



Denial and social and emotional outcomes in lung cancer patients: The protective effect of denial

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ABSTRACT

Denial is a well-known phenomenon in clinical oncology practice. Yet whether the impact of denial on patient well-being is beneficial or harmful remains unknown. The purpose of the current study is to investigate the relationship between denial and social and emotional outcomes in a large sample of lung cancer patients over an extended time period.

Denial and social and emotional outcomes were measured in 195 newly diagnosed lung cancer patients. Four assessments were conducted over 8 months. The level of denial was measured using the Denial of Cancer Interview. Patient-reported social and emotional outcomes were measured using the EORTC-QLQ-30 and the HADS.

Patients with a moderate or increasing level of denial over time reported better social outcomes (role functioning: $p=0.0036$, social functioning: $p=0.027$) and less anxiety ($p=0.0001$) and depression ($p=0.0019$) than patients with a low level of denial. The overall quality of life was better among lung cancer patients who displayed either moderate or increasing levels of denial compared with those who displayed low levels of denial ($p<0.0001$).

A certain level of denial in lung cancer patients can have a protective effect on social and emotional outcomes. Clinicians should take this into account when providing information about the illness and its prognosis.

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1. Introduction

When patients are told that they have lung cancer, they have to deal with major changes in their life and future perspective. Because of the limited curative treatment options [1], the diagnosis of lung cancer usually comes as a shock and can throw a patient off stride [2]. It is conceivable that lung cancer patients may try to protect themselves against this daunting situation by denying at least parts of the illness and its consequences. Indeed, the occurrence of denial in clinical practice is undisputed and a low to moderate level of denial has been found to be a normal phenomenon among lung cancer patients [3].

Current practice in the Western world is to fully inform patients about their diagnosis and prognosis. As a consequence, lay people as well as healthcare professionals may try to convince patients to face the full truth of having cancer and to stimulate them to openly discuss their illness experience. Yet whether some degree of denial is adaptive or maladaptive is still under debate [4–7]. Such

a strategy would be unwise if denial were positively linked to adaptation. Indeed, as Lazarus states: “denial can have a positive value under certain conditions and a negative value under others” [8]. It is therefore important to investigate the impact of denial among cancer patients.

The effect of denial in cancer patients on social functioning was investigated in two earlier studies [9,10]. In the first, avoidance of information was found to be related to poorer social functioning, while denial of feelings was found to be related to better social functioning. The second study found no relation between denial of the disease impact and related affect and social functioning.

Likewise, different results were found in studies concerning the relation between denial and psychological function. A literature search retrieved 14 studies in which different assessment tools were used and patients with different types of cancer were included. Consequently, results should be compared with caution. Besides, different types of denial were distinguished such as: ‘denial of diagnosis’, ‘denial of affect or emotions’, ‘denial of the disease impact’ and ‘behavioral escape’. Denial of diagnosis was shown to relate to poorer psychological functioning in two studies [11,12]. Denial of the disease impact was related to experiencing less distress in seven studies [9,13–18], but more in three other studies

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[12,19,20] and the same level of distress in another three [11,20,21]. Denial of affect and behavioral escape were shown to be related to more distress in four studies [16,17,19,21,22] and less distress in another [9]. In one study the denial of affect and the impact of disease caused improved well-being [23].

The effect of denial in cancer patients on psychological functioning may depend on the concept of denial used. Interestingly, studies in which denial of the disease impact was related to improved psychological functioning represented active strategies such as not letting the illness control life, brushing the illness aside and instead creating a positive outlook despite having cancer. In studies where denial was related to poorer psychological functioning, the following concepts were used: refusing to believe ‘it’ happened (denial of diagnosis), hoping a miracle might happen (denial of affect), and making oneself feel better by drinking, eating and smoking, or giving up (behavioral escape). Thus, distractive strategies seem to be related to reduced distress, whereas passive escape mechanisms seem to decrease psychological well-being [7].

Until now, extensive research concerning denial in lung cancer patients has been lacking, yet lung cancer patients may have more reason to deny than other cancer patients. First, lung cancer is related to smoking and patients may feel shameful or stigmatized [24,25]. Secondly, lung cancer patients often suffer from dyspnoea, which seriously limits functioning and may provoke severe anxiety [26,27]. Finally, given their poor prognosis and often quickly deteriorating condition, patients have limited time to adjust to the impact of their illness. The objective of the present study is, therefore, to investigate prospectively the relationship between denial and social and emotional outcomes in a large sample of lung cancer patients.

