Preferences of advanced lung cancer patients for information and participation in medical decision-making: a longitudinal multicentre EOLIC study (EOLIC = End Of Life Information and Communication).

Koen Pardon

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Doctoral dissertation

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Chapters 2-7 are based on the following publications or manuscripts:

Chapter 2 – Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Deliens L. Preferences of advanced lung cancer patients for patient-centred information and decision-making: a prospective multicentre study in 13 hospitals in Belgium. Patient Educ Couns 2009 December;77(3):421-9.

Chapter 3 - Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Are patients' preferences for information and participation in medical decision-making being met? Interview study with lung cancer patients. Palliat Med 2011 January;25(1):62-70.

Chapter 4 - Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Bossuyt N, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Changing preferences for information and participation in the last phase of life: a longitudinal study among newly diagnosed advanced lung cancer patients. Submitted.

Chapter 5 - Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Bossuyt N, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Advanced lung cancer patients’ preferences for the involvement of family and others in medical decision-making. J Palliat Med 2010 October; 13(10):1199-203.

Chapter 6 - Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Preferred and actual involvement of advanced lung cancer patients and their family in end-of-life decision-making. A multicentre study in 13 hospitals in Flanders, Belgium. Submitted.

Chapter 7 - Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Expressed wishes for euthanasia and incidence of end-of-life decisions in advanced lung cancer patients: a prospective study in Flanders, Belgium. Submitted.

Preface and acknowledgements

People who are confronted with a diagnosis of advanced cancer have to cope with difficult and delicate information and with complex medical decisions concerning treatment, location of care and the end of life. Research has shown that an attitude of openness and cooperation on the part of the physician has beneficial effects on the patient. However, not all patients with a life-threatening disease want to be informed about their condition in detail or to be fully involved in medical decision-making.

This doctoral thesis examines a group of advanced lung cancer patients and asks about 1) the degree to which the patient wants to be informed about diagnosis, prognosis, treatment options, palliative care and end-of-life decisions, 2) the degree to which he or she wants to be involved in medical decisions, 3) their preferences regarding the involvement of family in the medical decision-making process, 4) the degree to which the physician meets the information and participation preferences of the patient, 5) possible changes over time in those preferences, and 6) the actual involvement of the patient in end-of-life decisions. Advanced lung cancer patients were included in the study by pulmonologists or oncologists of 13 hospitals in Flanders, Belgium. The patients were interviewed up to a maximum of six times during their disease trajectory.

This work is the result of the efforts of many people. First and foremost I thank all the patients who participated in the study. In the interviews they proved to be very cooperative and open in answering often difficult and delicate questions about their disease trajectory. I have deep respect for the way in which they were dealing with their terrible disease and were willing to share their experiences to help others in the future.

Secondly I explicitly thank the participating hospitals and more specifically the pulmonologists and oncologists who were willing to ask all their consecutive advanced lung cancer patients for cooperation in the study over a period of one year. Knowing that they all have huge responsibilities towards their patients and the nursing staff in the hospital, I often took off my – imaginary – hat to them for the time and energy they still found to contribute to this study. It is due to these physicians that research with patients on physician-patient communication is possible in Belgium and that initiatives can be taken to improve patient-physician communication. The names of the participating hospitals and physicians are mentioned on page 21 of this book.
Other health-care professionals in the hospitals (e.g. research nurses) have also contributed to the study, such as Sisca, Alex and David, to name a few. To all these persons: many thanks.

This enterprise, because an enterprise it was, would not have been possible without Luc Deliens, my promotor, who fully trusted me and gave me the opportunity to do this doctoral research. Luc not only made sure that I was very well guided by him and other experts in the field, but also regularly gave very specific, to-the-point remarks that improved the analyses and papers remarkably, and taught me basically how to do scientific research and report it. I am very happy that I was and still am able to work with Luc, who is a very inspiring and engaged professor.

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Special thanks goes to Christine Pauwels-De Langhe who was brought into the study by Bob Vander Stichele: she made sure that a sufficient number of hospitals were included and that physicians stayed motivated to recruit patients. Thanks also to Jane Ruthven for English editing and the useful comments with regard to content, to Eva Michiels who started this project and to Nathalie Bossuyt and Johan Van Overloop for their help with analysis of the data. Finally, I want to say thanks to all the interviewers who took it upon themselves to meet and interview several patients. The interviewers were: Christine, Leen, Thierry, Bram , Saar, Lore, Aje, Samira, Najat, Fien, Greta and Veronique.

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I also owe my thanks to my colleagues and ex-colleagues for their suggestions, good spirits and continuous involvement. I would like to name them all, but there are over 30. I feel however that I can make an exception for the colleagues named Koen, as this name stands for bravery and competence. Koen Meeussen posed, together with Els Inghelbrecht, difficult questions in the solicitation procedure back in 2006, and still favoured engaging me. When asked, he will no doubt comment that he had no choice, as there were no other candidates. Koen and Els, thank you for your wise choices and also for your relevant feedback. During the first years of the doctoral trajectory, another Koen (Putman) had taken the desk right opposite mine. This led to enlightening statistical discussions and a software annex mail system that automatically warned the interviewers that a new appointment for interview had to be made with their patient.

And now it is time for family and friends. I thank my parents, my brother and sister (and their spouses and children), my family-in-law and my friends for their ongoing support. Sara, my love, I thank you for supporting me in whatever I do, even when it involves wild ideas such as making a doctoral thesis. You make my life a very, very happy one, as do my two very fantastic children Tess and Liv.

March 2011

Chapter 1:
Introduction

"The moment my doctor told me, I went silent. My mum and dad were with me. Then we all fell to pieces."
Kylie Minogue, on being diagnosed with breast cancer

1.1 Background

Optimal palliative care at the end of life implies putting the patient and his or her values and wishes first (1). At the end of life, the patient is confronted with emotionally taxing information and decisions concerning treatment, location of care and end-of-life decisions with possible life-shortening effects (ELDs) (2-4). These decisions are not always made with care: results of epidemiologic studies on the end of life suggest that there is a deficit in patient autonomy and an excess in physician paternalism (5;6).

Legal changes, changes in the deontology of physicians and a change in public attitudes increasingly suggest that the physician is no longer seen as the person who knows best, but as someone who informs and supports the patient (7-9). Also in scientific literature, the focus is on models of shared and informed decision-making as an alternative to the paternalistic model (10-15). This has led to the development of interventions to enhance the involvement of patients in the decision-making process; the so-called decision-aids (16;17). Paradoxically however, questions have been raised as to whether all patients in the last phase of life want to be fully informed e.g. about the imminence of death, or want to be actively involved in the often difficult medical decision-making process. Some authors have pointed out that not wanting to be informed or involved is as much part of the autonomy of the patient as wanting to, and that implementing models of shared decision-making can have a negative influence on the physician-patient relationship (13;18;19).

Research on the preferences of seriously ill patients for information and participation in medical decision-making has shown that most patients want to be fully informed (20-29). According to a UK study on 2331 cancer patients of which 36% were palliatively treated, 87% wanted all possible information, good and bad, and 98% preferred to know whether or not their illness was cancer (20). With regard to participation in medical decision-making, there are contradictory results; the number of patients who preferred an active role varied from one third to two thirds (23;30-33). In an early study (1988), Blanchard studied hospitalized cancer patients of which 70% had a prognosis of less than one year and found that 69% wanted to participate in therapeutic decision-making (23). In a recent systematic review on information-giving and decision-making in patients with advanced cancer, the authors concluded that two thirds of patients with advanced cancer wanted to participate actively in decision-making (31). There are however also other findings, for instance Degner studied newly diagnosed cancer and advanced cancer patients and found that the majority (59%) wanted physicians to make treatment decisions on their behalf (30).

Several studies have examined the degree to which the patients' information and participation preferences were met. These studies show that patients receive information to their satisfaction, but also that there remain important gaps with regard to some important information topics, such as prognosis and goals of treatment (34-37). Percentages of patients who did not achieve their preferred level of participation in medical decision-making varied from 39% to 66% (31;38-42). In a study of 233 cancer outpatients, one third of whom were treated with a palliative intent, 34% of the patients reported a match between their preferred and actual involvement, 37% reported that they were involved less than preferred and 29% that they were involved more than preferred (38).

A point of interest is that several patient outcomes have been investigated in relation to meeting patients' information and participation preferences, e.g. anxiety and satisfaction (38;40). These studies show that a discrepancy between preferred and actual information/participation levels has a negative influence on these outcome measures in the short term.

Relevance of this work

The studies on information and participation preferences such as those mentioned above have certain shortcomings. Firstly, they examine mostly people from the general population, patients with a non-life-threatening disease or patients with cancer who are mainly curatively treated. Patients with a disease with limited life expectancy, such as advanced cancer, have been studied less in relation to information and participation preferences. Additionally, the focus of the cancer studies is on specific types of cancer, especially breast cancer and to a lesser extent prostate and colorectal cancer, or on heterogeneous samples of patients with several types of cancers. Few studies have involved patients with lung cancer (43;44).

Secondly, the focus of the studies is on information about and participation in treatment decisions, while other decisions, e.g. those regarding the location of care or end-of-life decisions with possible or certain life-shortening effects (ELDs), are seldom or never considered (45;46). For patients with a disease with limited life expectancy, the latter decisions might however be as important as treatment decisions and because they are highly dependent on a patient's personal values and preferences, they might have a major impact on their quality of life.

Thirdly, participation preferences very seldom relate to a specific medical treatment decision that has recently been taken or will be taken in the immediate future (47). Instead, hypothetical treatment choice scenarios are used or the decisions under consideration are not specified, making it harder to make inferences about patients' actual preferences when they are confronted with specific decisions in real life.

Fourthly, the degree to which the information and participation preferences of incurably ill patients are met and its association with their quality of life – a very important outcome measure in palliative care - has not yet been studied.

Fifthly, most studies are cross-sectional and do not offer insight into possible changes in information and participation preferences over time or the determinants of these changes (48). Information about changes in preferences can help physicians to adjust their communication to a patient's specific preferences and thus optimise the physician-patient relationship.

Sixthly, little is known about the preferences of patients regarding the involvement of family members and other health-care professionals than the treating physician(s) in the information-giving and decision-making process (49).

1.2 Study objectives and research questions

1.2.1 Study objectives

The main objective of this dissertation is to gain insight into the preferences of patients with advanced lung cancer with regard to information and participation in medical decision-making, whether these preferences are met according to the patients and how the preferences evolve over time. Additionally, we aim to discover what the preferences of the patients are regarding involvement of family and other persons in medical decision-making.

A secondary objective of the study is to detect to what degree advanced lung cancer patients and their families are involved in medical end-of-life decisions with possible life-shortening effects and if this involvement corresponds with the patient's preferences for involvement as stated earlier in their illness trajectory.

Another secondary objective is to gain insight into the prevalence of wishes for euthanasia in patients with advanced lung cancer and the degree to which this leads to the expression of a repeated and explicit request for euthanasia and execution of this request.

Overall, the object of this study is to gain a picture of the physician-patient-family interaction in information provision and medical decision-making in advanced lung cancer patients. Important information topics for patients with advanced diseases concern: diagnosis, prognosis, treatment options, palliative care and ELDs. Medical decisions in the context of patients who are seriously ill can be defined as treatment decisions, transfer decisions and ELDs.

1.2.2 Research questions

The objectives of the study are translated in the following research questions.

1) Main objective:

Information and participation preferences

1. To what degree do advanced lung cancer patients want to be informed in general and particularly in regard to diagnosis, chances of cure, life expectancy, treatment options, palliative care and end-of-life decisions with possible life-shortening effects (ELDs)?
2. To what degree do advanced lung cancer patients want to be involved in medical decision-making in general and in treatment decisions, health-care-setting transfer decisions and ELDs in particular?
3. What socio-demographic and clinical patient characteristics are associated with these preferences?

Meeting the information and participation preferences

4. To what extent are advanced lung cancer patients' preferences regarding information about diagnosis, prognosis, treatment options, palliative care and ELDs met?
5. To what extent are advanced lung cancer patients' preferences regarding participation in medical decisions in general and specifically in treatment, health-care-setting transfers and ELDs met?
6. Do advanced lung cancer patients whose information and participation preferences are met have a higher quality of life?

Evolution of the preferences over time

7. Do preferences of advanced lung cancer patients concerning information and participation in medical decision-making change over time?
8. What are the characteristics of advanced lung cancer patients with stable versus evolving preferences?

Preferences for involvement of family in medical decision-making

9. Who do advanced lung cancer patients want to involve in medical decision-making while they are competent and are these persons involved?
10. Who do advanced lung cancer patients want to involve in medical decision-making when they are no longer able to make decisions themselves, and to what degree?

2) Secondary objective 1: actual involvement in end-of-life decisions

11. How involved in end-of-life decision-making are advanced lung cancer patients who are competent? For patients who are incompetent, are other persons (family, nurses, physicians other than the treating physician) involved?
12. Does the involvement of the patient or others in end-of-life decision-making correspond with the patient's previously stated preferences for involvement?
13. What characteristics of the patient and the ELD are associated with their involvement when competent, or the involvement of others when incompetent?

3) Secondary objective 2: Euthanasia wishes, requests and implementation of requests

14. How many advanced lung cancer patients desire and request euthanasia, and how often is their request implemented?
15. What characterises the patients who choose euthanasia?
16. What is the incidence of other ELDs among advanced lung cancer patients?

1.3 Methodology

1.3.1 Study design

Patients who had recently received an initial diagnosis of lung cancer in an advanced stage were interviewed with a standard questionnaire by trained interviewers (psychologists, nurses, interns, Koen Pardon (KP)). The interview was repeated every 2 months until the fourth and every 4 months until the sixth interview. When the patient died, the treating specialist and the general practitioner (GP) were asked to fill in an after-death questionnaire.

1.3.2 Sample selection and inclusion criteria

Pulmonologists or oncologists of three university hospitals and 10 general hospitals carried out the selection of the patients. All hospitals had a multidisciplinary oncology program. The pulmonologists and oncologists were instructed to ask every consecutive patient with an initial diagnosis of non-small-cell lung cancer (NSCLC) stage IIIb or IV to participate in the study, over a period of one year. NSCLC IIIb or IV patients were studied because of the high prevalence of the condition and the short median life expectancy of 6-9 months (50;51). Additional inclusion criteria were that the patient should be at least 18 years old, Dutch-speaking and physically and psychologically able to be interviewed. Both hospitalised patients and outpatients were eligible.

Patients had to give written informed consent and were subsequently contacted by an interviewer within two weeks of inclusion to schedule an interview. After each interview, the patients were asked for their agreement to take part in another interview. The interview took place at the patient's home or in another setting where the patient felt comfortable. When the patient died, the pulmonologist or oncologist as well as the GP had to fill in an after-death questionnaire. In the case of the GP, who was previously informed of the patient's participation in the study, a letter was sent with an invitation to fill out the questionnaire. The specialist was communicated with by e-mail or phone.

The recruitment period lasted from February 2007 to February 2008 (12 months), and the last interview took place in May 2009. Figure 1 and 2 give a schematic representation of the study. Figure 3 shows the number of participating NSCLC IIIb or IV patients in the study and those lost to follow-up over the course of the study.

1.3.3 Ethical considerations

The protocol of the study was approved by the Ethical Review Boards of the University Hospital of the Vrije Universiteit Brussel and of all the participating university hospitals and general hospitals. The patient was guaranteed that the data would be handled confidentially and processed anonymously. The patient was also assured that non-participation or ending the study prematurely would not under any circumstances affect their care. Because some questions were of a delicate nature, measures were taken to ensure good ethical practice, e.g. interviewers were selected on the basis of their education and experience in health-care settings and were trained by a psychologist (KP), interviews were audio taped allowing for feedback to the interviewers, etc.

1.3.4 Measures

1) Before the beginning of the selection process

The participating pulmonologists or oncologists were asked to fill in a questionnaire before the beginning of the selection process. The questionnaire measured the socio-demographic variables of the physician, their attitude with regard to informing and involving patients in medical decision-making, and an estimation of the number of patients that he or she was able to include during one year.

2) Upon inclusion

Upon inclusion, the pulmonologist or oncologist filled in an inclusion form for every patient who wished to participate in the study. This questionnaire recorded socio-demographic and clinical patient variables. The clinical variables included the type of treatment, intention of treatment, estimated life expectancy, comorbidity (Charlson et al. (52;53)) and performance status (ECOG, Eastern Cooperative Oncology Group (54)).

For patients who refused to participate or were not asked, the physician was also instructed to record socio-demographics, the reason for non-participation, performance status and estimated life expectancy.

3) Follow-up of patients

Shortly after inclusion a structured questionnaire with close-ended questions was administered to the patients in a face-to-face interview. This interview was repeated regularly, every 2 months and from the fourth interview every 4 months up to a maximum of 6 times. The questionnaire covered multiple areas including:

a) quality of life of the patient, measured with the Dutch version of the EORTC QLQ-C15-PAL(55;56),
b) information preferences and information level achieved, based on items of existing questionnaires for cancer patients that met at least some of the criteria of validity, reliability, responsiveness and burden, and based on data from qualitative research into incurable and terminally ill patients (57-63),
c) participation preferences and participation level achieved, measured with an adaption of the control preference scale, frequently used in other studies (38;64),
d) satisfaction with the decision-making process, measured by COMRADE (65). Data from this questionnaire were, however, not used in this thesis.

The patient interview was pilot-tested with seriously ill lung cancer patients for content validity, understanding, acceptability and burden.

4) When the patient died

As soon as possible after the patient died, the pulmonologist/oncologist and the GP of the patient had to fill in an after-death questionnaire. The questionnaire measured: performance status in the last week before death (ECOG (54)), whether the patient had died suddenly and unexpectedly, the setting of the patient’s death and the quality of death according to the physician (10-point rating scale from bad to good death), questions with regard to ELDs based on the classification of practices of previous nationwide ELD incidence studies (5;6;66), questions regarding expressed wishes for euthanasia and explicit and repeated requests, and characteristics of the physician.

2.5 Statistical analysis

The data were analysed with the statistical software package SPSS and STATA.

Figure 1: Schematic representation of the study

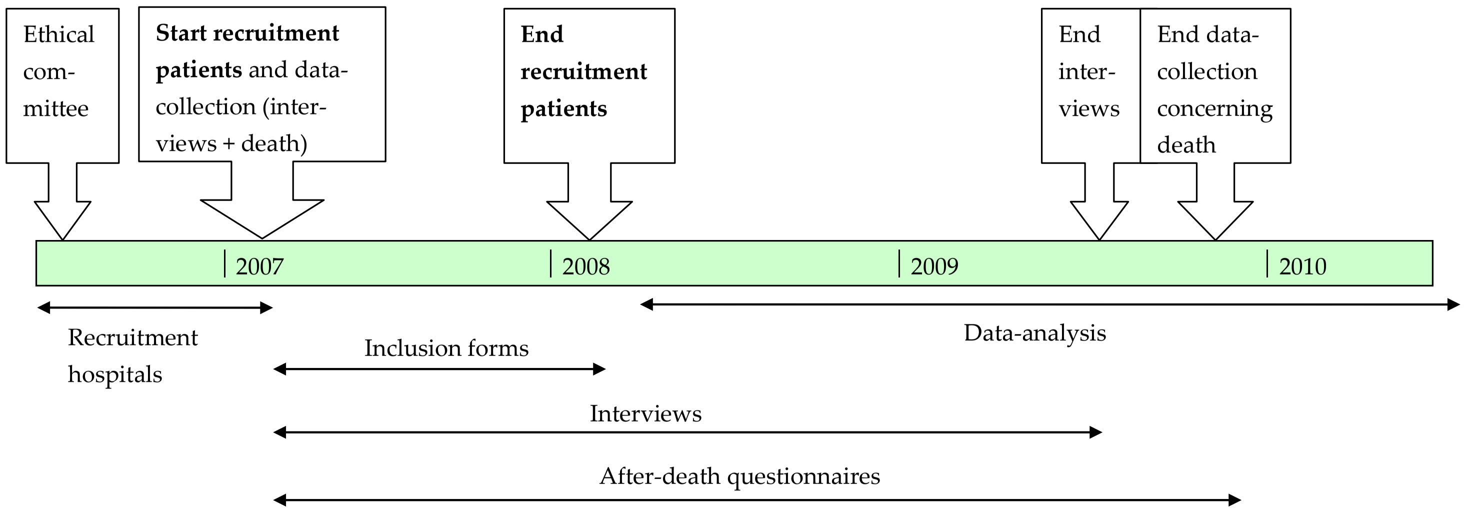


Figure 2: Study trajectory from the perspective of the patient: an example

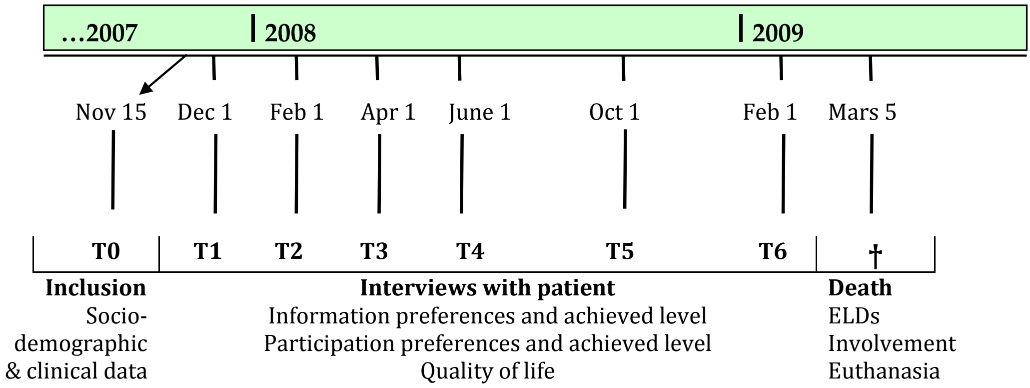
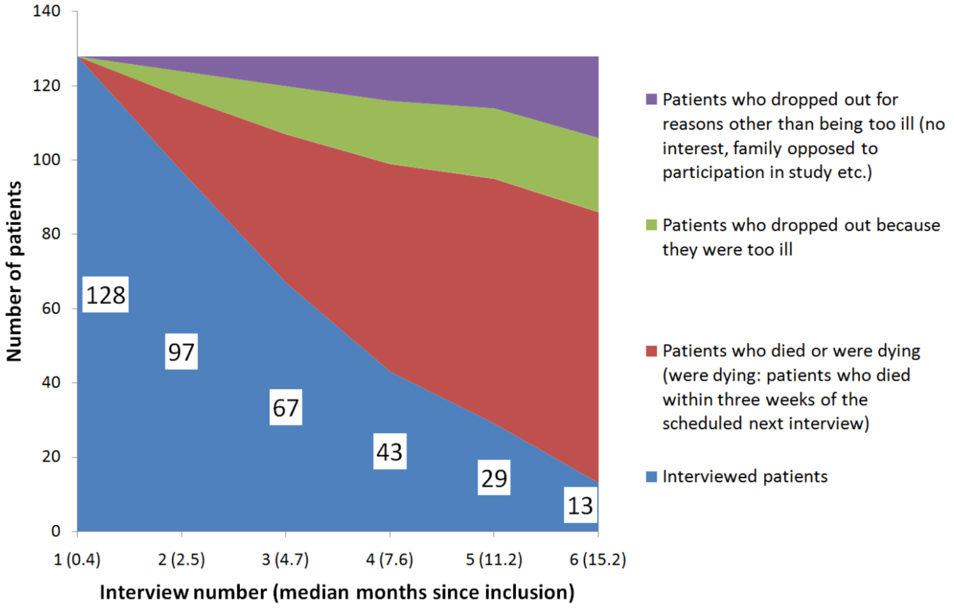


Figure 3: Participation of NSCLC IIIb or IV patients in study (N=128)



1.4 Dissertation outline

Following this introduction, chapters 2-7 of the dissertation are based on articles which have been published, accepted or submitted for publication. All of the chapters can be read independently.

Chapter 2 describes the preferences for information and participation in decision-making of the advanced lung cancer patients shortly after diagnosis of the cancer, chapter 3 reports on the degree to which these preferences were met according to the patients and chapter 4 describes the evolution of the preferences over time and determinants of change. Patients' preferences for involvement of family or other persons in medical decision-making when competent but also in case of future incompetence and change in these preferences over time are discussed in chapter 5.

The secondary objectives of the study are treated in chapters 6 and 7. They do not concern primarily the data gathered in the interviews of the advanced lung cancer patients, but predominantly focus upon the data gathered by the physicians after the death of the patients. These data offer information about the actual involvement in the patient's end-of-life decision-making (Chapter 6) and their expressed wishes for euthanasia, requests and implementations of requests (Chapter 7).

The final chapter of the dissertation, chapter 8, consists of the main findings of the study, reflections on its strengths and limitations, and the implications of the findings for health practice and future research.

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7. University Hospital Ghent
8. AZ Maria Middelares Hospital Ghent
9. ZNA Sint Erasmus Hospital Borgerhout
10. AZ City Hospital Aalst
11. AZ Jan Palfijn Hospital Ghent
12. ZNA Jan Palfijn Hospital Merksem
13. AZ Sint Elisabeth Hospital Turnhout

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Chapter 2:

Preferences of advanced lung cancer patients for patient-centred information and decision-making: a prospective multicentre study in 13 hospitals in Belgium

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Deliens L. Preferences of advanced lung cancer patients for patient-centred information and decision-making: a prospective multicentre study in 13 hospitals in Belgium. Patient Educ Couns 2009 December;77(3):421-9.

Abstract

Objective:
To identify preferences of advanced lung cancer patients for receiving information and participating in decision-making concerning treatment options, health-care-setting transfers and end-of-life decision-making.

Methods:
Over the course of 1 year, pulmonologists and oncologists in 13 hospitals in Flanders, Belgium, invited patients with an initial diagnosis of non-small-cell lung cancer IIIb/IV to participate in the study. Shortly after inclusion, the patients were interviewed with a structured questionnaire.

Results:
One hundred and twenty-eight patients with a median estimated survival time of 10 months participated. Almost all wanted information on diagnosis, treatment and cure rate and slightly fewer on life expectancy (88.2%). Information about palliative care was desired by 63.5% of patients and information about end-of-life decisions by 56.8%. The percentage of patients who preferred personal control over medical decision-making increased to 14.8% for treatment, 25.0% for transfer and 49.2% for end-of-life decisions, all of which were higher than for medical decisions in general (9.3%).

Conclusion:
Information and participation preferences of advanced lung cancer patients differ depending on the type of information or decision.

Practice implications:
As part of a patient-centred approach, physicians should not only check the general but also the specific information and participation preferences of their patients.

2.1 Introduction

Deontological, legal and social changes increasingly recommend that the physician is no longer seen as the person who knows best, but as someone who informs and supports the patient. In scientific literature, models of shared and informed decision-making have been proposed as alternatives for the ‘paternalistic’ model (1-3). This has led to the development of decision-making aids to promote the involvement of the patient in medical decisions (4;5).

Research on the information and participation preferences of advanced cancer patients shows that most patients want to be fully informed and that about two thirds want to share the treatment decisions with the physician or make the decisions themselves (4;6-9). However, there are also indications that patients in the last phase of life prefer not to be fully informed (e.g. about the imminence of death) and prefer to leave the responsibility to their proxy or caregiver (10;11). Some authors have therefore argued that not wanting to be informed or involved is part of the autonomy of the patient and that implementing models such as shared decision-making for all patients can have a negative influence on the physician-patient relationship (12-15). It has been proposed that inquiring up front about patient preferences for information and their desired level of participation is more respectful of patient autonomy, without impinging on physician benevolence (16).

This study adds in several ways to the existing empirical studies on information and participation preferences in advanced cancer patients. Firstly, we have not only focused on information and participation with respect to treatment decisions, but also with respect to other decisions, such as those concerning transfers between health-care settings (home, treatment centre or hospice) and end-of-life decisions with a possible or certain life-shortening effect (ELDs) (17;18). For advanced cancer patients, the latter decisions might be as important as treatment decisions, and because they are highly dependent on the patient’s personal values and preferences, they can have a major impact on their quality of life. Secondly, we have focused on a population of advanced lung cancer patients who have not been involved in many preference studies. One study of a decision aid for locally advanced non-small-cell lung cancer measured patient participation preferences at baseline: all 20 patients who completed the decision aid wished to participate in the treatment decision to some extent (19). Thirdly, instead of using hypothetical treatment-choice scenarios or unspecified decisions, we have assessed patients’ participation preferences with respect to a specific medical decision in which they have recently been involved (20). The patient’s actual preferences about concrete and specific decisions in the treatment and care process are likely to allow more reliable inferences. Fourthly, we have also examined the preferences of patients as to the involvement of family members and different health-care professionals in the information-giving and decision-making process (21).

The objective of this study was to assess the following in a sample of advanced lung cancer patients in Belgium:

1) patient preferences regarding information on diagnosis, chances of cure, life expectancy, treatment options, palliative care and end-of-life decisions;
2) patient preferences regarding participation in decision-making on treatment, transfer to other care settings and end-of-life decisions with a possible life-shortening effect;
3) socio-demographic and clinical patient characteristics associated with these preferences.

2.2 Methods

2.2.1 Study design

Lung cancer patients recently diagnosed with advanced disease were interviewed with a standard questionnaire. The interviews were also audio taped to allow interpretation of the data gathered. The study is part of a large longitudinal multicentre study on patient participation, including satisfaction with the decision-making process and quality of life.

2.2.2 Sample

1) Hospitals
To recruit a representative sample of lung cancer patients, we requested the cooperation of pulmonologists and oncologists from all university and general hospitals with a multidisciplinary oncology program in Flanders, the Dutch-speaking part of Belgium (6 million inhabitants). Four university hospitals and 19 general hospitals were approached, of which 3 university and 10 general hospitals agreed to participate. Reasons for refusal were: lack of time, no interest in communication studies or fear of overburdening patients. The hospitals were asked to involve all pulmonologists or oncologists who treated advanced lung cancer patients: 21 pulmonologists and 2 oncologists participated.

2) Patients
The pulmonologists and oncologists were instructed to ask every consecutive patient with an initial diagnosis of non-small-cell lung cancer (NSCLC) stage IIIb or IV to participate in the study, over a period of one year. The additional inclusion criteria were: the patient should be at least 18-year-old, Dutch-speaking and physically and psychologically able to be interviewed. Both hospitalised patients and outpatients were eligible. We chose to study NSCLC IIIb/IV patients because of the relative homogeneity of this population, the high prevalence of the condition and the short

median life expectancy of 6-9 months, significantly but modestly longer than without disease-directed treatment, with a small fraction of long-term survivors. All the hospitals practice chemotherapy and radiotherapy as standard treatment for this condition (22;23).

Patients who gave written informed consent were contacted by an interviewer within 2 weeks of inclusion and an interview was scheduled. The interview took place at the patient's home or in another setting where the patient felt comfortable.

2.2.3 Ethical considerations

The anonymity of the patients was guaranteed. The protocol of the study was approved by the Ethical Review Boards of the University Hospital of the Vrije Universiteit Brussel and of all the participating universities and general hospitals.

Because some interview questions were of a delicate nature, the interview was preceded by the statement that the same questions were used for every patient regardless of the seriousness of the disease. The interviewers were selected on the basis of their education and experience in health-care, trained by a psychologist (KP) and allowed to skip questions they felt would be too burdensome for the patient or his family. Audiotapes of the interviews and regular meetings with participating physicians provided information on patients' reactions to the interview and feedback to the interviewers.

2.2.4 Questionnaires

1) Inclusion form

Upon inclusion, the physician filled in an 'inclusion questionnaire', recording socio-demographic and clinical patient variables. To maximize the completeness and accuracy of the data, this was done in consultation with the patient except for questions relating to treatment and life expectancy variables. The socio-demographic variables were age, sex and educational level, whether the patient lived with a partner, their place of residence and religion or life stance. The clinical variables were the type of treatment, intention of treatment, estimated life expectancy, whether they had a general practitioner (GP), frequency of contact with their GP, comorbidity (Charlson et al. (24;25)) and performance status (ECOG (26)). In Charlson's Comorbidity Index, the physician had to mark the concomitant diseases the patient suffered from according to a list of 19 diseases that all bear a relative risk of death larger than 1.2. If no disease was marked, a score of 0 was given. Higher scores meant that the patient suffered from one or more concomitant diseases.

For patients who refused to participate or were not asked, the physician was also instructed to record socio-demographics, the reason for non-participation, performance status and life expectancy.

2) Patient interview

A structured questionnaire with 60 questions was used. It covered 4 areas: information preferences and information level achieved, participation preferences and participation level achieved, quality of life and satisfaction with the decision-making process.

Instrument 1: Information preferences. We developed an instrument to measure patients' needs for information as they approach death. We determined the content of essential disease-related information items on the basis of existing questionnaires for cancer patients that met at least some of the criteria of validity, reliability, responsiveness and burden, and using data from qualitative research into incurable and terminally ill patients (27;28). Seven recurrent information topics were selected that were presented to the patient in the form of statements. Patients were asked to rate the statements on a 6-point rating scale (totally disagree to totally agree). The first preference statement was: 'In general, I want to be fully informed'. The next six statements concerned information preferences on specific disease-related topics: diagnosis, chances of cure, life expectancy, treatment, palliative care and end-of-life decisions. Between the first general and the six specific statements, additional multiple response questions were asked to find out if the patient wanted relatives or health-care professionals to be informed or involved in medical decision-making in general.

Instrument 2: Participation preferences. To assess participation preferences in medical decision-making, we adapted the control preference scale which has frequently been used in previous studies with cancer patients (3;29). Patients were asked to select one of five responses to the question: 'Who do you want to take such decisions?' The five possible responses were: 1) the doctor on the basis of his/her knowledge, 2) the doctor but strongly taking my opinion into account, 3) myself and the doctor together on an equal basis, 4) myself but strongly taking the doctor's opinion into account and 5) myself on the basis of the information I have or receive. The 5 answers represent three categories of patients: patients preferring the doctor to take primary control of medical decision-making (categories 1 and 2), shared control (category 3) or patient control (categories 4 and 5). Patients were given the control preference scale in relation to four situations: 1) medical decisions in general, 2) treatment decisions, 3) transfer decisions and 4) end-of- life decisions. We asked patients to envisage real decision situations that had actually taken place in the 2 months before the interview whenever possible. We recorded actual past decisions using a list we developed ourselves of possible decisions, based on physicians' input and literature (22;30). If more than one decision had been taken in one of the decision situations (treatment, transfer or ELDs), we asked which was the most important and the patient had to use this decision to state his/her participation preference. If no decision had been made within the last 2 months, the patient was asked to state his/her preference for decisions such as those mentioned in the list.

Other instruments: Two items from instruments that were not used in this study were singled out and added to the patient characteristics because of their possible predictive power: item 5 of the EORTC QLQ-C15-PAL (31;32) regarding pain and a item we constructed ourselves where the patient was asked whether s/he had been informed about life expectancy (yes or no).

All questionnaires were in Dutch. Existing English instruments (Charlson, ECOG, CPS) were forward- and back-translated and corrected. For the EORTC QLQ-C15-PAL, we used the Dutch version provided by the European Organisation for Research and Treatment of Cancer (EORTC).

The patient interview was pilot-tested with 3 consecutive advanced lung cancer patients who were recruited according to the inclusion criteria by a pulmonologist from a general hospital: one interviewer interviewed 2 patients once and another interviewed 1 patient three times, every 2 months. The items were well understood and accepted, but on two occasions (concerning two different patients) the interview was perceived as rather long-winded and repetitive. We therefore shortened the patient questionnaire.

2.2.5 Statistical analysis

The information and participation preferences were categorized into wanting information versus not wanting information and into wanting primarily doctor control versus shared control versus patient control, and described using frequencies. The characteristics of the patients were tested for association with the information and participation preferences using Fisher's exact test and entered in multivariate logistic regression models (stepwise forward) to control for potential confounding factors. Because the number of patients in the three participation categories was too small for an ordinal or multinomial logistic regression, we categorized the participation preferences further into wanting doctor control versus shared/patient control. The cut-off between doctor control versus shared/patient control was chosen because it resulted in similar-sized groups to compare with respect to the medical decisions studied. Ordinal characteristics were recoded in dummy variables.
To compare the characteristics of the NSCLC IIIb/V patients who participated in the study with the eligible patients who were not asked to participate or refused, an independent-samples t-test, or the non-parametric equivalent Mann-Whitney U were used; significance was set at $P<0.05$. The data were analysed with the statistical software package SPSS 16.0.

2.3 Results

A total of 291 patients were diagnosed with NSCLC IIIb or IV by the hospital physicians during the inclusion period. Of these, 95 did not meet the inclusion criteria due to physical (45), psychological (34), language (12) or multiple problems (4), and 8 were not included although they met the inclusion criteria (e.g. because some patients were already involved in other studies), leaving 188 eligible patients. Thirty-six patients refused to participate. The main reasons for refusal were: too ill, not interested or expressing a wish not to be confronted with the disease. Of the 152 patients who consented, 19 were not interviewed because they were too ill or had died, 3 could not be contacted and 2 interviews had too many missing values, leaving 128 patients for analysis (68% participation rate). The interviews took place between February 2007 and February 2008.

Compared to patients who refused participation or were not included although they fitted the inclusion criteria, the patients included had a higher performance status (*P*=0.006) and mean estimated life expectancy (10.3 months versus 8.3 months since diagnosis, *P*=0.014). Included patients who were interviewed had a better performance status than those not interviewed (*P*=0.011).

The 128 patients interviewed had a mean age of 64.4 years (range 41-86), 79.7% were male, 76.6% had a partner and 97.6% lived at home (Table 1). The median estimated life expectancy was 10 months and ranged from 2 to 24 months. Eighty-two per cent were receiving chemotherapy, sometimes in combination with radiotherapy (26.6%); a minority of patients were only receiving radiotherapy (5.5%). The main treatment objectives were life prolongation (71.1%) and palliation, defined as comfort care with no intent to prolong life or cure the disease (21.1%).

