



## Depression, anxiety and disease-related distress in couples affected by advanced lung cancer



Markus W. Haun<sup>a,b,\*</sup>, Halina Sklenarova<sup>a</sup>, Matthias Villalobos<sup>c</sup>, Michael Thomas<sup>c</sup>, Anette Brechtel<sup>d</sup>, Bernd Löwe<sup>e</sup>, Wolfgang Herzog<sup>a</sup>, Mechthild Hartmann<sup>a</sup>

<sup>a</sup> Department of General Internal Medicine & Psychosomatics, Heidelberg University Hospital, Im Neuenheimer Feld 410, D-69120 Heidelberg, Germany

<sup>b</sup> Soteria Bern, University Hospital of Psychiatry Bern, Buehlstrasse 19a, CH-3012 Bern, Switzerland

<sup>c</sup> Department of Oncology, Thoraxklinik Heidelberg, Heidelberg University Hospital, Amalienstraße 5, D-69126 Heidelberg, Germany

<sup>d</sup> Division of Psycho-Oncology, National Centre for Tumour Diseases, Heidelberg University Hospital, Im Neuenheimer Feld 460, D-69120 Heidelberg, Germany

<sup>e</sup> Department of Psychosomatic Medicine and Psychotherapy, University Medical Centre Hamburg-Eppendorf and Hamburg-Eilbek (Schön Clinics), Martinistraße 52, Gebäude Ost 25 (O 25), D-20246 Hamburg, Germany

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### ABSTRACT

**Objectives:** Lung cancer patients and their partners are prone to high levels of depression and anxiety or severe distress related to the poor prognosis of the illness. However, there remain doubts regarding the extent to which this distress exceeds levels in the general population. This study explored levels of depression and generalized anxiety for comparison with matched data of a representative sample from the general population. Additionally, covariance of distress between the two partners, together with disease-specific components and differences were investigated.

**Materials and methods:** In a cross-sectional survey, 54 pairs of lung cancer patients and their partners ( $n = 108$ ) were assessed for depression and anxiety, cancer-related distress, unmet needs and disclosure in communication. Comparisons between distress levels of participating couples and matched community-comparisons ( $n = 162$ ) were conducted. Additionally, multilevel analysis for estimating intra-dyadic associations of anxiety and depression was computed. Components of distress, needs and aspects of communication were explored via item mean values.

**Results:** Lung cancer patients as well as their partners exhibited significantly higher levels of depression and anxiety when compared to community-based comparison subjects (patients: mean difference of 1.01 for depression with a relative risk (RR) of 4.5 and 0.84 for anxiety with RR=6.1; partners: 1.17 for depression with RR=4.6 and 1.59 for anxiety with RR=7.6). Partial intraclass correlations between patients and partners were weak (PIC=.29 for depression; PIC=.21 for anxiety). Fear of progression emerged as main component of distress for both patients and partners, although differing stressors were described.

**Conclusion:** Lung cancer-affected couples exhibit levels of depression and anxiety far exceeding those of the general community. In clinical practice, patients and partners should be assessed separately for distress against the background of weak intra-dyadic associations. In cases of significant depression or anxiety, referral for psychosocial treatment is indicated and has been shown to improve quality of life.

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## 1. Introduction

Accounting for approximately 13% of cancer diagnoses worldwide, lung cancer leads to more deaths in both genders than any

\* Corresponding author at: Department of General Internal Medicine & Psychosomatics, Heidelberg University Hospital, Im Neuenheimer Feld, 410 D-69120 Heidelberg, Germany. Tel.: +49 6221 56 87 74; fax: +49 6221 56 59 88.

E-mail address: [markus.haun@med.uni-heidelberg.de](mailto:markus.haun@med.uni-heidelberg.de) (M.W. Haun).

other cancer [1]. Despite therapies increasingly targeted at tumor growth, the five-year survival rate for all stages combined remains under 15% at the time of diagnosis [2]. With only 15% of lung malignancies detected at a localized stage, diagnosis often immediately threatens the physical integrity of patients. For the most frequent non-small cell lung cancer, the median time to progression in the advanced stage does not exceed five months on average [3]. These figures imply not only fast physical deterioration but also a heavy impact on the mental well-being of patients [4–6]. The overall prevalence rate of distress in lung cancer patients (43.4%)

outnumbers all other malignancies [7]. Predictable rapid decline that strengthens the awareness of poor prognosis and blame attributed to smoking are discussed as specific contributors to this particularly high level of distress [8–10]. In addition to distress in patients, there is also a greater risk of depression and anxiety in patient partners, with one study reporting levels as high as those in the lung cancer patients themselves [11,12]. Compared with the general population, patient partners show significantly reduced quality of life in terms of 'affects', 'role limitations due to emotional health', 'sleep problems', and 'cognition' [13]. However, the extent to which emotional distress levels in lung cancer patients and their partners exceed those of the general population remains unclear, as direct comparisons within matched samples, specifically in the advanced stage, are rare [14]. Moreover, a recent meta-analysis by Hagedoorn et al. [14] showed only a modest correlation ( $r = .29$ ) between distress in patients and their partners and also noted that partners reported more distress than patients only in couples with a male patient.

