

## Preferences of advanced lung cancer patients for information and participation in medical decision-making: a longitudinal multicentre study

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The main objective of this dissertation was to gain insight into the 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 (ELDs).

In the course of one year, physicians in thirteen 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 two months until the fourth interview and every four months until the sixth interview.

At inclusion, 128 patients were interviewed at least once; thirteen were interviewed six consecutive times. Nearly all patients wanted information about diagnosis, treatment and prognosis and a small majority wanted information about palliative care and ELDs. Preferences regarding participation varied according to the type of decision. Some preferences, more specifically the preferences for information about prognosis, palliative care and ELDs and the preferences for shared decision-making, were regularly not well met by the physician. Preferences were variable over time, at least when it concerned information preferences about palliative care, ELDs and participation preferences. Family was important in medical decision-making to 69% of the patients and to almost all patients in case of incompetence.

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 because preferences do change over time in ways they might not expect.

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## Introduction

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. Also, in scientific literature, the focus is on models of shared and informed decision-making as an alternative to the paternalistic model.<sup>1</sup> 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.<sup>2</sup> 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.<sup>3</sup> The main objective of this dissertation was to gain insight into the preferences of patients with advanced lung cancer with regard to information about diagnosis, prognosis, treatment, palliative care and end-of-life decisions with a possible or certain life-shortening effect (ELDs) and with regard to participation in medical decision-making, whether these preferences were met according to the patients and how the preferences evolved over time. Additionally, we aimed to discover what the preferences of the patients were regarding involvement of family and other persons in medical decision-making.

Advanced lung cancer patients were studied because of the high prevalence of the condition and the short median life expectancy of 6-9 months.

Patients with stage IIIb and IV non-small-cell lung cancer were included in the study by pulmonologists or oncologists of thirteen hospitals in Flanders, Belgium. The patients were interviewed up to a maximum of six times during their disease trajectory with a standardised questionnaire with close-ended questions.<sup>4</sup> The protocol of the study was approved by the Ethical Review Boards of the University Hospital of the Free University Brussels and of all the participating teaching hospitals and general hospitals.

We succeeded in interviewing 128 advanced lung cancer patients shortly after diagnosis of advanced lung cancer (68% participation rate). A total of 97 out of 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).

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).

## Information and participation preferences shortly after diagnosis

A first important finding of the study was 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 ELDs.

The preferences of the advanced lung cancer patients for participation in medical decision-making were studied with regard to medical decisions in general, treatment decisions, care setting 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). 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 not only in general.

## Meeting the preferences

We observed that nearly all of the patients who wanted information in general plus about diagnosis and treatment options, 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 other words, physicians seem to be 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.

With regard to participation in medical decision-making, 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 for this is that physicians do not seem to be able to interact with patients and make shared decisions, although this model of shared-decision-making is endorsed in the medical literature.

## Changing preferences

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. The preferences for participation in medical decision-making were also unstable: 50%- 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.

### Key messages for clinical practice

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.

**1. Explore the preferences of patients with regard to every important information topic and type of decision regularly over time**

The information and participation preferences of the newly diagnosed lung cancer patients depended on the information topic and type of medical decision and varied over time. This makes it important that physicians regularly explore the specific preferences of the patients to be able to meet these preferences.

**2. End-of-life communication training is necessary**

It is not surprising that physicians encounter difficulties in performing the complex and demanding tasks of giving patients 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. Therefore it is important that physicians are trained in end-of life communication.

**3. Acknowledge the importance of family**

Seriously ill patients clearly seem to have a need for trusted allies to be present in dealings with 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.

### Preferences for involvement of family

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. 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.

### Conclusion

This is the first longitudinal study of information and participation preferences in a cohort of newly diagnosed advanced lung cancer patients. The important findings of this study were:

1. Patients with newly diagnosed advanced lung cancer had a high need for information, but less concerning palliative care and ELDs. Preferences regarding participation in decision-making varied according to the type of decision.
2. The information preferences of the advanced lung cancer patients were not met by the physician when it concerned topics regarding limited life expectancy and death. Neither were the prefer-

ences for participation to the degree of sharing the decisions with the physician met.

3. The preferences for information about diagnosis, prognosis and treatment options were stable. In contrast however, the preferences for information about palliative care and ELDs and the preferences for participation in medical decision-making often changed over time.
4. Two thirds of the patients wanted their family involved in medical decision-making, and almost all patients wanted their family involved in case they would become incompetent at the end of life.

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