Table 1: Characteristics of the studied advanced lung cancer patients

		Participants (N=128)	
		N	%
Socio-demographic characteristics			
Age	<=54y	21	16.4
	55-64y	40	31.2
	65-74y	45	35.2
	>=75y	22	17.2
Sex	Male	102	79.7
	Female	26	20.3
Partner	Yes	98	76.6
	No	30	23.4
Living situation	Home, alone	31	24.2
	Home, with others	94	73.4
	With family	3	2.3

(Table 1 cont'd)		N	%
Education	Primary school	24	18.8
	Lower secondary	42	32.8
	Higher secondary	40	31.2
	University	22	17.2
Religion or life stance	Christian	77	60.2
	Religious, no specific religion	16	12.5
	Agnostic or atheistic	14	10.9
	Not religious	21	16.4
Clinical characteristics			
Treating hospital	University	59	46.1
	General	69	53.9
Treatment objective	Cure	9	7.0
	Life prolongation	91	71.1
	Palliation	27	21.1
	Other (no treatment)	1	0.8
Treatment	Chemotherapy	105	82.0
	Radiotherapy	41	32.0
	Experimental therapy	6	4.7
Contact with GP[a]	Once a week or more	11	8.6
	Once every 2 weeks	17	13.3
	Once every month	59	46.1
	Less	41	32.0
Co-morbidity score[b]	0	65	50.8
	1-2	53	41.4
	3-4	10	7.8
Performance status[c]	0	31	24.2
	1	81	63.3
	2	11	8.6
	3	3	2.3
	4	2	1.6
Life expectancy on inclusion[d]	0-6 months	28	22.4
	7-12 months	75	60.0
	>12 months	22	17.6

[a] Three patients reported that they did not have a GP, these were included in the category 'Less'.

[b] Comorbidity score of Charlson Index.

[c] Performance status according to ECOG: Eastern Cooperative Oncology Group, ranging from 0 = fully active to 4 = completely disabled.

[d] Estimated by treating physician; 3 missing values.

2.3.1 Information preferences (Table 2)

Of all the patients, 97.7% wanted to be fully informed when asked in general (in general: no medical information topic was specified). A similar result was found for the specific topics of diagnosis (99.2%), treatment (97.7%) and chances of cure (96.9%). There was more variation between patients on other specific topics: 88.2% of patients wanted information on life expectancy, 63.5 % on palliative care and 56.8% on end-of-life decisions.

2.3.2 Participation preferences (Table 3)

According to the patients, the most important treatment decision made within the last two months prior to the interview had been chemotherapy (65.6%), radiotherapy (8.6%), medication (6.2%), pleural drainage (6.2%), experimental therapy (4.7%) or not starting treatment (0.8%). About half of the patients (47.7%) said they had been transferred to hospital or from hospital to their home due to complications of illness or treatment, while for the other half no transfer decision had been made. Fourteen per cent (18 patients) had agreed with the physician to make end-of-life decisions in advance and half of these decisions were documented in written form. For 13 of these 18 patients the most important ELD was euthanasia (which has been regulated and legalised in Belgium), for one it was the decision not to resuscitate (DNR) and 4 could not decide which ELD was the most important.

For medical decisions in general and for decisions on transfer between health-care settings (to the hospital or from the hospital to home) half of the patients (49.2% and 47.7%, respectively) wanted primarily doctor control. For treatment decisions, 63.3% of patients wanted the physician to make decisions and for end-of-life decisions, 15.5%.

The percentage of patients who wanted primarily personal control over decision-making gradually increased across medical decisions, from 9.3% for medical decisions in general, to 14.8% for treatment, 25.0% for transfer and 49.2% for end-of-life decisions. The probability of preferring patient control (versus shared/doctor control) for medical decisions in general and treatment decisions was significantly lower than for transfer decisions, which was significantly lower than for ELDs ($P<0.001$, generalised linear modelling, repeated measures analysis with marginal probabilities as estimates).

2.3.3 Beyond the physician-patient dyad (Table 4)

Ninety-four point five percent of patients wanted to receive medical information in general from the treating specialist. Slightly less than half (46.9%) also wanted information from the GP, 10.2% from nurses and 7.0% from family.

Seventy-eight point one percent of patients would prefer relatives to be present when information is given and a few of them would also appreciate the presence of the GP or a nurse. Sixty-eight point eight percent also wanted to involve relatives or friends in the medical decision-making process in general.

2.3.4 Characteristics associated with information and participation preferences (Table 5)

1) Information preferences

Patients with a lower level of education or those who experienced no pain were less likely to want information with regard to life expectancy. Characteristics associated with the preference for information on palliative care as well as on end-of-life decisions were age, living situation and the level of information patients received about life expectancy: younger patients, those who lived alone and those who had been informed about life expectancy tended to desire more information. An additional patient characteristic predictive of information preference about palliative care was that those whose treatment had a curative or life-prolonging goal were less likely to want information on palliative care than those treated with palliative intent.

2) Participation preferences

Patients with a low level of education, those regularly in contact with their GP (at least once a month) and those who had received information on life expectancy were more likely to prefer shared or personal control than doctor control over medical decision-making in general. With regard to participation preference in treatment decisions, those living alone and those experiencing no pain were more likely to desire involvement (shared or patient control) in decision-making. Predictors for participation preference in transfer decisions were having no partner, being non-religious and having treatment with a palliative intent. Patients with no comorbidity according to the Charlson Index (score 0) were more likely to prefer involvement in end-of-life decision-making. Overall, logistic regression analyses revealed that associated socio-demographic and clinical patient characteristics explained 19%, 11%, 13% and 8%, respectively of the variation in participation preference in medical decisions in general and in treatment, transfer and end-of-life decisions.

As an exploratory analysis, we also examined whether having made the decision recently was likely to affect patient participation preferences. Preference for doctor control rather than shared or patient control over transfer decision-making was significantly higher among patients who had recently experienced a transfer than among those who had not been transferred within the previous two months (68.9% versus 28.4%, $P<0.001$). Patients who had made end-of-life decisions in advance wanted significantly more personal control over such decision-making than patients who had made no ELDs (83.3% versus 43.3%, $P=0.002$). The high significance of the patient's experience in decision-making remained after multivariate adjustment for socio-demographic and clinical characteristics.

Table 2: Information preferences of the advanced lung cancer patients (N[a] = 128)

	N(%)						%
Information preference statements[b]	Totally disagree	Disagree	Rather disagree	Rather agree	Agree	Totally agree	Agree (from rather to totally)
In general							
In general, I want to be fully informed	1(0.8)	1(0.8)	1(0.8)	7(5.5)	20(15.6)	98(76.6)	97.7
I want to be informed about:							
My diagnosis (= the exact name and main characteristics of the disease)	0(0.0)	1(0.8)	0(0.0)	8(6.2)	24(18.8)	95(74.2)	99.2
The chances of cure of the disease	0(0.0)	1(0.8)	3(2.3)	5(3.9)	24(18.8)	95(74.2)	96.9
My life expectancy with the disease	8(6.2)	5(3.9)	2(1.6)	11(8.6)	19(14.8)	83(64.8)	88.2
The different treatments, their side-effects and the result (goal) of every treatment	0(0.0)	2(1.6)	1(0.8)	11(8.6)	27(21.1)	87(68.0)	97.7
Options of palliative care (= only comfort care for patients who cannot be cured)	15(11.9)	25(19.8)	6(4.8)	10(7.9)	18(14.3)	52(41.3)	63.5
Possibilities at the end of life (= resuscitation, options to accelerate the end of life or options to discontinue or forgo life-prolonging treatments)	22(17.6)	24(19.2)	8(6.4)	5(4.0)	18(14.4)	48(38.4)	56.8

[a] Missing values for palliative care = 2, for end-of-life possibilities = 3.

[b] Responses to 6-point rating scaled questions.

Table 3: Participation preferences of the advanced lung cancer patients in medical decision-making in general and in treatment, transfer and end-of-life decisions (N[a] = 128)

	Medical decision-making N(%)			
Participation preference: who has to make the decision?[b]	In general	Treatment decisions	Transfer decisions	End-of-life decisions
The doctor on the basis of his/her knowledge	36 (28.1)	60 (46.9)	50 (39.1)	12 (9.8)
The doctor but strongly considering my opinion	27 (21.1)	21 (16.4)	11 (8.6)	7 (5.7)
The doctor and myself together on an equal basis	53 (41.4)	28 (21.9)	35 (27.3)	43 (35.2)
Myself but strongly considering the doctor's opinion	8 (6.2)	15 (11.7)	15 (11.7)	18 (14.8)
Myself on the basis of the information I have or receive	4 (3.1)	4 (3.1)	17 (13.3)	42 (34.4)
Total	128 (100)	128 (100)	128 (100)	122 (100)

[a] Missing values for participation preference in end-of-life decisions = 6.

[b] Control preference Scale.

Table 4: Preferences regarding the involvement of health-care professionals and family in information-giving and medical decision-making in general (N=128)

		N	% of cases
Information giving			
Who should give the information?[a]	Specialist	121	94.5
	GP	60	46.9
	Nurse	13	10.2
	Family/friends	9	7.0
	Other	2	1.6
Who should be present (besides yourself and the specialist) when information is given?[a]	GP	5	3.9
	Nurse	1	0.8
	Family/friends	100	78.1
	No one	23	18.0
	Other	2	1.6
Who should raise the issue?[b]	You (the patient)	36	28.3
	Other	91	71.7
If 'other' should raise the issue then: who?	The doctor	75	58.5
	Shared responsibility	16	12.5
Medical decision-making			
Besides the physician and yourself are there other people you want to involve in medical decision-making? [a]	Nurse	0	0.0
	Family/friends	88	68.8
	No one	38	29.7
	Other	2	1.6

[a] Respondents were given the option to select more than one item.

[b] Missing value for 'Who should raise the issue?' = 1.

Table 5: Patient characteristics associated with a patient's preference for information and participation in medical decisions (N=128)

Patient characteristics		Information preferences OR (95% CI)[a] for wanting information versus not wanting information			Participation preferences OR (95% CI)[a] for preference for shared/patient control versus doctor control over decision-making			
		Life expectancy (N=128)	Palliative care (N=125)	End-of-life decisions (N=124)	Medical decisions in general (N=127)	Treatment decisions (N=128)	Transfer decisions (N=127)	End-of-life decisions (N=122)
Age[b]		Ns	0.94* (0.89-0.99)	0.94** (0.90-0.98)	Ns	Ns	Ns	Ns
Education	Primary school	0.14** (0.04-0.50)	Ns	Ns	3.8* (1.3-11.1)	Ns	Ns	Ns
	Secondary/university (ref)	-	-	-	-	-	-	-
Partner	Yes	Ns	Ns	Ns	Ns	Ns	0.39* (0.16-0.98)	Ns
	No (ref)	-	-	-	-	-	-	-
Living situation	Home, alone	Ns	4.7* (1.5-15.4)	2.8* (1.1-7.8)	Ns	2.9* (1.2-6.7)	Ns	Ns
	Home, with others (ref)	-	-	-	-	-	-	-
Religion	Religious	Ns	Ns	Ns	Ns	Ns	0.42* (0.18-0.96)	Ns
	Not religious (ref)	-	-	-	-	-	-	-
Treatment goal	Cure/life prolongation	Ns	0.057** (0.007-0.47)	Ns	Ns	Ns	0.38* (0.15-0.97)	Ns
	Palliation (ref)	-	-	-	-	-	-	-
Contact with GP	At least once a month	Ns	Ns	Ns	2.9* (1.3-6.6)	Ns	Ns	Ns
	Less (ref)	-	-	-	-	-	-	-
Comorbidity-score	0	Ns	Ns	Ns	Ns	Ns	Ns	3.7* (1.3-11.2)
	>=1 (ref)	-	-	-	-	-	-	-
Performance status	0 (Active)	Ns	Ns	Ns	Ns	Ns	Ns	Ns
	>0 (Limited) (ref)	-	-	-	-	-	-	-
Information received on life expectancy	Yes	[c]	3.6** (1.4-8.8)	3.8** (1.7-8.5)	2.4* (1.3-5.2)	Ns	Ns	Ns
	No (ref)	-	-	-	-	-	-	-
Pain in last week before interview	Yes	9.3** (2.2-38.9)	Ns	Ns	Ns	0.41* (0.19-0.87)	Ns	Ns
	No (ref)	-	-	-	-	-	-	-
Nagelkerke R^2		0.27	0.41	0.28	0.19	0.11	0.13	0.08

OR = Odds Ratio; ref = reference category; Ns = not significant. * *P*-value < 0.05 ***P*-value < 0.01.

[a] Odds Ratio with 95% confidence intervals from multivariate logistic regression models.

[b] Age was entered as a continuous variable.

[c] Not entered in model: multicolinearity of independent with dependent variable (definitional overlap).

2.4 Discussion and conclusion

2.4.1 Discussion

Almost all newly diagnosed advanced lung cancer patients wanted information about their diagnosis, treatment options and prognosis while somewhat fewer wanted information about palliative care and end-of-life decisions. Preferences regarding decision-making varied according to the type of decision: the number of patients who wanted personal control over decision-making increased across the specific medical decisions, from treatment to transfer to end-of-life decisions, and was much higher compared to when asking about decision-making in general.

Our finding that most patients wanted information on disease and treatment-related matters is consistent with other studies of cancer and advanced cancer patients (8;9;33). Less researched in advanced cancer patients are preferences for information about palliative care and ELDs: the majority of patients (63% and 57% respectively) in our study wanted this information. In comparison, in a study where incurable metastatic cancer patients were asked when they wanted to discuss issues about dying and palliative care, one third said at diagnosis, one third later and one third said never or that they were unsure (33). It is worthy of note that 18 lung cancer patients (14%) had already discussed ELDs with the treating physician: for 13 of these patients euthanasia was the most important decision. This emphasis on euthanasia can be explained by the increased acceptance of euthanasia in Belgium over the last decade, resulting in the Belgian euthanasia legislation of 2002 (34).

Fifteen percent of patients wanted personal control over treatment decisions, 25% over transfer decisions and 49% over end-of-life decisions. This finding demonstrates that preferences of patients for personal control over decision-making varies by decision context. Apparently few patients want to be involved in medical decisions, but more want their say in personal choices and even more in existential matters. The study is also one of the first to show that patterns of responses seen when we ask patients about preferences in general are very different to their specific preferences: only 9% of patients wanted personal control over medical decisions in general.

Compared to other studies of advanced cancer patients, many patients in this study preferred to give the doctor primary control over the treatment decision-making process (one third versus two thirds) (4). Several explanations are possible. Firstly, lung cancer is perceived (correctly) as a particularly deadly disease and it has been suggested that patients who are more severely ill tend to entrust their physician with more control (35). Secondly, contrary to other studies, we measured participation preferences by referring to a real treatment decision that had actually been taken in the last two months. The patients in our study were newly diagnosed, had recently been given bad news by a hospital physician they had just met and had faced important treatment decisions. In this situation it is conceivable that the preference for participation is less than when one is asked to rate one's participation preference in a hypothetical situation or 'in general'. Thirdly, cross-national differences might play a role: countries might differ in acceptance or preference for physician paternalism, whether for cultural reasons or legal or regulatory reasons like the prevention of tort litigation.

Our results confirm that most patients who are seriously ill strongly desire their family members to be present when the physician gives them information and when medical decisions are made. Patients seem to have a clear need to have trusted allies present in dealings with the physician, when confronted with serious disease and with sometimes complex health-care systems. It seems that the presence of family or friends provides significant support for the patient. The GP has a similar supporting role in end-of-life care. Patients who have been in frequent contact with their GP (at least once a month) preferred more shared or patient control over decision-making in general than patients who had less or no contact with their GP. This demonstrates that the GP can play a special role in empowering patients to adopt more decisional control.

One difficult task patients with advanced lung cancer and their families face is coping with bad news. In our study, a minority of patients were reluctant to confront delicate issues such as life expectancy and especially palliative care and end-of-life decisions. However, the results of the study show that these preferences for information may shift depending on changes in the patient's situation (situational factors). Patients who experienced pain, for instance, were far more likely to want information about life expectancy than patients with no pain. Likewise, patients who were informed about their life expectancy were more likely to want information on palliative care and end-of-life issues. Furthermore, when the treatment goal is palliation and not life prolongation, patients were more open to information on palliative care.

Several studies on cancer patients demonstrated an association between a higher educational level and a preference for more involvement in decision-making (36). In this study, we found the opposite with regard to medical decision-making in general. An explanation might be that we studied patients who had been newly diagnosed with cancer in an advanced stage, rather than in an early stage, as did most other studies. It is possible that patients with a higher educational level were better aware overall of the gravity and terminal nature of their illness (e.g. we know that they were more likely to want information about life expectancy) and that this awareness led to a preference for less involvement in medical decisions in general.

A clinical characteristic that was significant in the patients studied here was their comorbidity: patients with comorbidity were less likely to prefer active involvement in end-of-life decisions than patients without. This is in line with the finding that patients who are more ill tend to be more passive in decision-making (35). The more complex the disease situation, the more the physician must accept being entrusted with decisions.

This study has several strengths. Firstly, we studied information and participation preferences regarding actual medical decision-making rather than vignettes of hypothetical situations, and we did this in a vulnerable and under-researched population of advanced cancer patients. Secondly, this research was not restricted to a convenience sample, but aimed to address each consecutive patient at the participating centres. Thirdly, data on the involvement of family and other health-care professionals in information-giving and patient participation were also collected. However, the study also has some limitations. A number of hospitals refused to participate because they lacked interest in communication studies, or because they did not want to overburden their patients. Hospitals without an oncology programme or whose programme was limited, and physicians not affiliated with a hospital despite treating NSCLC IIIb or IV patients, were not subject to selection. Another source of potential bias is that some physicians may have omitted to recruit some patients into the study. In comparison with patients within the inclusion criteria who were not asked to participate in the study or refused participation, the patients included had a higher performance status and estimated life expectancy. The patients included who were interviewed had a better performance status than those not interviewed. Therefore some caution is indicated in generalising from the data. An additional limitation concerns the use of face-to-face interviews instead of self-administered questionnaires: patients might have been inclined to give socially desirable answers in the presence of an interviewer (37).

2.4.2 Conclusion

This study supports the proposition that as part of a patient-centred approach physicians might do well to inquire up front about patient preferences for information and their desired level of participation (16). A novel finding is that they should not only check the general information and participation preferences of their patients but also the specific ones, because preferences differ depending on the topic of information and nature of the decision to be made. Physicians should also verify whether their patients want their family to be present in the information-giving and decision-making process and if they want their GP to be updated regularly.

2.4.3 Practice implications

Certainly in advanced lung cancer patients where delicate information has to be imparted and important decisions have to be made regarding treatment, location of care and end-of-life options, physicians should stay constantly alert to the information and participation preferences of the patient and his/her family.

2.5 References

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Chapter 3:

Are advanced lung cancer patients’ preferences for information and participation in medical decision-making being met?

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Are patients' preferences for information and participation in medical decision-making being met? Interview study with lung cancer patients. Palliat Med 2011 January;25(1):62-70.

Abstract

We examined the degree to which newly diagnosed patients with advanced lung cancer wanted to be informed and involved in medical decision-making, and whether the patients felt their preferences were met. Patients from 13 hospitals in Flanders were interviewed with a standard questionnaire. A total of 128 patients (68%) participated. Of the patients who wanted to be informed about life expectancy, half (53%) reported they were informed, and of those who wanted to be informed about palliative care and end-of-life decisions, 25% and 31% said they were informed, respectively. With regard to participation in medical decision-making (in general, about treatment, transfer or end-of-life), patients who preferred the doctor to make decisions or those who preferred to make the decision themselves often achieved this (in their perception), while patients who wanted an in-between position with some involvement, often did not. To conclude, preferences of patients with lung cancer for information concerning delicate topics and for shared decision-making with the physician were not well met.

3.1 Introduction

When faced with a diagnosis of advanced cancer, patients have to cope with emotionally taxing information and decisions concerning treatment, location of care and advance care planning (1-3). Research has demonstrated that a physician's attitude of openness and partnership has beneficial effects for the patient, but not all patients with a life-threatening disease want to be informed in detail or want to participate in the different medical decisions (4-6). Therefore some authors have suggested that physicians should also be flexible and adjust their communication and decision-making efforts to the specific preferences of their individual patients (7;8). However, little is known about the degree to which physicians meet the information and participation preferences of patients with advanced cancer, or about the effect of good or poor matches on patient outcomes.

Several preference match studies in patients with cancer and advanced cancer have demonstrated that most patients were dissatisfied with the provision of information (8-11). With regard to participation in decision-making over treatment, the proportion of patients whose preferences were met varied considerably between studies (11). In a study of 233 cancer outpatients, one third of whom were treated with a palliative intent, 34% of patients reported a match between preferred and actual decision-making roles, 37% were less involved and 29% were more involved than they wished to be (12). On the other hand, in a study of seven terminally ill cancer patients, there was high compatibility between desired and actual participation in decision-making, at least in the early stages of hospital treatment (13).

Several patient outcomes (anxiety, satisfaction) have been investigated in relation to meeting patients' information and participation preferences (12). In a study of 205 patients with breast cancer, quality of life was measured but not significantly related to patient reports of a match between preferred and actual involvement (14).

Preference match studies in advanced cancer are thus far seldom and limited to the topics of diagnosis, treatment and prognosis. They do not examine the equally relevant topic of information about palliative care and end-of-life options and decision-making for these issues. Advanced non-small-cell lung cancer (NSCLC), a disease with a high incidence and limited life expectancy, has not yet been studied with regard to preference match. The research questions of this study were:

1. To what extent are advanced lung cancer patients' preferences regarding information about diagnosis, prognosis, treatment options, palliative care and end-of-life decisions (ELDs) met?
2. To what extent are patients' preferences regarding participation in medical decisions in general and specifically in treatment, health-care-setting transfers and ELDs met?

3. Do patients whose information and participation preferences are met have a higher quality of life?

3.2 Methods

Over 1 year**,** pulmonologists and oncologists from three university and 10 general hospitals in Flanders, Belgium, invited consecutive patients with an initial diagnosis of NSCLC, stage IIIb or IV, to participate in the study. The inclusion criteria for patients were: at least 18 years old, Dutch-speaking and able to be interviewed. Within 2 weeks of inclusion, patients who gave written informed consent were interviewed by trained psychologists, nurses or interns using a standard questionnaire in a setting where the patient felt comfortable (home, hospital).

3.2.1 Inclusion form

The pulmonologist or oncologist gathered data on patient characteristics, including age, sex, educational level, treatment intention, estimated life expectancy, comorbidity (15;16), and performance status (17) (Table 1).

3.2.2 Patient interview

1) Information preferences and level
The patients had to describe how they would like the information exchange between themselves and their physician to take place, and how it actually took place. For this purpose, patients were asked if they agreed with statements about wanting information in general and about six specific disease-related information topics (6-point rating scale, from 'totally disagree' to 'totally agree'). Subsequently they were asked whether they had effectively been informed or not. The items are mainly based on existing questionnaires (18;19).
2) Satisfaction with the information
For every information topic, patients who stated that they had been informed were asked to evaluate this information as the preferred amount, less than preferred or more than preferred.
3) Participation preferences and level
To assess participation preferences and level in medical decision-making, we adapted the control preference scale which has frequently been used in previous studies with cancer patients (12;20). For medical decisions in general and important actual treatment decisions, transfer decisions and ELDs during the 2 months preceding the interview, the patient was asked whom he wanted to make the decision (preference) and who actually made the decision (level). The patient had to choose one of five responses: 1) the doctor on the basis of his/her knowledge, 2) the doctor but taking my opinion strongly into account, 3) myself and the doctor together on an equal basis, 4) myself but

taking the doctor's opinion strongly into account and 5) myself on the basis of the information I have or receive . The first two statements represent a preference for doctor control over decision-making: doctor control with (1) and without patient input (2). The third statement represents a preference for shared control with the physician (3) and the last two statements represent a preference for patient control: patient control with (4) and without doctor input (5).

4) Quality of life

Item 15 of the EORTC QLQ-C15-PAL quality of life scale was used: patients had to rate their overall quality of life during the past week on a 7-point rating scale ('very poor' to 'excellent') (21;22).

The patient interview was pilot-tested with seriously ill cancer patients for content validity, understanding, acceptability and burden.

3.2.3 Ethical approval

The anonymity of the patient was guaranteed. The study protocol was approved by the Ethical Review Boards of the University Hospital of the Vrije Universiteit Brussel and of all participating hospitals.

3.2.4 Statistical analysis

The responses to the information preference statements were dichotomized into 'yes, I want information' (tend to agree to totally agree) and 'no, I don't want information' (totally disagree to tend to disagree) and were subsequently cross-tabulated with the yes and no responses to the corresponding information level questions. With regard to participation, the same method was used. In this way, for every information topic and medical decision, groups were formed of patients who were informed or participated as preferred (match), and patients who had either more or less information and participation than they wished (mismatches).

The groups of patients formed were compared for quality of life, by means of the independent-samples *t*-test. As the groups had to consist of a sufficient number of patients, comparisons were only made for some information topics (chances of cure, life expectancy, palliative care and ELDs) and medical decisions (medical decisions in general and treatment decisions), and were limited to the group of patients whose preferences were met and the group of patients who had less information or participation than they wished. If a match or mismatch between preference and perceived level of information or participation was associated with a patient's quality of life at the 0.05 level, logistic regressions were conducted with preference match as a dependent variable and quality of life as an independent variable. Independent variables besides quality of life were variables listed in table 1.

The data were analysed with the statistical software package SPSS 17.0.

3.3 Results

Over 1 year, the participating physicians screened 291 patients with advanced lung cancer, of whom 196 conformed to the inclusion criteria. Of these patients, 152 were included and 44 were not because they refused participation (36) or were not asked to participate (8). At the time of the interview, 24 patients could not participate because they had died, were too ill or could not be contacted, leaving 128 patients who were analysed (68% participation rate). The patients included had a higher performance status (P=0.006, Mann-Whitney *U* test) and mean estimated life expectancy (10.3 versus 8.3 months since diagnosis, P=0.014, independent-samples *t*-test) than patients who were not included but conformed to the inclusion criteria; the patients interviewed had a higher performance status than patients who were included but not interviewed (P=0.011, Mann-Whitney *U* test).

3.3.1 Sample characteristics

The mean age of the patients was 64.4 years (SD=9.7); most patients were male (79.7%), receiving chemotherapy (82.0%) and had a median estimated life expectancy of 10 months (range 2-24 months). All patients reported that a treatment decision had been made in the 2 months prior to the interview; the most important decision was starting chemotherapy for 65.6% of patients. Of the patients, 47,7% were transferred from home to the hospital or vice versa, and 14.0% had made an ELD in advance. See Table 1.

3.3.2 Meeting patient preferences for disease-related information

Practically all patients wanted information when asked in general (97.7%) and about diagnosis (99.2%), treatment options (97.6%), chances of cure (96.9%) and life expectancy (88.2%), and of these patients respectively 95.2%, 96.9%, 90.2%, 75.6% and 52.7% reported that they received this information. With regard to palliative care and ELDs, more than half (63.5% and 56.8%) of the patients preferred information and 25.0% and 31.0% of these patients reported that they were given information. On the other hand, the considerable minority of patients who didn’t want to be informed about these topics said they were hardly ever informed (95.7% and 98.1% of patients). See Table 2.

Of the patients, 83.6% reported that neither the treating specialist nor any other physician (e.g. GP) had asked them how much information they wanted. Satisfaction with information received ranged from 88.4% (treatment options) to 95.8% (chances of cure).

Table 1: Characteristics of the advanced lung cancer patients studied

		Participants (N=128)	
Characteristics reported by the physician		N	%
Age	<=54y	21	16.4
	55-64y	40	31.2
	65-74y	45	35.2
	>=75y	22	17.2
Sex	Male	102	79.7
	Female	26	20.3
Education	Primary school	24	18.8
	Lower secondary	42	32.8
	Higher secondary	40	31.2
	University	22	17.2
Treating hospital	University	59	46.1
	General	69	53.9
Treatment goal	Cure	9	7.0
	Life prolongation	91	71.1
	Palliation	27	21.1
	Other (no treatment)	1	0.8
Performance status[a]	0	31	24.2
	1	81	63.3
	2	11	8.6
	3	3	2.3
	4	2	1.6
Estimated life expectancy on inclusion[b]	0-6 months	28	22.4
	7-12 months	75	60.0
	>12 months	22	17.6
Most important recent medical decisions made according to the patient[c]		Participants (N=128) N	 %
Treatment decision	Starting chemotherapy	84	65.6
	Starting radiotherapy	11	8.6
	Starting experimental therapy	6	4.7
	Other	27	21.1
Transfer decision	From hospital to home	43	33.6
	From home to hospital	18	14.1
Advance end-of-life decision[d]	Do not resuscitate	1	0.8
	Non-treatment	0	0.0
	Euthanasia	13	10.0
	Other	0	0.0

[a] Performance status according to ECOG: Eastern Cooperative Oncology Group, ranging from 0=fully active to 4=completely disabled.

[b] Missing values for ‘estimated life expectancy on inclusion’ n=3.

[c] Recent medical decision: made within 2 months prior to the interview.

[d] 18 patients made end-of-life decisions in advance but four did not mark the most important one.

Table 2: Preferences for information of the advanced lung cancer patients studied and the degree to which the preferences were met (N^a=128)

Information preference: I want information (yes or no):			N (%) of patients whose information preference was met
In general	Yes	N = 125	119 (95.2)
	No	N = 3	0 (0.0)
About my diagnosis (= the exact name and main characteristics of the disease)	Yes	N = 127	123 (96.9)
	No	N = 1	0 (0.0)
About the different treatments, their side-effects and the result (goal) of every treatment	Yes	N = 122	110 (90.2)
	No	N = 3	1 (33.3)
About the chances of cure of the disease	Yes	N = 123	93 (75.6)
	No	N = 4	2 (50.0)
About my life expectancy with the disease	Yes	N = 112	59 (52.7)
	No	N = 15	15 (100.0)
About options for palliative care (= only comfort care for patients who cannot be cured)	Yes	N = 80	20 (25.0)
	No	N = 46	44 (95.7)
About possibilities at the end of life (= resuscitation, options to accelerate the end of life or options to discontinue or forgo life-prolonging treatments)	Yes	N = 71	22 (31.0)
	No	N = 54	53 (98.1)

[a] Missing values for chances of cure and for life expectancy n=1, for palliative care n=2, and for treatment options and end-of-life possibilities n=3.

3.3.3 Meeting patient preferences for participation in medical decision-making

A considerable number of patients preferred doctor control over decision-making without input from the patient for medical decisions in general (27.6%) and decisions about treatment (46.9%) and transfer (39.1%). In all these decisions, 90% of patients reported that they achieved this preference (range 85.7-92.1%). Patients who wanted some input in doctors' decision-making or wanted shared decision-making reported that they achieved this in 43.7% (medical decisions in general), 46.9% (treatment) and 23.5% (transfer) of cases. Of the small number of patients who wanted personal control over decision-making, 58.0% reported that this preference was met in medical decisions in general, 79.0% in treatment and 71.0% in transfer decisions.

Overall, most patients reported that they participated as preferred in medical decisions in general (56.7%) and in treatment (69.5%) and transfer decisions (71.0%); those patients who didn't participate as preferred most often participated less than preferred rather than more than preferred: 33.1% of patients participated less than preferred in medical decisions in general, 21.9% in treatment decisions and 19.4% in transfer decisions.

Almost all patients who made an agreement with the physician on one or more ELDs to be implemented in the future (advance care planning) wanted to make these decisions themselves and effectively did so (patient control), resulting in a 94.1% match. See Table 3.

3.3.4 Meeting patients' information and participation preferences and quality of life

Patients with advanced lung cancer who, at the beginning of their disease trajectory, wanted information about chances of cure and reported that they were informed about this topic had a significantly higher quality of life than patients who wanted information and were not informed (P=0.004). We could make no inferences about patients who did not want information about chances of cure because they were too limited in number (n=4, 3% of all patients). The correlation observed persisted when controlling for the effects of socio-demographic and clinical patient characteristics in a logistic regression (P=0.01).

Patients reporting that their information preferences regarding life expectancy, palliative care and ELDs were met, were not significantly more likely to have a higher quality of life than those patients who reported that their preferences were not met. Similarly, patients reporting that their participation preferences were met, were not more likely to have a higher quality of life. See Table 4.

Table 3: Participation preferences of advanced lung cancer patients and the degree to which the preferences were met

Participation preference: I want the medical decision to be taken by[a]:			N (%) of patients whose participation preference were met	N (%) of patients who participated less than preferred
Medical decisions in general	The doctor, on the basis of his knowledge	N = 35	30 (85.7)	-
	The doctor, strongly considering my opinion	N = 27	14 (51.9)	9 (33.3)
	The doctor and myself together on a equal basis	N = 53	21 (39.6)	28 (52.8)
	Myself, strongly considering doctors’ opinion or on the basis of information I have or receive	N = 12	7 (58.0)	5 (42.0)
Treatment decisions	The doctor, on the basis of his knowledge	N = 60	53 (88.3)	-
	The doctor, strongly considering my opinion	N = 21	7 (33.3)	12 (57.1)
	The doctor and myself together on a equal basis	N = 28	16 (57.1)	10 (35.7)
	Myself, strongly considering doctors’ opinion or on the basis of information I have or receive	N = 19	15 (79.0)	4 (21.0)
Transfer decisions	The doctor, on the basis of his knowledge	N = 38	35 (92.1)	-
	The doctor, strongly considering my opinion	N = 5	1 (20.0)	3 (60.0)
	The doctor and myself together on a equal basis	N = 12	3 (25.0)	8 (66.7)
	Myself, strongly considering doctors opinion or on the basis of information I have or receive	N = 7	5 (71.0)	1 (14.0)
End-of-life decisions	The doctor, on the basis of his knowledge	N = 0	0 (0.0)	-
	The doctor, strongly considering my opinion	N = 0	0 (0.0)	0 (0.0)
	The doctor and myself together on a equal basis	N = 2	1 (50.0)	0 (0.0)
	Myself, strongly considering doctors’ opinion or on the basis of information I have or receive	N = 15	15 (100.0)	0 (0.0)

[a] Based on the control preference scale, the number of patients preferring personal control with and without doctor input are combined.

Table 4: Mean quality of life of patients with advanced lung cancer whose information and participation preferences were met and not met

Preference	Group 1: Preference met Mean quality of life[b] (N)	Group 2: Preference not met[a]. Mean quality of life[b] (N)	*P*-value
Information preference about:			
Chances of cure	58.1 (N= 95)	44.4 (N= 30)	0.004*
Life expectancy	54.3 (N= 74)	55.0 (N= 53)	0.856
Palliative care	53.1 (N= 64)	56.9 (N= 60)	0.351
End-of-life decisions	55.1 (N= 75)	55.4 (N= 49)	0.936
Participation preference in:			
Medical decisions in general	56.0 (N=72)	51.6 (N=42)	0.329
Treatment decisions	56.4 (N=89)	49.4 (N=28)	0.162

* $P<0.05$ for test of association with meeting patients' preferences: independent-samples *t*-test.

[a] Preference not met: for information = wanted information but not informed; for participation = participated less than preferred.

[b] Quality of life is measured by item 15 of the EORTC QLQ-C15-PAL, scores range from 0=very poor to 100= excellent.

We also examined whether the patients' perception that information and participation preferences were met, was related to the patients' age, sex, educational level, the presence of a partner, performance status and estimated life expectancy: patients who were younger were less likely to have their information preferences (preferences for wanting or not wanting information) met with regard to palliative care and ELDs than patients who were older ($P<0.01$).

3.4 Discussion

The main findings of this study were: 1) although a majority of newly diagnosed patients with advanced lung cancer wanted information about life expectancy on the one hand and palliative care and end-of-life options on the other, only one half and one quarter, respectively, of these patients reported that they were informed; 2) patients who preferred doctor control without patient input or personal control over treatment, transfer and advance end-of-life decision-making frequently achieved this preference in their perception, but patients who preferred an in-between position of some input or shared control with the physician did not; these patients were most often less involved than they wished to be; 3) no association was found between meeting patients' information and participation preferences (in the perception of the patient) and quality of life, except with respect to the preference for information about chances of cure.

A strength of the study is that we succeeded in including a large number of patients with advanced lung cancer in this study. This population of patients with advanced lung cancer has not yet been studied with regard to degree of preference match. We also attempted to cover most relevant information topics and decisions that were actually made. The study has also some limitations. Firstly, patient preferences were assessed after the consultations and may have been influenced by information received and decisions taken then, giving physicians no time to assess and meet the new preferences. Secondly, there may have been selection effects at the level of the participating doctors. The latter's interest in the research themes and sensitization by the questionnaire may have influenced their clinical behavior and caused a Hawthorne effect. Thirdly, patients with a higher-than-average estimated life expectancy and performance status were over-represented in the study sample. The possibility that some physicians may have been less strict with the instruction to screen every consecutive patient, may have added to selection biases.

The results show that physicians are less prone to giving information relating to death or short life expectancy than information that is more oriented towards 'dealing with the disease' or 'treatment options'. With regard to palliative care and ELDs, only a quarter of patients who wanted information said that they were informed. Patients themselves are divided as to the degree of information they want about issues of limited life expectancy and palliative and end-of-life care. Maybe this is why physicians take a prudent stance in providing information. However, physicians only inquired how much information the patient wanted in 16% of cases. It has been proposed that this be done systematically in Belgium, but this recommendation has not yet been integrated into treatment guidelines (23). Of interest in this context is a recent study of oncologists reporting that they communicate terminal prognoses only when specific preferences for prognosis information are expressed (24).

With regard to participation in treatment and transfer decision-making, about 70% achieved their preferred participation. Compared with other studies in patients with cancer, this degree of match is one of the highest observed (12;25-28). However, only those patients with a preference for doctor control without patient input or personal control over decision-making often reported that the decisions were made in this way, while patients who preferred the middle position of some involvement and shared decision-making with the physician often reported that the decisions were not made in this way. It may be that patients who prefer a middle position in medical decision-making are more critical or more open to nuances, and for this reason more often report that their preferences are not met. However, the 'nuances' were mostly in one direction: most patients reported having less participation than they wanted, rather than more. A more likely explanation is that the physicians were less able to adapt well to patients who preferred some involvement in decision-making. It seems that physicians are inclined to take an active role unless the patient clearly states otherwise at which time they surrender control, but that they are hesitant to interact with the patient and make decisions together. Reasons for this hesitance may be the complex and devastating nature of lung cancer or the fact that clear patient choices in this disease, contrary to other cancers, are not well documented in literature. More research is needed on how and on which important topics (e.g. the intent of treatment: palliation versus life prolongation) lung specialists might offer choice and the option for discussion with those patients who prefer to do so.

