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## Review

## We're in this together: Patients', caregivers' and health care providers' illness perceptions about non-small-cell lung cancer (NSCLC)



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## ABSTRACT

This study reviews empirical studies in the area of illness perceptions in patients with non-small-cell lung cancer (NSCLC). Beliefs about the illness and its consequences, including its medical management, are part of the review. Also, the relatively small research area of perceptions and views about patients with NSCLC of caregivers and health care providers is reviewed. Given our earlier review of the topic in this Journal [5], we now report on papers published after that 2011 publication. 38 papers were identified, a quite major increase in published research compared to the 15 papers in our previous publication (2011 and earlier).

Most papers report on psychosocial concepts that determine responses to the illness and its treatment. Increasingly, reactions of caregivers and health care providers are studied. These last two categories of respondents perceive the psychosocial consequences of NSCLC as more severe than the patients themselves.

Psychosocial variables appear to be stronger predictors of psychological distress and reduced quality of life than sociodemographic or clinical variables. These results are instrumental in the developing field of psychosocial interventions for patients with non-small-cell lung cancer and their caregivers, which may also be helpful for health care providers. Suggestions for research and clinical implications are presented.

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## 1. Introduction

Lung cancer is clearly associated with behaviour: every phase of the illness is closely linked to psychological factors and processes. Smoking tobacco is a major behavioural risk factor for the initiation of lung cancer. Once symptoms associated with lung cancer develop, symptom perception starts to play role: denying or misinterpreting symptoms causes delay in seeking medical care [1,2]. The psychological response to the diagnosis of lung cancer,

e.g. depression or active engagement, is a factor in determining quality of life (QOL) in the course of the illness [3]. Quality of life in patients with lung cancer is determined by sociodemographic, clinical and psychological characteristics [4,5]. Patients' behaviour regarding diagnostic and therapeutic procedures (e.g. adherence to chemotherapy [6] is shaped by psychological factors, such as beliefs about the effect of these procedures [7]).

The behaviours and their determinants given above are not unique for lung cancer. They are universal in patients with any illness, be it a somatic illness or a psychiatric illness [8]. Various theoretical models have been developed in order to study how patients respond to the various phase in the illness process. The stress-coping model [9] for example, guided research in

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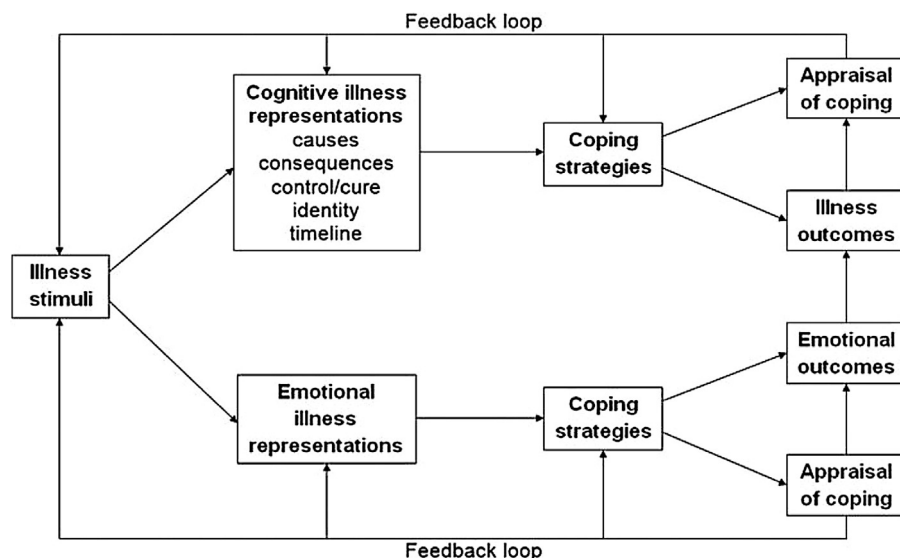


Fig. 1. The Self-Regulation Model.

behavioural medicine at the end of the 20th century. A more recent model appears to be even more helpful in elucidating relationships between sociodemographic (age, sex, socioeconomic status (SES)), clinical factors (type and stage of illness), psychological factors (see below), coping, and outcome as operationalized in 'quality of life' measures. The Self Regulation Model (SRM) encompasses these factors (Fig. 1) [10].

