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Determinants of Quality of Life in Patients Near the End of Life: A Longitudinal Perspective

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The primary objective of care for dying patients is to maintain or improve their quality of life (QOL) (Byock, 2000). However, major gaps exist in the knowledge regarding many problems related to end-of-life care, including how to enhance QOL for dying individuals (National Institutes of Health [NIH], 2004). When cure and prolongation of life are no longer possible, the individual's QOL and response to dying must be emphasized. The promotion of comfort and the enhancement of QOL become primary goals of nursing care (American Association of Colleges of Nursing, 1998). Most studies with dying patients have focused on hospice patients, but the majority of people in the United States do not receive hospice care when they are near the end of life (National Hospice and Palliative Care Organization, 2010). In fact, many patients with terminal illness actively seek treatment to prolong life or palliate symptoms. A high number of uncontrolled symptoms and a great amount of physical and psychological distress have been reported for patients who are nearing the end of life.

Although the literature examining QOL in patients near the end of life is small, patients in palliative care have been found to experience problems that affect all areas of their lives (McMillan & Weitzner, 2000). Diminished QOL often is seen as inevitable in the last stages of life; however, the limited research on QOL at the end of life has presented conflicted findings. Early work found that patients experience a dramatic decline in their QOL as they approach the end of life (Morris, Suissa, Sherwood, Wright, & Greer, 1986); however, QOL was assessed primarily as functional status, which is a limited measurement. In their extensive work with hospice patients, McMillan (1996), McMillan and Weitzner (2000), and McMillan and Small (2002) found this population to have a generally high QOL. Viewing QOL multidimensionally, McMillan (1996) and McMil-

Purpose/Objectives: To describe the quality of life (QOL) of patients near the end of life and to identify determinants of their QOL.

Design: Descriptive, longitudinal.

Setting: University-affiliated cancer center, two private oncologists' offices, and patients' homes.

Sample: 80 patients with either stage IIIb or IV lung cancer newly diagnosed in the previous month or recurrent lung cancer with distant disease.

Methods: Patients were interviewed for responses to instruments to assess demographic, physical, psychosocial, and spiritual characteristics. Baseline data were collected at the patients' places of oncology care. Home visits were made for the two-month and four-month data collection points.

Main Research Variables: QOL; symptom frequency, severity, and distress; functional status; anxiety; depression.

Findings: Fifty percent of patients died within five months of their lung cancer diagnosis. Patients reported a relatively high QOL that did not change significantly as they approached the end of life. Symptom distress was the strongest determinant of QOL, followed by symptom severity, symptom frequency, and depression.

Conclusions: QOL was most affected by symptoms experienced in patients with advanced lung cancer, particularly distress associated with symptoms. Interventions for symptom management must be implemented at diagnosis because patients in this population may approach the end of life quickly.

Implications for Nursing: A routine and thorough symptom assessment is imperative for patients with advanced lung cancer. Attention to symptom distress is important because of its effect on QOL.

lan and Weitzner (2000) reported that patients' QOL decreased primarily because of problems in physical functioning, although patients maintained a relatively high level of social and spiritual aspects of QOL. In patients with cancer newly admitted to hospice home care, McMillan and Small (2002) found widely varying but, again, relatively high QOL scores.

Although understanding QOL in patients receiving hospice care is important, many individuals at the end of life never become hospice patients but still require care that will improve or maintain their QOL. For example, patients with advanced cancer seek treatment while the progression toward death continues. Few studies exist that have examined QOL in this population. Research focusing on QOL in patients with advanced cancer has primarily measured QOL by symptom experience or functional status rather than with a multidimensional QOL tool. Patients with advanced cancer have a poorer QOL than patients diagnosed with other serious illnesses, with impairments primarily in physical and psychosocial functioning (Witteveen et al., 1999). A longitudinal study of patients with advanced cancer (about 33% with lung cancer) found that 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 increased, QOL decreased (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 than 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 other cancer populations, but the research available found that patients with advanced lung cancer typically have a lower QOL than patients with other types of cancer (Montazeri, Gillis, & McEwen, 1998). Many studies with patients with advanced lung cancer are clinical trials that focus on treatment effectiveness and prediction of survival. Attention to QOL in clinical trials has increased, but problems still exist, including poor compliance to QOL assessment, lack of uniformity in QOL assessment and data analysis (Tanvetyanon, Soares, Djulbegovic, Jacobsen, & Bepler, 2007), and high attrition (Bottomley, Efficace, Thomas, Vanvoorden, & Ahmedzai, 2003). In addition, QOL often is viewed in a narrow fashion and mostly as a secondary endpoint (Dooms & Vansteenkiste, 2004).

QOL seems to be disrupted for patients with lung cancer throughout their illness trajectory. Newly diagnosed patients reported decreased functioning, increased symptom severity, and a decrease in overall QOL when interviewed at initial diagnosis and three months after (Montazeri, Milroy, Hole, McEwen, & Gillis, 2003). Another study of newly diagnosed patients with advanced lung cancer found a high number of symptoms and decreased QOL (Temel et al., 2007). Sarna et al. (2005) reported that women with lung cancer at all disease stages reported major decreases in their QOL.

Symptom experience and functional status are important components of QOL in patients near the end of life.

