THE SEESAW BETWEEN THE LIVING AND THE DEATH: HOW PATIENTS AND THEIR CAREGIVERS COPE WITH LUNG CANCER DURING THE ILLNESS TRAJECTORY. A QUALITATIVE STUDY

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Submitted
ABSTRACT

Study Objective: To explore how lung cancer patients and their caregivers cope together with the diagnosis and treatment trajectory during the first three months of therapy.

Methods: Qualitative, prospective multiple case study. Semi-structured interviews were conducted with 14 newly diagnosed lung cancer patients, their 28 caregivers and 13 health care providers (pulmonary physicians, surgeons and nurses). Patients (8 men, 6 women, age range 49-82 years) started therapy in 3 clinics for pulmonary diseases in the Netherlands. Participants have been interviewed directly, 1 month and 3 months after diagnosis. A total of 21 hospital, 11 home and 97 telephonic interviews have been collected. A thematic analysis was performed.

Results: Patients and caregivers struggled together to learn how to live with lung cancer. They attempted to regain control over themselves and their (current) situation continuously. The way they dealt with the different issues they were facing either helped them to live their life in the present or helped them to face the future patient’s death and prepare for it, as though if they were moving from one side of an imaginary seesaw to the other, constantly shifting between the two opposing realities. “Going on with the present life” was achieved by focusing on the treatment calendar. Simultaneously, they were focusing on life outside of therapy by maintaining usual activities and living by the day, hereby protecting oneself and others from the confrontation with the disease and death. “Daring to face death” was achieved by allowing intense emotions to take over, open communication about death, looking for death related information and making plans for death. Tensions between patients and caregivers could occur with regard to their position on the seesaw and the way they coped with the same issue. Health care providers’ insight within the patients’ and caregivers’ coping process differed per specialty. All of them acknowledged that caregivers were important for patients, but they said that they were cautious with regard to the caregivers involvement with patient care, as they were aware of the possible negative aspects of such involvement.

Conclusions: Whilst lung cancer patients and their caregivers cope with the disease together and try to regain control, they continuously shift between trying to live in the present and simultaneously, daring to face the patients imminent death and prepare for it. They are united in their struggle, but as they also have different needs, the way they cope might differ and provoke tensions between them. Health care providers should involve caregivers with patients’ care and inquire about coping and tensions between them.
INTRODUCTION

Lung cancer is the most common cause of cancer death worldwide with a poor survival and a median life expectation of around 6 months. Starting from the moment of diagnosis and during the whole treatment trajectory, patients have to deal with a shortened life expectancy and incertitude, endure the disease’s related symptoms and bear toxic and potentially mutilating treatment regimens. This affects their quality of life (QoL) and provokes distress, which has been reported to be particularly intense as compared to other cancers. It has become clear that lung cancer also has a great impact on the patients’ informal caregivers. Like the patients, caregivers must also learn to live with their loved one being diagnosed with a life threatening disease, stand by him/her during the whole treatment and face the inevitable future of disease progression and ultimately the patient’s death. Both caregivers and patients share in the patient’s illness experience and their welfare is therefore interlinked. Additionally, caregivers actively take part in a lot of practical matters in the course of the patient’s treatment. Not only are they often present during consultations and do they search for disease related information, but they also participate actively in decision making and are involved in the everyday care and support of patients.

However, caring for a beloved one with lung cancer takes its toll. Caregivers face a lot of physical, psychological, social and spiritual challenges in their role as “informal” caregivers. They are challenged with the redistribution of their own resources to accomplish targets in both their personal calendars and the patient’s illness and treatment calendars, as described by Costain Schou and Hewison. How caregivers cope with these challenges might have impact on both their QoL and their ability to take care and support of their loved ones. The way individuals cope with threatening events -such as lung cancer- may be explained by the coping theory described by Folkman and Lazarus. They describe the application of coping strategies (e.g. problem or emotion focused coping) aimed at changing the experienced distress and influencing the individuals’ wellbeing in the long-term. One of the well-researched manners to evaluate an individual’s wellbeing is to measure the individual’s QoL.

Looking at the QoL of caregivers, a number of researches have shown that those close to a patient diagnosed with lung cancer are profoundly and significantly distressed and present lower levels of QoL than the general population. Ryan et al. and Murray et al. have even pointed out the need for structured assistance and support not only for lung cancer patients but also for their caregivers. In order to provide adequate assistance and support to lung cancer patients’ caregivers, it seems necessary to have more knowledge and insight into the roles they endorse and the way they cope -together with the patient- with lung cancer and the treatment trajectory until the patient’s death. To date, only a few studies have addressed this specific topic. Indeed, several studies have been dedicated to lung cancer patients and their caregivers. However, these have only reported on specific aspects of living with lung cancer, such as the experience of symptoms and its associated distress and the predictors of the QoL in both lung cancer patients and their caregivers. The association between caregiver burden and distress in both lung cancer patients and spouses has also been reported. However, only few qualitative studies where different aspects of life with lung cancer and its medical treatment were investigated, have been conducted examining caregivers together.

