

UNIVERSITY OF OSLO

# Communicating medical prognosis

---

Concepts, attitudes and practice

Lotte Rogg

2009-09-29



© **Lotte Victoria Rogg, 2010**

*Series of dissertations submitted to the  
Faculty of Medicine, University of Oslo  
No. 893*

ISBN 978-82-8072-578-3

All rights reserved. No part of this publication may be reproduced or transmitted, in any form or by any means, without permission.

Cover: Inger Sandved Anfinsen.  
Printed in Norway: AiT e-dit AS, Oslo, 2010.

Produced in co-operation with Unipub AS.  
The thesis is produced by Unipub AS merely in connection with the thesis defence. Kindly direct all inquiries regarding the thesis to the copyright holder or the unit which grants the doctorate.

*Unipub AS is owned by  
The University Foundation for Student Life (SiO)*



# Contents

---

<b>ACKNOWLEDGEMENTS .....</b>	<b>4</b>
<b>LIST OF PAPER.....</b>	<b>5</b>
<b>BACKGROUND .....</b>	<b>6</b>
INTRODUCTION .....	6
<i>Development of the current study .....</i>	<i>6</i>
COMMUNICATION .....	7
<i>Changing realities in medicine .....</i>	<i>7</i>
TRUTH-TELLING IN MEDICINE.....	8
<i>Informed consent.....</i>	<i>8</i>
PROGNOSIS .....	9
<i>Communication of prognostic information .....</i>	<i>9</i>
<i>Physicians' development of communication skills .....</i>	<i>10</i>
AIMS OF THE THESIS .....	12
<b>MATERIALS AND METHODS.....</b>	<b>13</b>
STUDY POPULATIONS.....	13
<i>The Norwegian Physician Health Survey .....</i>	<i>13</i>
The postal survey (Papers I and II) .....	13
<i>The focus group interviews (Paper III).....</i>	<i>13</i>
<i>The observational study (Paper IV) .....</i>	<i>14</i>
DATA SOURCES .....	14
<i>The postal survey (Papers I and II) .....</i>	<i>14</i>
<i>The focus group interview (Paper III) .....</i>	<i>15</i>
<i>The observational study (Paper IV) .....</i>	<i>16</i>
DATA COLLECTION PROCEDURE AND DATA MANAGEMENT .....	16
<i>The postal survey (Papers I and II) .....</i>	<i>16</i>
<i>The focus group interviews (Paper III).....</i>	<i>16</i>
<i>The observational study (Paper IV) .....</i>	<i>17</i>
ANALYSIS .....	17
<i>The postal survey (Papers I and II) .....</i>	<i>17</i>
<i>The focus group interview (Paper III) .....</i>	<i>18</i>
<i>The observational study (Paper IV) .....</i>	<i>18</i>
ETHICAL CONSIDERATIONS .....	19
<b>MAIN RESULTS AND SUMMARY OF PAPERS.....</b>	<b>20</b>
<i>Paper I .....</i>	<i>20</i>
<i>Paper II .....</i>	<i>20</i>
<i>Paper III .....</i>	<i>21</i>
<i>Paper IV .....</i>	<i>21</i>
<b>GENERAL DISCUSSION .....</b>	<b>22</b>
<i>Design .....</i>	<i>22</i>
<i>Sampling.....</i>	<i>23</i>
<i>Measures.....</i>	<i>25</i>
<i>Preconceptions .....</i>	<i>26</i>

<i>Analytical considerations</i> .....	27
PHYSICIANS, AND THE DETERMINANTS OF THEIR ATTITUDES AND PRACTICE.....	29
<i>Who are they and what shapes their attitudes?</i> .....	29
<i>Physicians' practices</i> .....	31
FUTURE PERSPECTIVES .....	32
<b>CONCLUSIONS</b> .....	<b>35</b>
CLINICAL IMPLICATIONS.....	36
SCIENTIFIC IMPLICATIONS .....	36
FINAL WORDS .....	37
<b>REFERENCES</b> .....	<b>38</b>
<b>PAPERS I-IV</b> .....	<b>44</b>
<b>APPENDIX</b> .....	<b>44</b>

## Acknowledgements

For some research is a product of passion and pain, while others insist on it being just another kind of job. I agree with both. It is overwhelming to have had the opportunity of following a path into the minds of physicians. Trying to understand the well-intended, self-conscious and hard-working physicians meeting patients in a time of crisis means to explore a more or less unknown and intensely intriguing field. Of course one has to be passionate about such research! Still, as most PhD-students experience, the challenges involved in any research project exceeds by far the imagination at the onset of the ordeal. Fortunately, everyday life keeps on existing in parallel with this ordeal, ensuring some level of sobriety and moderation.

I am indebted to my supervisors Peter K Graugaard, Jon Håvard Loge and Olaf G Aasland for supporting and inspiring me at all stages. We have had fascinating discussions concerning communication of prognosis, and adjacent topics. The lonely life as a researcher has not been that lonely, thanks to my dear friends and PhD colleagues Kjersti Bruheim, Aina Emaus and Sissi Espetvedt Finstad. Having people around that readily contributes with scientific as well as practical opinions and advices have been a great support. Thank you Inger Thune, Ragnfrid og Nils, and Medisinsk bibliotek, represented by Malene Gundersen. The possibility of discussing the project at different stages both at the Department of Behavioural Medicine, University of Oslo, and at the Cancer Centre at Oslo University Hospital Ullevål, has been fruitful. The research project would not have been possible without the financial support from the South-Eastern Norway Regional Health Authority, nor without the work facilities provided by Kjell Magne Tveit and Tone Ik Dahl at the Cancer Center. The practical support provided by the Research Institute of the Norwegian Medical Association in collecting the survey data has been of great importance. Finally, I am deeply indebted to the many physicians as well as patients participating in the studies. Without you, the thesis would never have happened.

A last word of gratitude goes to my darling daughters, Barbro and Mona. You have been intensely patient and tolerant towards a snappy and forever working mother. I promise you that better days await us!

*Lotte Rogg, Oslo September 2009*

## List of paper

- I. Rogg L, Graugaard PK, Loge JH. Physicians' interpretation of the prognostic term 'terminal': A survey among Norwegian physicians. *Palliative and Supportive Care* 2006; **4**: 273–278.
- II. Rogg L, Loge JH, Aasland OG, Graugaard PK. [Physicians' attitudes towards disclosure of prognostic information: A survey among a representative cross-section of 1605 Norwegian physicians](#). *Patient Education and Counselling*, in press, Available online 8 April 2009.
- III. Rogg L, Aasland OG, Graugaard PK, Loge JH. Direct communication, the unquestionable ideal? Oncologists' accounts of communication of bleak prognoses. Submitted 2009.
- IV. Graugaard PK, Rogg L, Eide H, Uhlig T, Loge JH. Ways of providing the patient with a prognosis: a terminology of employed strategies based on qualitative data. Submitted 2009.

## **Background**

### **Introduction**

The starting point of my thesis was two observations made during an effort to include the next of kin of patients with short life expectancy on a course. As we are located in a department of oncology, we thought that a course offering information about various aspects of challenges at the end of life would be welcomed. Instead, we experienced a shortage of potential participants. The recruitment was done in a stepwise manner: we approached the oncologists, asking them to point out patients with a maximum of 6 months' expected survival. Patients who fitted this criterion were then asked by their oncologist whether they thought that their closest relative(s) would be willing to participate in the course. Finally, the relative was able to accept or refuse the offer. The course lasted for 6 consecutive weeks, during which one of the four participating relatives was widowed.

Through this process we made two intriguing observations: (1) the huge difficulty in recruiting participants despite the fact that potentially there were many who could have benefited, and (2) a discrepancy in the perceptions of the patient and close relative with regard to the seriousness of the physical condition and the remaining survival time. There were several possible factors that could explain these observations pertaining to the patient and his or her next of kin, but we suspected that some of the recruitment difficulties, as well as the gap between patient's and relative's prognostic awareness, could be due to physician-related factors. When we asked the oncologists why recruitment was slow despite many potentially eligible participants, they seemed hesitant to point out which of their patients actually had a life expectancy of less than 6 months. In addition, some colleagues expressed concern that their patient would be devastated if he or she found out about the short life expectancy.

### **Development of the current study**

Despite advances in cancer treatment, oncologists will experience that approximately 50% of their patients currently in treatment eventually dying from the cancer. Oncologists are therefore regularly exposed to dying patients. They are expected to manage patients' needs for information, and emphasis is placed on communication skills. In fact, oncology is the only Norwegian speciality where a course in communication skills is a compulsory part of



the specialist training. Given the emphasis on open communication in the oncological community, how could patients and their relatives apparently be ignorant of the harsh realities? With my starting point as an oncology registrar I wanted to explore the oncologists' contribution to the observed gap between the reality and patients' and carers' understanding of the situation. The present thesis is the result of these efforts.

### **Communication**

The word communication, originating from the Latin *communis*, means sharing something in common [1]. Hence, it can be defined as the process by which meanings are exchanged between individuals through a common system of symbols. In the medical encounter the patient's illness narrative and the physician's disease narrative play an important, but often unrecognised, role. Most probably, the two narratives are far from identical, leading to an imbalance in communication. The patient-physician relationship is asymmetrical, with the patient in the more vulnerable role. Communication between the two must therefore take into account this vulnerability, in particular when the issues are as sensitive as life and death. The gap between such realities and expectations seems, however, to be growing, in the general population as well as among physicians [2].

### **Changing realities in medicine**

For many years cure was not achievable, and prevention and comfort were the mainstay of medical practice [3]. Along with the technical and medical advances of the nineteenth and twentieth centuries, diagnostic and curative capabilities eventually took over as the primary focus of medical activity [4]. These developments dramatically improved survival of previously fatal infectious diseases, which could now be effectively cured with a few weeks on antibiotics. As the illness panorama has changed further, from communicable to chronic diseases, over the last 60 years, medical practitioners can no longer expect to be primarily engaged in cure. However, the medical profession appears to have adapted their role as eradicators of disease more easily than their role of comforters of suffering [5]. At the same time the expectations of what modern medicine can achieve seems to be growing in the general population as well as among physicians. Also, the traditional asymmetrical patient-physician relationship has become more symmetrical, due to the disappearance of the monopoly on professional knowledge, new professional standards of transparency, accountability and evidence-based guidelines [6] and new legislation on patients' rights [7],

as well as a focus on patient autonomy. This seems to have influenced communication between patients and physicians.

