QUALITY OF LIFE OF LARYNGECTOMEE

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The purposes of this study were to explore quality of life of laryngectomee and analyze some of the associated factors which are age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group. The research sample consisted of 100 laryngectomees who were obtained through the out-patient otolaryngological clinic at Ramathibodi Hospital and Rajavithi Hospital from April to August 1999. Eligible subjects were interviewed by the researcher with a demographic questionnaire and subjective self-rating QOL-CA instrument of Padilla and colleagues. The time frame during which the laryngectomees were asked to recall their quality of life was 1 week before responding to the questionnaires. All data were analyzed by using a SPSS for Windows program.

The results showed that most of the laryngectomees had moderate to good overall QOL. There were statistically significant differences of overall QOL, and two subscales (psychosocial-existential well-being and physical-functional well-being) scores between participants who were and were not members in a laryngectomees' self-help group ($p < .05$). There were statistically nonsignificant differences found of overall QOL, subscale scores between laryngectomee who had differences in age, educational level, marital status, and time duration since total laryngectomy groups ($p > .05$)

The results of this study can be used as baseline information in planning specific nursing interventions for patients who have had a total laryngectomy.

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วนิดา ลิขิตสินโสภณ : คุณภาพชีวิตของผู้ไร้กล่องเสียง (QUALITY OF LIFE OF LARYNGECTOMEE) คณะกรรมการควบคุมวิทยานิพนธ์: ดรุณี ชุณหะวัต ค.ม. (จิตวิทยาการศึกษาและการแนะแนว) พรรณวดี พุธวัฒนะ วท.ด.(โภชนศาสตร์) 73 หน้า ISBN 974-664-568-4

การวิจัยครั้งนี้เป็นการวิจัยเชิงบรรยายเพื่อศึกษาคุณภาพชีวิตของผู้ไร้กล่องเสียงและปัจจัยที่เกี่ยวข้องกับคุณภาพชีวิตของผู้ไร้กล่องเสียงได้แก่ อายุ สถานภาพสมรส ระดับการศึกษา ระยะเวลาหลังการผ่าตัดกล่องเสียงออกทั้งหมด และการเป็นสมาชิกกลุ่มผู้ไร้กล่องเสียง กลุ่มตัวอย่างที่ศึกษาเป็นผู้ไร้กล่องเสียงที่มารับการตรวจรักษา ที่หน่วยตรวจผู้ป่วยนอก หู คอ จมูก ของโรงพยาบาลรามาธิบดี และโรงพยาบาลราชวิถี ระหว่างเดือนเมษายน 2542 ถึงเดือนสิงหาคม 2542 จำนวน 100 ราย เลือกกลุ่มตัวอย่างตามคุณสมบัติที่กำหนด วัดคุณภาพชีวิตด้วยแบบวัดคุณภาพชีวิตของพาดิลลาและคณะ ผู้วิจัยเก็บรวบรวมข้อมูลด้วยตนเอง โดยการสัมภาษณ์ตามแบบบันทึกข้อมูลส่วนบุคคล และให้กลุ่มตัวอย่างตอบแบบสอบถามคุณภาพชีวิตด้วยตนเอง โดยระลึกถึงเหตุการณ์ในช่วง 1 สัปดาห์ก่อนเก็บข้อมูล วิเคราะห์ข้อมูลโดยใช้โปรแกรมสำเร็จรูป SPSS / FW

ผลการวิจัยพบว่า คุณภาพชีวิตของผู้ไร้กล่องเสียงอยู่ในระดับปานกลางถึงดี โดยคะแนนคุณภาพชีวิตโดยรวมและรายด้าน เฉพาะความผาสุกด้านจิตใจและความผาสุกด้านร่างกาย มีความแตกต่างกัน ระหว่างกลุ่มที่เป็นและไม่เป็นสมาชิกกลุ่มช่วยเหลือตนเอง อย่างมีนัยสำคัญทางสถิติ ($p<.05$) คะแนนคุณภาพชีวิตโดยรวมและรายด้านของผู้ไร้กล่องเสียง ระหว่างกลุ่มที่มีความแตกต่างด้านอายุ สถานภาพสมรส ระดับการศึกษา และระยะเวลาหลังผ่าตัดกล่องเสียงออกทั้งหมด แตกต่างอย่างไม่มีนัยสำคัญทางสถิติ ($p>.05$)

ผลการศึกษาจะเป็นข้อมูลพื้นฐานที่สามารถนำไปใช้ประโยชน์ในการวางแผน เพื่อพัฒนารูปแบบการพยาบาล การให้ข้อมูล คำแนะนำที่เหมาะสมโดยตรงกับกลุ่มผู้ป่วยมะเร็งกล่องเสียงที่ได้รับการผ่าตัดกล่องเสียงออกทั้งหมดหรือผู้ไร้กล่องเสียง

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CHAPTER I

INTRODUCTION

Background and rationale

Laryngeal cancer is a chronic and life-threatening disease. It consistently occurs in men at a higher incidence rate than in women (McCorkle, et al., 1996: 784-785). It was ranked as having the seventh highest incidence rate relative to cancer in male patients at Ramathibodi Hospital (Tanphaichitr, Ed., 1995: 8).

Surgical and other cancer treatment modalities have the overall goal of prolonging life for this group of patients. However, both the disease and its treatment have some impact on physical, psychological, and social functioning (DeGraeff, et al., 1999: 291). These impacts appear to involve the quality of their daily living.

The impact of a laryngectomy on quality of life has received relatively much attention, with an emphasis on speech rehabilitation (Maas, 1991: 1374). Laryngeal cancer in early stages is treated with radiotherapy or partial laryngectomy, and has less impact on the patient's quality of life. The most common treatment for advanced laryngeal cancer is total laryngectomy which means removal of entire larynx, hyoid bone, preepiglottic space, strap muscle, and two or three of the tracheal rings (McCorkle, et al., 1996: 787; Haynes, 1996: 16B; Spiegel & Sataloff, 1992: 325). After total laryngectomy, the patients are no longer able to inhale air through the upper airway, but the windpipe must be brought out to the surface of the neck to form a permanent opening called a stoma. When a total laryngectomy patient (or a laryngectomee) inhales, air passes directly through the stoma into the trachea and then into the lungs. Removal of the larynx means that a laryngectomee will no longer have laryngeal speech. After the operation, the patient must learn a new manner of speaking. Patients are faced with potential impairments in eating (List, et al. 1990: 564), swallowing (Logemann, 1989: 205), breathing, and physical appearance. These functional deficits can affect a wide array of psychosocial, emotional, physical, and family-related roles (Weber & Reimer, 1993: 31-34). Therefore, these alterations will most likely reduce the overall quality of life of laryngectomees.

In Thailand, the policy of the Ministry of Public Health, as spelled out in the Eighth National Development Plan, highlights the ultimate "Health for All" and "Quality of Life" goals to enable local people to contribute more to overall national development. As commonly understood, the realization of the goal of "Health for All" is not only for the sick but the entire population. Further efforts to develop an operational definition of "quality of life" that reflects health concerns should consider the value assigned to duration of life as modified by impairment, functional states, perceptions and social opportunities which are influenced by disease, treatment, or policy. Cancer patients also need to develop their individual quality of life to their maximum potential ability, especially laryngectomees who are faced with deficits in eating, speaking, breathing and physical appearance.

Nurses are in the position of promoting patients' quality of life through assisting them to recover, achieve wellness, and live with their limitations. Therefore, they need to understand more about their patients and gather more information about specific factors that can help nurses to develop realistic goals. This study was conducted to explore self-perceived quality of life of laryngectomees, and the relationships between some of their personal characteristic factors and self-perceived quality of life. This basic data may be used to provide specific, helpful information for appropriate planning and implementing effective nursing interventions for patients suffering from cancer of the larynx.

Conceptual framework

The research framework in this study is derived from reviewed literature and research related to quality of life in cancer patients and patients with chronic illness. Based on Padilla and colleagues conceptualization, they define quality of life as a personal, evaluative statement summarizing the positivity or negativity of attributes that characterize one's psychological, physical, social, and spiritual well-being at a point in time when health, illness and treatment condition are relevant (Padilla, et al., 1996: 307). This definition indicates that "quality of life" is subjective and multidimensional, and likely includes health as a relevant construct at some point in a person's life. For example, some people with good health may not be concerned with their health when evaluating their quality of life, but they may focus on friendships, financial success, and their feeling of satisfaction with life.

Quality of life

The term "quality of life" (QOL) as defined in cancer nursing literature focuses on the degree of satisfaction with present life circumstances (Young & Longman, 1983 cited by Padilla & Grant, 1985: 46). It is viewed as a dynamic construct affected by one's ability to adapt at some point in that person's life. The quality of the patient's survival is associated not only with her/his inherent personal strength, but also with how well she/he manages the side effects of cancer therapy and adjustments to permanent changes in body image, functions, and appearance. However, a person's self-evaluation of the degree to which life is worth living is based on a number of criteria, and so "quality of life" is a multidimensional construct.

Based on this definition of quality of life, Padilla and colleagues further clarify health-related quality of life as a four-dimensional construct of well-being. Their model includes physical well-being and associated symptom distress, psychological, social, and existential/spiritual well-being (Padilla, et al., 1996: 301). Following this framework, perceived QOL was measured overall and relative to each of the four dimensions including:

1) Psychosocial-existential well-being: covering concerns such as enjoying life (fun), feeling happy, disease/treatment interference with personal relationships, and the hope that things will improve.
2) Physical-functional well-being: encompassing factors such as feeling useful, ability to pay attention, strength, and tiring easily.
3) Symptom distress: focusing on nutrition, appetite, eating sufficiently, nausea distress, pain, and bowel patterns.
4) Attitude of worry: concerns about tangible and intangible cost, weight, and unfinished business.

Previous studies indicated that there is a relationship between quality of life and a patient's personal characteristic factors. Factors that were found to be related to QOL were age (Padilla & Grant, 1985: 46-50, McGuirt & Davis III, 1995: 150-154, Mor, Allen & Maureen, 1994: 2118-2127), marital status, and educational level (Long, et al., 1996: 1086-1088).

In Thailand, there is little information available on the quality of life of laryngectomees from a patient perspective. Thus, in this study, the researcher explored their quality of life and the differences of quality of life of laryngectomees between the groups who were different in personal characteristic factors that included age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group.

Research questions

The following two research questions were addressed in this study:

1. What is the self-perceived quality of life of laryngectomees?
2. What are the differences in QOL of laryngectomees between the groups who were different in age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group?

Research objectives

The objectives of this research study were:

1. to explore the quality of life of laryngectomees;
2. to compare the QOL of laryngectomees between the groups who were different in age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group.

Research hypothesis

There is a difference between laryngectomee's quality of life scores of participants who were different in age, marital status, educational level, time duration since total laryngectomy groups, and membership in a laryngectomees' self-help group.

Significance of the study

The result of this study can be used not only for appropriate postoperative care planning and effective interventions, but also as a source of data with appropriate content for patient and family counseling.

The results of this study are likely to provide specific and helpful information for laryngeal cancer patients. Moreover, health care providers can use this information for appropriate preoperative and postoperative planning and effective interventions with their laryngeal cancer patients.

Assumptions of the study

For the purpose of this study, the following assumptions were made:

1. the QOL of participant laryngectomee can be assessed through self-rating questionnaires;
2. the study subjects responded sincerely to the questionnaires and the self-ratings were reliable.

Definition of terms

The operational definitions of the terms used in this study are as follows:

Quality of life: refers to a person's perception of positiveness or negativeness relative to life satisfaction in four dimensions: physical-functional well-being, psychosocial-existential well-being, symptom distress focusing on nutrition, pain and bowel pattern, and attitude of worry concerning tangible and intangible costs, weight, and unfinished business. It was measured by a Quality of Life–Cancer Questionnaire (Padilla, et al., 1996: 301-308). Higher scores indicate a better self-perceived quality of life.

Membership in a laryngectomees' self-help group: refers to the status of the laryngectomee as a member of a laryngectomees' self-help group. The group member should show a record of having attended and participated in-group meetings that were originally set up in each hospital (Ramathibodi Hospital and Rajavithi Hospital).