The Self Regulation Model outlines how illness gives rise to cognitive and emotional responses (together 'illness perceptions') which in turn determine coping behaviour. Illness perceptions and coping influence outcome operationalized in for example visiting a medical doctor, taking medications, 'quality of life', or self-management skills. Attempts to influence perceptions and thereby outcome should, therefore, aim at replacing maladaptive illness perceptions and coping behaviours by constructive, adaptive illness perceptions and coping. For example, in a study on patients with a myocardial infarction, replacing maladaptive illness perceptions by more productive ones resulted in patients in the experimental group in improvements in work resumption, sexual activity, and reductions in symptoms [11]. In the more clinical psychology domain, similar studies point at improvements in quality of life in patients with, for example, depression or eating disorders [8]. In the area of non-small-cell lung cancer (NSCLC) the study by Temel et al. reports how illness perceptions of newly diagnosed patients with NSCLC were successfully addressed, with beneficial effects for the patients [12].

In the Self Regulation Model, five dimensions of illness perceptions are distinguished: Causes, Consequences, Control/Cure, Identity, Timeline (see Fig. 1). The available questionnaires that assess illness perceptions refer to various conceptualizations of illness perception [see [www.uib.no/ipq](http://www.uib.no/ipq) for details]. Individuals differ in their perceptions, not so much as a consequence of type or severity of the illness, but as a consequence of information about the condition as shaped by parents, media, health care providers. Illness perceptions change over time, as a consequence of learning to live with an illness and its treatment, or as a consequence of attempts to change maladaptive perceptions into more constructive illness perceptions [13].

In 2011 we published a paper in this journal where we reviewed the topic of illness perceptions and quality of life in patients with non-small-cell lung cancer [5]. Four years later we now embark on a new study, examining beliefs ('perceptions') of patients about their lung cancer. Our previous paper reported a pilot study, in

preparation of the study proper. Given this, and given the quite substantial increase in the number of empirical (that is: data-based) papers in the area of biopsychosocial research in lung cancer between 2010 and 2015, we report here on a literature review on "illness perceptions and lung cancer". We included studies in our review if they were published after where we left in August 2010, and included papers published up till 5 July 2015.

## 2. Methods

A 5 July 2015 literature search in PubMed with search strategy "illness perceptions AND lung cancer", "illness representations AND lung cancer", and "explanatory models AND lung cancer" produced 38 papers that were published after our 2010 search. Excluded were abstracts, vignette studies, non-English publications, and papers that in addition to patients with lung cancer included patients with other types of cancer. Identified papers that studied patients with small-cell lung cancer only were excluded. Our current search includes papers on illness perceptions in health care providers and patients' caregivers as we aimed at sketching a comprehensive review of perceptions and beliefs about NSCLC in relevant categories of respondents, and the number of studies in these categories appears to reflect a rapidly growing interest in the topic.

## 3. Results

The 37 papers were divided in two categories and are reported in two Tables. Table 1 reports the 23 papers on responses of patients with NSCLC to their illness and treatment. Table 2 reports the 14 papers regarding the responses of family members, caregivers (usually spouses), and health care providers (mostly MDs). In both Tables, sociodemographic and medical regimen characteristics are given in the second columns (see legend at end of the Tables for explanations of abbreviations). All papers report on psychosocial concepts that determine responses to the illness and its treatment.

The great majority of studies are from the USA, demonstrating the strong interest in that country for psychosocial issues in patients with NSCLC. Sample sizes vary from 10 to 343 patients. A range of methods was applied (on-line telephone survey, questionnaires, interviews, focus groups, clinician reported distress, drawings). Most studies did use concepts (and therefore, variables and their associated measurement technique and questionnaires) from the Self Regulation Model. Major psychosocial impact of