### **Truth-telling in medicine**

The ethos of open, honest information and patient involvement in decision-making about treatment make sense when the patient will have to live with the illness for many years. However, the straightforward practice of telling the patient a truth implies that the truth is, in fact, a fixed object which merely awaits verbalisation. If an objective static medical truth existed, informing the patient of this truth can be seen as a procedure, rather than a process. Of course, there is no such thing as one truth. The nature and evolution of a disease, the treatment options, possible side effects and probable prognosis are objective elements of truth in medicine. Two other dimensions are equally important: the subjective, i.e. the patient's perception of the illness, and the contextual, varying according to the patient's and the physician's backgrounds [2].

### **Informed consent**

A particular version of truth telling in medical practice is linked to informed consent. The historical background can be said to be the Nuremberg Code, which subsequently led to the Helsinki Declaration on medical ethics principles regarding experimentation on human beings. Informed consent is a compulsory part of recruiting patients into medical trials, but has impacted upon other areas of medical activity as well [7]. We need to find a way of accommodating the patient's right to know and influence the treatment strategies of their medical care, together with the maintenance of hope, even when the prospects are bleak. According to McKenna and colleagues, valid informed consent should include the following elements: adequate information about risks and benefits; an ongoing process of communication between the physician and the patient rather than a one-off event; comprehension by the patient of detailed explanations provided in appropriate language and at an appropriate reading level; voluntary and non-coerced consent; and adequate documentation of the process used to obtain consent [8]. Straightforward as this may seem, there are several challenges, one being related to the patient's comprehension of the situation and the procedural information given by the physician [9].

## Prognosis

The potential risk and benefit of a particular treatment strategy are part of the prognostic considerations, leading to a specific communication task in patient management. In the early days of modern medicine, prognosis was linked to the mortality of a disease [10]. However, the ancient Greek meaning of the word was not restricted to medical matters, but effectively meant *to know beforehand*. Later development of the word in Latin to *prognosticatio* designated a prediction or forecast, especially of the future course of events based on present observation – the probable outcome of a process or event [1]. In modern usage prognosis is still not necessarily linked to medicine, but is widely used in the field.

## Communication of prognostic information

*Prognostication* is the act of formulating and communicating a prediction. In medical research with regard to communication of bad news, prognostication is rarely explicitly mentioned. However, the gravity of a diagnosis is closely linked to the likely prognostic scenarios. It is the prospect of a disease's natural course, as well as the potential success or failure of available treatment options that determine the disease's severity. The additional uncertainty in the prognosis of a disease, compared with the more straightforward and dichotomous nature of a diagnosis, renders communication about prognoses particularly challenging [11]. Research exploring prognostic information delivery is rather sparse, particularly with regard to late illness [12-14], and there is little evidence for the best method of communicating prognosis. Existing research displays a widespread opinion among healthcare professionals that patients should be told the truth about their prognosis [15-21]. However, in practice health professionals seem to avoid discussion of the topic, withhold information or use language that is difficult for patients and carers alike to understand [15;19;22-24]. Studies have pointed at the use of implicit rather than explicit communication concerning prognostic information [25-27], and reluctance to discuss Do – not – resuscitate orders with patients and carers [28]. Physicians' tendencies to be overly optimistic about their patients' remaining survival time increases further the gap between information imparted and actual survival [29;30]. When the physician avoids discussing the prognosis with terminally ill patients, there are indications that patients misunderstand their prognosis [20;31]. One study among patients suffering from chronic lymphocytic leukaemia found an association between physicians' use of euphemism and lower emotional quality of life among patients [32]. Thorough information concerning the incurable cancer diagnosis,

aim of cancer treatment and life expectancy did not elevate levels of anxiety in patients in an Australian study [33]. In a study measuring prognostic awareness and depression in terminally ill patients the authors found higher levels of depression among the patients not acknowledging their prognosis compared to those who demonstrated partial or complete acknowledgement [34]. However, this association does not show a cause and effect relationship. The lower incidence of depression among the prognostically aware could be explained by the fact that those who are less depressed in the first place feel more motivated to acquire information than do the more depressed patients. One consequence of end of life discussions found in a study by Wright and colleagues was a reduction in aggressive medical treatment near death [23]. This again was associated with better patient quality of life, and again, improved bereavement adjustment among carers. A Swedish population-based follow-up study exploring aspects of prognostic communication with carers, found that a substantial proportion of bereaved spouses learnt about the incurable condition of their wife's cancer during the last week of life, if at all [35]. Among physicians in intensive care units, although routinely engaged in discussing prognosis with carers, very few checked if the family wished to be informed, and few checked if the information had been understood [23]. A similar lack of negotiating the amount of information given to carers was found in a study by Clayton and colleagues [36].

There are several possible explanations to the observed shortcomings in physicians' communication of prognostic information. A reluctance among physicians to talk about death, due to fear of evoking sad feelings in patients and carers, and a discomfort in relation to own mortality has been found [37-40]. A lack of formal training in difficult end of life discussions may lead to reluctance towards engaging in these tasks [11;41].

### **Physicians' development of communication skills**

Despite signs of a more symmetrical relationship between patients and physicians [6], there is still some level of asymmetry with regard to knowledge and power. This asymmetry necessitates vigilance on the part of the physician. For the patient, the illness is a personal experience in his or her life, with a past, a present and a future, however short it might be. For the physician, the focus is a professional one, concerning the diagnosis and other objective dimensions of the disease, as well as a concern for the suffering patient. The physicians cannot therefore just use their normal everyday communication abilities in the

medical encounter. When the messages to be communicated are of a severe nature, such as prospects of functional decline or short life expectancy, special skills and attention are needed. Over the years different educational schemes have been developed to improve the physicians' communication skills and reduce their feeling of incompetence [11;41-43]. Efforts to improve the communication have resulted in guidelines and educational schemes [44-47]. In Norway, communication courses have been part of the medical curriculum at all the medical schools for more than ten years [48]. Despite differences in amount, timing and content of the educational scheme between the different curricula, a comparable level of skills was found across the medical schools at the end of the final year [49]. The development of communication skills after graduation has traditionally been achieved through watching the expert [50]. One Norwegian study found, however, that communication skills failed to improve during internship [51]. The efficiency of the compulsory communication skills training aimed at Norwegian oncologist registrars has not been formally evaluated. However, educational schemes that take into account the participants' individual perceptions of particularly challenging areas are shown to be effective, also at follow-up [50;52]. The usefulness of educational efforts depends, among other things, on physicians' willingness to change practice accordingly. Research into this area is not conclusive. The practice of communicating unfavourable prognostic information is complicated by the many conflicting considerations physicians have to take into account [13]. Not surprisingly therefore, the developing of communication skills is a complex task. For instance, patients' and carers wish for information, although with some important limitations, is relatively well established. However, when asking physicians if they would change their communication practice in line with such research, most stated that their practice would not change [53]. There is a relative scarcity of research exploring reasons for this reluctance towards change [13]. Uncovering some aspects of physicians' attitudes and practices in relation to prognostication is the overall theme of this thesis. A thorough understanding of the physicians' considerations when communicating bleak prognoses hopefully will contribute to the improvement of educational schemes as well as a more targeted focus on the specific challenges as perceived by the individual physician.

## Aims of the thesis

This thesis includes three studies presented in four papers (I–IV) and has the following two main aims:

1. To explore Norwegian physicians' perception of their own practice with regard to communication of prognostic information
2. To investigate how underlying attitudes lead to communication practice.

More specifically these aims were explored through the following research agenda:

- To examine how Norwegian physicians use the poorly defined yet commonly used prognostic term 'terminal' Furthermore, to examine whether demographic factors or work experience affected physicians' interpretation of the term 'terminal' (Paper I).
- To investigate whether attitudes towards disclosure of prognostic information vary by speciality, previous experience and demographic factors in a general physician population (Paper II).
- To investigate oncologists' notions of how they communicate unfavourable prognostic information and how they have acquired their communication skills. Furthermore, to explore underlying considerations concerning what oncologists say influences their clinical practice with regard to disclosure of prognostic information (Paper III).
- To identify, name and structure the specific strategies applied by physicians and patients to solve the intrinsic dilemmas in communication about prognosis (Paper IV).

## Materials and methods

Three different study designs were applied: a postal survey among a representative cross-section of Norwegian physicians; focus group interviews of oncologists; and an observational study of medical encounters between rheumatologists and haematologists and their patients.

### Study populations

An overview of the studies in the thesis is shown in Table 1 (Appendix I), and the populations of the three studies can be described as follows.

#### The Norwegian Physician Health Survey

In 1993 the Research Institute of the Norwegian Medical Association recruited a reference panel by inviting a random sample of 2000 active physicians to participate; 1272 agreed, and during subsequent years received questionnaires more or less annually. Twenty-one dropped out, due to death or voluntary withdrawal, before January 2000, when another 795 randomly selected physicians who had received their licence after 1993 were invited to join the panel; 365 of these agreed to participate. A further 11 individuals died or withdrew from the panel. The recruitment of new participants was done to ensure the representation of younger physicians and obtain a balanced sample.

#### *The postal survey (Papers I and II)*

In 2002 the reference panel consisted of 1605 physicians, which constituted the material of the current survey. After one reminder, the response rate was 69.5%, with a slight overrepresentation of general practitioners and older physicians, and an underrepresentation of those in the 35- to 44-year age group. The age distribution of the sample ranged from 28 years to 78 years, with a mean age ( $\pm$  SD) of 48.9 ( $\pm$  11.1) years. The female physicians were significantly younger than their male colleagues (mean 46.3 vs 49.8 years,  $t = -5.81$ ,  $p < 0.001$ ).

#### The focus group interviews (Paper III)

Oncologists were recruited from three of five university hospitals in Norway, one group from each hospital. The recruitment was carried out by contacting the head of department at each unit, and requesting a minimum of six and a maximum of eight participants, both residents and consultants. The head of department chose participants who were available at the time. No one who was asked to participate declined to do so. Oncologists from a fourth

university hospital were involved in piloting the interview guide and were thus excluded from the focus group interviews. Evaluation of new topics was done after each group interview; as no new topics or considerations emerged in the second and third group interviews, the fifth national university hospital was not contacted for data collection [54]. Each of the three focus groups consisted of six physicians, ranging from registrars with just months of practice to consultants coming up to retirement. Most participants had some years of practice in oncology. All groups consisted of both male and female physicians, in total 6 men and 12 women.

### **The observational study (Paper IV)**

Two different clinical settings were scrutinised in order to broaden the relevance of the findings to both acute life-threatening diseases and conditions with slowly developing impairment of function. Thus, patients from a haematology and a rheumatology department were recruited: 231 physician–patient consultations from the two different hospital wards were tape-recorded; 14 haematologists and 44 patients engaged in 122 patient–physician consultations at the haematology clinic. In addition, 11 rheumatologists and 98 patients were tape-recorded in a total of 109 encounters. The samples consisted of a mix of first, second and subsequent consultations between patient and physician. The samples were chosen out of convenience, including patients with diseases of varying severity.

