



Symptom frequency, severity, and quality of life among persons with three disease trajectories: cancer, ALS, and CHF



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ABSTRACT

Purpose: National reports on end-of-life symptom management reveal a gap in the evidence regarding symptoms other than pain and studies of diseases other than cancer. This study examines the frequency and severity of symptoms and quality of life (QOL) in persons with advanced cancer, amyotrophic lateral sclerosis (ALS), and congestive heart failure (CHF).

Methods: The present study is a cross-sectional examination of symptoms and QOL measured using the McGill QOL Questionnaire, among 147 participants.

Results: Forty one percent of participants had advanced cancer, 22% had ALS, and 37% had advanced CHF. A total of 266 symptoms were reported, with the common symptom categories being discomfort/pain, weakness/fatigue/sleep, and respiratory. Participants with CHF had the highest mean symptom severity and the lowest QOL.

Conclusion: Clinicians should be aware and attentive for symptoms other than pain in patients with advanced illness. Studies on diseases other than cancer, such as CHF and ALS, are important to improve symptom management in all disease groups.

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1. Introduction

During the last decade, several national reports have addressed problems with symptom management at the end of life in the U.S. In

2003, the National Cancer Policy Board in the Institute of Medicine issued a report, *Describing Death in America: What We Need to Know* (Lunney, Foley, Smith, & Gelband, 2003). In this report, authors concluded that while a great deal was known about where and when individuals die, insufficient information about the quality of life near death has limited the development of interventions to guide care at the end of life (Lunney et al., 2003). In 2004, the National Institute of Health (NIH) *State-of-the-Science Conference Statement on Improving End-of-Life Care* concluded that many Americans were dying in pain (National Institutes of Health, 2004). Although the literature on managing this symptom in persons with advanced cancer was growing, the report found that there is far less information on symptoms other than pain and on patients suffering from diseases other than cancer (National Institutes of Health, 2004). Likewise, the recent 2014 Institute of Medicine Report, *Dying In America: Improving Quality and Honoring Individual Preferences Near the End of Life* proposed the management of pain and other symptoms to be a core component of quality end-of-life care (Institute of Medicine, 2014). The 2011 NIH Report, *Science of Compassion: Future Directions in End-of-Life and Palliative Care* similarly recommended that persons with a variety of trajectories of illness be studied (National Institute of Nursing Research & Partners, 2011).

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2. Background

Symptoms in advanced illness vary according to the particular disease. According to the American Cancer Society common symptoms among cancer patients include unexplained weight loss, fever, fatigue, pain, and skin changes (American Cancer Society, n.d.). The five most prevalent symptoms in the last year of life among patients with cancer are fatigue, weakness, pain, shortness of breath, and cough (Doorenbos, Given, Given, & Verbitsky, 2006). In the last month of life, in addition to pain and fatigue, the symptoms most commonly reported are a reduced sense of well-being, decreased appetite, and trouble sleeping (Semionov, Singer, & Shvartzman, 2012). By contrast, patients with amyotrophic lateral sclerosis (ALS) most commonly report symptoms of muscle weakness, twitching and muscle cramping, difficulty speaking, and shortness of breath (ALS Association, n.d.). At the end of life patients with ALS commonly experience symptoms of constipation, pain, cough, insomnia, dyspnea, and sialorrhea (hypersalivation) (Simmons, 2005). In patients with congestive heart failure (CHF), common symptoms include shortness of breath, persistent coughing, edema, fatigue, and impaired thinking (American Heart Association, n.d.). Similarly, patients with CHF at the end of life report symptoms of shortness of breath, weakness, fatigue, nausea, anorexia, constipation, edema, cough, altered mental status, anxiety, depression, pain, and trouble sleeping (Bekelman, Rumsfeld, Havranek, et al., 2009; Whellan, Goodlin, Dickinson, et al., 2014).

What is not well known is whether the symptom severity and quality of life differ among patients who are in the advanced stages of GI/pancreatic cancer, ALS or CHF. The 2-year mortality rate and expected disease trajectories differ among patients with one of these three diseases. In this sample the 2-year mortality rate was 92% for persons with cancer, 81% for ALS, and 60% for CHF (Authors, 2007). The expected disease trajectories were a rapid, prolonged, or unpredictable decline in health status from diagnosis to death for persons with advanced cancer, ALS, and CHF respectively (Lynn & Adamson, 2003). Health professionals may assume that patients with advanced cancer who have the highest 2-year mortality rate and the most rapid trajectory of illness, would have the most severe symptoms but we know of no studies that have examined this. Therefore, the purpose of this study was to analyze the differences in the symptom type and severity of persons in these three disease groups and the relationship of symptom severity to quality of life.