2. Methods

2.1. Participants

Consecutive lung cancer patients were recruited from two outpatient clinics¹ for lung diseases in The Hague, the Netherlands. Inclusion criteria were (a) being newly diagnosed with primary lung cancer irrespective of histological type, stage or treatment; (b) age ≥ 18 years; (c) time since diagnosis < 2 months; (d) knowledge of the Dutch language; and (e) written informed consent. Exclusion criteria were (a) a serious cognitive disorder and (b) being too ill to be interviewed.

Patients were invited to participate by their chest physicians. Upon agreeing to participate, patients received written information and gave informed consent before the first interview.

2.2. Design

This study has a longitudinal explorative design. Four assessments were planned with each patient: the first within 8 weeks following diagnosis (T1) and, subsequently, at 8, 16, and 32 weeks afterwards (T2–T4). Each assessment consisted of a semi-structured interview lasting 30–45 min and the completion of written questionnaires.

This study was approved by the ethical committees of the hospitals involved.

2.3. Measures

Denial was measured by the Denial of Cancer Interview (DCI), a semi-structured interview, based on the definition of denial by

Weisman and Hackett [28,29]: ‘the conscious or unconscious repudiation of part or all of the total available meaning of an event to allay fear, anxiety or other unpleasant affects’. The DCI consists of nine specific items and two clinical impression scores covering the type and overall level of denial. It has proven to have good psychometric properties [30]: the reliabilities (Cronbach’s α) at the four assessment times were 0.82, 0.86, 0.84 and 0.84, respectively. Denial is represented on a continuous scale ranging from 3 to 19, with lower scores indicating less denial.

We previously [31,32] described that patients in our sample displayed three different patterns of denial over time. ‘Low deniers’ showed a low level of denial consistently over time. This class was most prevalent (69%, mean DCI = 5.34). ‘Moderate deniers’, showed a stable, moderate level of denial over time; this class was smaller (19%, mean DCI = 11.31). The class of ‘increasing deniers’, starting with a low level of denial and showing increased denial over time (13%, mean DCI at T1 = 6.28, mean DCI = 11.89 at T4) was the smallest. Consequently, these three patient classes will be presented here as low, moderate and increasing deniers.

Patient-reported social and emotional outcomes were measured with the generic EORTC quality of life questionnaire (EORTC-QLQ-C30) first. The QLQ-C30 incorporates nine multi-item scales of which (1) social outcomes, covering role functioning, social functioning, and financial difficulties, (2) cognitive functioning, (3) emotional functioning, and (4) overall quality of life, are relevant here.

Emotional functioning was also assessed with the Hospital Anxiety and Depression Scale (HADS) [33], a widely used well-validated self-report instrument designed to detect anxiety and depression in the medical setting [34–36].

Medical data, such as tumor type, disease stage at baseline and performance status (T1–T4), were provided by the chest physicians. Performance status was rated using the Zubrod-scale [37]. Sociodemographic factors, such as gender, age, marital status, level of education, and religion were collected in the interviews, as was current treatment and smoking history. Trait anxiety, suggesting a stable tendency to perceive and respond to stressful situations with elevated anxiety levels, was measured with the shortened 10-item version of the State-Trait Anxiety Inventory (STAI T-anx) [38].

2.4. Statistical analysis

In an earlier paper [32] three classes of patients were distinguished based on their longitudinal pattern of denial. Posterior probabilities of class membership were obtained for each patient. For each patient, the highest posterior probability determined the most likely class. Differences between these classes with respect to patient characteristics were assessed using contingency tables with variances adjusted for class membership uncertainty. Psychosocial functioning scales were analyzed using mixed models, with class, time (T1, . . . , T4 categorical) and class by time interaction as fixed effects, and with patient intercept as random effect. To account for class membership uncertainty in this analysis, multiple imputation (using $M = 10$ dataset completions) was used. In order to study a specific class by time interaction, mixed models with class, time and “increasing denial effect” were also fitted.

Further details of the statistical analysis are published elsewhere [31].

3. Results

3.1. Patient characteristics

Of 383 newly-diagnosed lung cancer patients, 139 were ineligible because of death ($n = 30$), being too ill ($n = 32$), ≥ 8 weeks since

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