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with lung cancer patients. Krishnasamy et al. reported about key domains of care provision needs during the treatment trajectory, Lindau et al. investigated communication difficulties within couples regarding sexuality and intimacy and Badr et al. explored the experience of social constraints. (30-32) Murray et al. showed that family caregivers followed clear patterns of wellbeing and distress, mirroring the lung cancer patients’ experiences in a similar time frame. (22) The et al. looked at “false optimism about recovery” among lung cancer patients and how it affected their behavior and attitude towards death during the treatment trajectory. (33) To our knowledge, only two studies by Ellis et al. and Mosher et al. respectively, specifically focused on exploring the actual coping of patients and caregivers with lung cancer and its related difficulties. These studies led to the identification of a number of coping strategies and factors mediating distress, (34;35) as well as identifying caregivers’ key challenges when facing their loved one’s disease (e.g. profound sense of uncertainty regarding the future, time consuming efforts to manage the patient’s emotional reactions to the illness and practical tasks). (35) The insights gained by the first study contributed to the knowledge of the coping of lung cancer patients and their caregivers (34) but are insufficient to provide a complete picture. In the study of Mosher et al., only the caregivers’ perspectives have been addressed. (35)

Besides the informal caregivers, health care providers (HCPs) also play an important role in helping cancer patients and their caregivers coping with the illness and treatment trajectory. Throughout each phase of this trajectory (i.e. diagnosis, treatment, remission, relapse, end of life and death), HCPs endorse the roles of providers of medical care, information and support. (36;37) The way they fulfill their roles is important as their behavior and communication skills are actually associated with patients’ coping and wellbeing, both positively and negatively. (37-39) They are essential in facilitating patients and caregivers’ positive coping. (38-39)

Although HCPs may not have complete insight into a patient and his caregivers’ personal situation, their position as independent yet involved and supportive health professionals permits them to get insight into the way patients and caregivers cope with the disease from a more distant and different perspective. Therefore, their point of view may be of great added value. In the available literature the integrated perspectives of the patient, caregiver and health care providers are rarely included (32) and usually reports from a restricted perspective. (30-32)

A study with the different perspectives of all persons involved in the lung cancer treatment trajectory could provide insight into how lung cancer patients and their caregivers cope together with the diagnosis of lung cancer and the treatment trajectory over time. In the future, this specific knowledge might contribute to the provision of better support and assistance to both patients and caregivers during the treatment trajectory and herewith improve coping and QoL.

Therefore, we conducted a qualitative study to explore how lung cancer patients and their caregivers cope together as a team with the diagnosis and treatment trajectory during the first three months of therapy, focusing in particular on the meaning, tasks and role that caregivers have in the life and illness experience of the lung cancer patient. We describe the perspectives of the patients themselves, their caregivers and their health care providers.
METHODS

Study design

A qualitative research approach was used to explore how patients and their caregivers cope together with lung cancer and its treatment trajectory over the first three months of illness. We conducted semi-structured interviews with newly diagnosed lung cancer patients and their caregivers at multiple time points during the treatment trajectory (just after diagnosis, 1 month and 3 months after diagnosis) and a single interview with their personal health care providers. (40) This study was approved by the Medical Ethics Committee of the VU University Medical Center Amsterdam, The Netherlands.

Procedure and participants

Recruitment took place between February 2008 and October 2008. All new patients attending three different clinics for pulmonary diseases in the Netherlands (one academic and two peripheral clinics in different regions) were asked by their pulmonary physicians to participate in our study (consecutive sampling) after the cancer diagnosis was made (SCLC/NSCLC/mesothelioma). No restrictions were made regarding treatment (surgery, chemotherapy, radiotherapy or a combination of treatment options). Once patients had indicated their interest for participation in the study, their pulmonary physicians gave their details to three trained interviewers (RCvH, RMS, MS, without any prior relationship to the study respondents), who contacted them by telephone within 0-5 days. During this first contact, the interviewers gave additional information, checked whether patients could speak and understand Dutch sufficiently, and planned an appointment for the first interview at a place of the patients’ convenience (home or hospital). At the time of the first interview (T1), patients identified their most important caregivers and they were approached for study participation according to the same procedure as previously mentioned for the patients. In addition, appointments for an interview were made with the involved HCPs. Of the 26 lung cancer patients who had given their permission to be contacted about the study and receive additional information, 10 refused to participate. Sixteen patients gave their consent for participation. Two of these 16 patients dropped out before the first interview: one because of unbearable psychological distress and the other because of poor physical condition. All 14 patients identified their most important caregiver(s) (1 to 4). One patient (P7) however, named her important caregivers but ultimately did not want the researcher to contact them as she thought that they would not want to participate because they were busy dealing with her disease and future treatment. Although we did not interview her caregivers, we chose to include this patient in the study because we only found out at a later point in time that she did not want her caregivers to participate. Ultimately, 14 patients were interviewed, together with 28 caregivers and 13 health care providers, i.e. 7 pulmonary physicians, 2 surgeons and 4 nurses (see table 2 for detailed information about the study participants and interviews).

Interviews

An interview guide has been made to prepare the interviews with different main topics for each type of participant. Patients were asked about their disease and its therapy, coping with
lung cancer, caregivers’ involvement and information needs during the treatment trajectory. Caregivers were asked about their involvement with patient care and their influence on the patient’s decisions, coping and medical encounters. HCPs were asked about their perspective on the patient-caregiver relationship and coping, communication and contact with the caregivers. All topics are listed in table 1.