Symptom management is an essential aspect of care for patients near the end of life, including patients with advanced cancer (Teno, Byock, & Field, 1999). Patients with terminal disease have identified their most prevalent unmet need as symptom control (Morasso et al., 1999). Studies have consistently identified a high prevalence of uncontrolled symptoms in individuals at the end of life. In the landmark SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risk of Treatments) project, more than 25% of patients with advanced lung cancer or metastatic colon cancer had serious pain in their last three months of life and more than 40% had serious pain in the last three days of life (McCarthy, Phillips, Zhong, Drews, & Lynn, 2000). Research has found a high number of uncontrolled symptoms in hospice patients (Ng & von Gunten, 1998) and in patients with advanced cancer, including lung cancer (Cella, 2004). The number of symptoms per patient has been strongly associated with increased psychological distress and decreased QOL (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Coyle, et al., 1994).

Although the number of symptoms has been found to correlate with increased emotional distress and QOL, the most frequent or intense symptom may not be the most distressing (Tishelman, Degner, & Mueller, 2000). The distress caused by a symptom is believed to provide the most information about QOL (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu, et al., 1994). Symptom distress is the degree of physical or mental discomfort caused by specific symptoms as reported by the patient (Rhodes & Watson, 1987). Patients with lung cancer have more symptom distress than patients with cancer at other sites, and patients with advanced lung cancer have more symptom distress than patients with early-stage disease (Degner & Sloan, 1995). Symptom distress has been significantly correlated with decreased functional status in patients undergoing palliative care (Schuit et al., 1998), women with lung cancer at various stages (Sarna, 1993), and men and women with advanced lung cancer (Sarna, 1998). In addition, patients indicating higher physical symptom distress were found to have increased emotional distress (Sarna, 1993). The relationship between symptom distress and QOL was examined by McMillan and Small (2002), who found symptom distress to be a predictor of QOL in hospice patients with advanced cancer in one study but not in a subsequent study (McMillan & Small, 2007). More work is needed to understand QOL at the end of life and its relationship with symptoms and other related factors.

In summary, patients near the end of life, including patients with advanced cancer, report a high number of uncontrolled symptoms and a large amount of symptom distress. The number of symptoms and degree of distress have been associated with decreased survival, decreased functional status, and increased emotional distress. The relationship between symptom distress

and QOL, when measured as a multidimensional concept, has rarely been studied in patients near the end of life, particularly in individuals who are not receiving hospice care. One of the most important components in achieving better care for dying patients is to decrease suffering through symptom control (Cooley, 2000). Many symptoms can be managed effectively; therefore, an increase in QOL could be accomplished through appropriate intervention. Understanding the symptom experience, particularly symptom distress, is crucial to improving care for individuals near the end of life.

The framework for this study viewed QOL as subjective (Cella, 2004; Lowy & Bernhard, 2004), dynamic (Ferrell, 1996), and multidimensional (Cella, 2004). Historically, no agreement has been reached related to the meaning of QOL; however, the concept is evolving and areas of conceptual agreement have surfaced (Varricchio, 2006). The dimensions encompassing QOL vary among researchers and clinicians but may include physical, functional, psychological, social, economic, and spiritual domains (Cella, 2004). Nurses were among the first to include the spiritual domain of individuals in QOL research (Ferrans, 1990), and others have since done likewise (Brady, Peterman, Fitchett, Mo, & Cella, 1999). For the current study, QOL was defined as "a composite of those aspects of life and human functioning that are considered essential for living a full life" (McMillan & Mahon, 1994, p. 437). QOL is viewed as encompassing four different but overlapping dimensions: physical, psychological, social, and spiritual.

Although researchers recognize that many dimensions contribute to QOL, the factor that has the most influence on determining QOL in patients near the end of life is not known. The purpose of this study was to describe the QOL of patients with advanced lung cancer near the end of life and to identify determinants of their QOL. Patients with advanced lung cancer were chosen for study because many patients with stage IIIB and IV disease experience a rapid progression toward death, despite treatment. The objective of the study was to examine the associations between QOL and each of the following: symptom distress, symptom frequency, symptom severity, depression, anxiety, functional status, and medical and demographic characteristics. To the authors' knowledge, no published study to date has examined those potential determinants of QOL at the end of life in a comprehensive manner.

Methods

Participants

Patients with advanced lung cancer were recruited from a local research and cancer treatment center and two private oncologists' offices. Inclusion criteria were being newly diagnosed within the previous month with stage IIIB or IV lung cancer or having a recurrent lung

cancer with distant disease, being aged 18 years or older, speaking English, residing within a 150-mile radius of the cancer center, and passing the Short Portable Mental Status Questionnaire (Pfeiffer, 1975). Procedures for this study were approved by the university institutional review board.

Procedure

Patients meeting inclusion criteria were interviewed for responses to a series of standardized instruments to assess demographic, physical, psychosocial, and spiritual characteristics. Data were collected at three time points

Table 1. Participant Demographic Characteristics at Baseline

Characteristic	n	%
Gender		
Male	52	65
Female	28	35
Race		
Caucasian	68	85
African American	12	15
Marital status		
Married	40	50
Divorced or separated	21	26
Widowed	12	15
Never married	6	8
No response	1	1
Annual family income (\$)		
5,000 or less	8	10
5,001–9,999	2	3
10,000–24,999	12	15
25,000–49,999	3	4
50,000 or more	3	4
No response	52	65
Employment status		
Retired	35	44
On disability	12	15
Unemployed	11	14
Full-time	9	11
Applied for disability	8	10
Leave of absence	4	5
Part-time	1	1
Education		
Grade school (1–8)	6	8
Some high school	20	25
Graduated high school	35	44
Technical or trade school	4	4
Some college	5	6
Graduated college	6	8
Completed graduate or professional school	3	4
No response	1	1
Religious preference		
Protestant	58	73
Catholic	13	16
Jewish	1	1
Muslim	1	1
No preference	6	8
No response	1	1

N = 80

Note. Because of rounding, not all percentages total 100.