CHAPTER II

LITERATURE REVIEW

The literature for this study was reviewed as follows:

1. Laryngeal cancer, treatment options, and impacts of disease and treatment;
2. Concept of quality of life and quality of life of laryngectomee;
3. Different factors which are related to quality of life.

Laryngeal cancer, treatment options, and impacts of treatment

Cancer statistics 1995, collected in the Ramathibodi Cancer Register, revealed that laryngeal cancer ranked the seventh highest in rate of incidence in male cancer patients. It was mostly found in patients over the age of 60. The ratio between male and female laryngeal cancer patients was 10:1 (Tanphaichitr, Ed., 1995: 8).

Cancer of the larynx is closely associated with smoking and alcohol consumption. Its incidence is higher in people who have a history of heavy smoking or drinking. The synergy between alcohol and tobacco results in increasing one's risk approximately 50 % more than if the effects of the two were simply additive (Flanders & Rothman, 1982 cited by McCorkle, et al., 1996: 785). Increased incidence of laryngeal cancer also occurs among persons who are exposed to asbestos, fumes, and dust wood. Communities in which paper, chemicals, or petroleum are manufactured show a higher incidence of laryngeal cancer (Cowles, 1983 cited by McCorkle, et al., 1996: 786). It can also occur in people who have a family history of laryngeal cancer.

Laryngeal cancer is a disease in which cancer cells are found in the tissues of the larynx. The larynx is a short passageway shaped like a triangle that is below the pharynx in the neck. It contains the vocal cords, which vibrate and make sound. The most common type of laryngeal cancer is known as squamous cell carcinoma (SCCA). It can originate in any region of the larynx: the glottis (the middle part of the larynx where the true vocal cords are), the supraglottis (the area above the cords and located below the base of tongue), and the subglottis (the area below the true vocal cord).

The TNM classification system, defined by the American Joint Committee on Cancer (AJCC), is used for staging cancer sites (Beahrs, Henson, Hutter & Kennedy, 1992: 25-54). The patient's T classification determines the treatment strategies as follows (Euswart, 1995: 437-440); T_1- the cancer is only in the area where it started and has not spread to lymph nodes in the area or to other parts of the body, and the vocal cords can move normally; T_2- the cancer is only in the larynx and has not spread to lymph nodes in the area or to other parts of body. The vocal cords may or may not be able to move normally; T_3- the cancer has not spread outside of the larynx, but the vocal cords cannot move normally; T_4- the cancer has spread to tissues around the larynx, such as the pharynx or the tissues out of larynx.

In cancer of the larynx, definitions of the early stages depend on where the cancer started. Stages of cancer are defined as early stage (stages I and II) and late stage (stages III and IV). Vocal fixation, clinically evident cervical node metastasis, or both separate early stages from the late stages (Silver & Moisa, 1990 cited by McCorkle, et al., 1996: 787).

Treatment options

Treatment options for cancer of the larynx are usually determined jointly by the otolaryngologist and the patient. It depends on the size of the tumor and a number of factors. Among these are the exact location and size of the tumor and whether the cancer has spread. To develop a treatment plan to fit each patient's needs, the doctor also considers the patient's age, general health, and the potential benefits of the treatment.

Cancer of larynx is usually treated with radiotherapy or surgery. These are the two types of local therapy, which affect cancer cells only in the treated area. Some patients may receive chemotherapy, called systemic therapy, meaning that drugs travel through the bloodstream (National Cancer Institute, 1993: 10; Lefebvre, 1998: 392).

Surgery is a type of local therapy. Laryngectomy is a broad term used for surgical removal of the larynx. Laryngectomy procedures may also be done as partial procedures.

Partial laryngectomy procedures have been called "conservation laryngectomy". They are designed to retain as much of the laryngeal structure as possible without compromising oncological safety. The goal of this procedure is to maintain the capacity of the laryngeal valve for purposes of respiratory, phonatory, and sphincteric function. Some of these procedures have been called cordectomy, hemilaryngectomy, which try to maintain a functional larynx without permanent tracheostomy (Lefebvre, 1998: 391). The patient is able to resume regular oral intake after a 2 to 3 weeks postoperatively period (Rademaker, et al., 1993 cited by Logemann, 1994: 361).

Total laryngectomy involves the surgical removal of the entire laryngeal framework in the region from the hyoid bone to the upper rings of the trachea, and the stoma is permanent. The postoperative patient is called a "laryngectomee", and she/he breathes through the stoma and must learn to speak in a new way.

Radiotherapy is a type of local therapy that uses high-energy rays to damage cancer cells and stop them from growing. In most centers, radiotherapy represents the initial treatment for T_1 and T_2 lesions, with surgery reserved for use if radiation fails to control the cancer growth. The expected advantages of radiotherapy instead of surgical intervention are a better quality of voice, major surgery is avoided, and it is less costly (McCorkle, et al., 1996: 787).

Radiotherapy may be combined with surgery; it can be used to shrink a large tumor before surgery or to destroy cancer cells that may remain in the area after surgery. In addition, radiation therapy may be used for tumors that can't be removed with surgery. If a tumor grows back after surgery, it is generally treated with radiation.

Generally, treatment of T_3 and T_4 patients combines total laryngectomy with postoperative irradiation. The usual time period for starting postoperative irradiation is within 6 weeks (Cutright, 1992: 506), which tends to reduce local and regional recurrence compared with a longer time interval (Ampil, Buechter, Baiirnsfather & Shockley, 1993 cited by McCorkle, et al., 1996: 787). Radiation therapy is usually given 5 days a week, for 6-week period.

Chemotherapy is the use of drugs to kill cancer cells. In some cases, anticancer drugs are given to shrink a large tumor before the patient has radiation therapy or surgery and it can be used after surgery too. Moreover, chemotherapy may be used for advanced cancers. Anticancer drugs to combat laryngeal cancer are usually given by direct injection into the patient's bloodstream.

Impacts of disease and treatment

The treatments applied to laryngeal cancer are very powerful. But, it is difficult to limit the effects of therapy, so that while the cancer cells are removed or destroyed, healthy cells also may be damaged.

The potential impacts depend mainly on the type and extent of treatment. After a total laryngectomy, the patient has lost the ability to produce normal voice or to live a normal life (Deleyiannis, et al., 1999: 319). Voice changes require rehabilitation, which may involve the use of an artificial larynx, esophageal voice, and/or surgical prosthetic voice restoration, usually a tracheoesophageal puncture technique. Currently, the most frequent pattern of rehabilitation is the immediate introduction of an artificial larynx postoperatively (Logemann, 1994: 361). The patient will also experience some minor changes in swallowing postoperatively, including some perceived increase in lingual effort (Logemann, 1989: 205).

In Junhavat and colleague's study (1990: 107) of the characteristics of the patients with carcinoma of the larynx and their adaptation after total laryngectomy, they found that patients had the greatest difficulty with communication problems (40%), speech rehabilitation problems (10%), and stoma care and social contacts (10%), respectively.

Communication problem

The removal of a patient's larynx leads to a loss in one of the most vital and unique human functions, which results in a considerably hindered ability to communicate, inability to sing, whistle, make quick verbal retorts, and laugh. Speech without a larynx is often intelligible after a postoperative patient chooses to use esophageal speech, an electrolarynx, or a tracheoesophgeal puncture (TEP).

Clement and colleague's study (1997: 493-496) demonstrated that laryngectomees who used esophageal speech self-rated their own speech as significantly better than patients who used other methods and most likely had an overall superior quality of life.

Although loss of speech is an obviously disabling condition and a laryngectomee is disfigured, only a minority of patients ranked speech as the most important factor in their QOL (Morton, 1997: 243-250). Also, Deleyiannis and colleague's (1999: 323), confirmed that functional limitations do not necessarily translate into a worsening of overall QOL.

Stoma problems

After total laryngectomy, the patient could no longer inhale air through the upper airway, and the windpipe must be brought out through the neck to form a permanent opening called a stoma. All laryngectomees must be able to care for the stoma and to use a stoma cover for appearance in public and to prevent inhalation of small particles. In addition, the patient may feel very uncomfortable in social surroundings because of the physical appearance of the stoma. Other restrictions include prohibition of swimming or journey by a boat. Currently, they have special instruction and equipment available such as swimming aids, shower shields or collars.

Psychosocial problems

A laryngectomee has lost her/his voice, sense of smell, ability to taste, and ability to make loud sounds from laughing or crying. In addition, a patient's femininity or masculinity may be reduced because of poor body image, low self-esteem and low self-confidence. Harwood and Rawlinson (1983: 335-338) found that approximately one-half of laryngectomized patients surveyed were unable to leave the house, lost their jobs, and became socially withdrawn. Jay (1991: 934-938) also reported that 45% of laryngectomized patients surveyed felt that their social acceptability was reduced.

Pain

A laryngectomized patient who has undergone radical neck dissection may have stiff shoulders as the result of inability to move the joint. They complained most bitterly of shoulder pain rather than limited motion (Terrell, et al., 1997: 1125-1132).

Swallowing problems

After total laryngectomy, patients do increase lingual pressures to compensate for the absence of a larynx and reduced pharyngeal wall function (McConnel, et al., 1986: 4). List and colleague (1997: 493-496) reported that approximately half of the laryngectomees surveyed were unable to eat solid foods or to eat out with others for 6 months after surgery.

Currently, impacts on a laryngectomee relative to both the disease and the treatment effects, e.g. impaired critical functions as speech, swallowing, and breathing were considered to be a part of planning and the treatment options (Logemann, 1994: 359). A realistic nursing goal should not be concerned only with patients' survival and decreased mortality, but also with the patient's perception or quality of life (Hanucharurnkul, 1988: 2).

Concept of quality of life

The term "quality of life" (QOL) is abstract and difficult to define. QOL has been defined as "an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns." (The Division of Mental Health of the World Health Organization, 1993 cited by Padilla, et al., 1996: 301).

There are various definitions of quality of life in the literature. Young and Longman (1983: 220) defined QOL as "the degree of satisfaction with perceived present life circumstances". These indices of QOL are likely to fluctuate in importance as changes occur in health status. Consistently, Engquist and colleagues (1979 cited by Padilla, et al., 1983: 118) viewed QOL as a dynamic construct with changing values over an individual's lifetime.

Ferrans (1990: 15) defined QOL as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her". This definition addresses the fact that people's values cause various aspects of life to have a varying impact on their overall QOL.

Grant and colleague (1990: 260) defined QOL as "a broad concept encompassing an extensive range of physical and psychological characteristics and limitations that describe an individual's ability to function and to derive satisfaction in doing so".

Padilla and colleagues define quality of life as "a personal, evaluative statement summarizing the positivity or negativity of attributes that characterize one's psychological, physical, social, and spiritual well-being at a point in time when health, illness and treatment condition are relevant (Padilla, et al., 1996: 307)". This definition indicates that quality of life is a subjective multidimensional evaluation, that likely includes health as a relevant construct at some point in a person's life. Consistently, Aaronson (1988: 71) viewed QOL is "a multidimensional construct composed of functional status, disease-related and treatment-related symptoms, psychological functioning, and social functioning".

The distinctive differences in defining the multifaceted concept of QOL are reflected in a variety of definitions and dimensions that Nantachaipan (1996: 34) has summarized as the important characteristics of quality of life:

1. QOL is viewed as a personal experience, an individual's perception of a sense of well-being. Assessment of QOL requires input from patients to ensure that the patients' perceptions are inclusive and accurate.

2. QOL is related to the process of interaction between one's personal life and external environment

3. QOL is viewed as a complex and multidimensional concept which encompasses physical, psychological, social, and spiritual dimensions.

4. QOL is viewed as a dynamic construct affected by one's ability to adapt during that individual's lifetime.

5. QOL is related to health status by referring to the impact of health conditions on the ability to function.

Quality of life in cancer patients

Quality of life in cancer patients is defined as a personal, evaluative statement summarizing the positivity or negativity of attributes that characterize one's psychological, physical, social, and spiritual well-being at a point in time when health, illness and treatment condition are relevant (Padilla, et al., 1996: 307). Based on the definition of QOL in WHO (1993), Padilla and colleagues (1996: 307) addressed the fact that people's values cause various aspects of life to have varying impact on their quality of life. This implies that the rating must be a personal perception of well-being which reflects physical, psychological, social well-being, patient satisfaction with levels of functioning, and the control of disease and/or treatment-related symptoms.

