**ORIGINAL ARTICLE** 



# Portraying a grim illness: lung cancer in novels, poems, films, music, and paintings

Ad A. Kaptein<sup>1</sup> · Melissa S. Y. Thong<sup>2</sup>

Received: 7 November 2017 / Accepted: 25 April 2018 / Published online: 7 May 2018  ${\rm (}{\rm \bigcirc}$  The Author(s) 2018

#### Abstract

**Purpose** We studied how lung cancer is represented in five art genres: novels, poems, films, music, and paintings, in order to put lung cancer in a biopsychosocial perspective. The Common Sense Model is the theoretical basis: illness perceptions regarding lung cancer are examined in exemplars of the art genres.

**Methods** Literature searches, websites, and personal files formed the database. They produced a fairly limited number of novels, poems, films, music pieces, and paintings with lung cancer as core element.

**Results** A resigned, rather depressive response associated with great emotional turmoil to the diagnosis of lung cancer, its treatment and dismal outcome, figure rather prominently in the identified sources.

**Conclusions** Living with lung cancer is scarcely portrayed in novels, poems, film, music, and paintings. When portrayed, a depressive and resigned attitude colors the illness perceptions. Elements from the Medical Humanities (e.g., expressive writing, photovoice, painting) deserve further study in order to examine whether they help improve the quality of life of patients with lung cancer.

Keywords Art · Illness perceptions · Literature and medicine · Medical humanities · Lung cancer · Patient-reported outcome

## Background

Examining an MRI, a chest X-ray or a CT scan is an important part of the diagnostic and therapeutic workup in patients suspected of or diagnosed with lung cancer; medical management impacts on survival and quality of life [1]. The concept "quality of life" refers to the views of patients themselves about the effects of their illness and its treatment on their functional status. In patients with lung cancer, the assessment of quality of life has reached an established status, with a reliable and valid set of methods to assess quality of life (e.g., [2]). Integrating psychosocial care and palliative care into optimal medical

Ad A. Kaptein a.a.kaptein@lumc.nl management for patients with lung cancer is associated with a better quality of life, with some studies even suggesting greater longevity [3].

Recently, research on illness perceptions has made clear how patients' cognitions (beliefs, views) and emotions play a role in adapting (and maladapting) to illness (e.g., [4]). Illness perceptions can be described as "a distinct, meaningfully integrated cognitive structure that encompasses (1) a belief in the relatedness of a variety of physiological and psychological functions, which may or may not be objectively accurate; (2) a cluster of sensations, symptoms, emotions and physical limitations in keeping with that belief; (3) a naïve theory about the mechanisms that underlie the relatedness of the elements identified in (2); and (4) implicit or explicit prescriptions for corrective action" [5]. Early research on the topic illustrated how five dimensions can be discerned in illness perceptions: causes, consequences, control/cure, identity, and timeline [6].

Research and clinical applications in the context of illness perceptions is conceptualized in the Common Sense Model (CSM) [7]. A review of illness perceptions in patients with lung cancer concluded that illness

<sup>&</sup>lt;sup>1</sup> Department of Medical Psychology, Leiden University Medical Centre (LUMC), PO Box 9600, 2300, RC Leiden, the Netherlands

<sup>&</sup>lt;sup>2</sup> Department Medical Psychology, Amsterdam Public Health Research Institute, Academic Medical Centre, University of Amsterdam, Amsterdam, the Netherlands

perceptions are not only fascinating reflections of idiosyncratic views, they also predict psychological distress and reduced quality of life; the review pointed at the need for psychosocial intervention and support for patients with lung cancer and their caregivers [8].

Assessing these perceptions is done usually with validated questionnaires [9, 10]. Asking patients to draw their illness is a second approach to assessing illness perceptions (see [11] for drawings of their lung cancer by afflicted patients and [12] for a systematic review of drawing studies). There is a third, quite novel approach to studying patient's views of their illness. The way an illness and its sufferers are depicted in novels reveals how an illness is perceived, by healthy persons; by persons with the illness, their relatives, their caregivers, the health care professionals involved with providing medical care for these patients; and by society at large. "Medical Humanities" and "Literature in Medicine" are two concepts which cover this approach to studying illness perceptions; the recent concept "Health Humanities" reflects the growing influence of (health) psychology in this area. Poems also reflect cognitions and emotions; a not insubstantial body of work is available on how various illnesses and the responses of their sufferers are represented in poems (e.g., [13]). Furthermore, films, music, and paintings are three additional art genres wherein illness and its many ramifications are represented, offering material for studying how patients, partners, physicians, and the public at large conceptualize illness and respond to its consequences.

