (pp. 327-334), Mount Kisco, N.Y.: Futura Publishing Company, Inc.
- Ganz, P.A., Haskell, C.M., Figlin, R.A., LaSoto, N., & Siau, J. (1988). Estimating the quality of life in a clinical trial of patients with metastatic lung cancer using the Karnofsky Performance Status and the Functional Living Index - Cancer. Cancer, 61(4), 849-856.
- Germino, B.B. (1987). Symptom distress and quality of life. Seminars in Oncology Nursing, 3(4), 299-302.
- Graham, K.Y., & Longman, A.J. (1987). Quality of life and persons with melanoma. Cancer Nursing, 10(6), 338-346.

- Greer, D.S. (1987). Quality of life measurement in the clinical realm. Journal of Chronic Diseases, 40(6), 629-630.
- Guyatt, G.H., Bombardier, C., & Tugwell, P.X. (1986). Measuring disease specific quality of life in clinical trials. Canadian Medical Association Journal, 134, 889-895.
- Hockley, J.M., Dunlop, R., & Davies, R.J. (1988). Survey of distressing symptoms in dying patients and their families in hospital and the response to a symptom control team. British Medical Journal, 296, 1715-1717.
- Holmes, S., & Dickerson, J. (1987). The quality of life: design and evaluation of a self-assessment instrument for use with cancer patients. International Journal of Nursing Studies, 24(1), 15-24.
- Hornquist, J.O. (1982). The concept of quality of life. Scandinavian Journal of Social Medicine, 10, 57-61.
- Jackson, B.S., Strauman, J., Frederickson, K., & Strauman, T.J. (1991). Long-term biopsychosocial effects of interleukin-2 therapy. Oncology Nurses Forum, 18(4), 683-690.
- Katz, S. (1987). The science of quality of life. Journal of Chronic Diseases, 40(6), 459-463.
- Kerlinger, F.N. (1979). Behavioral Research. New York: Holt, Rinehart and Winston.
- Kim, J., & Mueller, C.W. (1978). Factor Analysis: Statistical Methods and Practical Issues. Beverly Hills, California: Sage Publications.
- Levine, S. (1987). The changing terrains in medical sociology: emergent concern with quality of life. Journal of Health and Social Behavior, 28(1), 1-6.
- Lewis, F.M. (1982). Experienced personal control and quality of life in late stage cancer patients. Nursing Research, 3(2), 113-119.

- Lucas, C.C. (1990). Argument for esophageal cancer screening in high risk U.S. populations. Journal of the Florida Medical Association, 77(5), 526-9.
- Manitoba Cancer Treatment and Research Foundation. (1991). Annual Report and Statistics. Manitoba: The University of Manitoba Printing Group.
- McCorkle, R. (1981). Non-obtrusive measures in clinical nursing research. In R. Tiffany (Ed.), Cancer Nursing Update, Cassell Ltd., 20-26.
- McCorkle, R., Young, K. (1978). Development of a Symptom Distress Scale. Cancer Nursing, 373-378.
- McGown, I., Barr, H., & Krasner, H. (1989). Palliative laser therapy for inoperable rectal cancer - does it work? Cancer, 63(5), 967-969.
- Moinpour, C.M., Feigl, P., Metch, B., Hayden, K.A., Meyskins, Jr., F.L., & Crowley, J. (1989). Quality of life endpoints in cancer clinical trials: review and recommendations. Journal of the National Cancer Institute, 81, 485-495.
- Mor, V. (1987). Cancer patients' quality of life over the disease course: lessons from the real world. Journal of Chronic Diseases, 40(6), 535-544.
- Morris, J.N., & Sherwood, S. (1987). Quality of life of cancer patients at different stages of the disease trajectory. Journal of Chronic Diseases, 40(6), 545-553.
- Morris, J.N., Suissa, S., Sherwood, S., Wright, S.M., & Greer, D. (1986). Last days: a study of the quality of life of terminally ill cancer patients. Journal of Chronic Diseases, 39(1), 47-62.
- Najman, J.M., & Levine, S. (1981). Evaluating the impact of medical care and technologies on the quality of life a review and critique. Social Science and Medicine, 15F, 107-115.