Prior literature on studies the QOL of patients with cancer of the head and neck. Drettner & Ahlbom (1983: 307-314) studied the QOL of patients with cancer of the head and neck found that patients with a poor prognosis had a poor state of health and low quality of life. Moreover, patients with a considerable postoperative handicap reported a comparatively good health status because they adjusted themselves to a new situation after the operation, and were satisfied to be left with a handicap because they survived. Furthermore, Bjordal & Kaasa (1995: 592-597) found a high prevalence of psychological distress in head and neck cancer patients 7 to 11 years after curative treatment and a high level of treatment-related side-effects such as swallowing problems and reduced QOL.

In Thailand, Hanucharunkul (1988) and Takviriyanun (1991) studied the QOL of head and neck cancer patients while receiving and after the completion of radiotherapy. They found that quality of life after the completion of radiotherapy was reported to be better than while receiving radiotherapy. Head and neck cancer patients in these studies included laryngectomees.

Quality of life of laryngectomee

A review of the literature relating to the QOL status of laryngectomee showed limited of quality of life research studies in Thailand which directly assessed quality of life of Thai laryngectomees. In other countries, research was reported on the impact of treatment on quality of life. For example, List and colleagues (1996: 1-10) studied QOL over a 6 month period in laryngeal cancer patients divided into 3 treatment groups: group 1 total laryngectomy; group 2 hemilaryngectomy; and group 3 radiotherapy only. Their results showed that the QOL scores of laryngeal cancer patients in the total laryngectomy group were the lowest scores and statistically nonsignificant relative to treatment group. DeSanto and colleagues (1995: 763-769) reported on QOL after surgical treatment for cancer of the larynx. The researchers stated that most of laryngectomees were older persons near retirement age. They found that 60% in the total laryngectomy group reported that the operation had either no impact, or slight impact on their ability to perform their work. Furthermore, Long and colleagues (1996: 1084-1088) reported that the quality of life of patients with cancer of the larynx was better than patients with cancer of the oral cavity.

"Quality of life" is an appropriate outcome for evaluating the impact of cancer nursing because it is concerned not only with the patient's survival and decreased morbidity, but also with the patient's responses to the disease and treatment. A person's evaluation of the degree to which life is worth living is based on a number of criteria (Padilla & Grant, 1985: 47). Thus, if an instrument is to measure quality of life in cancer patients accurately, it must assess a person's subjective sense of well-being within a multidimensional construct.

Quality of life instrument

Choices of the instrument for assessment of QOL depend on the goal of the research, and some have a broader concept of QOL (Frank-Stromborg, 1988: 92; Cella & Tulsky, 1991: 10). Padilla and colleagues (Padilla, et al., 1996: 307), defined quality of life as a personal, evaluative statement summarizing the positivity or negativity of attributes that characterize one's psychological, physical, social, and spiritual well-being at a point in time when health, illness and treatment condition are relevant. Since this definition indicates that "quality of life" is subjective and multidimensional, its measurement must include the patient's perspective and be sensitive to changes over time.

The Quality of Life-Cancer scale (QOL-CA scale) is a subjective scale yielding quantitative data and measures four dimensions: psychosocial existential well-being, physical functional well-being, symptom distress, and worry (Padilla, et al., 1996: 301-308). The QOL-CA scale includes the following dimensions:

1. The psychosocial existential well-being dimension included items on: enjoying life (fun), feeling happy, satisfaction, and general quality of life. It included psychosocial adjustment items related to disease/treatment, sufficient affection given/received, disease/treatment interferes with personal relationships, and existential items (discouraged.. life not worth living, worried about outcome of disease/treatment, and hopeful things will improve), and sufficient sleep.

2. The physical functional well-being dimension included items on: feeling useful, doing things you like, ability to pay attention, strength, and tire easily. Additionally, items related to function were ability to care for personal needs, ability to get around, and satisfaction with appearance.

3. The symptom distress dimension focused on nutrition items: appetite, eat sufficiently, nausea distress, vomiting distress, and pain distress. Also, it includes items pertaining to taste change, amount of pain, and bowel patterns.

4. The attitude of worry dimension included items on: worry about cost, weight, and unfinished business.

Thus, the Quality of Life-Cancer scale (QOL-CA scale) is a multidimensional, single-scale, subjective, self-evaluation instrument which views quality of life as a broad concept. It is subjective so that it is measured QOL from the patient's perspective.

Different factors which are related to quality of life

A person's evaluation of the degree to which life is worth living is based on a number of criteria (Padilla & Grant, 1985: 46). These factors may include personal characteristics such as age, diagnosis characteristics such as the stage of cancer, and treatment characteristics such as length of time after surgery (Padilla & Grant, 1985: 53-55).

For this study, the researcher explored the surveyed laryngectomees' quality of life and the differences in quality of life of laryngectomees between the groups who were different in personal characteristic factors that included age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group.

Age

A patient's age indicates maturity and experience of the individual. Personal maturation and organic, psychic, and intellectual functioning vary within the period of the human life cycle. Older patients tend to be able to use experience for problem solving better than younger patients. A study by Greimel and colleagues (1997: 251-

255) reported nonsignificant differences relative to age in the surveyed QOL-CA scores. These results suggested that increasing age does not appear to significantly diminish physical outcome for adult cancer patients. However, the findings revealed age differences for specific impairments related to disease and treatment. Older patients reported significantly more cancer-related limitations than younger patients did. Similarly, Padilla & Grant (1985: 45-60) studied the QOL of patients with cancer and reported that there was nonsignificant correlation between age and physical well-being. Furthermore, the elderly undergo changes in structure and functioning of the body from having chronic illnesses, which cause complications and difficulties in recovering from these illnesses (Yamvong, 1995: 1)

Marital status

Marital status is an index of social support. Long and colleagues (1996: 1084-1088) found that the married patients with head and neck cancer had significantly higher QOL scores than patients living alone. This finding was related to marital status, which suggested that married patients received added support or pressure from their spouses to go out in public. In Goldberg's study (1975 cited by Maas, 1991: 1374) marital status was found to have a significant effect on speech rehabilitation. If a laryngectomee is married and/or has family or close friends, this will increase the need to speak and has a positive effect on speech rehabilitation.

Educational level

Education contributes to the development of knowledge and problem solving skills in decision-making (Jalowice & Power, 1981: 10-11). The study by Panawatanakul (1991: 33) found that years of education was positively correlated with

QOL in elderly persons. Similarly, Hanucharunkul (1988: 142) studied QOL in cancer patients receiving radiotherapy in Thailand and found that the higher educational-level patients had more knowledge and ability to seek health information and resources for self-care. In contrast, Long and colleagues (1996: 1084-1088) studied the factors related to QOL in 50 patients with head and neck cancer and reported nonsignificant differences of QOL scores between patients who were differences in educational level groups.

Time duration since total laryngectomy

Health problems are an important factors that indirectly affects quality of life (Hanucharunkul, 1994: 27). If a person has the ability to learn from life experiences to adjust to disease/treatment for a long-term period, than appropriate problem-solving has a positive effect on quality of life. Dirksen (1989: 939) studied the perceived well-being in malignant survivors and found that chronic illness or time of admission was negatively correlation with quality of life. In contrast, Long and colleagues (1996: 1084-1088) studied the factors related to QOL in 50 patients with head and neck cancer and reported that time since surgery was not significantly related to QOL scores.

Membership in a laryngectomees' self-help group

A self-help group was one type of social support system which was organized for the patient to share their feelings, experiences, and support each other (Junhavat, 1996: 286). Junhavat and colleagues studied (1993:101) reported the benefits from joining a self-help group for head and neck cancer patients receiving radiotherapy. Most of them reported that they were not alone, and they had other people to share their feelings and experiences with which gave them hope and motivation to live. Aimmak (1994: 60) studied the self-help groups for post-mastectomy patients receiving chemotherapy and found that, after participating in 3 sessions of the self-help group conference, significantly higher quality of life scores were reported than before participating in the self-help group.

Summary

A review of QOL studies of laryngectomees in Thailand revealed that several researchers had focused either on head and neck in-clinic cancer patients, or those who received outpatient radiotherapy later. However, there appears to be very little if any literature which specifically focused on a study of laryngectomee QOL. Although few somewhat related studies had been conducted in other countries, they were limited in scope and could only provide questionable generalization to Thai culture and society.

CHAPTER III

MATERIALS AND METHODS

The purposes of this descriptive study were to explore the self-perceived quality of life of laryngectomees and the differences in QOL of laryngectomees between the groups who were different in age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group.

Population and samples

The target populations of this study were all laryngectomees who were patients at the Otolaryngological Clinic at Ramathibodi Hospital and Rajavithi Hospital. These patients visited an outpatient clinic for regular checkups from April to August 1999. An appropriate sample size was calculated to be 25 percent (Krannasutra, 1981: 12) of 334 laryngectomees from those two hospitals. Therefore, the proper sample size was calculated to be about 85 laryngectomees. The subjects included in this study were 100 laryngectomees sampled from the target populations.

The inclusion criteria for the purposive samples in this study were: a) laryngectomees who had undergone total laryngectomy 6 months ago and longer, and definitive radiation treatment over 3 months; b) understood the Thai language and was able to complete the quality of life questionnaire by herself/himself; and c) was willing to participate in this study.

Setting

The settings for this study were the otolaryngological outpatient clinics at Ramathibodi Hospital and Rajavithi Hospital. They provide services for ear, nose, throat patients, including laryngectomees, Monday-Friday from 8.00 am to 4.00 pm. Otolaryngological physicians, a clinical nurse specialist, and registered nurses operate the clinics. During the patients' wait for checkup by a physician, they might receive suggestions on individual health problems. There is a self-help group for laryngectomees in each clinic. The group meeting at Ramathibodi Hospital is set on the third Wednesday of each month, and at Rajavithi is held every Tuesday. At each meeting, the group members come together for mutual assistance by sharing their experiences in dealing with illness, discussions of common feelings, and providing material assistance as well as emotional support. Every laryngectomized patient can freely attend or register to be a group membership.

Instruments

The instruments used in this study were two questionnaires: a demographic data form and the Quality of Life Questionnaire (see Appendix A).

1. A Demographic Data Form

A demographic questionnaire was developed by the researcher to describe the characteristics of the laryngectomee. It included: a) general information about the patient's gender, age, marital status, education level, current occupation, family income per month, way of treatment payment, the most frequent method of communication used, membership in a laryngectomees' self-help group, b) medical information regarding disease, cancer staging, operation date, treatment, and concomitant therapy.

2. The Quality of Life Questionnaire

The Quality of Life Questionnaire is a self-rating instrument of well-being for persons with cancer. It was designed to be personal, subjective evaluation of psychosocial existential, physical-functional well-being, symptom distress, and attitude of worry. It consists of 30 items with four subscales. Four psychological well-being items, three psychosocial items, and eleven existential items are contained in subscale1. Subscale2 contains eight items concerned with physical-functional well-being. Subscale3 contains eight items relative to symptom distress, focusing on nutrition, distress from pain, and bowel patterns. The last subscale consists of 3 items relative to attitudes of worry about cost, weight, and unfinished business.

Over the past 20 years, Padilla, and colleagues developed the original Quality of Life–Cancer scale (QOL-CA scale). The scale was developed from a very brief instrument that was pilot tested between 1979–1981 (Presant, et al., 1981: 26-30). The next questionnaire, called the Quality of Life Index (QLI), consisted of 14 items tested in 1983 (Padilla, et al., 1983: 117-126). In 1989, Ferrell and colleagues (Ferrell, et al., 1989: 2321-2327) expanded the questionnaire to 28 items, called it the City of Hope Medical Center Quality of Life Survey, and tested it with cancer patients who experienced pain. Padilla and colleagues (Padilla, et al., 1996: 301-308) distinguished their instrument from the Ferrans and Powers QLI (1985), and Spitzer's QL-Index (1981). They changed the name of their instrument to the Multidimensional Quality of Life Scale (MQOLS). Recently, the name was simplified to the QOL-CA scale, and it was tested with 227 home care cancer patients (Padilla, et al., 1996: 301-308). For this group of patients, the Cronbach alpha relative to the total scale was .91, to the psychosocial existential well-being subscale was .88, to the physical-functional well-being subscale was .80, to the symptom distress nutrition subscale was .77, to the symptom distress pain/bowel pattern subscale was .68, and to the attitude of worry subscale was .52. Construct validity of the questionnaires was verified by factor analysis, which showed that the subscales of the nutrition and pain/bowel patterns could be combined into one symptom distress subscale with a Cronbach's alpha coefficient of .77. The content validity of the questionnaire was determined after a content analysis of patient responses to questions about quality of life (Padilla, et al., 1990: 108-115).

