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Symptoms and problems with functioning among women and men with inoperable lung cancer—A longitudinal study

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Summary The aim of this study is to compare the prevalence and intensity of symptoms and problems with functioning between women and men with inoperable lung cancer (LC) during 3 months post-diagnosis. One hundred and fifty-nine patients completed the EORTC QLQ C-30 + LC13 at three time points: close to diagnosis and prior to treatment, and one, and 3 months later. Descriptive cross-sectional analyses and longitudinal analyses using repeated measure ANOVA were conducted. These patients reported many and intense symptoms and problems with functioning. The most salient finding from the cross-sectional analysis was that women reported both more, and more intense problems with emotional functioning close to diagnosis. Statistically significant improvements over time were found in both men and women with regard to emotional functioning, dyspnea, insomnia, cough, pain in arm/shoulder, while physical functioning, fatigue, constipation, dysphagia, peripheral neuropathy and alopecia deteriorated significantly over time. The longitudinal analyses suggest that, with the exception of emotional functioning, gender differences were not only related to biological sex alone, but were also found to be related to other components of the patients' life situation, such as education, age, civil status and type of LC. Sensitivity to different symptom experiences and responses to

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those experiences between and within women and men is also necessary in the management of symptoms in patients with inoperable LC.

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1. Introduction

Lung cancer (LC) is the leading cause of cancer-associated mortality worldwide among both women and men [1]. The high mortality rate is associated with advanced cancer at time of diagnosis, inhibiting curative treatment for most patients. Issues related to palliative care are therefore often important from diagnosis onward with treatment of symptoms as one essential aspect of such care. However, clinical research in patients with LC remains limited, although patients with LC are known to suffer from many and severe symptoms in comparison with other groups of cancer patients [2–5]. The severity of the disease and short survival time make longitudinal studies of symptom experience and quality of life (QoL) in LC even less common.

Over the past two decades, there has been a progressive shift in LC demographics with a marked increase in women patients [6,7]. Despite this change, most studies of symptoms and/or QoL in patients with LC are based on selected populations predominantly consisting of white, middle-income men with advanced LC [2]. Sarna's work on women with LC provides a notable exception [8–13]. Existing studies examining differences in symptom experience between women and men with LC are generally cross-sectional, with inconclusive findings [14,15]. Some studies indicate that women report more [4,16] and different symptoms than men [17,18], whereas Krech et al. found marginal differences between women and men [19] and de Perrot et al. reported that women were less symptomatic at diagnosis than were men [20].

Ethnic minorities, elderly, and women patients all remain at risk for being relatively neglected in LC research [21]. Bias toward the inclusion of men in research studies often leads to limited generalizability of findings [22]. Other research, such as that on cardiovascular diseases, indicates that symptomatology is not always similar for women and men, and that lack of knowledge about differences in symptom experiences between them may hinder appropriate action from the health care system [23].

The lack of longitudinal data, the inconsistent findings on differences between women and men and the potential detrimental effect of these knowledge gaps on clinical practice, make further studies in symptom experiences in relation to gender over time important. In this article, we use the term *gender* when describing differences in symptomatology experienced by women and men, to indicate interactions between biological sex and psychological, social and cultural influences.

The aims of this study are therefore to examine (1) the prevalence and intensity of symptoms and problems with functioning among women and men with inoperable LC at three time points close to diagnosis; (2) the extent

to which intensity of reported symptoms and problems with functioning change over time among women and men with inoperable LC; and (3) which patient characteristics influence the intensity of symptoms and problems with functioning in women and men over time.

2. Patients and methods

This study derives from a larger prospective longitudinal study of symptom experiences in a naturally occurring sample of patients with inoperable LC [24], based on 400 adults consecutively recruited close to time of diagnosis (mean 31 days, median 23 days) through the lung medicine departments of two university hospitals in the Stockholm region. The study was approved by the Regional research Ethics Review Board (KI 97-258, appendices 990503, 010220, 010731, 021212).

Staff at the lung medicine departments were asked to give patients a first information letter, with a copy also sent to the patient's home by the research team. A research nurse then contacted each patient to obtain informed consent for study participation. All data were collected in the presence of a research nurse, with efforts made for the same nurse to conduct data collection with the same patient at all time points. Data were collected at a venue determined by each patient, e.g. at homes, in hospital clinics or wards, at six time points: T1, close to diagnosis and prior to treatment; 2 weeks after T1; 1 month, 3 months, 6 months, and 1 year after T1. Patients completed a number of self-report instruments about symptom experiences at each time-point and were offered a 50-sek gift certificate donated by COOP Sweden, which is a national federation of cooperative store, after completing each interview. Demographic and disease/treatment information was obtained from the patients and from registry data from the Regional Oncologic Centre.

As this is a severely ill patient group, a large degree of non-random attrition and non-participation was found, due to deteriorating health (see Fig. 1). We therefore selected a sub-group of patients who had completed instruments at the same three time points, to avoid using imputation techniques for the analyses. The analysis presented here is therefore based on data generated from all the 159 patients who had completed the EORTC QLQ C30 + LC13 at baseline (T1), 1 month (T2) and 3 months (T3) after T1.

2.1. Self-reported data

2.1.1. EORTC QLQ-C30 version 3.0 + LC13

This self-reported health-related quality of life (HRQL) instrument was developed as an integrated system for assessing HRQL for cancer patients participating in inter-

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