- Neuhaus, B.E. (1988). Ethical considerations in clinical reasoning: the impact of technology and cost containment. The American Journal of Occupational Therapy, 42(5), 288-294.
- Northouse, P.G., & Northouse, L.L. (1988). Communication and cancer: issues confronting patients, health care professionals, and family members. Journal of Psychosocial Oncology, 5(3), 17-46.
- O'Young, J., & McPeck, B. (1987). Quality of life variables in surgical trials. Journal of Chronic Diseases, 40(6), 513-522.
- Ogilvie, A.L., Dronfield, M.W., Ferguson, R., & Atkinson, M. (1982). Palliative intubation of oesophagogastric neoplasms at fiberoptic endoscopy. Gut, 23, 1060-1067.
- Padilla, G.V., & Grant, M.M. (1985). Quality of life as a cancer nursing outcome variable. Advances in Nursing Science, 8(1), 45-60.
- Padilla, G.V., Presant, G., Grant, M.M., Metter, G., Lipsett, J., & Heide, F. (1983). Quality of life index for patients with cancer. Research in Nursing and Health, 6, 117-126.
- Pinch, W.J. (1986). Quality of life as a philosophical position. Health Values, 10(6), 3-7.
- Polit, D.F., & Hungler, B.P. (1987). Nursing Research: principles and methods (3rd ed.). Philadelphia: J.B. Lippincott Company.
- Priestman, T.J., & Baum, M. (1976). Evaluation of quality of life in patients receiving treatment for advanced breast cancer. The Lancet, 899-901.
- Pringle, D., & Taylor, D. (1984). Palliative care in the home: does it really work? The Canadian Nurse, 80(6), 26-29.
- Riemann, J.F., Lux, G., & Demling, L. (1985). Combined therapy of malignant stenoses of the upper gastrointestinal tract by means of laser beam and bougienage. Endoscopy, 17(2), 43-48.

- Sander, R., Poesl, H., & Spuhler, A. (1984). Management of non-neoplastic stenoses of the GI-tract. Endoscopy, 16(4), 129-164.
- Scanlon, C. (1989). Creating a vision of hope: the challenge of palliative care. Oncology Nursing Forum, 16(4), 491-496.
- Schipper, H. (1983). Why measure quality of life? Canadian Medical Association Journal, 128, 1367-1370.
- Schipper, H., Clinch, J., McMurray, A., & Levitt, M. (1984). Measuring the quality of life of cancer patients: the Functional Living Index - Cancer: development and validation. Journal of Clinical Oncology, 2(5), 472-483.
- Schipper, H., & Levitt, M. (1985). Measuring quality of life: risks and benefits. Cancer Treatment Reports, 69(10), 1115-1123.
- Selby, P.J., Chapman, J.W., Etazadi-Amoli, J., Dalley, D., & Boyd, N.F. (1984). The development of a method for assessing the quality of life of cancer patients. British Journal of Cancer, 50, 13-22.
- Selby, P., & Robertson, B. (1987). Measurement of quality of life in patients with cancer. Cancer Surveys, 6(3).
- Shaw, A. (1988). QL revisited. Hastings Center Report, 18(2), 10-12.
- Souttar, H.S. (1924). A method of intubating the oesophagus for malignant stricture. British Medical Journal, 782-783.
- Spitzer, W.O., Dobson, A.J., Hall, J., Chesterman, E., Levi, J., Shepherd, R., Battista, R.N., & Catchlove, B.R. (1981). Measuring the quality of life of cancer patients. Journal of Chronic Diseases, 34, 585-597.
- Storch, J. (1982). Patient's Rights. Toronto: McGraw-Hill, Ryerson.

Troidl, H., Kusche, J., Vestweber, K., Eypasch, E., Koeppen, L., & Bouillon, B. (1987). Quality of life: an important endpoint both in surgical practice and research. Journal of Chronic Diseases, 40(6), 523-528.

Wright, V.C., & Riopelle, M.A. (1984). An introduction to surgical lasers. Canadian Operating Room Nursing Journal, 17-20.