In this study, the researcher was given permission to use the QOL-CA scale by the developers (see Appendix B). It was translated into Thai, and the measurement scale response mode was changed to a 0 to 10 scale with a notched and numbered line. The revised scale replaced the current smooth and unnumbered 10-cm linear scales anchored at each end with an extreme positive or negative rating. This change was required to facilitate subject response by providing more intervals along the scale. Also, each interval was numbered for analysis purposes. Participants were asked to mark at any point of the line that indicated their feeling. A ruler is then used to measure the distance between the left end of the line and the participant's mark. This measure is the score of the response. The validity of the QOL-CA scale in the Thai version was examined by four experts (see Appendix C): one nursing expert who has studied about quality of life, two nursing experts in caring for head and neck cancer patients, and one otolaryngologist. They were also asked to evaluate the content validity. Item corrections were made at their suggestion. Afterwards, the reliability of the QOL-CA was assessed by using a pilot study group of 10 laryngectomees who were consistent with the inclusion criteria. The Cronbach's alpha coefficient of the total scale was .92; “psychosocial existential well being” was .73; “physical-functional well-being” was .81; “symptom distress nutrition/pain/bowel pattern was .81; “attitude of worry” was .52.

The QOL-CA Questionnaire used to measure the quality of life contained 30 total items. Items 1, 2, 5, 6, 7, 9, 12, 13, 14, 16, 17, 18, 20, 21, 22, 23, 28, 29 were scored from left (0) to right (10) using 10-cm lines. Items 3, 4, 8, 10, 11, 15, 19, 24, 25, 26, 27, 30 were scored from right (0) to left (10). An alternative scheme was to score all items from left (0) to right (10), and then subtract from 10 the score for items addressing poor quality of life responses on the right. The zero end of the scale indicated the poorest QOL outcome, while the 10 end indicated the best QOL outcome. The total possible raw scores ranged from 0-300. Possible raw scores of the four subscales were: “psychosocial existential well-being” from 0-110; “physical functional well-being” from 0-80; “symptom distress nutrition/pain/bowel pattern” from 0-80; “attitude of worry” from 0-30. QOL total or subscale scores were obtained by summation of item scores, and dividing by the total number of items in the scale, yielding the arithmetic mean score for each category. The range of scores possible for both the total and subscale scores was 0 to 10. Low scores indicated poor quality of life and high scores indicated good quality of life.

Protection of human subjects

All eligible subjects were asked to participate in the study. The researcher explained the purpose of the study, the data collection process, type of questionnaires, length of time for completing the questionnaires, and the subjects’ right to participate or not at the beginning or at any time thereafter. Their answers were not judged to be right or wrong, but they were simply a reflection of their feeling. Participants could refuse to participate and their decision would have no effect on their treatment or care. The subjects who agreed to participate were informed and assured that the data would be kept confidential and reported only as group data. (see Appendix D)

Data collection

Data collection began after permission was obtained from the Faculty of Graduate Studies, Mahidol University, according to the following steps:

1. Asking for permission to collect data by submitting the appropriate document from the Faculty of Graduate Studies, Mahidol University, to the directors of Ramathibodi Hospital and Rajavithi Hospital.

2. Chart reviews were conducted and screenings for eligible subjects were based on the inclusion criteria.

3. All eligible subjects were approached and, before the data had been collected, the researcher explained the study objectives, the data collection process, and the subjects' right (see Appendix D) to make their own decision to participate or not participate in this study.

4. The subjects who volunteered to participate were asked to complete the questionnaires from the researcher: the Demographic Data form, and the QOL-CA questionnaire. The data collection process was conducted at a suitable and convenient place for subjective self-evaluation, and care was taken to avoid any ratings on the Quality of Life scales by either the caregiver or a family member. Medical information was gathered by chart reviews conducted by the researcher.

5. In the case of subjects who were unable to read, they were asked to complete the questionnaire after the researcher had read the QOL-CA questionnaire 2

times. Care was taken to avoid giving them more information than the other subjects who could read themselves.

Data analysis

Data was analyzed by using a SPSS 8.0 for Windows statistical processing program:

1. Continuous demographic data was analyzed by using descriptive statistics: percentage, mean, and standard deviation. Categorical demographic data was analyzed by percentage.

2. The quality of life scores were analyzed using descriptive statistics: mean, standard deviation, and minimum and maximum of total scores, scores for each subscale and scores each instrument item.

3. Two-independent sample t-tests were performed to compare mean scores of the total and the subscales of quality of life between subjects who had different personal characteristic factors; age, educational level, marital status, and membership in a laryngectomees' self-help group.

4. A one-way ANOVA was performed to compare the mean scores of the total and the subscales of quality of life according to the time duration since total laryngectomy.

CHAPTER IV

RESULTS

The findings of the study are presented in this chapter. The sample of the study is described. The results of data analysis are presented in three parts; the demographic and medical characteristics of the samples; the self-perceived quality of life of the laryngectomees; and the differences in QOL of the laryngectomees between the groups who were difference in age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group.

Description of the population

The total population of this study consisted of 100 laryngectomees who were follow-up patients at out-patient clinics at Ramathibodi Hospital and Rajavithi Hospital from April 1999 to August 1999. One hundred laryngectomees were included in this study; 89 were obtained from Ramathibodi Hospital and 11 were obtained from Rajavithi Hospital. Forty-two subjects completed the questionnaires by themselves, and the remainder were unable to read but were able to rate the scales by themselves. For this latter group, each of the items was read to them twice by the researcher before the self-rating began. Each of the laryngectomees took about 20 – 30 minutes to complete the questionnaire.

Demographic and medical characteristics of the samples

One hundred laryngectomees were included in this study. As described in Table 1, the majority of them were male (88%), and married (79%). Their mean age was 64.07 years (SD = 11.35, range = 19 – 89 years), with 69% of them over 60 years of age. Primary school (Pratumsuksa) education was predominant (56%). Primary occupational backgrounds before the laryngectomy were merchants (35%), and agriculture (24%). After the laryngectomy, half were unemployed (50%). The poorest group of subjects had an average family income per month of less than 5,000 Baht (43%). Relative to medical expenses, 51% received total reimbursement and 40% were totally self-pay.

Most of the subjects (53%) used mouthing words combined with hand and facial gesturing as their main method of communication, and 25% used an electrolarynx. And 43% were members of a laryngectomees' self-help group.

The majority of the subjects in this study were in a late stage of cancer; 34% were in stage III and 38% were in stage IV. Most of them (86%) had undergone concomitant total laryngectomy and radiotherapy. The time duration since their total laryngectomy varied from 6 months to 213 months, with a mean of 52.01 (SD = 42.25) months.

Table1. Demographic characteristics of the samples (n=100).

Characteristics	%	M	Mdn	SD	Range
Gender					
Male	88.0				
Female	12.0				
Age (years)		64.07	64.50	11.35	19 - 89
≤ 60 years	31.0				
> 60 years	69.0				
Marital status					
Single	4.0				
Married	79.0				
Widowed/Divorced/Separated	17.0				
Educational background (years)		5.46	4.29	4.07	0 - 17
No formal learning	12.0				
Primary school (1 - 6 years)	56.0				
Secondary school (>6 – 12 years)	23.0				
Diploma/Certificate (>12 – 15 years)	3.0				
Bachelor's degree and higher (>12 years)	6.0				
Occupational background					
Government/partial government officer	18.0				
Merchant	35.0				
Student	1.0				
Employee	15.0				
Agriculture	24.0				
Retire/ Unemployed	7.0				
Current occupational status					
Employed (postoperative)	50.0				
Changed occupation	9.0				
Same occupation	41.0				
Unemployed	50.0				
Income (Baht / month)					
≤ 5,000	43.0				
5,001 - 10,000	23.0				
10,001 - 15,000	10.0				
15,001 – 20,000	12.0				
> 20,000	12.0				

Table1. Demographic characteristics of the samples (n=100)(continued).

Characteristics	%	M	Mdn	SD	Range
Medical expenses.					
Total self-pay	40.0				
Total reimbursement	51.0				
Partial reimbursement	5.0				
Social service	4.0				
Main method of communication.					
Mouthing words	53.0				
Electrolarynx	25.0				
Writing	5.0				
Esophageal speech	16.0				
Voice prosthesis	1.0				
Member of a laryngectomees' self-help group.					
No	57.0				
Yes	43.0				
Stage of cancer.					
Stage I	1.0				
Stage II	27.0				
Stage III	34.0				
Stage IV	38.0				
Concomitant treatment.					
Surgery alone	14.0				
Radiotherapy	86.0				
Time duration since total laryngectomy		52.01	44.50	42.25	6 – 213
6 - 12 months	19.0				
> 13 - 36 months	25.0				
$\geq$ 37 months	56.0				

Research question 1: " what is the self-perceived quality of life of laryngectomees?"

In response to the first purpose of this research study, "to explore the quality of life of laryngectomees", Table 2 contains the measured QOL-CA scores. The overall QOL-CA scores were distributed within a range from 56 to 287 (mean of total scores = 216.20, S.D. = 35.25), and the distribution had a negative skew (skewness = -.852). The QOL scores on each subscale were also reported. They represented a relatively wide range of scores from low to very high on all four subscales. The mean scores of subscales psychosocial-existential well-being, physical-functional well-being, symptom distress: nutrition/pain/bowel pattern, and attitude of worry were 77.03, 58.30, 61.30, and 19.56, respectively.

Table 2 Mean, standard deviation, range of the QOL-CA scores of the laryngectomees (n=100).

QOL-CA	Min - Max		M	S.D.
	Possible	Actual		
Psychosocial-existential well being	0 – 110	32.50 - 104.50	77.03	13.98
Physical- functional well being	0 - 80	10.00 - 77.50	58.30	11.50
Symptom distress	0 - 80	10.00 - 77.50	61.30	11.27
Attitude of worry	0 - 30	3.00 - 30.00	19.56	6.38
Overall	0 – 300	56.00 – 287.00	216.20	35.25

The mean scores of QOL-CA by questionnaire item are contained in Table 3. All items were transposed for analysis such that the anchors represent 0 as the worst outcome and 10 as the best outcome (Range 0-10). The table lists items in descending order from the lowest to the highest for each subscale item, thus depicting the areas of the worst to the best aspects of quality of life in the laryngectomees sample.

Results showed that the best overall outcome (relative to a maximum score of 10.0) was in the subscale of "symptom distress: nutrition/pain/bowel pattern" (mean = 7.66), followed by "physical-functional well-being" (mean = 7.29), and "psychosocial-existential well-being" (mean = 7.00). The worst outcome was in the subscale of "attitude of worry" (mean = 6.52). The overall quality of life mean score was = 7.21.

The lowest item mean scores were in the items of "disease interferes with personal relationship" (mean = 5.23), "tire easily" (mean = 5.35), "worry about cost" (mean = 5.69), "enjoy life" (mean = 6.61), and "worry about outcome of disease" (mean = 6.71), respectively. Items in the highest range of the scales which indicated positive outcomes were "vomit distress" (mean = 9.19), "nausea distress" (mean = 9.10), "able to care for personal needs" (mean = 8.79), "sufficient affection given/received" (mean = 8.08), and "do things you like" (mean =8.06).

Table 3 Mean, standard deviation, and range of each item of the QOL-CA scores of laryngectomees (n=100) (Range 0 - 10).

