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Patients with Advanced Lung Cancer: Quality of Life and Perception of Dyspnea

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UNIVERSITY OF SAN DIEGO
Hahn School Of Nursing And Health Science
DOCTOR OF PHILOSOPHY OF NURSING

PATIENTS WITH ADVANCED LUNG CANCER: QUALITY OF LIFE AND PERCEPTION OF DYSPNEA

By
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DISSERTATION COMMITTEE
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Abstract

Background: Dyspnea perception can be defined as a multidimensional experience of breathing discomfort, influenced by physiological, psychological, social, and environmental factors, that includes secondary psychological and behavioral responses and cannot be defined only by physical objective abnormalities (Mularski et al., 2010). Dyspnea is the most common and distressing symptom in patients with advanced lung cancer and decreases one's quality of life (QOL) (Smith et al., 2001). Furthermore, dyspnea has been found to interfere with physical activities such as walking, work, and psychological activities such as disposition, taking pleasure in life, relationship with others, and sleep (Tanaka, Akechi, Okuyama, Nishiwaki, & Uchitomi, 2002). Thus, it can be hypothesized that quality of life is related to perception of dyspnea in advanced lung cancer patients; although no published reports have examined this relationship in this population.

Objective: The purpose of this study was to examine the relationship between quality of life and perception of dyspnea in a group of advanced lung cancer patients.

Method: This was a descriptive correlational, cross-sectional study. Quality of life was measured using The Assessment of Quality of life at the End of Life (AQEL). Perception of dyspnea was measured using the Cancer Dyspnea Scale (CDS). The participants were 22 patients in a hospice care setting diagnosed with advanced lung cancer that reported dyspnea.

Results: The findings supported the literature review suggestions that there was indeed relationship between the subscales, AQEL, and CDS measurement total scores. In the sample of advanced lung cancer patients in the hospice care setting, results revealed the

AQEL subscales (basic function, activity, cognitive function an perception of care) had a significant correlation to the AQEL total score. In addition, the physical symptoms (pain and bowel movement) indicated a strong inverse relationship to the AQEL total score. As indicated by prior research, analysis revealed the CDS subscales (discomfort, anxiety, and sense of effort) had a strong significant relationship to the CDS total score. Furthermore, it is important to note that the result geared toward the second aim of this research study, indicated no significant relationships between the participants demographics, AQEL total score, and CDS total score.

Implications: Increased knowledge of the relationship between quality of life and perception of dyspnea in advanced lung cancer patients can provide a basis for the development of more refined assessment tools, enhanced symptom management, and overall improvement of the care of advanced stage lung cancer patients.

Conclusions: Precipitants of dyspnea included both physical and emotional sensations triggered by immediate reactions connected to participants' experience of dyspnea perception amongst advanced lung cancer patients in the hospice setting.

Dedication

Blessed with unconditional love from my family and friends, I am honored and privileged to dedicate my journey to the following people who have shared my life.

My Sister who inspired me to become a nurse and a nurse educator.

My Brother for always being supportive of my education and success.

My Mother for her struggle who made me the way I am.

My nephews Chris, Brandon and Isaiah, I hope to set a good example for all of you.

Bill Nelson who for the past 18 years never failed to love, care, and support me.

Because of you my life has changed. I will always tell the world that it's because of you!

What a great journey it has been. I love you all!

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My Statistician Susan Collins, thank you for your knowledge and expertise. You have made SPSS fun and enjoyable. I'm very grateful for all your help!

LIST OF TABLES AND FIGURE

Page

List of Figure

List of Tables

TABLE OF CONTENTS

Page

Chapter I Introduction

Chapter II Literature Review

Chapter III Methodology

Page

Page

CHAPTER I

Statement of Problem and Rationale

Dyspnea is a common and distressing symptom in patients with lung cancer and it decreases quality of life (QOL) (Smith et al., 2001). It has been acknowledged that this symptom experience consists of several components such as intensity, frequency, duration, affective impact, and the threat that is posed by this symptom (Dodd et al., 2001). Dyspnea perception can be defined as a subjective, multidimensional experience of breathing discomfort, influenced by physiological, psychological, social, and environmental factors that includes secondary psychological and behavioral responses and cannot be defined only by physical objective abnormalities (Mularski et al., 2010).

For lung cancer patients, living with an incurable disease means having to face the idea of dying (Kahana, 2000). Feelings of loneliness and concern for those near and dear influence the psychological impact experienced by lung cancer patients. Anxiety and tension have a documented relationship with dyspnea exacerbation (Henoch, Bergman, Gustafsson, Gaston-Johansson, & Danielson, 2007). Therefore, intensifying emotional reactions to dyspnea, creates an unpleasant or troublesome feeling and causes stress, creating worry and anxiety (Henoch et al., 2007). To the lung cancer patient, dyspnea is a constant reminder of how serious the consequences of being stricken by a life threatening disease are. Therefore, the psychological impact of both the dyspnea and this disease creates a state of vigilance that instills a negative influence on concentration resulting in the sufferer being restless, fearful, and physically weak (Henoch et al., 2007).

Background and Significance

Lung cancer is a significant public health concern because it is the second most diagnosed cancer and the number one cause of death among men and women in the United States, accounting for more deaths each year than breast, prostate, and colon cancers combined. It is estimated that 228,190 new cases will be diagnosed in the United States in 2013; 118,080 among men and 110,110 among women. There will be an estimated 159,480 deaths from lung cancer; 87,260 men and 72,220 women, accounting for around 27% of all cancer deaths (American Cancer Society, 2013). Patients with advanced lung cancer perceive physical symptoms as weakness and fatigue caused by dyspnea, with much awareness of lost strength (Henoch et al., 2007). McCorkle and Young (1978) defined symptom distress as the degree of discomfort reported by patients in relation to his/her perception of the symptom being experienced. Dyspnea limits activities and produces social isolation (Roberts, Thorne, & Pearson, 1993). Physiological impacts such as difficulty in breathing cause distress even in times of relatively low occurrence. Patients perceive breathing as a symbol of life, with dyspnea perceived as physically threatening, the feeling of inability to breathe creates an overwhelming sensation that paralyzes one's will to live. The physical aspect of this symptom creates distress, a concept denoting physical implications beyond the current moment (Tishelman et al., 2005).

It is well known that lung cancer is a leading cause of mortality and morbidity in industrialized countries and potentially one of the most preventable cancers. The major cause of this neoplasm is cigarette smoking. The U.S. government has made a concerted effort to decrease tobacco use by passing legislative regulation and promoting educational efforts that resulted in significant reductions in the number of smokers, decreasing the percentage of individuals who initiate the smoking habit, and increasing the number of people who quit. Nevertheless, there is a wide recognition of the need to address the issue of lung cancer prevention for those who are addicted to cigarettes or who are exposed to lung carcinogens in other ways (Schachter & Neuman, 2007).

Lung cancer is a severe disease and has a limited survival rate (Henoch et al., 2007). The most common symptom of dyspnea is caused by the underlying disease that is usually the cancer tumor (Pan, 2003). The significance of this problem lies within the complications and disease progression of lung cancer. As dyspnea creates a sensation of uncomfortable awareness of breathing, it creates a frightening distressing experience in patients with lung cancer (Pan, Morrison, Leipzig, Ness, & Fugh-Verman, 2000). Physiologic measures such as pulmonary function tests and blood oxygen saturation levels, do not necessarily correlate with the degree of dyspnea the individual is experiencing (Bruera et al., 2003). Recently, the development of instruments that measure the perception of dyspnea across such domains as sense of effort, anxiety, and discomfort have provided researchers with a new means of assessing the individual's perception of dyspnea (Tanaka et al., 2000).

Since dyspnea is a subjective experience of difficult or uncomfortable breathing (Kvale, Selecky, & Prakash, 2007), it is intuitive to conceptualize dyspnea as a complex symptom in relationship to quality of life, including the physiological, psychological, and social components of quality of life. Thus, it can be hypothesized that quality of life is related to perception of dyspnea in advanced lung cancer patients, although no published reports have examined this relationship in this population. This study was undertaken to explore the relationship between quality of life and perception of dyspnea in a group of advanced lung cancer patients in a hospice setting.

Statement of Purpose

This study was proposed to help fill the gap in knowledge regarding quality of life and dyspnea perception in the advanced lung cancer population. The overall purpose of this study was to examine the relationship between quality of life and perception of dyspnea in a group of advanced lung cancer patients.

The specific aims of this study were to:

1) Describe relevant demographic variables (age, race/ethnicity, educational level, relationship status, income level), levels of quality of life, including its subscale components (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care), and levels of dyspnea perception, including its subscale components (sense of effort, anxiety, discomfort).

2) Examine the relationship between relevant demographic variables, overall level of quality of life, and overall level of dyspnea perception.

3) Examine the relationships between relevant demographic variables, the subscale components of quality of life (basic function, activity, emotional function, cognitive function, social support, existential needs, and perception of care) and the subscale components of dyspnea perception (sense of effort, anxiety, and discomfort).

These specific aims addressed the following research questions in a group of advanced cancer patients in a hospice setting:

1) What are relevant demographic variables (age, race/ethnicity, educational level, relationship status, income level), levels of quality of life, including its subscale

components (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care), and levels of dyspnea perception, including its subscale components (sense of effort, anxiety, discomfort)?

2) What are the relationships between relevant demographic variables, overall level of quality of life, and overall level of dyspnea perception?

3) What are the relationships between relevant demographic variables, the subscale components of quality of life (basic function, activity, emotional function, cognitive function, social support, existential needs, and perception of care) and the subscale components of dyspnea perception (sense of effort, anxiety, and discomfort)?

Conceptual Model

The theory of unpleasant symptoms (TOUS) is a middle-range theory that includes elements believed to address the symptom experience and allows focus on either multiple symptoms occurring together or a single symptom (Peterson & Bredow, 2013). This theory consists of three major components: (1) physiological factors, (2) psychological factors, and (3) situational factors, understood as the antecedents of the symptom experience. Dyspnea as a symptom is the perceived indicator of change in normal functioning as experienced by patients with advanced lung cancer. The TOUS signifies the physiological factors, psychological factors, and situational factors that influence the dyspnea symptoms, which can impact one's perception of dyspnea in relationship to the performance factors. The physical stress that dyspnea precipitates in the human body, may occur at rest or with excursion. The feeling of shortness of breath, tightness of the chest, inability to get air, or feeling of suffocation affects the patients' survival factors in managing these symptoms (Dudgeon, Lertzman, & Askew, 2001).

Kamal, Maguire, Wheeler, Currow, and Abernethy (2011) indicated in their study the relationship between physical symptoms of dyspnea and anxiety, particularly panic attacks, is well documented. The associations between physiological, psychological, situational, and performance factors in the advanced lung cancer population requires much further study and elucidation, given the high prevalence of anxiety during end of life care (Kamal, Maguire, Wheeler, Currow, & Abernethy 2011).

The Theory of Unpleasant Symptoms (TOUS) implies management of the symptom will contribute to the management of other symptoms because patients with advanced lung cancer do not experience dyspnea in isolation, but rather in conjunction with other symptoms, concomitant stressors, and psychological existential distress; dyspnea cannot be fully addressed unless these physical and nonphysical factors are understood (Kamal, Maguire, Wheeler, Currow, & Abernethy 2011). Success is most likely when, as many as possible of the patient's individual dyspnea stressors and associative symptoms (anxiety, depression, panic attacks) are identified and addressed. This theory stresses symptoms may occur alone or together but when there are multiple symptoms they often are not in synchrony (Lenz, Suppe, Gift, Pugh, & Milligan, 1995). Thus, the TOUS is appropriate in guiding the proposed study of quality of life and perception of dyspnea in a group of advanced cancer patients, as it provides a multidimensional framework that includes physiological, psychological, and situational factors that impact performance factors.

Conceptual Model

Figure 1 The principles of Theory of Unpleasant Symptoms (TOUS) (Lenz et al., 1995).

