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Evaluating Satisfaction and Benefit from Nutrition Counseling from a Registered Dietitian among Head and Neck Cancer Patients Receiving Radiation Therapy

A thesis

presented to

the faculty of the Department of Family and Consumer Sciences

East Tennessee State University

In partial fulfillment

of the requirements for the degree

Masters of Science in Clinical Nutrition

by

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Keywords: cancer, nutrition counseling, weight loss, side effects, radiation

ABSTRACT

Evaluating Satisfaction and Benefit from Nutrition Counseling from a Registered Dietitian among Head and Neck Cancer Patients Receiving Radiation Therapy

by

Lori E. Watson

The purpose of this study was to determine if patients with head or neck cancer receiving radiation were satisfied with the nutrition counseling they were receiving and if they obtained any benefit. Radiation to the head or neck region promotes side effects such as taste changes and chewing and swallowing difficultly that decrease food and fluid intake. A reduction in nutrients leads to weight loss, and weight loss in cancer patients increases the risk of morbidity and morality as well as decreases quality of life. Subjects were recruited from a local cancer treatment facility and a survey was administered. Subjects were found to manage the side effects better after counseling from the registered dietitian, and a minimal amount of weight loss was observed. Registered dietitians when incorporated into a radiation treatment facility can provide an effective nutrition program targeted at reducing weight loss and improving quality of life.

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CHAPTER 1

INTRODUCTION

Statement of the Problem

The purpose of this study was to determine if patients with head or neck cancer receiving radiation were satisfied with the nutrition counseling they were receiving and if they obtained any benefit. Oral and pharyngeal cancer rank among the most common cancers in the US; 14th most common for women and 10th most common for men (1). Cancer of the head and neck region, in contrast to other types of cancer, often causes more nutritional problems for the individual because of the location of the malignancy. Numerous studies have shown that there are two common nutritional concerns with all cancer patients: malnutrition and weight loss. Malnutrition was defined by Allen and Crocker (2) as "any nutritional deficit associated with an increased risk of morbidity and mortality." The prevalence of cancer patients who are malnourished can range from 40% to almost 80%, and more often than not, patients with malnutrition caused by head or neck malignancies are on the upper end of this range (3, 4).

Significance of the Problem

Malnutrition and weight loss can play key roles in determining an individual's experience during treatment and response to treatment along with the survival rate (2). Malnutrition alone increases the patient's risk of infection, treatment side effects, and health-care costs for the individual and for the hospital. Malnutrition may decrease life expectancy and quality of life (4). Research has found that the five-year survival rate for

head and neck cancer is 53% (1). Thus, it is important to offer the best and most effective care to promote increased survival rates and improve quality of life.

Even though the long-term survival statistics can seem discouraging for patients, current research findings are helpful in suggesting ways for healthcare providers to enhance quality of life and improve survival rates. Recent studies examined the effects of different treatment options, nutrition counseling techniques as well as nutrition support routes and formulas to strengthen and improve upon the experience and response to radiation and chemotherapy treatment. Researchers are trying to better understand the mechanism causing cancer patients to experience such dramatic weight loss when compared to patients with other diseases as well as how to combat these issues before and during treatment. Encompassing all the aspects of cancer treatment, from nutritional interventions to emotional turmoil will improve the outcome not only for individuals with head and neck cancer but any individual battling cancer.

<u>Assumptions</u>

- It is assumed that individuals who indicate an improvement in side effects after nutrition counseling from a registered dietitian received benefit from the nutrition counseling.
- Benefit from nutrition counseling improves quality of life during radiation treatment.

Limitations

- Only patients receiving radiation therapy to the head or neck region participated in the research study.
- Patients being fed entirely by enteral feedings were excluded.
- Research took place in only one of the radiation therapy treatment facilities as opposed to multiple facilities in the geographic region.
- The sample size of participants was small.

Definitions

<u>Pharyngeal (pharynx)</u> – the throat, serves as a passage way for respiratory and digestive tracts. Divided into the nasopharynx, oropharynx, and laryngopharynx (5) <u>Enteral feedings</u> – the introduction of nutrients directly into the GI tract by feeding tube (5)

<u>Malignancy</u> – a cancer (5)

Stomatitis – an inflammation of the mucous membranes of the mouth (5)

Esophagitis – inflammation of the mucosal membrane of the esophagus (5)

<u>Mid-arm muscle circumference</u> – a measurement of the circumference of the arm at a midpoint between the shoulder and the elbow. It is an indication of upper arm muscle wasting (5)

<u>Edema</u> – abnormally large amounts of fluid in the body (5)

<u>Albumin</u> – a protein found in blood that serves as a carrier protein. Used in laboratory testing as an indicator of protein status and inflammation (5)

<u>Resting energy expenditure (REE)</u> – an equation used to measure the amount of energy used during a resting state

Tracheotomy – an incision made in the trachea through the neck below the larynx,

performed to gain access to the airway below a blockage with a foreign body or tumor

(5)

Flap reconstruction – an alternative to skin expansion as a method of breast

reconstruction after a mastectomy (5)

<u>Dysphagia</u> – difficulty in swallowing (5)

Squamous cell carcinoma - a slow growing malignant tumor of squamous epithelium (5)

Xerostomia – dryness of the mouth caused by cessation of normal salivary secretion (5)

<u>Mucositis</u> – any inflammation of a mucous membrane, such as the lining of the mouth

and throat (5)

CHAPTER 2

REVIEW OF LITERATURE

Etiology of Malnutrition and Weight Loss

It is essential for patients and healthcare professionals to understand that weight loss associated with any cancer is mulitfactorial (6). According to Capra, Ferguson, and Reid (3) "Malnutrition can result from the systemic effects of the tumor, the local effects of the tumor, or the side effect of anti-cancer treatments." Nitenberg and Raynard (7) described weight loss as a result of the 'parasitic' metabolism of the tumor on the host that impacts the metabolism of the host. Regardless of how the tumor affects those with cancer, the result is weight loss. Examples of ways the tumor may promote weight loss include anorexia and altered metabolism, but the effects may differ depending on the type and the complexity of the cancer (3). Local effects of the malignancy consist of malabsorption, obstruction, and diarrhea/vomiting (3). These four occurrences often decrease the individual's nutrient intake while increasing nutrient excretion from the body, leading to weight loss and ultimately malnutrition if these symptoms are allowed to continue for even a short period of time (8).