QOL-CA (Item)	Mean	S.D.	Min - Max
Total psychosocial-existential well-being	**7.00**	**1.27**	**2.95 - 9.50**
Disease interferes with personal relationship	5.23	3.07	0.40 - 10.00
Enjoy life (fun)	6.61	2.07	0.20 - 10.00
Worried about outcome of disease	6.71	3.35	0.50 - 10.00
Discouraged.....life not worthwhile.	6.77	3.04	0.40 - 10.00
Hopeful things will improve	7.05	2.35	0.50 - 10.00
Good quality of life	7.09	1.90	0.50 - 10.00
Feel happy	7.19	1.97	0.50 - 10.00
Have satisfying life	7.19	2.26	0.50 - 10.00
Adjust to disease/treatment	7.36	1.59	0.50 - 10.00
Sufficient sleep	7.75	1.91	0.50 - 10.00
Sufficient affection given/received	8.08	1.67	3.40 - 10.00
Total physical-functional well-being	**7.29**	**1.44**	**1.25 - 9.69**
Tire easily	5.35	2.87	0.50 - 10.00
Feel useful	6.76	2.44	0.40 - 10.00
Strength	7.12	2.28	0.40 - 10.00
Satisfied with appearance	7.14	2.24	0.30 - 10.00
Able to pay attention	7.36	2.01	0.50 - 10.00
Able to get around	7.72	2.27	0.50 - 10.00
Do thing you like	8.06	1.88	0.40 - 10.00
Able to care for personal needs	8.79	1.53	0.50 - 10.00
Total symptom distress: nutrition/pain/bowel	**7.66**	**1.41**	**1.25 - 9.69**
Distress from pain	6.69	3.31	0.00 - 10.00
Taste change	6.87	2.73	0.50 - 10.00
How much pain?	6.88	3.22	0.00 - 10.00
Bowel Pattern	7.43	2.73	0.20 - 10.00
Eat sufficient	7.53	2.12	0.00 - 10.00
Appetite	7.61	1.91	0.50 - 10.00
Nausea distress	9.10	1.81	0.50 - 10.00
Vomit distress	9.19	1.75	0.50 - 10.00
Total attitude of worry	**6.52**	**2.13**	**1.00 - 10.00**
Worry about cost	5.69	3.60	0.50 - 10.00
Worry about weight	6.90	3.15	0.40 - 10.00
Worry about unfinished business	6.96	3.06	0.50 - 10.00
Overall quality of life	**7.21**	**1.17**	**1.87 - 9.57**

Research Question 2: "what are the difference QOL of laryngectomees between the groups who were difference in age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group?"

In order to assess possible differences in QOL scores according to age, educational level, marital status, and membership in a laryngectomees' self-help group, two independent sample t-tests were computed to compare the mean scores of the overall QOL and its subscales (Table 4-8). The mean scores for the overall QOL and its subscales were compared by using a one-way ANOVA relative to groups corresponding to time duration since total laryngectomy (Table 9).

The appropriate use of a t-test for two independent groups was verified by computing the homogeneity of variance between groups who were different in age, educational level, marital status, and membership in a laryngectomees' self-help group.

The t-test results in Table 4 show a statistically nonsignificant difference in overall QOL scores between two groups relative to age, educational level, and marital status, respectively ($p > .05$). Membership in a laryngectomees' self-help group was the only characteristic factor which showed a statistically significant difference relative to QOL scores ($p < .05$). The members of a laryngectomees' self-help group had overall QOL scores higher than for those subjects who were not members.

Table 4 Comparison of overall quality of life scores between the groups of laryngectomees with selected characteristic factors (n = 100).

Characteristic Factors	n	Mean	S.D.	t
Age (years)				
≤ 60	31	213.85	42.98	$-.44^{ns}$
> 60	69	217.25	31.46	
Educational level (years)				
≤ 6	68	216.01	37.51	$-.07^{ns}$
> 6	32	216.59	30.43	
Marital status				
Married	79	217.50	30.50	$.54^{ns}$
Single/widowed/divorced/separated	21	211.30	49.88	
Membership in a laryngectomees' self-help group				
Nonmember	57	209.87	36.73	-2.10*
Member	43	224.58	31.67	

^{ns} $p > .05$

* $p < .05$

The t-test results in Table 5 show statistically nonsignificant differences relative to "psychosocial-existential well-being" subscale scores between two groups of age, educational level, and marital status, respectively ($p > .05$). Membership in a laryngectomees' self-help group was the only characteristic factor with which "psychosocial-existential well-being" subscale scores had a statistically significant difference ($p < .05$). The laryngectomees who were members of a self-help group had higher psychosocial-existential well-being scores than for those subjects who were not members.

Table 5 **Comparison of psychosocial-existential well-being subscale scores between the groups of laryngectomees with selected characteristic factors (n = 100).**

Characteristic Factors	n	Mean	S.D.	t
Age (years)				
≤ 60	31	77.00	14.93	-.01 ^{ns}
> 60	69	77.03	13.64	
Educational level (years)				
≤ 6	68	76.46	13.51	-.58 ^{ns}
> 6	32	78.22	15.09	
Marital status				
Married	79	77.77	13.05	1.03 ^{ns}
Single/widowed/ divorced/separated	21	74.22	17.10	
Membership in a laryngectomees' self-help group				
Nonmember	57	74.29	13.46	-2.29*
Member	43	80.64	13.98	

^{ns} $p > .05$

* $p < .05$

The t-test results in Table 6 show statistically nonsignificant differences relative to "physical-functional well-being" subscale scores between two groups of age, educational level, and marital status, respectively ($p > .05$). Membership in a laryngectomees' self-help group was the only characteristic factor relative to "physical-functional well-being" subscale scores, which had a statistically significant difference ($p < .05$). The laryngectomees who were member of a laryngectomees' self-help group had higher "physical-functional well-being" subscale scores than for those subjects who were not members.

Table 6 Comparison of physical-functional well-being subscale scores between the groups of laryngectomees with selected characteristic factors (n = 100).

Characteristic Factors	n	Mean	S.D.	t
Age (years)				
≤ 60	31	57.79	12.44	-.29 ^{ns}
> 60	69	58.53	11.14	
Educational level (years)				
≤ 6	68	58.21	12.96	-.13 ^{ns}
> 6	32	58.48	7.72	
Marital status				
Married	79	58.68	10.18	.63 ^{ns}
Single/widowed/ divorced/separated	21	56.87	15.76	
Membership in a laryngectomees' self-help group				
Nonmember	57	56.01	13.04	-2.34*
Member	43	61.33	8.26	

^{ns} $p > .05$

* $p < .05$

The t-test results in Table 7 show statistically nonsignificant differences relative to "symptom distress: nutrition/pain/bowel pattern" subscale scores between two groups of age, educational level, marital status, and membership in a laryngectomees' self-help group, respectively ($p > .05$).

Table 7 Comparison of symptom distress: nutrition/pain/bowel pattern subscale scores between the groups of laryngectomees with selected characteristic factors (n = 100).

Characteristic Factors	n	Mean	S.D.	t
Age (years)				
≤ 60	31	58.90	9.16	-1.44 ^{ns}
> 60	69	62.39	5.15	
Educational level (years)				
≤ 6	68	61.86	7.15	-.71 ^{ns}
> 6	32	60.13	5.53	
Marital status				
Married	79	61.90	5.82	1.03 ^{ns}
Single/widowed/ divorced/separated	21	59.05	9.94	
Membership in a laryngectomees' self-help group				
Nonmember	57	60.24	7.44	-1.08 ^{ns}
Member	43	62.71	5.36	

^{ns} $p > .05$

The t-test results in Table 8 show statistically nonsignificant differences relative to "attitude of worry" subscale scores differences between two groups of age, educational level, marital status, and membership in a laryngectomees' self-help, respectively ($p > .05$).

Table 8 Comparison of attitude of worry subscale scores between the groups of laryngectomees with selected characteristic factors (n = 100).

Characteristic Factors	n	Mean	S.D.	t
Age (years)				
≤ 60	31	20.16	6.95	.63 ^{ns}
> 60	69	19.28	6.14	
Educational level (years)				
≤ 6	68	19.47	7.03	-.23 ^{ns}
> 6	32	19.75	4.80	
Marital status				
Married	79	19.14	6.50	-1.28 ^{ns}
Single/widowed/ divorced/separated	21	21.14	5.77	
Membership in a laryngectomees' self-help group				
Nonmember	57	19.31	6.59	-.44 ^{ns}
Member	43	19.88	6.15	

^{ns} $p > .05$

The results of the ANOVA analysis in Table 9 show statistically nonsignificant differences of each subscale and overall QOL-CA scores among subjects who were grouped according to differences in time duration since total laryngectomy ($p > .05$).

Table 9 Comparison of QOL-CA overall and subscale scores among the groups laryngectomees with time duration since total laryngectomy (n = 100).

QOL-CA Subscale	Time Duration since laryngectomy (months).						
	6 –12(n=19)		>12-36(n=25)		>36(n=56)		
	M	S.D.	M	S.D.	M	S.D.	F
Psychosocial-existential well-being	75.85	10.99	77.91	17.72	77.03	13.21	.11^{ns}
Physical-functional well-being	61.16	8.97	55.76	16.08	58.46	9.66	1.20^{ns}
Symptom Distress	59.03	11.46	60.61	14.98	62.39	9.19	.68^{ns}
Attitude of Worry	19.84	6.80	18.88	6.29	19.76	6.37	.18^{ns}
Overall QOL-CA	215.90	27.67	213.17	49.04	217.65	30.49	.13^{ns}

^{ns} $p > .05$

CHAPTER V

DISCUSSION

In this chapter, the findings of the study including laryngectomee's demographic characteristics and self-perceived quality of life are presented and discussed.

Laryngectomee's demographic characteristics

The majority of the subjects (88%) in this study were male, and their mean age was 64.07 years old. This data is similar to subjects in other studies (Junhavat, et al., 1990: 111; Otto, et al., 1997: 694; Ackerstaff, et al., 1994: 296; Thurston-Hookway & Seddon, 1989: 5), and is consistent with other studies of the prevalence of laryngeal cancer. These prior studies reported that the prevalence of laryngeal cancer was higher in men than women aged over 60 years (McCorkle, et al., 1996: 784; Euswas, 1995: 430; Baker, 1995: 455). The majority of the subjects were married (79%), and an average primary school educational level or lower (68%).

Most of the subjects before laryngectomy were employed (93%), but, after their laryngectomy, half were unemployed (50%). One reason could be that the majority of subjects were elderly and may have had other age-related physiological changes, which caused the degeneration of other organs, all of which to combined affect alaryngeal communication. Although half of the subjects were unemployed after laryngectomy, 51% were able to obtain reimbursement for their medical expenses. On the other hand, this economic cost likely had an impact on individuals who could not obtain reimbursement for their medical expenses (44%), especially in cases of unemployment and/or low family income.

Most of the postoperative health care teams usually suggest that laryngectomized patients need to have speech rehabilitation by using an electrolarynx or practicing esophageal speech, because those are available ways to reestablish communications. However, there are many factors which limit the ability of laryngectomees to do so. In this study, the most commonly used of communication method was mouthing words combined with hand and facial gesturing (53%). It differs from the study of Clements (1997: 494), which stated that the most subjects communicate by using an electrolarynx. As an explanation of these findings, in Thailand an electrolarynx is very expensive nowadays - more than 35,000 baht. In a period of economic problems for the laryngectomees, it is difficult for many to afford the high cost of an electrolarynx. Although there is a Royally-sponsored project to help the voice handicapped by providing an electrolarynx for laryngectomee, it is not enough. Esophageal speech is a complex, learned method to produce speech after total laryngectomy taught by too few speech therapists. Additionally, esophageal speech requires practice for a long time, over 8 months to 1 year (Tuntranon, 1996: 194). The success rate of esophageal speech is low due to the laryngectomee's personality structure, the number of days between surgery, and completion of postradiation therapy (Miller, 1990: 174).

Furthermore, List and colleagues (1996: 1-10) stated that patients learned to cope rather effectively with their disease and treatment to the extent that functional limitations caused by a laryngectomy did not ruin their lives. Therefore, they did not experience a global decrease in life satisfaction, so that functional impairment resulting from a laryngectomy did not significantly diminish their overall QOL. In addition, the high economic cost of voice restoration may have an impact on individuals who could not otherwise obtain reimbursement for medical expenses, especially in cases of unemployment and/or low family income.