3. Methods

3.1. Design and sample

A purposive sample of 147 patients with advanced cancer, ALS, and CHF who participated in a longitudinal, multi-site study was obtained. The purpose of the main study was to describe the natural history of health care decision making in participants from diagnosis with advanced disease until death (Authors, 2005, 2007). This cross-sectional analysis focuses specifically on symptoms and quality of life (QOL) using data collected from all patients at baseline (the first interview timepoint).

Inclusion criteria were: Spanish or English speaking adults 18 and older who were within 8 weeks of being (1) diagnosed with non-resectable non-small cell lung cancer or stage III or IV gastrointestinal cancer, (2) hospitalized for New York Heart Association Class III or IV CHF, or (3) within 6 weeks of being diagnosed with ALS. The study was approved by the Johns Hopkins Hospital and Saint Vincent Hospital Institutional Review Boards.

3.2. Instrumentation

Symptoms and quality of life were measured at baseline with the McGill Quality of Life (QOL) Questionnaire, a 17-item, 10-point Likert scale (Cohen, Mount, Strobel, & Bui, 1995) that has been used with

subjects who have cancer and ALS (Rousseau, Pietra, Blaya, & Catala, 2011; Tang, Liu, Lin, et al., 2014). The present study analyzed data from the McGill QOL Questionnaire—Part A question one, and Part B questions 1–3. Part A question one asked the following question that provided a global measure of QOL: “Considering all parts of my life—physical, emotional, social, spiritual, and financial—over the past two (2) days, the quality of my life has been...” on a 10 point-Likert scale, ranging from very bad (0) to excellent (10). Part B questions 1–3 asked participants to list up to three troublesome symptoms in their own words, and rate the severity of the symptoms on a 10 point-Likert scale ranging from no problem (0) to a tremendous problem (10). These three questions had a Cronbach’s alpha of 0.85 (Cohen, Mount, Tomas, & Mount, 1996) in the present study.

For this analysis, the level of symptom severity was measured using the severity rating of the first identified troublesome symptom. All three symptom items were examined to determine the frequency and type of symptoms for the sample reported.

3.3. Procedures

Two of the authors classified all of the troublesome symptoms that were identified by participants into categories. Other study team members reviewed the classification, and revisions were made by the consensus of the entire study team.

3.4. Analysis

Using SPSS Version 16 [International Business Machines Corp (IBM), Armonk, New York], descriptive statistics were used to describe the sample characteristics and the number, type and severity of symptoms. One-way analysis of variance (ANOVA) was used to compare the mean QOL across the disease groups. ANOVA was also used to compare QOL across groups with different numbers of symptoms. Independent t-tests were used to examine the difference in mean QOL scores between males and females and between race categories dichotomized as Whites and non-Whites. The severity of symptoms was measured both as a continuous variable (0–10), and as a categorical variable: mild (0–3), moderate (4–7), and severe (8–10) (Abraham, Kutner, & Beaty, 2006). Severity scores of 0 were excluded in the severity analysis, to avoid distortion of results. The Kruskal-Wallis test was used to compare distributions of maximum and average severity across disease groups.

A multivariate linear model was fit to assess the relationship between symptom severity, sex, race, diagnosis and number of symptoms on QOL. An interaction term was used to test whether the relationship between symptom severity and QOL differed by sex. All tests were performed at a $p = 0.05$ statistical significance level.

4. Results

4.1. Sample characteristics

Among the 147 participants, 41% ($n = 60$) had advanced cancer, 22% ($n = 32$) had ALS, and 37% ($n = 55$) had advanced CHF. The sample was 65% White ($n = 94$) and 63% male ($n = 93$). The age of participants ranged from 27 to 89 years old with a mean of 62 years ($SD = 12.5$). Sixty-four percent ($n = 94$) had equal to or less than high school education. Table 1 provides further detail on the characteristics of the sample. There were statistically significant differences in religious affiliation, educational attainment and race across the diagnostic groups (Table 1).

4.2. Frequency and severity of symptoms

Overall 35% ($n = 51$) of participants reported three troublesome symptoms; 27% ($n = 39$), one symptom; 25% ($n = 37$), two symptoms; and 14% ($n = 20$), no symptoms. About one-third of participants in each disease group reported having three troublesome symptoms: 32% ($n =$

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