### **Data sources**

#### **The postal survey (Papers I and II)**

No previous questionnaires have been specifically designed to explore the attitudes towards prognostication among physicians, across all specialities. However, Christakis and Iwashyna formulated a questionnaire in order to investigate different attitudes towards communication of prognostic information among US internists [11]. Most of the items in the questionnaire were conceptually adequate for the purpose of this study, exploring the use of optimism, the experience of strain and the fear of loss of reputation. The development of the original survey by Christakis and Iwashyna involved pre-testing 14 physicians. No further validation has been reported.

With permission from Christakis we translated the 28 items relevant for this study into Norwegian, following standard procedures of translation and back-translation. A few minor



changes were made to adjust the questionnaire for Norwegian participants. All items but two were formulated as statements with which the physician could fully agree (1), partially agree (2), partially disagree (3) or fully disagree (4). In addition the questionnaire contained one item exploring the physicians' interpretation of the term 'terminal' in terms of weeks left to live. Finally, to explore previous experience with prognostication for patients nearing end of life, the participants were asked to indicate how often during the previous year they had been asked the question 'How long do I have to live?' by patients, with the following response categories: none, 1–4 times, 5–10 times or more than 10 times. The translated questionnaire did not undergo a formal validation process before being presented to the Norwegian physicians. A factor analysis was, however, performed, with subsequent removal of overlapping or redundant items.

### **Explanatory variables**

A total of 43 specialties and subspecialties were merged into 8 clinically relevant practice categories: general practice, laboratory medicine, internal medicine, surgical specialties, gynaecology, anaesthesiology, psychiatry and public health [55]. Physicians in specialist training were categorised according to their future speciality. Of the physicians, 27.2% (415) were practising with no speciality, and they were excluded from the analyses on specialties. In addition to the 28 items exploring aspects of prognostication, other themes covered in the 11-page survey were: the physician's role as gatekeeper to economic/social benefits such as sick leave, disability allowances, the right to drive and other social benefits; the relationship with the pharmaceutical industry; job satisfaction; changes in attitude towards people; and a section about the physician's personality. Approximately 35 minutes were needed to complete the questionnaire. (Questionnaire in Norwegian in Appendix II).

### **The focus group interview (Paper III)**

An interview guide was developed through discussions between the principal investigator (Lotte Rogg, LR) and a researcher experienced in focus group methods (Victoria Akre, VA), based on clinical experience and literature concerning communication of bad news and bleak prognoses. Finally the interview guide was piloted among a group of oncologists, and a few minor changes were made to warrant investigating all three research aims. The interview guide consisted of three outlines of patient cases, where challenges and dilemmas in communication of prognoses were presented. The cases functioned as triggers in the

discussion. Additional questions were prepared, and used when needed, in order to ensure discussion of all relevant topics. (Interview guide in Norwegian in Appendix III).

#### **The observational study (Paper IV)**

No specific interview tools were applied in the data collection. However, the participants in the haematological sample were informed that the purpose of the study was to examine patient–physician communication in general, and its potential consequences for patient satisfaction. The rheumatological sample was, in addition, informed that communication about the consequences of the disease was of special interest in the study. This information was given to patients as well as to participating physicians.

### **Data collection procedure and data management**

#### **The postal survey (Papers I and II)**

The survey was sent to the participants by mail in June 2002, filled in at the participants' homes and returned by mail, in a prepaid envelope. No financial incentive or gift was offered to the participants. After 2 months one reminder was sent to the non-responders.

The data registration was done manually and the data were checked for illegal values. Registration of the data was spot checked for systematic error. Analyses of missing responses revealed that 29% of the invited participants were non-responders to the entire survey, whereas 3% of the items were randomly missing. There was no significant difference in response rate between women and men, speciality groups or age groups. No substitution of missing values was done.

#### **The focus group interviews (Paper III)**

The three focus group interviews were conducted by the principal investigator, functioning as a moderator (LR), and an assistant experienced in the focus group method (Olaf Aasland, OA, or VA). The moderator was responsible for encouraging all participants to voice their opinions, and to prevent individuals from monopolising the discussion. The moderator welcomed the voicing of divergent opinions, and emphasised that there were no right and wrong answers to the issues discussed. The group sessions lasted for about 90 minutes each.

All focus group interviews were audio-taped and transcribed verbatim by the principal investigator (LR). The recordings from the three different hospitals were kept separate, thus facilitating analyses of potential differences between the sites.

### **The observational study (Paper IV)**

Patients visiting the outpatient clinic at the two respective hospital departments were asked if they were willing to participate in a study with the aim of improving communication. Before the data collection both patients and physicians in the rheumatology sample were asked to sign consent forms. In the haematological sample, only the patients were asked to sign such forms. The consultations taking place between the recruited patients and their physicians were tape-recorded, with the physician starting and ending the recording at each consultation.

The audio-taped consultations were transcribed by the principal investigator (Peter Kjær Graugaard, PKG). Indications as to whether the patient had a haematological or a rheumatological disorder were removed from the quotes used in the manuscript, as was information about the severity of the medical conditions, and sociodemographic information with regard to both patient and physician.

## **Analysis**

### **The postal survey (Papers I and II)**

Due to the large numbers of participants, we generally employed parametric statistics on continuous response variables [56].

The statistical procedures included chi-squared statistics for cross-tabulation of categorical variables, *t*-tests and ANOVA (analysis of variance) for testing group differences in continuous variables with normal distribution. In Paper I differences between groups were further analysed by post-hoc analyses of the least significant differences, where appropriate. Due to skewedness, the dependent variable 'weeks' was log transformed to reach a normal distribution. In Paper II linear regression analyses were used to explore simultaneous effects of *gender*, *age*, *speciality* and *experience with end-of-life prognostication* on the three factors. General practice was chosen as a reference in the analyses of speciality due to the sample size.

### **Factor analysis (Paper II)**

As a way of reducing the number of response variables, a factor analysis was applied to the 26 items about prognostication (the two remaining items being related to experience in prognostication and definition of the term 'terminal', respectively). Factor analysis is a statistical method by which underlying structures or 'latent variables' in a data matrix are identified, either to confirm presupposed relationships or to explore characteristics of the data matrix. In this paper, factor analysis has been used to reduce the number of variables from 26 to 3. Before the factor analysis, the data-set was tested for suitability of the procedure and, due to redundancy, 14 items were removed. Inspection of the scree plot suggested the presence of 3 factors, which contain 12 of the 26 items, and make sense conceptually and intuitively, explaining 34.6% of the variance. We named these three factors: 'Prognostic communication is stressful' (16.0%), 'Fearing loss of reputation' (9.9%) and 'Reinforcement of positive prospects' (8.7%).

### **The focus group interview (Paper III)**

The transcribed texts were analysed according to Giorgi [57], the method being modified by that of Malterud [58]. There were four steps in the analysis: (1) reading all the material to obtain an overall impression and bracketing passages that linked to previous preconceptions derived from literature and clinical experience; (2) identifying units of meaning, representing different aspects of the theme and coding for these; (3) abstracting the content of individual units of meaning; and (4) summarising their importance. Actively looking for areas of contradictory meaning in the transcribed text, as well as alternative interpretations of the meanings, was done to ensure validity in the analysis.

### **The observational study (Paper IV)**

Three researchers (PKG, Hilde Eide [HE] and LR) performed the analyses, which were done by both listening to the tape-recordings and reading the transcribed consultations [59]. Initially each of the 3 independently examined 20 haematological consultations, chosen non-randomly to secure inclusion of all 14 physicians, as well as patients with the most serious diagnoses. Start and end points of sequences regarding prognosis, and which of the parties initiated and closed the prognostic sequence, were noted along with tentative classifications of the prognostic communication. Consensus was reached through discussion. The same procedure was followed when analysing 30 randomly selected rheumatological

consultations, and subsequently 50 consultations from both hospital wards, until data saturation was reached and classification refined.

### **Ethical considerations**

According to precent practice by the regional ethics committee ethical approval for medical research is not required when patients are not involved in a study. Permission to store data was given by the Data Inspectorate. Efforts were made to secure confidentiality on behalf of the focus group participants, by not including information on which oncology departments were involved in the data collection, or indications about the source of the quotes used in the paper. The necessary ethics approvals and permissions from the Data Inspectorate and regional ethics committee were obtained in relation to the observational study, because patients were involved.

## **Main results and summary of papers**

### **Summaries of the papers**

#### **Paper I Physicians' interpretation of the prognostic term 'terminal': a survey among Norwegian physicians**

This paper examines the concept of one single term used in the clinical management of patients approaching death, as well as in research. The term 'terminal' implies prognostic considerations on behalf of the patient, and is used in the communication between healthcare professionals. When asked to indicate how many weeks a patient labelled 'terminal' had left to live, the response ranged from 0 to 26 weeks. The majority of responders (83.5%) defined 'terminal' as having fewer than 5 weeks left to live, whereas only 0.8% (8 respondents) defined survival as less than a week. Being exposed to end-of-life prognostication (as defined by how often the physician had been asked 'How long do I have left to live?' by patients during the last year) was not associated with different definitions of the term. The younger practitioners and those in somatic hospital-based specialities tended to use a shorter definition than their older colleagues and colleagues in general practice and psychiatry.

#### **Paper II Physicians' attitudes towards disclosure of prognostic information: a survey among a representative cross-section of 1605 Norwegian physicians**

The paper examines attitudes towards disclosure of prognostic information among a sample of Norwegian physicians, all specialities included. Physicians were generally in favour of skewing prognostic information in a positive direction. The physicians more experienced in prognostic communication with patients nearing the end of life were less inclined to reinforce positive prospects than their less experienced colleagues. General practitioners were more in favour of optimistic reinforcement than their colleagues in hospitals, particularly the anaesthesiologists. Loss of reputation as a consequence of erring in prognostication was feared by roughly half the respondents, and patients were assumed to judge erroneous prognoses more negatively than colleagues. Feeling strain in relation to prognostication was found in approximately half the respondents. The female physicians and the least experienced in communicating prognosis towards the end of life found it more stressful than the male and the more experienced physicians. Specialists in laboratory

medicine found prognostication more stressful than the other specialities. The detected differences were small and, despite being statistically significant, only differences between specialities reached the standardised effect size Cohen's level ( $d$ ) >0.8 [60].