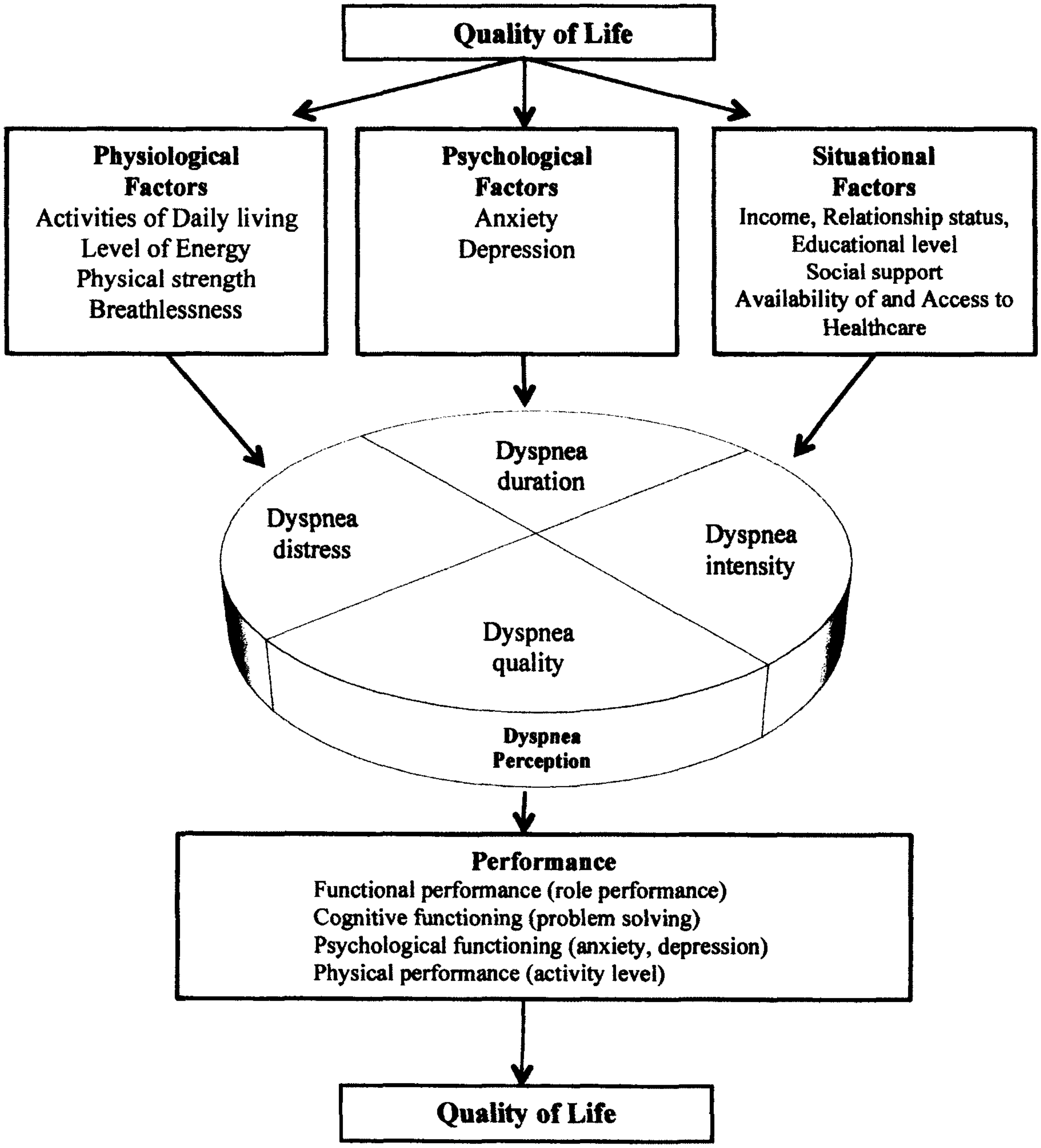

Figure 1. Middle-Range Theory of Unpleasant Symptoms

Note. Adapted From “Collaborative Development of Middle-Range Nursing Theories: Toward a Theory of Unpleasant Symptoms,” by E.R. Lenz, F. Suppe, A.G. Gift, L.C. Pugh, and R.A. Milligan 1995, *Advances in Nursing Science, 17(3),* p. 10. Copyright 1995 by Lippincott Williams and Wilkins.

Theoretical Definitions

Dyspnea. The term dyspnea, has been defined by Merriam-Webster Collegiate Dictionary (1993) as short of breath, difficult or labored respiration. As a word, it is derived from ancient Greek; “dys” meaning disordered or abnormal and “pnoia” means breath. Steadman’s Medical Dictionary for the Health and Professions and Nursing (2012), defined dyspnea as shortness of breath, a subjective difficulty or distress in breathing, usually associated with disease of the heart or lungs; occurs normally during intense physical exertion or at high altitude. Current literature defines dyspnea as a subjective, multidimensional experience of breathing discomfort, influenced by physiological, psychological, social, and environmental factors, which includes secondary psychological and behavioral responses and cannot be defined only by physical objective abnormalities (Mularski et al., 2010). The American Thoracic Society (1999) uses broad definition factors and states dyspnea is a subjective experience of breathing discomfort that consist of qualitative distinct sensations that vary in intensity. The sensation of dyspnea is a subjective phenomenon with physical, psychological, social, and spiritual existential contributors. Therefore, there is no objective method for measuring this phenomenon, much like pain; it is captured by patients' report (Thomas, 2009).

Existing theory and studies of dyspnea as a symptom in the lung cancer population had defined key attributes of dyspnea as frequency, intensity, and duration. The quantification of dyspnea can be an important judgment in the severity and prognosis in lung cancer patients. It can also lead to a limiting symptom that may be responsible for the economic and social disabilities (Bass, 1990). Brown et al. (1986) found the descriptions most frequently used by patients with lung cancer were difficulty breathing, shortness of breath, air hunger, shallow respiration, and suffocation. Notably, 97% of patients describe the chest as the location of their sensation, as well as an emotional feeling accompanied by the sensation of anger, anxiety, and fear (Brown et al., 1986). According to Rhodes and McDaniel (1999), the meaning people assign to physical sensation of dyspnea may have profound implications for their physical and psychological health and therefore, their QOL decreases. Roberts, Thorne, and Pearson (1993) found although dyspnea seems to be a significant symptom in advanced lung cancer patients it often remains unmanaged by healthcare professionals.

Dyspnea is considered a most distressing symptom that can be attributed by ascribing a positive and negative perspective on the symptom experience. How patients perceive the impact of dyspnea on their daily lives can lead to situational meaning that maybe triggered by inability to perform activities of daily living as a result of dyspneic episodes (Armstrong, 2003). Existential meaning may incorporate the patient's sense of vulnerability and mortality as a result reminding them of their cancer diagnosis. Therefore, the concept of dyspnea experience within the core of advanced lung cancer patients may include attributes of dyspnea occurrence and distress as not only the physiological, psychological, and environmental, but also the situational existential meaning or perception of individual suffering from dyspnea experience.

Perception. The term perception is defined as the process of attaining awareness or understanding of sensory information Wikipedia (2008). The New Thesaurus defines it as awareness, cognizance, consciousness, sense, concept, conception, idea, image, notion, and thought (1995). In a concept analysis of this term, McDonald (2011), concludes that perception is an individual landscape that could be a driving force for an action on one's view of processed information relating to past experience that creates vision of the world looking through a filter of influences from sociocultural aspect of humanity. Perception is never objective. It is an individual's or group's unique way of viewing a phenomenon that involves the processing of stimuli and incorporates memories and experiences in the process of understanding McDonald (2011). For the purpose of this research study, dyspnea perception and QOL was explored to find the relationship that describes awareness of the unique experiences of dyspnea symptoms as an individual component of one's perception that culminates comprehension of physiological, psychological, and situational factors in advanced lung cancer patients.

Hui et al. (2013) examined the association among subjective rating of dyspnea according to patients with advanced cancer, caregivers, nurses, and various physiologic measures. The Edmonton Symptom Assessment Scale (ESAS) rating, causes of dyspnea, vitals, and Respiratory Distress Observation Scale (RDOS) ratings were utilized using a numeric rating scale (0=none, 10=worst). This study found patients' expression of dyspnea was strongly associated with caregivers' assessment and patients' own ESAS dyspnea level. Findings from this study are consistent with the definition put forth by the

American Thoracic Society, in which dyspnea is defined as "subjective experienced of breathing discomfort that consist of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social and environmental factors, and may induce secondary physiological and behavioral response" (Parshall et al., 2012). Therefore, lack of correlation between dyspnea and physiologic measures in this study put forth further research to better characterize the major predictors of subjective dyspnea in relationship to qualitative distinct perception of dyspnea in advanced lung cancer population in determining factors that contributes to the overall dyspnea expression (Hui et al., 2013)

Quality of Life (QOL). The term "quality of life" often is used interchangeably with terms that have conceptually similar meanings, such as life satisfaction, well-being, functional status, or happiness (Hass, 1999). In an analysis of this term, Hass (1999) postulated life satisfaction, well-being, and happiness were subjective terms referring solely to the achievement of an individual goal, while functional status is related to externally evaluated performance task (McDaniel & Bach, 1994). Therefore, while each of these terms could constitute a component of QOL, they do not fully explain or define QOL in its entirety (Taylor, Gibson, & Franck, 2008). The key concept of QOL is difficult to define, and currently no universally accepted definition exists in the health care literature. Many authors agree on the subjective nature of global QOL which includes multiple dimensions of the human experience. Thus, QOL is a multifaceted phenomenon and has been conceptualized to include physical, psychological, social, and spiritual dimensions (Hass, 1999; Stewart et al., 1999). The World Health Organization (1997) provides a multi-dimensional definition that defines QOL as an individual's perception of their position in life in the context of the culture and value systems in which they live, in relation to their goal, expectations, standards, and concerns. For the purposes of this study, the WHO definition of QOL as a broad-ranging definition concept is used. Congruently, an underlying assumption of this study is QOL is affected in a complex way by the person's physical health, psychological state, and level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment.

A longitudinal study of patients with advanced cancer (about 33% with lung cancer) found symptom distress, functional status, and QOL began to decrease six months prior to death and markedly decreased about two to three months prior to death. As patients' symptom distress increases, QOL decreases (Hwang, Chang, Fairclough, Cogswell, & Kasimis, 2003). Patients with advanced lung cancer may be near the end of life while receiving treatment or even on initial diagnosis. Although more men and women in the United States die of lung cancer each year from breast, colon, and prostate cancers combined (American Cancer Society 2010), limited research has been conducted in this population, particularly when the cancer is advanced. QOL has been studied less often in patients with lung cancer than in any other cancer populations, but research available found patients with advanced lung cancer typically have a lower QOL than patients with other types of cancer (Montazere, Gilis, & McEwan, 1998). Many studies with patients with advanced lung cancer are clinical trials that focus on treatment effectiveness and prediction of survival (Hermann & Looney, 2011). Although attention to QOL in clinical trials has increased, little documentation of QOL assessment and analysis exists in the health care literature (Tanvetyanon, Soares, Djulbegovic, Jacobsen,

& Bepler, 2007), and high attrition (Bottomley, Efficace, Thomas, Vanvoorden, & Ahmedzai, 2003). In addition, QOL often has been viewed in previous studies in a narrow fashion and mostly as a secondary endpoint (Dooms & Vansteenkiste, 2004). Thus, this study was designed to decrease the gap in knowledge regarding the sub-components of QOL and its relationship to perceived dyspnea.

CHAPTER II

Literature Review

Physiological Factors

A study by Gupta, Braun, and Staren (2012) indicated QOL predictor improves global health and physical function correlating with better survival. The first of two key findings includes patient's physical function and global health at baseline. It provided prognostic information for survival after adjusting for the effects of age, gender, treatment history, and tumor stage. The second key finding was an improvement in physical function at three months in stage IV non-small cell lung cancer patient had a potential indicator of improved patient survival. This finding suggested QOL monitoring, coupled with treatment to improve global health and physical function when indicated, should be investigated in prospective studies in non-small cell lung cancer. Although some progress has been made with respect to the treatment of physical function in cancer patients, clinical effectiveness remains inconsistent and unpredictable. Furthermore, interventions aimed at improving physical functioning would be validated if interventions enhance specific QOL. This challenges the cancer research enterprise to develop greater understanding of the complex physiology responsible for all aspects of QOL, and to use this information to develop more effective and predictable methods to favorably modulate this critical aspect of patient health and wellness. As the consequences of this study, physical function and global health are independent determinants of survival in non-small cell lung cancer and should be regularly assessed and when indicated should be targeted for intervention (Gupta, Braun, & Staren, 2012).

Cai, Zhou, Yu, and Wan (2011) explored the level and predictors of the health-related QOL among patients who were newly diagnosed with lung cancer in China. A descriptive survey was used to collect data from 108 patients. Their finding indicated poor QOL in physical, psychological, social, and environmental domains utilizing the World Health Organization Quality of Life Questionnaire (WHOQOL-BREF). This might be related to the fact the patients were informed about their cancer diagnoses and that in China, cancer often still is considered to be equivalent of a death sentence. Future research in this study population should be directed towards investigating interventions that are developed in response to physiological QOL issues. Such information could advance the quality of healthcare, therefore could provide further direction regarding improvement of psychophysical in relevant to QOL outcomes of patients with lung cancer. Finally, it is important that further study should be conducted to fill the gap of the importance of useful characteristic that healthcare providers must possess in order to improve positive role in recognizing patients health and well-being (Cai, Zhou, Yu, & Wan, 2011).

A perspective study of patients diagnosed with lung cancer who were treated at home and at palliative care unit conducted by Leppert et al. (2011), examined the QOL evaluation and the seriousness of lung cancer is associated metastasis and high occurrence due to pollution, cigarette smoking, genetic factors, and poor prognosis. The core questionnaires European Organization Research Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) along with the lung module EORTC QLQ-LC13 were used for the QOL assessment. From the 78 patients recruited, 58 completed the study: 12 patients general condition significantly deteriorated, 8 died, and 5 had brain metastasis. Findings indicated lung cancer QOL is very important, especially in the advanced stage of the disease when cure is not possible and patients had multiple symptoms. For the majority of respondents, the EORTC QLQ-C30 symptom scale deterioration was reported. This study had numerous limitations including cross-sectional design and small sample size. The necessity of effective communication and the ability to fulfill the questionnaires and the exclusion of patients with cognitive impairment and brain metastasis were additional limitations. It seems early palliative care introduction, effective symptom management, especially pain, dyspnea, fatigue, loss of appetite, and constipation with psychosocial and spiritual support may significantly improve the quality of life in patients with advanced lung cancer (Leppert et al., 2011).

