



## The influence of symptom clusters and the most distressing concerns regarding quality of life among patients with inoperable lung cancer



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### A B S T R A C T

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**Purpose:** To explore the influence of symptom clusters and the most distressing concerns on global rating of quality of life (QoL) among patients with inoperable lung cancer (LC) over a three-month period following diagnosis.

**Methods:** Data were derived from a longitudinal study dealing with the symptom experiences of 400 patients with LC at three time points: close to diagnosis and one and three months later. The symptom clusters were derived from a QoL questionnaire using factor analysis, which resulted in three clusters: the Respiratory cluster, the Pain cluster and the Mood cluster. The most distressing concerns were derived from responses to a free listing question ('What is most distressing at present') and were categorised under three dimensions: Bodily distress, Life situation with LC and Iatrogenic distress. Cross-sectional, multivariate regression analyses with QoL as a dependent variable were used to determine predictors (symptom clusters and most distressing concerns) at the three time points.

**Results:** All three symptom clusters predicted QoL at each time point. Close to diagnosis, none of the dimensions of most distressing concerns predicted QoL, while the dimension Bodily distress was a significant predictor of QoL after one month. The Life situation with LC dimension was a significant predictor of QoL three months after diagnosis.

**Conclusions:** Symptom clusters are important to LC patients' QoL and need to be acknowledged by healthcare professionals. The present study shows the importance of patients' descriptions of key concerns, which vary from diagnosis onwards, and urges healthcare professionals to be vigilant to such changes.

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### Introduction

Patients with lung cancer (LC) are known to suffer from a number of severe physical, psychosocial and psychological problems compared to other groups of cancer patients (Barbera et al., 2010; Carlson et al., 2004; Cataldo and Brodsky, 2013). LC is the leading cause of cancer-associated mortality worldwide among both men and women (Jemal et al., 2010) and is associated with advanced cancer at the time of diagnosis, preventing the possibility of curative treatment for most patients. Consequently, palliative care issues are of greatest importance from diagnosis onwards, with treatment of symptoms and other distressing concerns an

essential aspect of such care. Uncontrolled symptoms complicate patient care and, if poorly managed, can potentially affect both quality of life (QoL) and the number of hospital admissions (Digel Vandyk et al., 2012). In palliative care, achieving the best QoL for the patient and the family is the main goal (WHO, 2002). Knowledge about factors that influence QoL is thus of great interest.

The QoL concept is often used in health research and although no precise definition has been agreed on, several definitions are widely accepted (Haas, 1999; Meeberg, 1993). QoL can be divided into two main types: one broad, overall concept and another more specific, i.e. health-related quality of life (HRQoL). Definitions of HRQoL are unclear but there is agreement that the concept is multidimensional. The European Organisation for Research and Treatment of Cancer (EORTC) study group on QoL has found aspects of HRQoL that are potentially important for cancer patients, i.e. physical, role, emotional, cognitive and social functioning together with symptoms and financial impacts (Aaronson et al., 1993; Bergman et al., 1994). There are several publications on

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symptoms and distressing concerns in patients with LC (see e.g. (Lehto, 2011; Lovgren et al., 2008; Tishelman et al., 2005, 2010), as well as different problems affecting global ratings of overall QoL (Ostlund et al., 2007; Liu et al., 2013; Rolke et al., 2008). Emotional functioning and fatigue (Ostlund et al., 2007) as well as anxiety and depression (Rolke et al., 2008) have been found to influence overall QoL ratings in patients with LC.

Despite the complex panorama of severe symptomatology in patients with LC, research has tended to focus on symptom prevalence and the deleterious effects of single symptoms on patients' outcomes. Clinical experience and an increasing body of literature (Brown et al., 2011; Cheville et al., 2011a; Kirkova et al., 2011; Wang et al., 2008) indicate the importance of shifting the focus from individual symptoms to 'symptom clusters' in order to manage better the vicious cycle of ongoing and unrelieved symptoms (Miaskowski et al., 2007) facing LC patients, their families and professionals.

Research dealing with symptom clusters is relatively new but expanding rapidly. As Henoeh et al. (2009) point out, there are a number of factors that currently limit the conclusions that can be drawn from the LC symptom cluster literature. These include lack of consistency in data collection instruments and analysis approaches, variability in the (often small) samples used with regard to disease stage, time points for data collection and participant characteristics, as well as lack of consensus on how symptom clusters are defined. These limitations require extreme caution when interpreting results (Henoeh et al., 2009; Kim and Abraham, 2008). Despite this variability, a respiratory cluster appears to be a salient experience affecting LC patients. This respiratory cluster is a consistent finding, indicating close associations between breathlessness and coughing and often closely associated with fatigue. Other symptoms that are suggested as being linked to the respiratory cluster in some way include anxiety, depression, pain and sleep difficulties (Chan et al., 2005; Cheville et al., 2011b; Fox and Lyon, 2006; Hoffman et al., 2007; Kirkova et al., 2011; Reyes-Gibby et al., 2013), although the nature of these interactions is not yet well established. It should also be recognised that current symptom cluster research is based mainly on statistical relationships between symptoms rather than clinical experience or the patients' explanatory models (Kirkova et al., 2011). Cancer patients who experienced symptoms in clusters also experienced higher levels of symptom frequency, severity and distress (Molassiotis et al., 2010).

