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

## Abstract

Dyspnea is 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. It has been found to create barriers in daily life among patients with advanced lung cancer which interferes with physical activities such as walking, work, and psychological activities such as disposition, taking pleasure in life, relationship with others, and sleep. A conceptual model of dyspnea experience within the core of patients with advanced lung cancer 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. Dyspnea is a symptom that is usually under-diagnosed and inadequately managed due to lack of recognition or availability of interventions. The impact of dyspnea management on the quality of life in advanced lung cancer patients requires more recognition and better quality of care. Despite the frequency and complexity of this symptom, little research has been conducted to specifically identify effective treatment in patients with advanced lung cancer. 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. Further investigations are needed in this area to assert the total dyspnea experience that could be influential in regards to the impact of dyspnea management on the quality of life in patients with advanced lung cancer.

## Introduction

Dyspnea is a common and distressing symptom in patients with lung cancer that 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 (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 (Mularski et al., 2010).

For lung cancer patients, living with an incurable disease means having to face the idea of dying (Kahana, 2000). Loneliness, anxiety and tension have a documented relationship with dyspnea exacerbation (Henoch, Bergman, Gustafsson, Gaston-Johansson, & Danielson, 2007). This intensifying emotional reactions lead to an unpleasant or troublesome feeling, causing stress, 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.

Lung cancer is the second most diagnosed cancer and the number one cause of death among men and women in the United States. Patients with advanced lung cancer perceive physical symptoms as weakness and fatigue (Henoch et al., 2007), and distress in relation to his/her perception of the symptom being experienced (McCorkle and Young, 1978). It also 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, with its physical aspect creating distress, a concept denoting physical implications beyond the current moment (Tishelman et al., 2005).

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 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. 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 and 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 address 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 that 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.

The 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. Therefore,

dyspnea cannot be fully addressed unless these physical and nonphysical factors are understood (Kamal, Maguire, Wheeler, Currow, & Abernethy 2011). Success is most likely when stressors and associative symptoms (anxiety, depression, panic attacks) are identified and addressed. The TOUS, therefore, is appropriate in guiding this study, as it provides a multidimensional framework that includes physiological, psychological, and situational factors that impact performance factors.

