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The impact of lung cancer surgery on quality of life trajectories in patients and family caregivers

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ABSTRACT

Objectives: Family caregivers (FCGs) play an important role in the quality of life (QOL) of lung cancer patients. FCGs experience significant psychological distress related to their caregiving role, but there is relatively little data about FCG QOL after cancer surgery. We sought to describe QOL trajectories for patients and their FCGs after lung cancer surgery.
Methods: This is a secondary analysis of a larger, prospective QOL study, testing the effectiveness of an interdisciplinary palliative care intervention for lung cancer patients and FCGs in a single institution. The intervention included interdisciplinary care planning and formal education sessions for both patients and FCGs. This subset analysis included patients who underwent surgery and had a matching FCG with complete QOL data (41 pairs of patients and caregivers out of 112 surgical patients). Patient QOL was assessed with the Functional Assessment of Cancer Therapy-Lung tool. FCG QOL was assessed with the FCG version of the City of Hope QOL tool. Psychological distress was assessed using the Distress Thermometer.
Results: Psychological distress levels were highest for patients (3.8/10) and FCGs (5.1/10) before surgery. Distress levels decreased among patients at six (2.9/10) and 12 weeks (2.2/10, $p = 0.001$) later, but remained elevated among FCGs (4.2/10 and 4.4/10, $p = 0.157$). Compared with usual care, patients in the intervention group reported improved physical and functional QOL outcomes at 12 weeks ($p < 0.01$), but there was no significant benefit seen for FCGs in any domain ($p > 0.05$).
Conclusions: FCGs of lung cancer patients experience significant psychological distress. FCGs continue to have impaired QOL 3 months after surgery. The trajectory of QOL for FCGs does not mirror that of patients. Our palliative care intervention showed improved QOL outcomes for this subset of patients but was not effective for their FCGs.

Trial Registration: NCI sponsored, trial identifier NCT00823667 https://clinicaltrials.gov/show/NCT00823667.

1. Introduction

Due to changes in the healthcare environment as well as advances in surgical care, patients are discharged from the hospital earlier and earlier following major surgery. This is despite an aging population with greater comorbidities. As such, a greater proportion of the caregiver burden has fallen on informal family caregivers (FCGs) [1]. Previous studies have demonstrated that FCGs of cancer patients experience decreased quality of life (QOL) and psychological distress related to their caregiver role [2].

Lung cancer patients often require significant care due to extensive comorbidities. The median age at lung cancer diagnosis is 70 [3]. Chronic obstructive pulmonary disease (COPD) and other smoking related illnesses are common [4]. Patients with lung cancer report greater levels of psychological distress than other types of cancer [5]. Baseline quality of life in these patients is often significantly lower than the general population [6]. These issues may

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be exacerbated by side effects of treatments. There is extensive data illustrating the significant impact of pulmonary resection on patient QOL [7]. In the period immediately following surgery for lung cancer, patients experience pain, fatigue, and decreased physical function. It may take patients three months or longer to regain physical quality of life [8].

There is an increasing awareness of the importance of FCGs in helping patients cope with cancer. A number of studies have examined interventions for FCGs of cancer patients [9]. Psychological, informational, and group interventions have all demonstrated varying degrees of improvements in FCG QOL and caregiver burden. There is relatively little data about interventions specific for FCGs of patients with lung cancer and there is even less information about surgical patients.

In order to further investigate the effect of lung cancer surgery on QOL of patients and FCGs, we performed a subset analysis of data collected as part of a broader National Cancer Institute-supported Program Project investigating an interdisciplinary palliative care intervention for patients with lung cancer and their FCGs [10,11].

2. Methods

2.1. Study design

This paper presents secondary analysis of QOL, symptoms, and psychological distress data for surgically-treated patients and their FCGs in an NCI-supported Program Project that tested the effectiveness of an interdisciplinary palliative care intervention in lung cancer. The study was a prospective, quasi-experimental trial with a tandem enrollment design where enrollment into the usual care group occurred first, followed by the intervention group. FCG enrollment occurred at the time a matching patient was consented. The palliative care intervention consisted of a comprehensive baseline QOL assessment for both patients and FCGs, interdisciplinary care planning, and four education sessions by a research nurse provided to the patient and four sessions separately provided for the FCG. Interdisciplinary care plans were developed in a weekly meeting attended by thoracic surgeons, medical oncologists, nurses, pain specialists, pulmonologist, physical therapist, social worker, chaplain, dietitian, physical therapist, and other members of the research team. Care planning included recommendations for symptom management and supportive-care referrals for patients and available community resources for FCGs. Accrual occurred between November 2009 and August 2014, with data collection ending in September 2014. The study was performed at an NCI-designated Comprehensive Cancer Center located in Southern California. All study protocols, procedures, and data safety monitoring plan were approved by the institutional review board.