A form of weight loss called cachexia is a condition often seen and studied in association with cancer. Early studies (8, 9) of cachexia in people with cancer were thought to be the outcome of a nutritional deficit caused by energy use by the tumor. Additionally, decreased nutrient intake was attributed to the tumor acting on the satiety sensation in the central nervous system, resulting in starvation. In thinking this was the weight loss mechanism, the most rational way to combat it was to attempt to increase intake in individuals (9). Healthcare providers soon discovered that regardless of how

many patients increased their intake, they continued to lose weight. This conclusion led to the identification of the phenomenon known as primary anorexia/cachexia syndrome (9). Cachexia is different from starvation in that during starvation there is a decreased intake of energy leading to decreased metabolism to conserve vital tissues, and fat is used for energy before lean tissue (8). Cachexia is coupled with an altered inflammatory state where catabolism is accelerated regardless of the nutrient intake, and peripheral proteins and lipids are mobilized for energy (9). Metabolism does not slow down as it does in starvation, and the end result is loss of fat and lean body mass, namely skeletal muscle (9).

Along with the metabolic alterations to address during cancer, there are several physical symptoms contributing to weight loss as well. Capra, Ferguson, and Reid (3) found in their research that 40% to 60% of individuals receiving radiation to the head or neck experienced swallowing problems because of stomatitis and esophagitis. When these symptoms presented, individuals complained of pain and bleeding that decreased and/or altered nutritional intake dramatically (3).

For people with head and neck cancer, changes in taste sensation are often the most common side effect of cancer treatment. Research has shown that 14% of individuals had taste changes before radiation treatments began and 84% developed changes by the fifth week of radiation therapy (3). Initial taste change may be directly affected by the tumor itself and is caused by an amino acid like substance secreted by tumor cells (10). Taste sensation is experienced through a stimulation of taste receptors. These receptors are located on the tongue in the form of taste buds, between the hard and soft palates, the throat, and in the nasal cavity (10). Taste receptors are sensitive to

five basic flavors. These include sweet, salty, bitter, sour, and acid, and the less familiar umami, which offers enhancement of the savory flavors (10). During therapy, taste changes occur because of cell damage when the radiation is directed at the head or neck region whereby receptors die and taste is affected (10). Individuals describe alterations in sweet, salty, bitter, and sour as being mild to completely absent (10). Bitter is often the most affected, leading to the avoidance of meat, tea, and chocolate (10). This may lead to a decrease in protein intake and ultimately result in muscle wasting (10). If the tip of the tongue (where sweet receptors are located) is included in the path of radiation, then the ability to detect sweetness may be hindered (10). Taste sensation should return within two to four months after termination of the treatments (10).

In addition to taste loss with cell damage, the salivary production can be reduced or absent during or after radiation therapy (10). Often the saliva will change consistency from clear and watery to viscous and semi-opaque, thus impacting swallowing and taste (3). It must be noted that taste and salivary changes do not only occur when an individual endures radiation therapy. Studies showed that 36% to75% of individuals receiving chemotherapy also experience taste change when certain chemotherapeutic drugs are present in their anti-cancer regimen (10).

Taste changes not only increase the risk of weight loss, secondary to decreased intake, but it may also have a psychological effect on the individual. Food plays a key role in social activities, and when food does not taste as it "should", individuals often become depressed and avoid social interactions with friends and families. Ravasco (10) reported that, "Forty percent of patients who reported that taste changes affected their lives reported that they felt depressed."

Tony Peregrin (11) conducted a study in which he interviewed two oncology registered dietitians, Bonnie Dixon and Barbara Grant, about ways of addressing taste changes in patients with cancer. They suggested that foods with strong flavor should be consumed cool or cold to reduce the aroma. If the smell of food while cooking makes the individual sick, offer recipes for cold food or salads. Because tooth decay is associated with dry mouth, a common side effect from radiation to the head or neck region, the registered dietitians included recommendations for managing dry mouth, such as visiting the dentist before starting their anti-cancer treatment to help increase the enamel strength of the teeth (11). Additionally, frequently rinsing one's mouth, keeping water nearby all the time, keeping lips moist, brushing teeth after each meal or snack, and reducing the amount of sugary or sticky foods consumed will also help combat dry mouth and tooth decay. Dixon and Grant (11) also communicated the role of the registered dietitian when caring for a person with cancer. Grant was quoted as saying, "When providing nutritional counseling, a food and nutrition professional needs to be proactive rather than reactive (11)."

Assessment of Nutritional Status/Requirements

By definition proactive means (12) "Serving to prepare for, intervene in, or control an expected outcome or situation especially a negative or difficult one." In being proactive, healthcare professionals would need to assess specific factors that alert them to an individual who was nutritionally deficient before treatment begins. One assessment tool used in a number of studies was the subjective global assessment (SGA). This questionnaire is a standardized tool developed to determine nutritional status in an easy, noninvasive, cost-effective way (13). After compiling the questionnaire, the individuals were identified as either: well nourished, moderately/suspectedly malnourished, or severely malnourished (13). The survey was originally validated in surgical patients but has since been modified in order to assess nutritional status of cancer patients (13).

A study performed by Thoresen et al. (13), attempted to validate the SGA questionnaire as an assessment tool when compared to a conventional objective assessment. A total of 46 patients were included for this three-month study. Nutritional status was measured in two ways: 1) objective criteria such as anthropometric measures of BMI, mid-arm muscle circumference (MAMC), and triceps skin fold (TSF) along with protein assays, 2) by the use of subjective SGA questionnaire (13). Malnutrition defined by Thoresen (13) included one or more of the following criteria: weight loss >5% during last month or >10% during last 6 months or >15% of prediagnosis weight, BMI <20, TSF < 5th percentile, MAMC < 5th percentile, serum albumin \leq 3.0 g/L, and serum prealbumin \leq 0.21 g/L. The SGA defines each of its malnutrition categories as follows: well nourished implies stable weight or increasing weight because of improvement in symptoms; moderately/suspectedly malnourished includes weight loss up to 10% during the last 6 months and eating less than usual; and severely malnourished is greater than 10% loss of body weight during the last 6 months and obvious signs of malnutrition such as muscle wasting and edema (13).