The quality of life of laryngectomees

One of the results of this research study showed the overall QOL-CA scores were distributed within a range from 56 to 287, with a mean of 216.20 and SD 35.25 (Table 2). Most of the self-ratings were in the high end of the range corresponding to a negatively skewed distribution of scores (Table 2). Furthermore, when all items was transposed for analysis by overall or subscale scores were obtained by summation of item scores, and dividing by the total number of items in the scale, yielding the arithmetic mean score for each category. The range of scores possible for item, subscale and overall was 0 to 10. This corresponds to an overall QOL item mean of 7.21 and SD of 1.17 (Table 3). These findings indicate that most laryngectomees reported a moderate-to-high overall QOL-CA score, and individual item scores implying a moderate-to-high QOL. One possible explanation for a part of this result is the availability of self-help groups for laryngectomees in each clinic. At these self-help groups, the patients can share their feelings, experiences, and provide material assistance and support to each other. Subjects in this study benefited from attending or participating in a laryngectomees' self-help group. Patients should be trained in adaptive coping skills, have continued contact with the veteran laryngectomees (McQuellon & Hurt, 1997: 238). Another explanation may be because of the prevention of psychosocial problems and early rehabilitation by the health-care professional team, which provided quality treatment and nursing care. In addition, good social and family support usually increase a laryngectomee's QOL

The "attitude of worry" subscale mean score (6.52) was the lowest among the four dimensions. It means poor quality of life dimension. Subjects worried most about the cost of their treatment. This may be explained by the effects of our continuing economic crisis and the increased complexity of health care systems such as the high cost of medical equipment, supplies and technology. 50% of the subjects were unemployed. Therefore, the high economic cost of treatment will have a negative impact on individuals who cannot be reimbursed for medical expenses (44%), especially in cases of unemployment and low family income (< 5000 Baht / month). A person who loses a job may not have enough money to purchase medical treatment.

The "psychosocial-existential well-being" subscale mean score (7.00) was also lower than the overall QOL-CA mean score. The subscale item relative to "disease/treatment interferes with personal relationships" received the lowest score (5.23). Subjects in this study reported great concern about personal relationships. Consistent with Byrne and colleagues study (1993: 175) found that depressed laryngectomees complained of poor communication skills, social isolation, isolation from services and peer support. In this study, 50% of subjects were unemployed after laryngectomy, which could account for the effects of their self-perceived negative feelings about their body and impaired communication functions. In addition, 53% of subjects communicated by mouthing words combined with hand and facial gesturing which may greatly interfere with personal relationships. Similarly, the Harwood and Rawlinson study (1983: 337) found approximately one-half of laryngectomees surveyed were unable to leave the house, thus losing their jobs and becoming socially withdrawn.

The "physical-functional well-being" subscale item of "tire easily" received the lowest score (5.35), which demonstrated mostly negative effects in the area of physical-functional well-being. Cancer patients linked their fatigue to disturbed sleep patterns related to stress, pain, aging, and poor nutrition (Camarillo, 1993: 41). These results might have reflected the effects of fatigue after laryngectomy. As an explanation for this result, most of laryngectomees were elderly and had age-related physiological changes which caused degeneration of many organs, combined with pulmonary complications because of their history of heavy smoking. Thus, they had post laryngectomy loss of their intrinsic positive end-expiratory pressure regulatory mechanisms (McGuirt & Davis III, 1995: 152), and may have had an alveolar collapse (Hess, et al., 1999: 988). In addition, Baker (1992: 399) found shoulder problems in cases that had undergone total laryngectomy along with radical neck dissection and radiotherapy, both of which could perhaps, impact on rehabilitation in a negative way.

The symptom distress subscale score had higher score. The subscale item of "distress from pain" demonstrated more positive scores than the other lowest subscale item. The experience of pain is subjective and multidimensional. As an explanation for this result, most of the subjects were elderly, suffered from cancer disproportionately compared to other chronic painful conditions, and had sensory impairments complicating pain assessment (Padilla, et al., 1990: 113; Ferrell, et al., 1994: 2139). In addition, laryngectomees who had undergone radical neck dissection might have stiff shoulders as a result of inability to move the joint. They complained most bitterly of shoulder pain rather than limited motion (Terrell, et al., 1997: 1125-1132).

The differences in quality of life of laryngectomees scores between the groups who were different in age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group.

The research results of this study showed there were statistically nonsignificant differences of overall QOL, and subscale scores between laryngectomee's group who were different in age, educational level, marital status, and time duration since total laryngectomy. In contrast, statistically significant differences were found relative to membership in a laryngectomees' self-help group and both the overall QOL and some subscale scores.

This study found statistically significant differences of overall QOL, and two subscales (psychosocial-existential well-being subscale, and physical-functional well-being) scores between subjects who were and were not member in a laryngectomees' self-help group. These results are consistent with the results of Junhavat and colleagues study (1993:101) which also reported the benefits from joining a self-help group for head and neck cancer patients receiving radiotherapy. Most of them reported that they were not alone, they had other people to share their feeling with and experiences, which gave them hope and motivation to live. In support, comparable benefits from membership in a laryngectomees' self-help group at Ramathibodi Hospital were reported (Junhavat, 1996: 286). Similar results were reported by Aimmak (1994: 60) in a study of the effects of a self-help group on post-mastectomy patients undergone chemotherapy. Aimmak (1994: 60) found that, after participating in 3 sessions of the self-help group meeting, they responded with statistically significantly higher QOL scores, especially in the area of physical well-being ($p < .01$).

The results of the present study showed statistically nonsignificant differences of overall QOL, subscale scores between the groups who were different in age, educational level, marital status, and time duration since total laryngectomy. Most of the subjects had high overall QOL scores. Higher scores indicated that they perceived a good quality of life. The results further showed that the older subjects tended to have higher QOL scores. These results might be explained by the fact that most Thai families are extended families, in which the elderly patients live with their relatives. In addition, most of them received sufficient affection (mean = 8.08), which might have resulted in higher self-rated subscale item scores.

Furthermore, the results showed that there were statistically nonsignificant differences of the overall QOL and subscale scores relative to marital status. These result are inconsistent with the result of Long and colleagues (1996: 1084-1088) who studied factors related to QOL in 50 patients with head and neck cancer. They found that married patients had statistically significantly, higher QOL scores than patients living alone, which suggested that married patients received added support and/or pressure from their spouses to go out in public. These results might be explained by the fact that most Thai families are extended families, in which the laryngectomees live with their spouse or relatives. In addition, all subjects were obtained from institutions where provide confidential health care for laryngeal cancer patients and have a laryngectomees' self-help group to support them.

There were statistically nonsignificant differences between overall QOL and subscale scores and the groups by educational level. Similarly, Long and colleagues

(1996: 1084-1088), who studied factors related to QOL in 50 patients with head and neck cancer, reported statistically nonsignificant differences between educational level and QOL scores.

Also, there were statistically nonsignificant differences of each subscale and overall QOL-CA scores relative to the time duration since total laryngectomy. Similarly, Long and colleagues (1996: 1084-1088), who studied factors related to QOL in 50 patients with head and neck cancer, reported statistically nonsignificant differences between time duration since total laryngectomy and QOL scores.

These results might be explained by the population from which subjects were obtained from Ramathibodi Hospital and Rajavithi Hospital. Both institutions provide confidential health care for laryngeal cancer patients. Therefore, they would receive information about the disease, its treatment, and how to provide self-care for themselves relative to improving their quality of life. In addition, they have a laryngectomees' self-help group to support them and to share their feeling, and experiences with.

Furthermore, the study outcome suggested that the self-rated QOL of the laryngectomees were not caused only by age, formal education, marital status and time duration since total laryngectomy, but also by many factors especially membership in a laryngectomees' self-help group.

Limitations of the study

The subjects were not randomly selected but were selected by purposive criteria. Generalization of the study findings to the total population of laryngectomees in Thailand is unsupported pending further research.

CHAPTER VI

CONCLUSION

This descriptive study aimed to describe the self-perceived quality of life of laryngectomees, and the differences in QOL between the groups who were different in age, marital status, educational level, time duration since total laryngectomy, and membership in a laryngectomees' self-help group. One hundred laryngectomees who met the eligibility criteria and came to the Otolaryngological Outpatient Clinics at Ramathibodi Hospital and Rajavithi Hospital from April 1999 to August 1999 were included in this study.

The instruments used in the study were a demographic data form and the Quality of Life-CA (QOL-CA) questionnaire. The QOL-CA used was a Thai version of an instrument developed by Padilla and colleagues. Demographic data was collected by means of structured interviews and transcribing some related data from patient medical records. The QOL questionnaires were completed by the laryngectomees themselves. All data was analyzed by using SPSS, and the study conclusions and findings are summarized in this section.

The majority of the purposive subjects in this study were male, with a mean age of 64.07 years, 79% were married, 43% had a family income less than 5,000 baht per month, half of the subjects were unemployed, 68% had an average educational level of primary school or lower, and about half of the subjects paid their hospital fees by themselves.

The most commonly used method of communication was by mouthing words combined with hand and facial gesturing (53%). The time duration since total laryngectomy ranged between 6 to 213 months (mean 52.01, SD 42.25).

The overall results of this study were:

1. The self-perceived quality of life of laryngectomees corresponded to moderate-to-high overall QOL-CA (mean 7.21, SD 1.17).
2. There were statistically significant differences of overall QOL, and two subscales (psychosocial-existential well-being and physical-functional well-being) scores between laryngectomees who were and were not member in a laryngectomees' self-help group ($p < .05$).
3. There were statistically nonsignificant differences of overall QOL, subscale scores between laryngectomees who were differences in age, educational level, marital status, and time duration since total laryngectomy groups ($p > .05$).

As a result, the stated hypothesis "There is a difference between laryngectomee's quality of life scores of participants who were different in age, marital status, educational level, time duration since total laryngectomy groups, and membership in a laryngectomees' self-help group" was partially supported in this study.

Implications of the findings

Implications for nursing practice:

Nursing care to promote a higher quality of life for laryngectomees should be highlighted in their nursing care plans. It is necessary to assess their QOL, provide for effective nursing intervention, and encourage them to become a member of a laryngectomee self-help group. Results of this research may give more information so cost-effective nursing care plans can be formulated and implemented that will provide high quality care for the individual laryngectomy patient.

Implications for nursing education:

For nurses who work with laryngectomees, inservice and continuing education should include, and emphasize, more content on the QOL of laryngectomees and the determination of QOL. Information from laryngectomee self-help groups should also be added into the nursing care plans of laryngectomees.

Implications for nursing research:

This study provided some baseline data to use in further research about the QOL of laryngectomees' and self-help groups. Other researchers may choose to replicate this study, but they should use a sample of laryngectomees from other hospitals in Thailand, consider other factors which may influence the QOL of laryngectomees, and explore the variety of patterns of effective self-help groups to improve the quality of life for them.

BIBLIOGRAPHY

Aaronson, N.K. (1988). Quality of life: What is it. How should it be measured? Oncology, 2 (5), 69-74.

Ackerstaff, A.H., Hilgers, F.J.M., Aaronson, N.K., & Balm, A.J.M. (1994). Communication, functional disorders and lifestyle change after total laryngectomy. Clin. Otolaryngol., 19, 295-300.

Aimmak, B. (1994). A study of self-help group on the post-mastectomy patients with chemotherapy. Master's thesis in Science (Adult Nursing), Faculty of Graduate Studies, Mahidol University.

American Joint Committee on Cancer. (1992). In O.H. Beahrs, D.E. Henson, R.V. Hutter, & B.J. Kemedy (Eds.). Manual for staging of cancer (4th ed., pp. 25-54). Philadelphia: J.B. Lippincott.

Baker, C.A. (1992). Factors associated with rehabilitation in head and neck cancer. Cancer Nursing, 15 (6), 395-400.

Bjordal, K., & Kaasa, S. (1995). Psychological distress in head and neck cancer patients 7-11 years after curative treatment. British Journal of Cancer, 71, 592-597.

