

# Dyspnea experience and quality of life among persons with lung cancer in palliative care

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## Abstract

**Background:** Dyspnea, a subjective, multidimensional experience of breathing discomfort commonly occurring in patients with incurable lung cancer, influences all aspects of life in the suffering persons. To optimally enhance quality of life (QoL) and to identify persons most vulnerable to this symptom, it is important to investigate how to assess dyspnea, how other symptoms and coping are related to dyspnea, and what the consequences of dyspnea are, especially on QoL.

**Aim:** The aim of this thesis was to describe how patients with lung cancer experience dyspnea and QoL over time when treatment options with curative or life-prolonging intent are no longer feasible.

**Methods:** The thesis has as its point of departure the Symptom Management Model (SMM). A descriptive design was used, with three quantitative studies and one qualitative study. Participants in the quantitative studies were 105 consecutive patients diagnosed with lung cancer, approached in palliative phase of disease. In the qualitative study, 20 of the patients with dyspnea were included.

Dyspnea, other symptoms, QoL, social support and coping capacity were measured with various questionnaires at baseline (Papers I and II) and some were repeated at 3, 6, 9 and 12 months (Paper III). Medical data, including performance status, were obtained from medical records. Narrative interviews with questions about dyspnea experiences and management were conducted and analysed using qualitative content analysis (Paper IV).

**Results:** More than half of the patients experienced dyspnea. Different aspects of dyspnea correlated positively with anxiety, depression, fatigue, cough, performance status and negatively with coping capacity. Lower coping capacity predicted dyspnea. Dyspnea, depression and global QoL deteriorated over time. Performance status, anxiety, depression, different aspects of dyspnea, pain and the meaningfulness component of coping capacity correlated with global QoL. Depression predicted QoL at 4/5 assessment points. Other predictors over time were coping capacity, anxiety, performance status, pain and social support. The CDS-S was found valid and reliable concerning criterion-related validity, convergent validity and internal consistency. The CDS-S correlated with the psychological dimension, but the visual analogue scale of dyspnea (VAS-D) did not.

In the content analysis emerged four areas comprising categories and subcategories, which all are presented in a model that could be used to gain a better understanding of the dyspnea experience. "Precedings of dyspnea" included circumstances contributing to dyspnea. "Expressions of dyspnea" consisted of physical features and immediate reactions. "Long-term consequences of dyspnea" included a changing life style and existential reflections. "Strategies for managing dyspnea" included bodily, psychological and medical measures.

**Conclusions:** Dyspnea is complex experience and should preferably be measured in a comprehensive way. The CDS-S proved to be a valid and reliable instrument to measure the dyspnea experience in patients in a palliative setting, which was also confirmed by the results in the qualitative study. The CDS-S was also found to better capture the emotional component of dyspnea than VAS-D could. Dyspnea increased over time and QoL deteriorated significantly from baseline to 3, 6 and 9 months and correlated strongly with anxiety and depression. Patients with lower coping capacity experienced higher levels of dyspnea and lower QoL. The meaningfulness component of coping capacity correlated with dyspnea at baseline and QoL over time. Dyspnea, as measured by the CDS-S, did not predict QoL, but depression was a consistent predictor of QoL. The consequences of dyspnea were life changes including limitations and increased dependence; and existential reflections. The patients used bodily, psychological strategies to manage their dyspnea. The results from the thesis could be useful when designing interventions to support patients in clinical practice and in research to evaluate interventions.

**Keywords:** Cancer Dyspnea Scale, CDS; Consequences; Content analysis; Coping; Depression; Dyspnea; Existential; Experience; Lung cancer; Management strategies; Palliative care; Quality of life; Reliability; Social support; Symptoms; Symptom experience; Validity.

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## **Akademisk avhandling**

som för avläggande av filosofie doktorsexamen  
vid Sahlgrenska Akademien vid Göteborgs Universitet  
kommer att offentligen försvaras fredagen den 2 februari 2007 kl 13.00  
i hörsal 2118

Institutionen för Vårdvetenskap och Hälsa,  
Arvid Wallgrens Backe, hus 2

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Institutionen för Omvårdnad, Karolinska Institutet, Huddinge

Avhandlingen baseras på följande delarbeten:

- I. Validation of a Swedish version of the Cancer Dyspnea Scale.**  
Hénoch, I., Bergman, B. & Gaston-Johansson, F.  
*Journal of Pain and Symptom Management* 31, 353-361, 2006.
- II. Dyspnea experience in patients with lung cancer in palliative care.**  
Hénoch, I., Bergman, B., Gustafsson, M., Gaston-Johansson, F. &  
Danielson, E. (Submitted).
- III. The impact of symptoms, coping capacity and social support on  
quality of life experience over time in patients with lung cancer.**  
Hénoch, I., Bergman, B., Gustafsson, M., Gaston-Johansson, F. &  
Danielson, E. *Journal of Pain and Symptom Management* (In press).
- IV. Experience of dyspnea in patients with lung cancer: Precedings,  
expressions, consequences and management strategies.**  
Hénoch, I., Bergman, B. & Danielson, E. (Submitted).



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