Results of this study showed that of the 46 patients involved, 38 of them had lost weight, and more specifically 24 had lost more than 10% of their original body weight (13). The SGA produced results that correlated highly with the objective criteria (BMI,

MAMC, TSF, and laboratory assays). There were significant differences between the SGA categories, meaning that participants matched accordingly to the defined categories of malnutrition defined in the survey. The variables associated with the objective tests estimate the body's energy stores (13). The SGA had high relationships with these variables, which proved the validity of the SGA. Researchers (13) noted there was a weaker correlation with the SGA and measures of albumin and prealbumin. This could lead to the conclusion that serum proteins are not a good indicator of nutritional status but more of a benchmark of illness or inflammation (13).

The researchers pointed out that there are advantages of using the SGA as opposed to the objective measures, one being that the questionnaire is more practical in a clinical setting. Anthropometric methods take time and require staff who have been trained to perform these measurements. Also the SGA listed contributory data for reasons of weight loss. Questions about the individual's symptoms were addressed and these could be used to determine individualized nutrition counseling (13).

The SGA is only one tool of assessment available for use. Facilities may choose to use a different assessment tool, but any general evaluation should include assessment of the symptoms that may lead to weight loss, functional ability, physical examination, use of supplements, of vitamins or of herbs, and current intake (8, 9).

Upon conducting the initial assessment, it would be necessary to use the information to estimate the patient's energy needs. Nutritional requirements for an individual with cancer will depend upon the degree of malnutrition and the current state of metabolic stress (14). Current resting energy expenditure (REE) can be increased, decreased, or unchanged from prediagnosis REE (15). If there are no indicators of a

change in energy expenditure, one is to assume it is normal (15). An article published in the European Society for Clinical Nutrition and Metabolism by Arends et al. (15) noted that in one quarter of individuals with cancer, when measured by indirect calorimetry, were found to have 10% higher REE and in another one quarter of patients was 10% lower than the predicted energy expenditure when measured by indirect calorimetry.

It is evident that there are no universal or standardized calculations for energy requirements for individuals with cancer. Two studies (14, 15) mentioned the use of the Harris Benedict and Schofield equations to calculate nutrient needs as well as a good "rule of thumb": 30 to 35 kilocalories per kilogram of body weight per day for individuals who are ambulant and 20 to 25 kilocalories per kilogram of body weight per day for those who are confined to bed. The alterations in protein metabolism are mentioned in numerous studies, but again the degree of protein repletion depends upon the amount of metabolic stress and the degree of malnutrition and wasting present in each individual. Scheuren (14) suggested that protein needs might range from 1.2 to 2.0 grams per kilogram of body weight per day. Carbohydrate intake in healthy individuals should range from 40% to 60% of the total energy intake. There are no current recommendations for carbohydrate intake in people with cancer (14). Fat intake is very important not only as an energy source but also for essential fatty acids and the transport and absorption of the fat-soluble vitamins. Fat should not be restricted during cancer treatments unless necessary (14).

Implications for Enteral Nutrition

Enteral feedings may be indicated if the individual is unable to consume enough nutrients orally because of reasons such as nausea, vomiting, taste changes, or in cases of head and neck cancer, tumor obstruction. Feeding tubes may be placed nasally or through the abdominal wall into either the stomach or the small intestine (8). A study performed by Cheng, Terrell, and Bradford (16) found seven variables that increase the probability of having an enteral feeding tube one month after completion of treatment. These variables were as follows: a tumor in the oropharynx/hypopharyx location; advanced stage cancers; tracheotomy; flap reconstruction; increased age; chemotherapy; and decreased time since treatment (16). Various limitations were noted in this. Information was collected at only one point in time, and there was no follow up. No distinction was made between whether the individual had the feeding tube placed before or during treatment. This information would be important to determine the reasons for the initial placement of the feeding tube – to prevent weight loss or complications in dysphagia (16). Despite its limitations, the study indicated several factors that may increase the need for tube feeding placement and inform healthcare professionals to be aware of these variables while performing assessments.

Several studies commented (4, 9, 15) that the evidence of providing nutritional support to increase survival rates is controversial and inconclusive. However, numerous studies (7, 9, 14, 15) suggest that enteral feedings may stabilize the deterioration of nutritional status. Initiating early enteral feeding at the first indication of malnutrition or early post-operatively, has been shown to decrease complications from surgery,

improve nitrogen balance, reduce protein catabolism, and reduce infections in cancer patients (14).

A well-designed research study by Daly and colleagues (17) attempted to compare nasogastric tube feeding with optimal oral nutrition in patients with head or neck cancer. Forty patients were selected on the criteria of having measurable, local advanced, inoperable, squamous cell carcinoma of the oral cavity, oropharynx, larynx, or hypopharynx. Patients were stratified according to their cancer location, if they had had previous head or neck cancer, and type of initial treatment. Each individual was assessed using anthropometric measures, serum albumin levels, and 24-hour diet recall. Toxicities defined by dysphagia, xerostomia, mucositis, nausea, vomiting, constipation, and diarrhea were assessed in a patient interview with a registered dietitian (17) and graded on a level of zero to four with zero being no toxicity, one being slight toxicity, two indicating moderate toxicity, three being severe toxicity, and four indicating life-threatening toxicity. For the group receiving oral nutrition, the goal nutrient intake was 40 kilocalories per kilogram of body weight per day, and 1 to 1.5 grams of protein per kilogram of body weight per day. All patients were given a diet pattern based on their individual body weight, height, previous weight loss, age, and sex. Those who needed additional intake were given commercial supplements as well as recipes to enhance intake (17). The registered dietitian saw patients twice a week during their eight-week radiation therapy treatment period. Individuals placed in the tube-feeding group were given the same nutrition counseling during the initial treatment phase to maximize caloric intake. When tube feedings were initiated, each patient was instructed on the correct techniques of preparation of formulas, rates of administration, care, and