**Table 1**  
Results of literature review on illness perceptions in patients with NSCLC.

First author Year Country [Reference]	N patients/respondents; (medical regimen(s))	Measure(s)/methodology	Results, remarks
Adorno 2014 USA [14]	12 US Veterans with late-stage lung cancer; (Chemotherapy and/or routine hospice care)	Individual in-depth semi-structured interview	'Loss of the person I know myself to be' is overarching theme
Berendes 2010 USA [15]	51 patients NSCLC stages I-III Chemotherapy 16% Radiation therapy 4%	Telephone survey	'Hope' inversely associated with pain, fatigue, cough, depression
Cataldo 2012 USA [16]	190 patient with self-reported diagnosis of lung cancer; (Not reported)	On-line survey	Lung cancer stigma strongly associated with depression and reduced QOL, irrespective of smoking history
Dalton 2015 USA [17]	12 newly diagnosed persons with lung cancer; (Not reported)	Pilot study of longitudinal assessment of beliefs, depression, catastrophizing and immune parameters	QOL and pain intensity are predicted by scores at baseline. Catastrophizing and loss of control are associated with greater pain and pain interference
Fujisawa 2015 USA [7]	125 NSCLC patients, stages IIIB & IV; (IV chemotherapy 81 Oral chemotherapy 44)	Questionnaires (anxiety, depression, QOL)	Anxiety and depression are associated with receiving chemotherapy at end-of-life, causing worse QOL
Gerber 2012 USA [19]	13 patients with advanced NSCLC; (Platinum doublet chemotherapy, some stereotactic radiotherapy)	Focus groups on comprehension and attitudes toward maintenance chemotherapy	'buying time', 'doing something', QOL, provider opinion, and logistics are major factors influencing considerations of maintenance chemotherapy
Gonzalez 2012 USA [20]	95 patients on chemotherapy for stages II-IV NSCLC; (Surgery 48% Radiation 43%)	Self-reported levels of stigma and depression	Association between stigma and depression
Greer 2014 USA [21]	144 metastatic NSCLC patients; (Platinum combined chemotherapy, radiation)	Self-perceived health and survival	Patients' self-perceived health predicted survival
Hamann 2014 USA [23]	42 Patients with lung cancer (stages 1 & 2: 7; stages 3 & 4: 33); (Not reported)	Focus groups and individual interviews	Perceived (felt) stigma and internalized (self) stigma are the two dimensions of stigma in people with lung cancer
Hirsch 2012 USA [24]	133 patients with lung cancer (stage I: 65; stages II- IV: 67); (Not reported)	Self-report surveys	Negative affect associated with poor QOL. Positive affect associated with better QOL
Hoogerwerf 2012 NL [25]	12 patients with NSCLC (stage I: 2; stages III & IV: 10); (Surgery 3 Chemotherapy 11 Radiation 7)	Illness perceptions; drawings; interviews	Optimism about prognosis in all three measures
Jonnalagadda 2012 USA [27]	335 patients (minority-nonminority) (Not reported)	Self-Regulation Model variables	Fatalistic beliefs more common in minority groups; blacks and Hispanics more misconceptions about advice directives and hospice care

Table 1 (Continued)

First author Year Country [Reference]	N patients/respondents; (medical regimen(s))	Measure(s)/methodology	Results, remarks
Kurita 2013 USA [28]	49 patients with lung cancer (Surgery 39% Chemotherapy 80% Radiation 53% Biological therapy 53%)	Questionnaires: depression, FACT-L, intolerance of uncertainty, illness uncertainty, impact of events, neuroticism	More stress and poor emotional well-being associated with higher levels of intolerance of uncertainty
Lehto 2011 USA [30]	34 patients with stage I–II NSCLC (Surgery 34)	Semi-structured interview, before and after surgery	12 domains identified (e.g. coping, worry, disease-related, information)
Lehto 2014 USA [31]	11 patients NSCLC; (Not reported)	Focus groups	Themes: societal attitudes, institutional practices and experiences, negative thoughts and emotions, stigmatization, smoking, causal attributions
Liao 2011 TAI [33]	152 NSCLC; (Chemotherapy 45% EGFR-TKI 22% Chemotherapy & radiation therapy 16%)	Questionnaires (symptom severity, anxiety, depression, cancer needs)	Information needs; psychological needs; patient care & support needs were the top three unmet supportive needs
Lowery 2014 USA [35]	183 NSCLC patients, survivors, stage I; (Surgical resection)	Questionnaires assessing symptom burden, QOL and performance status	More symptoms lead to adverse effects on QOL and functioning
Maguire 2014 UK [37]	10 patients, advanced lung cancer; (Not reported)	Qualitative data analysis (IPA) from individual interviews	Patients associate symptoms in clusters. Breathlessness and cough were associated with fear of death and embarrassment in public
Peeters 2012 BEL [40]	30 patients, NSCLC stage IV; (First-line platinum based doublet chemotherapy)	Attitude towards maintenance therapy (MT)	Overall survival, symptom control are major determinants of willingness for MT
Shen 2015 USA [43]	141 NSCLC patients, stages IA, IB; (Not reported)	Questionnaires on posttraumatic growth, stigma about smoking, psychological distress	Posttraumatic growth buffers against the negative effects of stigma on distress in post-diagnosis quitters
Temel 2010 USA [46]	151 NSCLC patients; (Chemotherapy ~50% Radiation therapy ~27%)	RCT palliative care vs standard oncologic care	Early palliative care increased QOL, reduced depression, and prolonged survival
Tishelman 2010 SWE [47]	343 NSCLC (mainly); (Chemotherapy 50% Chemotherapy & radiation 17% Radiation 12%)	Responses to "What do you find most distressing at present?"	Distress; contact with health care system; standard questionnaires do not assess these issues
Vos 2011 NL [2]	195 NSCLC (mainly); (Chemotherapy 38% Radiation 24% Surgery 12% No therapy 18%)	Questionnaires (denial; emotional outcomes)	Denial associated with better QOL

BEL = Belgium; NL = the Netherlands; SWE = Sweden; TAI = Taiwan; UK = United Kingdom; USA = United States of America; NSCLC = non-small-cell lung cancer; FACT (L) = Functional assessment cancer treatment (lung), IPA = interpretative phenomenological analysis, QOL = quality of life; RCT = randomized clinical trial.