### **Paper III Direct communication, the unquestionable ideal? Oncologists' accounts of communication of bleak prognoses: a qualitative study**

In this study oncologists' accounts of how they communicate prognostic information about life-limiting disease have been explored. Their emphasis when describing their own practice is on openness. The oncologists stressed the importance of making their patients understand the harsh realities in the transition from possible cure to a life-limiting illness. However, information at a more detailed level, as well as discussions about survival time, were reported to be avoided by the informants. Negotiations between patient and physician about level of detail of the imparted information appeared to be infrequent, and not applied by most of the informants. One's own experience and observation of other colleagues were seen as the two most important ways of acquiring skills in communicating unfavourable prognoses. Communication courses were perceived to be of lesser importance, and the potential use of guidelines was perceived as being of little value. There was a general agreement in the approach towards imparting prognostic information, between participants within the groups and across the three groups.

### **Paper IV Ways of providing the patient with a prognosis: a terminology of employed strategies based on qualitative data**

We discovered that the physicians applied a range of subtle strategies to regulate the extent and depth of the prognostic information as well as to balance the promotion of hope against true information. One finding was that the physicians seldom engaged in dialogue with the patients to clarify their needs and wishes for information – so-called meta-communication. The physicians also seldom gave detailed and full information about the prognosis. Instead they seemed to prefer the basic strategy of giving some initially limited or implicit information and then letting further information depend on the patient's response. Often the final result of this dialectical process turned out to be the transfer of rather sparse factual prognostic information to the patient.

## General discussion

It is methodologically challenging to investigate any field that employs three different types of data, applying both qualitative and quantitative methods. In addition, the field of interest in this thesis is complex, with a wide range of possible determinants for shaping practice. Communication of prognostic information from physician to patient is possibly influenced by factors related to society in general, cultural aspects and individual factors that pertain to both patient and physician. This thesis looks at the field through rather narrow lenses, focusing almost exclusively on the physicians. However, most of the existing research in the field has focused on patients and their carers. Physicians are key contributors to the discussion of prognoses. We therefore deliberately chose them as the focus for the thesis. The four papers thus represent snapshots from one part of a complex landscape. Another possible approach to the investigation of physicians' attitudes and practices could have been to apply only one method to different physician populations. However, application of mixed methods – triangulation – has the potential to achieve both a more precise and a multifaceted description of the phenomena under scrutiny [61]. Triangulation as methodology can combine information from quantitative and qualitative studies, and is a useful tool when investigating relatively underresearched areas.

## Design

The choice of a postal questionnaire made it possible to reach a large representative sample of Norwegian physicians, so we were able to explore attitudes to prognostication and self-reported practice in a general physician population. However, there are some drawbacks in this design. The respondents were offered fixed response categories only, which makes it difficult to pick up on potentially subtle nuances in attitudes. This was partly compensated for in the qualitative studies. Low response rate can also often be a problem for questionnaire surveys. However, the current study had a response rate that compares favourably with other similar surveys [11;22;62].

Focus group interviews were chosen to assess oncologists' ideas of how they communicated unfavourable prognostic information, and their opinions about how they had developed their communication skills. They are a method particularly suited to exploring the construction of opinions and attitudes [63-65]. In addition, the method produces relatively large amounts of data in a short period of time. The groups were effectively 'naturally



occurring' as the participants were colleagues, and could thus relate to comments on incidents from their shared daily lives. However, there is a risk that the 'norms' in the group could silence individual voices of dissent. Particularly active participants can monopolise the discussion and set a common standard for the rest of the group. Therefore the moderator must encourage all participants to give their opinions and, if necessary, constrain the more active participants. Furthermore, by pointing out different opinions as possible positions (in this study, for instance, when the moderator presented patients' stories where the group norm was challenged) could facilitate the raising of different opinions by participants. Finally, participants could present opinions in accordance with the common norm, but in clinical practice apply different communication strategies. Triangulation of methods, allowing for observations of actual practice (the observational study), thus serves to confirm the findings empirically.

An observational study has the obvious advantage of giving an account of actual practice, compared with the survey and interview. Information given in advance about the purpose of the study, to investigate patient–physician communication and its potential effect on patient satisfaction, could have influenced the consultations and hence the results. However, it is impossible to undertake research without informing the participants, and this should not prevent research on important issues such as communication in clinical practice being carried out. The presence of the tape-recorder could also prevent both patient and physician from acting naturally, but the impression from the tape-recordings is that participants soon forgot the research setting. In relation to the two other data-sets in this thesis, the observational study's particular strength is its contribution as a validation of what physicians says they do and what they actually do when communicating.

### **Sampling**

The ability to choose a representative physician population, across all specialities, was seen as important in papers I and II. The original survey, conducted in the USA, investigated only internists practising in private clinics or in hospitals. A previous study of the attitudes of the Norwegian population towards imparting diagnostic information [66] used a sample comparable to that in the survey. Although not a research question, we were intrigued to see whether the findings from the earlier study, those attitudes were similar across different specialities and despite different clinical experience, could be seen in relation to prognostic

communication as well. The sample was large, with more than 1000 respondents, and representative of the whole Norwegian physician workforce. The questions related to communication of prognostic information obtained a response rate of 69.5%. Analysis of responders and non-responders revealed no significant difference with regard to gender, age or speciality in relation to the 26 items about prognostication. The 29% non-responders were non-responders to the entire survey and, although a *volunteer bias* [56] could be present, it is not possible to see the direction of this bias, because it does not pertain to specific questions about prognostication.

The single item that investigates participants' interpretation of the term 'terminal' was answered by only 60.3%. A significantly lower response rate was obtained among psychiatrists and specialists in laboratory medicine, and among women. The low response rate among specialists not involved in this sort of prognostication and labelling of patients could be explained simply by their lack of experience in the field. It is less obvious why so few women answered this item. Could it be a result of the nature of the response categories, allowing responders to include the number of weeks that they thought were appropriate? Or could it be a disagreement with the concept of labelling someone as 'terminal'? A clinical impression is that female physicians, as well as nurses in palliative care, use this term just as freely as their male colleagues.

In the focus group interviews oncologists were chosen for two reasons: their clinical practice involves the management of patients with life-threatening diseases and treatment options with varying degrees of success and number of side effects; in addition, the oncological speciality has focused on communication skills for many years, and communication courses are compulsory in oncology training. The self-image of the oncological community is therefore linked to someone who has an empathetic and considerate way of communicating bleak prognoses. The choice of informants from this population was seen as a way to obtain accounts of experience of challenging communication. The three groups differed in terms of gender and mix of experienced and inexperienced individuals. One group had one male and five female participants, with four experienced and two less experienced participants. Another group consisted of equal numbers of male and female participants, one participant with many years of experience, three experienced and two less experienced. The third focus group consisted of two male and four female participants, two experienced, two relatively

experienced and two with little experience. These differences were not deliberately sought, but were a consequence of the physicians available.

In the observational study, all the physicians were consultants, implying extensive clinical experience. Rheumatologists see patients with more or less disabling diseases, with a much smaller threat to life than among cancer patients. Haematologists, on the other hand, see patients with a range of possible disease trajectories, varying from chronic, non-life-threatening illnesses to illnesses with a short life expectancy. Thus, the prognostic scenarios faced by these physicians differ, so the idea was that observation of these two physician categories would give a wide range of communication challenges as well as strategies to meet these. The data were collected at only two different wards, and common attitudes towards patient management on a ward can reduce the spectrum of variation in communication strategies detected. The information given to the physicians as well as to the patients about the aim of the data collection is likely to influence the way in which the consultations were conducted. The patients received a patient satisfaction questionnaire both before and immediately after the consultation. These data were not used in the analysis of the current study, but completion of these questionnaires is likely to have had an impact on the patients' attitudes and actions in the consultations.

### Measures

The development of the questionnaire used in papers I and II did not follow the necessary steps for full validation, in either the original American version [11] or the Norwegian one. Hence, the *internal validity* might be disputable [61]. The use of an existing questionnaire has advantages compared with the development of a questionnaire specifically aimed at the target population and the research questions of interest, but it also has some potential drawbacks. We thought that use of the existing questionnaire would strengthen our study, but, when analysing the data, it became evident that the questionnaire did not function optimally in our population of Norwegian physicians. Analysis of the 26 items one by one, as in the US study [11], was not seen as a good way forward, and many items appeared redundant. We identified three or four themes when looking at the single items, three of which were confirmed in the factor analysis, giving three factors with Cronbach's alpha coefficients of 0.75, 0.75 and 0.67, respectively. In addition, these three factors made

conceptual and intuitive sense, thus supporting the *content validity* and *reliability* of the shortened version of the questionnaire.

In Paper I the respondents' definition of the term 'terminal' is measured by the question 'When a patient is labelled "terminal", approximately how many weeks should the patient have left to live, in your opinion?'. The respondents had space to write in the number of weeks. Two issues arise with regard to this procedure: first, the mere mention of weeks as a response category could be a 'leading' question, potentially resulting in a longer time frame than the respondents would otherwise have given. However, as almost all the respondents indicated a survival of more than 1 week (only 0.8% of the responders defined 'terminal' as less than 1 week's survival), we can assume that the definition held by the respondents is in fact counted in weeks, not days or hours. Second, the definition of the term 'terminal' could, and perhaps even should, be related to aspects other than just length of survival. Definitions involving clinical signs would be more tangible, as would definitions indicating chance of survival for a certain period [67]. No such options were offered to the respondents.

The interview guide applied in the focus group study was developed on the basis of my own understanding, gained from clinical experience as an oncology registrar. In addition, theoretical considerations derived from the literature concerning a patient's wish for prognostic information, as well as existing guidelines for communication, contributed to formation of the interview guide. Finally, discussions with a non-oncologist (VA, a physician experienced in focus group methodology) shaped a preliminary interview guide which was finally piloted among a group of oncologists. Through the process of data collection, some additional changes were made to complete the interview guide in line with the emergence of new themes.

### **Preconceptions**

In the process of undertaking this part of the project, my preconception of the existence of right and wrong in relation to communicating bleak prognoses was challenged. My own deeply felt obligation to convey the full information was questioned through the literature, with emphasis on patients' changing and ambivalent wishes for information, the range of coping strategies, as well as the more philosophical questioning of the concepts of truth,

openness and hope. When the interview guide was being developed and the focus groups interviews were conducted, my position was that the physicians should negotiate the amount, level of detail and settings in relation to patient communication. This, alongside my critical opinion on indications from the focus group participants re ‘dumping’ of the truth, could influence the way in which I conducted the group interviews. On the other hand, as a colleague, although not at the same hospital, I feared that I would take for granted the good intentions of my colleagues. The two assistants, VA in one and OA in two of the groups, are both physicians, but not oncologists. Hence their contributions to the process, from development of the interview guide, through data collection to analysis, broadened the range of interpretations, and it is hoped contributed to a reduction in bias and an improvement in internal validity [58].