sanitation. Individuals were also given a booklet for home reference. Formulas and rates were specified for each patient based on body weight, age, sex, height, and degree of previous weight loss. The caloric target was the same as the oral nutrition group at 40 kilocalories per kilogram of body weight per day and 1 to 1.5 grams of protein per kilogram of body weight per day. The authors (17) evaluated calorie and protein intake, weight changes, duration and amount of therapy received, severity of reactions to therapies, patient acceptance, and complications that arose with nutritional interventions. The results showed that there was an improvement in body weight in individuals who received enteral feedings compared to those who were orally fed. Nevertheless, there were no significant differences in the tumor response, duration of response, or survival rate (17). Enteral feedings did not reduce toxicity levels, but they may have lessened the magnitude of hindrance during daily activities. The enteral group was also observed to take in more nutrients, 39 kilocalories per kilogram of body weight per day versus 30 kilocalories per kilogram of body weight per day, when compared to the orally fed group. Serum albumin levels indicating improved protein status also returned to normal in the enterally fed group in contrast to the oral group (17). Overall, the study showed promising results for enteral feedings for maintaining weight, serum albumin level, and nutrient intake.

Nutrition Counseling

Nutrition is an important component when treating any disease or condition, so it would be safe to assume that nutrition counseling should be part of any medical therapy process. In the previous section, the research study by Daly (17) compared nutritional counseling to tube feedings in helping reduce the rate of weight loss and increase oral intake in people with cancer. The study showed that the group receiving the tube feedings did increase the amount of nutrition they took in more than the group who did not receive tube feedings, but it should be noted that nutritional counseling did help patients keep their intake at 30 kilocalories per kilogram of body weight. This information supports nutrition counseling as a necessary component in helping individuals manage weight loss during their treatment.

Nutrition counseling has been shown through research to be very effective in improving nutritional status, functional ability, and quality of life in cancer patients (18). A study performed by Ravasco et al. (18) was one of the first to demonstrate that individualized counseling, based upon food preferences was the most effective in improving nutritional intake and quality of life when compared to a usual diet along with liquid supplements and an intake ad libitum. As mentioned in the first section of this paper, weight loss during treatment is an early marker of nutritional decline. The smallest amount of weight loss in Ravasco's study was seen in the group receiving the individualized nutrition counseling (18). This group was also able to maintain energy intake during treatment and into the follow-up period (three months following completion of radiation treatment), while the other two groups either returned to baseline status or fell below (18). Within the conditions of this clinical investigation, individualized nutrition counseling at the other two groups either returned to baseline status or fell below (18). Within the conditions of this clinical investigation, individualized nutrition counseling the the other two groups either returned to baseline status or fell below (18). Within the conditions of this clinical investigation, individualized nutrition counseling during radiation treatment was the most influential to ensure a sustained and adequate diet that was able to overcome the weight loss associated with radiation.

According to Ravasco (19), "Quality of life is a subjective multidimensional construct representing functional status, psychological well-being, health perceptions

and disease/treatment-related symptoms." At the end of the three-month follow-up period the nutrition counseling group improved all the quality of life function scores in the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire. The questionnaire was applied to measure participants' physical, emotional, cognitive, social role, and global health or quality of life levels during and after their radiation treatment (18). Ravasco et al. (19) used the EORTC questionnaire to evaluate quality of life in cancer patients. Patients were categorized into either high or low risk for nutritional deficiencies. The high-risk group included individuals with head/neck or gastrointestinal cancer. Low-risk was any other cancer location that could be treated by radiation. Overall high-risk individuals presented with poorer scores for quality of life than did those in the low risk group (19). Two associations were found in the analysis of the data. An association between worse nutritional status and worse mobility or anxiety/depression was identified as well as an association between anxiety/depression and nutritional intake (19). The authors noted the following, "Nutritional intake improvement was identified as a major determinant of the quality of life improvement registered at the end of the radiation treatment (19)." This study's conclusion concurs with the previous study that nutrition does play a key role in quality of life outcomes.

Registered dietitians and other health professionals have known that nutrition is an important component of quality care and treatment that contributes to better overall outcomes. However, it is also necessary to recognize how a patient feels about the importance of nutrition. Since the 1990s, research has shown that individuals with cancer have asked for information about their disease, although the amount, timing, and

type of information varies and contains no correlation with the patient's demographics or choice of treatment (20). Information has been provided in various ways including written, verbal, and audio or videotape, but the most common is written. Written education can be a valuable resource, but patient's understanding and accuracy of the information decide the patient's satisfaction with the written material.

Hartmuller and Desmond (20) performed a cross-sectional study to discover the nutritional needs of people with cancer as well as providing useful data to design successful approaches to educating people with cancer about their nutritional needs. A convenience sample of healthcare professionals, both registered nurses (RN) and registered dietitians (RD), were surveyed to establish their perceptions about nutritional needs of individuals with cancer during treatment. Six hundred sixty-six questionnaires were filled out by RNs who visited the National Cancer Institute exhibit at the 1996 Oncology Nursing Society Annual Congress. Two different sampling methods were performed to produce a representative sample of RDs. One hundred eighty guestionnaires were distributed at the National Cancer Institute exhibit at the 1996 American Dietetic Association Meeting and 195 questionnaires were returned by mail after placing them in the newsletter of the Oncology Nutrition Dietetic Practice Group (20). Eligibility criteria included a bachelor's degree, appropriate healthcare professional licensure, direct contact with patients during cancer treatment, and completion of all items on the questionnaire (20). Patient recruitment was also acquired through convenience sampling. Twelve institutions agreed to ask patients to participate in the study and 653 people with cancer seen in outpatient treatment facilities agreed to participate.

A 16-item questionnaire for the healthcare professionals was developed and designed by the researchers to measure constructs that would indicate differences in opinions between RNs and RDs (20). It was reviewed by a panel consisting of one RD, one RN, and two health educators from the National Cancer Institute Office of Cancer Communications (20). The first four items on the questionnaire dealt with demographics and education-related characteristics, followed by four items questioning the perceptions of the respondent about the dietary needs of their patients. Another question asked respondents to indicate the most preferred format for providing nutrition information, while another asked them to rank how important it was to receive different types of nutrition information. In conclusion, participants were asked to list the key items they felt should be appear on printed material; responses included, "coping with side effects resulting from treatment, tips for eating a balanced diet during cancer treatment, glossary of terms, hints to increase calories and protein, resources in the community, special dietary guidelines, suggested recipes, and use of nutritional supplements (20)."