Exploring illness perceptions in patients with lung cancer may help health care professionals to incorporate patient views into medical care, which may also impact positively on patients' QOL [14].

## Methods

Novels, poems, films, music, and paintings in relation to nonsmall cell lung cancer were identified in a number of ways.

- a. Columbia University New York's website: www. medhum.med.nyu.edu. This database lists novels, poems, and films (and additional sources, e.g., video) about all diseases and illnesses.
- b. PubMed searches: "lung cancer" as MeSH was combined with "-novels," "-poems," "-film," "-music," and "painting," respectively. Also, "lung cancer" was combined with "popular culture," "medical humanities," and "narrative medicine," consecutively.
- c. Journal sections in major medical journals were checked for material where the art genres are discussed in relation to lung cancer: Chest (in the "Pectoriloquy" section),

JAMA, Lancet, Lancet Respiratory Medicine, and Thorax. Also, journals in the Medical Humanities area were checked (e.g., Journal of Health Psychology, Journal of Medical Humanities, Medical Humanities).

d. Files with papers on illness perceptions and art genres in patients with lung cancer, built up in decades of research and teaching by the authors, were studied for relevant novels, poems, films, music, and paintings.

Identified sources of data were studied, and their content was categorized in the dimensions of illness perceptions defined in the questionnaire most often used in research (B-IPQ, Brief Illness Perception Questionnaire; www.uib.no/ipq).

## **Ethical approval**

For this type of study, a formal consent is not required. Informed consent was obtained from all individual participants included in the study: the widow (U.H.) of the patient in Fig. 2 declared "I took the picture at that time and I have no objection against publication" (email from U.H. to the first author, 29 July 2017).

#### Results

Lung cancer is the subject of central concern in the *novels* "The Quarry" by Iain Banks [15], "In gratitude" by Jenny Diski [16], "When breath becomes air" by Paul Kalanithi [17], and "Stadium IV" (Stage IV) by Sander Kollaard [18]. Two authors, who died because of lung cancer, wrote *poems* about their ordeal: Raymond Carver ("What the doctor said" [19]) and John Updike ("Needle biopsy" [20]).

Two *films* are highly relevant for the topic under discussion: "Thank you for smoking" (Reitman [21]) and "The Lake" (Harding [22]).

Two *music* pieces were identified: Jacques Brel, a Belgian artist, died of lung cancer and wrote and sang "Growing old" [23] about dying because of lung cancer. "Smoke! Smoke! Smoke! (That cigarette)" by Tex Williams [24] reflects the craving for cigarettes and the potentially fatal consequences of smoking tobacco.

*Paintings* about lung cancer by established painters were hard to find; a search via Google produced a number of paintings of lung cancer done by patients.

The *graphic novel* "Mom's cancer" by Fies [25] represents a mix of the two categories "novel" and "painting," illustrating a recent new category in literature and medicine: graphic medicine (http://www.graphicmedicine.org/).

#### Novels

Diski's and Kalanithi's books are autobiographies; the books by Banks and Kollaard are novels. The protagonists in all four novels die because of their lung cancer. The various phases of their illness trajectories can be discerned rather easily in the books. The final phase of the lives of the patients are sad reminders of the devastating manner in which lung cancer destroys human life, not only in a physical sense but also in particular in a psychological and social sense. Quotes from the novels illustrate illness perceptions regarding lung cancer.

#### Consequences

Banks: "... lost so much weight and his face, which was always thin, now looks cadaverous. There are dark circles under his large, blue, hooded eyes and his skin is dry and flaky. His lips look bruised all the time ... ... his back got bad ... takes long to get up the stairs."

Diski: "chemo-brain doesn't just dim my lights; it also has made me feel clumsy, not completely in control of my movements ... my superfast typing has many more errors, and I'm very wary of going downstairs or reaching for a glass. ... the ragged pain made it impossible to eat or swallow anything ... my taste buds are playing a cruel game."

Kalanithi: "... I was neither angry nor scared. It simply was. Weight loss ... back pain ... severe chest pain ... sweating at night."

Kollaard: "the chemo gives me poisonous dreams ... the chemo is attempted murder in order to prevent manslaughter ... the poisonous dreams were replaced by sleeplessness ... voice problems ... difficulty sleeping ... the chemotherapy had destroyed her sense of smell."

#### Timeline

Banks: "It's only going to get worse ... heading downwards ..." ... "... he has good days and bad days and good weeks and bad weeks, though month-to-month he's very obviously heading downwards, and the good days and good weeks now are like the bad days and bad weeks just a few months ago."