APPENDIX A

THE RELATIONSHIP BETWEEN SYMPTOM DISTRESS AND
QUALITY OF LIFE IN PATIENTS WITH ESOPHAGEAL CANCER
CONSENT FORM

I _____ agree to participate in the study "The relationship between symptom distress and quality of life in patients with esophageal cancer". The purpose of the study is to gain an understanding of the effects of symptoms of esophageal cancer on the quality of life.

The results of the study may be helpful to health professionals in providing information to patients and families about treatment choices. The results may also help health professionals learn how to provide better care for patients with esophageal cancer.

The study is conducted by Wendy Morgan-Eckley, Masters Student, Faculty of Nursing, University of Manitoba, and will form part of the course work for the Masters Degree.

My participation involves answering three short questionnaires and a short interview. It will take approximately one half hour. I understand that my participation is voluntary and that I may withdraw from the study at any time by simply telling the researcher. I understand that my decision to participate or not in the study will in no way affect my care.

The information that I provide will be confidential because my name will not be on the questionnaires. Findings from the research may be published, but the data will be grouped and no names used.

There are no known risks involved with participating in the study. The study offers no direct benefits to the participants. I understand that I will receive answers to any questions about the study at any time.

The researcher can be reached at: 477-3372 or 261-7044. The researcher's advisor is Dr. Linda Kristjanson (474-8937), University of Manitoba, Faculty of Nursing.

Signature: _____ Date: _____

APPENDIX B

Manitoba Cancer Treatment & Research Foundation Functional Living Index - Cancer (FLIC)