Hartmuller and Desmond created a 28-item questionnaire to be administered to the subjects with cancer. The panel that reviewed the healthcare professional questionnaire also reviewed the patient questionnaire for literacy level and content and face validity (20). The first six questions on the patient questionnaire related to demographic data. The next four items were designed similarly to the healthcare professional's survey to elicit the perceptions of what the patients felt was important about their nutritional needs during cancer treatment. There were two questions different from the healthcare professional's questionnaire asking if there were other methods of receiving education other than printed materials, and which of those was the

most preferred, as well as if the patients had any comments on cancer or its treatments to offer the authors (20).

Results of this study showed that all three groups (RNs, RDs, and patients) agreed that written material was the most effective way for providing/receiving education, leading to the conclusion that an all-inclusive booklet should be provided by healthcare professionals (20). Recipes were regarded with high importance in people with cancer and should be available to individual patients. RDs indicated that people with cancer would favor one-sheet education handouts. This differed from the opinions of RNs and patients. This may be the result of RDs providing individualized nutritional counseling and wanting to focus on primary eating problems, while RNs may not have the time to focus on one problem but must address all issues in one counseling session.

The top three nutrition concerns agreed upon by all three groups were: appetite loss; nausea and/or vomiting; and the ability to obtain enough nutrients (20). Patients expressed being concerned about vitamin supplementation, but this concern was not cited in either of the healthcare professional groups (20). RNs and RDs were found to value information related to tips for family members, information on previously described diets, and community resources more so than patients (20). Authors attributed this to family members of the individual with cancer being more interested in this kind of information rather than the patients themselves; the healthcare professionals were aware of that need. There was a consensus on the items to be included when healthcare professionals address people with cancer and they included: coping with side effects, eating a balanced diet, increasing calories and protein, and any other special dietary guidelines (20). Weight loss was a concern expressed by the healthcare

professionals but not by people with cancer; however, male patients were more concerned with weight loss than female patients (20). It was noted that in this study almost 50% of patients had weight loss at the time of diagnosis and did not receive professional nutritional counseling (20).

This study created a vast amount of valuable data related to the opinions of healthcare professionals and people with cancer that could be applied to the practice of nutrition. The most startling statistic generated by this research was that almost 50% of patients had weight loss and did not receive nutrition counseling. Healthcare professionals must be aware of this and make an attempt to offer individualized nutritional counseling by a registered dietitian. It was also learned that there were differences in opinions between healthcare professionals and people with cancer dealing with content of nutrition education. RDs and RNs should be cognizant of each patient's desire for education and schedule a personalized nutrition counseling session if such action is possible.

<u>Summary</u>

In summary, the literature available has given healthcare professionals an insight to how nutrition and nutrition counseling can be effective in helping people with cancer minimize side effects of treatments and maximize their overall health. Individuals receiving radiation to the head or neck often lose weight and become malnourished because of radiation therapy side effects such as taste changes, pain when swallowing, nausea and vomiting, malabsorption, and loss of appetite. Assessments of patients should include functional ability, physical examination, current intake, and symptoms that might lead to weight loss; these must be implemented early in the individual's care to minimize the risk of morbidity and mortality associated with malnutrition. The subjective global assessment (SGA) was a useful tool in assessing cancer patients and was validated by Thoresen and colleagues (13). Individuals with cancer may not require more calories or protein than a normal individual, but steps must be taken to ensure that they receive optimal nutrition to maintain weight. Enteral feedings, if initiated early, may help decrease the incidence of weight loss. Daly et al. (17), found that when tube feedings were compared to oral feedings, patients were able to maintain weight better by keeping nutrient intake at 39 kilocalories per kilogram of body weight per day.

Nutrition counseling is a valuable resource for people with cancer, and research has shown that it can improve quality of life by introducing ways to manage side effects caused by radiation therapy. By improving symptoms that cause patients to have a decrease in intake, their ability to perform day-to-day activities increases, thereby giving them a better and more hopeful outlook on life. Opinions on what should be included in nutrition counseling were similar between RNs, RDs, and people with cancer. These three groups also agreed that written information was the most effective way to educate people with cancer about their disease as well as providing them information on how to manage the symptoms associated with head and neck radiation therapy.

CHAPTER 3

DESIGN AND METHODOLOGY

Subject Recruitment

From November 2006 to February 2007 all individuals seeking cancer treatment through radiation therapy to the head or neck region at the Regional Cancer Center in Johnson City, Tennessee were invited to participate in the study. This population was desired for study participants specifically because radiation to the head and neck often causes symptoms that decrease nutrient intake, resulting in weight loss. The desired convenience sample size was set at 30 participants. Criteria for inclusion in the study were any patient over the age of 18 receiving radiation to the head or neck region and fed via oral feedings. Any individual receiving nutrition exclusively through alternative routes (enteral feedings) was excluded. Individuals were not required to give written informed consent, but verbal consent was made when they agreed to participate in the research study. The Institutional Review Board approved research.

<u>Instruments</u>

A survey was developed by the principle investigator, a registered dietitian, and the director of the cancer treatment center to measure the benefit received from the nutrition counseling during radiation treatment as well as if the participants were satisfied with the information received (Appendix A). Questions were formulated based on previous surveys found in the literature relating to benefit from nutrition counseling, and also what the staff at the cancer center felt was most important to know. Before introduction into the study, the survey was validated by a group of sixth grade students. The 21-question survey asked participants about symptoms they experienced throughout radiation and if the symptoms improved following education/counseling from the registered dietitian. A Likert (17) scale was used to measure patient's satisfaction, with one being the least satisfied and five being the most satisfied as well as a question on overall satisfaction using very satisfied, satisfied, unsatisfied, very unsatisfied. Age, sex, and last level of education completed were asked to demographically describe the sample. Knowing the last level of education patients had completed could be used to help the registered dietitian evaluate the effectiveness of the information being distributed at the Regional Cancer Center.