### Analytical considerations

The area under investigation in Paper II concerned attitudes towards a specific part of the physicians’ clinical practice, and *recall bias* would thus be expected to be minimal. However, *social desirability bias* [61] could be present, although it is not evident in what direction this would bias the responses. Many of the differences detected in the study were highly statistically significant. To minimise the risk of type 1 error in Paper II, the significance level was set at  $p \leq 0.01$ . However, in terms of effect sizes, several of the statistically significant results turned out to be questionable in terms of actual significance. The standardized measure of effect size, measured as the difference between two means divided by the standard deviation for the data, Cohen’s  $d$  [60], was applied. Cohen suggested that a Cohen’s  $d$  of 0.20 or less is small, values of 0.50 medium, while values of 0.80 or more implies a large, and thus clinically significant, effect size. In the factor ‘*Prognostication is stressful*’, the differences in relation to experience have a medium effect size, Cohen’s  $d = 0.51$ . Age and gender do not obtain sufficiently large values for Cohen’s  $d$  to be clinically significant (Cohen’s  $d = 0.35$  and  $0.32$ , respectively), despite what is reported in the paper. In relation to all three factors, speciality stands out as the only explanatory variable with a large effect size (Cohen’s  $d \geq 0.8$ ). In accordance with an earlier study about Norwegian physicians’ attitudes towards disclosure of diagnostic information [66], these findings can represent a true tendency towards consensus among Norwegian physicians. However, another explanation could be that the questionnaire is unable to detect existing differences.

Data collection for the focus group study was performed at the participants' workplace, and it was possible that some level of 'real-life' interaction would take place, although it would be naive to think that the oncologists responded to each other as they would have under non-interview conditions. It would be equally naive not to expect interactions between the participants to be influenced by their different roles in their professional lives. Focus group interviews have the potential to capitalise on group interactions, leading to more complex data, but to take advantage of this, one must apply interaction analysis methods to the interpretations, and this was not possible within the scope of the current project. Refraining from attempts to interpret the group dynamics, we needed two comments related to the group make-up. It could be presumed that the male participants would dominate the discussions, but, fact in the three groups, the most experienced colleagues were the most influential in leading the discussions, regardless of gender. Thus, clinical experience seemed to be more important than gender in relation to group dynamics. This striving for consensus within the groups raises an issue about choice of method: are divergent points of view lost in group interviews, as opposed to individual interviews? The research group discussed these two options when planning the whole project, and decided on focus group interviews for several reasons. From the literature [65], the group interview is regarded as useful for exploring how attitudes are formed. As the practice for imparting prognostic information was thought to be at least partly formed within the institution, a data collection method displaying some sort of interaction between its members was sought. The three sites for data collection differed in size and organisation, and yet similar results were found at all three. This, together with the fact that findings from the group interviews and the observational study are in accordance with each other, indicates that the findings do represent shared attitudes among the physicians.

The analysis of the observational study data was performed by three researchers with different backgrounds and competencies in qualitative methods. The emerging categories were discussed until a consensus was reached. Whether or not these consultations in fact concerned prognostic issues, and to what degree the physicians were able to detect patient cues, was not always initially agreed on, so some degree of negotiation took place within the research group to reach a consensus. Possibly, the interpretations could have been different with a different mix in the research group. A more theoretically based approach to

the analysis [58] could likewise have resulted in different interpretations. As the study suggests some immediate clinical implications, a cautionary comment is essential. The terminology derived from the study should be regarded as tentative, and further testing is needed before strong recommendations and guidelines can be suggested.

## **Physicians, and the determinants of their attitudes and practice**

### **Who are they and what shapes their attitudes?**

The participants in the survey represent a cross-section of Norwegian physicians with regard to age, gender, speciality and years in clinical practice. Despite some detected differences, the overall impression is one of common attitudes. This is most apparent with regard to the optimism found in the survey. The same pattern was found among North American internists by Christakis and Iwashyna in a similar study conducted 8 years previously [11]. Indications of common physician attitudes in relation to communication issues were also found in the study by Loge and colleagues, about attitudes towards imparting diagnostic information, conducted more than 10 years before this study [66]. Formation of a professional identity during medical school [68;69] as well as during the early years of clinical practice, is well known. Thus, one can in fact speak of a specific professional identity [70] that contributes substantially to physicians' attitudes and understanding of key concepts.

This thesis included investigation of one specific prognostic term. Physicians' definition of the term 'terminal' seems to have been shaped to some extent by their clinical practice. Most physicians held a definition of about 3–4 weeks left to live. Hospital-based physicians tended to have a shorter definition than their colleagues in general practice. To the extent that this term is used in the communication between health professionals when patients are referred from one level of the health service to another, this disparity could be problematic. The usefulness of the term could thus be questioned. An unambiguous term indicating that a patient is dying, with hours to a few days left of life, could be useful because the focus would naturally shift towards symptom control and care for the soon to be bereaved. However, such an understanding was almost non-existent among the respondents. Is the relatively vague timeframe a sign of unwillingness among the physicians to label a patient as being beyond curative medical treatment? Taken one step further, does the lack of a term

to show that a patient is in fact dying indicate an attitude among physicians in which death is seen as failure?

In a thesis that primarily focuses on attitudes, it is important to remember that they are not perfect reflections of true activity. Attitudes are commonly regarded as rational evaluations of objects, and of other people's opinion on the same object. But it is also mixed with emotions [71]. Still, attitudes are strong determinants of behaviour, and are therefore an interesting concept for research in order to understand physicians' actions towards their patients. Most probably it is not one single source for formation of attitudes in general. The contribution of professional as opposed to more personal factors in shaping attitudes is likely to differ, depending on the different areas under consideration. For instance, attitudes towards abortion probably depend on religious beliefs and ethical considerations, thus shaping some physicians' practice. Is it possible to disentangle personal and professional contributions to underlying questions of professional practice? An individual's preconception is likely to contribute to shaping professional attitudes, but the medical profession has been marked as the prototype of a classic profession [72], and implicit in this notion are common attitudes and moral standards shared by every member of the profession

This professional identity is not fixed, but is again shaped by changing demands and conditions outside the profession. What are these demands and conditions in relation to patient management in general and the communication of prognostic information in particular? Over the last 40 years increasing emphasis has been placed on the consumer's responsibility for their own welfare [73]. In relation to healthcare this has led to increased emphasis on the patient as an active participant in decisions related to treatment. A precondition for this involvement in shared decision-making is the well-informed patient [9]. A substantial body of evidence has been presented to support patients' wishes for information as well as their ability to absorb even bleak prognoses [74-77]. As citizens of their societies, one would expect changes in society to be mirrored in physicians' professional identity. A study comparing palliative care physicians in Canada and South America found that the South American physicians saw beneficence as their guiding principle in communication with terminally ill patients [78]. On the other hand, their Canadian colleagues emphasised autonomy as shaping their communication with patients.



These findings are in line with the general beliefs about communicating bad news in the two countries.

In this thesis one finding is that the physicians hold a position that is only partly in line with the general belief in open communication, and patients as responsible healthcare consumers, with both a right and a duty to participate in decision-making. Several possible explanations exists for this: first, could Norwegians in general be less influenced by the doctrine of informed consent and autonomy compared with those living in North America, the UK and Australia [79;80]? If so, the reluctance to share bleak prognostic scenarios would in fact be in line with the beliefs of the general population. However, research in these countries shows that physicians, despite positive attitudes towards openness, fail to impart tangible information [81;82]. Furthermore, studies of patient preferences do not show clear-cut conclusions. Patients display ambivalence in relation to the information that they want, and information needs change along a disease trajectory [80;83-86].

### Physicians' practices

Paper IV examines actual practice, although the data from all three studies seem to point more or less in the same direction. The almost universal agreement in the survey, emphasis on optimism, is also found in the observational study. In this study, strategies to emphasise favourable clinical signs and developments, as well as the evasion of negatively laden aspects, support the findings of the survey. The oncologists in the focus group interviews discussed the use of deliberate vagueness in relation to bleak prospects, and this was seen as a way of supporting patients' hopes. However, a coexisting worry was displayed by the participants that such a practice would support unrealistic understanding of the prognosis. An obligation to be truthful and open was not modified by considerations about the limitations of such concepts. This impression was supported by other studies [13]. The emphasis on truthful, open information, as well as the responsibility to support patients' hopes, has introduced a dilemma into physicians' patient care.

One possible strategy that has the potential to give patients prognostic information without jeopardising their hopes for unrealistic positive developments would be to negotiate how to impart this information. This applies to the amount, level of detail and pace of information delivery. Such negotiation, or meta-communication, was seen to a limited extent in the

observational study, with only one of eighteen oncologists describing such a strategy. This lack of patient-centred meta-communication is in line with previous studies in the field [82].

Another way of helping patients retain control of the flow of information was seen in the observational study. Physicians often gave some initial and rather sparse information, followed by subtle invitations to the patient to request more. In the survey, the vast majority agreed that discussions about prognostic issues should be initiated by the patient. One apparent drawback to such a strategy is the fact that patients tend to leave control of such discussions to the physician, regardless of whether or not they would like to receive information [87;88].

Approximately half the survey's respondents felt that prognostication put a strain on their practice, and a similar proportion felt that they were inadequately trained for this aspect of their job. Again, the finding is supported by results from other parts of the project. The oncologists stated that imparting a bleak prognosis was one of their most challenging tasks. Interestingly, they emphasised the importance of observing more experienced colleagues as well as learning through their own practice, while the usefulness of communication courses and guidelines was questioned. This attitude towards courses and guidelines as a way to acquire skills could be an obstacle to implementing changes in practice in line with new knowledge.

### **Future perspectives**

Attitudes towards and the practice of communicating bleak prognoses in medical care do not exist in a vacuum. Changes in the realities of medical care, as well as in society in general, contribute to shifts in expectations of the content of prognostic communication. Physicians from different cultures base their practice on principles of beneficence or patient autonomy, or a combination of the two [78]. The pendulum has shifted from the clear-cut paternalist physician, who knows what is in the best interest of the patient, i.e. to be treated like a child [43], to the consumerist version of the patient as a well-informed individual with the right and duty to participate actively in treatment decisions, and a corresponding fact-supplying physician [86]. At present there are indications that the pendulum is moving back towards a third, less clear position. Although not explicitly expressed, physicians seem to be struggling to navigate the landscape. Our findings suggest that physicians try to find a stance

that meets the somewhat conflicting needs of ambivalent patients, legislation governing medical practice and their own opinion of what is in line with best practice. The physicians find this part of their clinical practice challenging, and display a degree of uncertainty about how to solve the dilemmas involved. In addition, being with patients through several failing treatment efforts is potentially emotionally demanding, possibly leading to job-related stress [89].