Date: _____

1. Most people experience some feelings of depression at times. Rate how often you feel these feelings.

1	2	3	4	5	6	7
Never						Continually

2. How well are you coping with your everyday stress?

1	2	3	4	5	6	7
Not Well						Very Well

3. How much time do you spend thinking about your illness?

1	2	3	4	5	6	7
Constantly						Never

4. Rate your ability to maintain your usual recreation or leisure activities?

1	2	3	4	5	6	7
Able						Unable

5. Has nausea affected your daily functioning?

1	2	3	4	5	6	7
Not at all						A great deal

6. How well do you feel today?

1	2	3	4	5	6	7
Extremely poor						Extremely well

7. Do you feel well enough to make a meal or do minor household repairs today?

1	2	3	4	5	6	7
Very Able						Not Able

8. Rate the degree to which your cancer has imposed a hardship on those closest to you in the past two weeks.

1	2	3	4	5	6	7
No Hardship						Tremendous Hardship

9. Rate how often you feel discouraged about your life?

1	2	3	4	5	6	7
Always						Never

10. Rate your satisfaction with your work and your jobs around the house in the past month.

1	2	3	4	5	6	7
Very Dissatisfied						Very Satisfied

11. How uncomfortable do you feel today?

1	2	3	4	5	6	7
Not at all						Very Uncomfortable

12. Rate in your opinion how disruptive your cancer has been to those closest to you in the past two weeks.

1	2	3	4	5	6	7
Totally Disruptive						No Disruption

13. How much is pain or discomfort interfering with your daily activities?

1	2	3	4	5	6	7
Not at all						A Great Deal

14. Rate the degree to which your cancer has imposed a hardship on you (personally) in the past two weeks.

1	2	3	4	5	6	7
Tremendous Hardship						No Hardship

15. How much of your usual household tasks are you able to complete?

1	2	3	4	5	6	7
All						None

16. Rate how willing you were to see and spend time with those closest to you in the past two weeks.

1	2	3	4	5	6	7
Unwilling						Very Willing

17. How much nausea have you had in the past two weeks?

1	2	3	4	5	6	7
None						A Great Deal

18. Rate the degree to which you are frightened of the future.

1	2	3	4	5	6	7
Constantly Terrified						Not Afraid

19. Rate how willing you were to see and spend time with friends in the past two weeks.

1	2	3	4	5	6	7
Unwilling						Very Willing

20. How much of your pain or discomfort over the past two weeks was related to your cancer?

1	2	3	4	5	6	7
None						All

21. Rate your confidence in your prescribed course of treatment to those closest to you in the past two weeks.

1	2	3	4	5	6	7
No Confidence						Very Confident

22. How well do you appear today?

1	2	3	4	5	6	7
Extremely Poor						Extremely Well

**APPENDIX C
SYMPTOM DISTRESS SCALE**

Date: _____

Symptoms	Degree of Distress				
	1	2	3	4	5
Nausea (1)	I seldom feel nausea at all	I am nauseous once in awhile	I am often nauseous	I am usually nauseous	I suffer from nausea almost continually
Nausea (2)	When I do have nausea it is very mild	When I do have nausea, it is mildly distressing	When I have nausea, I feel pretty sick	When I have nausea, I feel very sick	When I have nausea, I am as sick as I could possibly be
Appetite	I have my normal appetite	My appetite is usually but not always pretty good	I don't really enjoy my food like I used to	I have to force myself to eat my food	I cannot stand the thought of food
Insomnia	I sleep as well as I always have	I have occasional spells of sleeplessness	I frequently have trouble getting to sleep and staying asleep	I have difficulty sleeping almost every night	It is almost impossible for me to get a decent night's sleep
Pain (1)	I almost never have pain	I have pain once in awhile	I frequently have pain several times a week	I am usually in some degree of pain	I am in some degree of pain almost constantly
Pain (2)	When I do have pain it is very mild	When I do have pain it is mildly distressing	The pain I do have is usually fairly intense	The pain I have is usually very intense	The pain I have is almost unbearable

Symptoms	Degree of Distress				
	1	2	3	4	5
Fatigue	I am usually not tired at all	I am occasionally rather tired	There are frequently periods when I am quite tired	I am usually very tired	Most of the time I feel exhausted
Bowel	I have my normal pattern	My bowel pattern occasionally causes me some concern	I frequently have discomfort from my present bowel pattern	I am usually in discomfort because of my present bowel pattern	My present bowel pattern has changed drastically from what was normal for me
Concentration	I have my normal ability to concentrate	I occasionally have trouble concentrating	I often have trouble concentrating	I usually have at least some difficulty concentrating	I just can't seem to concentrate at all
Appearance	My appearance has basically not changed	My appearance has gotten a little worse	My appearance is definitely worse than it used to be, but I am not greatly concerned about it	My appearance is definitely worse than it used to be and I am concerned about it	My appearance has changed drastically from what it was
Breathing	I usually breathe normally	I occasionally have trouble breathing	I often have trouble breathing	I can hardly ever breathe as easily as I want	I almost always have severe trouble with my breathing

Symptoms	Degree of Distress				
	1	2	3	4	5
Outlook	I am not fearful or worried	I am a little worried about things	I am quite worried, but unafraid	I am worried and a little frightened about things	I am worried and scared about things
Cough	I seldom cough	I have an occasional cough	I often cough	I often cough and occasionally have severe coughing	I often have persistent and severe coughing
Swallowing	I can swallow all food and liquids	I can swallow liquids and soft foods	I can swallow liquids	I can swallow small amounts of liquid only	I can't swallow anything at all
Choking	I never feel that I am choking	I rarely feel like I am choking	I sometimes feel like I am choking	I often feel like I am choking	I always feel like I am choking

APPENDIX E

INVITATION TO PARTICIPATE

My name is Wendy Morgan-Eckley, and I am a Graduate Student in the School of Nursing at the University of Manitoba. The purpose of your treatment is to relieve symptoms and provide you with a more comfortable quality of life. I am doing a research project about this type of care. The research involves asking you questions about your symptoms and your quality of life before the treatment and after the treatment.

Your participation would be totally voluntary and would involve answering three short questionnaires that would take approximately 10 to 20 minutes. If you decide to participate, you may withdraw from the study at any time simply by telling me. There is no risk to your care should you wish not to participate.

Any information that you provide will remain confidential and your name will not appear at any time on the questionnaires. Do you have any questions regarding the research project?