Study Design

Patients who met inclusion criteria were interviewed by the registered dietitian for an initial nutrition assessment. Initial weight before treatment was obtained by standard balance beam scales according to treatment center protocols. Taste changes and swallowing problems were assessed through patient's responses to questions from the registered dietitian, and receptiveness regarding nutrition education was evaluated within this initial interview. At that time the registered dietitian provided information concerning the side effects of radiation the individual could expect to experience throughout radiation therapy. Side effects discussed included, dry mouth, pain when swallowing, mouth sores, taste changes, and constipation because of consistency changes in the diet. Information was provided through written handouts and verbal guidelines expressing methods on how to manage side effects, including foods to avoid and/or include in a soft diet, eating snacks between mealtimes, taking smaller bites at meals, and recipes to increase calorie and protein content of foods. Throughout the course of the individuals' prescribed radiation treatment the registered dietitian continued to see patients on a weekly basis, according to protocol at the Regional Cancer Center. During these visits, the registered dietitian reassessed patients for weight loss from initial assessment, any changes in nutrient intake, newly developed constipation, taste changes, and swallowing problems. Commercial supplements were available from the registered dietitian throughout the entire course of treatment and were provided based upon nutritional need and willingness to try products. Upon completion of their radiation therapy treatments, patients were asked by the registered dietitian if they would like to participate in the study. The study was explained to individuals as an evaluation of the nutrition counseling they received during their treatment. It was also explained that the study would ask their opinion regarding the nutritional information provided and its helpfulness in managing their side effects of radiation treatment. Each individual was given a letter of explanation about the research project as well as a questionnaire. The registered dietitian instructed subjects to complete the questionnaire in the privacy of their home to decrease the feeling of coercion from staff at the Regional Cancer Center. If patients chose to participate, they completed the survey and returned it to the principle investigator via the self-addressed stamped envelope that was provided for them. Subjects were instructed not to place any identifying information (name and address) on the questionnaire to keep their answers anonymous. Completed surveys and storage files were kept in a locked file cabinet at the home of the principle investigator during the study. A control group was

not used in this study design as it is protocol to give nutrition counseling to all patients who seek treatment at the Regional Cancer Center.

Data Analysis

Data collected from surveys were compiled and placed in an SPSS computer program to evaluate the frequencies of answers for each individual question. Statistical analysis was not appropriate for this study.

CHAPTER 4

DATA/RESULTS

<u>Subjects</u>

Five surveys were distributed to patients who met the inclusion criteria. Four surveys were returned for an 80% response rate. The four subjects were described as follows: 50% of the respondents were male, and 50% were female; two respondents were in the age category of 56-65 years old, one was between 46-55 years old, and the other was between 76-85 years old. The education levels for the participants were: two of the participants (50%) had a middle school education, one (25%) participant had a college education, and one (25%) had a high school education.

Eating/Drinking Habits

Two participants (50%) reported decreased food intake during radiation treatments as well as consuming different foods than usual. After counseling from the registered dietitian, three patients (75%) were able to increase consumption. One patient said that there was more difficulty with eating. Three participants (75%) reported increased fluid intake during treatments, while one (25%) reported less than usual fluid intake. After counseling, two participants (50%) said they were able to drink more and one (25%) person indicated that he/she was drinking about the same despite the registered dietitian's counseling. The fourth participant failed to answer if the registered dietitian was able to affect fluid intake.

Side Effects

Results of responses from participants regarding side effects are located in Tables 1 and 2. All participants described having taste changes and chewing problems during radiation. Two subjects indicated that the dietitian helped with chewing difficulties, and one did not give a response. Two subjects said they felt that the registered dietitian helped them manage the taste change, while one subject did not answer whether the registered dietitian had helped manage the taste change. Three participants experienced swallowing problems during radiation therapy, and one reported no swallowing problem. One respondent reported that the registered dietitian helped manage his/her swallowing problem, and one subject did not give a response. Two subjects described experiencing constipation and one reported no constipation. Of the two patients who had constipation, one said that the education from the registered dietitian helped, and one did not give a response.

Table 1. Side effects reported by participants								
	Taste	Taste Change Swallowing Problems		owing lems	Chewing Problems		Constipation	
Participant 1	Yes	-	Yes	-	Yes	-	Yes	-
Participant 2	Yes	-	Yes	-	Yes	-	-	-
Participant 3	Yes	-	Yes	-	Yes	-	Yes	-
Participant 4	Yes	-	-	No	Yes	-	-	No

Table 2. Side effects reported after nutritional counseling								
	Taste Change		Swallowing Problems		Chewing Problems		Constipation	
Participant 1*	-	-	-	-	-	-	-	-
Participant 2	-	-	-	-	-	-	-	-
Participant 3	Yes	-	Yes	-	Yes	-	Yes	-
Participant 4	Yes	-	-	-	Yes	-	-	-
* Participants responses were omitted from data analysis								

Weight Change

Three participants (75%) expressed a weight loss from the beginning of treatment to the end of treatment. Table 3 indicates the amount of weight loss in each individual participant as reported by the participant. One respondent (25%) did not experience any weight change. The mean weight loss was 6.25 pounds.

Table 3. Weight change for participants							
	Weight Before Treatment (lbs)	Weight After Treatment (lbs)	Total Weight Loss (lbs)				
Survey #1	196	184	12				
Survey #2	150	150	0				
Survey #3	178	177	1				
Survey #4	140	128	12				

Printed Education Materials

All four subjects (100%) reported receiving printed education materials from the registered dietitian and all subjects responded that the educational materials were helpful during their radiation treatments.

Energy Level

Two participants (50%) reported that they had a decrease in energy since radiation treatment began, and two participants (50%) reported that they had not had a decrease in energy. Of the two respondents who indicated less energy, one found that after counseling from the registered dietitian he/she noticed an increase in energy, the other found no change in energy levels. One participant did not have a decrease in energy and after counseling found that there was no change in his/her energy levels. The fourth participant did not answer if the registered dietitian had made a difference in their energy levels.

Supplement Use

Subjects were asked if they had consumed any nutritional supplements or vitamins during radiation treatment. Three respondents indicated the use of a supplement. Two respondents indicated that they used Glucerna and Ensure, the third did not indicate which supplement was consumed.

Satisfaction

When participants were asked if they were satisfied with how the registered dietitian helped them maintain weight or decrease their weight loss, three subjects (75%) responded that they were most satisfied with the registered dietitian and one responded that he/she was satisfied. All four (100%) respondents were also very satisfied with the nutrition counseling they had received as a whole.