One reason why communication can be perceived as challenging is the physicians' uncertainty about their patients' information needs and abilities to handle bleak prognoses. Research in the field of patient preferences shows that this area is in fact far from clear cut. Patients' changing information needs, as well as their ambivalence about receiving bad news, particularly in relation to prognosis, is well documented [80;83-86]. The relative uncertainty inherent in prognostication, linked to an increased demand for accuracy, further reinforces the feeling that this is a difficult part of a physician's job. In acknowledgement of the difficulties in relation to imparting bad news, guidelines and communication courses have been developed, and compared with the extensive use of guidelines elsewhere in oncological practice it is surprising to find the disregard expressed for such among our informants. One reason could possibly be an appreciation of the shortcomings of existing methods, and better quality communication courses and guidelines on communicating prognoses would change this [14;90;91]. However, our findings suggest that the physicians see communication skills as going beyond the development of a professional identity – communication is not part of their professionalism, but rather part of their personality. Could physicians think that professionalization of communication would reduce their ability to respond empathetically to patients in crisis? Or that we cannot learn to be compassionate and empathetic, and the ability to communicate difficult matters in a sensitive and sensible way is an issue of personality and not professional skills? This raises the question of whether compassion can be learned in adult life, as opposed to being established during the formative years. Is empathy a skill or a trait? Is it always possible to show compassion and empathy, for instance, towards the very last patient at the end of a long working day? On the other hand, could simply being well mannered towards and showing signs of interest in an individual patient be sufficient, or possibly better than failing

to be compassionate [92;93]? The answers to these questions have consequences for all medical training, both undergraduate and postgraduate.

Another change in medical practice is the constant focus on new advances and improved medical treatment, the latest development being the hopes linked to genetics at an individual level. Unquestionably, these developments have led to a dramatic change in the trajectories of many diseases, with increased survival and improved level of functioning. It has also introduced challenging new communication tasks with regard to the risk of disease in healthy individuals, as well as more detailed information on possible treatment outcomes [94-96]. Has the emphasis on disease management increased at the expense of patient management [3;5;97]? The medical culture that emphasises the possibilities of treatment is well in line with increasing public expectations. However, the simultaneous move towards a more symmetrical patient–physician relationship, with increased demands on physicians’ communication abilities, might not be reflected in the medical culture in the same way.

A specific culture pertaining to the Nordic countries, and perhaps to Norway in particular, is its egalitarian structure of society. This is a good thing in many respects, but an intriguing question is whether it has contributed negatively to the way in which physicians respond to individual patients. Compared with more hierarchical societies, with an abundance of private clinics, one feature of the Norwegian healthcare system is that all members of society are treated in the same hospital wards and beds. Could the emphasis on equality and similarities between all members of society have contributed to a lack of appreciation of individual differences? Could this have led to a one-size-fits-all way of seeing patients, and less interest in finding out the particularities of information needs and coping strategies of the individual patient?

## Conclusions

The communication between patient and physician about a prognosis of short life expectancy or severe functional decline takes place in a field of mixed considerations. The patients, to varying degrees, want full information. Moreover, their wishes for information change over time, and are often ambiguous and ambivalent. The physicians have to take into account the conflict between making sure that the patients are aware of the situation and being supportive of patients' hopes.

The main findings can be summarised as follows:

- Most Norwegian physicians understood the prognostic term 'terminal' as having 3–4 weeks to live. Physicians in hospital-based somatic specialities held a shorter definition than general practitioners.
- The physicians were generally in favour of skewing prognostic information in a positive direction; this tendency was more prevalent among general practitioners than among hospital-based physicians.
- Loss of reputation as a consequence of erring in prognostication was a fear for roughly half the respondents, and patients were assumed to judge erroneous prognoses more negatively than colleagues.
- Female physicians and physicians with less experience in prognostic communication at the end of life perceived such communication to be more stressful than male and more experienced physicians. Approximately half the survey's respondents found imparting prognostic information stressful, and a similar proportion agreed that they were inadequately trained for this.
- Oncologists emphasised openness when describing their practice for imparting prognostic information. To make certain that patients had understood the transition from possible cure to a life-limiting illness was seen as fundamental. At the same time, supporting patients' hopes was seen as important. The potential contradictions in the two were perceived as challenging.
- The oncologists viewed their own practice and observation of colleagues as the most important way of acquiring communication skills. Communication courses were seen as useful, but less significant, and the usefulness of guidelines was questioned.
- Haematologists and rheumatologists applied a range of strategies to regulate communication of prognostic information as well as to balance supporting patients' hopes against the need to inform. The main strategy was giving some limited initial information and then letting subsequent information depend on the patient's

request for more, often leading to rather sparse factual prognostic information being given.

### **Clinical implications**

A consistent finding is that the physicians find communication of a bleak prognosis to be challenging and a stressor in their clinical practice. The finding that communication courses were not perceived as particularly useful does not mean that such courses should be abandoned. Instead, a specific focus on the particular challenges related to prognostic information delivery should be addressed in communication courses. Knowledge about the range of patient preferences for information, potential coping strategies applied by the individual patient, and the fluctuating and ambivalent nature of information needs among patients should be emphasised. In addition, practical training in uncovering patients' information needs, as well as in negotiation about mode of information delivery, should be part of such courses. Whether it is useful to train medical students, young physicians during specialisation or consultants is outside the scope of this thesis to answer, but some clinical practice is likely to improve the outcome of such training. Possibly, the discussion of experiences and particularly challenging cases of communication would be profitable. Support of physicians' abilities to overcome the feeling of failure in relation to treatment failure and patients' deterioration seems appropriate in an era of great expectations of medical advances.

### **Scientific implications**

Different initiatives to improve clinicians' communication skills have been put in place and are ongoing [98]. Their efficiency in changing physicians' practice, in both the short and the longer term has been found in some [45;99], but not all, studies investigating this [100]. The findings from the current thesis suggest that physicians regard communication skills as part of their personal rather than their professional abilities, and thus see training programmes as only partly useful. The existence of scientific knowledge with regard to different aspects of communicating bad news in general, and bleak prognostic prospects specifically, does not seem to transform into improved clinical practice. This is in line with the observed difficulties, in general, with regard to the implementation of scientific knowledge, and subsequent change in practice [101]. More knowledge is needed about the implementation of research findings into clinical practice in the area of communication. The notion of the best way forward in relation to communicating bleak prognoses has undergone a

transformation over a relatively short period of time. Research efforts to further increase our understanding of the complexities at work in both patients and health-care professionals with regard to prognostication are needed.

### **Final words**

The pendulum has moved from non-disclosure of prognostic information to an ideal of full disclosure and patient involvement in decision-making about treatment options. It is, however, questionable to what degree this ethos of full disclosure has actually reached clinical practice, at least here in Norway. Nevertheless, the notion that receipt of full information is a right as well as a duty of the modern patient seems to shape physicians' perception of their obligations to communicate. Still, they seem to lack the "instruments" needed for practicing medicine in this way. Considerations involving knowledge of patients' ambivalence, the range of coping mechanisms, the concept of informed consent and the more philosophical concept of truth could help physicians to find a third, and less extreme, position in their patient communication.

## References

- (1) Oxford English Dictionary. Oxford English Dictionary 2006(2006)Available from: URL: [http://dictionary.oed.com/cgi/entry/50249364?single=1&query\\_type=word&queryword=terminal&first=1&max\\_to\\_show=10](http://dictionary.oed.com/cgi/entry/50249364?single=1&query_type=word&queryword=terminal&first=1&max_to_show=10)
- (2) Surbone A. Information, truth and communication. For an interpretation of truth-telling practices throughout the world. New York: New York Academy of Sciences; 1997 p. XII, 540.
- (3) Shorter E. Bedside manners: the troubled history of doctors and patients. New York: Simon and Schuster; 1985.
- (4) McKinlay JB, Marceau LD. The end of the golden age of doctoring. *Int J Health Serv* 2002;32(2):379-416.
- (5) Le Fanu J. The rise and fall of modern medicine. London: Little, Brown & Co.; 1999.
- (6) Light DW, Aasland OG. [The new physician's role--quality, openness and confidence]. *Tidsskr Nor Laegeforen* 2003 Jun 26;123(13-14):1870-3. (Paper in Norwegian).
- (7) The Norwegian Directorate for Health and Social affairs. Pasientrettighetsloven [Patients' Rights Law] (Law in Norwegian), last amended 2008. Internet 2009 September 20Available from: URL: [http://www.helsedirektoratet.no/loverogregler/lover/pasientrettighetsloven\\_17294](http://www.helsedirektoratet.no/loverogregler/lover/pasientrettighetsloven_17294)
- (8) McKenna RJ, Sr., Laszlo J, Durant J, Hermann JF, Huguley C, Leventhal B, et al. Breakout I. Ethical considerations. *Cancer* 1990 May 15;65(10 Suppl):2407-8.
- (9) Pedersen R, Hofmann B, Mangset M. [Patient autonomy and informed consent in clinical practice]. *Tidsskr Nor Laegeforen* 2007 Jun 14;127(12):1644-7. (Paper in Norwegian).
- (10) Christakis NA. The ellipsis of prognosis in modern medical thought. *Soc Sci Med* 1997 Feb;44(3):301-15.
- (11) Christakis NA, Iwashyna TJ. Attitude and self-reported practice regarding prognostication in a national sample of internists. *Arch Intern Med* 1998 Nov 23;158(21):2389-95.
- (12) Hagerty RG, Butow PN, Ellis PM, Dimitry S, Tattersall MH. Communicating prognosis in cancer care: a systematic review of the literature. *Ann Oncol* 2005 Jul;16(7):1005-53.
- (13) Innes S, Payne S. Advanced cancer patients' prognostic information preferences: a review. *Palliat Med* 2009 Jan;23(1):29-39.
- (14) Parker SM, Clayton JM, Hancock K, Walder S, Butow PN, Carrick S, et al. A Systematic Review of Prognostic/End-of-Life Communication with Adults in the Advanced Stages of a Life-Limiting Illness: Patient/Caregiver Preferences for the Content, Style, and Timing of Information. *J Pain Symptom Manage* 2007 May 24.
- (15) Elkington H, White P, ddington-Hall J, Higgs R, Pettinari C. The last year of life of COPD: a qualitative study of symptoms and services. *Respir Med* 2004 May;98(5):439-45.
- (16) Schofield P, Carey M, Love A, Nehill C, Wein S. 'Would you like to talk about your future treatment options'? Discussing the transition from curative cancer treatment to palliative care. *Palliat Med* 2006 Jun;20(4):397-406.