Byrne, A., Walsh, M., Farrelly, M., & O'Driscoll, K. (1993). Depression following laryngectomy a pilot study. British Journal of Psychiatry, 163, 173-176.

Camarillo, M.A. (1993). The oncology patient's experience of fatigue. In M.B. Wheden (Ed.), Quality of life-A nursing challenge, vol.1 and 2, (pp. 39-44). Pennsylvania: Meniscus.

Cella, D.F. & Tulsky, D.S. (1991). Measuring quality of life today: Methodological aspects. In N.S. Tehekmedyian & D.F. Cella (Eds.), Quality of life in oncology-practice and research (pp. 9-18). New York: Dominus Publishing.

Clement, K.S., Rassekh, C.H., Seikaly, H., Hokamson, J.A., & Calhoun, K.H. (1997). Communication after Laryngectomy. Arch. Otolaryngol Head Neck Surgury, 123 (May), 493-496.

Cutright, L.H. (1992). Head and Neck Cancer. In J.C. Clark & R.F. Mc.Gee (Eds.), Core Curriculum for Oncology Nursing (2nd ed., pp. 499–521). Philadelphia: W.B. Saunders.

D'Antonio, L.L, Zimmerman, G.J., Cella, D.F., & Long, S.A. (1996). Quality of life and functional status measures in patients with head and neck cancer. Arch. Otolaryngol Head and Neck Surgery, 122, 482-487.

DeGraeff, A., et al. (1999). A prospective study on quality of life of laryngeal cancer patients treated with radiotherapy. Head and Neck, 21(4), 291-296.

Deleyiannis, F. W-B., et al. (1999). Quality of life after laryngectomy: Are functional disabilities important? Head and Neck, 21(4), 319-324.

DeSanto, L.W., Olsen, K.D., Perry, W.C., Rohe, D.E., & Keith, R.L. (1995). Quality of life after surgical treatment of cancer of the larynx. Ann. Otol. Rhinol. Laryngol, 104, 763-769.

Dirksen, S.R. (1989). Perceived well-being in malignant survivors. Oncology Nursing Forum, 16 (May / June), 939-942.

Drettner, B. & Ahlbom, A. (1983). Quality of life and state of health for patients with cancer in the head and neck. Acta. Otolaryngol, 96, 307-314.

Euswart, C. (1995). Laryngeal cancer. In S. Prakhunhunsit & B. Kulpaditharom (Eds.), The Textbook of otology rhinology and laryngology (pp. 430-441). Bangkok: Holistic.

Ferrans, C.E. & Powers, M.J. (1985). Quality of life index: Development and psychometric properties. Advances in Nursing Science, 8 (1), 15-23.

Ferrans, C.E. (1990). Development of a quality of life index for patients with cancer. Oncology Nursing Forum, 17 (Suppl. 3), 15-19.

Ferrell, B.R. & Rivera, L.M. (1993). Measurement of physical well-being as a dimension of quality of life. In M.B. Wheden (Ed.), Quality of Life - A Nursing Challenge, vol.1 and 2 (pp. 45-50). Pennsylvania: Meniscus.

Ferrell, B.R., Wisdom, C., & Wenzl, C. (1989). Quality of life as an outcome variable in the management of cancer pain. Cancer, 63 (Suppl. 11), 2321-2327.

Frank-Stromberg, M. (1984). Selecting and instrument to measure quality of life. Oncology Nursing Forum, 11 (September / October) , 88-91.

Frank-Stromberg, M. (1988). Single instrument for measuring quality of life. In M. Frank-Stromberg (Ed.), Instruments for assessing health and function. (pp.79-95). Norwalk: Appleton-Lange.

Greimel, E.R., Padilla, G.V. & Grant, M.M. (1997). Physical and psychosocial outcomes in cancer patients: a comparison of different age groups. British Journal of Cancer, 76 (2), 251-255.

Grant, M.M. & Padilla, G.V. (1990). Cancer nursing research. A Practical Approach. Connecticut: Appleton & Lange.

Grant, M.M., Padilla, G.V., Ferrell, B.R., & Rhiner, M. (1990). Assessment of quality of life with a single instrument. Seminars in Oncology Nursing, 6 (4), 260-270.

Guyatt, G.H., Feeny, D.H. & Patrick, D.L. (1993). Measuring health-related quality of life. Annals of Internal Medicine, 118 (8), 622-629.

Hanucharurnkul, S. (1988). Social support, self care and quality of life in cancer patients receiving radiotherapy in Thailand. Doctoral dissertation, College of Nursing. Wayne State University, Detroit, Michigan.

Hanucharurnkul, S. (1994). Nursing research for developing quality of life: Methodology of quantitative research. Nursing conference about nursing research for developing quality of life in the next century: Issue and trends (8th ed., pp. 25-38). Bangkok: Siriraj.

Harwood, A.R. & Rawlinson, E. (1983). The quality of life of patient following treatment for laryngeal cancer. Int. J. Radiation Oncology Biol. Phys., 9, 335-338.

Haynes, V.L. (1996). Caring for laryngectomy patient. American Journal of Nursing, 96 (5), 16B-16K.

Hess, I.M., Schwenk, R.A., Frank, W., & Loddenkemper, R. (1999). Pulmonary function after total laryngectomy. Laryngoscope, 109, 988-994.

Herranz-Gonzalez, J., Gavilan, J., Martinez-Vidal, J. & Gavilan, C. (1996). Supraglotic laryngectomy: Functional and oncologic results. Ann. Otol. Rhinol. Laryngol, 105, 18-22.

Jalowiec, A. & Power, M.J. (1981). Stress and coping in hypertension and emergency room patients. Nursing Research, 30 (January - February), 10-15.

Jalukar, V., Funk, G.F., Christensen, A.J., Karnell, L.H., & Moran, P.J. (1998). Health status following head and neck cancer treatment: patient, health-care professional and public perspectives. Head & Neck, 20, 600-608.

Jay, S. (1991). Laryngectomy: the patient's view. Journal of Laryngology and Otology, 105, 934-938.

Junhavat, D. (1996). Self care promotion by using self-help group. In S. Hanucharuenkul (Ed.), Self care: Nursing science (4th ed., pp. 267-289). Bangkok: VJ printing.

Junhavat, D., Luecha, Y., Pattaranuthaporn, P., & Rasmeeloung-on, J. (1993). Effects of self-help group on self-esteem and self-care agency in head and neck cancer patients receiving radiotherapy. Project Behavior Health Research Support by WHO 1992, Ministry of Public Health.

Junhavat, D., Luecha, Y., & Suntisukthana, S. (1990). The characteristics of the patients with carcinoma of the larynx and their adaptation after total laryngectomy at Ramathibodi Hospital. Ramathibodi Medical Journal, 13 (2), 105-111.

King, K.B., et al. (1985). Patients' descriptions of the experience of receiving radiation therapy. Oncology Nursing Forum, 12 (July / August), 55-61.

Krannasutra, P. (1981). Statistical for behaviour research. (pp. 12). Bangkok: Chulalongkorn.

Lefebre, J-L. (1998). Larynx preservation: The discussion is not closed. Otolaryngol Head and Neck Surgery, 118, 389-393.

List, M.A., et al. (1996). Longitudinal assessment of quality of life in laryngeal cancer patients. Head & Neck, 18, 1- 10.

List, M.A., Ritter-Sterr, C.A., & Lansky, S.B. (1990). A performance status scale for head and neck cancer patients. Cancer, 66 (August), 564-569.

Logemann, J.A. (1989). Swallowing and communication rehabilitation. Seminars in Oncology Nursing, 5, 205-212.

Logemann, J.A. (1994). Rehabilitation of the head and neck cancer patient. Seminars in Oncology Nursing, 21 (3), 359-365.

Long, A.S., D'Antonio, L.L., Robinson, E.B., Zimmerman, G., Petti, G., & Chonkich, G. (1996). Factors related to quality of life and functional status in 50 patients with head and neck cancer. Laryngoscope, 106 (September), 1084-1088.

Maas, A. (1991). A model for quality of life after laryngectomy. Soc. Science Medicine, 33(12), 1373-1377.

McConnel, F.M.S., Mendelsohn, M.S., & Logemann, J.A. (1986). Examination of swallowing after total laryngectomy using manofluorography. Head Neck Surgery, 8, 3-12.

McCorkle, R., Grant, M.M., Frank-Stromborg, M., & Baird, S. (1996). Cancer nursing. A comprehensive textbook (2nd ed., pp. 784-795). Philadelphia: W.B. Saunders.

McGuirt, W.F., & Davis III, S.P. (1995). Demographic portrayal and outcome analysis of head and neck cancer surgery in the elderly. Arch. Otolaryngology-Head Neck Surgery, 121, 150-154.

McQuellon, R.P. & Hurt G.J. (1997). The psychosocial impact of the diagnosis and treatment of laryngeal cancer. Otolaryngologic Clin.North America, 30 (2), 231-241.

Mohide, E.A., Archibald, S.D., Tew, M., Young, J.E., & Haines, T. (1992). Postlaryngectomy quality of life dimensions identified by patients and health care professionals. American Journal of Surgery, 166, 619-622.

Mor, V., Allen, S., & Malin, M. (1994). The psychosocial impact of cancer on older versus younger patients and their families. Cancer, 74, 2118-2127.

Morton, R.P. (1997). Laryngeal cancer: Quality of life and cost effectiveness. Head & Neck, 19, 243-250.

Nantachaipan, P. (1996). Development of self care agency model in persons with HIV infection / AIDS. Doctor of Nursing Science, Faculty of Graduate Studies, Mahidol University.

National Cancer Institute. (1993). What you need to know about cancer of the larynx. U.S. Department of Health and Human Service, National Institutes of Health.

Otto, R.A., Dobie, R.A., Lawrence, V., & Sakai, C. (1997). Impact of a laryngectomy on quality of life: Perspective of the patient versus that of the health care provider. Ann. Otol. Rhinol. Laryngol, 106, 693-699.

Padilla, G.V., Ferrell, B.R., Grant, M.M., & Rhiner, M. (1990). Defining the content domain of quality of life for cancer patients with pain. Cancer Nursing, 13 (2), 108-115.

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., Grant, M.M., Ferrell, B.R., & Presant, C.A. (1996). Quality of life - cancer. In B. Spilker (Ed.), Quality of life and pharmacoeconomies in clinical trials, (2nd ed., pp. 301-308). Philadelphia: Lippincott – Raven.

Padilla, G.V., Presant, C.A., Grant, M.M., Metter, G., Lipsett, J., & Heide, F. (1983). Quality of life index for patient with cancer. Research in Nursing and Health, 6 , 117-126.

Panawatanakul, S. (1991). Self concept, self-care agency and quality of life in elderly persons. Master's thesis in Science (Nursing), Faculty of Graduate Studies, Mahidol University.

Presant, C.A., Klahr, C., & Hogan, L. (1981). Evaluating quality of life in oncology patients: Pilot observation. Oncology Nursing Forum, 8 (3), 26-30.

Renner, M. J. (1995). Counseling laryngectomees and families. Seminars in Speech and language, 16 (3), 215-220.

Robbins, K.T., Medina, J.E., Wolfe, G.T., Levine, P.A., Sessions, R.B., & Pruet, C.W. (1991). Standardizing neck dissection terminology. Archives of Otolaryngology, 117, 601-605.

Spiegel, J.R., & Sataloff, R.T. (1992). Surgery for carcinoma of the larynx. In W.J. Gould, R.T. Sataloff & J.R. Spiegel, Voice surgery, (pp. 307-337). St.Louis: Mosby.

Spitzer, W.O., et al. (1981). Measuring the quality of life of cancer patients: A concise QL-Index for use by physicians. Journal of Chronic Disease, 34(12), 585.

Spilker, B. (1996). Introduction. In B. Spilker (Ed.), Quality of life and pharmacoeconomies in clinical trials, (2nd ed., pp. 1-9). Philadelphia: Lippincott – Raven.

Takviriyanun, N. (1991). Self care agency and quality of life in head & neck cancer patients while receiving and after the completion of radiotherapy. Master's thesis in Science (Nursing), Faculty of Graduate Studies, Mahidol University.