Moore et al. (2002) assessed the effectiveness of nurse led follow up in the management of patients with lung cancer. To measure their outcomes EORTC core questionnaire about QOL were used. Findings of this study indicated follow up of patients with lung cancer by clinical specialists is safe, acceptable, and cost effective. Hence can lead to greater patient satisfaction and more appropriate and timely interventions at the same or no greater cost, with no detriment to QOL. Notably, nurse led follow up reduced the number of routine investigations and the burden on outpatient resources and doctor's time (Moore et al., 2002). The importance of this study and management of patients with lung cancer is patients who receive interventions had less severe episode of dyspnea, had better outcomes, and emotional functioning that leads to overall improvement in patient's QOL. The implications of this study in the scope of nursing practice and knowledge include the finding a nurse-led follow up enhanced care across primary, secondary, and tertiary sectors reduces the burden on patients and acute services. Healthcare providers' satisfaction increased and the use of nurse led model of care in this study led to an advantage of increased QOL for the patient and their loved ones. Rather than going back and forth to the hospital, the patient has the comfort of knowing he/she is being taken care of in his/her own safety net, which is his/her home (Moore et al., 2002). Perhaps Moore et al. (2002) noted, replication at other centers in the United Kingdom, with a range of nurse specialists and outside the context of a research study is essential to support generalizable findings. The rate of attrition was high because of death or disability, which attributed to difficulties with recruitment and attrition are recognized problems of research studies conducted with very ill and dying patients. The number of outcomes analyzed in this study would imply that some findings might have occurred by chance. The primary outcome was assessed at three months; the results from patients investigated at six and 12 months should be interpreted with caution. The proposed study is designed to build upon to expand and enhance understanding of the relationship between dyspnea and QOL in a group of lung cancer patients receiving palliative care services.

Tishelman et al. (2007) conducted a study that examined symptom prevalence, intensity, and association with distress in patients with advanced lung cancer (Tishelman, Peterson, Degner, & Spragers, 2007). Their findings indicated breathing, pain, and fatigue ranked as symptoms associated with most distress. Measurement assessments used in this study were the European Organization for Research and Treatment of Cancer QOL Questionnaire C30 (EORTC QLQ-C30), EORTC-LC13, and Thurston Scale of

Symptom Distress (TSSD-LL). Authors found an association between the problem of dyspnea and distress and argue there is a need for evidence-based palliative care to support patients' QOL (Sepulveda, Marlin, Yoshida, & Ullrich, 2002). Clearly, the results in this study demonstrated it is likely the meaning attached to problems with dyspnea for patients with advanced lung cancer may be an important factor influencing their strong association with distress (Tishelman et al., 2007). These findings raised the question as to whether the patients' fears and anxiety about future symptom experiences may be of clinical concern especially in situations in which better knowledge of and access to palliative care may diminish unnecessary apprehension and suffering. Zabora, Brintezenhofeszoc, Curbow, Hooker, and Paintadosi (2001) found patients with advanced lung cancer to be at particular risk for psychological distress compared with other cancer patient groups. The study that was conducted population raises awareness of the importance of managing dyspnea as a distress symptom that further emphasized a need to understand suffering as related to individual prioritization of QOL.

Psychological Factors

According to Henoch et al. (2008), patients' experience of dyspnea included triggering factors, bodily manifestation, immediate, and long-term reaction. Their study indicated dyspnea can seldom be avoided and the trigger effects of this symptom among patients, but the immediate reactions cannot, they are unconditional due to symptom exacerbation on the basis of patient's own perception. Their study provided an opportunity to allow the patients to express the true meaning of breathlessness, their disease progression, and what it means to live in a future where existential impact of hope, hopelessness, and thoughts of death arises. This awareness resulted in the development of some strategies for managing dyspnea specifically the bodily strategies of avoided bodily exertion, which they knew would provoke dyspnea (Henoch, Bergman, & Danielson, 2008). The result of this study highlights the patients' need of support and acknowledgement of their worries about the future, which quite possibly can only occur in the care model where there is a partnership with reciprocity and mutual inquiry between a patient and a health care professional (Krishnasamy, Corner, Brendin, Plant, & Bailey, 2001). However, Henoch et al.'s (2008) sample was small when comparing dyspnea experience and strategies used, there were bodily, psychological, and existential experiences but only bodily, including medical, psychological strategies. Consequently, the existential impact was not met by any strategies by the patients. This discrepancy needs to be acknowledged by healthcare professionals and could be addressed with planned group sessions about life changes, QOL, and existential issues.

Teunissen, de Graeff, and Voest (2007) analyzed the relationship between anxiety, depressed mood, and the presence and intensity of physical symptoms in 79 hospitalized patients diagnosed with advanced cancer. This study compared different methods to measure anxiety and depressed mood on symptom presence and intensity. The scale used for this study was the Hospital Anxiety and Depression Scale (HADS), which is a simple, sensitive, and specific screening tool for psychiatric disorders in hospitalized patients avoiding the inclusion of somatic symptoms. Results indicated in a sample of terminally ill hospitalized cancer patients, it found high levels of anxiety and depressed mood but no relationship with the presence of physical symptoms and only a limited relationship with symptom intensity. This finding could have been due to the course of illness trajectory and it is possible relationship between anxiety, depressed mood, and physical symptoms existed during the early stage of the disease. Further study should be implemented to create a systemic screening for anxiety and depressed mood in relationship to physical symptoms that is clinically relevant in advanced cancer patients admitted for symptom control (Teunissen, de Graeff, & Voest, 2007).

Tanaka et al. (2002) studied the relationship between dyspnea and psychological effects in advanced lung cancer patients. Their findings indicated dyspnea in advanced lung cancer patients was significantly correlated with psychological distress, presence of organic causes, cough, and pain. When such high prevalence of 55% considered to have clinical dyspnea, it is in the interest of patients not to overlook psychological distress, to detect it early, and to emphasize therapeutically appropriate interventions. The intervention presented in the study was the appropriate use of assessments such as Cancer Dyspnea Scale (CDS) and Hospital Anxiety and Depression Scale (HADS). In using these assessments, healthcare providers can have a better understanding of the nature of dyspnea. According to the study, management of dyspnea in advanced lung cancer patients should be determined based upon the findings of this study that incorporates interventions for the management of pain and psychological distress. This includes psychotropic and psychological interventions for instance relaxation, which has been reported to be effective in relieving dyspnea (Tanaka, Akechi, Okuyama, Nishiwaki, & Uchitomi, 2002). This intervention can be applied to nursing practice to enhance the care of both physiological, as well as psychological well being. However, several limitations of Tanaka et al. (2002) study must be acknowledged including a cross-sectional design, precluding the assessment of cause and effect, and the participants were ambulatory outpatients; the results of this study may not apply to more severe dyspnea. The causal relationships between pain, psychological distress, and dyspnea need to be further examined. A prospective study is needed to examine whether management of pain and psychological distress, including psychotropic and psychological intervention such as relaxation, which have been reported to be effective in relieving depression and anxiety, is effective in relieving dyspnea. At this point, there are no current studies conducted since the 2002 Tanaka study. The proposed study will examine the relationship between dyspnea perception and QOL in a deeper manner.

Another study by Henoch et al. (2007) emphasized the impact of QOL in relationship to symptoms, coping capacity, and social support in patients with lung cancer. Their study clearly focused on the importance of symptom management, QOL, and healthcare professional endeavors concerning this patient population. Baseline measures used for this study were the Sense of Coherence Questionnaire (SOC), the Medial Outcomes Study Social Support Survey (SSS), Assessment of QOL, and the End of Life (AQEL), CDS, HAD, and the VAS to measure dyspnea intensity (VAS-D). Findings indicated QOL and dyspnea deteriorated over time in patients with incurable lung cancer. Significant deterioration was confined to sense of discomfort not only from physical impairment, but also from psychological, social, and existential distress (Henoch et al., 2007). Healthcare professionals should pay particular attention to this aspect of dyspnea. Nursing practice should emphasize the importance of a multidimensional approach to QOL assessment, as indicated in the conceptual definition and in research in palliative care. This study reports using assessments such as AQEL, CDS, and HAD helps healthcare practitioners identify the importance of dyspnea in relationship with emotional functioning and aspect of coping capacity as an explanatory factor for the QOL experience in a palliative setting (Henoch et al., 2007). However, the limitation of this study is 30% of the medically eligible patients declined to participate. Another problem is patient attrition due to disease progression and death decreases the power of the statistical analyses over time. Further studies are warranted to investigate the importance of dyspnea and its components in terminally ill patients. It is encouraging to note that coping capacity has a mitigating function and could be used in the design of interventions to enhance QOL at the end of life.

Situational Factors

Situational factors included aspects of the social and physical environment that may affect the individual's experience and reporting of dyspnea symptom. Potentially relevant social situational considerations include employment status, marital and family status, social support, availability of and access to health care resources, and lifestyle behaviors (Winningham, et al., 1994). The demographic tool utilized in this proposed study encompasses the component of variables affecting situational factors. John (2010) describes self-efficacy strategies used by lung cancer patients in relationship to the QOL using a phenomenological approach. This qualitative study used a one-on-one semi-structured interview in assessing QOL and self-care strategies. Findings indicated family and social support, functional independence, physical well-being, and spirituality is a significant aspect of QOL. Perception of QOL is a highly individual experience that documents the negative effects of fatigue on QOL during and after treatment for lung cancer. Many of these strategies focus on managing the fatigue that has such a pervasive negative effect on QOL; however, these strategies often are ineffective. Several limitations exist in this study, for most being the small sample size, varying length of time since diagnosis, and treatment for lung cancer. These patients should be advised about evidence-based strategies that might be more effective to manage symptoms and improve their QOL, and these strategies should be tailored to fit the specific needs and condition of the individual. Additional research also is needed about the roles of social support and spirituality and promoting QOL.

Peterson and Ritz (2010) explored the interaction of self-awareness with fearful beliefs about bodily sensation in relationship to increased attention towards self-leads to move on-line processing of sensory information. Thirty participants were recruited which included 11 males without any chronic respiratory disease or acute respiratory problem. Participants completed two appointments in which attention were directed either towards self or towards others. The Anxiety Sensitivity Index (ASI) was used as the instrument to measure fear of bodily sensation and Hospital Anxiety and Depression Scale (HADS) was used as the instrument to measure anxious and depressive mood. Both instruments were utilized referring to any physical sensation to assess whether negative mood or negative affect of specific body sensation would be more likely to influence the effect of self-awareness on sensation ratings.

Findings conclude that self-awareness is a determinant of which self-related information is greatly noticed. However, in a situation in which more and stronger sensations are expected, such as in a laboratory setting or in daily life during exercise and stress, over report was likely to occur than in situations, which has been labeled with no bodily symptoms which are not expected. The authors also conclude that in such "safe" situations, decision under external focus relied more on conservative strategies that led to underreport. In addition, the awareness of what other thinks about self might be related to over-report or under report of sensations depending on salient implicit and explicit social norms related to symptom report. It is clear that further emphasis and research in this study should focus on one's perception of self-awareness guided by external and internal cues relative to individuals own cognitive factors, beliefs, and ways of coping in relationship to certain situational factors that exacerbate breathing related sensations which affects levels of self-awareness towards fearful belief about bodily sensations guided by own individual perception (Petersen & Ritz, 2010).

Bachner and Carmel (2009) conducted a study assessing caregivers' perceived level of open communications about illness and death with their terminally ill relative and examined the contribution of caregivers and situational variables to the explanation of open communication. A total of 236 primary caregivers of terminal cancer patients participated in this study. Communication was measured by 6 items into 1 factor, which were composed of demographic variables, personality traits, and negative emotional reactions to caregiving. The situational variables, included the duration and intensity of caregiving, and perceived functioning and suffering of the patient. Structured questionnaire was developed by the author based on the openness to discuss cancer in the Nuclear Family Scale (Mesters et al., 1997). The questionnaire respectively elicited the perceptions and feeling of caregivers regarding their interpersonal communication with patients about both illness and approaching death during terminal stage as defined by the last 3 months of the patient's life. Sense of Coherence (SOC) also used to measure three dimensions in which an individual sees the world as comprehensible, manageable, and meaningful.

Findings from this study indicated that caregivers rated their level of open communication with patients about illness and death with a low rating. This result showed that difficulties in communicating with their loved one's about the illness and death were avoided due to emotional burden attached by discussing death and illness. One of the rationales could have been to protect patients to prevent further discomfort and for caregivers to protect themselves from own fear of cancer diagnosis and death. However, it is important to note that caregivers who have rated themselves with higher self-efficacy have a tendency to be more communicative and open about the topic of death and illness. Also, duration of caregiving was found to be a significant predictor to open communications. Limitations discussed in this study include bias based on caregiver's grief experience as well as the death trajectory of the illness and the nature of the cancer in which the patient died. The more caregivers are aware and involved in patient's death it becomes easier for them to discuss the dying process of their love one's. Further research should be explored to examine the association between caregivers' characteristic and their level of open communication with patients. Special attention should also be geared in assessing caregivers' reaction to exhaustion and depression. In doing so, deepening understanding of the mechanism behind these associations can generate positive outcome in relationship to situational factors that affect the well being of caregivers as well as patients (Bachner & Carmel, 2009).

Henoch, Axelsson, and Bergman (2010) conducted a study to further validate the Assessment of the Quality of Life at the End of Life (AQEL) instrument compared to the other widely used and validated Health Related Quality of Life (HRQL) instrument. One hundred six patients with lung cancer receiving palliative care services in a Swedish

Pulmonary Oncology Department completed the 20-item AQEL, the EORTC QLQ-C30, Hospital Anxiety and Depression Scale (HADS), Sense of Coherence (SOC13), and Social Support Survey (SSS). Findings indicated preliminary evidence of the validity of the HRQL included the existential items. The scales were supported by multitrait scaling such as basic function, activity, emotional function, cognitive function, and existential needs. A social support scale was supported by principal component analysis that resulted in a low internal consistency. This study concluded there was some evidence for the validity of the AQEL, and its use was feasible with patients with cancer in palliative care. However, additional work is needed to understand structure of the measure, as well as its responsiveness to palliative intervention and clinical change in populations of patients with cancer close to the end of their lives (Henoch, Axelsson, & Bergman, 2010). Therefore, testing the feasibility and reliability of AQEL instrument in my chosen population may be beneficial for the management of symptoms and maintenance of quality of life in an individual's life circumstances.