Table 1: Topics of questions

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<td>Patients</td>
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<td>Lung cancer diagnosis and treatment trajectory</td>
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<td>Decision making (e.g. with regard to treatment, hospital)</td>
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<td>Involvement of caregivers (in daily life/decision making/treatment/care)</td>
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<td>Consultations</td>
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<td>Influence on patient</td>
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<td>Encounters with treating physician</td>
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<td>Coping</td>
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<td>HCPs</td>
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<td>Own perspective on the patient-caregiver relationship and coping</td>
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<td>Communication with patient and caregivers</td>
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<td>Contact with caregiver without the patient</td>
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All interviews had the same format. Participants gave informed consent (ic) for participation before interview commencement (patients written ic, caregivers oral ic). The semi structured interviews were conducted by RvH, MS and/or RMS. Participants were encouraged to talk freely until all topics were discussed. At the end of the first interview, personal information about demographics and disease were asked for. The duration of the first interview was approximately 45-60 min and 30 min for the second and third interviews. The interviews were either taken in person (face to face at home or at the hospital) or by telephone (see table 2), resulting in 21 hospital, 11 home and 97 telephone interviews in total.

Patients, caregivers and HCPs were interviewed by the same interviewer throughout the study. According to our study protocol, all interviews were intended to be conducted with study participants separately. However, six of the first time interviews were conducted with caregivers and patients present at each other’s interview. In 4 cases, the patient and caregiver were interviewed simultaneously and in one case the patient and caregiver were interviewed one after another. One patient who had already notified us that she was unable to partake without her spouse, started the interview herself, but let her spouse take over immediately after he arrived. He spoke on behalf of her and himself.
Interviews in person (face to face) by RMS (PhD student and Medicine student at time of research) were audio taped (with consent), then transcribed verbatim into Word documents. Interviews in person by RCvH and by MS (medical anthropologist and theologian/ethicist, both expert interviewers) and all telephone interviews were written down verbatim with pen and paper during their conductance, then subsequently transcribed into Word documents directly after interview termination (hereafter these Word documents will systematically be called “interview transcripts”).

Apart from the interview transcripts, each interviewer kept a logbook where she wrote down notes with regard to her personal impressions during the interviews, information concerning appointment making with the participants and additional information on participants, gathered during the phone calls in aid of making appointments (e.g. the participants’ condition or mood, or whether patient has completed a chemotherapy cycle when calling). Those were attached as field notes to the interview transcripts.

Ultimately, all interview transcripts of each patient, his/her caregivers and own health care providers completed with the above mentioned field notes were compiled into one single Word document per patient. This lead to a total of 14 “patient-caregiver-health care provider”-unit files (PCH-unit file).

Analysis

We used a thematic approach for the analysis of the PCH-unit files (n=14). Constant comparison between the cases was performed throughout the whole analysis process.

After familiarisation with the data by reading it repeatedly and carefully, RMS first started with initial open coding of the transcripts. To facilitate coding, organising, collecting and selecting data from the interview transcripts MaxQDA version 10 was used.

In a second phase, RMS and MJW focused on how patients and caregivers cope with lung cancer in their daily illness experience. Hence, we first looked at the impact of the diagnosis and the treatment trajectory and the way participants dealt with it. Apart from this, we focused on the different roles endorsed by the caregivers and the tensions arising from their involvement with patient care, including the perspectives and knowledge of HCPs.

After numerous meetings with MJW focusing on the understanding and correct interpretation of the coded data, RMS derived the first potential themes and sub themes which described best the patients and caregivers’ struggle with lung cancer, namely their continuous efforts to regain control and constant shifting between two opposing realities: i.e. “going on with the present life” and “daring to face the patient’s approaching death”. The data was classified according to these themes. RMS looked specifically at the tensions arising between patients and caregivers with regard to these two main themes. For this purpose she used elements of the coping theory described by Folkman and Lazarus (17) and the theory developed by Horne et al. (43) After review of the potential themes and subthemes for coherence, RMS and MJW refined and re-organized these and recoded some data extracts. After this, RMS and MJW reviewed the entire dataset again and discussed the generated main themes and subthemes conscientiously and critically for coherency, consistency, robustness and representativeness. (41; 44)
RESULTS

Participants

The patients interviewed counted eight men and six women with a median age of 63 years (range 49-82) at time of the interviews. Most of them were diagnosed with advanced lung cancer and therefore received chemotherapy. Four patients underwent surgery, with one patient receiving adjuvant chemotherapy. All patients were Caucasian of origin, except for one who originated from Indonesia (P6). She received therapy within a trial setting. All patients but one were married (P7, widowed).

Most caregivers were children (n=13) and partners (n=12), two were friends and one a patient’s brother (see table 2 for detailed information on the included participants).

The seesaw between the living and the death

During the illness and treatment trajectory, caregivers shared the patients’ lung cancer experience intensively. Both narrated that they were continuously struggling to learn how to live with lung cancer and come through the treatment trajectory, with the inevitable threat of the patient’s death. In their struggle, patients and caregivers tried to regain control over their feelings and their situation. This helped them feeling that they still made part of their own social network including their inner family circle and friends, despite the disease.

Looking at their struggle to cope with cancer and regain control, it seems that patients and caregivers’ behaviour can be explained by using a metaphor inspired by Horne et al.’s model. (42) In the process they went through, they were constantly shifting between two opposing realities, i.e. “going on with the present life” and “daring to face the patient’s approaching death”, as if they were moving from one side of a seesaw to the other (see figure 1). The way they dealt with the different issues/challenges they were facing either helped them to live their life in the present or helped them to face the future patient’s death and prepare for it.

