

9

SUMMARY, DISCUSSION AND RECOMMENDATIONS



Being diagnosed with lung cancer and learning to live with it is particularly difficult for patients and their caregivers as compared to other cancer types. Patients and their caregivers have to deal with a disease with a bad prognosis and are confronted with a lot of issues within a short time period during the treatment trajectory until the patient's death. In order to accompany them well during this trajectory, the provision of optimal medical care is required.

The purpose of this thesis was to contribute to optimized care for the lung cancer patient and his caregivers, so as to give them tailored care in the near future. We investigated a number of elements potentially playing an important role within the different phases patients and caregivers go through during the lung cancer trajectory, from the moment of being at risk for lung cancer until the patient's death, focusing on the patient's behavior toward lung cancer, and his needs when trying to live with it, with emphasis on the role (and/or effect) of medical information. Therefore, we looked at the influence of the knowledge of being at risk for the development of lung cancer on smoking behavior as well as the patients' and their loved ones' information needs and seeking behavior, second opinion outcomes and how patients and their loved ones cope together with lung cancer.

The first aim of this thesis was to investigate whether the knowledge of already having premalignant lesions in the bronchial mucosa, and therefore voluntarily participating in a chemoprevention study, could influence the smoking behavior of an individual. Since smoking is a well-known major causative factor of lung cancer, smoking prevention might help reduce the number of persons affected with lung cancer. We hypothesized that participating to a chemoprevention trial for pre-malignant lung lesions, would influence the participants' smoking behavior. In **chapter 2**, we retrospectively interviewed (with telephone semi structured questionnaires) 146 volunteers for a chemoprevention trial about their smoking behavior ≥ 1 year after their first contact for the trial. The quitters at time of the first interview were interviewed a second time four years later. Of these volunteers, 83 were diagnosed with pre-malignant lung lesions and participated in the chemoprevention trial, while 63 had no pre-malignant lesions and were not enrolled. The smoking cessation rate of the total study group was 20% and the group of volunteers with pre-malignant lesions showed a higher cessation rate than the group without abnormal lesions. Within the group of volunteers interviewed twice, 15 out of 29 persons experienced screening and trial participation as having influenced their smoking cessation (major influence). Our data suggest that participation in a screening trial or program for a smoking related disease may be supportive to motivate smokers to quit smoking. The information of having premalignant bronchial lesions might thus play an important role on smoking behavior but our study is probably too small to find other associations than the observed one with male gender. It is known that the level of interest in quitting smoking, age of starting smoking, age of participant, education, marital status, history of cancer or lung diseases and previous attempts to quit smoking are associated with smoking cessation.(1-5) We suggest that future studies screening for smoking related diseases also assess and investigate their participants' smoking behavior and associated factors in larger populations.

Our second aim was to explore the information needs and the way lung cancer patients and other persons involved with them, looked for lung cancer related information and their reasons to do so. In **chapter 3** we described the launching of the Dutch Lung Cancer Information Center's

(DLIC) website (www.longkanker.info) (which aim is to provide reliable and comprehensible information on lung cancer to the Dutch population) and assessed its use during the first two years of its existence and the visitors' satisfaction with the website. We showed that the number of the DLIC website visitors exponentially increased over time to reach a steady high numbers of visitors (monthly 18.000). Additionally, we showed that the majority of visitors on the website (57%) were patients' caregivers (loved ones, family members, friends) and patients (8%), and that 89% of the visitors found the information they were looking for on the website. The interactive sections of the website such as the forum and 'Ask the Doctor' were also highly appreciated and consulted by visitors. In **chapter 4** we performed a content analysis of the first 2000 questions posted on the interactive page of the DLIC website 'Ask the Doctor', and assessed the identity of the visitors asking questions and classified these according to their content in order to make an inventory of the specific information needs they inquired about. We found that the majority of questions was again asked by caregivers (61%) and patients (13%) and that 1 out of 3 questions was asked by a daughter/grand-daughter. Most questions concerned specific information on lung cancer and lung cancer course (43%). The most inquired specific information topics were therapy side effects, diagnostics, general information on lung cancer, and regular therapy. The other topics visitors frequently inquired about were a personal (for the patient close to them) diagnosis or prognosis and a verification of the own doctor's information. There were differences in information topics inquired by patients versus other visitors (including caregivers). In **chapter 5** we performed a qualitative study exploring the reasons why lung cancer patients and their caregivers seek information and answers to their questions from the Internet and the online lung specialists on the interactive page 'Ask the Doctor' of the DLIC website. The interviews revealed that patients and caregivers used the Internet and the DLIC's interactive webpage to look for lung cancer related information (general/specific to their personal situation) and to cope with cancer. The information they sought helped them to achieve a better understanding of the information given by their own specialist and prepared them for the treatment trajectory and disease course. It provided them with emotional support and helped them with coping. The interactive webpage was also used as an alternative way to obtain a kind of "second opinion". Respondents did not always consult their own specialists with their questions because they experienced communication difficulties with them or had personal issues (e.g. shame to ask about an intimate/indecent topic, not wanting to ask a question or to burden or disturb the specialist). Additionally, anonymity and indirect contact made them feel more free to ask for any kind of information and the ability to pose a question instantly and receiving a quick reply to urgent questions on the interactive page made respondents feel an easing of their anxiety as they did not have to wait until the next consultation with their own specialist. A last important finding was the wish or willingness to have contact with a specialized oncology nurse for information, or email contact with a nurse or specialist.