Diski: "... but could you perhaps give me a general idea: years ... months ... weeks? ... how many inches will the weeping birch grow ...." Kalanithi: "... but I will want to talk about the Kaplan-Meier survival curves."

Kollaard: "... I sure have some time to live ...."

## **Personal control**

Banks: "He's taken smoking up again recently, reckoning there's nothing left to lose, and also, I think, as an act of defiance."

Diski: "... so how come I've remained so foggy about the details and possible trajectories of my cancer? I tell myself it's because I'm not so much in charge in cancerworld. I don't think I've ever felt so not in charge."

Kalanithi: "Okay," I said, "then I think everything is pretty clear. We'll hear from you tomorrow about the EGFR results. If yes, then we'll start a pill, Tarceva. If no, then we start chemotherapy Monday."

Kollaard: "it was the way it is, there was nothing more to say. ... There was no choice. What had to happen, had to happen."

#### Treatment control

Banks: "He forgets to take his medication, a lot, then sometimes takes too much ... I can see the opiate capsules have gone early; they usually do."

Diski: "... to treat, not to cure ...the cancer is in charge and leading them all a merry dance."

Kalanithi: "... stage IV lung cancer today was a disease whose story *might* be changing, like AIDS in the late 1980s: still a rapidly fatal illness but with emerging therapies that were, for the first time, providing years of life."

Kollaard: "So, let me get this straight: there is no stage V?" ... "the poison that would not cure her."

#### Identity

Banks: "... pain ... unable to go upstairs ... constipation ...."

Diski: "... fatigue ... unable to move ... shortness of breath ... trouble swallowing ... vomiting ...."

Kalanithi: "... fatigue ... concentration problems ... chest pain ...."

Kollaard: "... sleep problems ... disrupted sense of smell ... voice problems ... 'stinking breath' ...."

### Concern

Banks: "... do you f\*\*\*\*\* understand that I don't f\*\*\*\*\* want to die? ... I hate the thought of the world and all the people in it just going on merrily on without me after I'm gone. How f\*\*\*\*\* dare they?"

Diski: "... dying of lung cancer can be treated the same way (with palliative care, morphine), so the terror of death has been soothed to the fear of blank nothingness into eternity."

Kalanithi: "... I was physically debilitated, my imagined future and my personal identity collapsed, and I faced the same existential quandaries my patients faced."

Kollaard: "... what she saw in her husband was 'denial'. Leave me the truth, however, she thought. The truth, the whole truth and nothing but the truth."

# Coherence

Banks: "... it makes it hard to be f\*\*\*\*\*\* positive about any f\*\*\*\*\* thing, with the notable exception of feeling positive that you're going to f\*\*\*\*\*\* die ... so they tell you to think positively, as though that's going to help with a metastasizing cancer rampaging its way through your f\*\*\*\*\* body." ... "... You might as well walk into a burning building and try to put out the fire through the medium of modern dance. But it means when you do lose your brave battle – because it always has to be a brave battle, doesn't it? ... So you don't even get to die in peace; you don't even get to die without the implication that it's somehow your own fault because you weren't positive enough."

Diski: "I have 'non-small cell lung carcinoma'. I'm mystified by the term. By the negative for its opposite. Non-small. A robust sort of cancer then? Why not 'large' or 'quite big'?" ... "... I gathered some part of Elekta (the radiation therapy system) scanned my insides, while others moved into position to shoot beams into my lung and lymph nodes, moving upwards towards my neck."

Kalanithi: "Slowly the medical fog was clearing—at least now I had enough information to dive in the literature."

Kollaard: "After the physician had left, the man and woman-patient were silent. For her, she was silent as she did not know what to say. For her the cancer was a meaningless, characterless fact. She was dying. That was the way it was."

#### **Emotional representations**

Banks: "... 'f\*\*\*\*\* portable prison', 'f\*\*\*\*\* shitty horrible fucking cancer hasn't got there yet!'"

Diski: "'embarrassment', 'weariness', 'denial', 'sullen rudeness is a possible option handed to us cancerees', anger, rage."

Kalanithi: "depression, severe illness wasn't life-altering, it was life-shattering."

Kollaard: "panic, enemy, war, surrender, challenge."