The position of the seesaw varied a lot, from moment to moment, from day to day and during the whole treatment trajectory. Respondents could purposefully choose to be at one side of the seesaw, but could also be propelled beyond their control to the other side, depending of the circumstances. Diverse causes could induce a seesaw movement, such as a new step in the treatment trajectory, reading new information on the disease, or receiving negative comments from other persons.

The change of the seesaw position did not only give tensions to both patients and caregivers on their own, but also between them. Tensions usually arose when patients and caregivers found themselves to be at the opposing sides of the seesaw or when they had different ways of dealing with the same issue.

The results are presented according to the developed seesaw model we just introduced (see figure 1).

Going on with the present life during the treatment trajectory

Once diagnosed with lung cancer, patients and their caregivers told to focus on what was happening “now”. Therefore, they put their focus on the treatment calendar and organized their life around it during the treatment trajectory. Simultaneously, patients and caregivers tried to
live their lives “outside the hospital” as normally as possible. This was achieved by maintaining their usual activities and protecting themselves and significant others from confrontation with the disease and disease information. This protection was done by avoiding thinking or talking about lung cancer or death and living day by day, without planning for the near future.

Focusing on the treatment calendar
Most patients considered therapy as a last resort. Therefore, they accepted the treatment eagerly or surrendered to it, as they felt they had no other choice but to do so and put their focus on it. Some of them felt grateful as they were “getting a second chance”.

Because of the patient’s expected deteriorating physical condition, patients and caregivers described setting up entire networks in order to arrange all necessary tasks around patient care and support. Caregivers were involved with diverse practical issues (e.g. patient transport and accompaniment, decision making, household or personal care) and giving mental support. One particular task of caregivers was looking for disease related information on patient care and therapy related side effects, in order to support and provide for the patients as well as possible.

P6’s daughter: My mother takes combination therapy, she got medication that changed her taste. I want to know how it works and what kind of food I should give her. Appropriate food that tastes nice and does not taste like acid to her.

The way patients and caregivers gave shape to the organization of tasks for patient care and support differed. Some patients chose to delegate these tasks to one or more caregivers, including spouses, children and friends. Other patients wanted to be in charge of their care on their own or together with their spouse only. These couples engaged in therapy together and acted as “a unit”.

Figure 1: The seesaw model.
Table 2: Patients characteristics

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**NSCLC**: non small-cell lung cancer, **SCLC**: small-cell lung cancer

**Surg**: surgery, **chemo**: chemotherapy, **radio**: radiotherapy, **biol**: biologicals,

**T1**: time of 1st interview, directly after diagnosis, **T2**: time of the 2nd interview, 1 month after diagnosis, **T3**: time of the 3rd interview, 3 months after diagnosis

**HP**: hospital interview, **HO**: home interview, **TEL**: phone interview

**Pulm**: pulmonary physician, **Sur**: surgeon, **Nurs**: nurse, **Pulm2**: other pulmonary physician, **Nurs2**: other nurse, **CCNurs**: care coordinator nurse, **HCP**: health care providers

0: no interview, *1 extra telephone interview had been conducted, **2 extra telephone interviews have been conducted, I1: interview one

α: NB: 7 pulmonary physicians were interviewed, some patients had the same pulmonary physician.
P4: Yes, until now my partner has always come with me. I prefer not being alone for appointments. Once we are home, my partner and I listen to the audiotaped consultation with the doctor together.

Caregivers and patients said that starting therapy and organizing the care gave them satisfaction and helped them to regain a sense of control. However, things did not always go smoothly. The involvement of two or more caregivers facilitated the distribution of tasks related to patient care and relieved the related burden per person. However, disagreements occurred with regard to the coordination of care, the way care was given or tasks performed and the degree of involvement of caregivers in the patient’s care.

For instance, a female 70 year old patient who lived alone as her husband was admitted to a nursing home because of Alzheimer’s disease, had organized everything with regard to her care after having surgery. But at some point, she could not bear the continuous presence of her caregivers, as she was “not alone in her house anymore and kept having worries.”

Another couple (P14 and partner) who wanted to handle the treatment trajectory by themselves, told that they had to actively keep their three children at a distance, because they wanted to be involved in everything.

P14’s wife: We can always call the children, they are always ready to help us. We even need to stop them sometimes, like, “not now”. Otherwise it gets too much.

In another family, the sons of a male 82 year old patient (P5) said that they would rather see their parents less frequently like before the diagnosis because their intensified contact was too burdensome for them.

P5’s eldest son: We try to be there when it is needed. And at the moment we’re there more than usual, because of the current situation. Personally, I take my distances again quickly. My mother can be very clingy... if I am not needed, I prefer not to be present too often. Before you know it...yeah...she will take control over your life. I have experienced that before and I never want it to happen again.

When only one caregiver was in charge of patient care (usually the spouse), the related burden could become too much (physically and/or mentally) and exceed the caregiver’s own capacities and abilities. This resulted in caregivers breaking down emotionally/physically, discontinuing their job temporarily or taking “sick-leave”, or choosing purposefully to quit it or put the job on the back burner, as some of them wanted to “take care of the patient as much as possible” like P6’s husband.