## Theoretical Definitions

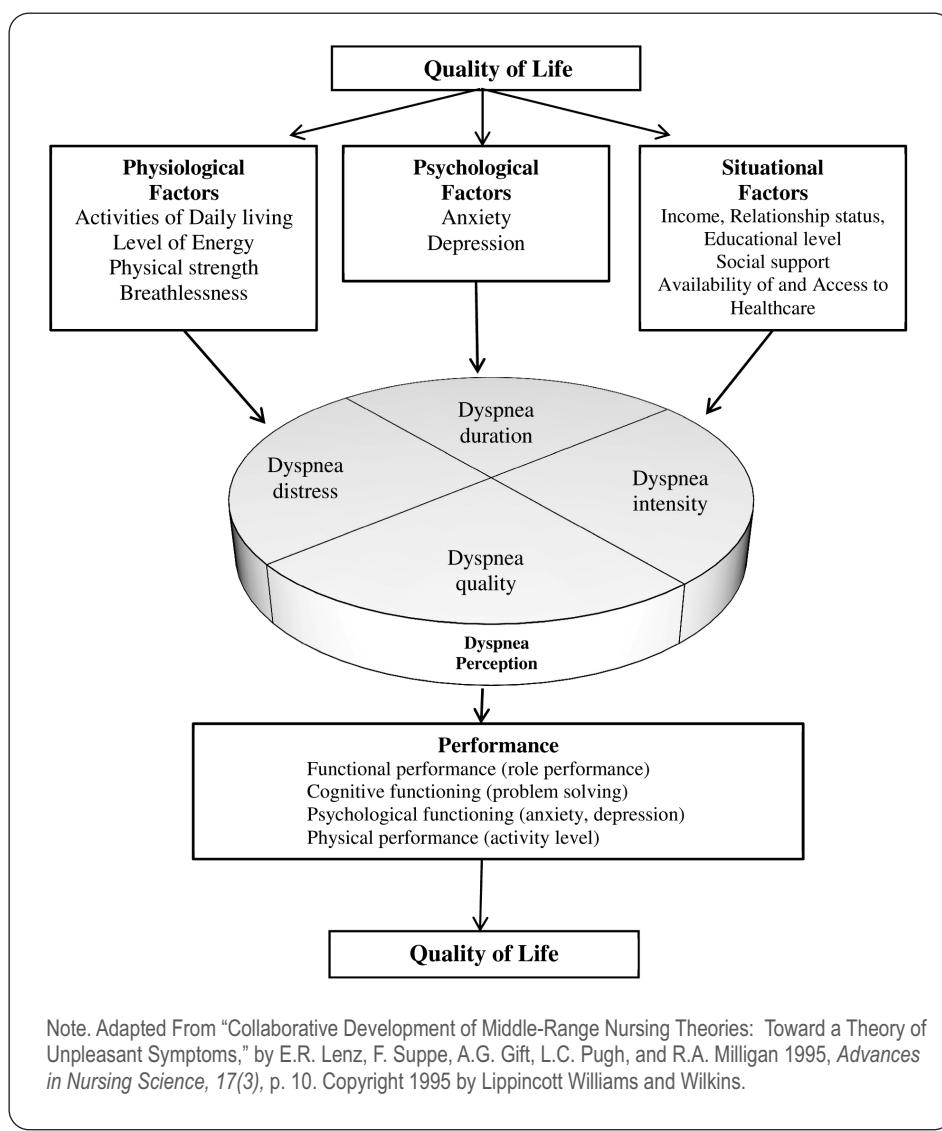
1) **Dyspnea.** Medical Dictionary for the Health and Professions and Nursing (2012), defined dyspnea as shortness of breath, a subjective difficulty or distress in breathing, usually associated with disease of the heart or lungs; occurs normally during intense physical exertion or at high altitude. The American Thoracic Society (1999) uses broad definition factors and states that 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 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, but can also lead to a limiting symptom that may be responsible for the economic and social disabilities (Bass, 1990).

2) **Perception.** In a concept analysis of this term, McDonald (2011), states 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

### Conceptual Model

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



influences from sociocultural aspect of humanity. It is never objective, but is rather 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.

3) **Quality of Life (QOL).** The term "quality of life" is often 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 that 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. 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.

## Summary of Literature Review

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 wellbeing.

A significant gap in the literature reviewed is currently on interventional strategies 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.

Overall, the literature review clearly indicates much is needed to further our understanding of dyspnea in relationship to quality of life. 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. 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.

## Methodology

### Research Design

A non-experimental, descriptive, correlational, cross-sectional design was conducted to facilitate an understanding of the relationship between dyspnea perception and QOL. Correlational research helped investigators establish a knowledge base for future research into causal inferences (Polit & Beck, 2012).

**Strengths.** This study sought to test and validate theories that are presently constructed about how and why phenomena happens. Dyspnea as a symptom, clearly impact one's perceived QOL. In utilizing the quantitative methodology for this study, it provides strength in that they produce answers that are solid and based on facts (Ratnesar & Mackenzie, 2006).

**Limitations.** Descriptive correlational study was used for sample description and relationship relevancy for this study. 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 stem 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).

## 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 decided purposely to select people who are judged to be typical of the population or particularly knowledgeable about the issue under study. 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 months of 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).

The initial available population for the study sample was only 61. 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. The sample of 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. 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.

### 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 is 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 a relative or healthcare provider. The questions were answered at the participant's home, a nursing facility or hospital. To minimize the burden on the participants, questionnaires were given to the participants during the initial meeting with the primary investigator, and then picked up the following week.

### 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).

### Data Collection Procedures

The data collection and management processes were handled by the primary investigator (PI). All data were retained and

**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

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 to ask about the purpose, type of study, concerns, as well as voluntary enrollment. Once questions were addressed to the participant's satisfaction and IRB approved, consent forms 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. Descriptive statistics were used for sample description and analysis. 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, based on Spearman's Rank and Pearson's correlational analyses. This 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 and the subscale components of dyspnea perception. Pearson's correlation coefficient described the 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 0.5. SPSS 20.0 software was utilized to perform the analyses described above.