(baseline, two months, and four months). Baseline data were collected at the patients' places of oncology care. Home visits were made at the two-month and four-month data collection points. Data on medical characteristics were obtained from patients' medical records.

Instruments

The **Hospice Quality of Life Index (HQLI)** (McMillan & Weitzner, 1998) is a 28-item self-report instrument that measures psychophysiologic, functional, and social-spiritual well-being. Each item has a numeric rating scale (0–10). The range of total scores is 0–280, with a higher score indicating higher QOL. Validity was supported by the HQLI differentiating between hospice patients and healthy controls using discriminant analysis ($p < 0.001$) and comparison of means ($p < 0.001$). Subscale alphas were 0.84, and the total scale alpha was 0.88. The HQLI has been used repeatedly with patients with cancer at the end of life.

The **Memorial Symptom Assessment Scale (MSAS)** (Portenoy, Thaler, Kornblith, Lepore, Friedlander-Klar, Kiyasu, et al., 1994) is a patient self-report instrument that assesses 32 physical and psychological symptoms common to people with cancer. Twenty-four symptoms are evaluated for frequency, severity, and distress, and eight symptoms are evaluated for severity and distress. The time period assessed is one week prior to completion of the tool. Validity has been supported by high correlations with clinical status and QOL measures. Alpha

reliabilities were 0.83–0.88. The MSAS consists of three subscales: psychological, physical, and the Global Distress Index (GDI). The GDI is recommended as the most accurate measure of a patient's distress and is calculated by the frequency scores for four psychological symptoms and the distress scores for six physical symptoms.

The **Karnofsky Performance Status (KPS)** scale (Karnofsky & Burchenal, 1949) was used to assess functional status. Information on ability to function at work and home, symptom severity, and the need for personal and medical care was used to score patients from 100 (asymptomatic, normal function) to 0 (equivalent to being dead). The KPS scale has been found to be a valid and reliable tool to assess functional status in patients with advanced cancer (Yates, Chalmer, & McKegney, 1980).

The **Hospital Anxiety and Depression Scale (HADS)** (Zigmond & Snaith, 1983) was used to assess anxiety and depression. The 14-item self-report scale was designed to measure depression (seven items) and anxiety (seven items) in patients with physical illness and has been used in studies of patients with advanced lung cancer (Hopwood & Thatcher, 1990). High levels of reliability and validity have been reported, as well as support for the scale's ability to measure anxiety and depression as two distinct emotional disturbances (Moorey et al., 1991).

Self-report was used at baseline to assess age, race, gender, marital status, education, employment status, income, and religious preference. Medical variables assessed via a chart review at each data collection point included lung cancer stage, time since diagnosis, treatment stage (newly diagnosed, active treatment with progression, or palliation), current treatment (radiation, chemotherapy, or none), time since last treatment, supportive care received (hospice or home health), and comorbid conditions.

Statistical Analysis

Longitudinal data were summarized using the area under the curve (AUC). This represents the overall value of an outcome measure or characteristic for each study participant over the entire course of the study. Random-effects regression models were used when comparing values across time points to make use of all available data. Statistical methods based on Fisher's z-transformation were used to test individual correlations for statistical significance and to construct 95% confidence intervals for the true correlation. Steiger's (1980) method for testing dependent correlations was used to assess for a significant difference between the absolute values of the correlations of any two variables with QOL. For example, Steiger's method was used to compare the correlation between QOL and symptom distress with the correlation between QOL and anxiety. Two-tailed tests with a significance level of 0.05 were used throughout. Continuous variables were summarized as mean and standard deviation.

Table 2. Medical Characteristics of Participants at Baseline

Characteristic	n	%
Stage of lung cancer		
IIIB	26	33
IV	54	68
Treatment stage^a		
Newly diagnosed	72	90
Active treatment with progression	11	14
Palliation	6	8
Current treatment		
Radiation only	47	59
Chemotherapy only	8	10
Radiation and chemotherapy	24	30
None	1	1
Supportive care received		
Hospice	2	3
Home care	6	8
None	72	90
Comorbid conditions		
Chronic lung disease	33	41
Hypertension	22	28
Heart disease	16	20
Arthritis	12	15

N = 80

^a Categories were not mutually exclusive.

Note. Because of rounding, not all percentages total 100.

Table 3. Change in Participants' Quality of Life Over the Course of the Study

Time	n	\bar{X}	SD
Baseline	80	194.6	40.3
Two months	55	195.2	40.9
Four months	41	196.6	44.2
Area under the curve	80	193.5	37.8

Note. $p = 0.612$ for comparison of baseline, two-month, and four-month quality of life using random-effects regression model.