About 10% of patients had already made arrangements with the physician for life-shortening ELDs (here mostly euthanasia) by advance directives or advanced care planning. These patients preferred to make these decisions themselves and reported that they actually did so. This finding seems to confirm that physicians are open to active input from patients. This is probably due to the nature of the decision, in most cases euthanasia, and was thus not only medical, but also existential. It also corresponds to the Belgian law on euthanasia, which can only be requested by the patient.

This study revealed no clear indication of an association between meeting patients' preferences (according to the patient) and their quality of life, except for the preference for information about chances of cure. Patients who wanted information about chances of cure and reported that they were informed had a significantly higher quality of life than patients who were not informed. However, more research is needed because no inferences can be made about the causality of this association, especially since physicians might be more inclined to give information to patients who have a better quality of life. It also has to be discerned whether the positive effects on quality of life are caused by the fact that patients no longer have to live in uncertainty or are given falsely positive information evidently leading to a higher – short term – quality of life.

In conclusion, the preferences of patients newly diagnosed with advanced lung cancer were met fairly well, according to the patients. Physicians frequently did not meet the preference of a number of patients regarding being informed about issues related to the lifespan-limiting aspects of lung cancer, and in collaborating with the physician in the decision-making. It is advisable that physicians regularly and actively assess specific information and participation preferences to ensure that all patients' preferences are known.

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Chapter 4:
Changing preferences for information and participation in the last phase of life: a longitudinal study among newly diagnosed advanced lung cancer patients

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Bossuyt N, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Changing preferences for information and participation in the last phase of life: a longitudinal study among newly diagnosed advanced lung cancer patients. Submitted.

Abstract

Introduction:
Objective is to explore changes over time in the information and participation preferences of newly diagnosed stage IIIb/IV non-small-cell lung cancer patients.

Methods:
Patients were recruited by physicians in 13 hospitals and interviewed every two months until the fourth and every four months until the sixth interview.

Results:
128 patients were interviewed once, 13 six times. The overall rates of wanting information or participation did not change much over time, but many individual patients changed their minds. Looking at the first three interviews over a period of four months (N=67), we observed that: 1) the preferences for information about diagnosis, prognosis and treatment were stable: practically all patients wanted this information shortly after diagnosis and kept on wanting it; 2) the preferences for information about palliative care and end-of-life decisions with a possible or certain life-shortening effect (ELDs) were unstable: of the patients who didn't want this information, a quarter changed towards wanting it, and of those who wanted this information, 39% (palliative care) and a quarter (ELDs) changed towards not wanting it; 3) the preferences for participation in medical decision making were also unstable: from 50% to 78% of patients, depending on the type of decision (in general, treatment, transfer, end-of-life), changed their preference towards wanting more or less participation. Changing preferences were associated with patients' quality of life: patients in a worse physical condition were more likely to persist in wanting information about palliative care and ELDs, and those with more pain were more likely to want more involvement in medical decisions in general and in transfer decisions as time passed.

Conclusions:
Doctors should ask their advanced lung cancer patients at the beginning of their illness how much information and participation they want, and should keep on asking them because preferences do change over time in ways they might not expect.

4.1 Introduction

There is a broad consensus that in physician-patient communication, for both ethical and clinical reasons, providing information to patients about their disease and treatment options and involving them in medical decision-making are important tasks (1-4). However, especially in a serious illness with limited life expectancy such as advanced cancer, some patients may be reluctant to be fully informed or involved (5;6). Therefore, various authors have suggested that physicians have to be flexible and adjust their communication and decision-making behavior to the specific preferences of the individual patient (7;8).

There are several studies on the preferences of (advanced) cancer patients for information and for participation in medical decision-making (9-12). However, these are mostly cross-sectional and little is known about whether and in what direction the preferences of cancer patients change over time throughout the illness trajectory nor about the mechanisms of such changes. Insight into change of preferences over time could help physicians to adjust their communication, optimise the patient-physician relationship and possibly promote patient well-being.

One study compared the information and participation preferences of cancer patients before and after a consultation with the physician and before a second consultation (13). It was found that general preferences were stable in the short term, while in the long term they were not. Situational factors were important: patients who attended for a routine follow up were more likely to move towards preferring more involvement in decision-making than were those whose condition had worsened.

The aim of this study was to examine changes over time in information and participation preferences in advanced lung cancer patients. Lung cancer patients were studied because of the high incidence of this disease and the lack of studies on information and participation preferences in this population (14;15). The preferences of the advanced lung cancer patients shortly after diagnosis have been described elsewhere (16). We observed that almost all advanced lung cancer patients wanted to be informed about their diagnosis, treatment options and chances of cure, slightly fewer about life expectancy (88%) and a small majority about palliative care and end-of-life decisions with a possible or certain life-shortening effect (ELDs). The participation preferences differed depending on the type of decision: the number of patients wanting personal control over decision-making was the lowest for treatment decisions, somewhat higher for decisions about transfer to health-care settings and the highest for ELDs, all of which were higher than for medical decisions in general.

The research questions of this study were:
1: Do preferences of advanced lung cancer patients concerning information and participation in medical decision-making change over time?
2: What are the characteristics of patients with stable versus evolving preferences?

4.2 Materials and methods

We studied non-small-cell lung cancer (NSCLC) patients who had recently been diagnosed with stages IIIb or IV and attended one of 13 hospitals in Flanders, Belgium (3 university and 10 general hospitals). The participating 21 pulmonologists and two oncologists were instructed to recruit every consecutive patient with an initial diagnosis of NSCLC IIIb or IV over one year. Other inclusion criteria were being at least 18 years old, Dutch-speaking and physically and psychologically able to participate in the study. Patients had to give written informed consent and were contacted within two weeks of inclusion by trained interviewers (psychologists, nurses, interns) for an interview with a standard questionnaire. After each interview the patient was asked for his or her agreement to take part in another interview, up to a maximum of six. The time between interviews was two months up to the fourth interview and four months up to the sixth; the reason for increasing the interval was not to overburden those patients who had already taken part in four interviews over a short period of time.

The recruitment period lasted from February 2007 to February 2008 (12 months), and the last interview took place in May 2009.

4.2.1 Measures

Socio-demographic and clinical patient characteristics were recorded by the physician at inclusion, including age, sex, educational level, whether the patient lived with a partner, place of residence, religion, type of treatment, intention of treatment, estimated life expectancy, whether the patient had a GP, frequency of contact with their GP, co-morbidity (Charlson (17;18)) and performance status (ECOG (19)) .

The patient interview consisted of a structured questionnaire including several question lists and scales. Information preferences were assessed via seven items, first information preference in general and further with regard to six specific medical information topics: diagnosis, chances of cure, life expectancy, treatment options, palliative care and end-of-life decisions with a possible or certain life-shortening effect (ELDs). The preferences were presented in the form of statements which patients had to rate on a 6-point rating scale (from totally disagree to totally agree). The general information preference statement was: 'In general, I want to be fully informed'. Palliative care was defined as 'comfort care only, for patients who cannot be cured' and ELDs were defined as 'non-resuscitation orders, options to accelerate the end of life, and options to forgo or withdraw life-prolonging treatments'. The achieved information level was also assessed by asking the patients whether they had been informed in general and about the specific topics (yes or no). The question lists were based on existing questionnaires for cancer patients with confirmed validity, reliability, responsiveness and burden, and on data from qualitative research into incurable and terminally ill patients (20;21).

Participation preferences were measured using an adaptation of the control preference scale, which is frequently used in cancer studies (12;22). Patients were asked the question 'Who do you want to take such decisions?' and had to choose one of five possible responses: 1) the doctor on the basis of his/her knowledge, 2) the doctor, but strongly taking my opinion into account, 3) myself and the doctor together on an equal basis, 4) myself, but strongly taking the doctor's opinion into account and 5) myself, on the basis of the information I have or receive. The first two statements denote a preference for primary doctor control over decision-making: doctor control without (1) and with patient input (2). The third statement (3) represents a preference for shared control with the physician and the last two statements represent a preference for primary patient control: patient control with (4) and without (5) doctor input. Patients were given the adapted control preference scale in relation to four situations: 1) medical decisions in general, 2) treatment decisions, 3) transfer decisions and 4) ELDs. We asked patients to wherever possible consider decision situations that had actually taken place in the two or four months before the interview. For this purpose we recorded actual past decisions using a self-developed list of possible decisions, based on the input of physicians and on literature (14;23).

To measure quality of life, the Dutch version of the EORTC QLQ-C15-PAL was used, an abbreviated 15-item version of the widely used EORTC QLQ-C30 (version3.0), developed for palliative care (24;25).

The patient interview was pilot-tested with three advanced lung cancer patients of whom two were interviewed once and one three times. The items were well understood and accepted. All interviews were audio taped for quality control and feedback to the interviewers, and for further analysis of the patient's reaction to the interview.

4.2.2 Ethics

Patients received a written explanation of the study and its goals and their informed and written consent was required for inclusion. The anonymity of the patient was guaranteed.

The protocol of the study was approved by the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel and of all participating university hospitals and general hospitals. The interview was preceded by the statement that the same questions were used for every patient regardless of the seriousness of the disease.

4.2.3 Statistical analysis

Firstly, we explored changes in the average score (population level) on the information and participation preference-items over the interview moments. We used the explorative LOWESS regression technique with the ratings on the preference items as dependent variable, and time (in days since inclusion) as independent variable (26). The LOWESS technique was chosen because it allows use of all data collected, despite the variable number of interviews per patient (ranging from 1 to 6 interviews).

Secondly, even if there are no changes in the average ratings over time (i.e. no temporal change at the population level), individual patients might still change towards wanting more or less information and participation over time (temporal change at the individual level). To examine these changes we selected the patients who had been interviewed three times and gave the percentages of patients who changed their preference at the second and/or third interview, compared with the first. For this purpose, the information preference items were dichotomized into wanting versus not wanting information and the participation preference items were categorized into wanting doctor, shared or patient control.

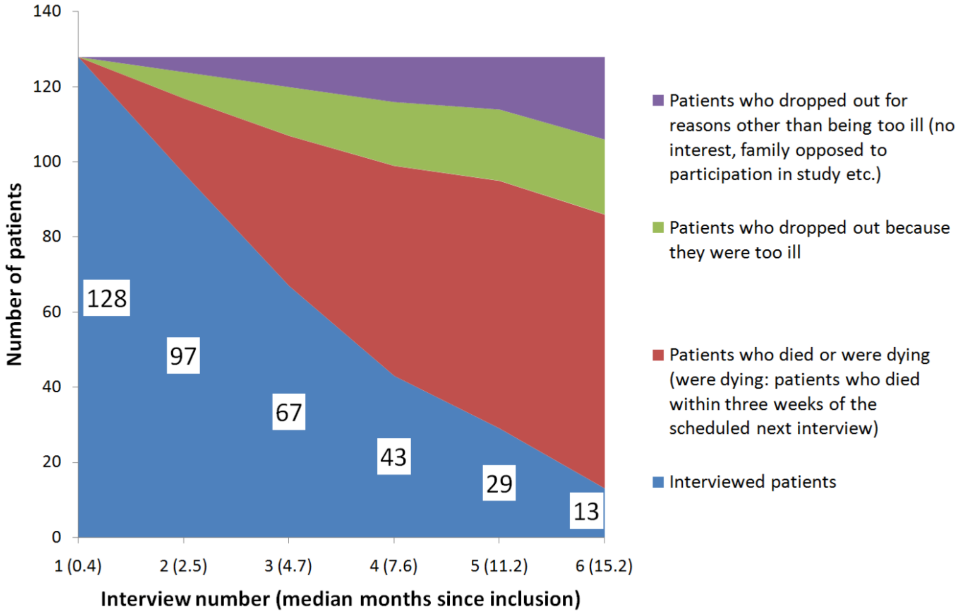
The predictors of change and no change in preferences were explored by testing patient characteristics for significant association with change/no change (from wanting to not wanting information and vice versa, and between wanting doctor, shared or patient control over decision-making), using the Mann-Whitney *U* test and the Fisher's exact test. The tested patient characteristics were limited to: most socio-demographic and clinical patient characteristics measured at inclusion (age, sex, educational level, having a partner, religion, treatment aim, comorbidity, performance status) and the average scores on the multiple-item EORTC QLQ-C15-PAL quality-of-life scales measured at each of the three interviews (physical and emotional functioning, fatigue and pain).
Data were analysed with the statistical software packages SPSS 17.0 and STATA 10.

4.3 Results

One hundred and ninety-six patients were reported to meet the inclusion criteria, of which 36 refused, eight were wrongly excluded, and 152 were included. Of the included patients, 19 could not be enrolled because they were too ill or had died before the first interview, three could not be contacted, and two interviews had too many missing values. In total, 128 patients were interviewed at least once (68% participation rate). Sixty seven of the 128 patients were interviewed three times.

Figure 1 shows the number of participants and those lost to follow-up over the course of the study. The median duration of follow-up was 15 months, counting from the first interview (14.8 months) as well as from inclusion (15.2 months).

Figure 1: Participation of NSCLC IIIb or IV patients in study (N=128)



4.3.1 Patient characteristics (Table 1)

The mean age of the 128 participants was 64 years (range 41-86), 80% were male and 77% had a partner. For 19% the highest level of education reached was primary school, for 64% secondary school and for 17% higher education. At inclusion, 71% were being treated with life-prolonging intent, 21% with palliative intent and 7% with curative intent. Eighty-two per cent were receiving chemotherapy, sometimes in combination with radiotherapy, and a minority of patients received radiotherapy alone (5.5%). Eighty-seven percent had a good performance status at inclusion (fully active or active) and half were suffering from comorbidity according to the Charlson Index. There were no significant differences between the inclusion sample and the 67 patients who completed three interviews.

4.3.2 Changes in information and participation preferences of the ‘average advanced lung cancer patient’ over six interviews

At the population level, advanced lung cancer patients’ preferences for information in general (without specifying the topic), and for information about diagnosis, prognosis and treatment options were high shortly after inclusion and remained so over time, until 15 months after inclusion. The preferences for information about palliative care and end-of-life decisions with a possible or certain life-shortening effect (ELDs) were lower, but also did not change over time (Figure 2).

The preferences for participation in medical decision-making hardly changed over time until approximately one year after inclusion, at which time preferences for participation in all medical decisions (general, treatment, transfer and end-of life decisions) began to increase gradually (Figure 3).

Figure 2: Information preferences of the studied patients over time (Lowess curve)

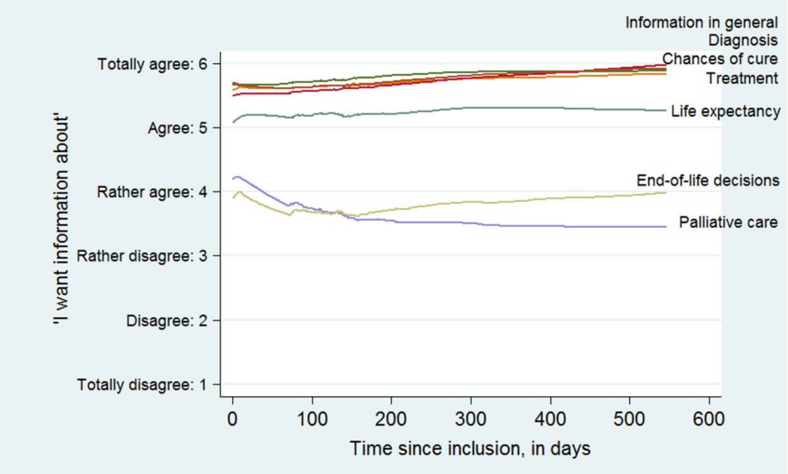
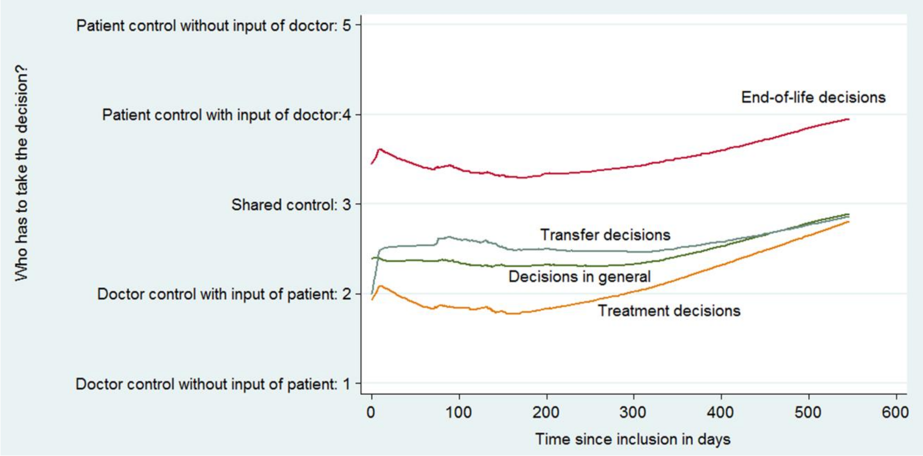


Figure 3: Participation preferences of the studied patients over time (Lowess curve)



4.3.3 Changes in preferences of individual patients over three interviews (N=67)

1) Information preferences

Practically all patients wanted information in general (98%), about diagnosis (100%), treatment options (100%), chances of cure (98%) and life expectancy (92%) at t1, shortly after diagnosis of NSCLC IIIb or IV. Almost all still wanted this information at t2 and t3, two and four months later, 97% with regard to information in general, 100% with regard to diagnosis, 92% with regard to treatment options, 97% with regard to chances of cure and 90% with regard to life expectancy.

As for the topics of palliative care and ELDs, respectively 64% and 52% wanted this information at t1, and 36% and 48% did not. Of the patients who did not want this information at t1, one quarter changed their minds towards wanting it at t2 or t3 (26% and 23%) and a very few fluctuated (not wanting – wanting – not wanting information, 0% and 6%). Of the patients who wanted this information at t1, 39% and 26% respectively changed towards not wanting it and some patients fluctuated (15% and 18%).

Table 1: Characteristics at inclusion of the advanced lung cancer patients studied

		All patients N=128	Patients with 3 consecutive interviews N=67
		Mean (SD)	**Mean (SD)**
Age		64.4 (9.7)	64.2 (9.8)
		N (%)	**N (%)**
Sex	Male	102 (79.7)	53 (79.1)
	Female	26 (20.3)	14 (20.9)
Partner	Yes	98 (76.6)	53 (79.1)
	No	30 (23.4)	14 (20.9)
Living situation	Home alone	31 (24.2)	17 (25.4)
	Home with others	97 (75.8)	50 (74.6)
Education	Primary school	24 (18.8)	12 (17.9)
	Lower secondary	42 (32.8)	17 (25.4)
	Higher secondary	40 (31.2)	25 (37.3)
	Higher education	22 (17.2)	13 (19.4)
Religion	Religious	93 (72.7)	49 (71.0)
	Not religious	35 (27.3)	18 (26.1)
Treating hospital	University	59 (46.1)	29 (43.3)
	General	69 (53.9)	38 (56.7)
Treatment aim	Cure	9 (7.0)	7 (10.4)
	Life prolongation	91 (71.1)	47 (70.1)
	Palliation	27 (21.1)	13 (19.4)
	Other (no treatment)	1 (0.8)	0 (0.0)
Type of treatment	Chemotherapy	105 (82.0)	53 (79.1)
	Radiotherapy	41 (32.0)	23 (34.3)
Contact with GP[a]	Once a week or more	11 (8.6)	3 (4.5)
	Once every 2 weeks	17 (13.3)	6 (9.0)
	Once every month	59 (46.1)	33 (49.3)
	Less	41 (32.0)	25 (37.3)
Co-morbidity[b]	0	65 (50.8)	32 (47.8)
	1-2	53 (41.4)	29 (43.3)
	3-4	10 (7.8)	6 (9.0)
Performance status[c]	0	31 (24.2)	22 (32.8)
	1	81 (63.3)	42 (62.7)
	2	11 (8.6)	2 (3.0)
	3	3 (2.3)	0(0.0)
	4	2 (1.6)	1 (1.5)
		Mean (SD)	**Mean (SD)**
Life expectancy (in months)[d]		10.6 (4.5)	11.8 (4.6)

[a] Three patients (in N=128) and two patients (in N=67) reported that they did not have a GP. They were included in the category 'Less'.

[b] Comorbidity score of Charlson Index.

[c] Performance status according to ECOG: Eastern Cooperative Oncology Group, ranging from 0 = fully active to 4 = completely disabled.

[d] Estimated by treating physician.

2) Participation preferences (Table 2)

For general medical decisions and treatment and transfer decisions, most patients (51% to 62%), wanted doctor control at t1 rather than shared or personal control; for ELDs most preferred personal control (49%) rather than shared (39%) or doctor control (12%). All preferences, whether for doctor control, shared control or patient control, in all studied medical decisions, were unstable, with half or more patients changing their preference towards wanting more or less control at t2 or t3. There was one exception: most patients (75.6%) who wanted doctor control in treatment decisions at t1 had not changed this preference at t2 or t3. Overall, 50% of patients changed their participation preference in treatment decisions at t2 or t3 compared with t1; 59% did this for ELDs, 62% for medical decisions in general and 77% for transfer decisions.

3) Characteristics associated with changes in preferences (Table 3)

Compared with older patients and those with a partner, younger patients and those without a partner were more likely to change their preference for information about palliative care over time from not wanting to wanting information. Religion was also related to change in preferences: non-religious patients were more likely to state they no longer wanted information about palliative care, and to want more participation (i.e. to change from doctor to shared or patient control) in treatment decisions.

A clinical patient characteristic that played an important role in changing preferences was the physical condition of the patient: those with a worse physical condition were more likely to continue over time to want information about palliative care and ELDs, and those with more pain were inclined to want more participation over time in decision-making, at least for medical decisions in general and for transfer decisions. A less than good performance status at inclusion was also related to wanting more participation over time in medical decisions in general.

We checked whether those who changed from wanting to not wanting information about palliative care and ELDs did so because the information had been provided by the physician in the meantime. We found that of these patients only 12% (palliative care) and 11% (ELDs) reported having been informed during the interview period. For comparison, of those who consistently wanted information, 53% and 47% had received it, and of those who consistently did not want it, 13% and 4% had.

Table 2: Change in preferences of advanced lung cancer patients for participation in medical decisions in general, treatment, transfer and end-of-life decisions during the first four months after diagnosis of NSCLC IIIb or IV (N=67)

	N(%) of patients who changed and did not change their participation preference at t2 and t3, compared to t1			
	Medical decisions in general	Treatment decisions	Transfer decisions	End-of-life decisions
Of patients who wanted doctor control at t1	**N=34 (100)**	**N=41(100)**	**N=37 (100)**	**N=7 (100)**
No change at t2 and t3	17 (50.0)	31 (75.6)	11 (29.7)	2 (28.6)
Evolution towards wanting shared or patient control	14 (41.2)	8 (19.5)	20 (54.1)	4 (57.1)
Fluctuation: doctor control/ … /doctor control	3 (8.8)	2 (4.9)	6 (16.2)	1 (14.3)
Of patients who wanted shared control at t1	**N=25 (100)**	**N=15 (100)**	**N=16 (100)**	**N=23 (100)**
No change at t2 and t3	8 (32.0)	1 (6.7)	1 (6.3)	7 (30.4)
Evolution towards wanting patient or doctor control	12 (48.0)	8 (53.3)	11 (68.7)	9 (39.1)
- Patient control	3 (12.0)	0 (0.0)	4 (25.0)	5 (21.7)
- Doctor control	9 (36.0)	8 (53.3)	7 (43.7)	4 (17.4)
Fluctuation: shared control/… /shared control; shared/doctor/ patient and shared/patient/doctor	5 (20.0)	6 (40.0)	4 (25.0)	7 (30.4)
Of patients who wanted personal control at t1	**N=7 (100)**	**N=10 (100)**	**N=13 (100)**	**N=29 (100)**
No change at t2 and t3	0 (0.0)	1 (10.0)	3 (23.1)	15 (51.7)
Evolution towards wanting shared or doctor control	6 (85.7)	6 (60.0)	5 (38.5)	10 (34.5)
Fluctuation: patient control/…/patient control	1 (14.3)	3 (30.0)	5 (38.5)	4 (13.7)
Of all patients (Total)	**N=66 (100)**	**N=66 (100)**	**N=66 (100)**	**N=59 (100)**
No change at t2 and t3	25 (37.9)	33 (50.0)	15 (22.7)	24 (40.7)
Evolution	32 (48.5)	22 (33.3)	36 (54.5)	23 (39.0)
Fluctuation	9 (13.6)	11 (16.7)	15 (22.7)	12 (20.3)

Table 3. Characteristics of patients who changed and did not change their preferences for information about palliative care and ELDs and for participation in medical decision-making

Characteristic	Change in preferences over time (at t2 or t3)	Mean or % of patients		*P**
		Change	**No change**	
Age (in years)	Change to wanting information about palliative care	Mean: 60.3 *(n=6)*	Mean: 71.3 *(n=17)*	0.015
Having no partner (versus having a partner)	Change to wanting information about palliative care	50.0% *(n=6)*	5.9% *(n=17)*	0.040
Not religious (versus religious)	Change to not wanting information about palliative care	87.5% *(n=16)*	47.7% *(n=19)*	0.030
	Change to wanting more involvement in treatment decisions	62.5% *(n=8)*	19.4% *(n=31)*	0.028
Average physical functioning over t1, t2 and t3 (high score: healthy level)	Change to not wanting information about palliative care	Mean: 86.1 *(n=16)*	Mean: 70.6 *(n=19)*	0.003
	Change to not wanting information about ELDs	Mean: 86.8 *(n=9)*	Mean: 73.5 *(n=19)*	0.019
Average pain over t1, t2, t3 (low score: healthy level)	Change to not wanting information about palliative care	Mean: 21.9 *(n=16)*	Mean: 37.7 *(n=19)*	0.029
	Change to wanting more involvement in medical decisions in general	Mean: 31.7 *(n=14)*	Mean: 14.4 *(n=17)*	0.040
	Change to wanting more involvement in transfer decisions	Mean: 24.4 *(n=20)*	Mean: 7.1 *(n=11)*	0.021
Average fatigue over t1, t2, t3 (low score: healthy level)	Change to not wanting information about palliative care	Mean: 28.4 *(n=16)*	Mean: 49.4 *(n=19)*	0.007
Comorbidity at inclusion (versus no comorbidity)	Change to not wanting information about ELDs	22.2% *(n=9)*	68.4% *(n=19)*	0.025
Performance status at inclusion: active(vs less)	Change to wanting more involvement in medical decisions in general	14.3% *(n=14)*	58.8% *(n=17)*	0.024

* *P*-value of significance testing ($P<0.05$) using Man-Whitney U or Fisher's exact test. Patient characteristics that were tested for a significant association with change and no change in preferences were: 1) socio-demographic and clinical characteristics measured at inclusion (age, sex, educational level, having a partner, religion, treatment aim, performance status, comorbidity) and 2) quality of life variables measured at each interview averaged over the three interviews (EORTC QLQ-C15-PAL scales: physical functioning, emotional functioning, fatigue, pain).

4.4 Discussion

This is the first longitudinal study of information and participation preferences in a cohort of newly diagnosed advanced lung cancer patients. Information preferences could be measured with regard to diagnosis, chances of cure, life expectancy, palliative care and end-of-life decisions with a possible or certain life-shortening effect (ELDs). Participation preferences could be measured with regard to medical decisions in general, treatment decisions, transfer decisions and ELDs.

Although the patients as a group did not change much over time towards wanting more or less information or participation, individual patients did. The preferences for information about diagnosis, prognosis and treatment options were stable: almost all patients wanted this information shortly after diagnosis and continued to want it two and four months later. In contrast, the preferences for information about palliative care and ELDs were unstable: of the patients who did not want this information at the onset, one quarter changed towards wanting it after four months, and of those who did want it, 39% (palliative care) and one quarter (ELDs) changed towards not wanting it. Patients in a worse physical condition were more likely to continue to want information about these topics. The preferences for participation in medical decision-making were also unstable: 50% to 78%, depending on the type of decision (general, treatment, transfer or end-of-life), changed their preference towards wanting more or less participation over four months. Patients who had more pain were more likely to change towards wanting more participation than patients with less pain, at least in medical decisions in general and in transfer decisions.

Strengths of the study were the attempt to have a representative sample of patients by recruiting a cohort of consecutive patients during one year in 13 hospitals, the limited drop-out throughout the study period due to reasons other than death or being too ill (although the latter reason may have concealed loss of interest in the study), and the measurement of aspects of quality of life (physical and emotional functioning, pain and fatigue) along with the preferences of the patients as possible predictors of the preferences.

There were also limitations. Firstly, only the first three interviews were analysed in detail due to the low number of patients continuing beyond three interviews, leading to a limited number of patients studied and not allowing for inferences about changes in preference beyond the first four months of the disease. Secondly, we explored the association between change in preferences and several patient characteristics, enhancing the likelihood of finding associations that are not existent on a population level. Therefore the individual P-values cannot be taken for granted and what has to be considered is the overall pattern of the results.

An important finding of the study was that almost all advanced lung cancer patients wanted and kept on wanting information about diagnosis, treatment options, chances of cure and life expectancy. So, even in those patients who received information about these topics, the preference for information persisted, suggesting that physicians would do well to update their patients regularly. This is in conformity with other study findings showing that advanced cancer patients want information provision to be an ongoing process where the physician continually checks their understanding and goals, particularly as the situation may change during the course of the illness (27).

In contrast, the preferences for information about palliative care and ELDs were more variable and unstable. Of the substantial minority of patients who initially did not want this information, one quarter later did. Of the majority who originally did want it, about half changed their minds – sometimes temporarily – to not wanting it. Thus, it seems that even after a longer period of time (four months after diagnosis), there remain many patients who are not open to information about palliative and end-of-life care. This might compromise their preparedness when they eventually reach the terminal phase and thus might affect the quality of their end-of-life care.

Two comments have to be made. Firstly, it could be that patients change from wanting to not wanting information about palliative care and ELDs because they receive the information in the meantime. However, this explanation is inadequate: only a fraction (one tenth) did actually receive information between interviews. Rather, we observed that a patient’s physical condition played a role: patients who were more ill kept on wanting information about palliative care, while patients who were less ill did not. This suggests that patients who change towards not wanting information might want information again later on, when their condition worsens. This carries the risk that, for those who deteriorate rapidly, there will not be time to become sufficiently informed and prepared with regard to palliative and end-of-life care. The fact that so few physicians gave information regarding palliative care and ELDs during the first few months is possibly also important in this context as it could lead a patient to think that the issues are not relevant precisely because the physician has not raised them.

Secondly, those patients who never wanted information about palliative care were more likely to be older and to have a partner. It might be that some of them rely more on their family or partner, in which case the physician might want to consider addressing family members or partners about palliative care and end-of-life issues in order to ensure good quality care according to the patient’s preferences (28).

Half of patients changed their preference regarding participation in treatment decisions over the first four months of the disease, around 60% for medical decisions in general and for end-of-life decisions and 77% for transfer decisions. These relatively high percentages make it necessary for the physician to check a patient’s preferences every time a decision is to be made.

Of interest is that patients who - over the first four months of their disease - had more pain were more likely to change over time from doctor control towards shared or patient control, at least in medical decisions in general and in transfer decisions than patients with less pain. Pain seems to be a trigger for patients to want more involvement, which somewhat contrasts with studies suggesting that patients who are more ill tend to give up more control (13;29).

Another characteristic which influenced patient information and participation preferences was whether they were religious or not. We found that religious patients were more likely to continue wanting information about palliative care, in contrast with non-religious patients, who were more likely to evolve over time towards not wanting such information. Also, religious patients were more likely to continue wanting the doctor to take the treatment decisions, while non-religious patients evolved over time towards wanting more personal involvement in these decisions. It may be that religious people are more acceptant towards death and, for this reason, more open to palliative care options and inclined to become less active in treatment decision-making over time. It may also be that religious people are more hierarchical and for this reason are more likely to follow the physician's opinion than non-religious patients. However, these are speculative explanations needing more research.

4.5 Conclusion

To conclude, the preferences of advanced lung cancer patients for information about palliative care and ELDs and for participation in medical decision-making were relatively unstable over time. This means that in order to take preferences into account in daily clinical practice, their immediate preferences need to be considered. Hence, physicians should check these preferences regularly. Preferences were also associated with quality of life: patients in a worse physical condition were more likely to persist in wanting information about palliative care and ELDs, and those with more pain were more likely to want more involvement in medical decisions in general and in transfer decisions as time passed.

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Chapter 5:
Advanced lung cancer patients' preferences for the involvement of family and others in medical decision-making

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Bossuyt N, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Advanced lung cancer patients' preferences for the involvement of family and others in medical decision-making. J Palliat Med 2010 October; 13(10):1199-203.

Abstract

Objective:
To explore the preferences of competent patients with advanced lung cancer regarding involvement of family and/or others in their medical decision-making, and their future preferences in case of loss of competence.

Methods:
Over 1 year, physicians in 13 hospitals in Flanders, Belgium, recruited patients with initial non-small-cell lung cancer, stage IIIb or IV. The patients were interviewed with a structured questionnaire every 2 months until the fourth interview and every 4 months until the sixth interview.

Results:
At inclusion, 128 patients were interviewed at least once; 13 were interviewed 6 consecutive times. Sixty-nine percent of patients wanted family members to be involved in medical decision-making and this percentage did not change significantly over time. One third of these patients did not achieve this preference. Ninety-four percent of patients wanted family involvement if they lost competence, 23% of these preferring primary physician control over decision-making, 41% shared physician and family control and 36% primary family control. This degree of preferred family involvement expressed when competent did not change significantly over time at population level, but did at individual level; almost half the patients changed their minds either way at some point during the observation period.

Conclusions:
The majority of patients with lung cancer wanted family involvement in decision-making, and almost all did so in case of future loss of competence. However, as half of the patients changed their minds over time about the degree of family involvement they wanted if they lost competence, physicians should regularly rediscuss a patient’s preferences.

5.1 Introduction

Respect for patient autonomy requires physicians to take into account a patient's preferences regarding medical decision-making, including the preference to involve the family. Considering end-of-life decisions, for instance (e.g. resuscitation, balance of lucidity and analgesia, site of terminal care etc.), might be a serious burden on the patient and require support from trusted family members or close friends (1).

At the point where the patient is no longer able to make medical decisions, the physician is confronted with a more complex problem: if he wants to respect the patient's preferences about decisions that must be made, their preferences must be clear and the physician may rely on information received from the patient when competent, sometimes in the form of written advance directives, or on the family of the patient, who are assumed to know them well (2). However, not all medical situations that may arise can be dealt with in advance care planning, nor can it be taken for granted that the family knows the patient's preferences (3;4). Therefore it has been suggested that physicians should not only pay attention to the preferences of the patient in relation to specific medical situations that might arise, but also to *how* the patient wants medical decisions to be made if he should lose competence e.g. does the patient wish other people to be involved, who does he wish to be involved and to what degree (5;6)?

To examine the involvement of family and/or other people in medical decision-making from the perspective of the patient's preferences, we investigated advanced lung cancer patients during the course of their disease.

The research questions were:

1. Who do patients with advanced lung cancer want to involve in medical decision-making while they are competent and are these persons involved?

2. Who do patients with advanced lung cancer want to involve in medical decision-making when they are no longer able to make decisions themselves, and to what degree?

5.2 Methods

Consecutive patients with non-small-cell lung cancer (NSCLC), stage IIIb or IV, were recruited by pulmonologists and oncologists at 13 hospitals in Flanders, Belgium, over 1 year. The patients were interviewed by trained interviewers using a structured questionnaire every 2 months until the fourth interview and every 4 months until the sixth interview.

5.2.1 Measurements

Patients were asked whether they wanted others involved in their medical decision-making both while they were competent and if they lose competence in future, and were asked to select one or more of four possible answers: nurse, family/close friends, no one, other. Patients were also asked whether these people were actually involved. On the assumption of future loss of competence, patients were asked to indicate the extent to which they wanted others involved, choosing one of five possible options representing three categories: a preference for primary physician, shared physician-representative(s) and primary representative(s) control over decision-making. This item is an adaptation of the control preference scale that has been used in other studies (7;8). Quality of life was measured with the Dutch version of the EORTC QLQ-C15-PAL (9;10). The patient interview was pilot-tested and the items were well understood and accepted. Socio-demographic and clinical characteristics were collected upon inclusion in the study.

5.2.2 Ethics

The protocol of the study was approved by the Ethical Review Boards of all the participating hospitals.

5.2.3 Statistical analysis

The characteristics of the patients collected upon inclusion and the quality of life measured during the interviews were tested for association with the involvement preferences with the Fisher’s exact test or Mann-Whitney *U* and entered in multivariate models (random coefficient analysis), together with time (in days since inclusion) (11;12).

5.3 Results

Upon inclusion, 128 patients (68% participation rate) were interviewed for the first time and 13 were interviewed six consecutive times. Figure 1 shows the progression of mortality and loss to follow-up. The characteristics of the patients upon inclusion are reported in table 1.