In one couple, both partners were affected by lung cancer (see textbox 1). The wife’s involvement in her husband’s care combined with her own deteriorating condition led her to a complete breakdown at time of the last interview.

Life next to therapy

Apart from following therapy, patients and caregivers expressed their wish to go on with their “normal” life as much as possible (e.g. continuing doing their activities and hobbies like before the diagnosis), as they did not want to get stuck in the patient and caregiver “roles” only.
P8: My caregivers/friends must do their own things. [...] Living and letting live. Everyone has their own responsibilities. I do not need to be taken care of. [...] I do not want others’ pity. Compassion is fine, but please just go on, lead your lives, go riding your bike, go painting...[...]

However, the patients’ physical and/or mental condition was determining to continue these activities and maintain roles in daily life. Patient 10 for example, kept on singing in his choir, as he felt quite well during the whole treatment. Simone talked about her experience of becoming her husband’s caregiver, telling that she switched to a very “different perspective” with different needs, having “feelings now that I did not have for myself”, next to “lots of different questions”, and being “more checking and controlling of everything” in comparison to when she was a patient/in the patient role. She also described how her own illness and the burden of caring for a her husband prevented her to be the “ideal” caregiver as she would have wanted to be, unfortunately leading her to a total breakdown.

Unable to be a caregiver and a patient at the same time
I can no longer keep it up. Sometimes I want to delegate things to my husband. [...] You want to be strong, but sometimes I just cannot. I cannot go to the hospital with him. I really want to. He also went to the hospital with me. You want to do something in return. But I just cannot do it. [...] I am okay with paracetamol and morphine patches, but I feel lousy, I am so tired, so terribly tired. [...] After my husband’s third chemotherapy cycle I was really sick. They ran some investigations. But there was nothing,[...] That was the time when I broke and was completely and utterly fed up with it. I could not take it anymore and thought I was slowly dying. I felt so miserable and was in such pain. My husband was also admitted to the hospital by that time after his 4th chemo. But it seems that he’s a lot better now. Actually I am jealous of him. He can start to recover. To work at his physical condition. I know that as soon as he starts seeing the physiotherapist again, he will start getting fitter and fitter. Of course I am happy for him but it is very bitter realizing that this will not be my reality any time soon. My physical condition is awful. And if you think about it, I take experimental drugs, which is also chemotherapy. Therefore I consider myself taking chemo every day. My physical condition will remain bad. And after such a bad month, it takes such a long time before I even reach the slightest bit of recovery. I wish I were better, but my body cannot take it. It is bad...

Textbox 1: Patient 3 and his spouse
Anthony, 49 years old, married with Simone (both fictive names), parents of two children aged of 14 and 17 years old, were both diagnosed with lung cancer 2 years after one another. The couple narrated their stupefaction after Anthony’s diagnosis following Simone’s and how they dealt with their illness and therapy while being patient and caregiver at the same time, on top of having to take care of young children with the knowledge of being sentenced to death. Simone talked about her experience of becoming her husband’s caregiver, telling that she switched to a very “different perspective” with different needs, having “feelings now that I did not have for myself”, next to “lots of different questions”, and being “more checking and controlling of everything” in comparison to when she was a patient/in the patient role. She also described how her own illness and the burden of caring for a her husband prevented her to be the “ideal” caregiver as she would have wanted to be, unfortunately leading her to a total breakdown.
as everything takes a lot of energy. After such an event, I feel completely drained and really need time to recover the day after.

As a part of trying to live their lives as normally as possible during treatment, patients not only tried to protect themselves, but they also tried to protect their caregivers from the confrontation with their disease and its prognosis. Therefore they deliberately did not always think, ask questions or even talk with their caregivers about it. Neither did they look for lung cancer related information. This also meant that patients stayed at a distance from people who constantly reminded them of their condition and only expressed their medical concerns to their treating physician.

Some caregivers were deliberately not involved with patient care or treatment (anymore) as they already had reached their own limits of psychological burden, or were considered to be too vulnerable by the patients (i.e. young children, older parent or family members with cancer).

P8: My mother is 97 years old. I did not tell her (about my diagnosis). She would freak out if she knew. It makes no sense to me telling her about it and it would only upset her. [...] Once I go bald, I will have to tell her, but it is not the case yet. We will see. I live day by day. [...] My partner, she's had enough. She does not want to have anything to do with it anymore or hear anything about it. She cannot handle it.

P8’s partner: My task is to stay calm. We have visited my brother last Sunday, it was nice. But for the rest I stay at home in my studio. But I know his schedule, when he has to go to the hospital, etc.

However, some of the “considered to be vulnerable” caregivers and other caregivers had difficulties with this protective attitude. Adult children felt sad, helpless or angry. An 18 years old son experienced troubles with coping with his mother’s disease (P4) because he wished to accompany her to the hospital and to talk with her about her death but felt (and knew) that she shut him out in order to protect him. Children of younger age reacted strongly.

P15’s wife: We have problems with the children. A lot of shouting and crying. The eldest has even run away from home. We see a psychiatrist now. She has sessions with him. The youngest one does not want to have anything to do with it. She does not want to hear anything about doctors, hospitals, etc. She cries a lot. [...] She is still so small.

Another adult son even spoke about his need for more medical information and support from health care professionals as he felt that caregivers received too little attention.