Cause dimension (smoking): We did not explicitly code the causal dimension as we used the B-IPQ dimensions—where "perceived causes" represent an open question, a format different from the eight other items of the B-IPQ that we attempted to illustrate. It goes without saying that attributions/perceived causes are important and fascinating, given the undeniable fact of smoking as a risk factor for lung cancer [26]. Patients with lung cancer tend to agree with smoking being a risk factor for lung cancer, although we should remind ourselves that one in seven persons with lung cancer never smoked. The protagonist in "The quarry" attributes his medical condition to "not being positive enough" (p. 169), while his son says: "It's your fault you smoked! I want to scream at him" (p. 169).

"Causes" seem to be observable in the following citations (in Banks) "... he has good days and bad days and good weeks and bad weeks, though month-to-month he's very obviously heading downwards, and the good days and good weeks now are like the bad days and bad weeks just a few months ago" (p. 23); and "... You might as well walk into a burning building and try to put out the fire through the medium of modern dance. But it means when you do lose your brave battle – because it always has to be a brave battle, doesn't it? ... So you don't even get to die in peace; you don't even get to die without the implication that it's somehow your own fault because you weren't positive enough" (p. 169).

In Diski: "... I gathered some part of Elekta (the radiation therapy system) scanned my insides, while others moved into position to shoot beams into my lung and lymph nodes, moving upwards towards my neck" (p. 126).

#### Poems

Raymond Carver (1938–1988) died of lung cancer when he was 50 years old. In "What the doctor said," Carver describes the encounter with his physician who tells the patient the result of diagnostic workups. The patient writes about not wanting to learn too many details about the findings, reflecting a response that has been identified in earlier research: denial and emotional turmoil [27].

What the doctor said He said it doesn't look good He said it looks bad in fact real bad He said I counted thirty-two of them on one lung before I quit counting them I said I'm glad I wouldn't want to know About any more being there than that

Kleppe outlines the value of this poem for teaching in courses of Medical Humanities. Her students are impressed by the poem and explore themes as remorse and dying [27].

A couple of weeks before his death, John Updike (1932–2009) wrote the "Needle biopsy" (below). The author seems to rather stoically face the reality of the outcome of the diagnostic procedure.

Needle biopsy 12/22/08 All praise be Valium in Jesus' name: A CAT-scan needle biopsy sent me Up a happy cul-de-sac, a detour not Detached from consciousness but sweetly part – I heard machines and experts murmuring about me – [...] All would be well, I felt, all manner of thing. The needle, carefully worked, was in me, beyond pain, Aimed at an adrenal gland. I had not hoped to find, in this bright place, so solvent a peace. Days later, the results came casually through: The gland, biopsied, showed metastasis.

## Films

Illness is a quite frequent subject matter in films, most likely as illness is a dramatic topic. Two films focus specifically on lung cancer.

In *The Lake* [22], a film of 15-min duration, the response of a middle-aged man who received the diagnosis of lung cancer is depicted. Illness perceptions that stand out are a strong wish for "personal control" ["I decide how this goes," [22], p. 151] and strong "emotional representations." The full impact of coping with the diagnosis and its consequences are shown in the movie, with a somewhat surprising end.

Thank you for smoking [21] based on a 1994 novel by Buckley shows the story of how tobacco companies falsely try to reassure the public that smoking is not bad for one's health. In a fairly sarcastic way, the movie shows the perverse strategy of Big Tobacco. Even "the Marlboro Man" is bribed for keeping silent about his smoking and lung cancer. Illness perceptions differ diametrically between the two victims of tobacco and the pushers of tobacco: from "consequences" to "emotional responses."

## Music

Music, classical and "popular," is able to translate cognitions and emotions into sound, perceived as beautiful, attractive, or awful and repulsive [29]. Illness is associated with strong emotions and cognitions. Lung cancer, therefore, also figures in music. Tex Williams sings in "Smoke smoke smoke that cigarette" (1947 [24]) about the craving for cigarettes and its potential lethal consequences.

Smoke smoke smoke that cigarette (Tex Williams) That ain't that I don't smoke myself And I don't reckon they'll injure your health I've smoked 'em all my life and I ain't dead yet But nicotine slaves are all the same At a pheasant party or a poker game Everything's gotta stop when they have that cigarette Smoke smoke smoke that cigarette Puff puff puff And if you smoke yourself to death Tell St Peter at the Golden Gate That you hate to make him wait But you just gotta have another cigarette

Jacques Brel, a Belgian artist, died as a consequence of lung cancer. His song "Vieillir" (1977 [23]) reflects on "blond cigarettes" and "dying in a fight against cancer":

Dying, laughing oneself to death It is possibly true By the way, just look – They don't dare laugh too much anymore Dying from playing the fool To cheer up the desert Dying in a fight against cancer Stopped by the referee ... Dying at the end of a blond cigarette Somewhere where nothing ever happens Where time's behind you Where your bed turns into a grave ...