Figure 1: Participation in study of patients with non-small-cell lung cancer, stage IIIb/IV

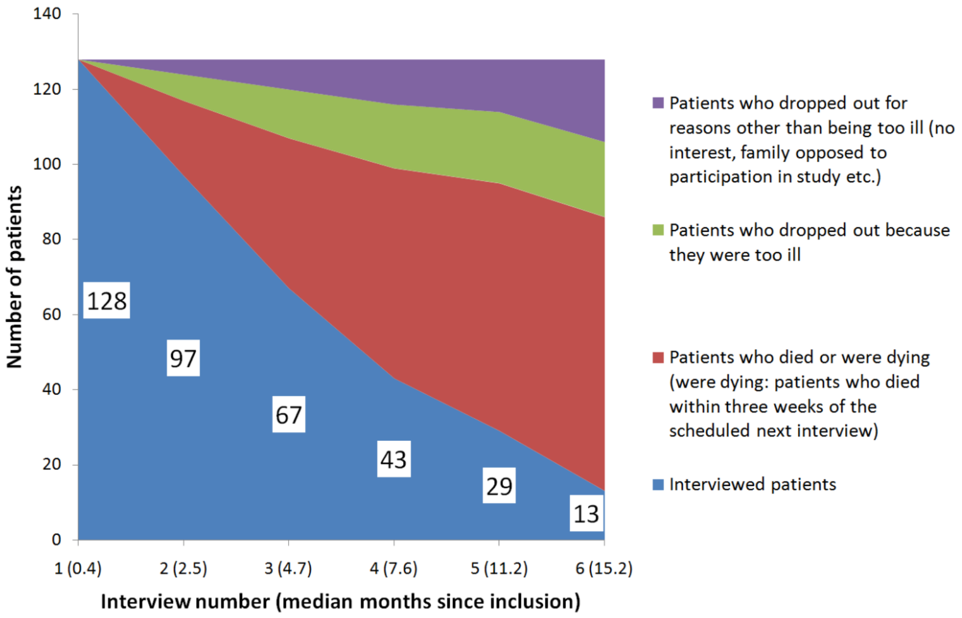


Table 1: Characteristics of the patients with advanced lung cancer studied at the time of inclusion (N=128)

		Mean (SD)
Age		64.4 (9.7)
		N (%)
Sex	Male	102 (79.7)
	Female	26 (20.3)
Partner	Yes	98 (76.6)
	No	30 (23.4)
Home circumstances	Living at home alone	31 (24.2)
	Living at home with others	97 (75.8)
Education	Primary school	24 (18.8)
	Lower secondary	42 (32.8)
	Higher secondary	40 (31.2)
	University	22 (17.2)
Religion	Religious	93 (72.7)
	Not religious	35 (27.3)
Treating hospital	University	59 (46.1)
	General	69 (53.9)
Type of treatment	Chemotherapy	105 (82.0)
	Radiotherapy	41 (32.0)
Contact with GP[a]	Once a week or more	11 (8.6)
	Once every 2 weeks	17 (13.3)
	Once every month	59 (46.1)
	Less	41 (32.0)
Comorbidity[b]	0	65 (50.8)
	1-2	53 (41.4)
	3-4	10 (7.8)
Performance status[c]	0	31 (24.2)
	1	81 (63.3)
	2	11 (8.6)
	3	3 (2.3)
	4	2 (1.6)
		Mean (SD)
Life expectancy on inclusion[d]		10.6 (4.5)

[a] Three patients reported that they did not have a GP. They were included in the category ‘Less’.

[b] Comorbidity score using Charlson Index.

[c] Performance status according to ECOG: Eastern Cooperative Oncology Group, ranging from 0 = fully active to 4 = completely disabled.

[d] Estimated by treating physician.

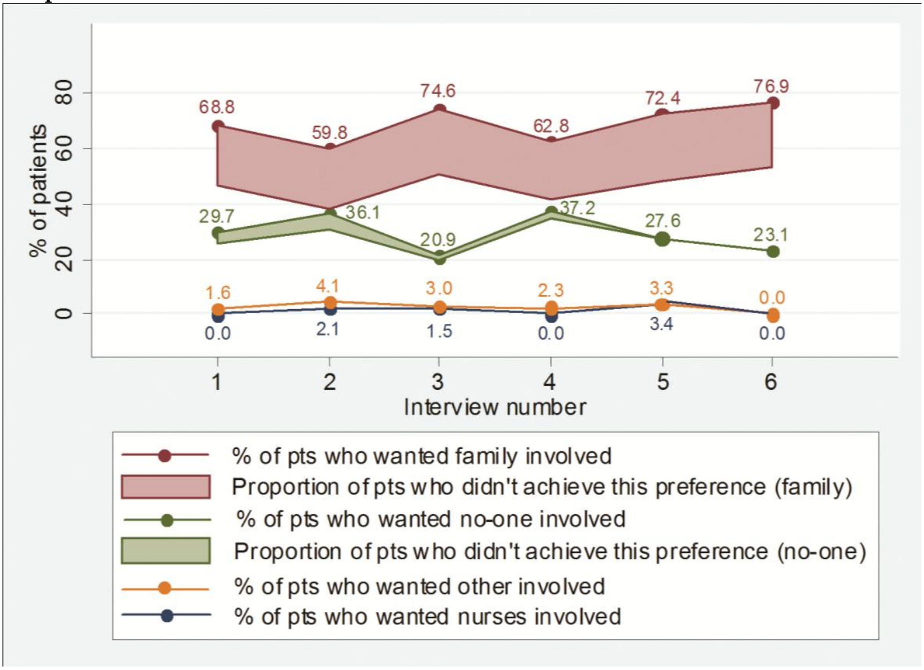
SD, standard deviation; GP, general practitioner

5.3.1 Involvement of others when the patient is competent

At the first interview, 68.8% of patients wanted family to be involved in medical decision-making, 0.0% nurses and 1.6% 'other'; 29.7% wanted no one involved (Figure 2). These percentages did not change significantly over time until 15 months after inclusion (results of random coefficient analyses), but there were changes at an individual level (not shown in figure 2). For example, 17.6% of patients changed their preference for family involvement from not wanting to wanting involvement or vice versa between the first and second interview. Predictors of wanting versus not wanting family involvement were: having a partner (OR: 4.8, *P*: 0.027, CI: 1.2-19.5) and having a lower level of physical functioning (OR: 0.98, *P*: 0.008, CI: 0.96-0.99).

Of the patients who wanted family involvement in decision-making at the first interview, a proportion of 68.2% reported that they had actually achieved this preference and of those who wanted no one involved, 86.8% had achieved it. The achievement rates were similar in subsequent interviews (Figure 2).

Figure 2: Percentage at interview 1 to 6 of patients with advanced lung cancer who wanted and achieved involvement of others in medical decision-making (while they were competent)



5.3.2 Involvement of others when the patient is incompetent

A total of 93.6% of patients wanted family to be involved in decision-making if they were to become incompetent, 0.8% wanted nurses involved and 6.4% wanted no one. Of the patients who wanted their family involved at the time of the first interview, 22.6% wanted primary physician control, 40.9% shared physician-family control and 36.5% wanted primary family control. At population level, the time since inclusion had no significant impact on this degree of preferred involvement (Table 2). There were, however, changes over time at an individual level: 49.4% changed their preferred role for family between the first and second interview and these percentages were similar between the next subsequent interviews (40.0%, 38.1%, 42.9% and 50.0%). Female patients, those whose emotional functioning was better or improved and those with pain were more likely to want shared physician-family control or primary family control rather than primary physician control over decision-making (Table 2).

Table 2: Predictors of advanced lung cancer patients wanting shared doctor-family control and primary family control, versus primary doctor control (in the event of incompetence)

Number of level 1 units = 329 *Number of level 2 units = 116* *Log likelihood = -326.49111*		**Odds ratio**[a]	**Std Error**	***P*-value**	**95% Conf interval**
Predictors of wanting shared doctor-family control (versus doctor control)					
Time since inclusion[b]		0.997	0.001	0.095	0.995-1.000
Sex of patient	Female	5.647	3.776	0.010	1.523-20.943
	Male (Ref)	-	-	-	-
Emotional functioning[c]		1.018	0.008	0.018	1.003-1.033
Pain[b]		1.020	0.007	0.005	1.006-1.034
Predictors of wanting family control (versus doctor control)					
Time since inclusion[b]		0.998	0.001	0.178	0.995-1.009
Sex of patient	Female	7.404	0.680	0.003	1.952-28.078
	Male (Ref)	-	-	-	-
Emotional functioning[c]		1.027	0.008	0.001	1.010-1.537
Pain[b]		1.020	0.007	0.006	1.006-1.412

[a] Odds ratio resulting from random coefficient analysis.

[b] Time: in days since inclusion (entered as continuous variable).

[c] Scales of the EORTC QLQ-C15-PAL with scores from 0 to 100 (entered as continuous variable).

5.4 Discussion

This study succeeded in including 128 patients with advanced lung cancer. Two thirds of the patients wanted family involvement in medical decision-making alongside their own involvement and that of the physician. This is similar to the finding in a study of 50 patients with a malignant disease in Germany (13). What is new in our study is that this proportion of patients did not change significantly over time after diagnosis.

Of the patients who wanted family involvement, one third reported that they had not achieved this. Reasons for not achieving concordance are not clear, and probably include families who are not able or willing to cooperate or patients who want to avoid burdening their families (14). A finding of particular interest is that patients with a partner were significantly more likely to want family involvement in decision-making. This suggests that patients without a partner might be at increased risk of having no one to make decisions for them, and thus perhaps need more intensive advance care planning up front.

Practically all patients wanted family involvement if they were to become incompetent and a large majority of these wanted the involvement to be substantial: 41% preferred shared family-physician control, 36% primary family control and only 23% primary physician control. This is comparable with the finding of a U.S. study in which patients with recent diagnoses of terminal illnesses had to weigh the physician's input against the input of family in decision-making (15). A possible explanation is that when advanced cancer patients lose competence, medical decisions are often end-of-life decisions, which are viewed as far more personal than, for example, treatment decisions.

Although the degree of preferred involvement of family in the event of incompetence did not change significantly over time at population level, it did at individual level: almost half of the patients changed their preference at some time between interviews (at intervals of 2 months), towards either more or less family involvement. This finding illustrates the importance of the physician's skills in family communication and implies that physicians should regularly rediscuss a patient's preferred degree of family involvement in the event of loss of competence, or that the physician should tell the patient that a change in preference is not uncommon and can always be communicated to them (16;17).

It is noteworthy that although many patients wanted their family involved in decision-making whether they were competent or not, very few wanted nurses involved. This might be in contrast to the findings of studies focusing on actual decision-making in terminal care, where nurses do play a major role (18).

Limitations of the study

There were several limitations. Firstly, caution is needed with generalising the data beyond the sample: 1) 32% of the eligible patients did not participate and 30% of the patients dropped out during the follow-up; 2) 80% of the patients in our sample were male; and 3) the patients studied were Flemish; culture might have a significant effect on the results. Secondly, the high loss to follow-up over time also makes it difficult to draw conclusions for the long term, i.e. 1 year or more. Thirdly, patients' preferences for involvement were examined with regard to medical decisions in general and using close-ended questions that did not allow for possible nuances in their answers.

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Chapter 6:
Preferred and actual involvement of advanced lung cancer patients and their family in end-of-life decision-making

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Preferred and actual involvement of advanced lung cancer patients and their family in end-of-life decision-making. A multicentre study in 13 hospitals in Flanders, Belgium. Submitted.

Abstract

Introduction:
Objective was to examine the involvement of advanced lung cancer patients and their families in end-of-life decision-making and to compare this involvement with their previously stated preferences for involvement.

Methods:
Patients with stage IIIb/IV non-small-cell lung cancer were recruited by physicians in 13 hospitals and regularly interviewed between diagnosis and death. When the patient died, the specialist and GP were asked to fill in a questionnaire.

Results:
Eighty-five patients who died within 18 months of diagnosis were studied. An end-of-life decision with a possible or certain life-shortening effect (ELD) was made in 52 cases (61%). According to the treating physician, half of the competent patients were not involved in the end-of-life decision-making, one quarter shared the decision with the physician and one quarter made the decision themselves. In the incompetent patients, family were involved in half of cases. Half of the competent patients were involved less than they had previously preferred and 7% more. Almost all the incompetent patients had previously stated they wanted their family involved in case of incompetence, but half did not achieve this. Factors associated with actual involvement of the patient or family included younger age, a palliative treatment goal and type of ELD (e.g. the more life-shortening ELDs).

Conclusion:
In half of cases, advanced lung cancer patients - or their families in cases of incompetence - were not involved in end-of-life decision-making, despite the wishes of most of them. Physicians should openly discuss ELDs and involvement preferences with their advanced lung cancer patients.

6.1 Introduction

Death is often preceded by medical decisions with a possible or certain life-shortening effect (ELDs), such as withholding or withdrawing of life-sustaining treatments, intensified alleviation of symptoms and administration of lethal drugs with the explicit intention of shortening a patient's life (euthanasia, physician-assisted suicide or ending life without the patient's explicit request) (1;2).

Respect for patient autonomy and thus the involvement of patients or, where they lack capacity, their families is an ethical imperative of decision-making at the end of life (3). This concern has led to models of shared decision-making where physician and patient or family reach a decision jointly, or to models of informed decision-making where the patient or family take the decision primarily among themselves (though in the case of euthanasia this must be the patient alone) (4-6). However, some ethicists and researchers have pointed out that seriously ill patients might not put a high value on autonomy in end-of-life decision-making and may prefer to delegate control to the physician because of the emotional burden of decision-making (7;8). Questions have also been raised with regard to the usefulness of shared decision-making at the end of life in situations where patient or family cannot be offered a real choice, e.g. because medically appropriate alternatives do not exist (9). Some argue that mere informed consent is needed in such situations (10).

Nationwide studies using physician reports on incidence of ELDs and involvement of patients and family in these decisions in several European countries show that ELDs were discussed with the patient in 38% to 92% of cases and with the family of incompetent patients in 39% to 85% (2;11). In Flanders, Belgium, discussion with competent patients took place in 67% of cases and discussion with family in cases of incompetence in 77%. A review of qualitative studies on end-of-life decision-making found a strong link between shared decision-making and a good death but also pointed out that there are a number of reasons why this is not being achieved in the secondary care setting (12).

This study aimed to add to the existing studies in several ways. Firstly, we wanted to ask the treating physicians not only whether ELDs were discussed with the patient, but to what degree the patient was involved and thus who made the decision: was it primarily the physician, the physician and patient together (shared decision-making) or primarily the patient (informed decision-making)? Secondly, to find out to what extent previously expressed preferences were realized in the actual involvement of patient and family, we wanted to compare actual involvement as reported by the physicians with the patient's previously stated preferences for involvement. Thirdly, we wanted to know what other patient characteristics as well as characteristics of the ELD were associated with actual involvement of the patient or their family.

We chose to examine the relatively homogeneous population of patients with advanced lung cancer, a condition which is usually terminal within one year (13;14).

The research questions of this study were:
1. How involved in end-of-life decision-making are advanced lung cancer patients who are competent? For patients who are incompetent, are other persons (family, nurses, physicians other than the treating physician) involved?
2. Does the involvement of the patient or others in end-of-life decision-making correspond with the patient's previously stated preferences for involvement?
3. What characteristics of the patient and the ELD are associated with their involvement when competent, or the involvement of others when incompetent?

6.2 Methods

6.2.1 Patients and procedure

Pulmonologists or oncologists from 13 hospitals in Flanders, Belgium, were instructed to invite every consecutive patient over a period of one year with a diagnosis of non-small-cell lung cancer (NSCLC), stage IIIb or IV, to participate in a longitudinal study. Additional inclusion criteria were: the patient should be at least 18 years old, Dutch-speaking and physically and psychologically able to be interviewed. Patients had to give informed consent and were subsequently interviewed with a structured questionnaire every 2 months until the fourth and every 4 months until the sixth interview by trained interviewers. When the patient died, the specialist and GP were asked to fill in an after-death questionnaire. In the case of the specialist already involved in the study as recruiter, this was done by mail or by phone. In the case of the GP, previously informed of the participation of the patient, a letter was sent with an invitation to fill in the questionnaire. If the GP failed to respond within one month, a reminder was sent.

6.2.2 Measurements

At inclusion, the pulmonologists/oncologists collected data on the patient's age, sex, educational level, whether living with a partner, intention of treatment, whether they had a GP and frequency of contact with their GP.

1) Patient interview
Patients were asked to what degree they wanted to be involved in making end-of-life decisions with a possible life-shortening effect (ELDs). ELDs were defined to the patients as 'decisions to withhold treatment or medical actions, or decisions to implement medical actions in the future, e.g. do not resuscitate, do not treat, euthanasia'. The five possible responses as to who was to make the decision were: 1)

the doctor on the basis of his/her knowledge, 2) the doctor but strongly taking into account my opinion, 3) myself and the doctor together on an equal basis, 4) myself but strongly taking into account the doctor's opinion and 5) myself on the basis of the information I have or receive. The five answers represent three categories of preferences: a preference for primary physician control (answers 1 and 2), shared physician-patient control (answer 3) and primary patient control (answers 4 and 5). This item is an adaptation of the control preference scale (CPS) used in other studies (15;16). Patients were then asked whether they wanted people other than the treating physician to be involved in medical decision-making in case of future incompetence (reduction or loss of consciousness, coma, etc). The four possible answers were: nurse, family/close friends, no one, other (multiple response item).

2) After-death questionnaire
The after-death questionnaire, to be filled in by both specialist and GP, had two parts. In the first part, it was assessed whether the patient had died suddenly and unexpectedly, and if not, whether ELDs were made and if so which. In the second part the decision-making process was investigated. In cases where more than one ELD was made, the decision-making process leading to the potentially most life-shortening ELD was to be detailed. Firstly, physicians had to state whether the patient was competent at the time of decision-making and he had to estimate the amount of time life was shortened by the ELD. Secondly, physicians were asked to what degree the competent patient was involved in the ELD (using the same CPS item) and, if incompetent, whether other people were involved (multiple-response item: other physicians, nurses, family/close friends, no one, other). The questionnaire, with the exception of the CPS item, was based on the validated Dutch questionnaire used in nationwide ELD-incidence studies in Belgium and the Netherlands (1;2). In addition, the physicians were also asked to rate the patient's quality of life in the last week before death using the Dutch version of the EORTC QLQ-C15-PAL (17;18).

6.2.3 Statistical analysis

The comparison between the preferred and actual involvement of the patient (where competent) or others (where incompetent) was made by cross tabulating the responses to the preference items with the responses to the actual involvement items. The preferences for involvement considered were those stated in the last interview before death.

Predictors of involving patients and other persons in medical decision-making were studied using Fisher's exact and Mann-Whitney *U* tests. Characteristics analysed were: age, sex and education, treatment goal at inclusion, physical and emotional functioning in the last week before death, time lived since inclusion, type of ELD and the estimated amount of time life was shortened by the ELD. Due to the small sample size, some variables with more than two answering possibilities were rearranged, dividing the patients into approximately equal groups. The variable measuring the involvement of the patient (CPS-responses) was divided into doctor-controlled versus shared or patient-controlled decisions. This was also the case for the predictor variable 'amount of time ELD shortened life', which was reduced to: 'probably no life-shortening or less than one day' versus 'more than one day'.

6.3 Results

Figure 1 describes the participation of the patients in the longitudinal study. Of the 196 patients who met the inclusion criteria, 36 refused participation and eight were incorrectly excluded. Of those included, 128 (68% participation rate) were interviewed once (19 were too ill or died, three could not be contacted and two had too many missing values), 97 twice, 67 three times, 43 four times, 29 five times and 13 six times.

Of the 128 patients who were interviewed at least once, 97 died within 18 months of inclusion, which was shortly after diagnosis. Long-term survivors were excluded because they required a longer follow-up period. Data about death were available in 85 patients (88% response rate). Reasons for missing data were non-response in three patients and too many missing values in nine. In 36 of 85 patients information was available from both specialist and GP, in 48 patients from the specialist only, and in one from the GP only. When a completed questionnaire was available from both physicians, that from the physician under whose care the patient had died was selected or, if this criterion did not apply, the questionnaire of the physician who had had the highest frequency of contact with the patient in the last weeks before death was used.

6.3.1 Characteristics of the sample and incidence of end-of-life decisions

At inclusion in the longitudinal study, those patients who died within 18 months of diagnosis had a mean age of 64.1 years (SD=9.7). Males numbered 86%, 73% had a partner and almost all had a GP (96%) but the degree of contact with the GP varied: one third of the patients saw their GP less than once a month. The treatment goal at inclusion was life prolongation in 76% of cases and palliation in 23%. The median survival time of the patients studied was 190 days from diagnosis. In the last week before death, 70% were completely disabled according to the ECOG performance status scale. The majority (71%) died under the care of the specialist (hospital), 12% under the care of the GP (at home) and 18% in another setting, e.g. nursing home (Table 1).

Figure 1: Participation of advanced lung cancer patients in the interview study and number of patients who died within 18 months after diagnosis of NSCLC IIIb/IV

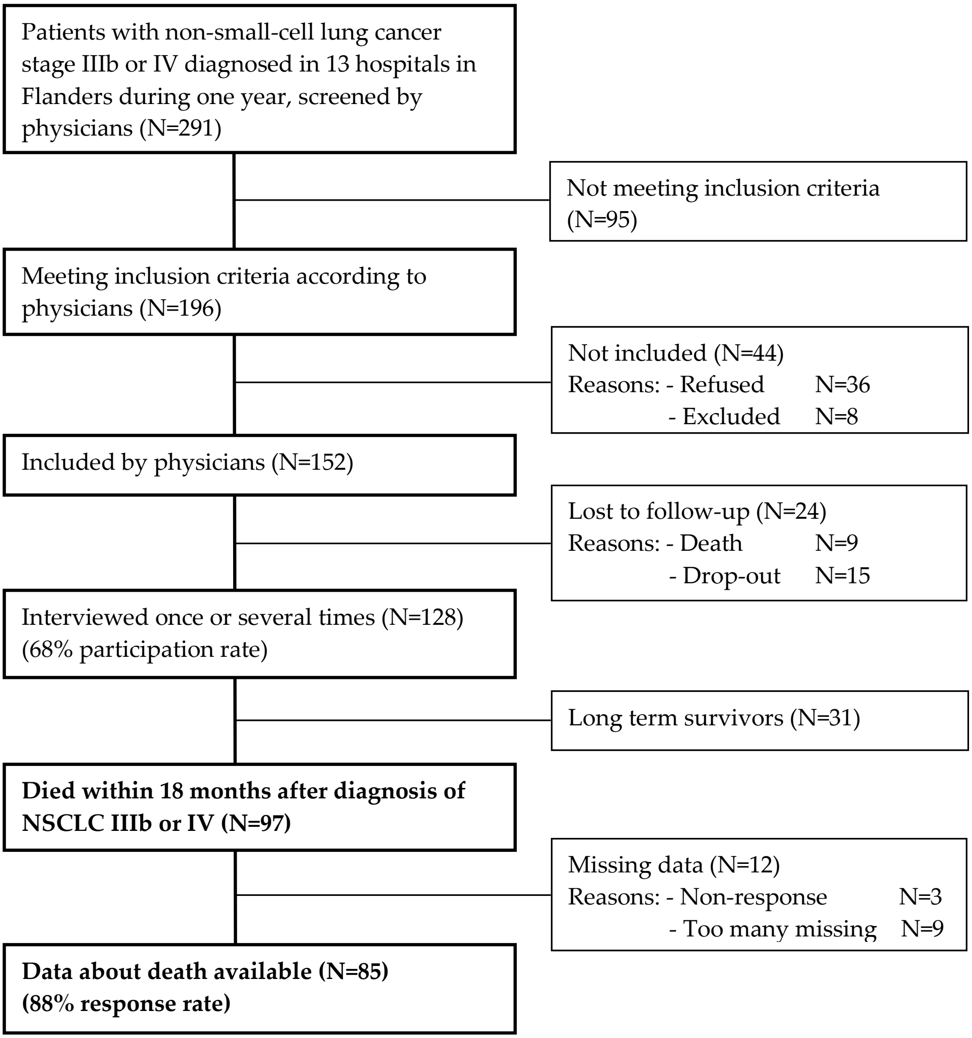

Table 1: Characteristics of the studied advanced lung cancer patients who died within 18 months after diagnosis of NSCLC IIIb or IV (N*=85)

Characteristics at inclusion (source: specialist or patient)		
		Mean (SD)
Age (y)		64.1 (9.7)
		N(%)
Sex	Male	73 (85.9)
	Female	12 (14.1)
Having a partner	Yes	62 (72.9)
	No	23 (27.1)
Education	Primary school	12 (14.3)
	Lower secondary	34 (40.5)
	Higher secondary	24 (28.6)
	Higher education	15 (17.9)
Having a GP	Yes	82 (96.5)
	No	3 (3.5)
Contact with GP*	More than once a month	20 (24.3)
	Once a month	36 (43.9)
	Less	26 (31.7)
Treatment goal	Life prolongation	65 (76.5)
	Palliation	20 (23.5)
Treating hospital	University	42 (49.4)
	General	43 (50.6)
Characteristics near or at death (source: specialist or GP)		
		Mean (SD)
Quality of life in last week before death[*a]		
1) Global quality of life		17.4 (17.1)
2) Functioning scales		
- Physical functioning		8.5 (13.7)
- Emotional functioning		49.7 (28.3)
3) Symptom scales		
- Fatigue		84.8 (15.3)
- Pain		56.4 (28.6)
- Nausea		35.8 (30.3)
- Dyspnoea		65.7 (31.3)
- Insomnia		45.9 (30.8)
- Appetite loss		68.2 (26.2)
- Constipation		32.8 (26.1)
		N(%)
Performance status in last week before death[*b]	0	0 (0.0)
	1	2 (2.5)
	2	5 (6.3)
	3	16 (20.3)
	4	56 (70.9)
		Median
Median survival (in days after inclusion)		190

(Table 1 cont'd)

		Mean (SD)
Good death (score from 0 to 10)[c]		7.8 (2.1)
		N(%)
Setting where patient died	Setting of specialist	60 (70.6)
	Setting of GP (at home)	10 (11.8)
	Other	15 (17.6)

* missing values: n=3 for contact with GP (3 patients had no GP), n=18 for quality of life in last week before death, n=6 for performance status in last week before death.

[a] Quality of life according to EORTC QLQ-C15-PAL: 10 scales with ratings between 0 and 100: high score is healthy level in global quality of life and in functional scales, but high score is unhealthy level in symptom scales.

[b] Performance status according to ECOG: Eastern Cooperative Oncology Group, ranging from 0 = fully active to 4 = completely disabled.

[c] Physicians were asked to judge the death of their patient on a scale from 0 (bad death) to 10 (good death).

Of the 85 deaths studied, 79 were non-sudden and of these 52 were preceded by one or more ELDs with a possible or certain life-shortening effect (66%). The amount of time life was shortened by the potentially most life-shortening ELD was: probably none in 33% of patients, less than 24 hours in 28%, one to seven days in 26% and more than a week in 13%. Slightly more patients were competent (29) at the time of decision-making than were incompetent (23).

6.3.2 Actual involvement of patient and family in end-of-life decision-making

For competent patients physicians reported that the end-of-life decision was made primarily by themselves in half of cases (54%), by themselves and the patient in 21% and primarily by the patient in 25% of cases. The decision to administer lethal drugs was never made under exclusive doctor control according to the physicians: one decision was made under shared physician-patient control and five under patient control. The decisions to withhold treatment and intensify alleviation of symptoms were made under all three kinds of control: physician, shared and patient (Table 2).

For the patients who were incompetent, physicians reported that family members were involved in 43% of cases; nurses or other physicians were involved in 48%. More specifically, the involvements were (in n=18 of 23): family + other physicians + nurses in five cases, family + nurses in one case, other physicians + nurses in two cases, family only in four cases, other physicians only in three cases and nurses only in two cases (Table 3).

6.3.3 Comparison with previously stated preferences for involvement

Compared to their previously stated preferences for involvement in end-of-life decision-making, as recorded in their last interview at a median time of 54 days before death (Q1: 36 days, Q3: 91), 42% of the competent patients achieved their preference: 50% were less involved than preferred and 7% more. Of the patients who preferred doctor control, 80% achieved their preference, of those who preferred shared control this was 22% and of those who preferred patient control it was 43% (Table 2).

Of patients lacking competence, 43% achieved their previously stated preference for involvement of family (expressed at a median time of 61 days before death: Q1: 28, Q3: 141). More specifically, of those who wanted their family involved, 43% achieved this, and of the few patients who did not want their family involved half achieved this. None of the incompetent patients had indicated earlier that they wanted the involvement of nurses, but nurses were involved in almost half of the cases. The preferred involvement of physicians other than the treating physicians was not studied (Table 3).

6.3.4 Factors associated with involvement

Patients whose treatment goal at inclusion was palliation rather than life prolongation were more likely to be involved in the end-of-life decision (shared or informed decision-making) (P=0.014). Also younger patients tended to be more involved (P=0.06). The type of ELD that was made also made a difference. When the ELD shortened patient life by more than one day, there was also a trend for patients to have been more involved in decision-making (P=0.06). When the decision concerned the administration of a lethal drug, according to the physicians, patients were always involved (Table 4).

In incompetent patients, family were more likely to be involved in end-of-life decision-making when the ELD (or one of the ELDs) was withholding or withdrawing treatment (P=0.017). Nurses and physicians other than the treating physician were more likely to be involved when the emotional functioning of the patient was judged extremely bad (P=0.044 for nurses and P=0.005 for other physicians) (Table 5).

Table 2: Degree to which competent patients were involved in end-of-life decision-making and correspondence with previously stated preferences for involvement (N*=29)

N(Row%)

		Actual involvement in the most potentially life-shortening ELD made Rated by physician shortly after patients' death			
		Doctor control	**Shared control**	**Patient control**	**Total**
Preferred involvement (in ELDs) Expressed by patient, at median time before death of 54 days (Q1: 36, Q3: 91)	**Doctor control**	🟦 **4 (80.0)** ELDs made: 2 alleviation of pain 2 withholding treatment +	🟥 1 (20.0) ELDs made: 1 withholding treatment +	🟥 0 (0.0)	5 (18.0)
	Shared control	🟩 6 (66.7) ELDs made: 6 alleviation of pain	🟦 **2 (22.2)** ELDs made: 1 withholding treatment 1 alleviation of pain	🟥 1 (11.1) ELDs made: 1 administation lethal drug	9 (32.0)
	Patient control	🟩 5 (35.7) ELDs made: 2 alleviation of pain 1 alleviation of pain + 2 withholding treatment +	🟩 3 (21.4) ELDs made: 1 withholding treatment+ 1 alleviation of pain 1 administration lethal drug	🟦 **6 (42.9)** ELDs made: 1 withholding treatment 1 alleviation of pain 4 administration lethal drug	14 (50.0)
	Total	15 (53.6) ELDs made: 10 alleviation of pain 1 alleviation of pain + 4 withholding treatment +	6 (21.4) ELDs made: 1 withholding treatment 2 alleviation of pain 2 withholding treatment + 1 administration lethal drug	7 (25.0) ELDs made: 1 withholding treatment 1 alleviation of pain 5 administration lethal drug	28 (100.0)

* missing value: n=1

Blue: patients who achieved their preference; Green: patients who were involved less than as preferred; Red: patients who were involved more than as preferred

ABBREVIATION: + = shortening of patient's life intended; ELDs= end-of-life decisions with a potential or certain life-shortening effect

Table 3: Actual involvement in end-of-life decision-making of other persons in patients who were incompetent at the time of the decision-making and correspondence with previously stated preferred involvement in medical decision-making (N=23)

Actual and preferred involvement of family				
		Actual involvement[a]		
		Yes (N, Row%)	No (N, Row%)	Total (N, Row%)
Preferred involvement[b]	Yes	9 (42.9)	12 (57.1)	21 (100.0)
	No	1 (50.0)	1 (50.0)	2 (100.0)
	Total	10 (43.5)	13 (56.5)	23 (100.0)
Actual and preferred involvement of nurses				
		Actual involvement[a]		
		Yes (N, Row%)	No (N, Row%)	Total (N,Row%)
Preferred involvement[b]	Yes	0 (0.0)	0 (0.0)	0 (100.0)
	No	11 (47.8)	12 (52.2)	23 (100.0)
	Total	11 (47.8)	12 (52.2)	23 (100.0)
Actual and preferred involvement of no one				
		Actual involvement[a]		
		Yes (N, Row%)	No (N, Row%)	Total (N,%)
Preferred involvement[b]	Yes	0 (0.0)	2 (100.0)	2 (100.0)
	No	5 (23.8)	16 (76.2)	21 (100.0)
	Total	5 (21.7)	18 (78.3)	23 (100.0)

[a] Indicated by physician shortly after patient died.

[b] Expressed by patient, at a median time before death of 61 days (Q1: 28, Q3: 141).

Table 4: Case characteristics associated with actual involvement of competent patients in end-of-life decision-making[a] (N=29)

			Degree to which the competent patient was involved in the end-of-life decision-making (according to the physician)		
Case characteristics			Shared patient-physician or patient controlled decision-making	Doctor controlled decision-making	***P*[b]**
Age of patient (y)		Mean	60.1	67.5	0.061*
Estimated life- shortening by ELD	Probably none or less than 24 h	N(%)	6 (33.3)	12 (66.7)	0.060*
	One day or more	N(%)	8 (72.7)	3 (27.3)	
Treatment goal at inclusion of patient in study	Life prolongation	N(%)	7 (33.3)	14 (66.7)	0.014**
	Palliation	N(%)	7 (87.5)	1 (12.5)	
Administration, prescription or supply of drugs with explicit intention to shorten life	Yes	N(%)	6 (100.0)	0 (0.0)	0.006**
	No	N(%)	8 (34.8)	15 (65.2)	

* significant at 0.1 level

** significant at 0.05 level

[a] Only significant associations are given in the table.

[b] Association was tested using Fisher's exact test and Mann-Whitney *U* test.

Table 5: Case Characteristics associated with actual involvement of others in end-of-life decision-making in incompetent patients[a] (N=23)

Involvement of family (according to the physician)					
Case characteristic			**Involved**	**Not involved**	***P*[b]**
Withholding or withdrawing of potential life-prolonging treatment	Yes	N(%)	6 (85.7)	1 (14.3)	0.017*
	No (other decision made)	N(%)	4 (25.0)	12 (75.0)	
Involvement of other physicians than the treating physician (according to the physician)					
Case characteristic			**Involved**	**Not involved**	
Emotional functioning of patient[c]		Mean	25.7	66.6	0.005*
Involvement of nurses (according to the physician)					
Case characteristic			**Involved**	**Not involved**	
Emotional functioning of patient[c]		Mean	28.3	59.3	0.044*

* significant at 0.05 level

[a] Only significant associations are given in the table.

[b] Association was tested using Fisher's exact test and Mann-Whitney *U* test.

[c] Functional scale of EORTC QLQ-C15-PAL, with ratings between 0 to 100, high score is healthy level.

6.4 Discussion

Eighty-five advanced lung cancer patients who died within 18 months of diagnosis of NSCLC IIIb or IV were studied. Physicians reported that an end-of-life decision with a possible or certain life-shortening effect (ELD) was made in 52 patients. Half of the patients who were judged competent at that time were, according to the physicians, hardly or not at all involved in the decision-making, one quarter shared the decision with the physician and one quarter made the decision primarily themselves. In the incompetent patients, relatives were involved in half of cases, as were nurses and physicians other than the treating physician. Half of the competent patients were involved less than they had previously preferred and 7% more. Almost all the incompetent patients had previously stated they wanted their family involved in case of loss of competence, but half did not achieve this preference. Factors associated with actual involvement of the patient or the family included a palliative treatment goal.

Strengths of this study were the focus on the actual involvement of an understudied population of advanced lung cancer patients and their family in end-of-life decision-making and the comparison with the patient’s previously stated involvement preferences as an indicator of quality of care at the end of life. Methodologically, by obtaining the data from the attending physician shortly after the patient had died, second-hand information and recall bias were avoided.
Limitations are the small sample size and the limited generalisability of the results: although representativity of the data was enhanced by involving several hospitals across Flanders to recruit consecutive patients, the participation rate (68%) of the patients in the longitudinal study was limited and the response rate of the physicians reporting on the deaths of these patients was not perfect (88%). Another limitation is that a patient’s preferences for involvement in the decision-making process were not assessed at the time of the actual decision-making but earlier in the disease trajectory. There were ethical reasons for this, but as a consequence it cannot be ruled out that preferences may change when patients are actually confronted with the need to make an ELD.

A significant finding of the study is that, according to the physicians involved, half of all competent patients were not involved in the ELD, one in four shared the decision-making with the physician and one in four made the decision themselves. It is difficult to compare this with studies reporting that 67% of patients had discussed the end-of-life decision with their physician, because discussing a decision is not the same as making a decision (11). When compared with the norm that patients should be at least involved to the degree of sharing the decisions with the physician, a high number of the patients did not achieve this.

Where the patient was lacking in competence, family was involved in end-of-life decision-making in half of cases, as were nurses and other physicians. In 22% of the cases no other person was involved. Thus, family involvement in incompetent patients is as frequent as involvement of competent patients themselves. Compared to the nationwide ELD incidence study in Flanders, Belgium, according to which discussions with families took place in 77% of incompetent patients, involvement is lower in this study (11).

Our study found considerable discrepancies between the preferences expressed to the interviewers and the actual involvement of the patient or family in end-of-life decision-making: half of competent patients wanted more involvement and 7% wanted less, and half of the incompetent patients wanted their family involved when they were not. Even taking into account possible changes in preference between the time when the preferences were expressed and the time of decision-making, these are high proportions. Treating physicians may either not be aware of their patient's preferences or, if aware, may choose not to involve them or their family, e.g. out of fear of overburdening them (19).

That the involved patients tended (*P*=0.061) to be younger (mean 60 years) than the uninvolved (mean 67 years) may be because younger patients are more assertive, or because physicians perceive them as more resilient and have more respect for their autonomy. Patients whose treatment goal at inclusion was palliation (only comfort care without any intent to prolong life) rather than life prolongation were also more likely to be involved in the end-of-life decision-making. An explanation may be that these patients had had more time to adjust to the terminal nature of their illness and/or were more open to discussing difficult decisions (20).