**Table 2**  
Results of literature review on illness perceptions in patients with NSCLC, in relation to those of family members, caregivers, and health care providers.

First author Year Country [Reference]	N patients/respondents; (medical regimen(s))	Measure(s)/methodology	Results, remarks
Finney Rutten 2011 USA [18]	1,765 in US open population; (Not applicable)	Telephone survey, inspired by the Common Sense Model	'illness perceptions', 'worry' and 'perceived risk' associated with perceived lung cancer risk; smokers reporting higher worry and risk
Hamann 2013 USA [22]	Clinicians delivering medical care to patients with lung cancer; (ECOG 0 & 1: 436; 2-4: 85); (Not reported)	Forms filled out by clinicians about their perceived care difficulty, and QOL and symptoms in patients with lung cancer	Patients with lung cancer are more difficult to treat, with poorer QOL, higher symptom reports, according to clinicians
Iyer 2014 USA [26]	450 patients NSCLC stage IIIB/IV; MDs reported on 5 consecutive patients; (First, second, and third-line treatment)	Lung Cancer Symptom Scale (LCSS), FACT-Lung (FACT-L)	Considerable lack of concordance between patients and physicians regarding symptom burden, threatening QOL as a treatment goal
Lee 2015 USA [29]	13 dyads (patient and caregiver); (Not reported)	Qualitative interviews	Poor illness related understanding in dyads
Leydon 2012 UK [32]	113 patients with NSCLC, 70 corresponding caregivers, 188 treating physicians; (Not reported)	Online survey	Patients tended to be more positive than caregivers and physicians. Physicians more positive about disease information communication than perceived by patients
Lobchuck 2012 CAN [34]	304 dyads: patients and their primary caregivers; (Not reported)	Self-report questionnaires, re smoking behaviour	Continued smoking behaviour impacted negatively on caregivers' empathic behaviour
Lyons 2014 USA [36]	109 dyads, patients with advanced lung cancer (Not reported)	Patient symptoms and physical function assessment in patients and family providers of care	Family members rate patients' problems more severely than patients themselves
Milbury 2012 USA [38]	Dyadic adjustment in 158 couples with one partner with lung cancer; (Chemotherapy 56% Radiation therapy 24% Surgery 17%)	Questionnaires	Disconcordance in blame for lung cancer, associated with distress
Miller 2015 USA [39]	108 dyads; (Not reported)	Questionnaires	Family members rate patients' physical function worse than the patients themselves. Patient-family disconcordance is associated with communication problems
Porter 2011 USA [41]	233 patients with lung cancer NSCLC and their caregivers; (Surgery 60% Chemotherapy 40% Radiation 26%)	Caregiver-assisted coping skills training, RCT	Patients in both treatment conditions improved (pain, depression, QOL, self-efficacy), and in caregivers (anxiety, self-efficacy). Stage of cancer may mediate relationships
Sagan 2012 POL [42]	30 patients with lung cancer, 94 health care providers, 303 med students; (Surgery and chemotherapy)	Illness perception questionnaire about lung cancer	Health care providers and med students perceive lung cancer more negatively than lung cancer patients
Siminoff 2010 USA [44]	190 lung cancer patients, and their primary caregivers; (Surgery and radiation therapy)	Semi structured interviews, questionnaires	Quality of family environment impacts on patient's and caregiver's level of depression and QOL
Stone 2012 USA [45]	35 familial caregivers of parent who died from lung cancer; (Not reported)	Semi-structured interviews	Situational and relational influences on communication
Zhang 2010 USA [48]	184 patients advanced NSCLC, 171 primary caregivers; (Not reported)	Telephone interview	Disagreements between patients and caregivers about treatment and care decisions contribute to depression in patients and caregivers

CAN = Canada; POL = Poland; UK = United Kingdom; USA = United States of America; NSCLC = non-small-cell lung cancer; FACT (L) = functional assessment cancer treatment (lung), QOL = quality of life; RCT = randomized clinical trial.