Both music pieces focus to quite some degree on smoking tobacco, while the novels and poems hardly mention smoking at all. The films discussed earlier appear to take a middle position in this respect. In all genres of art, the quotes presented here reflect a somewhat stronger emphasis on more or less an accepting and resigning response, which seems to translate into "personal control" and "consequences," and "emotional illness perceptions."

Music is being used in medical education in order to teach medical students about, for instance, suffering, mourning, and death [28]. Cochrane reviews make clear that listening to music may have helpful effects in ill persons during diagnostic and therapeutic procedures and in living with a chronic illness [29]. Pop music or country and western music, as is shown in the Cochrane review by Bradt et al., address smoking tobacco quite often. Classical music and opera deal with smoking and death as well—the opera Carmen has the main character working in a cigar factory, where the consequences of smoking tobacco become evident [30]. Bro et al. recently reviewed the effects of music, specifically for people with cancer, as an adjunct to the biomedical treatments of the disease [31].

## Paintings

Paintings of illness and ill patients represent a substantial area of research (e.g., [32]). As illness is a stimulus that elicits very strong emotional responses—as can be seen in novels, poems, films, and music—it comes as no surprise that paintings also quite frequently have "being ill" as the subject matter. The book "Medicine and art" [32] presents hundreds of paintings, from medieval times to current, where illness (physical and psychiatric) is shown—in various categories of illness (e.g., cardiology, rheumatology, dermatology). Lung cancer has not yet been subject of paintings. On sites of patients with lung cancer, paintings are a frequently used form of expressing emotions and cognitions about the illness. Below, a painting by a patient with lung cancer appears to reflect a rather grim and somewhat aggressive view of lung cancer (https://www. google.nl/search?q=lung+cancer+painting) (Fig 1).

In Fig. 2, a relatively young man who celebrates his final weeks of his life on a tropical island shows his representation of his lung cancer. His bitter-sweet facial expression may



Fig. 1 A painting of lung cancer (website)



**Fig. 2** Representing one's lung cancer (picture reproduced with permission of relative)

reflect his cognitions and emotions about his physical situation (photo reproduced with permission from a relative).

## Discussion

Lung cancer is the subject of novels, poems, films, music, and—to a limited extent—paintings. Given the prevalence of lung cancer, however, the size of literary and artistic work on this "recalcitrant disease" [33] is limited (www.medhum. med.nyu.edu).

Despite the relatively high incidence and prevalence of lung cancer, the disease is not often a subject in works of art. The stigmatized nature of lung cancer ("working class disease," "patients cause their illness themselves by smoking," "lung cancer is a grim, dirty disease") seems not helpful in creating a sympathetic image of people with lung cancer or in stimulating the production of works of art about lung cancer (e.g., [34]. An organization such as Pink Ribbon that raises awareness and creates moral support for (patients with) breast cancer does not exist for patients with lung cancer; a similar organization for people with lung cancer, and their relatives, might be very helpful in creating a less stigmatized image of (patients with) lung cancer.

The number of novels on cancer is very extensive. Our objective in this paper, however, is to focus specifically on lung cancer as represented in various art genres, given its status of "orphan disease," both in behavioral research and art. Other categories of cancer, for example breast cancer or Hodgkin's disease, have a more "popular, positive" image in society and in health care and behavioral research and art. This in itself is a rather interesting phenomenon but outside the scope of our paper. Our paper intends to explore lung cancer in novels, poems, films, music, and paintings. The books by Radley [35, 36] are valuable sources of approaches to research on representations and images of persons with serious illness.

Not really surprising is how the novels—partly autobiographical—speak of the shock the authors or the protagonists experience when they learn of the diagnosis of lung cancer. At least as striking is the virtual absence of rage and anger as an initial psychological response. Resignation and withdrawal from the social world figure more prominently in the various representations of lung cancer in the art genres discussed here. Even the decision in "The Lake" by the protagonist and victim to "decide this by himself" can be seen as an expression of giving up resisting a fatal illness. The rage, verbalized by the character with lung cancer in "The Quarry" can be seen in a similar fashion.

Illness perceptions can be deduced from the artistic material albeit that further work is needed on the operationalization of illness perceptions in novels, poems, films, music, and painting [37]. A theme in these studies is the degree to which illness characteristics (i.e., degree of concordance between severity of the disease and psychological consequences) are discernable in the novels. Our paper, we believe, is the first in the area of lung cancer.