The sample size calculation for this research was focused on the statistical comparison of dependent correlations. In addition to the sample size, the power of Steiger's test depends on the true difference between the two correlations being compared, as well as the true correlation between the two variables being correlated with QOL. Based on the results of Sarna (1993), the authors anticipated that the true correlation between symptom distress and QOL for the current study would be about 0.7. If the true correlation between another variable (e.g., anxiety) and QOL is about 0.4 and the true correlation between symptom distress and anxiety is 0.2 or larger, then a sample size of 80 yields power of at least 80% for detecting a difference in dependent correlations of this magnitude using $\alpha = 0.05$. Conversely, if the true correlation between anxiety and QOL is closer to that for symptom distress (e.g., 0.6), then $n = 80$ yields 80% power only if the true correlation between symptom distress and anxiety is 0.9 or greater. However, if the true correlations of symptom distress and anxiety with QOL are that close in magnitude, one may reasonably expect that the true correlation of symptom distress and anxiety would be high. Therefore, the authors determined that a sample size of 80 would provide adequate power for this study. A sample size of 80 also yields more than adequate power for hypothesis testing for individual correlations. Using a two-tailed test and $\alpha = 0.05$, $n = 80$ yields 80% power for detecting a true correlation of 0.3 or larger.

Results

Participants

Eighty participants with a mean age of 61 years were enrolled in the study. Data were collected from 55 participants at two months and from 41 participants at four months. Except for one patient, all attrition was caused by the death of the participant. Demographic and medical characteristics of the study participants are summarized in Tables 1 and 2. Most were men, Caucasian, and married or divorced or separated. The majority were diagnosed with stage IV lung cancer, with the remaining participants having stage III lung cancer. Ninety percent were newly diagnosed (within one month of entry into

the study), with a mean time since diagnosis of 23 (SD = 19) days. The most commonly occurring comorbid conditions were chronic lung disease, hypertension, heart disease, and arthritis. At baseline, 99% of patients were receiving radiation, chemotherapy, or a combination. Throughout the study, only 3% of the patients ever received hospice care.

Quality of Life in Patients Near the End of Life

Table 3 shows the mean score for QOL at each time point and reflects changes in QOL over the course of the study, along with the mean AUC, which combines the results at the three time points for each participant. No significant change occurred over the course of the study in terms of QOL; however, an examination of frequency polygons at each time point indicated a shift in the positive direction for the distribution of QOL as the study progressed (see Figure 1).

Correlations for Potential Determinants of Quality of Life

Table 4 gives the correlations of QOL with each of the potential determinants considered in this study. The variable most highly correlated with QOL was symptom distress, as measured by the GDI, followed by symptom frequency, symptom severity, and depression. Symptom distress, as measured by the total distress score for all items on the MSAS, was the next strongest correlate with QOL, followed by anxiety and functional status. Among the medical characteristics, only time since lung cancer diagnosis was significantly correlated with QOL. The only demographic characteristics correlated with QOL were age, being retired, and Protestant religion.

Based on the authors' review of the literature, they hypothesized that symptom distress, functional status,

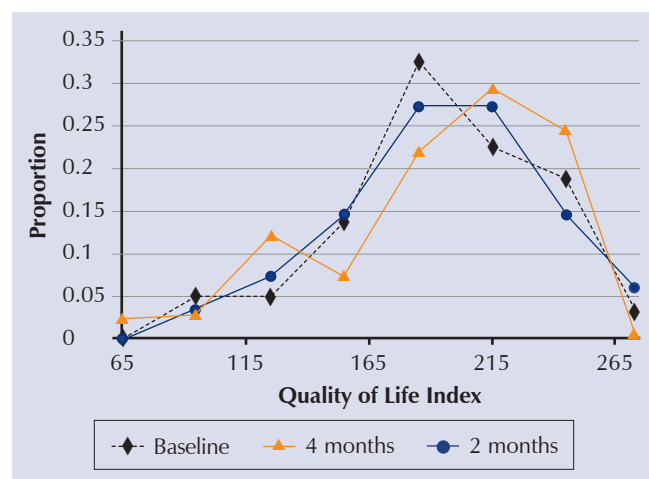


Figure 1. Frequency Polygons for Quality of Life Index at Baseline and Each Follow-Up Time Point Using All Available Data

Table 4. Correlations of Determinant Variables With Quality of Life

Variable	r	n	p
Determinants			
Symptom distress (GDI AUC)	−0.76	80	< 0.001
Symptom frequency (MSAS AUC)	−0.73	80	< 0.001
Symptom severity (MSAS AUC)	−0.66	80	< 0.001
Depression (HADS AUC)	−0.66	80	< 0.001
Symptom distress (MSAS AUC)	−0.53	80	< 0.001
Anxiety (HADS AUC)	−0.49	80	< 0.001
Functional status (KPS AUC)	0.34	80	0.002
Medical characteristics			
Lung cancer stage IV	−0.04	80	0.726
Time since lung cancer diagnosis	−0.22	80	0.049
Newly diagnosed cancer	−0.02	80	0.895
Active treatment with progression	−0.05	80	0.637
Palliation	0.15	80	0.18
Chemotherapy	−0.01	80	0.913
Radiation	0.08	80	0.458
Chemotherapy plus radiation	0.02	80	0.87
No treatment	−0.11	80	0.337
Received hospice care	0.05	80	0.677
Received home care	−0.02	80	0.875
Received no supportive care	−0.01	80	0.937
Arthritis	−0.07	80	0.561
Chronic lung disease	−0.06	80	0.593
Heart disease	−0.05	80	0.694
Hypertension	0.18	80	0.108
Demographic characteristics			
Age	0.28	80	0.013
Caucasian	−0.16	80	0.165
Male	0.2	80	0.073
Married	0.08	79	0.464
High school graduate	0.04	79	0.714
Retired	0.33	80	0.003
Protestant religion	0.24	79	0.032
Income	0.08	28	0.69