2.2. Participants

For this analysis, we included survivors that met the following inclusion criteria: (1) those with histologic diagnosis of stage I–III resectable NSCLC; (2) age 18 years or older; (3) underwent curative intent surgery; (4) had no previous history of cancer within three years of enrollment; (5) completed baseline assessments preoperatively; and (6) had a matching FCG enrolled in the study. An FCG refers to either a family member or friend identified by the patient as being the primary caregiver. All participants completed written informed consent prior to study participation.

2.3. Patient-reported outcome measures

Quality of life and symptoms were assessed using the Functional Assessment of Cancer Therapy-Lung (FACT-L) tool. The FACT-L contains 27 items with questions divided into the physical, social/family, emotional, and functional well-being domains. An additional lung cancer subscale (LCS) is included to assess disease-specific symptoms. All items are scored on a 5-point Likert scale (0 = not at all; 4 = very much). Higher scores indicate better QOL, and the total score ranges from 0 to 140 [12]. The Functional Assessment of Chronic Illness Therapy-Spirituality Subscale (FACIT-Sp-12) was used to assess spiritual well-being. This is a 12-item, 5-point Likert scale measure that assesses sense of meaning, peace, and faith in illness. Total score ranges from 0 to 48, and higher score indicate better spiritual well-being [13]. Psychological distress was assessed using the Distress Thermometer (DT). The DT is an efficient, low burden method to evaluate distress, based on a scale of 0–10 (0 = no distress; 10 = extreme distress) [14]. Demographic and health status data (age, gender, race/ethnicity, education level, marital status, living situation, employment, religious preference, annual household income, co-morbidities, smoking history) were self-reported by patients at baseline. Disease and treatment characteristics, including stage of disease and type of surgical procedure were obtained through electronic medical records (EMR). All survivors completed baseline assessments prior to surgery, and were re-assessed at 6 and 12 weeks following surgery.

2.4. Family caregiver-reported outcome measures

FCG QOL was assessed using the FCG version of the City of Hope QOL Tool (COH-QOL-FCG). This is a 37 item instrument that measures FCG QOL in the physical, psychological, social, and spiritual well being domains. Items are rated on a 1–10 scale, with higher scores representing worse QOL. The test-retest reliability was $r = 0.89$ and internal consistency was alpha $r = 0.69$ [15]. Perceived caregiving skills preparedness was assessed using Archbold's Caregiving Preparedness Scale. This eight-item scale evaluates FCG's comfort with the physical and emotional patient needs and are scored from 0 to 4, with higher scores representing better preparedness. Internal consistency ranges from 0.88 to 0.93 [16]. The Distress Thermometer was also used to assess psychological distress for FCGs [17]. FCGs completed baseline assessments prior to surgery, and were re-assessed at 7 and 12 weeks following surgery.

2.5. Statistical analysis

Data were analyzed using the Statistical Package for the Social Sciences, v. 21. (IBM Corp. Released 2012. IBM SPSS Statistics for Windows, Version 21.0. Armonk, NY: IBM Corp.) Scores were computed for study outcome scales and subscales. Descriptive statistics were computed on baseline, 6- and 12-week data (the primary end-point of the studies) for all outcome variables. Repeated measures Analysis of Variance (RMANOVA) was conducted over time for patient and FCG outcomes in order to understand the trajectory from pre-op to immediate post-op to longer term outcomes related to having surgery for early stage lung cancer. Differences in outcomes measures were tested using factorial analysis of covariance controlling for baseline scores. Means were adjusted for baseline scores as covariates.

3. Results

A total of 544 patients and 366 FCGs were enrolled in the study, and 112 patients underwent surgery. Because the purpose of this analysis was to describe the impact of lung cancer surgery on patients and their FCGs, we chose to only include patients who underwent surgical resection for their lung cancer, had a designated FCG, had baseline data that were collected before surgery, and had complete follow-up data (complete QOL surveys at all time points) after surgery. Based on these criteria, 41 pairs of patients and FCGs (N = 82; 20 usual care, 62 intervention) were included in