- (17) Aabom B, Kragstrup J, Vondeling H, Bakketeig LS, Stovring H. Defining cancer patients as being in the terminal phase: who receives a formal diagnosis, and what are the effects? *J Clin Oncol* 2005 Oct 20;23(30):7411-6.
- (18) Christakis NA. *Death foretold*. Chicago: University of Chicago Press; 1999.
- (19) Hancock K, Clayton JM, Parker SM, Wal dS, Butow PN, Carrick S, et al. Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliat Med* 2007 Sep;21(6):507-17.
- (20) The AM, Hak T, Koeter G, van der WG. Collusion in doctor-patient communication about imminent death: an ethnographic study. *BMJ* 2000 Dec 2;321(7273):1376-81.
- (21) Fallowfield L, Jenkins V. Communicating sad, bad, and difficult news in medicine. *Lancet* 2004 Jan 24;363(9405):312-9.
- (22) Daugherty CK, Hlubocky FJ. What are terminally ill cancer patients told about their expected deaths? A study of cancer physicians' self-reports of prognosis disclosure. *J Clin Oncol* 2008 Dec 20;26(36):5988-93.
- (23) White DB, Engelberg RA, Wenrich MD, Lo B, Curtis JR. The Language of Prognostication in Intensive Care Units. *Med Decis Making* 2008 Aug 27.
- (24) Hancock K, Clayton JM, Parker SM, Walder S, Butow PN, Carrick S, et al. Discrepant Perceptions About End-of-Life Communication: A Systematic Review. *J Pain Symptom Manage* 2007 May 31.
- (25) Miyaji NT. The power of compassion: truth-telling among American doctors in the care of dying patients. *Soc Sci Med* 1993 Feb;36(3):249-64.
- (26) Rodriguez KL, Gambino FJ, Butow P, Hagerty R, Arnold RM. Pushing up daisies: implicit and explicit language in oncologist-patient communication about death. *Support Care Cancer* 2007 Feb;15(2):153-61.
- (27) Rodriguez KL, Gambino FJ, Butow PN, Hagerty RG, Arnold RM. 'It's going to shorten your life': framing of oncologist-patient communication about prognosis. *Psychooncology* 2008 Mar;17(3):219-25.
- (28) Sullivan KE, Hebert PC, Logan J, O'Connor AM, McNeely PD. What do physicians tell patients with end-stage COPD about intubation and mechanical ventilation? *Chest* 1996 Jan;109(1):258-64.
- (29) Glare P, Virik K, Jones M, Hudson M, Eychmuller S, Simes J, et al. A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ* 2003 Jul 26;327(7408):195.
- (30) Alexander M. Bias and asymmetric loss in expert forecasts: a study of physician prognostic behavior with respect to patient survival. *J Health Econ* 2008 Jul;27(4):1095-108.
- (31) Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat Med* 2002 Jul;16(4):297-303.

- (32) Shanafelt TD, Bowen DA, Venkat C, Slager SL, Zent CS, Kay NE, et al. The physician-patient relationship and quality of life: lessons from chronic lymphocytic leukemia. *Leuk Res* 2009 Feb;33(2):263-70.
- (33) Tattersall MH, Gattellari M, Voigt K, Butow PN. When the treatment goal is not cure: are patients informed adequately? *Support Care Cancer* 2002 May;10(4):314-21.
- (34) Chochinov HM, Tataryn DJ, Wilson KG, Ennis M, Lander S. Prognostic awareness and the terminally ill. *Psychosomatics* 2000 Nov;41(6):500-4.
- (35) Dahlstrand H, Hauksdottir A, Valdimarsdottir U, Furst CJ, Bergmark K, Steineck G. Disclosure of incurable illness to spouses: do they want to know? A Swedish population-based follow-up study. *J Clin Oncol* 2008 Jul 10;26(20):3372-9.
- (36) Clayton JM, Butow PN, Tattersall MH. The needs of terminally ill cancer patients versus those of caregivers for information regarding prognosis and end-of-life issues. *Cancer* 2005 May 1;103(9):1957-64.
- (37) Baile WF, Lenzi R, Parker PA, Buckman R, Cohen L. Oncologists' attitudes toward and practices in giving bad news: an exploratory study. *J Clin Oncol* 2002 Apr 15;20(8):2189-96.
- (38) Curtis JR, Patrick DL. Barriers to communication about end-of-life care in AIDS patients. *J Gen Intern Med* 1997 Dec;12(12):736-41.
- (39) Curtis JR, Patrick DL, Caldwell ES, Collier AC. Why don't patients and physicians talk about end-of-life care? Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Arch Intern Med* 2000 Jun 12;160(11):1690-6.
- (40) Steinhäuser KE, Christakis NA, Clipp EC, McNeilly M, Grambow S, Parker J, et al. Preparing for the end of life: preferences of patients, families, physicians, and other care providers. *J Pain Symptom Manage* 2001 Sep;22(3):727-37.
- (41) Tulsky JA, Chesney MA, Lo B. See one, do one, teach one? House staff experience discussing do-not-resuscitate orders. *Arch Intern Med* 1996 Jun 24;156(12):1285-9.
- (42) Baile WF, Lenzi R, Parker PA, Buckman R, Cohen L. Oncologists' attitudes toward and practices in giving bad news: an exploratory study. *J Clin Oncol* 2002 Apr 15;20(8):2189-96.
- (43) Taylor KM. "Telling bad news": physicians and the disclosure of undesirable information. *Sociol Health Illn* 1988 Jun;10(2):109-32.
- (44) Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a Cancer Research UK communication skills training model for oncologists: a randomised controlled trial. *Lancet* 2002 Feb 23;359(9307):650-6.
- (45) Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or carers. *Cochrane Database Syst Rev* 2004;(2):CD003751.
- (46) Finlay E, Casarett D. Making difficult discussions easier: using prognosis to facilitate transitions to hospice. *CA Cancer J Clin* 2009 Jul;59(4):250-63.

- (47) Jenkins V, Fallowfield L. Can communication skills training alter physicians' beliefs and behavior in clinics? *J Clin Oncol* 2002 Feb 1;20(3):765-9.
- (48) Gude T, Anvik T, Baerheim A, Fasmer OB, Grimstad H, Hjortdahl P, et al. [Teaching clinical communication to medical students in Norway]. *Tidsskr Nor Laegeforen* 2003 Aug 28;123(16):2277-80. (Paper in Norwegian).
- (49) Baerheim A, Hjortdahl P, Holen A, Anvik T, Fasmer OB, Grimstad H, et al. Curriculum factors influencing knowledge of communication skills among medical students. *BMC Med Educ* 2007;7:35.
- (50) Back AL, Arnold RM, Baile WF, Tulsky JA, Barley GE, Pea RD, et al. Faculty development to change the paradigm of communication skills teaching in oncology. *J Clin Oncol* 2009 Mar 1;27(7):1137-41.
- (51) Gude T, Vaglum P, Anvik T, Baerheim A, Fasmer OB, Grimstad H, et al. Do physicians improve their communication skills between finishing medical school and completing internship? A nationwide prospective observational cohort study. *Patient Educ Couns* 2009 Aug;76(2):207-12.
- (52) Finset A, Ekeberg O, Eide H, Aspegren K. Long term benefits of communication skills training for cancer doctors. *Psychooncology* 2003 Oct;12(7):686-93.
- (53) Novack DH, Plumer R, Smith RL, Ochitill H, Morrow GR, Bennett JM. Changes in physicians' attitudes toward telling the cancer patient. *JAMA* 1979 Mar 2;241(9):897-900.
- (54) Bloor M. Focus groups in social research. London: Sage; 2001.
- (55) Forde R, Aasland OG, Steen PA. Medical end-of-life decisions in Norway. *Resuscitation* 2002 Dec;55(3):235-40.
- (56) Altman DG. Practical statistics for medical research. London: Chapman and Hall; 1991.
- (57) Giorgi A. The role of observation and control in laboratory and field research settings. *Phenomenology Pedagogy* 1986;4:22-8.
- (58) Malterud K. Qualitative research: standards, challenges, and guidelines. *Lancet* 2001 Aug 11;358(9280):483-8.
- (59) Suchman AL FAU, Markakis KF, Beckman HB FAU, Frankel R. A model of empathic communication in the medical interview.(0098-7484 (Print)).
- (60) Cohen J. Statistical power analysis for the behavioral sciences. Hillsdale, N. J.: Laurence Erlbaum; 1988.
- (61) Bowling A. Research methods in health: investigating health and health services. Buckingham: Open University Press; 2002.
- (62) Bovier PA, Perneger TV. Stress from uncertainty from graduation to retirement--a population-based study of Swiss physicians. *J Gen Intern Med* 2007 May;22(5):632-8.
- (63) Halkier B. Fokusgrupper. Frederiksberg: Samfundslitteratur & Roskilde Universitetsforlag; 2002.

- (64) Kitzinger J. Qualitative research. Introducing focus groups. *BMJ* 1995 Jul 29;311(7000):299-302. (Book in Danish).
- (65) Mays N, Pope C. Qualitative research: Observational methods in health care settings. *BMJ* 1995 Jul 15;311(6998):182-4.
- (66) Loge JH, Kaasa S, Ekeberg O, Falkum E, Hytten K. Attitudes toward informing the cancer patient--a survey of Norwegian physicians. *Eur J Cancer* 1996 Jul;32A(8):1344-8.
- (67) Lynn J, Harrell FE, Cohn F, Hamel M, Dawson N, Wu AW. Defining the "terminally ill": insights from SUPPORT. *Duquesne Law Rev* 1996;35(1):311-36.
- (68) Becker HS, Geer B, Hughes EC, Strauss AL. Boys in white: student culture in medical school. Chicago: 1961.
- (69) Gude T, Vaglum P, Tyssen R, Ekeberg O, Hem E, Rovik JO, et al. Identification with the role of doctor at the end of medical school: a nationwide longitudinal study. *Med Educ* 2005 Jan;39(1):66-74.
- (70) Larsen Ø. The dynamics of a profession: some concluding comments on being a Norwegian physician. In: Larsen Ø, editor. The shaping of a profession. Physicians in Norway, past and present. Canton, USA: Watson Publishing International; 1996. p. 535-43. (Book in Norwegian).
- (71) Sabini J. Social Psychology. New York: Norton; 1992.
- (72) Abbott A. The system of professions. An essay on the division of expert labor. In: Freidson E, editor. Profession of medicine: a study of the sociology of applied knowledge. Chicago: University of Chicago Press; 1988. p. xix, 419.
- (73) Neumann I, Sending O. [Du skal regjere deg selv]. *Le Monde Diplomatique*, Nordic edition 2003;1-2. (Newspaper article in Norwegian).
- (74) Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA* 1992 Apr 22;267(16):2221-6.
- (75) Mack JW, Wolfe J, Cook EF, Grier HE, Cleary PD, Weeks JC. Hope and prognostic disclosure. *J Clin Oncol* 2007 Dec 10;25(35):5636-42.
- (76) Friedrichsen MJ, Strang PM, Carlsson ME. Breaking bad news in the transition from curative to palliative cancer care--patient's view of the doctor giving the information. *Support Care Cancer* 2000 Nov;8(6):472-8.
- (77) Gattellari M, Voigt KJ, Butow PN, Tattersall MH. When the treatment goal is not cure: are cancer patients equipped to make informed decisions? *J Clin Oncol* 2002 Jan 15;20(2):503-13.
- (78) Bruera E, Neumann CM, Mazzocato C, Stiefel F, Sala R. Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Palliat Med* 2000 Jul;14(4):287-98.
- (79) Fallowfield L, Ford S, Lewis S. No news is not good news: information preferences of patients with cancer. *Psychooncology* 1995 Oct;4(3):197-202.

