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Lung cancer patients' quality of life during chemotherapy: comparison of patients and their partners perceptions

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**Background:** Quality of life (QoL) is recognized as a significant prognostic factor in lung cancer patients, most of whom have a poor prognosis. In Greece partners play a substantial role during patients' illness trajectory. The purpose of this study is the comparison of Greek patients' and their partners' perceptions about patients' QoL during chemotherapy.

Material and Methods: The sample consisted of patients diagnosed with primary lung cancer and their partners (n = 40) hospitalized in departments in the metropolitan area of Athens. Patients and partners completed in the same day, the same measurement instruments in separate rooms, one after the other. Measurement instruments completed at three different points during (before, in the middle and after) chemotherapy course were: European Organization for Research and Treatment of Cancer (EORTC) QLQ-C30 and LC13, and Partner Relationship Inventory. Instruments had appropriate psychometric characteristics in the study sample.

**Results:** Almost all of the couples were married (97.5%). The majority of patients were male (95%) with mean age 60.3 years, advanced disease (62.5%) and 59% metastasis. Partners mean age was similar to patients (55.1 years).

High attrition rate reduced sample size during chemotherapy to 25 couples at second measurement and to 10 couples at the third. The most common attrition factors were patient's death (33.3%) and partners' denial (26.7%) to participate to the study, at the second measurement and partners' denial (26.7%), chemotherapy discontinuation due to disease control (26.7%) and patient's death (20%) at the third one.

Partners evaluated sufficiently patients' QoL with EORTC scale during chemotherapy. Statistically significant differences were observed only in fatigue (p = 0.030) at the first measurement and emotional functioning (p < 0.001) at the second. Partners overestimated their responses about patients fatigue and emotional functioning during chemotherapy.

Demographic and clinical data was not related with the level of agreement between patients and partners estimations about patients' QoL. Contrary partners' perception of the quality of couple relationship (p = 0.046) affected negatively the level of agreement with patients.

Conclusions: This first Greek study comparing patients and partners perceptions about patients QoL recognized the significance of partnership relationship when partners are used as proxy estimators of patients QoL, despite high attrition rate of patients.

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Health-related quality of life in significant others of patients dying from lung cancer

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Background: The interconnectedness between patients and their families has previously been demonstrated; illness is consequently a family matter. The rapid disease trajectory of inoperable lung cancer stresses the importance of studying health-related quality of life (HRQOL) for significant others of patients dying from lung cancer, through the disease trajectory and in the bereavement phase. This study compares HRQOL in significant others of patients dying from lung cancer, with a general population sample. Further, it explores the course of HRQOL from diagnosis (T1), at a time point close to the patient's death (T2), and six months after the patient's death (T3).

Material and Methods: The Swedish Health-Related Quality of Life Survey, SWED-QUAL, assessing functioning and well-being in aspects of the physical, mental and social domains were selected. For group comparisons at T1 and T3, independent t-test were used including 137 and 74 significant others respectively. For these group comparisons a random sample from the Swedish population was used for composing matched groups. For longitudinal analyses repeated measures ANOVA were used including 38 significant others. In the case of statistically significant effects, patterns of change in these scales were identified.

Results: The group comparisons at T1 showed that the significant others scored significantly lower on the scales in the mental domain compared to a general population sample. These results were the same at T3, when the significant others also scored lower on most of the scales in the physical and social domains. In the longitudinal analyses there were significant changes in five scales or items, and three patterns of change were identified: a decrease-increase pattern for 'self-rated health', 'emotional well-being' and 'positive affect'; a constant decrease pattern

for 'family functioning'; and a decrease-stable pattern for 'satisfaction with family functioning'.

**Conclusion:** Living with inoperable lung cancer in the family and then facing the death of a family member affects most of the HRQOL dimensions.

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Significant others' perceptions of the development in relational functioning during lung cancer

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Background: Due to a rapid disease trajectory, high symptom distress, and most patients cared for at home, significant others to lung cancer patients often take an active supportive role for the patient, emotionally and physically. The success of this support may be dependent on how the relation to the patient is perceived by the significant other and how the relation is developing over the disease trajectory. The aim of this study was therefore to study relational functioning between significant others and lung cancer patient from the perspective of the significant other, and to explore developmental patterns of relational functioning during the course of the illness on both group and individual level.

Materials and Methods: In a sample of 91 significant others to lung cancer patients, data was collected four times during the first year after diagnosis. Statistical analyses were conducted for group distribution. In addition a classification of stability and change in individual development in relational functioning was carried out. To explore patterns of change over time, individual empirical growth curves were constructed and deductively classified into four typical patterns of change.

Results: Results show that relational functioning skewed towards good functioning, even though 30% of the significant others reported problems in relational functioning at first occasion. Fifty-two percent of significant others reported change in relational functioning during disease trajectory, while 48% reported stability. Of the significant others who were stable in relational functioning, 36% reported consistently low levels of relational functioning. Four typical patterns of change were identified; two showed approximate linear changes in either a positive direction (15%) or a negative direction (49%) and two showed non-linear changes with a temporary ascending curve (11%) or descending curve (26%).

Conclusion: This study shows that lung cancer may be a trigger for changes in relational functioning, with a linear or temporary decrease as the most common pattern. This implies that changes toward a more problematic relation are most common. Those significant others as well as patients in problematic relations would most probably benefit from interventions aiming to maintain good relational functioning throughout the disease trajectory.

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The professional family dialogue – a Danish approach to a dialogue with terminal ill patients

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**Background:** At the oncology/haematology ward O81, Roskilde Hospital, we focus on giving our dying patients the best quality of the remaining life. Therefore O81 has a special area called "section for Palliative treatment" (ALB). The visions of ALB are inspired by WHO's Definition of Palliative Care. All our patients are offered a professional family dialogue, based on the patients need and desires, life situation and conditions.

Material and Methods: This survey is based on material from 100 professional family dialogues during 2006. We help the patient to identify close relatives, and invite them to a dialogue lasting 45–60 minutes. A staff nurse and a doctor are always in attendance. We invite the patient and their relatives to the dialogue, prepare the patient and their relatives about issues that might be discussed. The professional family dialogue described here starts from a hermeneutic point of view. We have two focuses in the dialogue: the patient and the relatives. We manage the focus but the patient places the focus. We invite the family to talk, to open up on the unspoken words, to talk openly about the illness, death and where the patient wants to die. We try to help the family to solve some of the problems they have as a family living with cancer.

Results: The relatives are often not at the same level of realization, before the professional family dialogue, as the patients, or vice versa. Afterwards the family talks more openly about the future and often join the family closer together. As a result of the dialogues, we make sure that all the participants are at the same level, and we ensure all of them get the opportunity to speak, ask questions or express how they feel. The illness is now more legitimate, and we encourage the family to continue the conversation. During the dialogue the patient and relatives move to a new