APPENDIX G
QUALITATIVE QUESTIONNAIRE

1. What symptoms of your disease were most distressing?
2. What has been most relieved by your treatment?
3. What has been most difficult for you in dealing with your disease?
4. How have nurses been helped in relieving any distress?
5. What could nurses have done differently that would have been more helpful in dealing with your disease?
6. Are there any other comments about your treatment or care that would be useful for nurses and doctors to know?

DEFINITION OF TERMS

Several terms require operational definitions for the purpose of this study.

Laser: A powerful tool that can remove or destroy tissue with relatively few complications (Wright, & Riopelle, 1984). The principle of light amplification by stimulated emission of radiation (laser) was first articulated in 1958 and is a relatively new concept in surgery. There are various types of surgical lasers in use today. The neodymium yttrium aluminum garnet (Nd:YAG) laser was developed in the early 1960s with Federal Drug Administration (FDA) approval for medical use following in the late 1970s. Its penetrating depth makes it preferable for deep tissue coagulation, hemostasis, and vaporization of tissue (Ball, 1986; Lehr, 1989). The advantages of using the laser are decreased trauma, bleeding, and swelling (Carter, 1986). The Nd:YAG laser is passed on a flexible fibre through a fibreoptic endoscope and allows the surgeon to access the tumour in the esophagus.

Endoprosthesis: A tube that is inserted into the esophagus during fibreoptic endoscopy. It remains in the esophagus permanently and its purpose is to maintain a patent lumen in the esophagus. The first prostheses were metal; the ones currently in use are plastic (Souttar, 1924; den Hartog Jager, Bartelsman, & Tytgat, 1979; Boyce, 1988). The prosthesis used for patients in this study were Atkinson by KeyMed.

Quality of Life: Degree of satisfaction with present life circumstances, as perceived by the patient (Graham & Longman, 1987, p.339). Quality of life is a dynamic and complex concept that is difficult to define and to measure (Ferrans, & Power, 1985). There are subjective components which the patient is best able to judge. Quality of life was measured by the Functional Living Index - Cancer (FLIC).

Palliative Surgical Treatment: Refers to surgical intervention aimed at providing symptom relief rather than cure. Palliative treatment for the purposes of this study was either laser treatment or insertion of an endoprosthesis to maintain a patent esophageal lumen after obstruction due to cancer.

Nursing Care: Includes interventions and approaches used by the nurse to ease physical and psychological pain and discomfort when caring for a patient. In this study, nursing care was considered in relation to the particular needs of patients with esophageal cancer (Davies, & Oberle, 1990).

Symptom Distress: The "degree of discomfort from the specific symptom being experienced as perceived by the patient" (McCorkle & Young, 1978, p.374). In this study, symptom distress was measured by the Symptom Distress Scale developed by McCorkle & Young (1978).