Involvement in decision-making was also related to the nature of the ELD. When the ELD shortened life by more than one day, patients were more likely to have been involved. It seems that when the predictable life-shortening is substantial, physicians are more circumspect – or at least report themselves as more circumspect - in implementing ELDs and will not readily take such decisions without the patient's involvement. Similarly, when the ELD involved the administration of a lethal drug with the explicit intent of shortening life, the patient was always involved. This is in conformity with the Belgian legal framework (21). When the ELD (or one of the ELDs if more than one was made) consisted of withholding or withdrawal of treatment in patients lacking in competence, relatives were more likely to have been involved than in cases of potentially life-shortening drug administration.

It is noteworthy that other health-care professionals (nurses and other physicians) were more involved in cases where the patient's emotional functioning in the last week before death was very bad. Maybe this is because it is more difficult to take

ELDs in patients whose physical condition is further complicated by severe emotional problems.

To conclude, half of competent patients were hardly or not at all involved in end-of-life decision-making and half of those lacking in competence did not have their family involved, though most had stated previously that this is what they wanted. Involvement seems to be related to being younger, having been given a palliative treatment goal and to the type of ELD. To ensure that medical decision-making at the end of life respects a patient's autonomy and their preferences for involvement, open discussions with the patient regarding their views on ELDs and the involvement of their family in the case of future loss of competence are important and should preferably occur early on in the course of the disease (22).

6.5 References

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Chapter 7:
Expressed wishes for euthanasia and incidence of end-of-life decisions in advanced lung cancer patients

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Expressed wishes for euthanasia and incidence of end-of-life decisions in advanced lung cancer patients: a prospective study in Flanders, Belgium. Submitted.

Abstract

Objective:
To explore expressed wishes and requests for euthanasia and the incidence of end-of-life decisions with possible or certain life-shortening effects (ELDs) in stage IIIb/IV lung cancer patients.

Methods:
Design: a prospective, longitudinal, observational study of a consecutive sample of advanced lung cancer patients who died within 18 months of diagnosis. The pulmonologist or oncologist and the general practitioner (GP) of the patient were asked to fill in a questionnaire on the medical circumstances surrounding the death, immediately after the patient died.
Subjects: relevant information was available for 105 of 115 deaths.
Main outcome measures: relation between expressed wishes for euthanasia, repeated and explicit requests and implementation of requests. Number of patients whose death was preceded by an ELD and incidence of the different types of ELD.

Results:
According to the specialist or GP, 20% of the patients had expressed a wish for euthanasia, three quarters of these (14.3% of all patients) had made an explicit and repeated request and half of these (7.6% of all patients) received euthanasia. Those who had expressed a wish for euthanasia but had not made an explicit and repeated request (5.7% of all patients) did not receive euthanasia. Patients with a palliative treatment goal at diagnosis of the advanced cancer, and those who lived longer were significantly more likely to express a wish for euthanasia and to receive euthanasia. Death was preceded by an ELD in 62.9% of all patients. This was a non-treatment decision in 14.3%, intensifying alleviation of symptoms in 39.1% and administration of lethal drugs with the explicit intention to shorten life in 9.5% (euthanasia in 7.6%, physician assisted suicide in 0.0% and ending the patient’s life without request in 1.9%).

Conclusion:
Physicians acted with care and did not perform euthanasia on the basis of an expressed wish only, without explicit and repeated request; however, a proportion of explicit and repeated requests were not carried out either because the patient died or because the treating physician was not aware they had been made.

7.1 Introduction

All over the world, physicians receive requests for euthanasia from their seriously ill patients and sometimes accede to these requests (1-5). However, euthanasia is legally permitted - under well-defined conditions - in only three countries in Europe: Belgium, the Netherlands and Luxembourg (6-8). The fundamental conditions that are laid down in the euthanasia law in these countries are that 1) the patient must be in a condition of constant and unbearable physical and/or psychological suffering caused by illness or accident, with no possibility of improvement and 2) the request must be made voluntarily and be well considered and repeated.

Several nationwide population studies in Belgium and the Netherlands have determined the incidence of euthanasia and other end-of-life decisions with possible or certain life-shortening effect (ELDs) (2;9;10). This study focuses on advanced lung cancer patients and studies the process leading to euthanasia, the most controversial of ELDs, in more depth. Advanced lung cancer is one of the most deadly diseases, with a high symptom burden, usually requiring a high level of care and therapy (11;12).

In Belgium and the Netherlands, it has been shown that the practice of euthanasia is relatively rare when considering all deaths (1.9% in Flanders, Belgium, in 2007 and 1.7% in the Netherlands in 2005) and more prevalent in deaths caused by cancer (5.6% in Flanders and - together with physician assisted suicide - 5.1% in the Netherlands) (2;10). Little is known however about the processes that lead to euthanasia, more specifically about the number of patients who express a wish for euthanasia to the physician, whether this is an explicit and repeated request and whether it leads to euthanasia. According to a physician survey in the Netherlands an estimated 8,400 explicit requests for euthanasia or physician-assisted suicide were made in 2005 of which about 2,400 were granted and implemented (13;14). No such data are available for Belgium.

Therefore, this study aims to examine the relationship between euthanasia wishes, euthanasia requests and euthanasia practices in a sample of advanced lung cancer patients in Flanders, Belgium, and the incidence of end-of-life decisions among these patients. The research questions of this study were:

1. How many patients with advanced lung cancer wish and request euthanasia, and how often is their request implemented?
2. What characterises the patients who choose euthanasia?
3. What is the incidence of other ELDs than euthanasia among patients with advanced lung cancer?

7.2 Methods

For the purpose of analysis in this paper, we selected patients who were included in a longitudinal interview study (15). Patients conformed to the following inclusion criteria: a recent initial diagnosis of non-small-cell lung cancer (NSCLC) stage IIIb or IV, 18 years or older, Dutch speaking and physically and psychologically able to participate in the study. The patients were recruited consecutively during one year (February 2007-February 2008) by pulmonologists and oncologists in 13 hospitals in Flanders. We asked the pulmonologist or oncologist and the general practitioner (GP) of the patient to fill in an after-death questionnaire for those patients who died within 18 months of inclusion in the study, which was shortly after diagnosis of the advanced lung cancer.

7.2.1 Measurements

1) Inclusion form
At inclusion in the longitudinal interview study, socio-demographic and clinical characteristics of the patients were collected including age, sex, educational level, whether the patient lived with a partner, intention of treatment, comorbidity (Charlson's Comorbidity Index(16;17)), whether the patient had a GP and how frequent the contact with the GP was.

2) After-death Questionnaire
In the after-death questionnaire to be filled in by the treating pulmonologist or oncologist as well as by the GP, the physicians were asked whether the patient had ever expressed a wish to them to administer drugs with the explicit intention of hastening death (we deliberately used a descriptive definition of euthanasia). Then the physician was asked whether explicit and repeated requests had been made. Finally, we measured the occurrence of those end-of-life decisions with certain or possible life-shortening effects (ELDs): 1) withholding or withdrawing potentially life-prolonging treatment (whether taking into account the possibility of hastening death or actually intending it), 2) intensifying alleviation of symptoms (taking into account or co-intending the hastening of death) and 3) physician assisted death (PAD): euthanasia, physician assisted suicide and ending of life without the patient's explicit request. In addition to these ELDs, we asked whether the patient had been deeply sedated until death with or without the artificial administration of food or fluid. The wording of the questions and classification of practices were identical to previous nationwide incidence studies (1;2).
In a separate section of the questionnaire, characteristics of the patient and of death were measured: performance status in the last week before death (ECOG, Eastern Cooperative Oncology Group(18)), whether the patient had died suddenly and unexpectedly, setting of the patient's death and quality of death according to the physician (10-point rating scale from bad to good death).

7.2.2 Ethical aspects

All patients were asked for informed consent to taking part in the study, and this was renewed at each interview. The protocol was approved by the Ethics Committees of all participating hospitals.

7.2.3 Statistical analysis

To compare the characteristics of those patients who had expressed a wish for euthanasia with those who had not and to compare the characteristics of those who died after euthanasia and those who did not, the Mann-Whitney *U* or Fisher's exact test was used; significance was set at $P<0.05$.

7.3 Results

Pulmonologists and oncologists of the participating hospitals screened 291 patients with a recent initial diagnosis of non-small-cell lung cancer (NSCLC), stage IIIb or IV, of which 196 met the inclusion criteria. Of these, 152 were included in the study: 36 patients refused participation and eight were excluded by the specialist (e.g. because they were already participating in another study). Of the 152 patients who agreed to participate, 115 died within 18 months of diagnosis of NSCLC IIIb or IV. Finally, a valid after-death questionnaire was returned from the treating physician or physicians for 105 patients (see Figure 1). The response rate of specialists was 91.3% and of GPs 54.8%.

7.3.1 Characteristics of the studied patients (Table 1)

The mean age of the studied patients at inclusion was 64.6 years (SD: 10.6); 82.9% were male and 74.5% had a partner. The highest level of education was primary school for 17.5% of the patients, secondary school for 63.1% and higher education for 19.4%. At inclusion, three quarters of the patients received treatment from pulmonologists and oncologists with a life-prolonging intent and one quarter with a palliative intent. Most received chemotherapy. None went into a palliative care unit. The number of contacts with the GP was fewer than once a month for one third of the patients.

In the last week before death 72.2% were completely disabled according to the ECOG performance-scale. The median time of survival for all patients in the study was five months from diagnosis. Seventy point nine percent died in the hospital where they were receiving treatment, 14.6% died in the setting of the GP i.e. at home or in a nursing home, and 14.6% died elsewhere e.g. in a hospice. Ten point five percent (11 patients) died suddenly and unexpectedly.

Table 1: Characteristics of the studied advanced lung cancer patients who died within 18 months after diagnosis of NSCLC(N=105)

		All patients N= 105	**Patients who had euthanasia wish, compared to those who did not**			**Patients who received euthanasia, compared to those who did not**		
			Wish N= 21	**No wish N= 84**	***P*-value[d]**	**Euthanasia N=8**	**No euth. N=97**	***P*-value[d]**
Characteristics at inclusion of the patient in the study (source: specialist and patient)								
		Mean (SD)	**Mean (SD)**	**Mean (SD)**		**Mean (SD)**	**Mean (SD)**	
Age (in years)		64.6 (9.9)	63.2 (10.6)	64.9 (9.7)	0.576	62.0 (8.6)	64.8 (10.0)	0.413
		N(%)	**N(%)**	**N(%)**		**N(%)**	**N(%)**	
Sex	Male	87 (82.9)	18 (20.7)	69 (79.3)	1.000	6 (6.9)	81 (93.1)	0.623
	Female	18 (17.1)	3 (16.7)	15 (83.3)		2 (11.1)	16 (88.9)	
Having a partner*	Yes	76 (74.5)	16 (21.1)	60 (78.9)	0.775	5 (6.6)	71 (93.4)	0.417
	No	26 (25.5)	4 (15.4)	22 (84.6)		3 (11.5)	23 (88.5)	
Education*	Primary school	18 (17.5)	4 (22.2)	14 (77.8)	0.567	1 (5.6)	17 (94.4)	0.379
	Lower secondary	37 (35.9)	5 (13.5)	32 (86.5)		3 (8.1)	34 (91.9)	
	Higher secondary	28 (27.2)	6 (21.4)	22 (78.6)		2 (7.1)	26 (92.9)	
	Higher education	20 (19.4)	5 (25.0)	15 (75.0)		2 (10.0)	18 (90.0)	
Contact with GP*	More than once a week	5 (4.8)	1 (20.0)	4 (80.0)	0.756	2 (40.0)	3 (60.0)	0.176
	Once a week	8 (7.6)	2 (25.0)	6 (75.0)		0 (0.0)	8 100.0)	
	Once every two weeks	13 (12.4)	2 (15.4)	11 (84.6)		2 (15.4)	11 (84.6)	
	Once a month	44 (41.9)	10 (22.7)	34 (77.3)		2 (4.5)	42 (95.5)	
	Less (or no GP)	35 (33.3)	6 (17.1)	29 (82.9)		2 (5.7)	33 (94.3)	
Treatment goal*	Life prolongation	77 (74.0)	12 (15.6)	65 (84.4)	**0.057**	3 (3.9)	74 (96.1)	**0.027**
	Palliation	27 (26.0)	9 (33.3)	18 (66.7)		5 (18.5)	22 (81.5)	
Treating hospital	University	51 (48.6)	7 (13.7)	44 (86.3)	0.146	4 (7.4)	47 (92.2)	1.000
	General	54 (51.4)	14 (25.9)	40 (74.1)		4 (7.8)	50 (92.6)	
Comorbidity[a]	No comorbidity	48 (45.7)	7 (14.6)	41 (85.4)	0.230	2 (4.2)	46 (95.8)	0.285
	Comorbidity	57 (54.3)	14 (24.6)	43 (75.4)		6 (10.5)	51 (89.5)	

Characteristics near or at death (source: specialist or GP[b])								
		N(%)	**N(%)**	**N(%)**		**N(%)**	**N(%)**	
Performance status in last week before death*[c]	0	0 (0.0)	0 (0.0)	0 (0.0)	0.570	0 (0.0)	0 (0.0)	0.964
	1	2 (2.1)	0 (0.0)	2 (100.0)		0 (0.0)	2 (100.0)	
	2	5 (5.2)	2 (40.0)	3 (60.0)		1 (20.0)	4 (80.0)	
	3	20 (20.6)	2 (10.0)	18 (90.0)		1 (5.0)	19 (95.0)	
	4	70 (72.2)	15 (21.4)	55 (78.6)		6 (8.6)	64 (91.4)	
		Median	**Median**	**Median**		**Median**	**Median**	
Survival time (in months after inclusion)		5.0	8.0	4.0	**0.021**	10.0	4.0	**0.006**
		Mean (SD)	**Mean (SD)**	**Mean (SD)**		**Mean (SD)**	**Mean (SD)**	
Good death (scores from 0 to 10)		7.8 (2.1)	8.2 (2.1)	7.7 (2.1)	0.221	8.7 (1.2)	7.7 (2.2)	0.114
		N(%)	**N(%)**	**N(%)**		**N(%)**	**N(%)**	
Setting where patient died*	Specialist care	73 (70.9)	11 (15.1)	62 (84.9)	0.101	8 (11.0)	65 (89.0)	0.095
	GP care	15 (14.6)	5 (33.3)	10 (66.7)		0 (0.0)	15 (100.0)	
	Other (nursing home,…)	15 (14.6)	4 (26.6)	11 (73.3)		0 (0.0)	15 (100.0)	
Sudden, unexpected death	No	94 (89.5)	19 (20.2)	75 (79.8)	1.000	8 (8.5)	86 (91.5)	0.596
	Yes	11 (10.5)	2 (18.2)	9 (81.8)		0 (0.0)	11 (100.0)	

* missing values: n=3 for having a partner, n=2 for education, n=1 for treatment goal, n=8 for performance status in last week before death, n=8 for good death, n=2 for setting where patient died.

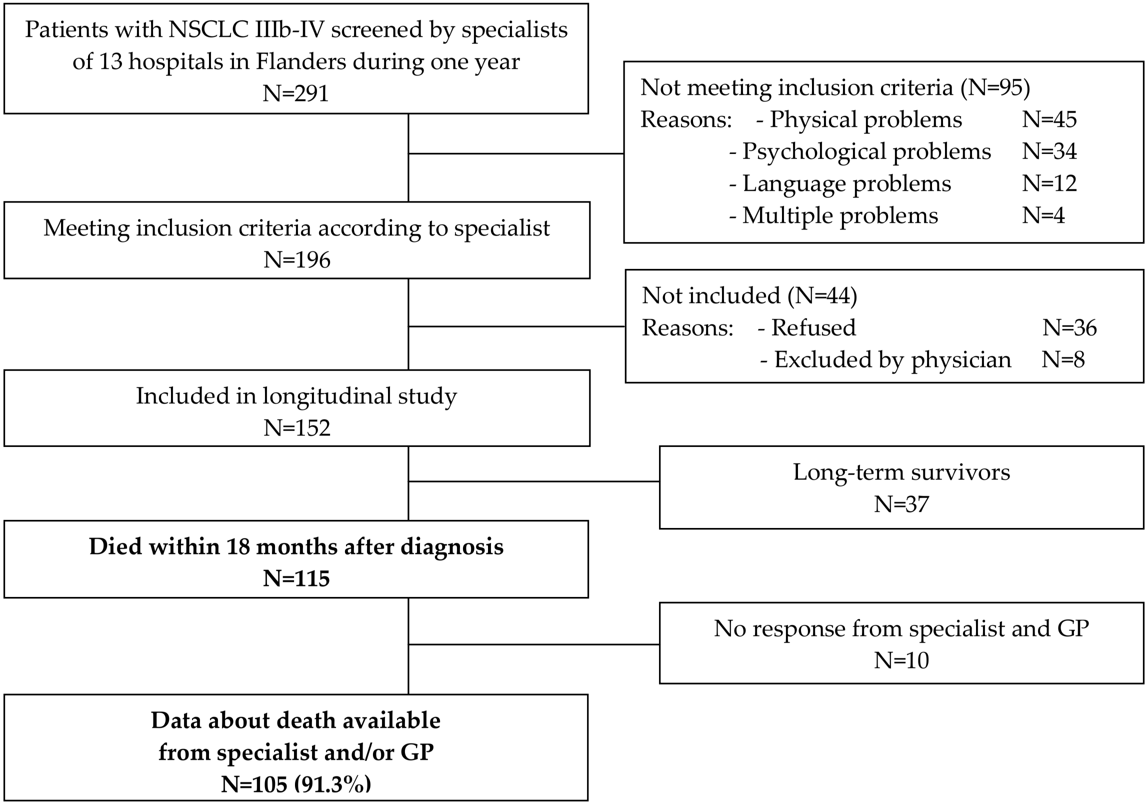
[a] Comorbidity according to Charlson Index.

[b] According to the physician (GP or specialist) in which setting the patient died or if patient died in another setting according to physician who had the most contact with the patient in the last month before death.

[c] Performance status according to ECOG: Eastern Cooperative Oncology Group, ranging from 0 = fully active to 4 = completely disabled.

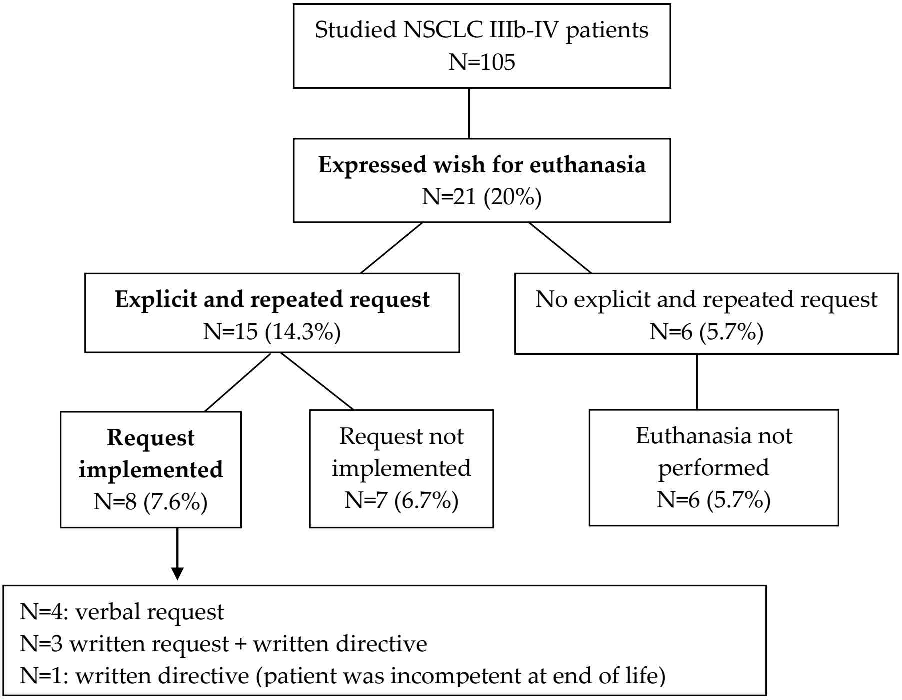
[d] Significance testing with Mann-Whitney *U* or Fisher's exact test.

Figure 1: Selection of NSCLC IIIb-IV patients for study



7.3.2 Euthanasia: expressed wish, request and implementation of request (Figure 2)

Figure 2: Euthanasia in advanced lung cancer patients, according to the treating specialist and/or GP of the patient*



*When , if both were applicable, specialist and GP disagreed over presence of wish or explicit and repeated request, presence of wish or explicit and repeated request was entered in the flow chart.

According to the specialist and/or GP, 21 of 105 (20%) advanced lung cancer patients who died within 18 months of diagnosis had expressed a wish for euthanasia. Specialist and GP did not always agree on the existence of a wish. Of the 13 patients with a euthanasia wish for which both specialist and GP had filled in the questionnaire, six were reported to have a wish by both physicians, and seven only by one physician (four specialists and three GPs reported an expressed wish, while their colleagues reported that no such wish had been expressed).

Of the 21 patients who had expressed a wish for euthanasia, 15 (14.3% of all patients) had asked the physician (specialist and/or GP) for euthanasia explicitly and repeatedly and of these 8 (7.6% of all patients) received euthanasia. Of the patients who had expressed a wish but made no explicit and repeated request (5.7% of all patients), none received euthanasia.

Possible reasons for not performing euthanasia despite an explicit and repeated request could be found in the comments of the physicians (not shown in Figure 2). Comments were given in three of the seven cases, each time by the GP. In one case the patient died before euthanasia could be performed; in another case the patient died in a palliative care unit where he had not repeated his request. In a third case, the patient had asked for euthanasia when suffering became intolerable, but this did not happen according to the physician. In four of seven cases no explanation for not performing euthanasia was given, but we observed that these four patients died in a setting other than that of the reporting physician. In two of these four cases the GP had reported a wish and an explicit and repeated request for euthanasia while the specialist had not, and the patient died in the setting of the specialist. In one case both physicians (specialist and GP) had reported an explicit and repeated request but the patient died in yet another setting. In the last case, only the GP had filled in the questionnaire regarding the death of the patient, but the patient died in a setting other than that of the GP.

7.3.3 Characteristics associated with a wish for euthanasia and implementation of euthanasia (Table 1)

Patients who expressed a euthanasia wish did not significantly differ from other patients with regard to age, sex, education and having a partner. Neither were there significant differences with regard to clinical characteristics such as the frequency of contact with the GP or comorbidity. Patients with a palliative treatment goal at diagnosis did appear more likely to express a euthanasia wish than those with a life-prolonging treatment goal, but the effect was not significant at the 0.05-level (P=0.057).

There was a significant positive association between the length of time after diagnosis and the expression of a euthanasia wish (P=0.021). There was a positive (but not significant) trend in the association between dying at home (in the setting of the GP) and having expressed a wish for euthanasia.

Comparing the patients for whom euthanasia was actually performed with those for whom it was not gave similar results: there were no significant differences with regard to most patient characteristics, but patients with a palliative treatment goal at diagnosis and those who lived longer were significantly more likely to receive euthanasia (P=0.027 and P=0.006).

7.3.4 End-of-life decisions other than euthanasia, including continuous deep sedation (Table 2)

Sudden death struck 10.5% of the patients; 26.6% died non-suddenly without a preceding ELD and 62.9% of the patients died with at least one ELD preceding death.

Euthanasia was performed in 7.6% of all studied patients. In 14.3%, the ELD consisted of withholding or withdrawing potential life-prolonging treatment (without intent to shorten life in 2.9% of cases and with intent in 11.4%). In 39.1% of the patients, symptom control was intensified but in most of these cases (32.4%) life-shortening was not an additional intention. In 1.9% lethal drugs were administered with the explicit intention of shortening the patient's life without their explicit request.

Independently of whether or not the above-mentioned ELDs were present, a separate question was asked about the incidence of continuous deep sedation until death. This procedure was applied in 12.4% of cases (4.8% with artificial hydration and/or nutrition and 7.6% without).

Table 2: Frequency of end-of-life decisions in advanced lung cancer patients who died within 18 months after diagnosis of NSCLC[a] (N=105)

	N(%)
All deaths preceded by at least one ELD	**66 (62.9%)**
Witholding or withdrawing of potential life-prolonging treatment	**15 (14.3)**
Life-shortening not intended	3 (2.9)
Life-shortening intended	12 (11.4)
Intensifying alleviation of symptoms with a potential life-shortening effect	**41 (39.1)**
Life-shortening not intended	34 (32.4)
Life-shortening additionally intended	7 (6.7)
Physician assisted death (PAD)	**10 (9.5)**
Euthanasia	8 (7.6)
Physician assisted suicide (PAS)	0 (0.0)
Ending of life without patients explicit request	2 (1.9)

[a] According to the physician (GP or specialist) in which setting the patient died or if patient died in another setting according to physician who had the most contact with the patient in the last month before death.

7.4 Discussion

This is the first study of the expression of wish, request and performance of euthanasia and of the incidence of end-of-life decisions with possible or certain life-shortening effects (ELDs) in a representative consecutive sample of lung cancer patients. In contrast with nationwide death-certificate studies, the assessment of the end-of-life decisions taken before death was performed by questioning both the treating specialist and the GP, and immediately after the patient had died, thus avoiding recall bias (19).

One fifth of the studied advanced lung cancer patients who died within 18 months of diagnosis of terminal lung cancer had expressed a wish for euthanasia according to their GP and/or specialist. In three quarters of these (14.3% of all patients) this request was explicit and repeated and one half of these (7.6% of all patients) effectively received euthanasia. Patients whose treatment goal was exclusively palliative and those who lived longer after diagnosis were more likely to express a wish for euthanasia and to receive euthanasia. ELDs were made in 62.9% of cases.

Limitations of the study were the relatively small sample size and the limited response rate of GPs who however were probably less involved in the care at the end of life.

A substantial number (20%) of the studied advanced lung cancer patients who died within 18 months of diagnosis had expressed a wish for euthanasia. Three quarters of these patients had also explicitly and repeatedly requested euthanasia. Thus, it seems that in most patients an expressed wish for euthanasia reflects determination, and not a reversible state of mind, or a reaction to a temporary condition.

Of those patients who had made an explicit and repeated request, only around half actually received euthanasia. In the physician study from the Netherlands from 2005 of cancer and non-cancer deaths, this ratio was one in three (13;20). The findings of both studies show that though a patient makes repeated explicit requests for euthanasia, euthanasia will not necessarily be performed. The most frequent reason given for this discrepancy in our study as well as in some Dutch studies was that the patient withdrew the request or died suddenly (21). However, in our study we observed that in some cases the physician in whose setting the patient died was not aware of the wish, let alone the request, because these had been expressed to another treating physician. This points to the importance of patients telling all their treating physicians what they want at the end of life and the necessity of better communication between treating physicians.

The mere expression of a wish for euthanasia short of an explicit and repeated request did not result in euthanasia according to the reporting physicians. This suggests that the physicians are aware of the stringent legal requirements of due consideration and reiteration of requests for euthanasia, that they comply with them and that they do not perform euthanasia lightly (6). It may also indicate that only determined patients, who are able to verbalize their wishes unambiguously and repeatedly, will have their requests granted.

Expressing a wish for euthanasia or receiving euthanasia was independent of a patient's age, sex and education. There was an association with the setting of a palliative goal in the care plan at diagnosis and this may have different explanations. It is possible that these patients were more ill and therefore more inclined to discuss end-of-life issues including euthanasia. It is also possible that a life-prolonging therapeutic objective deflects concerns about the end of life. Patients who survived longer were more inclined to express a wish for euthanasia. This suggests among other things that a long therapeutic relationship may be needed for a wish of euthanasia to be expressed.

Explanations for our finding of an association between an expressed wish for euthanasia and dying at home in the primary care setting can only be speculative and require further research. One hypothesis is that patients having a preference for euthanasia also prefer to die at home and have more confidence in their GP carrying out their requests.

The incidence of ELDs in advanced lung cancer patients is similar to that in the total population of cancer patients in Flanders: at least one ELD was made in 62.9% and 64.2% of patients respectively. Looking at the specific ELDs, the incidence of non-treatment decisions in our lung cancer patient sample was almost the same as in cancer patients as a whole, and so were the incidences of intensified symptom alleviation and physician assisted suicide. Because of these similarities, one can hypothesise that our conclusions may also apply to the larger population of cancer patients in Flanders.

To conclude, a substantial fraction of advanced lung cancer patients expressed a wish for euthanasia, most of these also expressed this wish explicitly and repeatedly and half received euthanasia. Patients with a palliative treatment goal at diagnosis and those who had lived longer since diagnosis were more likely to express a wish for euthanasia. Physicians seemed to act with care and did not perform euthanasia on the basis of an expressed wish only, without explicit and repeated request; however, a proportion of explicit and repeated requests were not carried out either because the patient died or because the treating physician was not aware they had been made.

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Chapter 8:
General discussion and conclusion

8.1 Main findings and discussion

This study succeeded in interviewing 128 advanced lung cancer patients shortly after diagnosis of advanced lung cancer (68% participation rate). A total of 97 of the 128 patients were interviewed a second time, 67 a third time, 43 a fourth time, 29 a fifth time, and 13 a sixth time. Those lost to follow up were due to death (n=73), being too ill (n=20), or other reasons (n=22). Of the 128 patients, 97 died within 18 months of diagnosis. Information from the physician regarding the death of these patients was available for 85 of them.

The 128 patients interviewed had a mean age of 64 years (range 41-86), 80% were male and three quarters had a partner. The median estimated life expectancy was 10 months (range 2-24). Eighty-two percent received chemotherapy, 32% received radiotherapy mostly in combination with the chemotherapy, and 5% received experimental therapy. The main treatment objectives were life prolongation for 71% of the patients and palliation, defined as comfort care with no intent to cure or prolong life, for 21%.

The main findings of the study are described and discussed below. They concern:

1) The preferences for information and participation in medical decision-making of the advanced lung cancer patients shortly after diagnosis, the degree to which these preferences were met according to the patients, the change in the preferences over time and the preferences of the patients for involvement of family in medical decision-making during the course of the disease (main objective of the study: 8.1.1)
2) The actual involvement of the patient in end-of-life decision-making as reported by the physician after the patient died (secondary objective: 8.1.2)
3) The euthanasia wishes, requests and implementation of the requests of the patients according to the physicians (secondary objective: 8.1.3)

The findings of the main objective of the study are based on the patient interviews and the findings of the secondary objectives are mainly based on the after-death questionnaires filled in by the physicians.

8.1.1 Information and participation preferences of advanced lung cancer patients

1) Information and participation preferences shortly after diagnosis (chapter 2)

A first important finding of the study is that there was a high need for information in the studied advanced lung cancer patients shortly after diagnosis of the cancer.

Practically all patients wanted to be informed in general and about diagnosis, treatment options and chances of cure, 88% wanted to be informed about their life expectancy and a small majority of respectively 63% and 57% wanted information about palliative care and end-of-life decisions with a possible or certain life-shortening effect (ELDs). These findings are consistent with other studies of cancer and advanced cancer patients (1-5). When asked who should give the information, 94% of patients indicated the specialist, which was not surprising since the specialist was the main treating physician. Almost half of the patients also wanted information from the GP and only 10% indicated nurses as possible informants besides the physician. We also asked the patients who they thought should raise the issues and thus initiate the communication. Almost 60% of patients wanted the doctor to raise the issue, 28% wanted to initiate the communication themselves and 12% saw it as a shared responsibility. This is an important finding given previous studies which find oncologists tend not to give delicate information unless it is explicitly requested by the patient (6).

The preferences of the advanced lung cancer patients for participation in medical decision-making were studied with regard to various medical decisions. These decisions were: medical decisions in general, treatment decisions, transfer decisions and ELDs. Patients were asked each time to envisage a recent important decision and to indicate who they wanted to make such a decision: primarily the doctor (doctor control), doctor and patient together (shared control) or primarily the patient (patient control) (7;8). Two findings were of interest. Firstly, the percentage of patients who preferred personal control over medical decision-making increased across the specific medical decisions from 15% for treatment decisions to 25% for transfer decisions and 49% for ELDs, all of which were higher than for medical decisions in general (9%). In other words, physicians who want to meet patients' preferences for participation in medical decision-making should explore these preferences with regard to every type of decision and e.g. not only in general. Secondly, the percentage of patients who wanted doctor control over treatment decisions, and thus wanted primarily the doctor to take the treatment decisions, was very high (63%) compared with what has been found in other studies in patients with cancers other than lung cancer i.e. from one third to half (5;9). This might be due to the fact that lung cancer is seen as one of the most deadly diseases, a view resulting in patients tending to give up control (10-12). Another explanation for the difference might be that in our study patients were asked to envisage important real decisions that were recently made. These were newly diagnosed patients who had recently received the bad news and were confronted with difficult treatment decisions. This might make it more difficult to take control over decision-making. Cultural differences in acceptance of physician paternalism between countries may also explain the different study results (13).

2) Meeting the preferences (chapter 3)

One of the main research questions of this study was whether the information and participation preferences of the newly diagnosed patients had been met by the physician(s) according to the patients themselves. We observed that of the patients who wanted information in general plus about diagnosis and treatment options, almost all reported they received this information. On the other hand, of those who wanted information about chances of cure, three quarters were given information. Furthermore, of those who wanted information about life expectancy, half were given information and of those who wanted information about palliative care and ELDs, one quarter were informed. In comparison: according to analyses of audio tapes of the consultations of 118 incurable cancer patients in Australia, 85% of the patients were given information about the goal of treatment and only 57% about life expectancy (14). It seems that physicians are less inclined to provide information relating to death or short life expectancy, despite the patients' preferences for such information, than information with regard to 'fighting the disease' and 'treatment options' (15;16).

The patients who received information in our study were asked whether they were satisfied with the information received and this was the case for most patients in all topics: the percentages of satisfied patients ranged from 88% (with regard to treatment options) to 96% (with regard to chances of cure). High scores of satisfaction with communication and information have also been found in a lot of other studies of cancer patients and might be partly due to ceiling effects of satisfaction instruments as well as to the fact that many patients cannot make comparative judgments because they are only familiar with one oncologist or pulmonologist (17). We also asked the patients whether their physician had asked of them if they required information and how much: only 16% of patients indicated however that this was the case. For the remainder, this may be in contradiction with the truth-telling guidelines in medical literature that advise physicians to elicit patients' preferences for information before actually imparting it (18-20).

With regard to participation in medical decision-making (in general, about treatment, transfer or end-of-life), patients who preferred the doctor to make decisions or those who preferred to make the decision themselves often achieved this (in their perception), while those who wanted an in-between position with some involvement often did not. A possible explanation is that patients who prefer some involvement instead of doctor control or patient control over decision-making are more critical and more open to nuances and for this reason will more often indicate that their preferences for involvement were not met. It is also possible that physicians are not well able to interact with patients and make decisions together, although this model of shared-decision-making is endorsed in the medical literature (21;22).

We compared the quality of life of patients whose preferences were met with the quality of life of those whose preferences were not met – for every information and participation preference – and found no significant differences in mean quality of life between the two groups. One exception concerned the preference for information about chances of cure: patients who wanted to know about their chances of cure and were informed had a higher quality of life than those who wanted to know and were not informed. However, this finding does not allow us to conclude that giving information about chances of cure to patients who want this information has a positive effect on the quality of life of these patients. The found relationship might be a reverse one with physicians giving more information to patients with a higher quality of life. It is also possible that the patients are given incorrect positive information, readily explaining the higher quality of life.

3) Changing preferences (chapter 4)

Although the patients as a group did not change much over time towards wanting more or less information or participation, individual patients did. To assess this change on an individual level, we selected the 67 patients who were interviewed three consecutive times during the first four months after diagnosis of NSCLC IIIb or IV. With regard to the information preferences, we observed that almost all of the patients wanted and kept on wanting information in general and about diagnosis, treatment options, chances of cure and life expectancy during the first four months of the disease. This suggests that physicians should regularly re-inform and update their patients about these topics. In contrast, the preferences for information about palliative care and ELDs changed over time: one quarter of the patients who did not want this information initially, did so after four months, while 40% (palliative care) and one quarter of patients (ELDs) who initially wanted this information changed to not wanting it any longer.

We observed that younger patients were more likely to want information about palliative care and ELDs over time from an initial position of not wanting the information. A possible explanation is that younger patients are more open to receiving information regarding death. Patients who had no partner were also more likely to change from not wanting to later wanting information about palliative care and ELDs: this may be because these patients are more independent or have to rely more upon themselves for the organisation of their care. With regard to the more surprising change over time from wanting to *no longer wanting information* about palliative care and ELDs, no relationship was found with being informed by the physician: only a very small fraction of the patients who changed from wanting to not wanting information about these topics reported they were given information earlier. Rather, the physical condition of the patient was important: those patients who functioned better physically were more likely to change over time from wanting to not wanting the information, maybe because they felt that information about palliative care and ELDs was not yet relevant to them. This also may imply that these patients will change again to wanting this information about palliative care and ELDs when their conditions worsen.

The preferences for participation in medical decision-making were also unstable: 50% to 78%, depending on the type of decision (general, treatment, transfer or end-of-life), changed their preference towards wanting more or less participation over a period of four months. Patients who had more pain were more likely to change towards wanting more participation, at least in medical decisions in general and in transfer decisions. Therefore pain seems to be a trigger to patients to become more involved which contrasts with studies suggesting that patients give up more control when they become more ill (12;23). It also contrasts with a previous finding of this study in chapter 1 that patients with pain tended to want less involvement in treatment decision-making than those without pain. More research is needed to explain these discrepant results.

To conclude, a lot of patients changed their information and participation preferences over time over a period of four months. This suggest that these preferences are not stable personality traits but rather variable states that are influenced by situational factors such as physical functioning and pain among, probably, many other factors. For this reason, physicians cannot rely on their first impressions of the patients to determine whether and to what degree they will inform and involve them. Rather, they have to re-evaluate a patient's preferences for information and participation regularly over time.

4) Preferences for involvement of family (chapter 5)

Sixty-nine percent of the studied advanced lung cancer patients indicated that they wanted family members or close friends involved in medical-decision making besides themselves and the physician. This percentage did not change significantly over time, at least not until the end of the follow-up period of more than a year after inclusion. In other words: clinical specialists will always have approximately one third of their advanced cancer patients preferring that their family is not involved. This does not mean that patients do not change their opinion over time and go from not wanting to wanting family involvement or vice versa. In fact, after a period of two months, between the first and second interview, a relatively low percentage of the studied patients (18%) changed their minds, and a similar proportion did between the next subsequent interviews. Predictors of wanting family involvement were having a partner and having (or evolving to) a lower level of physical functioning.