In addition to the Common Sense Model (CSM), other theoretical frameworks also focus on how people make sense of illness. Illness narratives and narrative medicine are central concepts in the work of Charon, Frank, Kleinman, and Radley, representing theoretical approaches with a focus on medical ethics, medical sociology, psychiatry and medical anthropology, and social psychology, respectively [36, 38-40]. In the current paper, we used the CSM as it has a strong empirical basis (see systematic reviews and meta-analyses by Dempster et al. [41] and Hagger et al. [42]), and it is the model that has guided our research over the past decades. Nevertheless, the Common Sense Model may benefit from additional research approaches. This is one of the factors that encouraged the current authors to examine the potential contribution of studying novels and other art genres to the subject of how people make sense of an illness (e.g. [43]). Also, a recent work on drawings in illness attempts to extend the CSM: it studied whether patients' drawings of their illness contribute to the CSM by identifying illness perceptions that may be underrepresented in the model and its assessment approaches [12].

We selected four books where lung cancer is the central theme, albeit with different emphasis. Two of the four publications are novels proper (Banks; Kollaard), the other two (Diski; Kalanithi) might better qualify as autopathography or autobiography ([44]; Radley uses the concept "victim art" [35], p. 18). Given the quite limited number of novels on lung cancer and the high literary quality of the two chosen autopathographies, we believe these four books represent a valuable set of works to examine illness perceptions and illness narratives in people with lung cancer. Further research is warranted on the strengths and weaknesses of novels and autopathographies in research on illness narratives. Also, the topic is quite complex as even high-quality literary novels may be written by authors who suffered the illness that is central in the novel (e.g., Cancer Ward, Solzhenitsyn).

The Common Sense Model posits how illness perceptions affect coping and thereby outcome. The books we used in this paper illustrate this theoretical prediction. The protagonist in The Quarry "stopped smoking five years ago, about twenty years too late. He's taken it up recently, reckoning there's nothing left to lose, and also, I think, as an act of defiance" (Banks, p. 33). Here, perceptions of (a low degree of) personal control lead to changes in smoking behaviour. Diski illustrates how her perception of treatment control is associated with her decision to be unwilling to undergo various diagnostic and therapeutic procedures: "The cancer's in charge and leading them all a merry dance. Perhaps that's why I've so little taste for investigation. There's an awful lot of uncertainty for patients and doctors in this cancer business" (page 118). Kalanithi, a physician, has strong perceptions of treatment control: "... stage IV lung cancer today was a disease whose story might be changing, like AIDS in the late 1980s: still a rapidly fatal illness but with emerging therapies that were, for the first time, providing years of life" (p. 139), which leads him to desperately embrace every option for medical treatment. Kollaard's protagonist in "Stage IV" says: "For her cancer is a senseless, characterless fact, about which one simply cannot say anything meaningful, despite its shattering implications. She was going to die." (p. 32)—this emotional giving up makes her decide to refrain from chemotherapy.

Illness perception research contributes to examining patients' responses to an illness and to examining how exhibiting adaptive illness perceptions is instrumental in improving medical outcome. Clinically, various studies show how substituting maladaptive illness perceptions by adaptive illness perceptions results in, for example, earlier return to work, reduced symptoms, quicker resumption of sexual activities, and associated outcome measures [45].

Modifying illness perceptions is a burgeoning field in (health) psychology. Recent reviews and meta-analyses make clear that addressing maladaptive illness perceptions may impact on coping and may modify outcomes in a positive way. Up to now, this research approach has not yet been applied to patients with lung cancer. Nevertheless, some encouraging research studies are available. Corbett et al. demonstratedin a descriptive study-how illness perceptions in persons with lung cancer explained substantial variance in fatigue [46]. The work by the research group of Temel focusing on palliative care for persons with lung cancer shows the potential contribution of addressing illness perceptions in this category of patients [47]. The mindfulness intervention study seems to fit in with the work by Temel et al. [48]. Given this empirical work, it appears that enhancing perceptions of personal control, coherence, and treatment control may translate into more adaptive coping, which may translate into a better QOL. Given the poor survival rates, outcomes of such interventions should not focus on (improvements in length of) survival but on issues such as quality of life. Monitoring quality of life may in itself even be associated with gains in survival (e.g. [49]). Bouazza et al. offer a systematic review of patient-reported outcome measures for persons with lung cancer [50]; Lehto reviews the area of psychosocial interventions in lung cancer [51]. Encouraging findings from these studies appear to point at areas for future research.

The books, poems, music, and films discussed in this paper, of course, are case studies. Huge individual differences exist in the way people make sense of illness. Review papers give some impression of these variations—and communalities (e.g., [8, 42, 43]). Future research might explore these issues by using a range of methods in studying how persons with lung cancer give meaning to their grim disease.