Combining the findings of chapters 3, 4 and 5 together, a number of observations can be made: 1) the need for lung cancer related information is great/major/large/huge, 2) caregivers play an important role in the collection of information for both patients and themselves and 3) their own information needs are undeniable and 4) information definitely helps with coping with lung cancer. It is obvious that there is a large need for information among the population of lung cancer patients and more strikingly their caregivers, despite the information offered during

normal consultations with the doctor. This finding is in accordance with published data on lung cancer and other cancer types, showing the important percentages patients and caregivers surfing the Internet for health related/medical information.(6-8) In addition, our data is consistent with the fact that caregivers are actively involved in information search and supply. (9;10) Content analysis of the information caregivers and patients were looking for demonstrated that most of the information they searched could (and should?) have been obtained from the treating specialists. This may indicate that the current information supply to lung cancer patients and their caregivers is not matching their needs sufficiently. Possible causes for such a mismatch between information needs and supply mentioned in literature are: dissatisfaction with the received information, insufficient, inadequate and unclear information given during specialist consultations, and information being not well understood or remembered.(11-16) Also our data shows and confirm that the needs of patients and caregivers differ and that caregivers tend to have more unmet needs and concerns than patients (17;18) as a result of their perception of themselves as being helpless observers and their lesser involvement with health care providers.(19) This may contribute to the possible/probable mismatch between patients' and caregivers' information needs and supply. The reasons given by caregivers and patients for their Internet search and use of the DLIC's interactive page in chapter 5 partially confirm this, as they mentioned barriers in the communication with their own physician. The other reasons they gave rather show the additional function and value of online information and contact with specialists and confirm that information is crucial to facilitate coping with cancer, its disease course and treatment trajectory.(9;10) The online information they found really helped them regaining a certain degree of control and thus helped them coping with lung cancer. Nevertheless, further research is needed to continue identifying the possible reasons for the mismatch in information needs and supply and to further improve information supply to lung cancer patients and their caregivers. We suggest the observation of consultations when information is supplied to a patient and his/her caregivers, and the collection of the patient's, the caregivers' and the health care providers' perspectives and wishes on the issue of information supply. In addition, research on the further implementation of an online dialogue with lung cancer specialists should be considered, as well as with a specialized oncology nurse.

Our third aim was to gain more insight into the additional information provided on diagnosis and therapy by a second opinion and its potential impact on patients' outcomes. In **chapter 6** we made a comparison between the data from the initial evaluation of patients referred for a second opinion with the data of the re-evaluation in a specialist center to identify discrepancies in diagnosis, stage and therapeutic advice. Subsequently, we attempted to classify these discrepancies according to their potential impact on patient outcomes in terms of potential minor, identical and major impact. Data from 188 medical records of patient initiated second opinions were collected and quantitatively analysed. The majority of patients had a diagnosis (92.6%) and a stage (86.2%), and had received prior therapy (84%) and a therapeutic advice (73%) at time of referral. After comparison between the initial and the second evaluation, there were discrepancies found in diagnosis (9%), stage (13%) and therapeutic advice (37%), with a total of 91 discrepancies. Of these, 53(58%) discrepancies had a potential major impact on patient outcomes in terms of survival, morbidity and quality of life. For patients with advanced lung cancer, the

percentages of changed stages, therapeutic advices and discrepancies with a potential major impact on patient outcomes were slightly higher (15%, 40% and 51% respectively). **Chapter 7** is a series of four case reports illustrating some of the potential benefits of second opinions for lung cancer. The data presented in chapter 6 and 7 show that second opinions provide additional and meaningful information on diagnosis and therapy for a substantial number of lung cancer patients and that they even may be beneficial in term of outcomes, also for patients with advanced cancer. This is in accordance with published literature for other cancer types and chronic diseases.(20-24) Our findings again highlight the importance that disease and treatment related information can have for a patient, in terms of potential impact on diagnosis, therapy and outcomes, as a result of purposefully looking for additional and more complete information. The relatively high percentages of discrepancies we found between the first and second opinions are striking but should nevertheless be interpreted cautiously as our research showed some limitations. Therefore prospective (controlled) studies are needed to confirm the added value of second opinions for lung cancer patients and their effect on patient outcomes.