NSCLC was observed; distress was associated with worse QOL. Quite striking were the findings about denial, apparently an often used coping strategy in patients with NSCLC. The Table gives details about the included studies.

Increasingly, reactions of caregivers and health care providers are included in empirical studies on patients with NSCLC. Table 2 reports on the 14 studies that explore responses from the persons closely associated with the patient with NSCLC, i.e. partners, family members, care givers, and health care providers, to the psychological plight of the patients. Given the complexities of including patients with lung cancer in research (patients are often too ill to participate in research), one can only express admiration for the researchers who managed to include quite substantial numbers of patients in their studies. The results of the various studies illustrate these problems on another level as well: caregivers and health care providers seem to be finding it rather difficult to cope with the problems of the patients. These last two categories of respondents perceive the psychosocial consequences of lung cancer as much more severe than the patients themselves.

#### 4. Discussion

A number of results stand out from this review of the literature. It appears that the topic of study – illness perceptions about lung cancer in patients, caregivers and health care providers – enjoys a quite considerable increase in research attention. Between August 2010 and July 2015, some 40 empirical papers were published, while we identified 15 papers in all the years preceding this period. It is not only the quantity of studies on illness perceptions in persons with lung cancer that seems to increase. The designs of the studies reflect methodological sophistication (e.g. multilevel analysis; solid theoretical embedding), and even the beginnings of clinical applications (e.g. [41]). Also, the field of illness perception research in lung cancer seems to include quite a few qualitative studies. These studies clearly help develop the field regarding theory and methodology (assessment of concepts not yet covered in the most commonly used questionnaires). The majority of studies (~75%) are from the USA. One can only hope that more biopsychosocial research on persons with lung cancer will be done in other countries as well.

The studies in the review illustrate the very grave impact of the diagnosis 'lung cancer' for patients, their partners, caregivers and their social environment. A consistent finding is that distress, impairment in quality of life and associated psychosocial problems are determined not that much by demographic or clinical characteristics but by the psychosocial response of the patient hit by the diagnosis of lung cancer. Also, caregivers and health care providers perceive lung cancer to have graver and more dramatic consequences than the patients themselves. Denial may play a role here in protecting the patients from unbearable worrying.

We acknowledge a number of limitations in our paper. We may have missed relevant papers. It will be a future challenge for other researchers to repeat our study with more included papers as the number of relevant papers will by definition increase. Also, not all papers are detailed enough when it comes to defining the precise diagnostic criteria (for NSCLC in this case). In some papers, patient with small-cell lung cancer are included, albeit as a small minority. In quite a few papers details about the medical background of the patients and the medical regimen appear to be rather rudimentary or entirely lacking. Also, relationships between clinical characteristics and quality of life, illness perceptions and distress are waiting to be explored.

Many research implications follow from our review. A more illness specific set of questionnaires to assess the impact of the diagnosis of lung cancer and the ensuing medical management seems a worthwhile area of research (cf. [49] for a similar paper on quality of

life in small-cell lung cancer). Studying the effects of psychosocial interventions (e.g. support programmes [50], coping skills training [33,51]) are one implication. Secondly, similar studies seem indicated in partners and caregivers of persons with lung cancer, given the major impact of the diagnosis of lung cancer in the patient. Regarding theory and theoretical models, the SRM is the guiding theory in a major review paper on stigma and nihilism in patients with lung cancer [52]. Quite a few papers in our review use theoretical models, especially from the (health) psychology domain. The voice of the patient might be louder by asking them what they would want in so far as psychosocial support goes [50,51]. We realize that many patients with lung cancer are too exhausted to make their voice heard, however. Devitt et al. and Maguire et al. [50,51] make a great contribution in this respect.

Clinically, the development of support programmes and coping training seem useful options to develop [50,51]. In both of these studies, patients themselves help clinical staff with suggestions about the topics they would want to be addressed in such programmes. Weiss et al. describe how it took a few decades for psychosocial issues in lung cancer "to come out of the closet" [53]. It is a bit sad to notice how in one of the major journals in respiratory medicine, the "Update in Lung Cancer 2014" [54] does not devote one single word to psychosocial issues about lung cancer. This topic is addressed in the area of Literature & Medicine, e.g. by a novelist who developed lung cancer himself (T. Mann, [55]), and in a graphic novel ("Mom's cancer", Fies [56]). Lung cancer is also represented in novels, poems, music, films, and paintings [57]. It should not take another few decades for high quality psychosocial research and clinical applications to enter the area of care for persons with lung cancer.

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