Interview and questionnaire methods do result in valuable insights into the patient's world. In the current paper, we attempted to examine the potential contribution of some art genres to shed additional light on the patient's world. In addition to interviews, questionnaires, and art genres, one may suggest a fourth strategy in (health psychology) methods to explore the patient's world: drawings by patients of their illness [12]. Reading novels and poems, studying paintings, and listening to music in the context of research on patients making sense of illness seems a worthwhile undertaking, if not alone for the intellectual pleasure this may bring. Enlarging the biomedical view (on lung cancer, but also much broader) to a biopsychosocial view by studying various genres of art may be instrumental in strengthening the quality and intellectual power of research-in any field. Furthermore, medical students, physicians-in-training, and other (health care) professionals may become better researchers and clinicians if they read novels and poems, watch films, and listen to music, related to health and illness; this might also be true for patients (see for a review of the area [43]) suffering from a grim disease.

#### **Compliance with ethical standards**

**Conflict of interest** The authors declare that they have no competing interests.

**Open Access** This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 International License (http:// creativecommons.org/licenses/by-nc/4.0/), which permits any noncommercial use, distribution, and reproduction in any medium, provided you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons license, and indicate if changes were made.

## References

- Hirsch FR, Scagliotti GV, Mulshine JL, Kwon R, Curran WJ Jr, Wu YL, Paz-Ares L (2017) Lung cancer: current therapies and new targeted treatments. Lancet 389:299–311
- Bergman B, Aaronson NK, Ahmedzai S, Kaasa S, Sullivan M, for the EORTC Study Group on Quality of Life (1994) The EORTC QLQ-LC13: a modular supplement to the EORTC Core Quality of Life questionnaire (QLQ-C30) for use in lung cancer clinical trials. Eur J Cancer 30A:635–642
- Chandrasekar D, Tribett E, Ramchandran K (2016) Integrated palliative care and oncologic care in non-small-cell lung cancer. Curr Treatm Options Oncol 17:23
- Petrie KJ, Weinman J (2006) Why illness perceptions matter. Clin Med 6:536–539
- Lacroix JM, Martin B, Avendano M, Goldstein R (1991) Symptom schemata in chronic respiratory patients. Health Psychol 10:268–273
- Kleinman A, Eisenberg L, Good B (1978) Culture, illness, and care. Ann Intern Med 88:251–258
- Leventhal H, Phillips LA, Burns E (2016) The common-sense model of self-regulation: a dynamic framework for understanding illness self-management. J Behav Med 39:935–946

- Kaptein AA, Kobayashi K, Matsuda A, Kubota K, Nagai S, Momiyama M, Sugisaki M, Bos BCM, Warning TD, Dik H, Klink R, Inoue K, Ramai R, Taube C, Kroep JR, Fischer MJ (2015) We're in this together: patients', caregivers' and health care providers' illness perceptions about non-small-cell lung cancer (NSCLC). Lung Cancer 90:575–581
- 9. Wolf P (2013) The epileptic aura in literature: aesthetic and philosophical dimensions. An essay. Epilep 54:415–424
- Wexler A (2014) Huntington's disease in popular culture: a brief historical perspective. J Huntington's Dis 3:1–4
- Hoogerwerf MA, Ninaber MK, Willems LNA, Kaptein AA (2012) "Feelings are facts": illness perceptions in patients with lung cancer. Respir Med 106:1170–1176
- 12. Broadbent E, Schoones JW, Tiemensma J, Kaptein AA (2018) Patients drawing their illness: a systematic review. Health Psychol Rev (in press)
- 13. Salcman M (ed) (2015) Poetry in medicine. Persea Books, New York
- Morrison EJ, Novotny PJ, Sloan JA, Yang P, Patten CA, Ruddy KJ, Clark MM (2017) Emotional problems, quality of life, and symptom burden in patients with lung cancer. Clin Lung Cancer 18:497–503
- 15. Banks I (2013) The quarry. Little Brown, London
- 16. Diski J (2016) In gratitude. Bloomsbury, London
- 17. Kalanithi P (2016) When breath becomes air. Random House, New York
- 18. Kollaard S (2015) Stadium IV [stage IV]. van Oorschot, Amsterdam
- Carver R (2003) What the doctor said. In: Carver R (ed) All of us the collected poems. The Harvill Press, London, p 289
- Updike J (2009) Needle biopsy 12/22/08. In: Endpoint and other poems. Alfred A. Knopf, New York, pp 27–28
- Reitman J (2006) Director. Thank you for smoking [Motion Picture, D.O. Sacks, Producer]. Fox Searchlight Pictures, USA
- 22. Harding E (2016) Films—The Lake. Lancet Oncol 17:151
- Brel J (2017) Vieillir. wwwlyricstranslatecom/en accessed 20 July 2017
- 24. Williams T (2017) Smoke smoke smoke that cigarette! 1947 www. play.google.com/music. Accessed 28 July 2017
- 25. Fies B (2006) Mom's cancer. Abrams, New York
- Vos MS, Putter H, van Houwelingen HC, de Haes HCJM (2011) Denial and social and emotional outcomes in lung cancer patients: the protective effect of denial. Lung Cancer 72:119–124
- Kleppe SL (2006) Medical humanism in the poetry of Raymond Carver. J Med Human 27:39–55
- Butler DJ (2009) Teaching about the traumatic impact of vehicular crashes: rock 'n' roll never forgets. Fam Med 41:549–551
- Bradt J, Dileo C, Grocke D et al (2011) Music interventions for improving psychological and physical outcomes in cancer patients. The Cochrane Database of Systematic Reviews 8:CD006911
- Hutcheon L, Hutcheon M (1996) Opera—desire, disease, death. University of Nebraska Press, Lincoln
- Bro ML, Jespersen KV, Hansen JB, Vuust P, Abildgaard N, Gram J, Johansen C (2018) Kind of blue: a systematic review and meta-