P14’s son: I mean, I just heard that my father has cancer. What will happen next? What should I do with that news? I think it would be useful if someone offered some help, help to cope with it. [...] The need for help is still getting greater and greater.

Daring to face death

As they engaged in the treatment trajectory, patients and caregivers said to be repeatedly confronted with the patient’s declining condition and shortened life expectancy. Therefore they said that ultimately it was inevitable to pick up the courage to face death and think about it. This
confrontation took place by allowing emotions to take over, open communication about death and looking for information related to death and prognosis and making plans for the patient’s death.

Allowing emotions to take over

Patients and caregivers said that they dared to feel intense emotions such as anger, fear or sadness when thinking about death.

P7: If one of us wants to cry, we (patient and her sister) cry together. We have stopped keeping up the front of always being strong and not allowing yourself to be sad. Like I briefly did this afternoon when I went outside. Tears started rolling down my cheeks just like that. You cannot be strong and carry on all the time, because at some point, it will come out. Sometimes you feel like suffocating in your own impotence. At some point the crying stops and then we talk again and it is over. Once it’s over we can laugh again and make jokes.

At first, patients and caregivers said that these emotions made them experience a lot of anxiety, helplessness and a total loss of control. But after that, they experienced relief, regain of control and acceptance of the illness and future death.

P11: But you know, we have put an end to it. I see cancer as a kind of friend now. You should not be fighting it and it does not hurt you. I find myself not being busy thinking about it anymore every day. I have more space for my own old “me” now. And it feels good.[...] I feel at peace with myself.

Open communication about death

Especially patients said that they purposefully chose to talk about their disease, death and dying with their loved ones, also in order to discuss (old) existing problems within their families which they wished to be solved before the end of their life.

P2: I may have three months to live, maybe three years. I am positive, I am a fighter. I told all my children “Listen to me, it is probable that your father will not be here anymore in 3 months. If there is something that you need to discuss or say to me, you should not wait.” You have to be honest. There is no use to be worried about it. That is just the way it is.

Talking about death led to relief, the realization and equanimity that there was “no way back” and acceptance of the reality of living with lung cancer and the approaching death. However, not all caregivers were ready for this confrontation and could react strongly. For example, a patient said that her son even stayed away (at a physical distance) from her because he could not handle her being so open about her disease and future death (P11). Other caregivers tried to listen and talk to the patients in accordance with the patients’ desire, but stopped quickly because the confrontation was too much for them.
Looking for information related to death and prognosis and making plans for death

Patients and caregivers said that not only they searched for information with regard to the prognosis and the time left together, but also for information about the end of life, dying and practical (administrative or financial) matters around death. Patients in particular, took measures with regard to their own preferences for the end of life (i.e. euthanasia or not wanting to suffer), the preservation of familial security and the prevention of burden and inconveniences for their family at time of their death (i.e. financial matters, funeral, guardianship of the children after death). This comforted them and helped them having control over their situation.

“...Yes I have talked about it in case things go wrong. I have, well, spoken about what I want then. A cremation? It’s such a hard decision. I do not want my ashes to be scattered like my husband and my child. The water is too wide for me, where will I end up? My husband was a sailor, which is why he wanted it that way. I said: put me in an urn and from that point I will make a decision on what next when I’m ready for it. [...] I told my sister, she knows where to find all important administrative things, the insurance, my bank account, all that kind of stuff. My youngest son will not be able to deal with it. It is too emotional for him. I can do that. If I should die tomorrow during the operation, it will be terrible. Because he is too young to be an orphan.”[P7]

The health care providers’ views on the value of caregivers

Health care providers (HCPs) witnessed how patients and their caregivers dealt with lung cancer and its treatment from a more distant perspective. They all acknowledged the importance of caregivers to patients but the extent to which they had insight in the way they coped together differed. They also pointed out difficulties related to caregivers’ involvement with the patients, such as acting out of own interest and interfering with professional medical care.

The extent to which HCP’s had insight within a patient and his/her caregivers’ coping and situation varied, depending of the HCP’s function.

Oncology nurses had the best insight on how patients and their family were coping with lung cancer, as they saw patients and their caregivers most during hospital admissions. Caregivers could also meet nurses individually in order to receive more extensive information about lung cancer or an explanation about the patient’s current condition when they needed it. Pulmonary physicians were also able to give a quite accurate description of a patient’s situation and coping, as they saw them regularly at follow-up. They said to involve caregivers too, but mentioned that patients were and remained their first priority.

P4’s pulmonary physician: I think that I… Doctors are there primarily for patients, and not for caregivers. You understand what I mean? I would really find myself in a difficult position if it would happen that I would discuss something about the patient without the patient present and that the patient is not informed about it. I always have protected myself for that kind of things.

They also said to be cautious with regard to the information they communicated to caregivers as some of them could have a double agenda.
P1’s pulmonologist: I never speak to a caregiver separately from the patient. Especially not by phone. You never know who you are talking to and what might be the underlying question. Maybe you’re dealing with someone who would like to divide the inheritance quickly? I am very reluctant of that kind of contact. This question does actually come sometimes. I never speak about this kind of thing by phone. Caregivers and family can always come by, but the patient must have given his consent first.

Surgeons had the least contact with caregivers and therefore knew the least about them, except for one surgeon who experienced the presence of a caregiver during the operation. The caregiver (a general practitioner) was so involved during surgery that she almost interfered with his work.