AUC—area under the curve; GDI—Global Distress Index; HADS—Hospital Anxiety and Depression Scale; KPS—Karnofsky Performance Status; MSAS—Memorial Symptom Assessment Scale

and depression would be the strongest determinants of QOL. Therefore, the authors performed a statistical comparison of the correlations of QOL with each of those variables versus the correlations of QOL with other potential determinants.

Symptom Distress

The correlation between QOL and symptom distress (as measured by the GDI) was -0.76 ($n = 80$, $p < 0.001$). No significant differences were found when comparing the correlation between QOL and symptom distress with the correlations between QOL and symptom frequency (-0.76 versus -0.73 , $p = 0.55$), symptom severity (-0.76 versus -0.66 , $p = 0.079$), or depression (-0.76 versus -0.66 , $p = 0.15$). When compared with the correlations between QOL and anxiety, functional status, and each of the medical and demographic characteristics, the correlation

between QOL and symptom distress was significantly greater in every case ($p < 0.001$ for every comparison).

Functional Status

The correlation between QOL and functional status (as measured by the KPS scale) was 0.34 ($n = 80$, $p = 0.002$). When compared with the correlations between QOL and symptom distress, symptom frequency, and depression, the correlation for functional status was significantly less in absolute value than that for frequency (0.34 versus -0.73 , $p < 0.001$), severity (0.34 versus -0.66 , $p = 0.002$), and depression (0.34 versus -0.66 , $p < 0.001$). When compared with the correlations between QOL and anxiety and the medical and demographic characteristics, the correlation between QOL and functional status was significantly greater than the correlations between QOL and each of the following dichotomized variables: lung cancer stage IV ($p = 0.034$), active treatment ($p = 0.049$), treatment with chemotherapy ($p = 0.044$), treatment with chemotherapy and radiation ($p = 0.031$), received home care ($p = 0.033$), received no supportive care ($p = 0.05$), chronic lung disease ($p = 0.04$), and heart disease ($p = 0.035$). All remaining correlations with QOL were not significantly different from the correlation between QOL and functional status.

Depression

The correlation between QOL and depression (as measured by the HADS) was -0.66 ($n = 80$, $p < 0.001$). No significant differences were found when comparing the correlation between QOL and depression with the correlation between QOL and symptom frequency (-0.66 versus -0.73 , $p = 0.27$) or symptom severity (-0.66 versus -0.66 , $p = 0.979$). When compared with the correlations between QOL and anxiety and the medical and demographic characteristics, the correlation between QOL and depression was significantly greater than the correlations between each of those other variables and QOL ($p < 0.001$ for every comparison except for anxiety, $r = -0.49$, $p = 0.024$; age, $r = 0.28$, $p = 0.001$; and retired, $r = 0.33$, $p = 0.002$).

Discussion

A major finding in the current study was the high attrition rate of participants because of death. Although 90% of participants were within one month of diagnosis of advanced lung cancer on entry into the study, only 50% were alive at the four-month data collection point. This highlights the need for palliative care aimed at symptom management and QOL to begin at diagnosis. Although 49% of participants died prior to the four-month data collection point, only 3% of the patients were receiving hospice care, supporting the assertion by Griffin et al. (2003) that patients with lung cancer are admitted too

late to hospice programs to experience the benefits inherent in hospice care. Models of end-of-life care must be developed and tested for individuals who are receiving treatment while rapidly progressing toward death.

The findings related to the QOL of the patients in the current study are consistent with previous investigators who reported a relatively high QOL among patients near the end of life (McMillan, 1996; McMillan & Small, 2002; McMillan & Weitzner, 2000). Although patients' QOL increased slightly over time, the change was not significant. This supports McMillan and Small's (2007) finding of no change in QOL over time in patients receiving home hospice care. Although the participants in this study were near the end of life, few were hospice patients. Studies examining QOL in patients with lung cancer have found that treatment may improve QOL (Fallowfield & Harper, 2005); however, the problem of attrition of the most symptomatic patients from clinical trials may be causing an overestimation of QOL.

The high rate of attrition of participants in the current study may have affected the magnitude of the QOL scores. Individuals who were able to live longer periods of time may have been healthier and may have had a higher overall QOL. Future studies with this population will require more frequent data collection points to more accurately reflect the rapid changes that may occur in patients' QOL. The fact that participants in this study died more quickly than anticipated, resulting in a substantial amount of missing data, is an issue frequently encountered in research with patients near the end of life (McMillan & Weitzner, 2003; NIH, 2004). Studies at the end of life should be planned using appropriate and rigorous analytic techniques to account for high attrition. When designing end-of-life studies, attrition must be anticipated, as it was in the current study.