Finally, our last aim was to explore how lung cancer patients and their caregivers cope together with lung cancer and the treatment trajectory with the focus on the meaning, tasks and role of caregivers in the life and illness experience of the patients. In **Chapter 8** we performed a qualitative multiple case study conducting interviews with 14 newly diagnosed lung cancer patients, their caregivers and health care providers at different time points during the first three months after the diagnosis. We found that patients and caregivers coped with lung cancer by continuously trying to regain some degree of control. In their attempt to regain control, they were constantly shifting between trying to live in the present and to dare to face the patient's future death at the same time. This repeated shifting between these two opposites was a continuous struggle from the beginning of the treatment trajectory. Because this struggle did not necessarily take place simultaneously for patients and caregivers, it caused tensions. Their different needs and different ways to cope with lung cancer also provoked issues between them. Our findings provide new insights into coping with lung cancer by patients and caregivers by using a seesaw metaphor to elucidate their behavior. In addition, we confirm the essential and beneficial participation of caregivers to the patient's cancer experience during the treatment trajectory. Caregivers give mental and physical support to patients throughout the treatment trajectory (25;26) and their presence facilitates medical encounters between patients and specialists.(27;28) They also look for lung cancer related information and thereby serve/act as medical information sources, as previously shown in the results in chapters 3-5.

We also deepened the downside of caregivers' involvement such as the arising of tensions between them and patients; and more importantly, their experienced burden (frequently exceeding their own capacities) when caring for the patients. The occurrence of tensions between spouses and family members have previously been described, (29;30) originating from communication problems, disagreement on different issues (e.g. routine treatment decisions, use of hospice care etc.) and differences in (information) needs.(30;31) The confirmation of caregivers' burden during the treatment trajectory (32-35) needs to be emphasized, as it might affect their quality of life and their ability to provide care and support to their loved ones (the patients) at home.(36) Points of action in order to reduce this burden are needed

since the caregivers' involvement to patient home care is expected to and wanted to increase (by the Dutch government) in the near future.(37) Further research on caregivers' burden is thus mandatory. We suggest here the exploration of perspectives with regard to solutions for burden reduction and improved coping (including an assigned role for a specialized oncology nurse as a source of support and information). Additionally, research on using our "seesaw metaphor" in practice as a tool to assess/detect tensions may yield new insights. Furthermore, since we only investigated patients with Dutch and Indonesian backgrounds, complementary investigations about coping with lung cancer by persons from other cultures are necessary. At last, we did not explore patients' and caregivers coping longer than 2-3 months after the diagnosis and start of therapy. Further research on coping during the other following phases of the treatment trajectory is needed.

In conclusion, it can be stated that information plays a crucial role for the lung cancer patient and his caregivers throughout the treatment trajectory and its pre-phase. Information has the power to influence (smoking) behavior, and facilitate and help patients and caregivers with coping. Furthermore, it has the potential to contribute to a change in diagnosis/therapy (through second opinions) with possible impact on patient outcomes. Moreover, knowledge of the specific needs of lung cancer patients and their caregivers contribute to the necessary insight of health care providers into coping and might help detecting tensions between patients and caregivers during the treatment trajectory.

Recommendations for practice

Reflecting on the greater purpose of this thesis and the discussed findings, we recommend the following for lung cancer patients' care:

1. Always inquire about someone's smoking behavior and offer counseling for smoking cessation or possibilities for participation to smoking cessation programs. Inform patients about the risks and consequences of smoking.
2. Refer patients and their caregivers to reliable sources of information if they have information needs and inquire about these needs repeatedly during the treatment trajectory. Otherwise, give printed or written information to patients and caregivers.
3. If you are positive about digital modes of communication and inclined to give your email address to patients: encourage email contact with patients for urgent questions or specific information needs.
4. Consider a second opinion in case of (medical) doubts.
5. Inquire about the patients' point of view with regard to second opinions and whether they would wish to have one. If you consider requesting a second opinion, do it in accordance with the patient and preferably before starting therapy.
6. Consider training specialized oncology nurses to inform and support patients and caregivers.
7. Inquire about the caregivers and their specific roles/tasks/duties to the patients. Ask about their needs and possible burden. Direct them to specialized oncology nurses for assistance/support.
8. Inquire from patients about difficulties/tensions between them and their caregivers with regard to caregivers' involvement with patient care.

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