A study on the force of circumstances and impact of situational features and personal characteristic on coping patterns across situations by De Ridder and Kerssens (2003) quantified situational impacts in comparison to the impact of one's personal characteristics on the basis of symptom perception. There were 403 healthy participants recruited to elicit coping response. Personal characteristics such as mental health, self-esteem, perceived social support, and dispositional coping style were assessed to identify the situational features and personal characteristics that were responsible for situation-related variance and person-related variance. Participants were given 20 brief evocative descriptions of stressful situations depicting daily hassles that were systematically varied according to the situational features such as ambiguity, social context, and concern at stake (De Ridder & Kerssens, 2003).

Results indicated that all three situational features proved to be significant contributors that differentiate situation-specific coping patterns. This study assumed that coping, as concerns, are considered to motivate coping by creating action-preparedness while ambiguity and social context limits the possibility of options that can be applied in a particular situation. It is clear that the role of situational features as relevant determinants of coping response in a stressful situation can be a valuable complement for future coping research. In doing so, an approach in which adaptive behavior can be exclusively viewed as the expression of dispositional coping styles rather than to be taken for granted on the basis of situational demands that may constraint coping preference. Further research should be focused on specific insight to develop coping measures that are tailored to the specific demand of stressors such as bereavement, chronic pain, and cancer (De Ridder & Kerssens, 2003).

Summary of Literature Review

The articles reviewed suggest possible relationship between dyspnea and QOL. Data from the articles reviewed probable association between dyspnea as a distress symptom, increased morbidity, and a diminished sense of control, thus impacting QOL. Hence, the patient's attitude towards performance status given that QOL is as meaningful as the actual length of life in patients with advanced lung cancer, which can be used in clinical practice to systematically address QOL related problems throughout the treatment course. The literature reviewed demonstrated a possible association between dyspnea perception and QOL, while elucidating a patient's improved functional capacity enhances a sense of control and normalities of one's well being.

A significant gap in the literature reviewed is currently no published interventional strategies have been tested to improve QOL in the advanced lung cancer population. In the descriptive studies summarized above, relevant variables were often not addressed, and poor performance patients were overrepresented among the non-participants. Consequently, very little documentation exists to provide a basis for the development of effective interventional strategies. Thus, as a first step, the relationship between dyspnea perception and QOL must be examined more closely as a basis for planning more appropriate and timely interventions to enhance QOL in the dyspneic lung cancer population.

Importance of Dissertation

Overall, the literature review clearly indicates much is needed to further our understanding of dyspnea in relationship to quality of life in advanced lung cancer. At present, the most commonly used intervention for dyspnea is supplemental oxygen and medication (Henoch et al., 2007). Nursing research and randomized controlled studies conducted in the United Kingdom support the use of nursing interventions such as behavioral modification and psychosocial support. Behavioral interventions have been the cornerstone of nursing interventions for many related symptoms, such as pain, anxiety, and nausea. Anecdotally in the researcher's experience, some dyspneic patients with advanced lung cancer have benefitted from more effective breathing exercises. Future directions for my research in this topic will be focused on developing a uniform evidence-based clinical practice guideline for the management of dyspnea in advanced lung cancer. In addition, studies that incorporate symptom management and QOL in the care of dyspneic patients are important issues in healthcare professionals' endeavors and it should be further explored. Other factors, such as coping capacity, can be hypothesized to serve a mitigating function in decreasing dyspnea symptom distress and enhancing QOL in the advanced lung cancer population. Data from the proposed study can form a basis for future studies of other factors contributing to QOL in this population, ultimately resulting in the testing of an intervention designed to decrease dyspnea while enhancing QOL.

CHAPTER III

Methodology

Specific Aims/Research Questions

The specific aims of this study were to:

1) Describe relevant demographic variables (age, race/ethnicity, educational level, relationship status, income level), levels of quality of life, including its subscale components (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care), and levels of dyspnea perception, including its subscale components (sense of effort, anxiety, discomfort).

2) Examine the relationship between relevant demographic variables, overall level of quality of life, and overall level of dyspnea perception.

3) Examine the relationships between relevant demographic variables, the subscale components of quality of life (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care) and the subscale components of dyspnea perception (sense of effort, anxiety, discomfort).

These specific aims addressed the following research questions in a group of advanced cancer patients in a hospice setting:

1) What are relevant demographic variables (age, race/ethnicity, educational level, relationship status, income level), levels of quality of life, including its subscale components (basic function, activity, emotional function, cognitive function, social

support, existential needs, perception of care), and levels of dyspnea perception, including its subscale components (sense of effort, anxiety, discomfort)?

2) What are the relationships between relevant demographic variables, overall level of quality of life, and overall level of dyspnea perception?

3) What are the relationships between relevant demographic variables, the subscale components of quality of life (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care) and the subscale components of dyspnea perception (sense of effort, anxiety, discomfort)?

Research Design

A non-experimental, descriptive, correlational, cross-sectional design was conducted to facilitate an understanding of the relationship between dyspnea perception and QOL. A correlational study was appropriate at this beginning stage of understanding the complex relationships between the factors contributing to dyspnea and QOL in the advanced lung cancer population. In addition, correlational research helped investigators establish a knowledge base for future research into casual inferences (Polit & Beck, 2012).

Setting

Participants were recruited through a hospice care agency distributing information sheets to the clients upon admission to the hospice care setting with a diagnosis of advanced lung cancer who reported dyspnea. A phone number was given for eligible participants to call to receive information in which the study will be described. Potential participants were given a consent form at the hospice setting for them to read, review, and discuss in which questions were answered at that time. All participants meeting the eligibility criteria were given an IRB approved brochure describing the study.

Power Analysis

Power analysis is built on the concept of an effect size, which expresses the strength of relationships among research variables. If there is a reason to expect the independent and dependent variables will be strongly related, then a relatively small sample may be adequate to reveal the relationship statistically (Polit & Beck, 2012). The sample size of this study was decided by using an effect size, desired power, and an acceptable significance level. According to Polit and Beck (2012), power analysis is used to decrease the chances of Type II errors thus adding to the validity of the statistical analysis by estimating how big the sample size should be. The effect size is the estimated population effect size and this determines the magnitude of the relationships between the independent and dependent variables. Therefore, based on a power analysis table, which provides the estimated population correlation coefficient, alpha, and power, the required sample size for a moderate size correlation coefficient ($\rho = .40$), an alpha of 0.05, and a power of .80 are approximately 47 (Polit & Beck, 2012).

Sample

Purposive sampling was used to gather knowledge about the population to select sample members. Researchers might decide purposely to select people who are judged to be typical of the population or particularly knowledgeable about the issue under study. The proposed sample study consisted of 22 patients in a hospice care setting diagnosed with advanced lung cancer that reported dyspnea. Inclusion criteria are patients having advanced lung cancer at stage IIIA or above and able to read, write and understand

English. An exclusion criterion is severe mental or cognitive impairment. Attrition is most likely to occur in this population due to death or disability, which will be addressed during the 3 to 6 month data collection period by a 20% increase participants drawn from the newly admitted lung cancer patients at Elizabeth Hospice Center (Polit & Beck). In the case of advanced lung cancer patients, estimating sample size needs should be a factor in anticipated loss of participants over time. Therefore, the researcher should expect a certain amount of participant loss and recruit accordingly (Polit & Beck, 2012).

Operational Definitions

For the purposes of this study, perception of dyspnea qualities was measured by the Cancer Dyspnea Scale (CDS) developed by Tanaka and colleagues (2000). The scale measures three factors: 1) sense of effort; 2) sense of anxiety; and 3) sense of discomfort. Quality of life will be measured by the Assessment of Quality of Life at the End of Life (AQEL) scale, developed by Henoch et al (2010). This scale includes seven subscales: basic function; activity; emotional function; cognitive function; social support; existential needs; and perception of care.

Instruments

The CDS and AQEL consisted of a total of 33 questions answered by the participants with the help of relatives or staff. The questions were answered at home and in a nursing facility and at hospital. To minimize the burden on the participants, questionnaires were given to the participants during the initial meeting with the primary investigator. One week later, the primary investigator picks up questionnaires.

Cancer Dyspnea Scale

The CDS consists of 12 items, with a 5-point scale ranging from 1 (not at all) to 5 (very much), which may be grouped into three factors according to the original validation analysis (Tanaka *et al.* 2000). The factors include a physical factor called sense of effort (5 items), a psychological factor called sense of anxiety (4 items), and a factor reflecting the uncomfortable feeling at rest called sense of discomfort (3 items). The reliability and validity of the CDS are presented in Table 1 below.

Assessment of Quality of Life at the End of Life

The AQEL is a QOL assessment scale developed for palliative care and consists of 20 questions across four basic domains (physical, psychological, social, and existential.) The physical domain is assessed with the items: need to rest at daytime, activities of daily living, strength, pain, nausea, bowel problems, and dyspnea (7 items). The psychological domain is measured by memory, worry, insomnia, concentration, and depression (5 items). The social domain is measured by sharing problems with family and being regarded as usual by family and friends (2 items). The existential domain is measured by ability to do what one wants, meaningfulness, and happiness (3 items). In a subsequent, revised version (2000), the authors developed these domains into seven subscales: basic function; activity; emotional function; cognitive function; social support; existential needs; and perception of care. Initial assessment demonstrated a strong correlation with the well-validated QLQ-C30 (Axelsson & Sjoden, 1999).

Table 1.

Measurement Instruments

Variable	Instrument	Description	Reliability	Validity
Dyspnea Perception	Cancer Dyspnea Scale (CDS)	12 items, with a 5-point scale ranging from 1 (not at all) to 5 (very much)	Cronbach's alpha coefficients were 0.83,0.81 and 0.94(Tanaka et al., 2000)	Factors significantly correlate with VAS $r=0.57, p<0.001$ (Tanaka et al., 2000)
Quality of Life	Assessment of Quality of Life at the End of Life (AQEL)	QOL assessment scale consisting of 20 questions about QOL and one complementary question	The alpha coefficient of internal consistency varied between 0.55 and 0.76 (Axelsson & Sjoden, 1999)	AQEL correlated strongly $(r>.70)$ with QLQ-C30 (Axelsson & Sjoden, 1999)
Demographic Form	Basic Demographic Information	age, race/ethnicity, education level, relationship status, income level	N/A	N/A

Data Collection Procedures

The data collection and management processes were handled by the primary investigator (PI). All data were retained and treated securely by the PI. Informed consent, as required by the USD IRB committee and participating facilities, were obtained from all participants. All participants understood this study is strictly voluntary and confidential. Participant data were given numerical assignments during the collection of data. The study began immediately following institutional review board (IRB) approval from the University of San Diego (USD) and the hospice care setting facilities. Data were collected for analysis and stored in a secured and locked file cabinet in the office of the PI.

Human Subjects

IRB approval was obtained from both the University of San Diego and participating facilities. Participants received a copy of the informed consent and Bill of Rights, which were reviewed and discussed with the participant prior to agreeing to participate. During the recruitment process, participants had the opportunity for a question and answer period to address the purpose, type of study, concerns, as well as voluntary enrollment. Once questions were addressed to the participant's satisfaction and IRB approved consent form were provided for voluntary participation, and a signed copy was given to the participant.

Data Management and Analysis

In order to achieve the specific aims of the study, the following data analysis strategies were used for each specific aim as described below.

Specific Aim #1: Describe relevant demographic variables (age, race/ethnicity, educational level, relationship status, income level), levels of quality of life, including its subscale components (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care), and levels of dyspnea perception, including its subscale components (sense of effort, anxiety, discomfort).

Descriptive statistics were used for sample description and analysis, which is intended to describe the sample characteristics. Frequency distributions are displayed utilizing tables. The central tendency of the mean, mode, median, and standard deviation were obtained and ranges examined.

Specific Aim #2: Examine the relationship between relevant demographic variables, overall level of quality of life, and overall level of dyspnea perception.

Spearman's Rank and Pearson's correlational analyses examined the relationship between relevant demographic variables, overall level of quality of life, and overall level of dyspnea perception Spearman's Rank and Pearson's correlational analyses examined the relationships between relevant demographic variables, the subscale components of quality of life (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care) and the subscale components of dyspnea perception (sense of effort, anxiety, discomfort).

Specific Aim #3: Examine the relationships between relevant demographic variables, the subscale components of quality of life (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care) and the subscale components of dyspnea perception (sense of effort, anxiety, discomfort).

Pearson's correlation coefficient described significant relationship between the study variables. Pearson correlations coefficient (r) was used to determine association among continuous variables; Spearman Rank correlation (r_s) analysis was used to establish a relationship between ordinal and continuous variables (Mertler & Vannatta, 2012; Munro, 2008; Polit, 2010). The value range for r is -1 to 1 with 0 having no relationship between the variables. A positive r coefficient signifies direct relationship where a negative r reveals an inverse relationship. The established p value is pre-determined at 05. SPSS 20.0 software was utilized to perform the analyses described above.

Strengths and Limitations of Methods

This quantitative study examined the relationship of quality of life at the end of life and perception of dyspnea in a group of advanced lung cancer patients. This study sought to test and validate theories that are presently constructed about how sometimes, why phenomena happens. Dyspnea as a symptom, clearly impact one's perceived QOL, therefore, it was hypothesized that quality of life is related to perception of dyspnea. In utilizing the quantitative methodology for this study, it provides strength in that they produce answers when done correctly, that are solid, unlike an opinion on common sense answer (Ratnesar & Mackenzie, 2006). Hence, some might argue there are limitations of quantitative methods that tend to be difficult to read and understand, most especially the statistical aspect of report, which can be technical and difficult to distinguish for an average journal reader.