Qualitative Data

Respondents were given the opportunity to give advice for patients taking radiation in the future. Table 4 lists some of the responses:

Table 4. Advice to future patients
Listen to what your dietitian tells you. Write it down because you will forget.
Drink bottled water at room temperature.
Stop drinking carbonated soft drinks and coffee. You don't need the sugar.
Start drinking Ensure with bananas.
Just hang in there. It goes by faster than you think.
I took pain medication and the mouthwash before eating. That helped!

Participants were also questioned if they had anything that affected their eating or drinking habits that they did not expect. Two respondents (50%) said that yes something did happen they didn't expect, one (25%) responded no, and one chose not to answer. The comments were as follows (Table 5).
 Table 5. Responses to unexpected experiences

Not unexpected, but food had no taste the last two to three weeks. The doctor had

explained this before treatment began.

Dry mouth, fatigue, irritations, burning sensations, throat very irritated and swollen,

constipation.

Very sore throat and couldn't hardly swallow, and the food and liquid didn't have any taste.

CHAPTER 5

DISCUSSION, CONCLUSIONS, RECOMMENDATIONS

Discussion

This study was performed to determine if head and neck cancer patients received benefit from nutritional counseling. The sample size in this study was too small to perform any quantitative analysis, but the results did show significant qualitative data. Of the data collected from the surveys, it was noted that participants did experience changes in food and beverage consumption patterns during the radiation therapy, but were able to manage them better with nutrition counseling from the registered dietitian. The one patient who indicated that he/she had more difficulty with food intake could be explained by the possibility of that subject having had a longer treatment series then the other respondents, or simply as treatment continued the pain with eating increased regardless of consumption of the recommended foods. It should be noted that two participants answered two of the questions with multiple responses. One expressed eating less than usual and different foods than usual, and was drinking more fluids than usual and different fluids than usual. Another was also consuming more fluids than his/her usual amount as well as different fluids. These multiple responses were unable to be entered into the SPSS computer program but were important to include. When different foods or fluids are consumed for comfort, there may be a change in the amount of calories and protein consumed, ultimately impacting nutritional status.

Taste changes and chewing issues were the most common side effect of radiation expressed by the respondents. With regard to the registered dietitian helping

manage these side effects, one survey was incomplete. The respondent indicated experiencing side effects but did not respond to whether the registered dietitian had influenced the management of those side effects which skewed the data. Another participant also expressed experiencing side effects, but said that the registered dietitian did not help with any management. It must be noted that in the margin of the survey the respondent wrote, "She gave us a list of soft foods that helped!" and "He can eat and drink better a week after radiation stopped." The data from these questions were omitted because of not being able to interpret how the respondent felt about the registered dietitian helping with the management of side effects.

Three participants experienced weight loss, with one patient reporting no weight loss. At the end of radiation treatment the survey was distributed to subjects and it asked participants to record weight before and after treatment. Therefore, body weight and weight changes recorded may not be accurate because of the length of time between initial measurement and response to survey. The average weight loss was 6.25 pounds. The nutritional counseling offered by the registered dietitian may have been a factor in keeping this number to a minimum, but there are other factors that could have also kept this number low including the patients response to treatment as well as families help and encouragement during meal times. Referring to the literature, large amounts of weight loss can be detrimental for a cancer patient. Weight loss increases the risk of morbidity and mortality and being able to keep weight loss at a minimum would greatly improve the individual's outcome.

Regarding satisfaction of participants, there was an overall very positive response. All subjects noted being very satisfied with the nutrition care they received,

and three of the four respondents were most satisfied with the registered dietitian's assistance in slowing down their weight loss. All participants received written education material and gave positive feedback reporting that the material was helpful. Energy level decreases were noted in two participants, but only one gave a positive response indicating counseling from the registered dietitian had been able to effect his/her energy level. Many different aspects of cancer treatment can affect energy levels. Radiation alone can decrease energy levels despite a balanced and adequate nutrient intake. Nutrition plays a role in energy levels, but overall the assumption was that the registered dietitian would be unable to increase energy levels entirely with nutrition.

The open-ended question was included in the survey to illicit information regarding how well informed the patients were to the side effects they could experience during radiation treatment. This information was important for the treatment facility staff to determine if they were providing education on each aspect of potential issues that may arise with treatments. One participant verbalized that the doctor had explained everything before treatment began, while the other two participants who chose to answer the question simply mentioned the side effects they had experienced. They may have chosen to answer the question in this manner because of the severity of the symptoms or the sudden onset of problems. The researcher theorizes that the side effects were explained to them, but the information was one of many instructions or potential problems related to the patient and family before the start of the radiation treatment.

<u>Conclusions</u>

Individuals with head or neck cancer did benefit from nutritional counseling by the registered dietitian. Patients were able to manage their side effects as well as reduce the amount of weight lost. Participants were very positive about the nutrition counseling they received from the registered dietitian. Subjects expressed that the counseling was beneficial and the education was used; therefore, the assumption was that the quality of life was improved. Subjects and healthcare professionals had a very good relationship in this research setting. The registered dietitian was very skilled at building rapport with the patients and their families in order to give them the most effective nutritional counseling throughout their treatment. Even though the sample size was small, this study was an important step in proving that registered dietitians can enhance the quality of life and nutritional well being of cancer patients undergoing radiation treatment in this particular setting.

<u>Recommendations</u>

In the future it would be more beneficial to incorporate more than one radiation treatment facility. It may also be in the best interest to include all cancer patients receiving radiation therapy for cancer treatment instead of limiting it to only head and neck cancer patients. Extending the scope of eligible patients would greatly enhance the data and produce more significant results. I would also recommend to continue the research by adding a follow-up survey to evaluate how symptoms improve, change, and affect the remainder of patients' lives.

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APPENDICES

APPENDIX A

Nutrition Care Survey

Please return survey as soon as possible in the envelope supplied. Please DO NOT

provide your name.