### Results

A detailed analysis of research findings examined 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 is organized around the three Research aims:

#### Research Aim 1 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 8<sup>th</sup> 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

**Table 2.** Frequency Distributions for Demographic Information (N = 22)

Variables	Count	Percentage
<b>Gender</b>		
Male	10	45.5%
Female	12	54.5%
<b>Educational level</b>		
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%
<b>Relational Status</b>		
Single	3	13.6%
Married	9	40.9%
Divorced	2	9.1%
Widowed	8	36.4%
<b>Ethnicity/Race</b>		
Caucasian	18	81.8%
African American	1	4.5%
Hispanic Latino	2	9.1%
Asian	1	4.5%
<b>Age in Years</b>		
50-69	5	23%
70-79	5	23%
80-89	8	37%
90.00	4	18%
<b>Annual Income</b>		
.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%

included Caucasian (81.8%), African American (4.5%), Hispanic Latino (9.1%), and Asian (4.5%). The average age in years was  $77 \pm 11.40$  years old with a range of 50 to 90. The average annual income was  $\$40,000.00 \pm \$52,328.29$  with a range of \$0 to \$250,000.00 (Table 2).

### 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.

### 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-

**Table 3.** Descriptive Statistics for Assessment of Quality of Life at End of Life (N = 22)

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

SD= Standard Deviation, SE=Standard error

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.

Research 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

**Table 4. Descriptive Statistics for Cancer Dyspnea Scale and Subscales (N = 22)**

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

SD= Standard Deviation, SE=Standard error

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 ( $r=-.292, p = .19$ ).

Research 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 their 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

**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*

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).

## Discussion

As indicated by the literature review conducted in this study, dyspnea is the most prevalent symptom in patients with advanced lung cancer (Zhou et al., 2009). Even though the level of dyspnea is generally assessed through objective parameters that rely on respiratory function tests 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. 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.

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 that describes the triggering factors influencing dyspnea perception and QOL.

## Demographics

This study was conducted in a socio-economic status setting of an affluent neighborhood. As expected, socioeconomic status played an influential role in the ways of coping and adapting. Income, education, and health insurance coverage influenced access to appropriate early detection, treatment, and palliative care (Ward, et al., 2004).

The American Cancer Society's (2014) recent report indicated that 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.

## Patient Sample

The vulnerability of the patients' sample used for this study led to challenges, most especially regarding participants recruitment and retention. Terminally ill patients constituted a vulnerable group and had more difficulties due to presence of multi-symptoms and severe psychophysiological problem (Addington-Hall, 2007). 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 arise 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. 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 QOL 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 perceived 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 participants 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 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).

### Assessment of 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 suggested that 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 and is 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, 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), where 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 possible reason female participants in this 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.

The aims of this 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. For instance, as age increased, participants in general perceived lower quality life and lower breathing discomfort scores. Hence, the small sample size may have hindered the relevancy outcome of the study.

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. In addition, the AQEL and CDS questionnaires were well established instruments as evidenced by strong reliability and validity scores. 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 would benefit from implementing evidence based 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 actual attrition due to disease progression and death. Thompson, Sola, and Cubrana (2005) indicated that 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. This study also met with some difficulties in terms of enrollment retention due to disease progression and disease comorbidity. Severe cognitive decline was noted on potential participants due to brain metastasis or increase dose of narcotic medication. Severe weakness and pain were also noted in patients with pre-existing diabetes, renal failure and cardiovascular disease. The population of this study was also notably conducted in a setting consistent with an affluent community.

### 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 will enable nurses in a hospice setting to determine the efficacy of a preventative approach to reduce the burden of dyspnea. The need for continuing education that focuses on the multidisciplinary training may yield to improving treatment of dyspnea and the 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. 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 for the betterment

of enhanced symptom management and overall care of advanced lung cancer in a hospice setting.

## Conclusion

The study described the patients' perception of dyspnea in relationship to QOL at the end of life in advanced lung cancer population. This study investigated physiological, psychological, and situational factors that influenced participants' own perception of dyspnea correlated with their own QOL status. The findings of the study 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.

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 (Froggett & 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.

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 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.

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