Practically all patients said they wanted their family to be involved in medical decision- making, besides the physician, if they became unable to participate themselves because of e.g. coma or cognitive decline. Most of these patients wanted their family involved to a high degree: 41% of patients wanted their family to share the decision-making with the physician, 36% wanted primarily their family to take the decisions, while only 23% wanted primarily the physician to take the decision. This is comparable with the results of a US study on this topic (24). In our study however, we also observed that almost half of the patients changed their preferred involvement of family at some time between interviews (over intervals of two months), either towards wanting more or wanting less family involvement. Female patients, patients who functioned better emotionally than others and those who had a higher level of pain were more likely to change towards wanting more involvement of their family over time. However, it has to be noted that these characteristics can only very partially explain why patients shift their preferences. This means that the physician should regularly re-discuss the patient's preferred degree of involvement of family in medical decision-making in case of future incompetence.

Worthy of note is that we asked the patients whether they had discussed the involvement of family in medical decision-making in case of future loss of competence with the physician (not in manuscript). Thirty-five of the 128 patients reported they had discussed this during their illness trajectory, be it mostly only with either the GP or the specialist and seldom with both. On the basis of a survival analysis of the data (Kaplan Meier) the probability of advanced lung cancer patients discussing involvement of family with the physician in case of future incompetence was 11% at two months after diagnosis, 28% after six months and 44% after one year. This leads to the question how the physicians are able to know what their patients want in regard to decision-making at the end of life when this is not discussed? Another study on family-physician conferences in the context of incapacitated patients showed that physicians also seldom discussed what role the family wanted to play in decision-making (25). It seems that talking about the procedure of decision-making, rather than about the content of the decisions, is not yet part of physicians' communication behavior.

8.1.2. Actual involvement in end-of-life decision-making (chapter 6)

After the death of the patient, the specialists and the GPs were asked whether the patient had actually been involved in ELDs. Eighty-five patients who died within 18 months of diagnosis were studied (88% response rate). In 52 of these (61%) an ELD was made. According to the physicians, half of those who were competent at the time of decision-making were not or hardly involved, one quarter shared the decision with the physician and one quarter made the decision themselves. In half of the incompetent patients, family was not involved in the decision-making.

These proportions of involvement of the patients and their family seem low compared to what can be seen in all deaths in Flanders, Belgium (i.e. cancer and non-cancer deaths): a recent nationwide ELD incidence study showed that 67% of competent patients and 77% of family in incompetent patients were involved in the end-of-life decision-making (26).

We compared the actual involvement of the advanced lung cancer patients in the decision-making with their preferences for involvement and we observed that 50% of the competent patients wanted more involvement and 7% wanted less. With regard to family, practically all patients wanted their family involved in case of future incompetence , and thus half did not achieve this preference. These results suggest that open and timely discussions with patients with regard to ELDs and involvement in ELDs are necessary to ensure that the autonomy of patients with advanced lung cancer at the end of life is respected.

Competent patients were more likely to be involved in ELD-making when they were younger and when they were palliatively treated at inclusion rather than with life-prolonging intent (27). Involvement in decision-making was also related to the nature of the ELD. When the ELD shortened life by more than one day, it was more likely that patients were involved. This indicates that, although physicians might not respond well to a patient's preferences for involvement, they still act with care and do not make, or report having made, life-shortening decisions when the life-shortening is substantial.

8.1.3 Wishes for euthanasia, requests and implementation of requests (Chapter 7)

After the death of the patient, the specialists as well as the GPs were also asked whether the patient had expressed a wish for euthanasia to them, whether this was an explicit and repeated request and whether this request had led to euthanasia. The physicians reported that one fifth of the studied advanced lung cancer patients who died within 18 months after diagnosis had expressed a wish for euthanasia during their illness trajectory. Most of these patients who had expressed a wish for euthanasia also had explicitly and repeatedly requested euthanasia (14% of all patients), suggesting that an expressed wish for euthanasia in patients with advanced lung cancer often reflects determination. The patients who had made an explicit and repeated request received euthanasia in half of the cases (in 8% of all patients). This means that an explicit and repeated request does not automatically lead to euthanasia. One problem we encountered in this context in some cases is that the specialist was not aware of the existence of a euthanasia wish and request, while the GP was. Patients who only expressed a wish for euthanasia but did not make explicit and repeated requests on the other hand did not receive euthanasia. It seems that physicians are careful in implementing euthanasia and comply with the legal requirement for repeated requests (28).

We examined in more detail the characteristics of the patients who expressed a wish for euthanasia and received euthanasia. The age, sex and educational level of the patients were not associated with the expression of a euthanasia wish. We did observe however that patients who were treated with palliative intent early on in the disease process and patients who lived longer were more likely to express a wish for euthanasia and to receive euthanasia.

The incidence of the different ELDs in the advanced lung cancer patients, i.e. euthanasia and also withholding or withdrawing potential life-prolonging treatment, intensified alleviation of symptoms, physician assisted suicide and ending of life without patient request, were similar to those in the total population of cancer patients in Flanders (29). Because of the similarities, it might be that our conclusions also apply to the larger population of cancer patients in Flanders.

8.2 Strengths and limitations of the study

This study has several strengths and limitations. The most important are discussed below.

8.2.1 Strengths of the study

A strength of the study is that patients with a disease with limited life expectancy were studied and more specifically patients with advanced lung cancer. These patients have never been studied before with regard to information provision and participation in medical decision-making, despite the high incidence of the disease and the fact that lung cancer is perceived as one of the most brutal cancers (10;11). Instead, patients with breast cancer and, to a lesser extent, those with prostate cancer and colorectal cancer have particularly been the object of research on information and participation in decision-making thus far. This is probably because breast cancer patients tend to organise themselves more in advocacy groups than e.g. lung cancer patients do (5;30-33).

Another strength of the study is that we did not only study the patient's preferences for information with regard to diagnosis, treatment and prognosis, but also with regard to the topics of palliative care and end-of-life decisions with possible life-shortening effects (ELDs). These topics, pointing clearly to the end of life and limited life expectancy, are especially delicate to study because patients might not want to be confronted with their own mortality (34). For this reason, we took several precautionary measures to enable this line of questioning without burdening patients or interfering with the physician-patient relationship. These consisted of conducting face-to-face interviews with the patients rather than only administering questionnaires, by training experienced health-care professionals such as psychologists and nurses in doing these interviews, by following up the interviewers through audiotapes of the interviews etc. Overall patients received the questions well and with one exception did not verbally express resistance to these questions according to the audiotapes. This in itself is an important study finding because it indicates that the fear expressed by physicians that many advanced cancer patients might be emotionally unable to talk about delicate end-of-life topics is not justified (6;35;36).

With regard to patients' preferences for participation in medical decision-making, we did not only study the participation preferences in medical decisions in general or in relation to treatment decisions, but also the participation preferences in transfer decisions and in ELDs. These latter decisions are considered to be as important for patients who are incurably ill and have a limited life expectancy as decisions regarding treatment (17).

This study is one of the first to measure the information and participation preferences of the patients on a regular basis, throughout the illness trajectory. To our knowledge, there is only one other longitudinal study that has measured information and participation preferences at different time points, but it only measured before and after a consultation and before a second consultation (23). In our study, we repeated the interviews regularly up to a maximum of six times, with time intervals of 2 and 4 months. The reasons for the lack of longitudinal studies in an otherwise elaborately documented field of research is probably to be found in the cost and energy consuming side of longitudinal studies (37;38). However, knowing whether and to what degree preferences change over time and determinants of these changes, including quality of life of the patients as a possible determinant, is acknowledged to be essential as much for scientific reasons as for reasons of improving the practice of physicians. In this study we were able to follow up a substantial number of patients without a high drop-out rate for reasons other than death or being too ill.

A strength of the study related to its design was the attempt to study a representative sample of advanced lung cancer patients. For practical reasons it was not possible to draw a random sample of advanced lung cancer patients out of the population of advanced lung cancer patients. Instead, we approached all hospitals with an oncology program, because most cancer patients are treated in these hospitals, and of these hospitals three university and 10 general hospitals agreed to participate. The participating pulmonologists and oncologists were subsequently asked to screen all consecutive patients with advanced lung cancer (i.e. NSCLC, IIIb or IV) during one year. Reasons for non-participation of hospitals or patients, together with additional information such as socio-demographics of these patients, were also gathered to be able to make inferences with regard to the generalisability of the findings in our study sample to the whole population of advanced lung cancer patients.

A final strength of the study is that we did not only follow up the patients during their illness but also gathered information regarding their death through questioning the pulmonologist/oncologists and GP immediately after death. In this manner we were able to form a complete picture of the trajectory of the patient. More specifically it allowed us to know whether patients were involved in end-of-life decision-making according to the physician and whether this corresponded with their earlier stated preferences for involvement in these decisions. We also studied the practice of euthanasia in more detail than is usual, by asking the physicians not only to report the number of euthanasia cases, but also to give information with regard to patients' wishes and requests for euthanasia and the relationship between wishes, requests and implementation of requests. The design used for the physician survey also offered some advantages. We did not only question one physician, e.g. the GP or the specialist, but both physicians, giving us information on e.g. discrepancies between physicians, and enhancing the chances that information comes from the best possible source. Also, the physicians were asked to fill in the questionnaire immediately following patient's death, which prevented recall bias.

8.2.2 Limitations of the study

A limitation of the study is the limited generalisability of the data to the whole population of advanced lung cancer patients. There are several reasons for this. Firstly, hospitals with an oncology program were approached for participation in the study because most patients with lung cancer are treated in these hospitals. However, this does not mean that lung cancer patients may not be treated in hospitals without such a program or by physicians who are not affiliated to a hospital. Secondly, a number of hospitals refused to participate because of lack of interest or because of fear of that the study was too burdensome for the patients. Thirdly, some participating physicians might have omitted to screen some patients for participation in the study. Fourthly, the patients who were included in the study had a higher performance status and estimated life expectancy than those within the inclusion criteria who were not asked to participate or refused participation. Included patients who were interviewed had a better performance status than those not interviewed.

We administered the questionnaires in face-to-face interviews with the patients and thus did not use questionnaires that patients had to fill in on their own and send back to the researchers. This was done for ethical reasons and for reasons of response. However, a limitation of the use of patient interviews instead of self-administered questionnaires is that patients might have been inclined to give socially desirable answers in the presence of an interviewer, despite the guaranteed anonymity.

In the study, we compared the information and participation preferences of the patients with their assessments of the achieved level of information and participation. A limitation of this comparison was that patients' preferences were assessed after the consultations: these preferences may have been influenced by information received and decisions taken since then, giving physicians no time to assess and meet the new preferences. We also made a comparison between patients' preferences for participation in end-of-life decision-making and the actual participation according to physician reports after the patients had died. A limitation of this is that we did not ask the patients themselves whether their involvement preferences were met because this would have required a different study design that would have been difficult to organise for practical and ethical reasons: most patients were in a bad condition at the time of the decision-making and often died shortly after the decision was made.

When studying the change over time in the information and participation preferences on population level we used the statistical LOWESS technique (39). Although this technique depicts possible change clearly in a curve, it is only descriptive and does not allow for statistical significance statements. When looking at the change at the individual level, we only analysed the first three interviews in detail due to the low number of patients continuing beyond three interviews. Limitations of this are that not all data are used and that no inferences can be made beyond the first four months after diagnosis with regard to change in preferences. The more sophisticated longitudinal statistical technique of random coefficient analysis was used when studying the change in preferences for involvement of family and other persons in medical decision-making (40;41). This technique did allow for statistical significance statements with regard to change on population level. All data were also used. A disadvantage however is that an analysis of the determinants of change is more difficult because the resulting odds ratios of the technique can be interpreted cross-sectionally as well as longitudinally and that it cannot be discerned which interpretation is the true one (40).

A final limitation concerns the study of the association between the preferences of the patients and the socio-demographic and clinical patient characteristics. In all of the analyses we explored the association with *several* patient characteristics enhancing the likelihood of finding associations that are not existent on population level. Therefore the individual *P*-values cannot be taken for granted. To remedy this problem, we limited the number of patient characteristics under consideration and always considered the overall pattern of the results.

8.3 Recommendations for clinical practice and future research

8.3.1 Practice recommendations

On the basis of the findings of this study, recommendations can be made to improve information provision to patients and patient participation in medical decision-making according to their preferences. The objectives of these improvements are to optimise physician-patient communication in patients with a life-threatening disease.

The recommendations are listed below and are specifically directed at physicians treating patients with advanced lung cancer. Of course, physicians are not the only party responsible for optimal communication: responsibility lies with all parties involved including patients, family, other health-care professionals than the treating physician, and the broader context of all these persons. This also means that recommendations can be made to all these persons or organisations involved. Such recommendations are however beyond the scope of this thesis.

1) Explore the preferences of the patients with regard to every important information topic and type of decision and explore them regularly over time

There is consensus in medical literature that patients' preferences for information about their disease and prognosis and for participation in medical decision-making should be respected for ethical reasons and for reasons of the well-being of the patient, certainly when patients are confronted with a life-threatening disease such as cancer (42). In this context a lot of studies have been done to examine the preferences of cancer patients for information and participation and these studies show that patients vary in the degree to which they want to be informed and to participate in medical decision-making. This led to the recommendation that physicians should always explore in every patient to what degree he or she wants to be informed and involved before effectively informing and involving him or her. Our study is the first to show that cancer patients' information and participation preferences – and more specifically those of advanced lung cancer patients - differ depending on the information topic and the decision situation. The patients we studied had a high preference for information but less with regard to the topics of palliative care and ELDs, and their preference for participation became stronger over the medical decisions, from medical decisions in general, to treatment decisions, to transfer decisions to end-of-life decisions. An important recommendation for physicians is thus that they should explore the information and participation preferences of their patients with regard to every information topic and every decision situation, at least in patients who are seriously ill and in which cases information and decision-making regarding treatment, location of care and end of life are important.

The study is also one of the first to show that preferences for information and participation are unstable over time. More specifically, over a period of the first four months of the disease, half of the advanced lung cancer patients had changed their information preferences regarding palliative care and ELDs from wanting to not wanting information or vice versa, and more than half had changed their participation preferences between wanting doctor control, wanting shared control and wanting personal control over medical decision-making. Several patient characteristics (e.g. age, quality of life) were associated with the preferences of the patients and with change in these preferences but these characteristics only explained a small part of the observed variation. For this reason, physicians cannot rely on these patient characteristics alone in discovering what the patient will prefer. Instead, it is recommended that physicians check their patients' preferences regularly over time to be able to meet them.

A question that can be asked is *how* physicians should explore their patients' preferences. Studies have shown that physicians are not well able to assess a patient's information and participation preferences (43-45). Also in this study there was a low correlation between pulmonologists' or oncologists' assessment of the information and participation preferences at inclusion in the study and patients' reports of these preferences at the time of the first interview (results not in thesis). An important specific recommendation for physicians to improve their ability to meet patients' preferences is therefore to actually engage with the patient in meta-communication by openly asking the patient how much information or involvement he or she wants, certainly at the time that difficult news is to be imparted or major decisions have to be made as well as when the physician thinks the patient might want more or less information or participation that he or she is getting. This is not standard practice yet as our study shows: most patients reported that their physicians had not asked them how much information or involvement they wanted.

2) End-of-life communication training is necessary

Patients reported that their information and participation preferences were rather well met, with the exception of preferences for information about delicate topics and preferences to share decisions with the physicians. More research is needed as to the reasons why. With regard to informing patients about prognosis, some studies have been done. These studies indicate that physicians do not inform their patients despite their wish to be informed for several reasons such as discomfort talking about prognostic issues, uncertainty about the disease trajectory and concern for a negative impact on the patient (6;15;46;47). With regard to sharing decisions with patients, no studies have specifically been done on why this is problematic, but one of the reasons might be that physicians find it difficult to interact with patients. An important recommendation to be made to physicians is to check whether these problems also arise in their practice and to address the reasons for them.

Overall, it is not surprising that physicians encounter difficulties in performing the complex and demanding tasks of giving the patient bad news and sharing decisions with them. Both communication tasks require a set of specific communication skills that are not commonly used and have to be taught (48). However, only a few physicians have received formal education or training in end-of-life communication. Recently, several educational programs for physicians and other health-care professionals have been developed and tested for their ability to affect end-of-life communication skills. A controlled trial of a British three-day residential communication skills training for oncologists found significant improvement in the question-asking skills of the oncologists and in their ability to respond to patient emotions (49). A US study of a short course to improve physicians' communication with residents at the end of life demonstrated statistically significant increases in their overall skill ratings in the delivery of bad news, with improvement in the specific areas of information giving and responding to emotional cues (50). In other words, the evidence seems to indicate that physicians actually can improve in giving bad news and in medical decision-making with the patient when they actively and intensely exercise these communication tasks in small groups with other physicians under the supervision of a communication specialist.

3) Acknowledge the importance of family

Most studied patients wanted their family to be present when the physician gave information about the disease and treatment. Two thirds also wanted their family involved in the medical decision-making. It seems that seriously ill patients have a need for trusted allies to be present in dealings with the physicians. It is important that physicians acknowledge this need and thus also inform and involve the family members of the patient to the degree the patient wants this. We observed that one third of the patients who wanted their family involved in medical decision-making had not achieved this. More research is needed as to the reasons why, but it is also important that the physicians themselves explore why some patients who desire their family to be involved do not succeed in this. These patients might be more vulnerable than others and require more support from the physician.

With regard to family involvement in decision-making in case the patient becomes incompetent in the future, patients differed in the degree they wanted their family involved: most wanted an important, decisive role for their family, but others wanted primarily the physician to take the decision. Physicians are therefore recommended to have timely discussions regarding the end of life with their patients and to specifically ask them which role they want for their family – and for which family member - in case of future incompetence. A complication however is that patients tend to change their preferred degree of family involvement over time. Therefore, physicians should tell their patients that a change in preferences is not uncommon and can at all times be re-discussed with the physician.

4) Discuss ELDs in a timely fashion with the patient

End-of-life communication comprises a lot of specific tasks for physicians and one of these tasks is to discuss ELDs with their seriously ill patients (38). As defined earlier, ELDs are those decisions made at the end of life that potentially or certainly shorten life and are often made in the case of cancer patients (51). In the studied advanced lung cancer patients for instance, these decisions were made in 61% of cases. Respect for patient autonomy requires physicians to discuss these decisions with their patients.

However, in our study, only a small proportion of the patients discussed and made ELDs in advance with the physician. The decision under consideration in most cases concerned euthanasia while other ELDs, e.g. withholding or withdrawing potentially life-prolonging treatment or intensifying alleviation of pain and symptoms, were not discussed. This emphasis on euthanasia is probably due to the increase in attention paid to euthanasia in Belgium over the last decade, leading to the Belgian euthanasia legislation of 2002 (28). A majority of patients did want information on the different ELDs early on in the disease trajectory, but a lot of them reported they were not given the information they required. This raises the question, among others, of whether physicians themselves have enough knowledge with regard to ELDs. Most patients also definitely wanted to be involved in ELDs, but we saw at the end of life that only half of them were actually involved according to the specialist or GP. It is an important recommendation in this context that physicians speak in good time with their patients about ELDs, where the patient actually wants to, because it is indeed difficult to begin the discussion on ELDs at the time of the actual decision-making when the patient is frail and has not been prepared for such discussions.

Discussing ELDs requires communication skills that can be taught in communication training, but also requires a lot of medical, ethical and legal knowledge. In medicine that is traditionally oriented at cure and life prolongation, it cannot be taken for granted that all physicians are fully aware of the ELDs that can be made, what the legal status of the different ELDs is and how concerns of the patients can be translated in advance care planning. The End-of-Life Care Research Group of the Vrije Universiteit Brussel and the Ghent University has drawn up specific guidelines that provides physicians with information about ELDs and how to discuss them (52;53). The advantage of these guidelines is that they are adapted to the Belgian situation with its specific laws on patient rights and euthanasia (28;54). This specificity is important since Belgium has a unique position in the world as one of the few countries that legally allows euthanasia under certain conditions.
A disadvantage of the guidelines is that they are only directed at GPs and not at oncologists and pulmonologist or other specialists. This study of patients with advanced lung cancer can be used as a basis to adapt the existing guidelines in the future to oncologists and pulmonologists. It is recommended that these physicians

and specifically, in the first instance, those who often treat patients with limited life expectancy, incorporate these guidelines.

8.3.2 Research recommendations

Several recommendations can be made for future research and some of these are described below.

1) Filling the theoretical gap

The research with regard to physician-patient communication and decision-making is predominantly explorative and oriented at clinical practice and is less theory-driven compared to some other fields of health research. This does not mean that the studies do not depart from models and theories of communication and psychology. Points of departure in this study were evidently the models of paternalistic, shared and informed decision-making, but also – be it implicitly- values and principles of Rogerian counseling (e.g. the importance of meeting and exploring preferences), aspects of system theory (e.g. the importance of family) and aspects of other psychological disciplines (e.g. explaining the relationship between behavior and outcomes) (55-57). However, a developed and refined model of patient-physician communication and more specifically of information provision and medical decision-making that orients the research is lacking and needs to be systematically developed.

2) Need for additional studies in other patient groups

The advantage of this study is that many new and important topics were investigated regarding end-of-life care and change in information and participation preferences over time, but this was done in a specific population of advanced lung cancer patients. It can be questioned whether the findings of this study can be generalised to patients who suffer from cancers other than lung cancer or to all incurably ill patients with a disease with limited life expectancy. This makes replication studies in other patient groups necessary.

Also, as in many other studies on information and participation preferences, we excluded specific groups such as patients who are not able to speak Dutch (probably excluding in this way a lot of immigrants) or patients with psychiatric problems. These patient groups might be very different in the degree they want to be informed and involved in medical decision-making compared to the studied patients (15;58).

3) Focus groups clarifying why preferences are not met

Several study findings are in need of further clarification. We observed for instance that advanced lung cancer patients who preferred to share the important medical decisions with regard to treatment, health-care setting transfers and the end of life often reported that they did not achieve this. Reasons for this are however not yet clear. Similarly, it was observed that one third of the patients who also wanted their family involved in medical decision-making besides themselves did not achieve this, but it is not yet known why this is. Focus groups with patients, family members and physicians can lead to additional insights into existing communication problems and to new suggestions for how to address these problems.

4) Interventional research

This study has pointed to several fundamental communication problems and challenges that exist in the advanced lung cancer setting, e.g. problems with informing patients about prognosis and end-of-life care, problems with shared decision-making, and the lack of involvement of patients in end-of-life decision-making. In follow-up research it would be useful to make interventions for physicians or patients that address these problems and to test these interventions in randomized controlled trials. Such interventional research would enhance insight into the existing problems and provide an evidence-based tool for clinical practice. With regard to giving bad news to the patient for instance, several interventions have already been made and tested such as communication skills training programs for physicians. These interventions should be updated on the basis of our study findings e.g. with regard to decision-making and end-of-life options.

The interventional research should not only examine the relationship between interventions and improved communication, i.e. improved information provision and medical decision-making, but should also examine the relationship between improved communication and important patient outcomes at the end of life, such as satisfaction, quality of life and survival of the patient (38). In our study we specifically looked at the relationship between meeting patients' information and participation preferences and patient quality of life. This descriptive way of studying the relationship between behavior and patient outcomes has its merits but is also limited because no inferences can be made with regard to the causality of the relationship. Randomized controlled trials can give strong evidence for causal relationships between optimal communication on the one hand and positive patient outcomes on the other.

A recent randomized controlled trial found evidence for a positive causal relationship between the early initiation of palliative care and the patient outcomes quality of life and survival (59). More specifically, the study randomly assigned patients with newly diagnosed metastatic non–small-cell lung cancer to receive either palliative care integrated with standard oncological care or standard oncological care alone. The researchers found that the palliative care group did better with regard to quality of life as well as with regard to median survival. This is an important finding in the context of communication research because several authors consider the timely initiation of palliative care to be an important intermediate outcome of optimal physician-patient communication at the end of life.

5) Increased attention to the role of family

Our study indicated that advanced lung cancer patients attach great importance to their families in the information provision and medical decision-making. More in-depth studies are needed as well to patients' preferences for family involvement as to which role the families actually play in e.g. remembering information for the patient and discussing treatment or care options with the patient. It would be of particular interest to examine how physicians can make optimal use of the family of the patient in order to improve patient care and patient outcomes.

6) Coping styles and information and participation preferences

An important finding of this study is that the type of information and the type of decision, and thus the situational factors, were important in relation to the information and participation preferences of advanced cancer patients. We also observed that several socio-demographic and clinical patient characteristics (e.g. age, physical condition) were associated with patients' preferences and change in preferences over time. In this study however we did not examine the effect of personality traits such as coping styles on the preferences of the patients. Some studies have already shown that cancer patients with monitoring coping styles, defined as coping by cognitive confrontation with the life-threatening illness, were more likely to want involvement in medical decision-making (60). In future research, it would be of interest to further explore this relationship between coping style and participation preferences, especially in the specific situation of patients with a disease with limited life expectancy such as advanced cancer.

8.4 References

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Chapter 9:
Nederlandstalige samenvatting

9.1 Inleiding

Veranderingen in publieke opinie, wetgeving en deontologie van artsen hebben ertoe geleid dat de arts niet langer gezien wordt als iemand die het het beste weet, maar wel als iemand die zijn of haar patiënt informeert en betrekt bij de medische besluitvorming. Ook in de wetenschappelijke literatuur focust men op modellen van 'gedeelde besluitvorming' als alternatief voor het zogenaamde paternalistische model. De vraag rijst echter of patiënten in de laatste fase van hun leven wel volledig willen geïnformeerd worden, of volledig willen betrokken worden in de vaak moeilijke medische besluitvorming. Sommige auteurs stellen dat de wens om niet geïnformeerd of betrokken te worden evenzeer behoort tot de autonomie van de patiënt, en dat het opleggen van modellen van 'gedeelde besluitvorming' een negatieve invloed kan hebben op de relatie tussen dokter en patiënt.

9. 2 Doelen en onderzoeksvragen

Het hoofddoel van dit onderzoek is inzicht te krijgen in de wensen van patiënten met gevorderde longkanker m.b.t. informatie over hun diagnose, prognose en behandeling, en m.b.t. participatie in de medische besluitvorming. Patiënten met longkanker in een gevorderd stadium werden bestudeerd omdat ze een homogeen ziekteverloop hebben met een beperkte levensverwachting van 6-9 maanden.
De onderzoeksvragen zijn:
1. In welke mate willen gevorderde longkankerpatiënten geïnformeerd worden in het algemeen en specifiek over diagnose, kansen op genezing, levensverwachting, behandelingsopties, palliatieve zorg en medische beslissingen aan het levenseinde met een mogelijk of zeker levensverkortend effect (MBLs)? In welke mate willen deze patiënten betrokken worden in medische beslissingen in het algemeen en specifiek in behandelingsbeslissingen, beslissingen m.b.t. de plaats van zorg en MBLs? (Hoofdstuk 2)
2. In welke mate wordt aan de informatie- en participatiewensen tegemoetgekomen volgens de patiënt? (Hoofdstuk 3)
3. Veranderen de informatie- en participatiewensen over de tijd, gedurende het ziekteproces? (Hoofdstuk 4)
4. Wat zijn de wensen van gevorderde longkankerpatiënten m.b.t. het betrekken van familie of andere personen in de medische besluitvorming? (Hoofdstuk 5)

Een eerste secundaire doelstelling van het onderzoek is na te gaan in welke mate patiënten met gevorderde longkanker effectief betrokken zijn in MBLs (Hoofdstuk 6). Een tweede secundaire doelstelling is inzicht te verkrijgen in de mate waarin de patiënten euthanasie wensen, de mate waarin deze wensen leiden tot expliciete en herhaalde verzoeken voor euthanasie en de mate waarin verzoeken worden uitgevoerd (Hoofdstuk 7).

9.3 Methode: een longitudinale multicentrum-studie

Pneumologen en oncologen van 3 universitaire en 10 algemene ziekenhuizen in Vlaanderen werden geïnstrueerd om gedurende een jaar elke nieuwe patiënt met longkanker in een gevorderd stadium (i.e. niet-kleincellige longkanker, stadium IIIb of IV) te vragen om deel te nemen aan de studie. Andere inclusiecriteria waren: de patiënt moet Nederlandstalig zijn, meerderjarig, en fysisch en psychisch in staat om deel te nemen aan de studie. Nadat de patiënt zijn schriftelijke akkoord had gegeven voor deelname, vulde de pneumoloog of oncoloog – gedeeltelijk samen met de patiënt – een vragenlijst in om sociodemografische en klinische patiënt-karakteristieken te meten.

Binnen de twee weken na inclusie van de patiënt in het onderzoek, nam een getrainde interviewer contact op met de patiënt, werd een datum voor interview afgesproken en werd de patiënt geïnterviewd. Het interview werd herhaald om de twee maanden tot het vierde interview en om de vier maanden tot het zesde interview. Het interview gebeurde aan de hand van een gestandaardiseerde vragenlijst met gesloten vragen en bestond uit verschillende instrumenten die respectievelijk het volgende beoordeelden: de kwaliteit van leven van de patiënt, de informatie- en participatiewensen van de patiënt en het gepercipieerde informatie- en participatieniveau.
Wanneer de patiënt overleed, werden zowel de specialist als de huisarts gevraagd een vragenlijst bij overlijden in te vullen. Deze vragenlijst beoordeelde o.a. MBLs, de betrokkenheid van patiënten en familie bij MBLs en de mate waarin patiënten euthanasie wensten en verzochten.

Het protocol van de studie werd goedgekeurd door de Ethische commissies van het Universitair Ziekenhuis Brussel en van alle deelnemende universitaire en algemene ziekenhuizen.

9.4 Resultaten en bespreking van de resultaten

We slaagden erin 128 recent gediagnosticeerde gevorderde longkankerpatiënten te interviewen kort na hun inclusie in de studie. Van de 128 patiënten werden er 97 een tweede keer geïnterviewd, 67 een derde keer, 43 een vierde keer, 29 een vijfde keer en 13 een zesde keer. De drop-out van patiënten tijdens de interviewperiode was te wijten aan sterfte (n=73) en in mindere mate ook aan ziekte (n=20) of andere redenen (n=22) zoals bijvoorbeeld gebrek aan interesse. Van de 128 patiënten stierven er 97 binnen de 18 maanden na diagnose van de longkanker. Informatie over de dood was beschikbaar voor 85 patiënten.

De 128 patiënten hadden een gemiddelde leeftijd van 64 jaar, gaande van 41 tot 86 jaar. Tachtig procent was mannelijk en drie vierde had een partner. De mediaan van de geschatte levensverwachting door de arts bedroeg 10 maanden sinds inclusie, gaande van 2 tot 24 maanden.

9.4.1 Informatie- en participatiewensen van gevorderde longkankerpatiënten

1) Informatie- en participatiewensen kort na diagnose

Een eerste belangrijke bevinding van het onderzoek is dat de bestudeerde longkankerpatiënten een hoge nood aan informatie hadden. Bijna alle patiënten wilden informatie over diagnose, behandelingsopties en kansen op genezing, 88% wilde informatie over levensverwachting en een kleine meerderheid van 63% en 57% wilde informatie over palliatieve zorg en MBLs. Wanneer gevraagd werd aan de patiënten wie de communicatie moest initiëren, antwoordde 60% de arts, 28% de patiënt zelf en 12% zowel de arts als de patiënt. Dit is een interessante bevinding omdat eerdere studies hebben aangetoond dat artsen en met name oncologen niet geneigd zijn delicate informatie te geven aan hun patiënten tenzij ze er expliciet om verzoeken.

De wensen voor participatie in de medische besluitvorming van de gevorderde longkankerpatiënten werden onderzocht m.b.t. medische beslissingen in het algemeen, behandelingsbeslissingen, transferbeslissingen (i.e. beslissingen m.b.t. de plaats van zorg) en MBLs. Patiënten werden bij elke beslissing gevraagd om een recente daadwerkelijk genomen beslissing voor de geest te halen en aan te geven wie zij wilden dat de beslissing nam: voornamelijk de dokter (doktercontrole), dokter en patiënt samen (gedeelde controle) of voornamelijk de patiënt (patiëntcontrole). Twee bevindingen zijn van belang. Ten eerste stijgt het percentage van patiënten dat persoonlijke controle wilde over de specifieke medische beslissingen van 15% bij behandelingsbeslissingen naar 25% bij transferbeslissingen naar 49% bij MBLs, en al deze percentages waren hoger dan het percentage bij medische beslissingen in het algemeen (9%). Met andere woorden, dokters die willen tegemoetkomen aan de participatiewensen van hun patiënten, moeten deze wensen exploreren m.b.t. elke soort beslissing. Ten tweede was het percentage van patiënten dat doktercontrole wilde over behandelingsbeslissingen erg hoog (63%) vergeleken met wat werd gevonden in andere studies van patiënten met andere kankers dan longkanker. Mogelijk is dit omdat longkanker gezien wordt als een van de dodelijkste ziekten, waardoor mensen de controle over de besluitvorming aan de arts delegeren.

2) Tegemoetkomen aan de informatie- en participatiewensen

Een van de belangrijkste onderzoeksvragen van de studie is of aan de informatie- en participatiewensen van de longkankerpatiënten werd tegemoetgekomen volgens de patiënt. We stelden vast dat patiënten die informatie wilden in het algemeen en specifiek over diagnose en over behandeling, deze informatie in de meeste gevallen ook kregen. Anderzijds, van de patiënten die informatie wilden over kansen op genezing, kreeg drie vierde deze informatie; van deze die informatie wilden over levensverwachting was dat de helft; en van deze die informatie wilden over palliatieve zorg en MBLs was dat ongeveer een vierde. Het ziet ernaar uit dat artsen minder geneigd zijn om informatie te geven m.b.t. de dood of beperkte levensverwachting, ondanks de wens van de patiënt voor deze informatie, dan dat ze bereid zijn om informatie te geven m.b.t. behandeling en het aanpakken van de ziekte.

Met betrekking tot participatie in de medische beslissingen, zagen we dat patiënten die doktercontrole wilden en deze die persoonlijke controle wilden over de medische beslissingen dit meestal ook bereikten, terwijl patiënten die een tussenpositie of gedeelde controle wensten, dit vaak niet bereikten. Een mogelijke verklaring is dat artsen minder goed in staat zijn om in interactie te gaan en om samen beslissingen te nemen, ook al wordt dit model van gedeelde besluitvorming sterk gepromoot in de medische literatuur.

3) Veranderende informatie- en participatiewensen

Hoewel de patiënten als groep (i.e. gemiddeld genomen) niet veel veranderden over de tijd naar meer of minder informatie of participatie willen, veranderden individuele patiënten vaak wel. Om deze verandering op individueel niveau te meten, selecteerden we de 67 patiënten die drie achtereenvolgende keren geïnterviewd waren geweest gedurende de eerste vier maanden na diagnose van de longkanker. Met betrekking tot de informatiewensen, observeerden we dat bijna alle patiënten informatie wilden en bleven willen m.b.t. diagnose, behandelingsopties, kansen op genezing en levensverwachting gedurende de eerste vier maanden sinds diagnose van de ziekte. Dit geeft aan dat artsen hun patiënten regelmatig moeten herinformeren en updaten m.b.t. deze topics. De wensen voor informatie over palliatieve zorg en MBLs daarentegen veranderden wel over de tijd: een vierde van de patiënten die initieel geen informatie wilde, wilde dit wel na vier maanden, terwijl 40% (palliatieve zorg) en een vierde van de patiënten (MBLs) die initieel wel informatie wilde, veranderde naar het niet meer willen van deze informatie.

Jongere patiënten en patiënten zonder partner hadden meer kans om te veranderen van het niet naar het wel willen van informatie over palliatieve zorg en MBLs. Met betrekking tot de meer verrassende verandering naar het niet langer informatie willen over palliatieve zorg en MBLs, stelden we vast dat dit niet samenhing met het feit dat deze patiënten geïnformeerd waren geweest in tussentijd, want dit bleek voor slechts een heel klein percentage het geval. Eerder was de fysieke conditie van de patiënt belangrijk: de patiënten die fysisch beter functioneerden, hadden meer kans om te veranderen van wel naar geen informatie willen dan patiënten die slechter functioneerden, misschien omdat ze dachten dat informatie over palliatieve zorg en MBLs nog niet relevant was voor hen.

De wensen voor participatie in de medische besluitvorming waren ook onstabiel: 50% tot 78%, afhankelijk van het type beslissing, veranderde hun wens naar meer of minder participatie willen over een periode van vier maanden. Patiënten die meer pijn hadden, hadden meer kans om meer betrokkenheid te willen over de tijd, tenminste in medische beslissingen in het algemeen en in beslissingen m.b.t. de plaats van zorg.

4) Wensen m.b.t. betrokkenheid van familie

Negenenzestig procent van de bestudeerde gevorderde longkankerpatiënten gaf aan dat ze familie of naaste vrienden wilden betrekken in de medische besluitvorming, naast henzelf en de arts. Dit percentage veranderde niet significant over de tijd, tenminste niet tot het einde van de follow-up periode van meer dan 1 jaar na inclusie.

Bijna alle patiënten zegden dat ze hun familie wilden betrekken in de medische besluitvorming, naast de arts, als ze zelf niet meer in staat zouden zijn om beslissingen te nemen bv. door coma. De meeste van deze patiënten wilden dat hun familie in hoge mate betrokken was: 41% wilde dat hun familie de beslissing samen met de arts nam en 36% wilde dat de familie de beslissing zelf nam, terwijl maar 23% wilde dat het voornamelijk de dokter was die besliste. We observeerden echter ook dat bij bijna de helft van de patiënten hun gewenste mate van betrokkenheid van familie veranderde naar meer of minder betrokkenheid over een periode van twee maanden. Dit betekent dat de arts regelmatig deze gewenste mate van betrokkenheid van familie in geval van toekomstige incompetentie van de patiënt met de patiënt moet herbespreken of moet bespreekbaar houden zolang hij nog competent is.