analysis of music interventions in cancer treatment. Psycho-Oncol 27:386–400

- 32. Bordia G, d'Ambrosio LP (2010) Medicine in art. Getty Publications, Los Angeles
- Timmermann C (2014) A history of lung cancer. The recalcitrant disease. Palgrave, New York
- Steffen LE, Vowles KE, Smith BW, Gan GN, Edelman MJ (2018) Daily diary study of hope, stigma, and functioning in lung cancer patients. Health Psychol, in press 37:218–227
- Radley A (2009) Works of illness. InkerMen Press, Ashby-de-la-Zouch
- 36. Radley A (ed) (1993) Worlds of illness. Routledge, London
- Camic PM (2008) Playing in the mud. Health psychology, the arts and creative approaches to health care. J Health Psychol 13:287–298
- Charon R (2006) Narrative medicine. Oxford University Press, Oxford
- Frank AW (1995) The wounded storyteller. The University of Chicago Press, Chicago
- 40. Kleinman A (1988) The illness narratives. Basic Books, New York
- Dempster M, Howell D, McCorry NK (2015) Illness perceptions and coping in physical health conditions: a meta-analysis. J Psychosom Res 79:506–513
- Hagger MS, Koch S, Chatzisarantis NLD, Orbell S (2017) The common sense model of self-regulation: meta-analysis and test of a process model. Psychol Bull 143:1117–1154
- Kaptein AA, Hughes BM, Murray M, Smyth JM (2018) Start making sense: art informing health psychology. Health Psychol Open 5:1–13
- 44. Aronson JK (2000) Autopathography: the patient's tale. BMJ 321: 1599–1602
- Petrie KJ, Cameron LD, Ellis CJ, Buick D, Weinman J (2002) Changing illness perceptions after myocardial infarction: an early intervention randomized controlled trial. Psychosom Med 64:580–586
- Corbett T, Groarke AM, Walsh JC, McGuire BE (2016) Cancerrelated fatigue in post-treatment cancer survivors: application of the common sense model of illness representations. BMC Cancer 16:919
- Temel JS, Greer JA, El-Jawahri A et al (2017) Effects of early integrated palliative care in patients with lung and GI cancer: a randomized clinical trial. J Clin Oncol 35:834–841
- Chambers SK, Morris BA, Clutton S, Foley E, Giles L, Schofield P, O'Connell D, Dunn J (2015) Psychological wellness and healthrelated stigma: a pilot study of an acceptance-focused cognitive behavioural intervention for people with lung cancer. Eur J Cancer Care 24:60–70
- Basch E, Deal AM, Dueck AC, Scher HI, Kris MG, Hudis C, Schrag D (2017) Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. JAMA 318:197–198
- Bouazza YB, Chiairi I, Kharbouchi OE et al (2017) Patient-reported outcome measures (PROMs) in the management of lung cancer: a systematic review. Lung Cancer 113:140–151
- Lehto RH (2017) Psychosocial challenges for patients with advanced lung cancer: interventions to improve well-being. Lung Cancer: Targets Ther 8:79–90