Study Limitations

Descriptive correlational study was used for sample description and relationship relevancy for the proposed study. Correlational research is often efficient in collecting much more data about a problem and is often strong in realism. Unlike many experimental studies, correlational research is seldom criticized for its artificiality (Polit & Beck, 2012). Notably, limitations of correlational research include difficulty of interpreting correlational findings that stems, from the fact that in the real world, behaviors, attitudes, and characteristics, are interrelated in a complex way. Therefore, interpretations of most correlational results should be considered tentative, particularly if the research has no theoretical basis and if design is cross-sectional (Polit & Beck, 2012).

CHAPTER IV

This chapter provides a detailed analysis of research findings examining the relationship of quality of life and perception of dyspnea in a group of advanced lung cancer patients. A summary of the participant demographic and descriptive data is presented in detail. The result of the study findings are organized around each of the following aims:

Specific Aim #1: *Describe relevant demographic variables (age, race/ethnicity, educational level, relationship status, income level), levels of quality of life, including its subscale components (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care), and levels of dyspnea perception, including its subscale components (sense of effort, anxiety, discomfort).*

Specific Aim #2: *Examine the relationship between relevant demographic variables, overall level of quality of life, and overall level of dyspnea perception.*

Specific Aim#3: *Examine the relationships between relevant demographic variables, the subscale components of quality of life (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care) and the subscale components of dyspnea perception (sense of effort, anxiety, discomfort).*

Sample Description

The purposive study sample included 22 advanced lung cancer patients at stage IIIA or above who reported dyspnea and were able to read, write, and understand English. Data collection was done at the Elizabeth Hospice Center from January 2014 to August 2014. The proposed original study was to include 47 participants, however due to the severity of the illness such as cognitive decline, death and disability, and patient's refusal to participate, it lowered the number of eligible participants during the 8-month period of data collection to 22 participants. In addition, there was low census of advanced lung cancer patients during the data collection period, which played an important role in regards to enrollment and attrition status in my study.

Descriptive Findings

Specific Aim #1: *Describe relevant demographic variables (age, race/ethnicity, educational level, relationship status, income level), levels of quality of life, including its subscale components (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care), and levels of dyspnea perception, including its subscale components (sense of effort, anxiety, discomfort).*

Characteristics of the sample included 54.5% female and 45.5% male. The educational level ranges from 8th grade to PhD degree with the majority of 36.4% with a high school degree. Relational status included single (13.6%), married (40.9%), divorced (9.1%), and widowed (36.4%). Ethnicity/race included Caucasian (81.8%), African American (4.5%), Hispanic Latino (9.1%), and Asian (4.5%). The average age in years was 77 ±11.40 years old with a range of 50 to 90. The average annual income was $40,000.00 ±$52,328.29 with a range of $0 to $250,000.00 (Table 2).

Table 2.

Frequency Distributions for Demographic Information (N = 22)

Variables	Count	Percentage
Gender		
Male	10	45.5%
Female	12	54.5%
Educational level		
8th grade	2	9.15%
High School	8	36.4%
Some College	7	31.8%
BA	3	13.6%
MA	1	4.5%
Grad (PhD)	1	4.5%
Relational Status	3	13.6%
Single	9	40.9%
Married	2	9.1%
Divorced	8	36.4%
Widowed		
Ethnicity/Race		
Caucasian	18	81.8%
African American	1	4.5%
Hispanic Latino	2	9.1%
Asian	1	4.5%
Age in Years		
50-69	5	23%
70-79	5	23%
80-89	8	37%
90.00	4	18%
Annual Income		
.00	2	9.1%
15000.00	2	9.15%
20000.00	2	9.1%
25000.00	5	22.7%
28000.00	1	4.5%
30000.00	3	13.6%
35000.00	2	9.1%
43000.00	1	4.5%
45600.00	1	4.5%

50000.00	1	4.5%
120000.00	1	4.5%
250000.00	1	4.5%

Assessment of the Quality of Life at the End of Life (AQEL)

The AQEL scores were calculated for 22 participants. Table 3 presents the descriptive statistical results based on 20 questions about quality of life at the end of life. Quality of life at the end of life was scored on a 1 – 10 scale. Overall, the AQEL score mean revealed an approximate average level of quality of life at the end of life (*M* = 5.55, *SD* = .45). For Frequency Distribution for Assessment of Quality of Life at End of Life, see appendix A

Table 3.

Descriptive Statistics for Assessment of Quality of Life at End of Life (N = 22)

	Mean ± SD	SE
Subscales		
Basic Functions	5.63 ± 9.05	1.93
Activity	4.45 ± 2.28	0.49
Emotional Function	4.64 ± 1.27	0.27
Cognitive Function	5.82 ± 2.43	0.52
Social Support	5.45 ± 1.94	0.41
Existential Needs	5.27 ± 1.32	0.28
Perception of Care	9.66 ± 0.52	0.11
Total Score	5.55 ± 0.45	0.10
Physical Symptoms		
Q 4: Pain	4.48 ± 3.03	0.65
Q 5: Nausea	2.05 ± 2.40	0.51
Q 6: Bowel trouble	4.20 ± 3.03	0.65
Q 7: Dyspnea	4.32 ± 2.80	0.60

SD= Standard Deviation, SE=Standard error

Cancer Dyspnea Scale (CDS)

The CDS was used to measure dyspnea perception, which includes its subscale components of discomfort, anxiety, and sense of effort. Table 4 presents the descriptive statistical results based on the dyspnea scale which has a total of 12 items with a 5-point scale ranging from 1 (not at all) to 5 (very much). The overall total mean score of CDS revealed relatively mild perception of dyspnea (*M* = 14.27, *SD* = 7.64). Standard error indicates 1.63 average error for a sample size of 22. For Frequency Distribution for Cancer Dyspnea Scale, see appendix B

Table 4.

Descriptive Statistics for Cancer Dyspnea Scale and Subscales (N = 22)

Subscales	Mean ± SD	SE
Discomfort	5.84 ± 3.86	0.82
Anxiety	3.84 ± 3.11	0.66
Effort	4.45 ± 2.32	0.50
Total Score	14.27±7.64	1.63

SD= Standard Deviation
SE=Standard error

Data Analysis and Research Questions

Specific Aim #2: *Examine the relationship between relevant demographic variables, overall level of quality of life, and overall level of dyspnea perception.*

There is no relationship between demographic variables, overall level of quality of life, and overall level of dyspnea perception. However, data analysis revealed the following trends. AQEL total score indicated females appears to have a slightly higher level of QOL than males (*r*=.224, *p* = .32). In addition, CDS total score data analysis indicated the following possible trends. As the patient becomes older they tend to have higher level of dyspnea (*r*=.326, *p* = .14) and married individuals experience less dyspnea than single, divorced, widowed individuals (*r*=-.292, *p* = .19).

Specific Aim #3: *Examine the relationships between relevant demographic variables, the subscale components of quality of life (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care) and the subscale components of dyspnea perception (sense of effort, anxiety, discomfort).*

Demographics

Education and income had a strong significant relationship. The more educated the participants were, the higher the level of income, (r_s (1, 20) = 0.58, p = 0.005).

Quality of Life Subscales

There was a positive correlation between educational level and AQEL existential needs (r_s (1, 20) = 0.450, p = .036). The higher the level of education the participants attained, they report higher satisfaction in life's meaning.

Physical Symptoms

There was a significant inverse relationship between pain and age. As the participants aged they report less pain, (r_s (1, 20) = -0.511, p = .015). There was a significant inverse relationship between AQEL total scores and pain. The higher the level of pain the participant experienced, the lower their overall quality of life, (r_s (1, 20) = -0.449, p = .036). There was a significant relationship between pain and cognitive function. The higher the participants cognitive awareness are, the greater their level of pain, (r_s (1, 20) = 0.483, p = .023). There was a significant relationship between nausea and cognitive function. The higher the level of nausea is, the higher the participants' level of cognitive function, (r_s (1, 20) = 0.459, p = .032). There was a significant relationship between nausea and pain. The higher the level of nausea is, the higher the participants' level of pain, (r_s (1, 20) = 0.500, p = .018).

Quality of Life Total Score

Basic function was significantly related with the AQEL total score. The more independent the participants were with activity of daily living (ADLs,) the higher their overall quality of life, (r_s (1, 20) = 0..480, p = 0.024). Activity was significantly related with the AQEL total score. The higher degree of physical strength the participant had the higher their overall quality of life, (r_s (1, 20) = 0.49, p = 0.020). There was a significant inverse relationship between cognitive function and overall quality of life. As the participants' cognitive awareness declines, the QOL appears to increase, (r_s (1, 20) = -0.524, p = .012). There was a strong inverse significant relationship between perception of care and the AQEL total score (r_s (1, 20) = -.603, p = .003). As participants' perception of care increases their overall QOL decreases. There was an inverse relationship between bowel movement and AQEL total score. As the difficulty of bowel movements increased, the participants overall quality of life decreased, (r_s (1, 20) = -0.572, p = 0.005).

Cancer Dyspnea Scale

There was a strong significant relationship between CDS anxiety and CDS discomfort. The higher the level of anxiety is, the higher the participants' level of discomfort, (r_s (1, 20) = 0.823, p = .000).

Cancer Dyspnea Scale Total Score

There was a strong significant relationship between the CDS total score and the CDS discomfort score, the higher the level of discomfort participants felt, the higher the CDS total score, (r_s (1, 20) = 0.936, p = .000). There was a strong significant relationship between CDS anxiety and CDS total score, the higher the level of anxiety the participants felt, the higher the CDS total score, (r_s (1, 20) = 0.882, p = .000). There was a significant relationship between the CDS sense of effort and CDS total score. The higher the participants level of breathing effort, the higher their overall CDS total score, (r_s (1, 20) = 0. 456, p = 0.033). (See Table 5 below for Correlation Matrix).

Table 5.

Spearman's Rank Correlations Between Measures

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
(1) Age															
(2)Education	-.034														
(3)Income	.097	.580**													
(4)AQEL Total	.095	-.132	-.312												
(5)AQ Basic Function	.157	.221	.161	.480*											
(6)AQ Activity	-.060	-.250	-.418	.490*	.035										
(7)AQ Cog. Function	-.350	.016	.381	-.524*	-.407	-.380									
(8)AQ Exis. Needs	-.017	.450*	.192	.041	-.017	-.206	-.115								
(9)AQ Percept Care	.066	-.142	-.258	-.603**	.059	.421	-.328	.030							
(10)AQ 4 Pain	-.511*	-.076	.126	-.449*	-.297	-.137	.483*	-.064	-.291						
(11)AQ 5 Nausea	-.269	.158	.278	-.392	-.243	-.372	.459*	.021	-.141	-.500*					
(12)AQ 6 Bowel	.215	.320	.331	-.572**	-.002	-.235	-.135	.349	-.253	.051	.021				
(13)CDS Discomf	.178	.237	.372	-.249	-.098	-.237	.095	.002	.102	.126	.271	.115			
(14)CDS Anxiety	.145	.172	-.237	-.274	-140	.016	-.011	.090	.169	.285	.130	.331	.823**		
(15)CDS Effort	.052	.101	-.210	-.088	-.110	.054	.045	.253	-.233	.417	.187	.087	.298	.147	
(16) CDS Total Score	.210	.295	-.370	-.263	-.234	.093	.068	.154	.004	.353	.222	.337	.936**	.882**	.456*

** Correlation is significant at the 0.01 level (2-tailed)

* Correlation is significant at the 0.05 level (2-tailed)

Results Conclusion

The aims of this proposed study were formulated to address the research questions of whether relationships existed between relevant demographic variables, the subscales component of AQEL and CDS, and the total score for both the Assessment of Quality of Life at the End of Life and the Cancer Dyspnea Scale. In the sample of advanced lung cancer patients in the hospice care setting, results revealed that the AQEL subscales (basic function, activity, and cognitive function) had a significant correlation to the AQEL total score. This would be expected because the total AQEL score is derived from the same items as are in the instrument's subscales. In addition, the physical domain (pain and bowel movement) indicated a strong inverse relationship to the AQEL total score. Furthermore, it is important to note that the result geared toward the second aim of this research study, indicated no significant relationships between the participants demographics, AQEL total score, and CDS total score. However, examination of data trends revealed possible relationships between some of the variables.

CHAPTER V

Discussion

The primary purpose of this study was to examine the relationship between quality of life and perception of dyspnea in a group of advanced lung cancer patients. This study hypothesized that quality of life is related to perception of dyspnea as indicated by hospice patients own bodily reaction and manifestation in strategies that describes the triggering factors in relationship to QOL and their own dyspnea perception. This chapter will provide detailed analysis and significance of the research findings as well as discussion of strengths, limitations, and study implication that will guide future directions of research findings on the basis of the outcome of the proposed study.

Demographics

The sample of 22 advanced lung cancer patients at stage IIIA or above participated in this proposed study. Characteristics of the sample included 54.5% female and 45.5% male. The educational level ranges from 8th grade to PhD degree with the majority of 36.4% with a high school degree. Relational status included single (13.6%), married (40.9%), divorced (9.1%), and widowed (36.4%). Ethnicity/race included Caucasian (81.8%), African America (4.5%), Hispanic Latino (9.1%), and Asian (4.5%). The average age in years was 77 ±11.40 years old with a range of 50 to 90. The average annual income was $40,000.00 ±$52,328.29 with a range of $0 to $250,000.00. This study was conducted in a setting where socio-economic status consisted of affluent family and neighborhood that had a sufficient economic stability. As expected, socioeconomic status played an influential role in regards to ways of coping and adapting into psychophysiological components of perceived burden of QOL. It is also important to note that socioeconomic factors influence cancer risk factors such as tobacco use, poor nutrition, physical inactivity, and obesity. Income, education, and health insurance coverage influenced access to appropriate early detection, treatment, and palliative care (Ward, et al., 2004).