Participants' QOL ratings may not have decreased over time as one might expect because of changing views of how people perceive QOL. As individuals approach the end of life, they may experience a change in their conceptualization of QOL (Lowy & Bernhard, 2004) as they adapt to their disease (often referred to as response shift). The extent to which patients adjust their perception of QOL is not known, but the current study's findings must be viewed with this possibility in mind. In addition, the HQLI may not have been sensitive to the changes in QOL that were occurring. Further research is needed.

Comparing findings among studies is difficult because of variations in population (hospice versus patients with cancer; early-stage versus advanced-stage cancer), conceptualization and measurement of QOL, and study attrition. However, QOL in patients near the end of life such as patients with advanced lung cancer clearly should be addressed because medical treatment is primarily palliative in nature. In addition, QOL has been found to be a predictor of survival for patients with cancer at various sites (Chang et al., 1998), includ-

ing lung cancer (Dharma-Wardene et al., 2004; Sarna & Reidinger, 2004). Efforts aimed at enhancing QOL may increase survival for patients. QOL in the current study was measured by the HQLI, a QOL tool developed for patients near the end of life and used in McMillan's studies (McMillan, 1996; McMillan & Mahon, 1994; McMillan & Small, 2002, 2007; McMillan & Weitzner, 1998). Measuring QOL with a different tool may yield different QOL scores.

The symptom frequency, severity, and distress reported by participants were not as high as expected. The high death rate may have affected the results. In addition, the treatment being received could have decreased tumor growth that may, in turn, have led to decreased symptom experience. The MSAS was used to measure the symptom experience because of the high number of symptoms it addresses. A more in-depth analysis of the symptoms that were most problematic for patients with advanced lung cancer is needed.

Several study variables were significantly correlated with QOL. The significant correlations of QOL with symptom distress, frequency and severity, anxiety, depression, and functional status support others' findings that a high number of symptoms and the severity of the symptoms led to decreased QOL (Longman, Braden, & Mishel, 1999). This underscores the importance of thorough assessments to identify the myriad difficulties patients with advanced lung cancer may experience. Of note, four variables—symptom distress, symptom frequency, symptom severity, and depression—had significantly higher correlations with QOL than any of the other potential determinants examined in the current study. This indicates that patients experiencing the most symptom frequency, severity, and distress, as well as depression, reported the lowest QOL, and that those four characteristics are the most important determinants of lower QOL. For patients with advanced lung cancer, nurses and other healthcare professionals should pay particular attention to the assessment of those concepts and be ready to intervene as appropriate for patients' overall symptoms, including depression. The strong association of symptom distress with decreased QOL is an important finding that has not been reported previously in this population and warrants additional study.

Researchers may be hesitant to study patients near the end of life because of concern related to patients not wanting to participate. Fewer than 10 individuals approached for inclusion in the current study declined to participate. Except for one patient, all attrition was caused by death. The patient who did not complete the study wanted the nurse doing data collection to visit but did not wish to complete the instruments. Many stated they wanted to participate to help others in the future. This supports earlier findings that indicated patients near the end of life have a desire to help others (Hermann, 2001).

Respondent burden was a major consideration during study design. Instruments were chosen in an attempt to ascertain as much information in as expeditious a manner as possible. Although included in the total HQLI score, spirituality as a separate concept and its relationship to QOL were not examined. The importance of spirituality to patients near the end of life has been documented (Hermann, 2007), and further exploration of the association of spirituality with QOL in patients near the end of life is needed.

Conclusion

Significant gaps exist in the knowledge related to the care of individuals near the end of life. One of the most important components in achieving better care for dying patients is to decrease suffering through control of symptoms (Cooley, 2000). Many symptoms can be man-

aged effectively; therefore, an increase in QOL could be effected through appropriate intervention for the various symptoms that patients experience. Understanding the symptom experience, particularly symptom distress, is crucial to improving care for patients near the end of life.