Therefore, the present study aimed to assess distress levels of couples affected by advanced lung cancer using different methods. First, we investigated distress on the general level of depression and anxiety by comparing data from patients and partners with a matched sample from the general population [15]. At the same time, we were interested in the concordance rates of depression and anxiety within the couples.

Second, we examined the specific disease-related components of distress in lung cancer to gain a more comprehensive perspective of the assumed strains. We focused on specific contributors to disease-related distress, supportive care needs and cancer-related communication.

## 2. Methods

### 2.1. Study design and sample

A cross-sectional survey of consecutively recruited pairs of advanced lung cancer patients and their partners was conducted. Patients were either outpatients or inpatients at Thoraxklinik, National Center for Tumor Diseases (NCT), Germany. The study was approved by the Ethical Committee of Heidelberg Medical School (S-287/2012).

### 2.2. Eligibility and recruitment

The inclusion criteria were adults with a confirmed diagnosis of lung cancer and required participation of both the patient and caregiver. Patients or caregivers not able to read German or those with severe cognitive/psychiatric impairments or an unclear information status about the diagnosis and stage were excluded. There was no restriction regarding length of time since diagnosis. Subjects were identified by the attending physician and approached in person. After agreement of the partner, but prior to enrollment, informed consent was obtained from participants. All subjects separately completed self-report questionnaires and returned them either directly or from home via postage-paid envelopes. The community sample, out of which the matched subjects were drawn, was investigated in a nationally representative face-to-face household survey conducted in Germany. The survey was conducted in 2006 by professional interviewers of a demographic consultation company (USUMA, Berlin) following a random-route procedure. Further details can be found in Löwe et al. [15].

### 2.3. Measurements

Sociodemographic data were provided by participants, whereas medical data were obtained from medical records and confirmed by

the attending physicians. Patients rated their quality of life in order to obtain their global functional status [Functional Assessment of Cancer Therapy–Lung, FACT-L; 16]. To quantify cancer patients' general well-being and activities of daily life from an expert view, ECOG (Eastern Cooperative Oncology Group) performance status was assessed. To estimate treatment response, Response Evaluation Criteria In Solid Tumors (RECIST) were evaluated. For subsequent refusal/non-responder analysis, age, gender, and reason for refusal/non-response were documented for all subjects.

To assess depression and anxiety, the Patient Health Questionnaire-4 [PHQ-4; 17], which is a composite measure of the PHQ-2 and Generalized Anxiety Disorder Scale-2 (GAD-2), was used. PHQ-2 is the short version of the 9-item PHQ-9 and evaluates the core criteria for depression, depressed mood and anhedonia [18]. GAD-2 represents a two-item screener for generalized anxiety and is derived from the 7-item GAD-7 [19]. For clinical practice, subscale scores of 3 or greater have been recommended as a "yellow flag" for a significant depressive or anxiety disorder. Normative data for the PHQ-2 and GAD-2 are available from a representative survey of members from the German general population ( $N = 5030$ ) [15]. To measure disease-related distress, the Questionnaire on Distress in Cancer Patients – Short Form [QSC-R10; 20], the subscale "cancer-related disclosure" of the Cancer Communication Assessment Tool [CCAT-PF; 21], and the Supportive Care Needs Survey [SCNS-SF34-G/SCNS-P&C-G; 22, 23] for measuring supportive care needs across several domains were used.

### 2.4. Statistical analysis

Only pairs of questionnaire sets completed by both patients and partners were subject to analysis, performed with SAS 9.3®. To investigate representativeness of the sample, non-responder analysis running Fisher's exact test for gender and independent  $t$ -test for age was conducted.

To appropriately test the hypothesis of elevated depression and anxiety levels in couples facing lung cancer, we conducted a direct comparison with a demographically matched subsample from the above-mentioned population-based survey [15]. Lung cancer patients and their partners were separately and randomly assigned to comparison subjects as individuals, not dyads, in the proportion of one to three based on age, gender and education. Two-tailed Student's  $t$ -tests were conducted to assess differences between groups of matched comparison subjects and groups of patients and partners. Effect sizes were calculated as Cohen's  $d$  coefficients for symptom scores and relative risks for categorical variables. Associations with medical data were tested using Spearman's correlation (for time since diagnosis) or using the independent  $t$ -test (for metastatic status) and ANOVA (for disease stage).

Referring to the sample size of 54 lung cancer dyads, a power analysis was performed. Given a 0.05 level of significance (two-tailed) and a power of 0.80, this sample size is sufficient to detect large or medium differences of at least approximately 0.5 standard deviations between groups.

To analyze patient-caregiver-concordance as well as differences in means simultaneously a multilevel modeling approach was used as suggested by Campbell & Kashy [24]. This approach accounts for nonindependence between patient and partner data and also allows investigating further variables that may affect couples' emotional distress. Unit of analysis was the dyad; PHQ-2/GAD-2 scores were specified as primary outcome variables. The model was adjusted for gender, patient-partner-role and gender interaction. Differences between patient and partner were estimated as regression coefficients. The degree of concordance was described as partial intraclass correlations (PIC).

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