FIGURE #1

*PALLIATIVE & SURGICAL
TREATMENT*

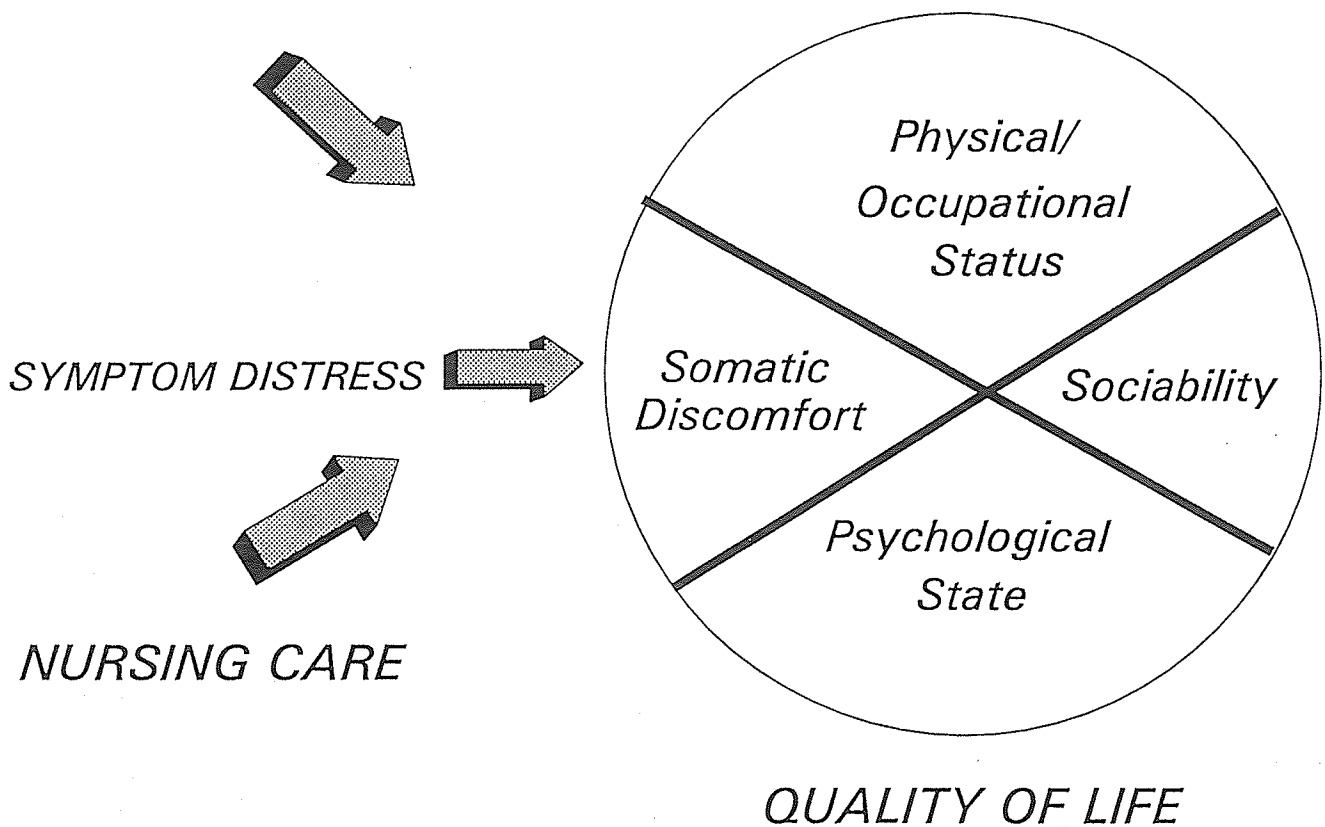
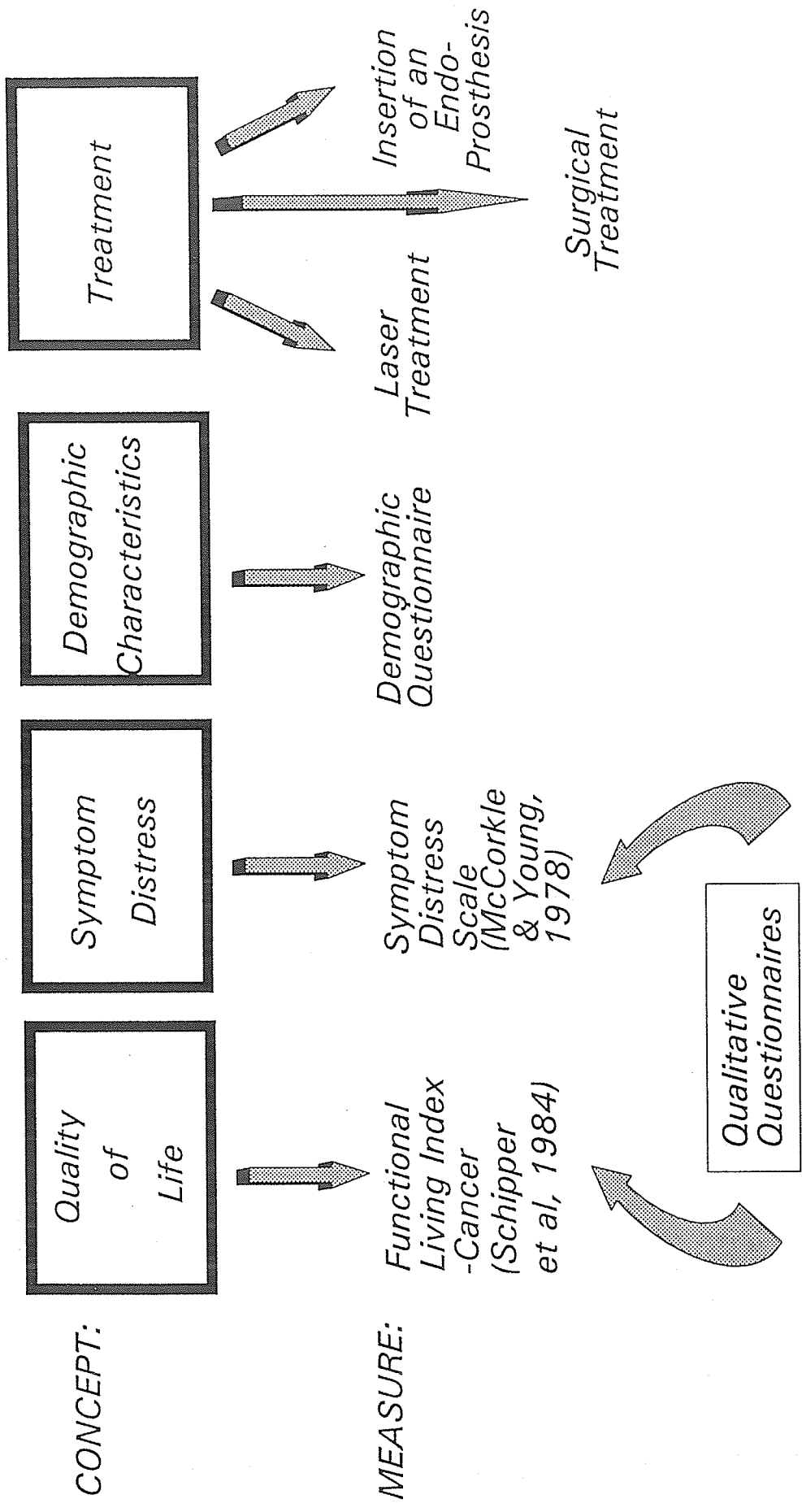