9.4.2 Betrokkenheid van gevorderde longkankerpatiënten in MBLs

Na de dood van de patiënt werd aan de specialist en de huisarts gevraagd of de patiënt betrokken was geweest in MBLs. In totaal werden 85 patiënten die gestorven waren binnen de 18 maanden na diagnose van de longkanker bestudeerd en bij 52 van deze patiënten was een MBL genomen. Volgens de artsen was de helft van de patiënten die competent waren op het moment van de besluitvorming niet of amper betrokken, had een vierde de beslissing samen genomen met de arts en had een vierde de beslissing zelf genomen. In de helft van de incompetente patiënten was de familie niet betrokken geweest in de besluitvorming.

We hebben deze feitelijke betrokkenheid van de gevorderde longkankerpatiënten vergeleken met hun wensen voor betrokkenheid zoals ze geuit werden in de patiënteninterviews, en daar bleek dat 50% van de competente patiënten minder betrokken was geweest dan gewenst en 7% meer. Met betrekking tot familie wilden bijna alle patiënten dat hun familie betrokken was, maar bij de helft hiervan was dit niet gelukt.

Deze resultaten suggereren dat open en tijdige besprekingen met de patiënten m.b.t. MBLs en betrokkenheid bij MBLs nodig zijn zodat de keuze van de patiënt om al dan niet betrokken te worden, kan worden gerespecteerd.

9.4.3 Euthanasiewensen, euthanasieverzoeken en uitvoeringen van verzoeken

Na de dood van de patiënt werd zowel de specialist als de huisarts ook gevraagd of de patiënt een wens voor euthanasie had geuit, of de patiënt expliciet en herhaaldelijk had verzocht om euthanasie en of dit verzoek had geleid tot euthanasie. De artsen rapporteerden dat een vijfde van de longkankerpatiënten die overleden waren binnen de 18 maanden na diagnose, een wens voor euthanasie had geuit gedurende het ziektetraject. De meeste van deze patiënten hadden ook expliciet en herhaaldelijk om euthanasie verzocht (14% van alle patiënten). Met andere woorden: gevorderde longkankerpatiënten die een euthanasiewens uiten, zijn vaak gedetermineerd in die wens. De patiënten die een expliciet en herhaald verzoek voor euthanasie deden, kregen euthanasie in de helft van de gevallen (8% van alle patiënten). Dit betekent dat een expliciet en herhaald verzoek voor euthanasie niet noodzakelijk en automatisch leidt tot euthanasie. Patiënten die enkel een euthanasiewens uitten, maar er niet herhaaldelijk en expliciet om verzochten, kregen in geen enkel geval euthanasie. Het ziet er met andere woorden naar uit dat artsen zorgvuldig zijn in het toepassen van euthanasie en de wettelijke vereiste van herhaalde en expliciete verzoeken involgen.

We onderzochten meer in detail welke patiënten een euthanasiewens uitten en kregen. Leeftijd, geslacht en opleiding van de patiënten waren niet geassocieerd met het uiten van een euthanasiewens of het krijgen van euthanasie. We zagen wel dat patiënten die behandeld werden – van in het begin van hun ziekte - met een palliatief behandeldoel in plaats van een levensverlengend behandeldoel meer kans hadden om een euthanasiewens te uiten en euthanasie te krijgen.

9.5 Aanbevelingen voor de praktijk

Op basis van de bevindingen van deze studie kunnen we aanbevelingen doen aan artsen om het informeren en het betrekken van de patiënt in medische beslissingen, in overeenstemming met zijn of haar wensen, te verbeteren.
Deze aanbevelingen zijn:

1) Exploreer de wensen van de patiënten met betrekking tot elk belangrijk informatietopic en elke type van medische beslissing en exploreer de wensen regelmatig over de tijd heen

Onze studie is de eerste die laat zien dat de informatie- en participatiewensen van kankerpatiënten, en meer specifiek deze van gevorderde longkankerpatiënten, verschillen afhankelijk van het soort informatie of het type beslissing. De patiënten die we bestudeerden, wilden in grote mate geïnformeerd worden, zij het minder over palliatieve zorg en MBLs. Met betrekking tot participatie in medische beslissingen, zagen we dat de mate waarin patiënten persoonlijke controle wilden over de medische beslissingen veranderde naargelang het type van beslissing: ze was laag bij medische beslissingen in het algemeen, iets hoger bij behandelingsbeslissingen, nog hoger bij transferbeslissingen, en het hoogst bij MBLs. Een belangrijke aanbeveling voor artsen is dus dat ze de informatie- en participatiewensen m.b.t. elk informatietopic en elke beslissingsituatie moeten exploreren, tenminste als ze aan de wensen van de patiënten willen tegemoetkomen.

De studie is ook de eerste om te laten zien dat de wensen voor informatie en participatie niet stabiel zijn over de tijd heen. Daarom is het eveneens aanbevolen dat de artsen de wensen van hun patiënten regelmatig exploreren en bevragen, en niet alleen in het begin van het ziekteproces.

2) Training in levenseindecommunicatie is noodzakelijk

De bestudeerde patiënten gaven aan dat er aan hun informatie- en participatiewensen redelijk goed was tegemoetgekomen, met uitzondering van de informatiewensen m.b.t. delicate topics en hun wensen om beslissingen te nemen samen met de artsen. Er is meer onderzoek nodig naar de redenen waarom dit zo is.

Algemeen echter is het niet verrassend dat artsen moeilijkheden ondervinden in het uitvoeren van complexe en veeleisende taken zoals het geven van slecht nieuws aan de patiënt en het gezamenlijk nemen van beslissingen. Beide communicatietaken vereisen specifieke communicatievaardigheden die aangeleerd moeten worden. Slechts een klein aantal artsen heeft echter een formele opleiding of training in (levenseinde)communicatie gekregen.
Recent zijn er verschillende opleidingsprogramma's voor artsen en andere zorgverleners ontwikkeld en getest op de mate waarin ze een effect hebben op de communicatievaardigheden m.b.t. het levenseinde van de arts. Een gecontroleerd, gerandomiseerd Brits onderzoek van een driedaagse residentiële training in communicatievaardigheden voor oncologen bijvoorbeeld vond een significante verbetering in de vraagstellingscapaciteiten van de oncologen en in hun kunde om te reageren op de emoties van de patiënt. Deze en andere studies geven aan dat de communicatie van artsen effectief kan verbeteren na communicatietraining.

3) Erken het belang van familie

De meeste longkankerpatiënten wilden dat hun familie of naaste vrienden aanwezig waren als de arts informatie gaf over ziekte en behandeling. Twee derde van de patiënten wilde ook dat hun familie betrokken was bij de medische besluitvorming, naast henzelf en de arts. Het ziet ernaar uit dat ernstig zieke patiënten in hun omgang met de artsen nood hebben aan de steun van mensen die ze goed kennen en vertrouwen. Het is belangrijk dat artsen deze nood erkennen en aldus ook de familieleden of vrienden van de patiënt informeren en betrekken in de besluitvorming, tenminste in de mate dat de patiënt dit wil.

4) Bespreek MBLs tijdig met de patiënt

Levenseindecommuncatie behelst verschillende specifieke taken voor de arts. Eén van deze taken is het bespreken van MBLs met hun ernstig zieke patiënten. Zoals eerder gedefinieerd zijn MBLs beslissingen die aan het einde van het leven van de patiënt worden genomen en mogelijks of zeker het leven verkorten. Dit soort beslissingen werd bij 61% van de bestudeerde kankerpatiënten genomen. Respect voor de autonomie van de patiënt vereist evenwel dat artsen deze MBLs met hun patiënten bespreken.
In onze studie zagen we dat slechts een klein deel van de patiënten MBLs op voorhand besproken met de arts. In de meeste van deze gevallen ging het om euthanasie, terwijl andere MBLs zoals het stoppen of niet opstarten van potentieel levensverlengende behandelingen of het opdrijven van de pijn- en symptoom-controle niet werden besproken. De nadruk op euthanasie heeft wellicht te maken met de verhoogde aandacht dat euthanasie in het laatste decennium heeft gekregen in België, met o.a. de totstandkoming van de euthanasiewet in 2002.

Een meerderheid van de patiënten wilde informatie over MBLs, maar slechts weinigen kregen informatie. Dit roept o.a. de vraag op of artsen zelf voldoende kennis hebben over MBLs. In een geneeskunde die traditioneel gericht is op genezing en levensverlenging, kan het niet als vanzelfsprekend beschouwd worden dat artsen ten volle bewust zijn van de MBLs die genomen kunnen worden, van de wettelijke status van de MBLs en van hoe de bezorgdheden van de patiënt kunnen vertaald worden in voorafgaande zorgplanning. De onderzoeksgroep Zorg rond het Levenseinde van de VUB en de UGent heeft specifieke richtlijnen ontwikkeld die artsen informatie geven over MBLs en over de wijze waarop ze kunnen besproken worden met de patiënt. Het voordeel van deze richtlijnen is dat ze zijn aangepast aan de Belgische situatie. Deze specificiteit is belangrijk omdat België een unieke positie heeft in de wereld als een van de weinige landen die euthanasie onder bepaalde condities wettelijk toelaat.

Vrije Universiteit Brussel

UNIVERSITEIT GENT

Patiënteninformatie en toestemmingsformulier

Patiëntenbetrokkenheid bij medische beslissingen. Een onderzoek op basis van interviews met patiënten naar de gewenste versus feitelijk verkregen informatie en betrokkenheid en effect hiervan op kwaliteit van leven.

De Vrije Universiteit Brussel en de Universiteit Gent doen momenteel onderzoek naar de noden van patiënten met een ernstige longaandoening. Het gaat meer bepaald over noden van patiënten m.b.t. informatie en betrokkenheid bij beslissingen. Omdat wensen en opvattingen van patiënten hierin centraal staan en we een beeld willen krijgen van wat ervaringen, wensen en problemen hieromtrent zijn, willen we verschillende patiënten bevragen. Deze zaken kunnen in de loop van de tijd veranderen. Daarom zouden we een aantal mensen opvolgen in de tijd.
Het is reeds gebleken dat dergelijke studies een bijdrage kunnen leveren aan de verbetering en aanpassing van de zorg.

Het verloop van de studie is als volgt:

- De specialist stelt u enkele vragen (o.a. leeftijd, levensbeschouwing, gezondheids-toestand,…). Dit neemt ongeveer vijf minuten in beslag.
- Uw adres en het adres van uw huisarts en naasten wordt door uw specialist doorgegeven aan de onderzoekers.
- De onderzoekers nemen telefonisch contact met u op om een afspraak te maken voor een gesprek. Wanneer u na drie pogingen onbereikbaar blijft, contacteren ze uw huisarts en/of naaste.
- Het gesprek vindt plaats op de door u gekozen plaats (thuis, ziekenhuis,…). U bent vrij te kiezen wie er bij dit gesprek aanwezig is (partner, familie,…). Er wordt gebruik gemaakt van een ‘identieke’ vragenlijst voor alle patiënten, onafhankelijk van de ernst van de ziekte. Indien u hierin toestemt, wordt het gesprek opgenomen op band.
- Elke twee maanden wordt u door de onderzoeker telefonisch gecontacteerd. Er wordt een afspraak gemaakt voor een nieuw interview.
- De onderzoekers brengen uw huisarts via de post op de hoogte van u deelname aan deze studie, tenzij u dit uitdrukkelijk anders wenst.
- De looptijd van de studie is ongeveer één jaar vanaf het eerste interview, maar u kan natuurlijk op elk moment beslissen uit de studie te stappen.
- Indien u op een bepaald moment, om één of andere reden, niet in staat bent de vragenlijst in te vullen, zullen we contact opnemen met uw arts.

Weet ook dat:

- De gegevens bekomen uit het interview vertrouwelijk behandeld zullen worden in overeenstemming met de Belgische Wetgeving op de bescherming van de persoonlijke levenssfeer. Dit wil zeggen dat de interviewers gebonden zijn aan zwijgplicht en de gegevens niet zullen doorgegeven worden aan uw arts of andere zorgverleners.

Patiënteninformatie en toestemmingsformulier

- De gegevens anoniem verwerkt zullen worden. Dit wil zeggen dat bij de verwerking uw naam nooit gekoppeld zal worden aan uw antwoorden en dat uw antwoorden samengebracht zullen worden met de antwoorden van andere patiënten.
- U volledig vrij bent om de vragen al dan niet te beantwoorden en u op elk moment het interview kan stoppen. Ook wanneer u beslist niet deel te nemen aan de studie of het interview vroegtijdig te beëindigen, om welke reden dan ook (geen belangstelling meer, vermoeid,…) zal dit geen invloed hebben op de verdere zorgverlening.
- Wij er rekening mee zullen houden dat de duur van het interview beperkt zal zijn en niet langer dan door u gewenst.
- Deze studie uitgevoerd wordt in het kader van een doctoraatsthesis.
- Deze studie de goedkeuring heeft van de Commissie Medische Ethiek van het AZ-VUB na raadpleging van de Commissies Medische Ethiek van alle deelnemende ziekenhuizen.
- Er een verzekering werd afgesloten voor deze studie in navolging van de wet van 7 mei 2004 betreffende experimenten op de menselijke persoon.

De contactpersoon van de studie is Dhr Koen Pardon, psycholoog, momenteel werkzaam aan de vakgroep Medische Sociologie van de Vrije Universiteit Brussel. Hij wordt onder andere bijgestaan door een aantal getrainde interviewers met een medische/paramedische vooropleiding of een opleiding in de Humane Wetenschappen. U kan steeds contact opnemen met Dhr. Koen Pardon, Laarbeeklaan 103, 1090 Brussel, tel: 02/477.47.68, email: Koen.Pardon@vub.ac.be.

Indien u nog vragen heeft kan u steeds terecht bij uw arts :
Dr. …………………………….. ***Tel:***

Wettelijk gezien zijn we verplicht u te vragen om, indien u wenst deel te nemen, onderstaande verklaring te tekenen, voorafgegaan van de eigenhandig geschreven vermelding: gelezen en goedgekeurd.

Ondergetekende (naam + voornaam patiënt)_______________________________________

Verklaart een volledige uitleg te hebben ontvangen over de studie waaraan ik zal deelnemen. Ik verklaar te weten dat ik op gelijk welk moment mijn medewerking aan deze studie kan stopzetten.

(gelezen en goedgekeurd)

Datum: ……………..

Handtekening: ………………………………..

Vrije Universiteit Brussel

UNIVERSITEIT GENT

Patiëntenbetrokkenheid bij medische beslissingen. Vragenlijst vooraf.

Om te vermijden dat u bij elke inclusie van een patiënt eenzelfde vragenlijst zou moeten invullen met achtergrondkenmerken, willen we u vragen deze lijst éénmalig in te vullen. Vervolgens kan u dan het identificatienummer, vermeld onderaan deze vragenlijst, invullen op alle volgende documenten. Tenzij anders vermeld, is er slechts één antwoord mogelijk per vraag.

1. Uw geslacht?
   - ☐ M
   - ☐ V

2. Uw leeftijd?

   ______ jaar

3. Bent u werkzaam als:
   - ☐ specialist
   - ☐ specialist in opleiding

4. Welk klinisch specialisme is uw hoofdactiviteit?
   - ☐ pneumologie
   - ☐ andere, nl. ____________________________

5. Hoeveel jaren bent u reeds werkzaam in de directe patiëntenzorg?

   ______ jaar

6. Aan welke universiteit bent u afgestudeerd als arts?
   - ☐ KUL/UCL
   - ☐ UG
   - ☐ UIA
   - ☐ VUB/ULB
   - ☐ Andere Belgische universiteit
   - ☐ Buitenlandse universiteit

7. Heeft u ooit een intensieve opleiding (met certificaat) ‘palliatieve zorg en/of stervensbegeleiding’ gevolgd?
   - ☐ ja
   - ☐ nee

8. Heeft u ooit een intensieve opleiding (met certificaat) ‘communicatie vaardigheden’ gevolgd?
   - ☐ ja
   - ☐ nee

9. Hoeveel terminale patiënten heeft u verzorgd gedurende de laatste 12 maanden? ___________

Patiëntenbetrokkenheid bij medische beslissingen. Vragenlijst vooraf.

10. Wie is er in uw naaste omgeving overleden? **(Meerdere antwoorden mogelijk)**

☐ kind(eren) en/of partner
☐ ouders
☐ vriend(in) en/of naast familielid
☐ niemand van de aangeboden keuze

11. Welke levensbeschouwing is voor u het meest toepasselijk?

☐ christelijk, rooms-katholiek
☐ christelijk, anders dan rooms-katholiek
☐ gelovig, doch geen specifieke religie
☐ niet gelovig
☐ vrijzinnig
☐ andere, nl. ________________________

12. Is uw levensbeschouwing belangrijk bij het nemen van medische beslissingen rond het levenseinde van uw patiënten?

☐ heel belangrijk
☐ belangrijk
☐ noch belangrijk, noch onbelangrijk
☐ onbelangrijk
☐ heel onbelangrijk

13. Patiënten moeten volledig geïnformeerd worden.

helemaal niet akkoord	niet akkoord	eerder niet akkoord	eerder wel akkoord	wel akkoord	helemaal wel akkoord
☐	☐	☐	☐	☐	☐

14. Welk van onderstaande stellingen leunt het dichtst aan bij hoe volgens u medische beslissingen genomen moeten worden?

☐ Ik moet beslissen op basis van mijn kennis
☐ Ik moet beslissen maar in sterke mate rekening houden met de opinie van de patiënt.
☐ De patiënt en ik moeten samen beslissen, op gelijke basis
☐ De patiënt moet beslissen maar in sterke mate rekening houden met mijn opinie.
☐ De patiënt moet beslissen op basis van al de informatie die hij/zij heeft of verkrijgt.

15. Kan u een schatting maken van het aantal patiënten dat zich aanbood op uw consultatie en aan de inclusiecriteria (NSCLC stadium IIIb en IV) voldeed in het afgelopen jaar (2005)?

_________ patiënten

16. Hoeveel van deze groep patiënten denkt u dat bereidt zou zijn deel te nemen aan deze studie?

_________ patiënten

Uw identificatienummer: …………… Datum:......................

Vrije Universiteit Brussel

UNIVERSITEIT GENT

Patiëntenbetrokkenheid bij medische beslissingen. Vragenlijst bij inclusie.

Gelieve de onderstaande vragen samen met de patiënt in te vullen (sommige zaken zijn waarschijnlijk opgenomen in het medisch dossier, maar gelieve toch even te overlopen met patiënt voor de volledigheid). Tenzij anders vermeld, is er slechts één antwoord mogelijk per vraag.

1. Identificatie patiënt:

Naam ______________________

Straat, nr ______________________

Postcode, gemeente ______________________

Telefoonnummer ______________________

2. Identificatie naaste:

2.1. Wie is het meest betrokken bij uw zorg en kunnen we contacteren indien u onbereikbaar bent?

Naam ______________________

Straat, nr ______________________

Postcode, gemeente ______________________

Telefoonnummer ______________________

2.2. Wat is uw relatie met deze persoon?

- ☐ Echtgenoot/echtgenote
- ☐ Partner
- ☐ Kind
- ☐ Schoonzoon/dochter
- ☐ Ouder
- ☐ Broer/zus
- ☐ Vriend
- ☐ Anders nl: ______________

Patiëntenbetrokkenheid bij medische beslissingen. Vragenlijst bij inclusie.

3. Identificatie huisarts:

3.1. Heeft u een huisarts?

☐ ja
☐ nee ⇨ ga naar vraag 4

3.2. Wie is uw huisarts?

Naam ____________________

Straat, nr ____________________

Postcode, gemeente ____________________

Telefoonnummer ____________________

3.3. Hoe vaak had u contact met hem/haar in de afgelopen drie maanden?

☐ meer dan 1 keer per week
☐ 1 keer per week
☐ 1 keer per twee weken
☐ 1 keer per maand
☐ minder, nl. ____________

4. Co-morbiditeit (gebruik de legende op p.4):

(Meerdere antwoorden mogelijk)

☐ Myocard infarct
☐ Congestief hartfalen
☐ Perifere vasculaire aandoeningen
☐ Cerebrovasculaire aandoeningen (uitgezonderd hemiplegie)
☐ Dementie
☐ COPD
☐ Bindweefsel ziekten
☐ Peptische ulcera
☐ Milde lever aantasting
☐ Diabetes (zonder complicaties)
☐ Diabetes met orgaan schade
☐ Hemiplegie
☐ Matig tot ernstig nierfalen
☐ Tweede solide tumor (niet metastatisch)
☐ Leukemie
☐ Lymfoom, multiple myeloom
☐ Matige tot ernstige leveraantasting
☐ Tweede metastatische solide tumor
☐ AIDS

Patiëntenbetrokkenheid bij medische beslissingen. Vragenlijst bij inclusie.

5. Sociodemografische gegevens van de patiënt:

5.1. Leeftijd _______ jaar

5.2. Geslacht
☐ M
☐ V

5.3. Vaste partner
☐ ja
☐ nee

5.4. Verblijfplaats (huidige)
☐ thuis, alleen
☐ thuis, met anderen (preciseer aantal) ________
☐ bij familie
☐ ziekenhuis, gewone afdeling
☐ ziekenhuis, palliatieve eenheid
☐ RVT/ROB
☐ anders nl. ____________________

5.5. Opleiding patiënt (hoogst **voltooide** opleiding of diploma)
☐ lager onderwijs of minder
☐ lager middelbaar onderwijs
☐ hoger middelbaar onderwijs
☐ hoger onderwijs, universiteit, zo ja: medisch of paramedische opleiding? ☐ ja nl. ____________________
☐ nee

6. Functionele status:

0	Volledig actief, alle normale bezigheden kunnen uitvoeren zonder beperkingen, zoals vóór het optreden van de ziekte.
1	Beperkt in het verrichten van zware fysieke activiteiten, maar ambulant en in staat om lichte werkzaamheden of werk al zittend te verrichten, vb. licht huishoudelijk werk, bureauwerk
2	Ambulant en in staat om zichzelf volledig te verzorgen, maar niet in staat om enig ander werk te verrichten. Voor meer dan 50% van de dag uit bed.
3	Slechts gedeeltelijk in staat zichzelf te verzorgen, voor meer dan 50% van de dag in bed of stoel
4	Volledig geïnvalideerd. Niet in staat zichzelf te verzorgen. Volledig bedlegerig of aan de stoel gekluisterd

Patiëntenbetrokkenheid bij medische beslissingen. Vragenlijst bij inclusie.

Legende:

Myocard infarct	**Geschiedenis van** medisch gedocumenteerd myocard infarct
Congestief hartfalen	**Symptomatisch** CHF **met antwoord op** specifieke behandeling
Perifere vasculaire aandoeningen	Intermittente claudicatio, perifere arteriële bypass voor insufficiëntie, gangreen, acute arteriële insufficiëntie, onbehandeld aneurisma (≥ 6cm)
Cerebrovasculaire aandoeningen (uitgezonderd hemiplegie)	**Geschiedenis van** TIA of CVA **zonder of met mineure sequelen**
Dementie	Chronisch cognitieve tekortkoming
COPD	**Symptomatische** dyspnoe door chronische respiratoire aandoeningen (inclusief astma)
Bindweefsel ziekten	SLE, polymyositis, mixed CTD, polymyalgia rheumatica, matig tot ernstige RA
Peptische ulcera	Patiënten die **behandeld werden** voor PUD
Milde lever aantasting	Cirrose **zonder PHT**, chronische hepatitisch
Diabetes (**zonder complicaties**)	Diabetes **met medicatie**
Diabetes **met orgaan schade**	Retinopathie, neuropathie, nefropathie
Hemiplegie (of paraplegie)	Hemiplegie of paraplegie
Matig tot ernstig nierfalen	Kreatinine > 3mg/dl (265µmol/l), dialyse, transplantatie, uremisch syndroom
Tweede solide tumor (niet metastatisch)	**Initiëel behandeld in de laatste vijf jaar**. Exclusief niet-melanomateuze huidkankers en cervix carcinoom *in situ*
Leukemie	CML, CLL, AML, ALL, PV
Lymfoom, multiple myeloom	Non-Hodgkin lymfoom (NHL), Hodgkin lymfoom, Waldenström, multiple myeloom
Matige tot ernstige leveraantasting	Cirrose met PHT +/- variceuze bloedingen
Tweede metastatische solide tumor	Zichzelf verklarende
AIDS	Aids en AIDS gerelateerde aandoeningen

CHF, congestief hartfalen; TIA, transient ischemic attack; CVA, cerebro-vasculair accident; SLE, systemische lupus erythematosis; CTD, connective tissue disease; RA, rheumatoïde artritis; PUD, peptic ulcer disease; PHT, portale hypertensie; CML, chronisch myeloïde leukemie; CLL, chronisch lymfoïde leukemia; AML, acute myeloïde leukemie; ALL, acute lymfoblastische leukemie; PV, polycythemia vera.

Einde vragenlijst met patiënt.

Patiëntenbetrokkenheid bij medische beslissingen. Vragenlijst bij inclusie.

Gelieve dit deel zelf in te vullen (zonder hulp van de patiënt).

Uw identificatienummer: __________

7. Informatiewensen en betrokkenheid:

7.1. Deze patiënt wil volledig geïnformeerd worden.

helemaal niet akkoord	niet akkoord	eerder niet akkoord	eerder wel akkoord	wel akkoord	helemaal wel akkoord
☐	☐	☐	☐	☐	☐

7.2. Welk van onderstaande stellingen past het best bij deze patiënt?
- ☐ De arts moet beslissen op basis van zijn/haar kennis
- ☐ De arts moet beslissen maar in sterke mate rekening houden met de opinie van de patiënt.
- ☐ De arts en de patiënt moeten samen beslissen, op gelijke basis
- ☐ De patiënt moet beslissen maar in sterke mate rekening houden met de opinie van de arts.
- ☐ De patiënt moet beslissen op basis van al de informatie die hij/zij heeft of verkrijgt.

8. Type therapie en intentie:

8.1. Doel van de behandeling?

curatie (genezing)	☐ ja	☐ nee
levensverlenging	☐ ja	☐ nee
palliatie (niet curatief, niet levensverlengend)	☐ ja	☐ nee

anders, nl. ______________________________

8.2. Welke behandelingen krijgt de patiënt, naar uw weten, momenteel? **(Meerdere antwoorden mogelijk)**
- ☐ Chemotherapie
- ☐ Radiotherapie
- ☐ Experimentele therapie (in het kader van een studie)
- ☐ Chirurgie
- ☐ Medicamenteus
- ☐ Kunstmatige vocht en/of voeding toediening
- ☐ Pleurapunctie
- ☐ Niet conventionele behandeling (homeopathie,…)
- ☐ Anders, nl. ______________________________

Patiëntenbetrokkenheid bij medische beslissingen. Vragenlijst bij inclusie.

9.Geschatte overlevingsduur:

9.1. Zou u verbaasd zijn als deze patiënt zou overlijden binnen de 3 maanden?

- ☐ ja
- ☐ nee

9.2. Hoelang, denkt u, zal deze patiënt nog leven? U kan dit uitdrukken in dagen, weken, maanden of jaren.

- ☐ … dagen
- ☐ … weken
- ☐ … maanden
- ☐ … jaren

Datum:...........................

Vragenlijst NSCLC IIIb/IV Patiënten die niet deelnemen aan het onderzoek

Patiëntennummer	**Datum beslissing**	**Leeftijd**	**Geslacht**	**Niet deelname**	**Functionele status** [1]	**Geschatte overleving** (in dagen, weken, maanden of jaren)
........./901				☐ weigering, reden: ☐ niet aangesproken, reden:		…… dagen …… weken …… maand …… jaar
........./902				☐ weigering, reden: ☐ niet aangesproken, reden:		…… dagen …… weken …… maand …… jaar
......../903				☐ weigering, reden: ☐ niet aangesproken, reden:		…… dagen …… weken …… maand …… jaar
......../904				☐ weigering, reden: ☐ niet aangesproken, reden:		…… dagen …… weken …… maand …… jaar
........./905				☐ weigering, reden: ☐ niet aangesproken, reden:		…… dagen …… weken …… maand …… jaar
........./906				☐ weigering, reden: ☐ niet aangesproken, reden:		…… dagen …… weken …… maand …… jaar

1 Functionele status

0 Volledig actief, alle normale bezigheden kunnen uitvoeren zonder beperkingen, zoals vóór het optreden van de ziekte.
1 Beperkt in het verrichten van zware fysieke activiteiten, maar ambulant en in staat om lichte werkzaamheden of werk al zittend te verrichten, vb. licht huishoudelijk werk, bureauwerk.
2 Ambulant en in staat om zichzelf volledig te verzorgen, maar niet in staat om enig ander werk te verrichten. Voor meer dan 50% van de dag uit bed.
3 Slechts gedeeltelijk in staat zichzelf te verzorgen, voor meer dan 50% van de dag in bed of stoel.
4 Volledig geïnvalideerd. Niet in staat zichzelf te verzorgen. Volledig bedlegerig of aan de stoel gekluisterd.

Patiëntenidentificatiecode: **Interview nr. 1/2/3/..**
Datum interview: **Geluidsopname: JA/NEE**
Plaats van interview:
Interviewer:

A. Kwaliteit van leven:

Eerst en vooral zou ik u enkele vragen willen stellen over hoe u zich de laatste dagen gevoeld heeft. Ik ben geïnteresseerd in bepaalde dingen over u en uw gezondheid. Wilt u de vragen beantwoorden door het getal aan te duiden dat het meest op u van toepassing is. Er zijn geen "juiste" of "onjuiste" antwoorden.

geef antwoordkaart 1

		Helemaal niet	Een beetje	Nogal	Heel erg
1.	Heeft u moeite met het maken van een korte wandeling buitenshuis?	1	2	3	4
2.	Moet u overdag in bed of in een stoel blijven?	1	2	3	4
3.	Heeft u hulp nodig met eten, aankleden, uzelf wassen of naar het toilet gaan?	1	2	3	4
Gedurende de afgelopen week:					
4.	Was u kortademig?	1	2	3	4
5.	Heeft u pijn gehad?	1	2	3	4
6.	Heeft u moeite met slapen gehad?	1	2	3	4
7.	Heeft u zich slap gevoeld?	1	2	3	4
8.	Heeft u gebrek aan eetlust gehad?	1	2	3	4
9.	Heeft u zich misselijk gevoeld?	1	2	3	4
10.	Had u last van obstipatie? (was u verstopt?)	1	2	3	4
11.	Was u moe?	1	2	3	4
12.	Heeft pijn u gehinderd in uw dagelijkse bezigheden?	1	2	3	4
13.	Voelde u zich gespannen?	1	2	3	4
14.	Voelde u zich neerslachtig?	1	2	3	4

Wilt u voor de volgende vraag het getal tussen 1 en 7 aanduiden dat het meest op u van toepassing is.

geef antwoordkaart 2

15. Hoe zou u uw algehele "kwaliteit van het leven" gedurende de afgelopen week beoordelen?

1	2	3	4	5	6	7
Erg slecht						Uitstekend

B. Informatie wensen en bereikt niveau:

Ik zou het nu met u willen hebben over hoe u zou willen dat de informatie uitwisseling tussen u en uw arts gebeurt en over hoe ze in werkelijkheid gebeurt. Eerst ga ik een algemene stelling voorleggen en u moet aanduiden op de antwoordkaart in hoeverre u akkoord gaat met de stelling.

geef antwoordkaart 3

De algemene stelling is:

16. Ik wil globaal genomen volledig geïnformeerd worden

16.1.

helemaal niet akkoord	niet akkoord	eerder niet akkoord	eerder wel akkoord	wel akkoord	helemaal wel akkoord
☐	☐	☐	☐	☐	☐

indien 'helemaal niet akkoord' of 'niet akkoord' ⇨ 16.2
indien anders ⇨ 16.3

16.2. Moet uw arts deze informatie aan iemand anders geven?

- ☐ nee
- ☐ ja, aan wie (relatie tot persoon) ____________________________

ga door met vraag 16.6

Ik ga nu een aantal bijvragen stellen bij deze stelling.

geef antwoordkaart 4

16.3. Wie moet u deze informatie geven?
(Meerdere antwoorden mogelijk)

- ☐ specialist
- ☐ huisarts
- ☐ verpleegkundige
- ☐ familie/naaste
- ☐ niemand
- ☐ andere nl. ___________________

16.4. Wie moet erover beginnen?

- ☐ uzelf
- ☐ anders, nl _______________

geef antwoordkaart 4

16.5. Wie moet er naast uzelf aanwezig zijn als er informatie gegeven wordt?
(Meerdere antwoorden mogelijk)

- ☐ huisarts
- ☐ verpleegkundige
- ☐ familie/naaste
- ☐ niemand
- ☐ andere nl. ___________________

geef antwoordkaart 5

Ik heb daarjuist gevraagd in welke mate u graag geïnformeerd wil worden door de arts. Nu wil ik even weten in welke mate u daadwerkelijk bent geïnformeerd.

16.6 Werd u globaal genomen geïnformeerd?

- ☐ JA
- ☐ NEE

- Door wie allemaal?

(Meerdere antwoorden mogelijk)

- ☐ specialist
- ☐ huisarts
- ☐ verpleegkundige
- ☐ familie/naaste
- ☐ niemand
- ☐ andere nl. ____________________

- In welke mate?

- ☐ minder dan gewenst
- ☐ zoals gewenst
- ☐ meer dan gewenst

16.6. Heeft uw arts gevraagd hoeveel informatie u wil krijgen?

- ☐ nee
- ☐ ja, zo ja welke arts: ________________________

Nu gaan we dezelfde soort stellingen (als de algemene stelling) over informatie overlopen, maar het gaat telkens over een specifieke thema. De arts kan informatie geven over diagnose, prognose, behandelingen, etc.. We gaan elk thema even overlopen. Het zijn 6 standaardstellingen die we aan alle patiënten voorleggen, onafhankelijk van de ernst van de ziekte. Sommige zijn waarschijnlijk dan ook niet van toepassing op uw situatie en kunnen misschien raar/confronterend overkomen.

Overloop antwoordkaarten van 6 tot 17

17.	**1. De eerste stelling is:** Ik wil geïnformeerd worden over **mijn diagnose**. (= juiste naam en kenmerken van de ziekte): hel. niet akkoord ☐ niet akkoord ☐ eerder niet akkoord ☐ eerder wel akkoord ☐ wel akkoord ☐ hel. wel akkoord ☐	Werd u geïnformeerd over **uw diagnose**? JA/NEE Door wie?_______________ In welke mate? minder dan gewenst ☐ zoals gewenst ☐ meer dan gewenst ☐
18.	**2.** Ik wil geïnformeerd worden over de **kans op genezing van de ziekte**. hel. niet akkoord ☐ niet akkoord ☐ eerder niet akkoord ☐ eerder wel akkoord ☐ wel akkoord ☐ hel. wel akkoord ☐	Werd u geïnformeerd over de **kans op genezing**? JA/NEE Door wie?_______________ In welke mate? minder dan gewenst ☐ Zoals gewenst ☐ meer dan gewenst ☐
19.	**3.** Ik wil geïnformeerd worden over **mijn levensverwachting met de ziekte.** hel. niet akkoord ☐ niet akkoord ☐ eerder niet akkoord ☐ eerder wel akkoord ☐ wel akkoord ☐ hel. wel akkoord ☐	Werd u geïnformeerd over de **levensverwachting**? JA/NEE Door wie?_______________ In welke mate? minder dan gewenst ☐ zoals gewenst ☐ meer dan gewenst ☐
20.	**4.** Ik wil informatie over de **verschillende soorten behandelingen**, hun bijwerkingen en het te verwachte resultaat (doel) van elke behandeling. hel. niet akkoord ☐ niet akkoord ☐ eerder niet akkoord ☐ eerder wel akkoord ☐ wel akkoord ☐ hel. wel akkoord ☐	Werd u geïnformeerd over de **behandelingen**? JA/NEE Door wie?_______________ In welke mate? minder dan gewenst ☐ zoals gewenst ☐ meer dan gewenst ☐
21.	**5.** Ik wil informatie over **opties op het vlak van palliatieve zorg**. (=enkel comfortzorg voor mensen die niet meer kunnen genezen) hel. niet akkoord ☐ niet akkoord ☐ eerder niet akkoord ☐ eerder wel akkoord ☐ wel akkoord ☐ hel. wel akkoord ☐	Werd u geïnformeerd over **palliatieve zorg**? JA/NEE Door wie?_______________ In welke mate? minder dan gewenst ☐ zoals gewenst ☐ meer dan gewenst ☐
22.	**6.** Ik wil informatie over de **mogelijkheden aan het levenseinde.** (= reanimatie, opties om het levenseinde te bespoedigen of om mogelijk levensverlengende behandelingen stop te zetten of niet in te stellen) hel. niet akkoord ☐ niet akkoord ☐ eerder niet akkoord ☐ eerder wel akkoord ☐ wel akkoord ☐ hel. wel akkoord ☐	Werd u geïnformeerd over **mogelijkheden levenseinde**? JA/NEE Door wie?_______________ In welke mate? minder dan gewenst ☐ zoals gewenst ☐ meer dan gewenst ☐

Nog 2 vragen over informatie:

23. Zijn er nog andere onderwerpen waarover u informatie wil van de arts?

……………………………………………………………………………………………

…………………………………………………………………………………………….

24. Heeft u informatie over uw ziekte opgezocht?

24.1 Op het internet?

☐ Nee
☐ Ja, maar geen interessante informatie
☐ Ja, wel interessante informatie

⮡ Welke?

24.2. Op een andere manier?

…………………………………………………………………………………………

C. Participatiewensen en bereikt niveau:

Ik zou het nu met u willen hebben over hoe u betrokken wenst te worden bij bepaalde beslissingen en hoe u tot nog toe betrokken werd. Ik zou weer met een aantal algemene vragen willen starten.

25. Wie moet volgens u de medische beslissingen over het algemeen nemen (Wie wil je dat…)?

geef antwoordkaart 18

1. **De arts** op basis van zijn/haar kennis
2. **De arts** maar in sterke mate rekening houdend met mijn opinie.
3. **De arts en ik samen,** op gelijke basis
4. **Ikzelf** maar in sterke mate rekening houdend met de opinie van de arts.
5. **Ikzelf** op basis van al de informatie die ik heb of verkrijg.