The American Cancer Society (2014) recent report indicated lung cancer mainly occurs in older people. About 2 out of 3 people diagnosed with lung cancer are 65 or older; fewer than 2% of all cases found in people younger than 45, the average age at time of diagnosis is about 70 years old (ACS, 2014). In comparison to my study participants, it is about the same as the general assumption with the exception of 4 participants in their 90's. This may be attributed to their higher social economic status, which affords a higher level of health care.

Overview

As indicated by the literature reviewed conducted in this study, dyspnea is the most prevalent symptom in patients with advanced lung cancer and it is supported by decreased level of physical well being, psychological well being, and situational well being (Zhou et al., 2009). Even though the level of dyspnea is generally assessed through objective parameters that rely on respiratory function test such as arterial blood gasses values, subjectively perceived dyspnea is not always consistent with objective dyspnea indicators (Karapolat, et al., 2008). Therefore, this study recommends effects of dyspnea in QOL should be thoroughly assessed in concurrent to objective indicators of dyspnea in relationship to the subjective perception in the most accurate way in dealings with patients suffering from advanced lung cancer in a hospice setting. Hence, it is important to note that most of the participants in this study had their own perception of dyspnea, as described by their own physical features, involvement, and immediate reactions to their environment, physical characteristics, and psychosocial state of mind. To date, the possible long-term consequences of this study population, involves life changes with limitations and dependence of their own QOL guided by existential reflection of subjective meaning of dyspnea in relationship to the objective precipitation of dyspnea symptoms.

Patient Sample

The vulnerability of the patients sample used for this study, constituted concerns about cognitive status, inability to consent, response burden, measurement intrusiveness, patients' lack of time, complexity of research design, participants recruitment and retention, diversity of the palliative care population, and involving others (hospice personnel, patients themselves, family and caregivers) with such dilemmas, these led to challenges most especially regarding participants recruitment and retention. Although, the majority of the study participants met the logistic criteria for this research study, it is essential to acknowledge terminally ill patient constitute a vulnerable group and participants face more difficulties due to presence of multi-symptoms and severe psychophysiological problem (Addington-Hall, 2007). Hence, Ferrell (2004) writes, "There is no option to avoid research within the field of palliative care, as like all disease areas, there is critical need to conduct research to advance the field. Improved care will not happen without inquiry" (p. 408). Therefore, even if challenges and concern arises in this chosen population, both exquisite practicality and ethical dilemma of palliative research must be conducted (Ferrell, 2004).

Assessment of Quality of Life at the End of Life (AQEL)

The overall AQEL score mean revealed an approximate average level of QOL at the end of life (M=5.55, SD= .45). The overall AQEL total score indicated that more than 50% of the participant reports a satisfactory quality of life at the end of life. Due to the limited available research on the AQEL scale, all significant relationships between AQEL total score, AQEL subscales, and AQEL physical symptoms were reported. The subscale component of AQEL such as basic function and activity had a significant relationship with the overall AQEL total score, indicating an increased level of satisfaction with their physical well being. A negative relationship was also found between cognitive function and total AQEL score. This indicated that as the participants cognitive function declined their overall QOL appeared to increase. However, this would be expected because the total AQEL score is derived from the items in the instrument's subscale item. Past literature found that when cognitive function declines, due to the disease progression, it inhibits patients' self report of their overall QOL. Therefore, it appears as if the patient's perception of OQL improved. Positive relationship is also noted between existential need and educational level. The majority of the participants perceive life's meaning in relationship to happiness on the basis of educational attainment and or life's accomplishment. There was a strong inverse significant relationship between perception of care and the AQEL total score. As participants' perception of care increases their overall QOL decreases. This indicates that with dependence of perceive care participants QOL declines due to disease progression.

The AQEL overall total score was also calculated for significance and relationship with physical symptoms such as pain, nausea, bowel movement, and difficulty breathing. Negative relationship was found between pain and age indicating that as participant age they report less pain. This could be due to the trajectory of the advanced lung cancer disease and metastasis to the brain, which declines cognitive function that inhibits participant's ability to report pain. Significant relationship was found between pain and cognitive function indicating that the higher the participants cognitive awareness, the greater their level of pain report. Negative relationship was also noted between AQEL total score with pain indicating the higher the participant's level of pain, the lower their overall QOL. Negative relationship was found between bowel difficulties and AQEL total score indicating as participants report higher difficulty with bowel movements, their overall QOL decreases. Finally, a significant relationship was found between nausea and cognitive function and nausea and pain. These indicate that participant's higher-level report of nausea relates to an increase of cognitive function and self report of pain level.

Findings from the AQEL results are supported by past research conducted by Henoch, Axelsson, and Bergman (2010). Their study gathered some evidence for the validity of AQEL when used with palliative care patients. Relationships were found among physical symptoms, existential need, basic function, and activity scales. However, based on this proposed study, additional work is further needed and recommended to understand the structure of the measure as well as its responsiveness to palliative information and clinical changes in population of patients with advanced lung cancer close to the end of life (Henoch, Axelsson, & Bergman 2010).

Cancer Dyspnea Scale (CDS)

The total mean score of CDS (*M* = 14.27, *SD* = 7.64) indicated a relatively mild perception of dyspnea among the study participants. However, a strong positive relationship between CDS anxiety and CDS discomfort was noted, in addition to a strong positive relationship between CDS total score, CDS anxiety, CDS discomfort, and CDS sense of effort. This result concluded participants with increased level of physical and emotional discomfort reported higher level of anxiety, which indicated difficulty of breathing pattern. Findings from this study is supportive of Tanaka et al. (2002) which discussed that dyspnea as perceived symptom is related to psychological distress which has been reported to decrease QOL in patients with advanced lung cancer (Tanaka et al., 2002). Further emphasis in psychosocial interventions, such as relaxation techniques and visibility of social support from family care giver and hospice nurses should be explored so that it can lead to improved reporting of perceived dyspnea among patients with advanced lung cancer in the hospice setting.

Finally, in examining the relationship between relevant demographics variables, overall level of quality of life, and overall level of dyspnea perception, notably there were no significant relationships found. However, data analysis revealed the following possible trends between AQEL total score and female participants indicating females reported better QOL than males. This is contrary to study conducted by Weiner et al (2002) their findings suggest that women with asthma report more symptoms, use more rescue medications, experience poorer QOL, and are admitted to the hospital more frequently than men. Their study suggested that because women seek more medical attention and experience poorer QOL, women then actually experience greater discomfort to airflow obstruction than men. The fact that women report poorer quality of life than men indicates that women's perception of airway obstruction may be different than men (Weiner et al., 2002). The possible reason female participants in this proposed study might have reported better QOL than men could be due to the ratio of women more than men, social and economical disparity, and participants educational level. Findings might be different if study is conducted in diverse population. In regards to age and CDS total score, it revealed that older participants reported higher level of dyspnea. The possible explanation for this finding could be that aging process in cancer patients affects precipitation of disease progression that leads to difficulty of breathing pattern. With married people reporting less dyspnea than single, divorced, and widowed individuals, literature reviewed for this study indicates that social support from your husband or wife leads to better QOL and less disposition on physical impact of dyspnea pattern. It is important to note however, that if the population afforded more participants, the results of the correlations might reveal significance.

Summary

The aims of this proposed study were formulated to address the research questions of whether relationships existed between subscales and total score for both the Assessment of Quality of Life at the End of Life and the Cancer Dyspnea Scale in relationship to QOL and perception of dyspnea in a group of advanced lung cancer patients in a hospice setting. The results confirmed the literature review suggestions that there was indeed some relationship between the subscales, AQEL, and CDS measurement total scores. In the 22 sample participants of advanced lung cancer patients in the hospice care setting, results revealed that the AQEL subscales (basic function, activity, and cognitive function) had a significant correlation to the AQEL total score. In addition, the physical domain (pain and bowel movement) indicated a strong inverse relationship to the AQEL total score. As indicated by prior research, analysis revealed that the CDS subscales (discomfort, anxiety, and sense of effort) had a strong significant relationship to the CDS total score. Furthermore, it is important to note that the result geared toward the second aim of this research study, indicated no significant relationships between the participants demographics, AQEL total score, and CDS total score. However, examination of data trends revealed possible relationships between some of the variables. Hence, the small sample size may have hindered the relevancy outcome of the proposed study.

Research Strengths and Limitations

The strength of this descriptive study is it constituted an initial step in examining the relationship between dyspnea perception and QOL in patients with advanced lung cancer. The methods were validated via AQEL and CDS questionnaires in which the relationship of quality of life and dyspnea perception encompasses the true meaning of quality of life through psychological, physiological, and situational factors. This enabled participants to minimize symptom burdens with one week given to complete the questionnaires with the help of family or caregivers. The investigation of this relationship, in a multidimensional way, served as a basis for future studies to develop and test interventions to decrease dyspnea and enhance QOL in this population (Gallo-Silver & Pollack, 2000). The need to explore numerous interventions in lung cancer and dyspnea is imperative. It is vital the healthcare team work therapeutically with patients and family to help them live better with illness and its manifestations. In doing so, this forms a large part of the researcher's role in educating nurses about dyspnea management in lung cancer patients. All practitioners in hospice settings, who work with patients who are dyspneic, would benefit from incorporating the interventions that was suggested in the evidence-based practice research, or aspect of it, into their everyday clinical practice. Thus, they can take the lead in implementing research interventions that further suits the relationship of dyspnea perception with psychophysical aspects concurrently to improve QOL.

The limitations of this study included its small sample size and the potential for attrition due to disease progression and death. Thompson, Sola, and Cubrana (2005) indicated although treatment advances have led to a steady increase in survival prognosis, for the majority of patients, the average survival remains at about eight months from diagnosis. Therefore, the need for high quality care to support patients and reduce the devastating symptom of dyspnea is essential for early assessment and implementation of psychophysical impact of dyspnea in relationship to QOL in a palliative care setting. This study also met with some difficulties in terms of enrollment retention due to disease progression and disease comorbidity. Severe cognitive decline were noted on potential participants due to brain metastasis or increase dose of narcotic medication and severe weakness and pain were also noted in patients with pre-existing diabetes, renal failure and cardiovascular disease. This inhibited them from study enrollment. Lastly, the population of this study was conducted in a setting consistent with an affluent community. The majority of participants were Caucasian, married, have financial stability, and good social support from friends and love one's. This could have resulted in a better reporting of OQL and dyspnea perception. Nevertheless, the analysis from this study yielded some interesting report in terms of symptom management in relationship to physiological, psychological, and situational factors of perceived dyspnea in relationship to QOL in advanced lung cancer patients in a hospice setting.

Implication for Nursing Practice

Quality of Life and perception of dyspnea in advanced lung cancer in a hospice setting involves extensive exploration and adaptation when it comes to coping strategies with individuals perceived difficulty of breathing leading to feeling of anxiety, hopelessness, and fear of impending death (Twycross, Wilcock, & Stark-Toller, 2009). The adapted conceptual theory of unpleasant symptoms (Lentz et al., 1995) guiding the study supports nursing practice in understanding the concept of QOL in relationship to perceived dyspnea symptom that affects the essential component in treating breathlessness in an effort to improve patients' QOL. Focusing on dyspnea perception, functioning capacity, and psychosocial factors such as psychological distress and anxiety will enable nurses in a hospice setting to determine the efficacy of a preventative approach to reduce the burden of dyspnea in advanced lung cancer patients. Nevertheless, dyspnea is a multidimensional construct commonly occurring with clusters of other symptoms, requiring a multimodality approach. Therefore, nurses needs continuing education that focuses on the multidisciplinary training combined with involving opioids, dyspnea management, relaxation techniques, and psychometric intervention that may yield to improving treatment of dyspnea as well as improving quality of life in patients with advanced lung cancer.

Another factor this study identified is the effect of dyspnea on quality of life in general, which appeared bothersome and interfered with every aspect of a person's life and being. Understanding this symptom from the participants' perspective evoked powerful images in the language they used to describe dyspnea (O'Drisscoll, Corner, & Bailey, 1999). Many reported feelings of anxiety, fear, and panic during attacks of dyspnea and some correlated this sensation to impending death. Therefore, plan of care with a refined assessment tool must be considered most especially the functional and psychosocial aspect of dyspnea, which examines quality of life issues that were significant for each individual person. In doing so, this provides healthcare practitioner with accurate assessment findings for the betterment of enhanced symptom management as well as improve overall care of advanced lung cancer in a hospice setting.

Future Research

Practitioners involved in palliative care and end of life care need training in interventions to improve dyspnea management in relationship to perceived breathlessness and QOL (Froggatt & Walford, 2005). Although this study provided significant relationships between QOL and perception of dyspnea, further research on a larger diverse sample is needed to elucidate findings that clearly identify the true meaning of perceived dyspnea and QOL. Diversity regarding socioeconomic status, ethnicity, and race would be an important factor for future research since such characteristics may be related to various responses to the QOL questionnaires as well as to the experience of dyspnea. For example, Kwak and Haley (2005) identified racial differences in end of life care and participants perception of care in a hospice setting. Their findings indicated that perception of care such as pain and dyspnea were most likely unmet due to disparities in end of life care the minority receives. Future studies would benefit in exploring diversity in understanding cause of racial differences in perception of dyspnea and QOL, well being in advanced lung cancer population.