Figure #1: Conceptual Model

The relationship between symptom distress, nursing care, palliative and surgical treatment and quality of life

(Graham & Longman, 1987; Schipper & Levitt, 1985; Calman, 1984)

FIGURE #2



The relationship between study concepts and instruments

The University of Manitoba
SCHOOL OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number N#91/09

Proposal Title: "The relationship between symptom distress and quality of life in patients with esophageal cancer who experience palliative surgical treatment - a pilot study."

Name and Title of Researcher(s): Wendy Morgan-Eckley
Master of Nursing Graduate Student
University of Manitoba School of Nursing

Date of Review: May 06, 1991.

APPROVED BY THE COMMITTEE: MAY 06, 1991.

Comments: _____

Date: May 13th, 1991
Erna J. Schilder, RN, DNS Chairperson
Associate Professor
University of Manitoba School of Nursing
Position

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 91/01/11/se



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June 3, 1992

Wendy Morgan-Eckley

Winnipeg, Manitoba
R

Dear Ms. Morgan-Eckley:

The revisions to your proposal titled "The Relationship between Symptom Distress and Quality of Life in Patients with Esophageal Cancer" were reviewed by the Ethical Review Committee of the Faculty of Nursing at the June 1, 1992 meeting. The committee approved your proposed changes as outlined in your submission.

On behalf of the committee, I wish you every success in the completion of your research.

Sincerely,

Karen Chalmers RN, PhD
Associate Professor
Ethical Review Committee

Inter-Departmental Correspondence

DATE: January 31, 1991

TO: Wendy Ann Morgan-Eckley

FROM: Rita Upton, Graduate Program Secretary, School of Nursing *RU*

SUBJECT: THESIS COMMITTEE

This is to advise you that your thesis committee has been approved as follows:

Chairperson:	Prof. Linda Kristjanson School of Nursing
Member:	Dr. Lesley Degner School of Nursing
Member:	Dr. Charles Olweny Dept. of Internal Medicine Faculty of Medicine

U

We wish you every success in your thesis endeavour.

/ru