- 1. Describe your general **eating** habits since you began radiation treatment. Are they:
 - _____ the same as usual
 - _____ more than usual
 - _____ less than usual
 - _____ different foods than usual
- 2. After counseling from the Registered Dietitian were you:
 - _____ able to eat more
 - _____ had more difficulty with eating
 - _____ eating about the same
- 3. Think about what **fluids** you **drink** and how much you drink. Since you began radiation treatment, are you drinking:
 - _____ the same as usual
 - _____ more than usual
 - _____ less than usual
 - _____ different drinks than usual
- 4. After counseling from the Registered Dietitian were you:
 - _____ able to drink more
 - _____ had more difficulty with drinking
 - _____ drinking about the same
- 5. Has your weight changed since you began radiation treatments?
- 6. What was your weight before your radiation treatment started? _____lbs
- 7. What was your weight during the last week of your treatments? _____lbs

8. On a scale of 1 to 5 with 1 being the least satisfied and 5 being the most satisfied how would you rate your satisfaction with how the Registered Dietitian helped you maintain or slow down your weight loss during radiation treatment?

Least _____1 ____2 ____3 ____4 ____5 Most

 While you were taking radiation treatments, did something happen that affected your eating and drinking habits that you did not expect?
 Yes

Any comments?

10. Do you have any advice to give someone who is beginning the same radiation treatments as you?

11. Have you had any of the following problems?

Taste change	Yes	No
Chewing problems	Yes	No
Swallowing problems	Yes	No
Constipation	Yes	No

12. If yes, after counseling from the Registered Dietitian were you better able to manage:

Taste change	Yes	No
Chewing problems	Yes	No
Swallowing problems	Yes	No
Constipation	Yes	No

- 13. Have you had less energy since your treatment began? _____Yes _____No
- 14. If yes, after counseling from the Registered Dietitian did you notice a change in energy level:

_____ more energy _____ less energy _____ no change

15. Did you take any nutritional supplements or vitamins during your radiation treatments?

16. Did you receive printed educational materials (pamphlets or hand-outs) from the Registered Dietitian?

____Yes____No

17. If yes, did you find these materials:

_____ helpful

_____ not helpful

18. Overall, how do you feel about the nutrition care you received?

_____Very satisfied

- _____Somewhat satisfied Somewhat unsatisfied
- Very unsatisfied

19. Are you: _____Male _____Female

20. Please check your age category:

_____18-25 _____26-35 _____36-45 _____46-55 _____56-65 ______66-75 _____76-85 _____86-95 _____96-105

21. What was your last level of education completed:

Elementary
 _Middle School
High School
 _College
Other

Please give any additional comments you wish to share:

Thank you so much for participating in this research project! Your responses and comments will help us give better nutrition care in the future. We ask that you return this survey as soon as possible in the envelope that we have provided for you. Please do not include your name.

APPENDIX B

Data Analysis

Describe your eating habits since radiation began

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	less than usual	2	50.0	50.0	50.0
	Different foods than usual	2	50.0	50.0	100.0
Total		4	100.0		

After counseling from the RD were you:

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
able to e	eat more	3	75	75.0	75.0
More d	ifficulty	1	25	25.0	25.0
Total		4	100.0	100.0	

Since radiation began are you drinking?

		Frequency	Percent	Valid Percent	Cumulative Percent
	more than usual	4	100	100.0	100.0
Total		4	100.0		

After counseling from the RD were you:

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	able to drink more	2	50.0	50.0	50.0
drinking about the same	1	25.0	25.0	25.0	
	Total answered	3	75.0	75.0	100.0
	Missing	1	25.0		
Total		4	100.0	100.0	

Have you had taste change?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	4	100.0	100.0	100.0
	Missing	0	00.0		
Total	_	4	100.0		

Have you had chewing problems?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
У€	es	4	100.0	100.0	100.0
no	0	0	0.00	0.00	
Total		4	80.0	100.0	

Have you had swallowing problems?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	3	75.0	100.0	100.0
1	no	1	25.0		
Total		4	100.0		

Have you had constipation?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	2	50.0	50.0	50.0
	no	1	25.0	25.0	25.0
	Total	3	75.0	100.0	
	Missing	1	25.0		
Total	_	4	100.0		

Did the RD help with taste change?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	2	50.0	100.0	100.0
	Missing	2	50.0		
Total		4	100.0		

Did the RD help with chewing problems?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	1	25.0	100.0	100.0
	Missing	3	75.0		
Total	_	4	100.0		

Did the RD help with swallowing problems?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	2	50.0	100.0	100.0
	Missing	2	50.0		
Total	_	4	100.0		

Did the RD help with constipation?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	1	25.0	100.0	100.0
	Missing	3	75.0		
Total	-	4	100.0		

Did you experience weight change?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	3	75.0	75.0	75.0
	no	1	25.0	25.0	25.0
Total		4	100.0	100.0	

Descriptive Statistics – Weight Loss

	N	Minimum	Maximum	Mean	Std. Deviation
How much weight change did you experience	4	.00	12.00	6.250 0	6.65207

Did you receive printed educational materials from the RD?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	4	100	100.0	100.0
	Missing	0	0.0		
Total	_	4	100.0		

Was the education helpful?

			Perce	Valid	Cumulative
		Frequency	nt	Percent	Percent
	helpful	4	100.0	100.0	100.0
	Missing	0	0.0		
Total	_	4	100.0		

Have you had less energy since radiation began?

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	yes	2	50.0	50.0	50.0
	no	2	50.0	50.0	50.0
	Total	4	100.0	100.0	
	Missing	0	0.0		
Total	-	4	100.0		

Did the RD help with your energy level?

		Frequency	Percent	Valid Percent	Cumulative Percent
	more energy	1	25.0	25.0	25.0
	no change	2	50.0	50.0	50.0
	Total	3	75.0	75.0	
	Missing	1	25.0		
Total		4	100.0		

Rate how satisfied you are with how the RD helped you maintain your weight

				Valid	Cumulative
		Frequency	Percent	Percent	Percent
	satisfied	1	25.0	25.0	25.0
	most satisfied	2	50.0	50.0	50.0
	Total	3	75.0	75.0	
	Missing	1	25.0		
Total		4	100.0		

How do you feel about the nutrition care you received?

		Frequency	Percent	Valid Percent	Cumulative Percent
	very satisfied	4	100.0	100.0	100.0
	Missing	0	0.0		
Total	_	4	100.0		

VITA

LORI E. WATSON

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