P1’s lung surgeon: “I remember it very well, because it was very special. I have never experienced anything like it. She was incredibly involved with the operation, very interested, she really wanted to learn from it. She came very close to me, so close that I was almost pushed away from the operation table, so to speak.”

DISCUSSION

Principal findings

The present study adds knowledge to the way patients and their caregivers cope with lung cancer during the lung cancer treatment trajectory. Patients and caregivers coped with lung cancer by incessantly trying to regain control. This was achieved by constantly shifting between trying to live in the present and to daring to face the patients future death at the same time. This shifting between two opposites was a continuous struggle and did not necessarily take place simultaneously for patients and caregivers. The way in which they tried to cope with lung cancer often differed too and their needs could be opposed to each other, causing tensions. The following is an elucidation of the patients and caregivers behaviour in more depth, applying the seesaw model we developed (see figure 1). This includes the perspective of the coping theory (17) and the notion of “calendars” as described in Costain Schou and Hewison’s book. (15) The practical implications of the results are discussed as well.

Patients and caregivers dealt with many challenges during the treatment trajectory (e.g. the transition from the diagnostic phase to the start of therapy, post-chemotherapy fatigue or other matters such as coping with worried children). Each new issue was tackled using different coping strategies, as described by Schou and Hewison and Folkmann and Lazarus.(15;17) When categorizing these coping strategies according to the model we developed (see figure 1), it can be observed that each time, the used strategies originated from either one or the other side of the seesaw.

Going on with life

The aims of patients and caregivers with regard to the seesaw side “going on with life”, were twofold throughout the treatment trajectory. On one hand, they used the treatment calendar and organized their life around lung cancer therapy. On the other hand, they tried to continue their “normal” life as much as possible and protected themselves from the confrontation with cancer and death. As reported by other authors,(33; 45) the focus on the treatment calendar
permitted patients and caregivers to cope with the feeling of helplessness/impotency by actually doing something about lung cancer. It gave them a “plan” (trajectory) to follow in the close future and distracted them from the long term future, therefore ignoring the issue of prognosis and the patient’s death. Within the stages of the treatment trajectory, The et al. (33) also described the occurrence of “false optimism about recovery” among lung cancer patients, whose interpretations of their prognosis were defined by a considerably more optimistic outcome than those of their doctors. The functional adherence to such “recovery plot” by both patients and caregivers and implicitly not denied by health care providers permitted patients to gain some “peace of mind” after the initial existential crisis at diagnosis and carry on during the treatment. (33) The difference with our findings is that The et al. (33) describe the ambiguous process of “knowing and not knowing” about the issue of the prognosis during the final stages of the treatment trajectory in particular, while we observe that this process is present during the whole trajectory and that the extent of the act of “knowing” varies continuously. The focus on daily life out of the hospital and the avoidance of everything related to cancer, is an expression of denial, a coping strategy frequently seen in cancer patients. It is part of the grieving process individuals go through when they are confronted with death, (46) with patients being actively busy with “not knowing”. Ultimately, the grieving process leads to the acceptance of disease and imminent death, with denial as a normal and temporary response to rationalize overwhelming emotions.

**Daring to face death**

Most patients eventually dared to face death and prepared for it by arranging practical matters, with or without sharing this with their caregivers. This is in lieu with the illness and treatment calendars, where preparation for death and death itself are the last stages to achieve. (15) As previously mentioned, it also fits within the grieving process, with the last phase being acceptance after daring to confront one’s self with death. (46) The et al. (33;47) also mentioned this final confrontation, promoted by the patient’s deteriorating condition and the contact with their fellow sufferers dying, forcing them to face the inevitable. As mentioned earlier, our findings are in accordance with the previously mentioned but add some nuance to this process as we found that patients and caregivers were continuously switching between life and death from the beginning of the trajectory. The confrontation with death does not exclusively belong to the last stages of illness, but happens alternately, gradually and continuously during the whole treatment trajectory.

The observed arrangement of practical matters around death supports known evidence to anticipate for the (practical, financial, emotional) consequences of the patient’s death. (43;48-50) It is also known from other cancer types or aging people, that patients take care of such matters to preserve familial security and avoid inconveniences for their families. (43;49;50) The other advantage of “facing death” is that it gives the patients and their caregivers the opportunity to say “farewell” on time. (33;48)

**Tensions**

The position of the seesaw could change per person each time they dealt with a new issue, and could also differ between patients and caregivers. These discrepancies led to tensions.
Tensions have often been reported among families and couples facing cancer, sometimes even leading to divorce. The need to talk about death or life long problematic issues in order to solve them before passing away, is strongly present among patients who know their end is near. However, this need is not always present among caregivers, as also seen in our results. Patients and caregivers also described distinct personal ways and needs to cope with lung cancer, even when they were facing the same issue, confirming our findings from previous researches.

We also observed a shift in duties between caregivers and patients and a shift of personal activities and priorities in favour of the patients’ needs. This led to the redistribution of resources from both private and the illness related calendars, as described by Costain Schou, giving rise to problematic competition between calendars. It is well known that especially spouses take over many of the patients’ tasks, diminish their working time to take care of them and experience a high burden or distress. The experienced care burden and distress can vary and depends on the number of responsibilities and duties resting on caregivers. If there is only a single caregiver involved, it is probable that he/she becomes overloaded quickly. Tensions with regard to the distribution of tasks and duties were also reported by respondents, as also described in other publications.