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References

- American Association of Colleges of Nursing. (1998). *Peaceful death*. Report presented at the meeting of the Robert Wood Johnson End-of-Life Care Roundtable, Washington, DC.
- American Cancer Society. (2010). *Cancer facts and figures 2010*. Retrieved from <http://www.cancer.org/acs/groups/content/@nho/documents/document/acspc-024113.pdf>
- Bottomley, A., Efficace, F., Thomas, R., Vanvoorden, V., & Ahmedzai, S. (2003). Health-related quality of life in non-small-cell lung cancer: Methodologic issues in randomized controlled trials. *Journal of Clinical Oncology*, 21, 2982–2992. doi: 10.1200/JCO.2003.01.203
- Brady, M.J., Peterman, A.H., Fitchett, G., Mo, M., & Cella, D. (1999). A case for including spirituality in quality-of-life measurement in oncology. *Psycho-Oncology*, 8, 417–428.
- Byock, I. (2000). Completing the continuum of cancer care: Integrating life-prolongation and palliation. *CA: A Cancer Journal for Clinicians*, 50, 123–132.
- Cella, D. (2004). Quality-of-life considerations in patients with advanced lung cancer. *Seminars in Oncology*, 31(6, Suppl. 11), 16–20. doi: 10.1053/j.seminoncol.2004.10.004
- Chang, V.T., Thaler, H.T., Polyak, T.A., Kornblith, A.B., Lepore, J.M., & Portenoy, R.K. (1998). Quality of life and survival: The role of multidimensional symptom assessment. *Cancer*, 83, 173–179.
- Cooley, M.E. (2000). Symptoms in adults with lung cancer: A systematic research review. *Journal of Pain and Symptom Management*, 19, 137–153.
- Degner, L.F., & Sloan, J.A. (1995). Symptom distress in newly diagnosed ambulatory cancer patients and as a predictor of survival in lung cancer. *Journal of Pain and Symptom Management*, 10, 423–431.
- Dharma-Wardene, M., Au, H.J., Hanson, J., Dupere, D., Hewitt, J., & Feeny, D. (2004). Baseline FACT-G score is a predictor of survival for advanced lung cancer. *Quality of Life Research*, 13, 1209–1216. doi: 10.1023/B:QURE.0000037481.36604.eb
- Dooms, C.A., & Vansteenkiste, J.F. (2004). Treatment of patients with advanced non-small cell lung cancer: Importance of symptom management and attention to quality of life or clinical benefit. *American Journal of Cancer*, 3, 281–290. doi: 10.2165/00024669-200403050-00002
- Fallowfield, L.J., & Harper, P. (2005). Health-related quality of life in patients undergoing drug therapy for advanced non-small-cell lung cancer. *Lung Cancer*, 48, 365–377. doi: 10.1016/j.lungcan.2004.11.018
- Ferrans, C.E. (1990). Development of a quality-of-life index for patients with cancer. *Oncology Nursing Forum*, 17(3, Suppl.), 15–19.
- Ferrell, B.R. (1996). The quality of lives: 1,525 voices of cancer. *Oncology Nursing Forum*, 23, 907–916.
- Griffin, J.P., Nelson, J.E., Koch, K.A., Niell, H.B., Ackerman, T.F., Thompson, M., . . . American College of Chest Physicians. (2003). End-of-life care in patients with lung cancer. *Chest*, 123(1, Suppl.), 312S–331S. doi: 10.1378/chest.123.1_suppl.312S
- Hermann, C.P. (2001). Spiritual needs of dying patients: A qualitative study. *Oncology Nursing Forum*, 28, 67–72.
- Hermann, C.P. (2007). The degree to which spiritual needs of patients near the end of life are met. *Oncology Nursing Forum*, 34, 70–78. doi: 10.1188/07.ONF70-78
- Hopwood, P., & Thatcher, N. (1990). Preliminary experience with quality of life evaluation in patients with lung cancer. *Oncology*, 4, 158–162.
- Hwang, S.S., Chang, V.T., Fairclough, D.L., Cogswell, J., & Kasimis, B. (2003). Longitudinal quality of life in advanced cancer patients: Pilot study results from a VA medical cancer center. *Journal of Pain and Symptom Management*, 25, 225–235.
- Karnofsky, D.A., & Burchenal, J.H. (1949). The clinical evaluation of chemotherapeutic agents in cancer. In C.M. McLeod (Ed.), *Evaluation of chemotherapeutic agents* (pp. 191–205). New York, NY: Columbia Press.
- Longman, A.J., Braden, C.J., & Mishel, M.H. (1999). Side-effects burden, psychological adjustment, and life quality in women with breast cancer: Pattern of association over time. *Oncology Nursing Forum*, 26, 909–915.
- Lowy, A., & Bernhard, J. (2004). Quantitative assessment of changes in patients' constructs of quality of life: An application of multilevel models. *Quality of Life Research*, 13, 1177–1185.
- McCarthy, E.P., Phillips, R.S., Zhong, Z., Drews, R.E., & Lynn, J. (2000). Dying with cancer: Patients' function, symptoms, and care preferences as death approaches. *Journal of the American Geriatric Society*, 48(5, Suppl.), S110–S121.
- McMillan, S.C. (1996). The quality of life of patients with cancer receiving hospice care. *Oncology Nursing Forum*, 23, 1221–1228.
- McMillan, S.C., & Mahon, M. (1994). Measuring quality of life in hospice patients using a newly developed Hospice Quality of Life Index. *Quality of Life Research*, 3, 437–447.
- McMillan, S.C., & Small, B.J. (2002). Symptom distress and quality of life in patients with cancer newly admitted to hospice home care. *Oncology Nursing Forum*, 29, 1421–1428. doi: 10.1188/02.ONF1421-1428
- McMillan, S.C., & Small, B.J. (2007). Using the COPE intervention for family caregivers to improve symptoms of hospice homecare patients: A clinical trial. *Oncology Nursing Forum*, 34, 313–321. doi: 10.1188/07.ONF313-321