26. Zijn er naast de arts en uzelf andere mensen die u wilt betrekken bij het nemen van medische beslissingen?

☐ verpleegkundige
☐ familie/naaste
☐ niemand
☐ andere nl. ________________________

27. Hoe vindt u dat medische beslissingen doorgaans genomen worden? Hoe gebeurt het in werkelijkheid?

geef antwoordkaart 19

1. **De arts beslist** op basis van zijn/haar kennis
2. **De arts beslist** maar houdt in sterke mate rekening met mijn opinie.
3. **De arts en ik beslissen** samen, op gelijke basis
4. **Ik beslis** maar houd in sterke mate rekening met de opinie van de arts.
5. **Ik beslis** op basis van al de informatie die ik heb of verkrijg.

28. Zijn er naast de arts en uzelf doorgaans andere mensen die betrokken worden bij het nemen van medische beslissingen? Hoe gebeurt het in werkelijkheid?

☐ verpleegkundige
☐ familie/naaste
☐ niemand
☐ andere nl. ________________________

Nu zou ik wat dieper willen ingaan op een aantal beslissingen die genomen kunnen worden. De kaart geeft een overzicht van een aantal mogelijke beslissingen. Ook hier gebruiken we dezelfde vragen voor alle patiënten ongeacht de ernst van hun ziekte. Sommige zijn waarschijnlijk dan ook niet van toepassing op uw situatie en kunnen misschien raar/confronterend overkomen. We willen het met u hebben over de beslissingen die genomen werden in de laatste twee maanden.

geef antwoordkaart 20

29. Behandeling opstarten, voortzetten of stoppen:

29.1. Werd er, in de laatste twee maanden, beslist één of meerdere van de behandeling op de kaart op te al dan niet te starten, voort te zetten of te stoppen? (Meerdere antwoorden mogelijk)

overloop alle behandelingen met de patiënt door ze hardop voor te lezen en kruis aan.

	Opstarten	**Niet Opstarten**	**Voortzetten**	**Stoppen**
Chemotherapie	☐	☐	☐	☐
Radiotherapie	☐	☐	☐	☐
Experimentele therapie (in het kader van studie)	☐	☐	☐	☐
Operatie	☐	☐	☐	☐
Medicamenten	☐	☐	☐	☐
Kunstmatige vocht en/of voeding toediening	☐	☐	☐	☐
Pleurapunctie	☐	☐	☐	☐
Niet conventionele behandeling (o.a. homeopathie,…)	☐	☐	☐	☐
Beademing	☐	☐	☐	☐
Anders, nl.	☐	☐	☐	☐

☐ geen behandelingen opgestart, voortgezet of gestopt ⇨ 29.4

Indien er meerdere beslissingen genomen werden ⇨ 29.2
Indien er slechts één beslissing genomen werd ⇨ 29.3

29.2. Welke van deze beslissingen was voor u de belangrijkste?

omcirkel deze beslissing in vraag 29.1

29.3. Wie nam deze (belangrijkste) beslissing?

geef antwoordkaart 21

1. **De arts** op basis van zijn/haar kennis
2. **De arts** maar in sterke mate rekening houdend met mijn opinie.
3. **De arts en ik samen,** op gelijke basis
4. **Ikzelf** maar in sterke mate rekening houdend met de opinie van de arts.
5. **Ikzelf** op basis van al de informatie die ik heb of verkrijg.

29.4. Wie moet zo'n beslissingen volgens u nemen (Wie wil je dat…)?

geef antwoordkaart 21

1. **De arts** op basis van zijn/haar kennis
2. **De arts** maar in sterke mate rekening houdend met mijn opinie.
3. **De arts en ik samen,** op gelijke basis
4. **Ikzelf** maar in sterke mate rekening houdend met de opinie van de arts.
5. **Ikzelf** op basis van al de informatie die ik heb of verkrijg.

30. Overplaatsingen

geef antwoordkaart 22

30.1. Werd er, <u>in de laatste twee maanden,</u> beslist tot overplaatsing? Kruis aan van waar naar waar.
(Wanneer u meer dan één maal overgeplaatst werd, kies dan voor de laatste overplaatsing)

Van:	**Naar:**
☐ thuis	☐ thuis
☐ huis van familie/naaste	☐ huis van familie/naaste
☐ rusthuis	☐ rusthuis
☐ ziekenhuis	☐ ziekenhuis
☐ palliatieve eenheid	☐ palliatieve eenheid
☐ elders, nl. ____________________	☐ elders, nl. ____________________

☐ geen overplaatsing ⇨ 30.3

30.2. Wie nam deze beslissing?

geef antwoordkaart 23

1. **De arts** op basis van zijn/haar kennis
2. **De arts** maar in sterke mate rekening houdend met mijn opinie.
3. **De arts en ik samen,** op gelijke basis
4. **Ikzelf** maar in sterke mate rekening houdend met de opinie van de arts.
5. **Ikzelf** op basis van al de informatie die ik heb of verkrijg.

30.3. Wie moet zo'n beslissingen volgens u nemen?

geef antwoordkaart 23

1. **De arts** op basis van zijn/haar kennis
2. **De arts** maar in sterke mate rekening houdend met mijn opinie.
3. **De arts en ik samen,** op gelijke basis
4. **Ikzelf** maar in sterke mate rekening houdend met de opinie van de arts.
5. **Ikzelf** op basis van al de informatie die ik heb of verkrijg.

31. Beslissingen betreffende onthouden van (be)handelingen of het uitvoeren van (be)handelingen in de toekomst:

geef antwoordkaart 24

31.1. Werden er <u>in de laatste twee maanden</u> afspraken gemaakt over het onthouden van (be)handelingen of het uitvoeren van handelingen in de toekomst? Zo ja, welke? (Meerdere antwoorden mogelijk)

overloop alles met de patiënt door het hardop voor te lezen en kruis aan.

- ☐ ja, een niet-reanimeer beleid (= afspraak dat indien uw hart stopt met kloppen, er geen poging ondernomen wordt om het weer op gang te brengen)
- ☐ ja, een niet-behandel beleid (= afspraak dat er behalve ondersteunende maatregelen verder geen behandelingen gegeven zullen worden)
- ☐ ja, m.b.t. euthanasie
  - ↳ wat precies? --
- ☐ andere, nl. --

Werd deze beslissing (of beslissingen) schriftelijk vastgelegd ? (zo ja, plaats een ‘**S**’ voor het ☐ bij deze beslissing)

- ☐ nee, geen van bovenstaande afspraken schriftelijk vastgelegd ⇨ 31.4

Indien er meerdere beslissingen genomen werden ⇨ 31.2
Indien er slechts één beslissing genomen werd ⇨ 31.3

31.2. Welke van deze beslissingen was voor u de belangrijkste?

omcirkel deze beslissing in vraag 31.1

31.3. Wie nam deze (belangrijkste) beslissing?

geef antwoordkaart 25

1. **De arts** op basis van zijn/haar kennis
2. **De arts** maar in sterke mate rekening houdend met mijn opinie.
3. **De arts en ik samen,** op gelijke basis
4. **Ikzelf** maar in sterke mate rekening houdend met de opinie van de arts.
5. **Ikzelf** op basis van al de informatie die ik heb of verkrijg.

31.4. Wie moet zo’n beslissingen volgens u nemen?

geef antwoordkaart 25

1. **De arts** op basis van zijn/haar kennis
2. **De arts** maar in sterke mate rekening houdend met mijn opinie.
3. **De arts en ik samen,** op gelijke basis
4. **Ikzelf** maar in sterke mate rekening houdend met de opinie van de arts.
5. **Ikzelf** op basis van al de informatie die ik heb of verkrijg.

Als laatste van dit deel zou ik het met u willen hebben over hoe u zou willen dat de beslissingen genomen worden indien u zelf niet meer in staat zou zijn om zelf te beslissen.

32. Stel dat u niet meer in staat zou zijn zelf te beslissen (bewustzijnsdaling, coma,…), wie vindt u dat naast uw arts bij de medische beslissingen betrokken zou moeten worden? (Meerdere antwoorden mogelijk)
    - ☐ verpleegkundige
    - ☐ familie/naaste
    - ☐ niemand
    - ☐ andere nl. __________

indien niemand ⇨ ga naar vraag 34

33. Wie moet volgens u de medische beslissingen dan nemen?

GEEF ANTWOORDKAART *geef antwoordkaart 26*

1. **De arts** op basis van zijn/haar kennis.
2. **De arts** maar in sterke mate rekening houdend met de opinie van mijn vertegenwoordiger(s).
3. **De arts en mijn vertegenwoordiger(s**) ,op gelijke basis.
4. **Mijn vertegenwoordiger(s)** maar in sterke mate rekening houden met de opinie van de arts.
5. **Mijn vertegenwoordiger(s),** op basis van al de informatie die hij/zij heeft (hebben) of verkrijgt (verkrijgen).

34. Heeft u dit besproken met een arts?

- ☐ nee
- ☐ ja, welke arts: ____________________________

D. Tevredenheid met de besluitvorming:

In dit deel zou ik het met u willen hebben over hoe tevreden u bent met de wijze waarop bepaalde beslissingen genomen werden. Vandaag zou ik het met u willen hebben over hoe de beslissing om chemotherapie al dan niet op te starten genomen werd. *⇨ ga naar vraag 36 op deze pagina*

geef antwoordkaart 27

Vanaf het tweede interview

In dit deel zou ik het met u willen hebben over hoe tevreden u bent met de wijze waarop bepaalde beslissingen genomen werden. Vorige keer hadden we het over de beslissing om chemotherapie al dan niet op te starten. Vandaag zou ik het met u willen hebben over een beslissing die in de laatste twee maanden genomen werd en die voor u de belangrijkste (het meest ingrijpend) was.

35. Welke van de beslissingen, aangekruist op de antwoordkaart 20, 22 of 24, was voor u de belangrijkste (de meest ingrijpende)?

____

____

____

geef antwoordkaart 27

⇨ ga naar vraag 36 op pagina 13

Items m.b.t. communicatie.	Helemaal oneens				Helemaal eens
36. De arts bracht me op de hoogte van de verschillende beschikbare behandelingen	1	2	3	4	5
37. De arts gaf me de kans om mijn mening te uiten over de verschillende beschikbare behandelingen.	1	2	3	4	5
38. De arts gaf me de kans om zoveel informatie te vragen als ik nodig achtte over de verschillende beschikbare behandelingen.	1	2	3	4	5
39. De arts gaf me voldoende informatie over de verschillende beschikbare behandelingen.	1	2	3	4	5
40. De arts gaf voldoende *uitleg* over de informatie betreffende de verschillende beschikbare behandelingen	1	2	3	4	5
41. De informatie die me gegeven werd was gemakkelijk te begrijpen.	1	2	3	4	5
42. Ik ken de voordelen van al dan niet behandelen.	1	2	3	4	5
43. Ik ken de nadelen van al dan niet behandelen.	1	2	3	4	5

44. De arts gaf me de kans om te beslissen welke behandeling ik dacht dat het best voor mij was. 1 2 3 4 5

45. De arts gaf me de kans om betrokken te zijn bij de beslissingen tijdens de consultaties. 1 2 3 4 5

Helemaal oneens Helemaal eens

Items m.b.t. vertrouwen.

46. In zijn geheel genomen ben ik tevreden met de informatie die me gegeven werd. 1 2 3 4 5

47. Mijn arts en ik waren akkoord over welke behandeling (of geen behandeling) het best voor mij was. 1 2 3 4 5

48. Ik kan gemakkelijk mijn situatie opnieuw bespreken met mijn arts. 1 2 3 4 5

49. Ik ben tevreden met de manier waarop de beslissing genomen werd tijdens de consultatie. 1 2 3 4 5

50. Ik ben er zeker van dat de genomen beslissing de juiste was voor mij persoonlijk. 1 2 3 4 5

51. Ik ben tevreden dat ik adequaat geïnformeerd ben over de zaken belangrijk voor de beslissing. 1 2 3 4 5

52. Het is duidelijk welke keuze de beste is voor mij. 1 2 3 4 5

53. Ik ben me bewust van de verschillende behandelingsmogelijkheden die ik heb. 1 2 3 4 5

54. Ik voel dat er een geïnformeerde keuze gemaakt werd. 1 2 3 4 5

55. De beslissing maakt duidelijk wat het belangrijkst is voor mij. 1 2 3 4 5

⇨ EINDE ga naar deel E

E. Afsluiting interview:

Tot slot zou ik u nog een allerlaatste vraag willen stellen over alternatieve therapieën zoals o.a. homeopathie, aromatherapie, klei-aarde therapie.

56. Hebt u overwogen om alternatieve therapieën te volgen?

☐ nee ⇨ *sla vraag 57 en 58 over*
☐ ja, welke ______________________

57. Hebt u dit besproken met uw arts(en)?

☐ nee
☐ ja, met ______________

58. Hebt u deze therapieën ook gevolgd?

☐ nee
☐ ja

Eenmalig vragen (eerste interview) Welke is uw Levensbeschouwing

☐ christelijk, rooms-katholiek
☐ christelijk, anders dan rooms-katholiek
☐ gelovig, doch geen specifieke religie
☐ niet gelovig
☐ vrijzinnig
☐ andere, nl. ________________

In de eerste plaats zou ik u heel erg willen bedanken voor uw tijd en moeite. Anderzijds zou ik u willen vragen of het goed is dat ik u binnen twee maanden opnieuw contacteer om nogmaals deze vragenlijst met u te overlopen.

59. Gaat akkoord nogmaals gecontacteerd te worden:

☐ nee
☐ ja

60. Mag de huisarts verwittigd worden van deelname aan het onderzoek?

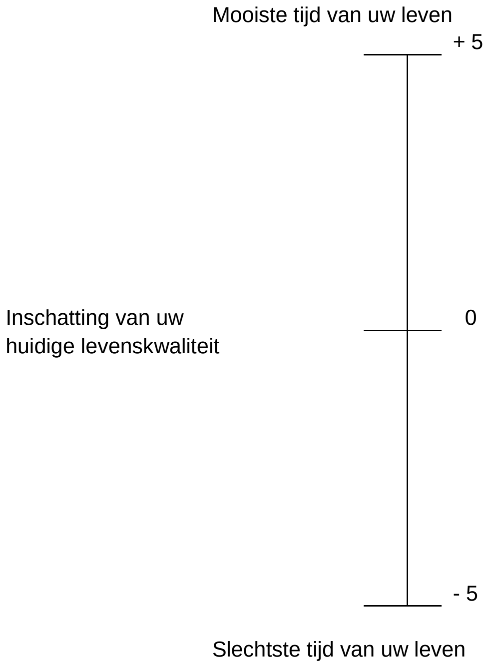
☐ nee
☐ ja

OPTIONEEL

geef antwoordkaart 28

60. Met de volgende schaal (lijnstuk) willen we nagaan hoe jij je persoonlijke levenskwaliteit van de laatste tijd plaatst tegenover de beste en de slechtste periodes die jij zelf al ooit hebt meegemaakt. Stel dat we afspreken dat de top van de schaal overeenkomt met hoe jij je voelde in de periode die voor jou de beste tijd van je leven tot nu toe is geweest. Neem nu aan dat de bodem van de schaal overeenkomt met de voor jou slechtste periode in je leven tot nu toe.
    Als je denkt dat de periode die je momenteel doormaakt dichter staat bij de beste tijd uit je leven, zet dan een kruisje dichter bij de top van de schaal. Als je vindt dat de huidige periode meer overeenstemt met de slechtere periode uit je leven, zet dan een kruisje dichter bij de onderkant van de schaal.
    Hoe dichter je een kruisje plaatst bij het uiteinde van de schaal, hoe meer je vindt dat je je nu voelt zoals toen je de beste (of slechtste) tijd van je leven doormaakte.

    Waar zou je het kruisje zetten dat aangeeft hoe jij je de laatste tijd hebt gevoeld in vergelijking met de beste en de slechtste periode in je leven?



NA HET INTERVIEW:

Ruimte voor opmerkingen van de interviewer:

Vrije Universiteit Brussel

UNIVERSITEIT GENT

Vragenlijst specialist/huisarts na overlijden patiënt. **Patiëntcode: ....**

Opmerking vooraf: één antwoord mogelijk per vraag, tenzij anders vermeld.

Algemeen

17. Hoe lang ongeveer maakte deze patiënt deel uit van uw praktijk?

☐ < 1 maand
☐ 1-3 maanden
☐ 4-6 maanden
☐ 7-12 maanden
☐ 1-5 jaar
☐ > 5 jaar

18. Hoe vaak had u (gemiddeld geschat) **contact** (consultaties, huisbezoeken, **excl.** telefonisch contact) met patiënt?

laatste week vóór overlijden	**2de t/m 4de week vóór overlijden**	**2de en 3de maand vóór overlijden**
…x per **week**	…x per **week**	…x per **maand**

19. Hoe vaak had u (gemiddeld geschat) **contact** (consultaties, huisbezoeken, **excl.** telefonisch contact) met naaste betreffende de patiënt?

laatste week vóór overlijden	**2de t/m 4de week vóór overlijden**	**2de en 3de maand vóór overlijden**
…x per **week**	…x per **week**	…x per **maand**

☐ niet van toepassing

Vragen over kwaliteit van leven van de patiënt in de **laatste week**.

20. Hoeveel dagen verbleef de patiënt in de laatste week voor overlijden in de setting waar u werkzaam bent?

☐ ____________ dagen op zeven

☐ verbleef in de laatste week nooit in de setting waar ik werkzaam ben ⇨ ga naar vraag 20

		Helemaal niet	**Een beetje**	**Nogal**	**Heel erg**
21.	Had de patiënt last met het maken van een <u>korte</u> wandeling buitenshuis?	1	2	3	4
22.	Moest de patiënt overdag in bed of in een stoel blijven?	1	2	3	4
23.	Had de patiënt hulp nodig met eten, aankleden, zichzelf wassen of naar het toilet gaan?	1	2	3	4

Gedurende de laatste week:

24.	Was de patiënt kortademig?	1	2	3	4
25.	Heeft de patiënt pijn gehad?	1	2	3	4
26.	Heeft de patiënt moeite met slapen gehad?	1	2	3	4

27.	Heeft de patiënt zich slap gevoeld?	1	2	3	4
28.	Heeft de patiënt gebrek aan eetlust gehad?	1	2	3	4
29.	Heeft de patiënt zich misselijk gevoeld?	1	2	3	4
30.	Had de patiënt last van obstipatie?	1	2	3	4
31.	Was de patiënt moe?	1	2	3	4
32.	Heeft pijn de patiënt gehinderd in zijn dagelijkse bezigheden?	1	2	3	4
33.	Voelde de patiënt zich gespannen?	1	2	3	4
34.	Voelde de patiënt zich neerslachtig?	1	2	3	4

35. Hoe zou u zijn/haar algehele "kwaliteit van het leven" gedurende de laatste week beoordelen? (Omcirkel het getal tussen 1 en 7 dat het meest op de patiënt van toepassing is.)

Erg slecht	1	2	3	4	5	6	7	Uitstekend

Functionele status patiënt in de laatste drie maanden voor overlijden.

36. Wat was de functionele status van de patiënt?

a. Tijdens de 2de en 3de maand vóór overlijden?

0	Volledig actief, alle normale bezigheden kunnen uitvoeren zonder beperkingen, zoals vóór het optreden van de ziekte.
1	Beperkt in het verrichten van zware fysieke activiteiten, maar ambulant en in staat om lichte werkzaamheden of werk al zittend te verrichten, vb. licht huishoudelijk werk, bureauwerk
2	Ambulant en in staat om zichzelf volledig te verzorgen, maar niet in staat om enig ander werk te verrichten. Voor meer dan 50% van de dag uit bed.
3	Slechts gedeeltelijk in staat zichzelf te verzorgen, voor meer dan 50% van de dag in bed of stoel
4	Volledig geïnvalideerd. Niet in staat zichzelf te verzorgen. Volledig bedlegerig of aan de stoel gekluisterd

b. Tijdens de laatste maand vóór overlijden (met uitzondering van de laatste week)?

0	Volledig actief, alle normale bezigheden kunnen uitvoeren zonder beperkingen, zoals vóór het optreden van de ziekte.
1	Beperkt in het verrichten van zware fysieke activiteiten, maar ambulant en in staat om lichte werkzaamheden of werk al zittend te verrichten, vb. licht huishoudelijk werk, bureauwerk
2	Ambulant en in staat om zichzelf volledig te verzorgen, maar niet in staat om enig ander werk te verrichten. Voor meer dan 50% van de dag uit bed.
3	Slechts gedeeltelijk in staat zichzelf te verzorgen, voor meer dan 50% van de dag in bed of stoel
4	Volledig geïnvalideerd. Niet in staat zichzelf te verzorgen. Volledig bedlegerig of aan de stoel gekluisterd

c. Tijdens de laatste week vóór overlijden?

0	Volledig actief, alle normale bezigheden kunnen uitvoeren zonder beperkingen, zoals vóór het optreden van de ziekte.
1	Beperkt in het verrichten van zware fysieke activiteiten, maar ambulant en in staat om lichte werkzaamheden of werk al zittend te verrichten, vb. licht huishoudelijk werk, bureauwerk
2	Ambulant en in staat om zichzelf volledig te verzorgen, maar niet in staat om enig ander werk te verrichten. Voor meer dan 50% van de dag uit bed.
3	Slechts gedeeltelijk in staat zichzelf te verzorgen, voor meer dan 50% van de dag in bed of stoel
4	Volledig geïnvalideerd. Niet in staat zichzelf te verzorgen. Volledig bedlegerig of aan de stoel gekluisterd

Overlijden patiënt

37. Zou u willen aangeven op een schaal van 0 tot 10 hoe u het overlijden van de patiënt beoordeelt?

Onzachte dood	0	1	2	3	4	5	6	7	8	9	10	Zachte dood

38. Was het overlijden plotseling en geheel onverwacht?

☐ ja
☐ nee

Medische beslissingen met een potentieel levensverkortend effect

39. Heeft u of een collega arts in het ziekenhuis één of meerdere van de volgende handelingen uitgevoerd (of doen uitvoeren), <u>wetende dat</u> deze handelswijze het levenseinde van de patiënt kon bespoedigen? **(gelieve zowel vragen 23a en 23b te beantwoorden)**

a. Niet opstarten of stopzetten van een behandeling*?

☐ ja
☐ nee

b. Het intensiveren van de pijn- en/of symptoombestrijding door gebruik van een geneesmiddel?

☐ ja ⇨ ga naar vraag 24
☐ nee ⇨ ga naar vraag 25

*In dit onderzoek omvat ‘behandeling’ ook kunstmatige voeding en/of hydratatie.

40. Was het bespoedigen van het levenseinde <u>mede het doel</u> van de handelswijze zoals beschreven in vraag 23b?

☐ ja
☐ nee

41. Was het overlijden het gevolg van één of meerdere van de volgende handelswijzen die u of een collega arts in het ziekenhuis beslisten uit te voeren <u>met het expliciete doel</u> het levenseinde te bespoedigen*?

a. Niet opstarten of stopzetten van een behandeling**?

☐ ja
☐ nee

* ‘het levenseinde te bespoedigen’ <u>*of*</u> ‘het leven niet te verlengen’.
** In dit onderzoek omvat ‘behandeling’ ook kunstmatige voeding en/of hydratatie.

42. Was het overlijden het gevolg van het gebruik van een geneesmiddel dat werd voorgeschreven, verstrekt of toegediend door u of een collega arts in het ziekenhuis <u>met het expliciete doel</u> het levenseinde te bespoedigen (of de patiënt in staat te stellen zelf zijn of haar leven te beëindigen)?
    a.
    - ☐ ja
    - ☐ nee

    b. Zo ja, wie diende dit middel toe (=bracht het in het lichaam)?
    (kruis zoveel antwoorden aan als toepasselijk)
    - ☐ de patiënt
    - ☐ uzelf of een andere arts
    - ☐ verpleegkundig personeel
    - ☐ iemand anders

Wanneer <u>ten minste één</u> van de onderdelen van vragen 23, 24, 25 of 26 met 'ja' werd beantwoord, ga naar vraag 27.
Wanneer <u>alle onderdelen</u> van de vragen 23, 24, 25 en 26 met 'nee' werden beantwoord, ga naar 34.

Beslissingsproces

Let op: vragen 27-33 hebben betrekking op <u>de laatstgenoemde handelswijze in vragen 23 tot 26, d.w.z. het laatste 'ja' antwoord op de vragen 23-26.</u>

43. Een vraag in verband met deze (laatstgenoemde) handelwijze: Met hoeveel tijd is naar uw schatting hierdoor het leven van de patiënt verkort?
    - ☐ meer dan zes maanden
    - ☐ één tot zes maanden
    - ☐ één tot vier weken
    - ☐ één tot zeven dagen
    - ☐ minder dan 24 uur
    - ☐ het leven werd waarschijnlijk helemaal niet verkort

44. Heeft u of een collega arts in het ziekenhuis met de patiënt de (mogelijke) bespoediging van het levenseinde ten gevolge van de (laatstgenoemde) handelwijze besproken?
    - ☐ ja, tijdens het uitvoeren van de handeling of kort ervoor
    - ☐ ja, enige tijd ervoor
    - ☐ nee, geen bespreking

45. Werd de beslissing betreffende de (laatstgenoemde) handelwijze genomen op expliciete vraag van de patiënt?
    - ☐ ja
    - ☐ nee, maar de patiënt had een wens geuit
    - ☐ nee, en de patiënt had nooit een wens geuit

46. Achtte u de patiënt op dat moment in staat om zijn of haar situatie in te schatten en daarover op adequate wijze een besluit te nemen?
    - ☐ ja
    - ☐ nee, niet volledig in staat, rede: ______________________
    - ☐ nee, helemaal niet in staat, rede: ______________________

47. Welk van onderstaande stellingen leunt het dichtst aan bij hoe volgens u deze (laatstgenoemde) beslissingen genomen werd?
    - ☐ Ik (of een collega arts in het ziekenhuis) besliste op basis van mijn (zijn/haar) kennis
    - ☐ Ik (of een collega arts in het ziekenhuis) besliste maar hield in sterke mate rekening met de opinie van de patiënt.
    - ☐ De patiënt en ik (of een collega arts in het ziekenhuis) beslisten samen, op gelijke basis
    - ☐ De patiënt besliste maar hield in sterke mate rekening met mijn opinie (of die van een collega arts in het ziekenhuis).
    - ☐ De patiënt besliste op basis van al de informatie die hij/zij had of verkreeg.

48. Waren er andere betrokken bij het nemen van deze (laatstgenoemde) beslissing?
    (Meerdere antwoorden mogelijk)
    - ☐ ja, één of meerdere artsen
    - ☐ ja, verplegend personeel
    - ☐ ja, familie/naaste
    - ☐ ja, iemand anders, nl. ________________________
    - ☐ nee ⇨ ga naar vraag 34

Beslissingsproces vervolg.

49. Welk van onderstaande stellingen leunt het dichtst aan bij hoe volgens u deze (laatstgenoemde) beslissingen genomen werd?
    - ☐ Ik (of een collega arts in het ziekenhuis) besliste op basis van mijn (zijn/haar) kennis
    - ☐ Ik (of een collega arts in het ziekenhuis) besliste maar hield in sterke mate rekening met de opinie van de ‘andere’.
    - ☐ De ‘andere’ en ik (of een collega arts in het ziekenhuis) beslisten samen, op gelijke basis
    - ☐ De ‘andere’ besliste maar hield in sterke mate rekening met mijn opinie (of die van een collega arts in het ziekenhuis).
    - ☐ De ‘andere’ besliste op basis van al de informatie die hij/zij had of verkreeg.

50. Werd de patiënt tot aan het overlijden vrijwel doorlopend in slaap gehouden d.m.v. hoge dosering sedaties (b.v. benzodiazepines of barbituraten)?
    - ☐ ja, en kunstmatige voeding en hydratatie werden <u>niet</u> toegediend
    - ☐ ja, en kunstmatige voeding en hydratatie werden toegediend
    - ☐ nee

51. Heeft u of een collega arts in het ziekenhuis op voorhand duidelijk afgesproken dat in geval van een hart en/of ademhalingsstilstand geen poging zou worden ondernomen om de patiënt te reanimeren? (een zogenaamde ‘Niet-Reanimeer-Beslissing’)
    (kruis zoveel antwoorden aan als toepasselijk)
    - ☐ ja, samen met de patiënt
    - ☐ ja, samen met de familie van de patiënt
    - ☐ ja, samen met andere zorgverlener(s)
    - ☐ niet expliciet voor deze patiënt, maar impliciet, op basis van de overeenkomst dat over het algemeen geen poging tot reanimatie wordt gedaan in onze instelling/praktijk
    - ☐ nee

Wanneer ten minste één van de eerste twee stellingen aangekruist werd, ga naar vraag 36.

Wanneer geen van de eerste twee stellingen aangekruist werd, ga naar vraag 37.

52. Welk van onderstaande stellingen leunt het dichtst aan bij hoe volgens u deze (‘Niet-Reanimeer’) beslissing genomen werd?
    - ☐ Ik (of een collega arts in het ziekenhuis) besliste op basis van mijn (zijn/haar) kennis
    - ☐ Ik (of een collega arts in het ziekenhuis) besliste maar hield in sterke mate rekening met de opinie van de patiënt en/of familie.
    - ☐ De patiënt en/of familie en ik (of een collega arts in het ziekenhuis) beslisten samen, op gelijke basis
    - ☐ De patiënt en/of familie besliste maar hield in sterke mate rekening met mijn opinie (of die van een collega arts in het ziekenhuis).
    - ☐ De patiënt en/of familie besliste op basis van al de informatie die hij/zij had of verkreeg.

Wens/verzoek van de patiënt

53. Heeft de patiënt, voor zover u weet, ooit een wens geuit tot het voorschrijven, verstrekken of toedienen van een geneesmiddel met het expliciete doel het levenseinde te bespoedigen, het leven in te korten of te beëindigen of de patiënt in staat te stellen zijn eigen leven te beëindigen?
    - ☐ nee, de patiënt had geen wens kenbaar gemaakt ⇨ ga naar vraag 39
    - ☐ ja, de patiënt had wens geuit tot toedienen van een geneesmiddel door arts met het expliciete doel het levenseinde te bespoedigen, het leven in te korten of te beëindigen [*euthanasie*] ⇨ ga naar vraag 38
    - ☐ ja, de patiënt had wens geuit tot voorschrijven of verstrekken van een geneesmiddel om zelf het leven te beëindigen [*hulp bij zelfdoding*] ⇨ ga naar vraag 38

54. In welke mate was er sprake van een uitdrukkelijk en herhaald verzoek toen de wens voor het laatst besproken werd?
    - ☐ in zeer sterke mate
    - ☐ in sterke mate
    - ☐ in mindere mate
    - ☐ weet niet

    Ruimte voor toelichting: ____________________

    ____

55. Had de patiënt wensen over de medische behandelingen die hij aan het einde van het leven nog wel of niet zou willen ontvangen? Indien ja, kan u omschrijven welke hij/zij verbaal uitte en welke op papier stonden? **(Meerdere antwoorden mogelijk)**

	Verbaal	Op papier
a. ja, een niet-reanimeerverklaring (Do Not Resuscitate)	☐	☐
b. ja, een voorafgaande wilsverklaring inzake euthanasie, d.i. verklaring waarin verzocht wordt euthanasie uit te voeren voor het geval de patiënt wilsonbekwaam zou worden in de toekomst.	☐	☐
c. ja, een actueel verzoek tot euthanasie	☐	☐
d. ja, een verklaring tegen actieve euthanasie	☐	☐
e. ja, een niet-behandelverklaring	☐	☐
f. ja, een zorgverklaring (= hoe de patiënt juist wel of juist niet medisch en verpleegkundig verzorgd wil worden)	☐	☐
g. ja, een expliciete vraag naar palliatieve zorg	☐	☐
h. ja, anders, nl: ____________________ ☐		☐
i. nee		

56. Indien gewenst, kan u hier uw antwoorden op de voorgaande vragen verduidelijken of aanvullen.

    ____

    ____

    ____

    ____

Enkele vragen m.b.t. uzelf

Indien u reeds patiënten includeerde in deze studie en u een identificatienummer heeft, is dit het einde van de vragenlijst, vul hier uw identificatienummer in: _______________

Indien u geen identificatienummer heeft ⇨ ga naar vraag 41

57. Uw geslacht?
    - ☐ M
    - ☐ V

58. Uw leeftijd?

    ______ jaar

59. Bent u werkzaam als:
    - ☐ specialist
    - ☐ specialist in opleiding
    - ☐ huisarts ⇨ vraag 45
    - ☐ huisarts in opleiding ⇨ vraag 45

60. Welk klinisch specialisme is uw hoofdactiviteit?
    - ☐ algemeen internist
    - ☐ algemene chirurgie
    - ☐ anaesthesie
    - ☐ cardiologie
    - ☐ neuro-chirurgie
    - ☐ neurologie/psychiatrie
    - ☐ gastro-enterologie
    - ☐ geriatrie
    - ☐ gynaecologie
    - ☐ KNO-heelkunde
    - ☐ oncologie
    - ☐ orthopedie
    - ☐ pneumologie
    - ☐ urologie
    - ☐ andere, nl. ____________________________

61. Welke praktijkvorm(en) is voor u van toepassing?
    (Meerdere antwoorden mogelijk)
    - ☐ solo-praktijk
    - ☐ duo-praktijk
    - ☐ groepspraktijk
    - ☐ gezondheidscentrum
    - ☐ ziekenhuis

62. Hoeveel jaren bent u reeds werkzaam in de directe patiëntenzorg?

    ________ jaar

63. Aan welke universiteit bent u afgestudeerd als arts?
    - ☐ KUL/UCL
    - ☐ UG
    - ☐ UIA
    - ☐ VUB/ULB
    - ☐ Andere Belgische universiteit
    - ☐ Buitenlandse universiteit

64. Heeft u ooit een intensieve opleiding (met certificaat) ‘palliatieve zorg en/of stervensbegeleiding’ gevolgd?
    - ☐ ja
    - ☐ nee

65. Heeft u ooit een intensieve opleiding (met certificaat) ‘communicatie vaardigheden’ gevolgd?
    - ☐ ja
    - ☐ nee

66. Welke levensbeschouwing is voor u het meest toepasselijk?
    - ☐ christelijk, rooms-katholiek
    - ☐ christelijk, anders dan rooms-katholiek
    - ☐ gelovig, doch geen specifieke religie
    - ☐ niet gelovig
    - ☐ vrijzinnig
    - ☐ andere, nl. __________

67. Is uw levensbeschouwing belangrijk bij het nemen van medische beslissingen rond het levenseinde van uw patiënten?
    - ☐ heel belangrijk
    - ☐ belangrijk
    - ☐ noch belangrijk, noch onbelangrijk
    - ☐ onbelangrijk
    - ☐ heel onbelangrijk

68. Hoeveel terminale patiënten heeft u verzorgd gedurende de laatste 12 maanden?

    ____

Nummer vragenlijst:

Curriculum Vitae

Koen Pardon, born May 19, 1969 (Leuven, Belgium), is a clinical psychologist and psychotherapist (KUL), a candidate in law (VUB) and a postgraduate in business administration (Ehsal). During the period 1994-1998, he worked as a psychologist in the psychiatric university hospital of Kortenberg and in a mental health service in Antwerp. From 1998 until 2000 he was a staff member of the 'Nationaal Verbond van Socialistische Mutualiteiten' and from 2000 to 2006 he worked as a staff member and press officer of the federal government ministers of social affairs, employment and e-government. Since 2007 he is associated as a researcher at the end-of-life care research group of the VUB and the University of Ghent.
He and his wife Sara Vercauteren have two fantastic children, Tess and Liv.

List of publications and presentations

International peer reviewed publications

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Deliens L. Preferences of advanced lung cancer patients for patient-centred information and decision-making: a prospective multicentre study in 13 hospitals in Belgium. Patient Educ Couns 2009 December;77(3):421-9.

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Are patients' preferences for information and participation in medical decision-making being met? Interview study with lung cancer patients. Palliat Med 2011 January;25(1):62-70.

Pardon K, Deschepper R, Vander Stichele R, Bernheim JL, Mortier F, Bossuyt N, Schallier D, Germonpré P, Galdermans D, Van Kerckhoven W, Deliens L. Advanced lung cancer patients' preferences for the involvement of family and others in medical decision-making. J Palliat Med 2010 October; 13(10):1199-203.

Published abstracts

Deschepper R, Vander Stichele R, Bernheim JL, Pardon K, Deliens L. The involvement of terminal patients in end-of-life care research: why and how? 9th Public Health Symposium: Public Health at the End of life, Jette, Belgium, 14 December 2007. Archives of Public Health 65(Suppl 1):18.

Pardon K, Deschepper R, Vander Stichele R, Michiels E, Deliens L. Patient participation in medical decisions at the end of life: a study protocol. 9th Public Health Symposium: Public Health at the End of life, Jette, Belgium, 14 December 2007. Archives of Public Health 65(Suppl 1):40.

Deschepper R, Vander Stichele R, Bernheim JL, Pardon K, Mortier F, Deliens L. The involvement of terminal patients in end-of-life care research: why and how? 11th Congress of the European Association for Palliative Care, Vienna, Austria, 7-10 May 2009. European Journal of Palliative Care: 125.

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Presentations

Pardon K. Patient participation in medical decisions at the end of life: a study protocol. 9th Public Health Symposium: Public Health at the End of Life, Jette, 14/12/2007.

Pardon K. Een longitudinaal onderzoek naar informatie- en participatiewensen van longkankerpatiënten: een studieprotocol. 6de Vlaams-Nederlands onderzoeksforum palliatieve zorg, Rotterdam, 20/03/2009.

Pardon K. Preferences of advanced lung cancer patients for patient-centred information and decision-making. A prospective multicentre study in 13 hospitals in Belgium. 11th Congress of the European Association for Palliative care, Vienna, 7/5/2009.

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