Tanphaichitr, V. (Ed.). (1995). Annual report. Ramathibodi Cancer Registry, Faculty of Medicine Ramathibodi Hospital, Mahidol University, Bangkok, Thailand.

Terrell, J.E., Nanavati, K.A., Esclamado, R.M., Bishop, J.K., Bradford, C.R., & Wolf G.T. (1997). Head and neck cancer specific quality of life. Archives of Otolaryngological of Head and Neck Surgery, 123, 1125-1132.

Thurston – Hookway, F. & Sedden, S. (1989). Care after laryngectomy. Nursing, 3 (35), 5-8.

Weber, M. & Reimer, M. (1993). Laryngectomy: Grieving disfigurement and dysfunction. The Canadian Nurse, 89 (3), 31 - 34.

Yamvong, C. (1995). Effects of application of Orem's nursing system on patients' and relatives' satisfaction with care and functional outcomes in hospitalized elderly patients. Master's thesis in Nursing Science (Adult Nursing), Faculty of Graduate Studies, Mahidol University.

Young, K.J., & Longman, A.J. (1983). Quality of life and persons with melanoma. Cancer Nursing, 6, 219-225.

APPENDIX

APPENDIX A

Instruments

Part I : Demographic Data Form

Subject number..............

Hospital number.............

Date of interview.............

The following questions are to be completed by the researcher according to the medical records and the information provided by the laryngectomees.

General demographic data

1. Gender ( ) Male
( ) Female

2. Age..............years.

3. Marital status ( ) Single
( ) Married
( ) Widowed / Divorced / Separated

4. Educational background
( ) No formal learning
( ) Primary school or Prathomsuksa
( ) Secondary school or Mattayomsuksa
( ) Certificate / Diploma
( ) Bachelor degree
( ) Master degree
( ) Other ; please identify...........

5. Education (institution attended) ....years.

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13. Have you ever been a member of a self-help laryngectomee's group?

( ) Not a member and never attended a group meeting.

( ) A member and has attended a group meeting:

( ) less than 3 times / year.

( ) over 3 times / year.

<u>Medical information (from medical records)</u>

14. Time duration after total laryngectomy...........months.

15. Staging of cancer (At operation date)

( ) Stage I

( ) Stage II

( ) Stage III

( ) Stage IV

16. Type of treatment

Type of surgery.., Date of surgery...............

17. Concomitant therapy

( ) Radiotherapy Date of start........., Date of completion...........

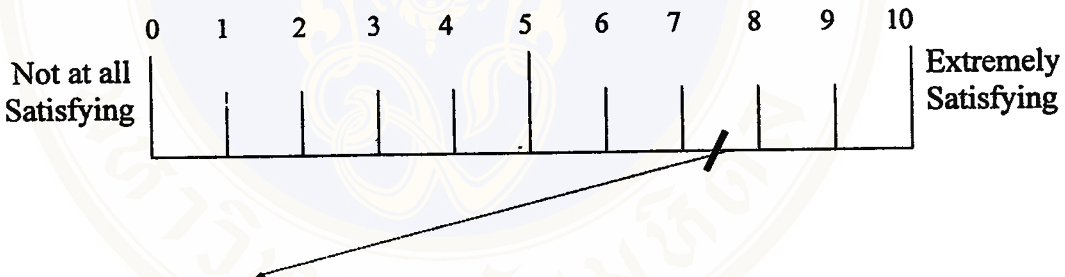
( ) Chemotherapy Date of start........., Date of completion...........

Part II: Quality of Life Questionnaire.

The following questions are about your perceptions or feeling. Please answer the following questions by placing an / on the line that best shows what is happening to you at present (recall 1 week before responding to the questionnaires).

Example:

How satisfying is your quality of life?



The / shows that you feel your satisfaction score 7.5
It is slightly less than extremely satisfying.

Note: Your answers are no right or wrong, it is simply a reflection of your feeling. The best answer is your perception of your present state of well-being.

1. How easy or difficult is it to adjust to your disease and treatment?

	0	1	2	3	4	5	6	7	8	9	10	
Not at all Easy to Adjust												Extremely easy to adjust

2. How much enjoyment are you getting out of life?

	0	1	2	3	4	5	6	7	8	9	10	
No enjoyment at all												Tremendous Enjoyment

3. Do you worry about the cost of your medical care?

	0	1	2	3	4	5	6	7	8	9	10	
Not at all worried												Extremely Worried

4. If you have pain, how distressing is it?

	0	1	2	3	4	5	6	7	8	9	10	
Not at all Distressing												Extremely Distressing

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26. Do you vomit?

0 1 2 3 4 5 6 7 8 9 10

Never Vomit — Vomit All the time

……

29. How satisfied are you with your appearance?

0 1 2 3 4 5 6 7 8 9 10

Completely Dissatisfied — Completely Satisfied

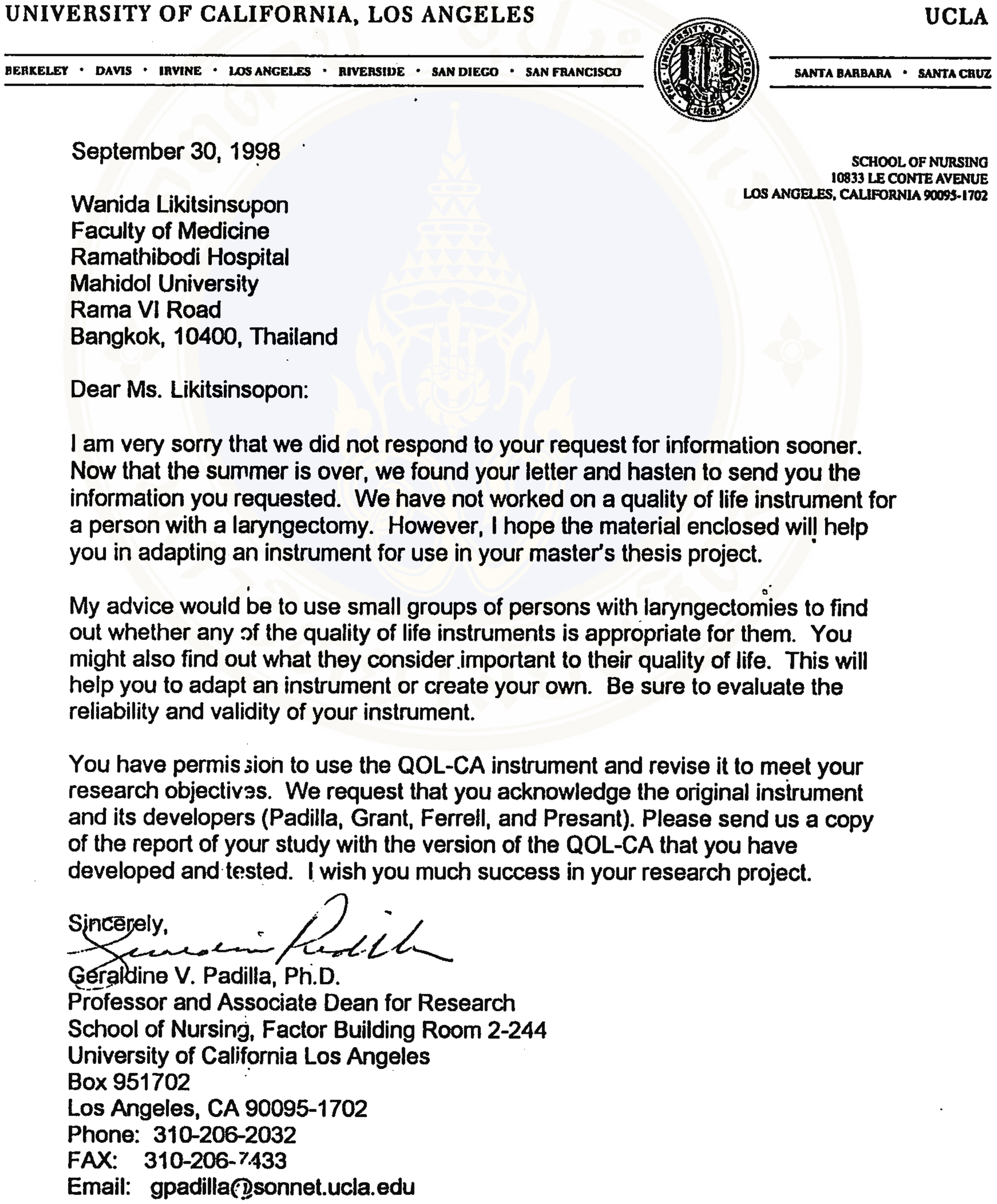
30. Are you worried about unfinished business?

0 1 2 3 4 5 6 7 8 9 10

Not at all worried — Extremely Worried

APPENDIX B

Permission to Use the QOL-CA Instrument



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LOS ANGELES, CALIFORNIA 90095-1702

September 30, 1998

Wanida Likitsinsopon
Faculty of Medicine
Ramathibodi Hospital
Mahidol University
Rama VI Road
Bangkok, 10400, Thailand

Dear Ms. Likitsinsopon:

I am very sorry that we did not respond to your request for information sooner. Now that the summer is over, we found your letter and hasten to send you the information you requested. We have not worked on a quality of life instrument for a person with a laryngectomy. However, I hope the material enclosed will help you in adapting an instrument for use in your master's thesis project.

My advice would be to use small groups of persons with laryngectomies to find out whether any of the quality of life instruments is appropriate for them. You might also find out what they consider important to their quality of life. This will help you to adapt an instrument or create your own. Be sure to evaluate the reliability and validity of your instrument.

You have permission to use the QOL-CA instrument and revise it to meet your research objectives. We request that you acknowledge the original instrument and its developers (Padilla, Grant, Ferrell, and Presant). Please send us a copy of the report of your study with the version of the QOL-CA that you have developed and tested. I wish you much success in your research project.

Sincerely,

Geraldine V. Padilla, Ph.D.
Professor and Associate Dean for Research
School of Nursing, Factor Building Room 2-244
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APPENDIX C

List of Experts Consulted on Validation of the Instruments

Relative to the study's conceptual framework and method of measurement, the content validity of the questionnaires was determined by four consulting experts:

1. Associate Professor Somyos Kunachak M.D.,
   Diplomate Thai Broad of Otolaryngology
   Department of Otolaryngology
   Faculty of Medicine, Ramathibodi Hospital, Mahidol University.
2. Associate Professor Dr. Payom Euswas
   Department of Nursing
   Faculty of Nursing, Thammasart University.
3. Assistant Professor Suchinda Rimsrithong
   Department of Nursing
   Faculty of Medicine, Ramathibodi Hospital, Mahidol University.
4. Miss Suwimol Suntisukthana RN. CNS.
   Department of Nursing
   Faculty of Medicine, Ramathibodi Hospital, Mahidol University.

APPENDIX D

Human Right for Research Population

Verbal explanation to subjects

My name is "Wanida Likitsinsopon", a graduate nursing student, Nursing Department, Faculty of Medicine, Ramathibodi Hospital, Mahidol University. I am currently conducting research study about quality of life of laryngectomee. The research will be beneficial to clarify the quality of life of laryngectomee. However, the research will not be possible without your participation.

If you agree to participate, you will be interviewed and asked to complete demographic data and the questionnaire by me. It will take you about 20 minutes. All of the responses and the information will be kept confidential and used only to present an overall picture.

You can refuse or participate in this research study with no effect on the treatment or care that you receive. If you would not like to participate in this research study, you have the right to withdraw at any time without prejudice. I hope you are able to do me this favor. Thank you very much.

BIOGRAPHY

NAME	Miss Wanida Likitsinsopon
DATE OF BIRTH	24 June 1957
PLACE OF BIRTH	Bangkok, Thailand
INSTITUTION ATTENDED	Mahidol University, 1977 - 1979 Diploma in Nursing and Midwifery Mahidol University, 1979 - 1980 Bachelor of Science (Nursing) Mahidol University, 1997 - 2000 Master of Nursing (Adult Nursing)
POSITION & OFFICE (1980 –Present)	Ramathibodi Hospital, Faculty of Medicine, Mahidol University Position: Nurse 6