- McMillan, S.C., & Weitzner, M. (1998). Quality of life in cancer patients: Use of a revised hospice index. *Cancer Practice*, 6, 282–288.
- McMillan, S.C., & Weitzner, M. (2000). How problematic are various aspects of quality of life in patients with cancer at the end of life? *Oncology Nursing Forum*, 27, 817–823.
- McMillan, S.C., & Weitzner, M.A. (2003). Methodologic issues in collecting data from debilitated patients with cancer near the end of life. *Oncology Nursing Forum*, 30, 123–129. doi: 10.1188/03.ONF.123-129
- Montazeri, A., Gillis, C.R., & McEwen, J. (1998). Quality of life in patients with lung cancer. *Chest*, 113, 467–481.
- Montazeri, A., Milroy, R., Hole, D., McEwen, J., & Gillis, C.R. (2003). How quality of life data contribute to our understanding of cancer patients' experiences? A study of patients with lung cancer. *Quality of Life Research*, 12, 157–166. doi: 10.1023/A:1022232624891
- Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., . . . Bliss, J. (1991). The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *British Journal of Psychiatry*, 158, 255–259. doi: 10.1192/bjp.158.2.255
- Morasso, G., Capelli, M., Viterbori, P., Di Leo, S., Alberisio, A., Costantini, M., . . . Henriquet, F. (1999). Psychological and symptom distress in terminal cancer patients with met and unmet needs. *Journal of Pain and Symptom Management*, 17, 402–409.
- Morris, J.N., Suissa, S., Sherwood, S., Wright, S.M., & Greer, D. (1986). Last days: A study of the quality of life of terminally ill cancer patients. *Journal of Chronic Diseases*, 39(1), 47–62.
- National Hospice and Palliative Care Organization. (2010). *NHPCO facts and figures: Hospice care in America*. Retrieved from http://www.nhpc.org/files/public/Statistics_Research/Hospice_Facts_Figures_Oct-2010.pdf
- National Institutes of Health. (2004). *NIH State-of-the-Science Conference statement on improving end-of-life care*. Retrieved from <http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024PDF.pdf>
- Ng, K., & von Gunten, C.F. (1998). Symptoms and attitudes of 100 consecutive patients admitted to an acute hospice/palliative care unit. *Journal of Pain and Symptom Management*, 16, 307–316.
- Pfeiffer, E. (1975). A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *Journal of the American Geriatrics Society*, 10, 433–441.
- Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar, H., Coyle, N., . . . Hoskins, W. (1994). Symptom prevalence, characteristics, and distress in a cancer population. *Quality of Life Research*, 3, 183–189.
- Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar, H., Kiyasu, E., . . . Norton, L. (1994). The Memorial Symptom Assessment Scale: An instrument for evaluation of symptom prevalence, characteristics, and distress. *European Journal of Cancer*, 30, 1326–1336.
- Rhodes, V.A., & Watson, P.M. (1987). Symptom distress. The concept: Past and present. *Seminars in Oncology Nursing*, 3, 242–247.
- Sarna, L. (1993). Correlates of symptom distress in women with lung cancer. *Cancer Practice*, 1, 21–28.
- Sarna, L. (1998). Effectiveness of structured nursing assessment of symptom distress in advanced lung cancer. *Oncology Nursing Forum*, 25, 1041–1048.
- Sarna, L., Brown, J.K., Cooley, M.E., Williams, R.D., Chernecky, C., Padilla, G., & Danao, L.L. (2005). Quality of life and meaning of illness of women with lung cancer. *Oncology Nursing Forum*, 32, E9–E19. doi: 10.1188/05.ONF.E9-E19
- Sarna, L., & Reidinger, M.S. (2004). Assessment of quality of life and symptom improvement in lung cancer clinical trials. *Seminars in Oncology*, 31(3, Suppl. 9), 1–10. doi: 10.1053/j.seminoncol.2004.04.007
- Schuit, K.W., Sleijfer, D.T., Meijler, W.J., Otter, R., Schakenraad, J., van den Bergh, F.C., & Meyboom-de Jong, B. (1998). Symptoms and functional status of patients with disseminated cancer visiting outpatient departments. *Journal of Pain and Symptom Management*, 16, 290–297.
- Steiger, J. (1980). Tests for comparing elements of a correlation matrix. *Psychological Bulletin*, 87, 245–251.
- Tanvetyanon, T., Soares, H.P., Djulbegovic, B., Jacobsen, P.B., & Bepler, G. (2007). A systematic review of quality of life associated with standard chemotherapy regimens for advanced non-small-cell lung cancer. *Journal of Thoracic Oncology*, 2, 1091–1097. doi: 10.1097/JTO.0b013e31815cff64
- Temel, J.S., Jackson, V.A., Billings, J.A., Dahlin, C., Block, S.D., Buss, M.K., . . . Lynch, T.J. (2007). Phase II study: Integrated palliative care in newly diagnosed advanced non-small-cell lung cancer patients. *Journal of Clinical Oncology*, 25, 2377–2382. doi: 10.1200/JCO.2006.09.2627
- Teno, J.M., Byock, I., & Field, M.J. (1999). Research agenda for developing measures to examine quality of care and quality of life of patients diagnosed with life-limiting illness. *Journal of Pain and Symptom Management*, 17(2), 75–82.
- Tishelman, C., Degner, L.F., & Mueller, B. (2000). Measuring symptom distress in patients with lung cancer. A pilot study of experienced intensity and importance of symptoms. *Cancer Nursing*, 23, 82–90.
- Varricchio, C.G. (2006). Measurement issues in quality-of-life assessments. *Oncology Nursing Forum*, 33(1, Suppl.), 13–21. doi: 10.1188/06.ONF.S1.13-21
- Witteveen, P.O., Jacobs, H.M., van Groenestijn, M.A.C., Lodder, A.C., van Boxtel, A.H., Nieuwland, M., . . . Blijham, G.H. (1999). Assessment of the quality of life of patients with advanced and end-stage cancer or serious infections with a symptom-based or impact-based instrument. *Supportive Care in Cancer*, 7, 64–70.
- Yates, J.W., Chalmer, B., & McKegney, F.P. (1980). Evaluation of patients with advanced cancer using the Karnofsky performance status. *Cancer*, 45, 2220–2224.
- Zigmond, A.S., & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67, 361–370.