Healthcare providers

We noticed that healthcare providers’ insight into the way patients and caregivers coped with the lung cancer treatment trajectory differed between the specialties. This can probably be explained by the different roles of the specialists in keeping with their specialties. In The Netherlands, the primary specialist taking care of lung cancer patients is the pulmonologist. Thoracic surgeons perform surgery and usually refer patients back to their treating pulmonologist immediately afterwards. Oncology nurses had a good insight into the patients’ situation. It is known that they are usually the closest HCPs to patients (not only emotionally, but also practically as they are also the easiest to get in contact with). They are therefore an indispensable source of support for patients and may be an important information source for physicians.

The observation of the HCPs’ ambiguous position towards the caregivers is surprising, yet understandable. It is known that consultations addressing more than one person are difficult and require high communication skills from health care providers. Moreover, disproportional involvement of caregivers with medical issues has been reported to cause tensions and have consequences on patients and caregivers’ wellbeing. Furthermore, laws and guidelines require a good patient-doctor relationship in first instance, although involving caregivers is recommended. Still, most HCPs emphasized the added value of caregivers, as reported in the current literature.

Study limitations

The way data collection took place differed per interviewer. Firstly, the interviews held in person by RvH and MS were not audio recorded. Secondly, not all interviews were held in person (except for almost all first patient interviews). At the convenience of the respondents (due to their physical condition or personal preference), most interviews were done by phone and were not audio
recorded. This may have led to bias and information loss during the simultaneous transcription of the interviews. However, this is not likely since the investigators were expert interviewers, used to collecting information in this particular manner. In addition, we assume a good insight has been gained into the process respondents went through, as the present study is a multiple case study with several interviews over time, performed by the same interviewer per patient case and encompassing the different perspectives of patients, caregivers and HCP’s.

Because data collection took place a few years ago, our findings may not reflect the current situation entirely. However, lung cancer has remained the most important cause of death in the Western world,(67) therefore we think our findings are still highly relevant and could aid health care professionals to optimize the provision of patient care. Moreover, the limited quantity of literature on the subject of coping with lung cancer by both patients and caregivers indicates that there still is an information void that needs to be filled.(30-32;34;35)

A last question to address is whether our study sample is representative for the lung cancer population in The Netherlands. We excluded two patients because they dropped out and we eventually interviewed 14 patients with 28 caregivers and 13 health care providers. The numbers seem small in comparison to the national (lung cancer) population. This might be due to the poor condition lung cancer patients are often in, which would make them less inclined to participate in studies with interviews. In an attempt to maximize heterogeneity, we recruited from multiple hospitals and gathered a palette of different families with different backgrounds for this study. In addition, we reached thematic saturation as we performed data analysis. Our participants came from Dutch and Indonesian backgrounds only. Therefore, other cultures were excluded. Further research on lung cancer patients from other backgrounds is needed since it is known that coping with cancer is also determined by culture.(68)

**Practical implications**

Our findings confirm the undeniable and essential participation of the caregivers in the patients cancer experience during the treatment trajectory, as previously reported by our own group and other researchers.(7;56-58) HCPs should therefore assess the meaning of caregivers to patients and inquire how they are coping together and ask about caregivers’ needs. In addition they should inquire about the existence of tensions or relational problems between patients and caregivers and try to involve caregivers with patient care when possible. This would allow them to provide patients (and caregivers) with support matching their own situation and needs. In case of tensions, HCPs could inquire about both the patients and the caregivers perspective.

Our seesaw model might also be used as a helpful tool to determine the origins of the tensions (Is there a difference in the seesaw position/side? Where are the patient and the caregiver in the process of coping with lung cancer?) and help gain more insight. HCPs should be particularly alert towards picking up on tensions caused by excessive caregiver burden. Assessing the caregivers burden and needs is mandatory in order to maintain the caregivers role as informal patient care provider and is essential in solving related tensions. In The Netherlands, but also in other countries, informal care by partners/relatives is expected to become an important part of national health care in the future.(69) The question is whether informal caregivers can handle this responsibility and whether specific measures should be taken to make it possible.
As it is quite difficult to inquire about all mentioned issues within a limited consultation time, we suggest a specialized oncology nurse takes this responsibility and becomes a permanent contact person for patients and caregivers. The nurse should be tasked with signalling tensions and reporting to treating physicians if needed. There are already specialized oncology nurses working in the Netherlands but their number needs to be increased.(70) Even though caregivers are important to patients and try to defend the patients’ interests, it has also been ascertained that caregivers’ involvement can have negative aspects, like communication problems,(62;63;71) as mentioned in this study’s by the interviewed HCPs. Disproportional involvement interfering with medical care has also been described.(63) HCPs should thus involve caregivers with the care of patients but should also remain alert of signals of “interfering” behaviour.

CONCLUSIONS
Whilst lung cancer patients and their caregivers cope with the disease together and try to regain control, they continuously shift between trying to live in the present and simultaneously, daring to face the patients’ imminent death and prepare for it. Their struggle is joint but as they also have different needs, the way they cope might differ and provoke tensions between them. Health care providers should involve caregivers with patients’ care and inquire about coping and tensions between them.

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