Notably, it is essential to consider that conducting research in patients who require palliative care can be ethically challenging (Dorman et al., 2009). The nature of dyspnea in the lung cancer population and the rapid decline towards death means it is difficult to participate in clinical research (Booth, Moosavi, & Higginson, 2008). However, despite this obvious dilemma, further studies involving development of course specific to healthcare professionals with skills for patient assessment, meeting the physiological, psychological, and social aspect of quality of life and dyspnea is greatly needed to provide the best possible care and alleviate distress in this group of patients.

Conclusion

The study described the patients' perception of dyspnea in relationship to QOL at the end of life in advanced lung cancer population. Because patients do not experience dyspnea in isolation but rather in conjunction with other symptoms, concomitant stressors, existential distress, and dyspnea cannot be fully addressed unless these physical and non-physical factors are understood (Kamal et al., 2012). This study investigated physiological, psychological, and situational factors that influenced participants' own perception of dyspnea correlated with their own QOL status. Strong significance was found among associative variables and certain components of AQEL instrument and CDS measurement. The findings suggested precipitant of dyspnea included both physical and emotional sensations triggered by immediate reactions connected to participants' experience of perceived dyspnea. Acknowledging the importance in assessment of dyspnea and its dramatic effects on independence and QOL can refine and improve our understanding of ability to recognize as well as the capacity to effectively treat this disabling symptom.

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APPENDIX A

Frequency Distributions for Assessment of Quality of Life at End of Life (N = 22)

	Count	Percentage	Cumulative Percentage
Subscales			
Basic Functions			
1.50	3	13.6%	13.6%
3.25	1	4.5%	18.2%
3.50	1	4.5%	22.7%
4.00	3	13.6%	36.4%
4.50	2	9.1%	45.5%
5.00	1	4.5%	50.0%
5.50	1	4.5%	54.5%
6.50	1	4.5%	59.1%
6.75	1	4.5%	63.6%
7.00	2	9.1%	72.7%
7.50	1	4.5%	77.3%
9.00	2	9.1%	86.4%
9.25	1	4.5%	90.9%
9.50	2	9.1%	100.0%
Activity			
1.50	1	4.5%	4.5%
2.00	4	18.2%	22.7%
2.50	1	4.5%	27.3%
3.00	2	9.1%	36.4%
3.50	2	9.1%	45.5%
4.00	3	13.6%	59.1%
4.50	1	4.5%	63.6%
6.00	3	13.6%	77.3%
6.50	1	4.5%	81.8%
7.00	2	9.1%	90.9%
8.50	1	4.5%	95.5%
9.50	1	4.5%	100.0%
Emotional Func			
2.00	1	4.5%	4.5%
2.33	1	4.5%	9.1%
3.67	2	9.1%	18.2%
4.00	4	18.2%	36.4%
4.33	3	13.6%	50.0%
4.67	3	13.6%	63.6%
5.00	2	9.1%	72.7%
5.33	1	4.5%	77.3%
5.67	1	4.5%	81.8%
6.33	3	13.6%	95.5%
7.33	1	4.5%	100.0%

	Count	Percentage	Cumulative Percentage
Cognitive Function			
1.00	2	9.1%	9.1%
2.00	1	4.5%	13.6%
3.50	1	4.5%	18.2%
4.00	1	4.5%	22.7%
4.50	2	9.1%	31.8%
5.00	1	4.5%	36.4%
5.50	1	4.5%	40.9%
6.00	3	13.6%	54.5%
7.00	2	9.1%	63.6%
7.50	3	13.6%	77.3%
8.00	3	13.6%	90.9%
8.50	1	4.5%	95.5%
10.00	1	4.5%	100.0%
Social Support			
2.00	1	4.5%	4.5%
3.00	2	9.1%	13.6%
3.50	1	4.5%	18.2%
4.00	1	4.5%	22.7%
4.50	2	9.1%	31.8%
5.00	3	13.6%	45.5%
5.50	5	22.7%	68.2%
6.00	2	9.1%	77.3%
7.00	2	9.1%	86.4%
7.50	1	4.5%	90.9%
9.50	1	4.5%	95.5%
10.00	1	4.5%	100.0%
Existential Needs			
3.50	2	9.1%	9.1%
4.00	3	13.6%	22.7%
4.50	3	13.6%	36.4%
5.00	3	13.6%	50.0%
5.50	5	22.7%	72.7%
6.00	2	9.1%	81.8%
6.50	3	13.6%	95.5%
9.50	1	4.5%	100.0%
Perception of Care			
2.00	14	63.6%	63.6%
3.00	3	13.6%	77.3%
4.00	3	13.6%	90.9%
5.00	2	9.1%	100.0%

	Count	Percentage	Cumulative Percentage
Total Score			
4.50	1	4.5%	4.5%
5.00	1	4.5%	9.1%
5.13	1	4.5%	13.6%
5.15	2	9.1%	22.7%
5.20	1	4.5%	27.3%
5.30	2	9.1%	36.4%
5.45	1	4.5%	40.9%
5.55	3	13.6%	54.5%
5.65	2	9.1%	63.6%
5.70	1	4.5%	68.2%
5.78	1	4.5%	72.7%
5.85	1	4.5%	77.3%
5.90	1	4.5%	81.8%
5.95	2	9.1%	90.9%
6.30	1	4.5%	95.5%
6.53	1	4.5%	100.0%
Physical Symptoms			
Q 4: Pain			
1.00	2	9.1%	9.1%
2.00	1	4.5%	13.6%
3.00	1	4.5%	18.2%
4.00	2	9.1%	27.3%
4.50	1	4.5%	31.8%
5.00	1	4.5%	36.4%
6.00	2	9.1%	45.5%
7.00	1	4.5%	50.0%
8.00	3	13.6%	63.6%
9.00	4	18.2%	81.8%
10.00	4	18.2%	100.0%
Q 5: Nausea			
1.00	16	72.7%	72.7%
2.00	2	9.1%	81.8%
3.00	1	4.5%	86.4%
4.00	1	4.5%	90.9%
8.00	1	4.5%	95.5%
10.00	1	4.5%	100.0%
Q 6: Bowel Diff.			
1.00	1	4.5%	4.5%
3.00	5	22.7%	27.3%
5.00	1	4.5%	31.8%
6.00	2	9.1%	40.9%
7.00	1	4.5%	45.5%
8.00	4	18.2%	63.6%

9.00	1	4.5%	68.2%
9.50	1	4.5%	72.7%
10.00	6	27.3%	100.0%
Q 7: Dyspnea			
1.00	6	27.3%	27.3%
2.00	2	9.1%	36.4%
3.00	2	9.1%	45.5%
4.00	1	4.5%	50.0%
5.00	2	9.1%	59.1%
6.00	2	9.1%	68.2%
7.00	4	18.2%	86.4%
8.00	2	9.1%	95.5%
9.00	1	4.5%	100.0%

APPENDIX B

Frequency Distributions for Cancer Dyspnea Scale and Subscales (N = 22)

	Count	Percentage	Cumulative Percentage
Subscales			
Discomfort			
.00	1	4.5%	4.5%
1.00	3	13.6%	18.2%
2.00	1	4.5%	22.7%
3.00	2	9.1%	31.8%
4.00	2	9.1%	40.9%
4.50	1	4.5%	45.5%
5.00	2	9.1%	54.5%
7.00	2	9.1%	63.6%
8.00	2	9.1%	72.7%
9.00	1	4.5%	77.3%
10.00	1	4.5%	81.8%
11.00	2	9.1%	90.9%
12.00	2	9.1%	100.0%
Anxiety			
.00	4	18.2%	18.2%
1.00	4	18.2%	36.4%
2.00	1	4.5%	40.9%
3.00	1	4.5%	45.5%
4.00	2	9.1%	54.5%
5.00	2	9.1%	63.6%
6.00	3	13.6%	77.3%
7.00	3	13.6%	90.9%
8.00	1	4.5%	95.5%
10.50	1	4.5%	100.0%
Effort			
.00	2	9.1%	9.1%
2.00	1	4.5%	13.6%
3.00	6	27.3%	40.9%
4.00	2	9.1%	50.0%
5.00	2	9.1%	59.1%
6.00	6	27.3%	86.4%
7.00	1	4.5%	90.9%
8.00	1	4.5%	95.5%
9.00	1	4.5%	100.0%
Total Score			
.00	1	4.5%	4.5%
1.00	1	4.5%	9.1%
4.00	1	4.5%	13.6%
8.00	3	13.6%	27.3%

9.00	1	4.5%	31.8%
13.00	2	9.1%	40.9%
14.00	3	13.6%	54.5%
15.00	1	4.5%	59.1%
17.00	1	4.5%	63.6%
17.50	1	4.5%	68.2%
19.00	2	9.1%	77.3%
21.00	1	4.5%	81.8%
22.00	1	4.5%	86.4%
23.00	1	4.5%	90.9%
25.00	1	4.5%	95.5%
29.50	1	4.5%	100.0%

APPENDIX C

University of San Diego
Institutional Review Board

Research Participant Consent Form

For the research study entitled:
Quality of Life and Perception of Dyspnea in Advanced Lung Cancer Patients

I. Purpose of the research study

Barbara A. Roces is a PhD nursing student at the University of San Diego. You are invited to participate in a research study he/she is conducting. The purpose of this research study is: Examine the relationship between quality of life and perception of dyspnea in a group of advanced lung cancer patients.

II. What you will be asked to do

If you decide to be in this study, you will be asked to:

Complete three questionnaires that ask you questions about your age, race/ethnicity, relationship status, educational level, income level, levels of quality of life, including its subscale components (basic function, activity, emotional function, cognitive function, social support, existential needs, perception of care), and levels of dyspnea perception, including its subscale components (sense of effort, anxiety, discomfort).

Your participation in this study will take a total of 45 minutes.

III. Foreseeable risks or discomforts

a) Sometimes when people are asked to think about their feelings, they feel sad or anxious. If you would like to talk to someone about your feelings at any time, you can call toll-free, 24 hours a day: San Diego Mental Health Hotline at 1-800-479-3339

IV. Benefits

While there may be no direct benefit to you from participating in this study, the indirect benefit of participating will know that you helped researchers better understand the relationship between quality of life and perception of dyspnea in a group of advanced lung cancer patients.

V. Confidentiality

Any information provided and/or identifying records will remain confidential and kept in a locked file and/or password-protected computer file in the researcher's office for a minimum of five years. All data collected from you will be coded with a number or pseudonym (fake name). Your real name will not be used. The results of this research project may be made public and information quoted in professional journals and meetings, but information from this study will only be reported as a group, and not individually.

VI. Compensation

a) If you participate in the study, the researcher will give you a $15 Wall-Mart gift card in the following way: (personally.)
You will receive this compensation even if you decide not to complete the entire questionnaire.

VII. Voluntary Nature of this Research

Participation in this study is entirely voluntary. You do not have to do this, and you can refuse to answer any question or quit at any time. Deciding not to participate or not answering any of the questions will have no effect on any benefits you're entitled to, like your health care, or your employment or grades. **You can withdraw from this study at any time without penalty.**

VIII. Contact Information

If you have any questions about this research, you may contact either:

1) Barbara A. Roces
Email: broces@sandiego.edu
Phone: (323) 533-0924

2) Dr. Jane Georges
Email: jgeorges@sandiego.edu
Phone: (619) 260-4566

I have read and understand this form, and consent to the research it describes to me. I have received a copy of this consent form for my records.

Signature of Participant Date

Name of Participant **(Printed)**

Signature of Investigator Date

APPENDIX D

Appendix D

Ann Sturley, DrPH, RN, BSN, CHPN
Education Manager
The Elizabeth Hospice
500 La Terraza Blvd., Suite 130
Escondido, CA 92025

October 14, 2013

Jane Georges PhD, RN
Dissertation Chair
University of San Diego
Hahn School of Nursing and Health Science
5998 Alcala' Park
San Diego, CA 92110

Re: Barbara A. Roces
Dissertation Study Site

Dear Dr. Georges:

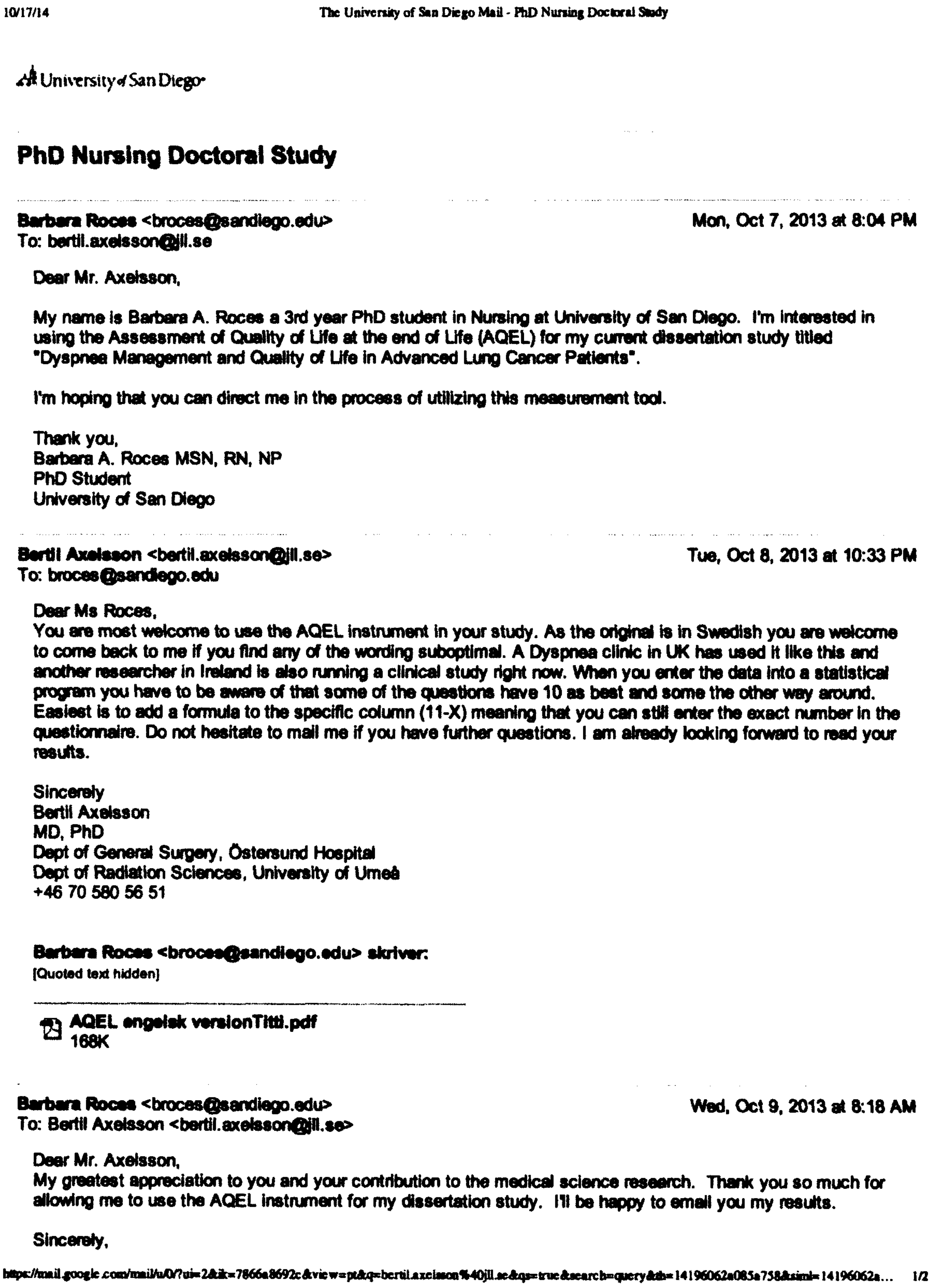
We are pleased to inform you that we have approved your doctoral student Barbara A. Roces to conduct her dissertation study at Elizabeth Hospice on Quality of Life and Perception of Dyspnea in Advanced Lung Cancer Patients.

We look forward to her research contribution to nursing science. Please feel free to contact me at (760) 737-2050 x 2508 if you have any questions.

Sincerely,

Ann Sturley, DrPH, RN, BSN, CHPN

APPENDIX F



University of San Diego

PhD Nursing Doctoral Study

Barbara Roces <broces@sandiego.edu> Mon, Oct 7, 2013 at 8:04 PM
To: bertil.axelsson@jll.se

Dear Mr. Axelsson,

My name is Barbara A. Roces a 3rd year PhD student in Nursing at University of San Diego. I'm interested in using the Assessment of Quality of Life at the end of Life (AQEL) for my current dissertation study titled "Dyspnea Management and Quality of Life in Advanced Lung Cancer Patients".

I'm hoping that you can direct me in the process of utilizing this measurement tool.

Thank you,
Barbara A. Roces MSN, RN, NP
PhD Student
University of San Diego

Bertil Axelsson <bertil.axelsson@jll.se> Tue, Oct 8, 2013 at 10:33 PM
To: broces@sandiego.edu

Dear Ms Roces,
You are most welcome to use the AQEL instrument in your study. As the original is in Swedish you are welcome to come back to me if you find any of the wording suboptimal. A Dyspnea clinic in UK has used it like this and another researcher in Ireland is also running a clinical study right now. When you enter the data into a statistical program you have to be aware of that some of the questions have 10 as best and some the other way around. Easiest is to add a formula to the specific column (11-X) meaning that you can still enter the exact number in the questionnaire. Do not hesitate to mail me if you have further questions. I am already looking forward to read your results.

Sincerely
Bertil Axelsson
MD, PhD
Dept of General Surgery, Östersund Hospital
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Barbara Roces <broces@sandiego.edu> skriver:
[Quoted text hidden]

AQEL engelsk versionTitti.pdf
168K

Barbara Roces <broces@sandiego.edu> Wed, Oct 9, 2013 at 8:18 AM
To: Bertil Axelsson <bertil.axelsson@jll.se>

Dear Mr. Axelsson,
My greatest appreciation to you and your contribution to the medical science research. Thank you so much for allowing me to use the AQEL instrument for my dissertation study. I'll be happy to email you my results.

Sincerely,

APPENDIX G

AQEL 20 – Quality of Life form

Before you fill in this form, we ask you to consider how things have been the past week. How you have felt? What has been bothering? What has been good?

Sometimes things are better, sometimes worse. Try to weigh together how things have been and circle the figure between 1 and 10 on the scale, which best corresponds with the last week. Do not ponder too long, just circle the figure which spontaneously seems to agree to your state. Only circle one figure at each question.

1. Approximately how many hours per day (8 a.m. to 8 p.m.) have you been lying down

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

One hour at most 10 hours or more

2. How much help have you needed with dressing and hygiene?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

No help at all Help with everything

3. How has your body strength been?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

None As healthy persons of same age

4. How much pain have you had during the last week?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Pain free Worst possible pain

5. How much nausea have you had during the week?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

None Worst possible nausea

6. Have you had any trouble with your bowel movements?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

None Worst possible

7. Have you felt breathlessness?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

None Worst possible

8. Have you been able to do what you like to do last week?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Not at all Yes, completely

9. How has your memory been for things lately?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Have had great difficulty in remembering No problem in remembering

10. Have you felt worried?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Not worried at all Very worried

11. Have you had difficulty sleeping?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

None at all Very difficult

12. How has your ability to concentrate been?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Very bad Very good

13. Have you felt depressed/low in mood?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Not at all Very depressed/low in mood

14. How much of your worries have you shared with any member of your family?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Nothing Everything

15. Have your friends regarded you as usual?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Not at all Completely as usual

16. Has your day felt meaningful?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Not at all Completely

17. Has anything made you happy last week?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Nothing A lot

18. How easy/hard has it been to get a hold of medical staff who know you when it has been needed?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Very easy Very hard

19. Have you received the medical care you have needed?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Not at all Completely

20. How has your quality of life been last week?

1-------2-------3-------4-------5-------6-------7-------8-------9-------10

Very poor Best possible

21. Has anything especially pleasant or unpleasant happened during the last week? In your family? With your disease? Write a couple of lines to explain.

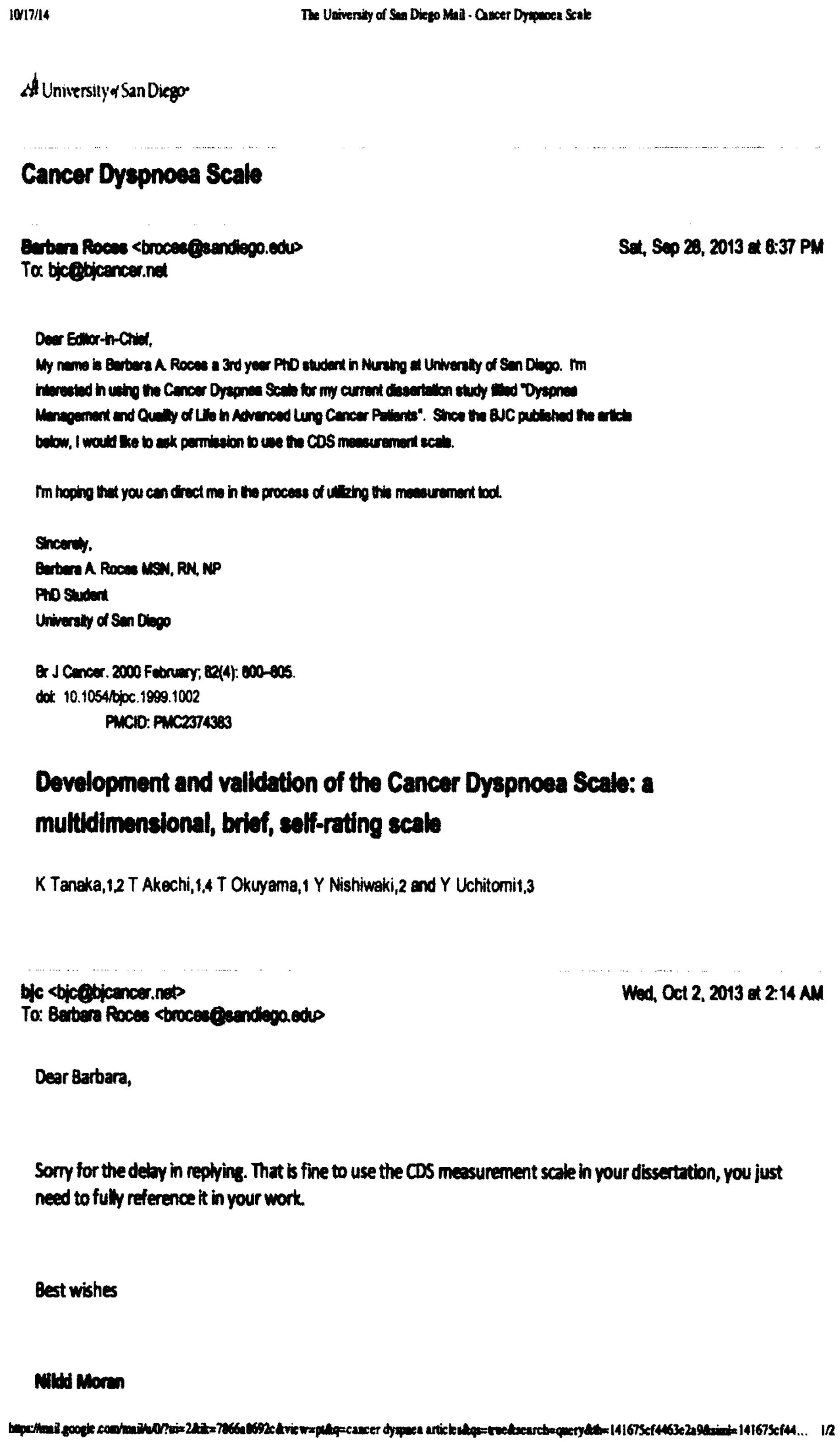
Reference

Qual Life Res (2010) 19:739-750

DOI 10.1007/s11136-010-9623-7

(Springer)

APPENDIX H



10/17/14 The University of San Diego Mail - Cancer Dyspnoea Scale

University of San Diego

Cancer Dyspnoea Scale

Barbara Roces <broces@sandiego.edu> **Sat, Sep 28, 2013 at 6:37 PM**
To: bjc@bjcancer.net

Dear Editor-in-Chief,
My name is Barbara A. Roces a 3rd year PhD student in Nursing at University of San Diego. I'm interested in using the Cancer Dyspnea Scale for my current dissertation study titled "Dyspnea Management and Quality of Life in Advanced Lung Cancer Patients". Since the BJC published the article below, I would like to ask permission to use the CDS measurement scale.

I'm hoping that you can direct me in the process of utilizing this measurement tool.

Sincerely,
Barbara A. Roces MSN, RN, NP
PhD Student
University of San Diego

Br J Cancer. 2000 February; 82(4): 800–805.
doi: 10.1054/bjoc.1999.1002
PMCID: PMC2374383

Development and validation of the Cancer Dyspnoea Scale: a multidimensional, brief, self-rating scale

K Tanaka,1,2 T Akechi,1,4 T Okuyama,1 Y Nishiwaki,2 and Y Uchitomi1,3

bjc <bjc@bjcancer.net> **Wed, Oct 2, 2013 at 2:14 AM**
To: Barbara Roces <broces@sandiego.edu>

Dear Barbara,

Sorry for the delay in replying. That is fine to use the CDS measurement scale in your dissertation, you just need to fully reference it in your work.

Best wishes

Nikki Moran

https://mail.google.com/mail/u/0/?ui=2&ik=7866a0692c&view=pt&q=cancer dyspnea article&qs=true&search=query&th=141675cf4463e2a9&siml=141675cf44… 1/2

APPENDIX I

The Cancer Dyspnea Scale

We would like to ask you about your breathlessness or difficulty in breathing. Please answer each question by circling only the numbers that best describes the breathing difficulty that you felt during the last few days. Base your response on your first impression.

1. Can you inhale easily?
   Not at All A little Somewhat Considerably Very Much

2. Can you exhale easily?
   Not at All A little Somewhat Considerably Very Much

3. Can you breathe slowly?
   Not at All A little Somewhat Considerably Very Much

4. Do you feel short of breath?
   Not at All A little Somewhat Considerably Very Much

5. Do you feel breathing difficulty accompanied by palpitations and sweating?
   Not at All A little Somewhat Considerably Very Much

6. Do you feel as if you are panting?
   Not at All A little Somewhat Considerably Very Much

7. Do you feel such breathing difficulties that you don't know what to do about it?
   Not at All A little Somewhat Considerably Very Much

8. Do you feel your breath is shallow?
   Not at All A little Somewhat Considerably Very Much

9. Do you feel your breathing may stop?
   Not at All A little Somewhat Considerably Very Much

10. Do you feel your airway has become narrower?
    Not at All A little Somewhat Considerably Very Much

11. Do you feel as if you are drowning?
    Not at All A little Somewhat Considerably Very Much

12. Do you feel as if something is stuck in your airway?
    Not at All A little Somewhat Considerably Very Much

Calculation Method

1. Add the scores for each factor together
   a. Factor 1 = (items 4+6+8+10+12) – 5
   b. Factor 2 = (items 5+7+9+11) – 4
   c. Factor 3 = 15- (items 1+2+3)
2. Add the total scores for each factor together

Reference:
British Journal of Cancer (2000) 82(4), 800-805. © 2000 Cancer Research Campaign