Some studies have found a relationship between symptom clusters and QoL in elderly patients with cancer (Cheng and Lee, 2011), in patients with breast cancer (Dodd et al., 2010) and in patients with ovarian cancer (Fox and Lyon, 2007). In LC survivors, the results are to some extent contradictory. One study reports symptom clusters to impact QoL (Fox and Lyon, 2006) and another study has found that symptom clusters predict survival but not QoL (Cheville et al., 2011b), although the presence of fatigue and dyspnoea or a combination of these symptoms was predictive of QoL. As regards self-reported QoL close to diagnosis, there is little research into the relationships between LC patients' symptom clusters and other distressing problems. The aim of this study was to explore the influence of symptom clusters and the most distressing concerns on the global rating of overall QoL among patients with inoperable LC during the three months following diagnosis.

## Material and methods

This study is a mixed-methods study derived from a larger, longitudinal study dealing with symptom experiences based on 400 patients with inoperable LC (Tishelman et al., 2005). The patients were recruited consecutively, close to the time of diagnosis, through the lung medicine departments of two university hospitals

in the Stockholm region, Sweden. The study was approved by the Regional Research Ethics Review Board (KI 97-258, appendices 990503, 010220, 010731, 021212). Data were collected by a research nurse at different places determined by the patients, e.g. at home or in a hospital ward, and at six time points: T1, close to diagnosis and prior to commencement of treatment; two weeks after T1 and commencement of treatment; one month, three months, six months, and one year after T1. All the patients gave their informed consent to participate in the study.

Patients completed a number of self-report instruments dealing with symptom experiences and QoL [see e.g. (Lovgren et al., 2008; Tishelman et al., 2005)] at each time point. At the beginning of the interview, the patients were asked to answer an open question: "What do you feel is most distressing at present?" This was inspired by a free listing approach (Tishelman et al., 2010). Free listing is an approach derived from anthropology that allows identification of relevant issues, uncoloured by the researchers' assumptions. Patients were asked to provide, spontaneously, up to five concerns they found most distressing. Responses varied from single words to sentences, documented in field notes by the research nurse and using direct quotes when possible. Demographic and disease/treatment information was obtained from the patients and from registry data at the Regional Oncology Centre. The present study is based on data from an HRQoL questionnaire, European Organisation for Research and Treatment of Cancer (EORTC QLQ C30+LC13), and the free listing question.

As this study aimed to explore symptom clusters and the most distressing concerns close to diagnosis, three time points close to diagnosis were chosen. The time points were close to diagnosis and prior to commencement of treatment or two weeks later and after commencement of treatment ( $N = 400$ , in the present study designated T1); at one month ( $N = 326$ , in the present study designated T2) and at three months ( $N = 272$ , in the present study designated T3) after the first time point for the interview.

EORTC QLQ C30 and LC13 are self-report HRQoL instruments (Aaronson et al., 1993; Bergman et al., 1994). The core QoL questionnaire (QLQ C30) (Aaronson et al., 1993) assesses general aspects of HRQoL through 30 items, consisting of five functional scales (physical, role, cognitive, emotional and social), three symptom scales (fatigue, pain and nausea and vomiting), a global health status/QoL scale, and several single items (dyspnoea, appetite, insomnia, constipation, diarrhoea and perceived financial impact of the disease). An LC-specific module (LC13) (Bergman et al., 1994) assesses disease-specific symptoms (cough, haemoptysis, dyspnoea and site-specific pain), treatment-related side effects (sore mouth, dysphagia, peripheral neuropathy and alopecia) and pain medication. Each item is assessed on a four-point Likert scale: (1) 'not at all', (2) 'a little', (3) 'quite a bit', (4) 'very much', with the exception of the global health status/QoL items, where the responses range from (1) 'very poor' to (7) 'excellent'.

From the data collection described above, published data on symptom clusters derived from the symptom scales from EORTC QLQ C30+LC13 were used in this study (Henoeh et al., 2009). A published coding scheme of most distressing concerns based on data from the free listing question (Tishelman et al., 2010) was also included. The symptom clusters and the coding scheme of most distressing concerns are described below. The global QoL scale from the EORTC QLQ C30 was used as a measure for overall QoL.

## Symptom clusters

Eleven symptoms common to patients with LC were taken from the symptom scales in EORTC QLQ C30 and LC13. Nine of the symptoms were used on the item level as measured by the EORTC QLQ C30, i.e. depression, worry, concentration, insomnia, pain,

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