- (80) Kirk P, Kirk I, Kristjanson LJ. What do patients receiving palliative care for cancer and their families want to be told? A Canadian and Australian qualitative study. *BMJ* 2004 Jun 5;328(7452):1343.
- (81) Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. *Support Care Cancer* 2004 Oct;12(10):692-700.
- (82) Audrey S, Abel J, Blazeby JM, Falk S, Campbell R. What oncologists tell patients about survival benefits of palliative chemotherapy and implications for informed consent: qualitative study. *BMJ* 2008;337:a752.
- (83) Johnston G, Abraham C. Managing awareness: negotiating and coping with a terminal prognosis. *Int J Palliat Nurs* 2000 Nov;6(10):485-94.
- (84) Rodin G, Mackay JA, Zimmermann C, Mayer C, Howell D, Katz M, et al. Clinician-patient communication: a systematic review. *Support Care Cancer* 2009 Jun;17(6):627-44.
- (85) Jones I, Kirby A, Ormiston P, Loomba Y, Chan KK, Rout J, et al. The needs of patients dying of chronic obstructive pulmonary disease in the community. *Fam Pract* 2004 Jun;21(3):310-3.
- (86) Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR, et al. Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *BMJ* 1996 Sep 21;313(7059):724-6.
- (87) Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ* 2006 Oct 28;333(7574):886.
- (88) Gordon EJ, Daugherty CK. 'Hitting you over the head': oncologists' disclosure of prognosis to advanced cancer patients. *Bioethics* 2003 Apr;17(2):142-68.
- (89) Gerrity MS, Earp JA, DeVellis RF, Light DW. Uncertainty and professional work: Perceptions of physicians in clinical practice. *American Journal of Sociology* 1992;97:1022-51.
- (90) Eggly S, Penner L, Albrecht TL, Cline RJ, Foster T, Naughton M, et al. Discussing bad news in the outpatient oncology clinic: rethinking current communication guidelines. *J Clin Oncol* 2006 Feb 1;24(4):716-9.
- (91) Wittenberg-Lyles EM, Goldsmith J, Sanchez-Reilly S, Ragan SL. Communicating a terminal prognosis in a palliative care setting: deficiencies in current communication training protocols. *Soc Sci Med* 2008 Jun;66(11):2356-65.
- (92) Falkum E. [Is it possible to learn empathy?]. *Tidsskr Nor Laegeforen* 2000 Dec 10;120(30):3662. (Paper in Norwegian).
- (93) Kahn MW. Etiquette-based medicine. *N Engl J Med* 2008 May 8;358(19):1988-9.
- (94) Hayry M, Takala T. Genetic information, rights, and autonomy. *Theor Med Bioeth* 2001 Sep;22(5):403-14.
- (95) Howard KL, Filley CM. Advances in genetic testing for Alzheimer's disease. *Rev Neurol Dis* 2009;6(1):26-32.

- (96) Trepanier A, Ahrens M, McKinnon W, Peters J, Stopfer J, Grumet SC, et al. Genetic cancer risk assessment and counseling: recommendations of the national society of genetic counselors. *J Genet Couns* 2004 Apr;13(2):83-114.
- (97) Nylenna M. [The "two cultures" in medicine]. *Tidsskr Nor Laegeforen* 2000 Dec 10;120(30):3732-5. (Paper in Norwegian).
- (98) Gulbrandsen P, Krupat E, Benth JS, Garratt A, Safran DG, Finset A, et al. "Four Habits" goes abroad: report from a pilot study in Norway. *Patient Educ Couns* 2008 Sep;72(3):388-93.
- (99) Bernard M, de RY, Despland JN, Stiefel F. Communication skills training and clinicians' defenses in oncology: an exploratory, controlled study. *Psychooncology* 2009 Mar 9.
- (100) Merckaert I, Libert Y, Delvaux N, Marchal S, Boniver J, Etienne AM, et al. Factors that influence physicians' detection of distress in patients with cancer: can a communication skills training program improve physicians' detection? *Cancer* 2005 Jul 15;104(2):411-21.
- (101) Sladek RM, Bond MJ, Phillips PA. Why don't doctors wash their hands? A correlational study of thinking styles and hand hygiene. *Am J Infect Control* 2008 Aug;36(6):399-406.

## Papers I-IV

## Appendix



Rogg L, Graugaard PK, Loge JH. Physicians' interpretation of the prognostic term 'terminal': A survey among Norwegian physicians. *Palliative and Supportive Care* 2006; 4: 273–278.

DOI: 10.1017/S1478951506060342

The original publication is available at  
<http://journals.cambridge.org/action/displayAbstract?aid=504624>

© 2006 Cambridge University Press

Access to the published version may require journal subscription.





## Physicians' interpretation of the prognostic term "terminal": A survey among Norwegian physicians

LOTTE ROGG, M.D.,<sup>1</sup> PETER KJÆR GRAUGAARD, M.D.,<sup>2</sup>  
AND JON HÅVARD LOGE, M.D.<sup>1</sup>

<sup>1</sup>Department of Oncology, Ulleval University Hospital, Oslo, Norway

<sup>2</sup>Department of Behavioral Sciences in Medicine, University of Oslo, Oslo, Norway

(RECEIVED March 3, 2006; ACCEPTED March 26, 2006)

### ABSTRACT

**Objective:** Optimal clinical practice depends upon a precise language with common understanding of core terms. The aim of the present study was to examine how Norwegian physicians understand the commonly used but poorly defined term "terminal."

**Methods:** A questionnaire was mailed to 1605 Norwegian physicians, representative of the Norwegian medical community. Nine hundred and sixty-eight responded and defined "terminal" in expected weeks left to live. The effects of gender, age, specialty, and experience with prognostication toward end of life on the estimation of "terminal" were investigated.

**Results:** Norwegian physicians on average expect a "terminal" patient to have 3.6 ( $\pm 3.5$  SD) weeks to live with expectation ranging from 0 to 26 weeks. The majority (83.5%) defined "terminal" as less than 5 weeks' survival; 15.0% as 5 to 12 weeks' survival and 1.5% as more than 12 weeks' survival. No difference between genders was observed, whereas the youngest physicians (27–39 years) held shorter definitions than the other age groups. Physicians in internal medicine, surgery, and anaesthesiology held significantly shorter estimations of "terminal" than did physicians in general practice, public health, and psychiatry.

**Significance of results:** Our study shows that the majority of Norwegian physicians restrict "terminal" to the last 2–4 weeks of patients' lives. A life expectancy of a few days compared to several weeks should lead to different clinical actions. Efforts should therefore be made to come to a common definition of the term. In our opinion the use of "terminal" should be limited to when death is expected within a few days.

**KEYWORDS:** Conceptual research, Terminology, Terminal, End-of-life

### INTRODUCTION

Common understanding of core terms among health care professionals is essential to achieve best clinical practice. The terms "terminal," "terminally ill," and "terminal care" are such important concepts widely used in everyday exchange of medical information as well as in medical research. To illustrate,

a search in PubMed, using the terms "terminal care" and "terminally ill" gives 27,761 and 5388 hits, respectively. For "terminal care," 994 of the hits are title words and for "terminally ill" 1129 are title words. Furthermore, both "terminal care" and "terminally ill" are MESH terms, the former introduced in the MESH database in 1968 and the latter in 1997. The topics in scientific papers using these terms vary from euthanasia and physician-assisted suicide (Emanuel et al., 2000) to the management of symptoms and problems experienced by patients with advanced life-threatening diseases (Hugel et al., 2004) and documents evaluating best practice and

Corresponding author: Lotte Rogg, Department of Oncology, Ulleval University Hospital, Kirkeveien 177, N-0407 Oslo, Norway. E-mail: l.v.rogg@usit.uio.no

health care services (The SUPPORT Principal Investigators, 1995; Brandt et al., 2005).

Etymologically, the word "terminal" originates from Latin and means *end, limit, or boundary* (Simpson & Weiner, 2006). Historically it has been used in the medical literature to describe the final stage of a fatal disease, patients suffering from such a disease, and institutions in which such patients are cared for (Saunders, 1961). In spite of the frequent use of "terminal," few researchers have suggested an exact definition of its prognostic meaning (Emanuel et al., 2000; Levorato et al., 2001; Hugel et al., 2004; Clayton et al., 2005) and those who do vary considerably. Some researchers define the "terminal phase" to be the last few days (Twycross & Lichter, 1998), whereas others have a much wider time frame in mind, such as the last 6 months (Vig & Pearlman, 2004; Okie, 2005). Some do not specify a time frame but define "terminal" according to a specified stage of a disease (Weeks et al. 1998), when treatment of the underlying condition is no longer feasible (Llobera et al. 2000), or according to a set of clinical signs and symptoms (Kutner et al., 1999; Ellershaw, 2002; Brandt et al., 2005).

The lack of a generally accepted definition of "terminal" is reflected in clinical practice. Thus experience from management of patients with cancer indicates that even on the same hospital ward, different members of the staff will use "terminal" differently. This clinical impression of variation has also been supported in a survey conducted among North American internists (Christakis & Iwashyna, 1998). In this study it was found that the physicians varied between 0 and 72 weeks in their expectation of a patient's remaining time to live when designated "terminal." As "terminal" so often is used to categorize patients in the communication between health professionals, the clinical, practical, and emotional consequences of laxity in the definition may be sizable. An example is how the wording of a referral may be misleading because the referrer holds a wider time frame when referring a "terminal" patient than does the physician taking over the care of the patient. A gap in expected survival can range from months to a few days between the two physicians. Different understandings of "terminal" among the staff may result in ambiguous or even contradictory information to the patient and relatives. Such unsatisfactory communication is especially unfortunate, because of the vulnerability of the persons involved.

The aim of the present study was to examine how Norwegian physicians define "terminal" in terms of weeks left to live. We furthermore wanted to examine if demographic factors or work experience affected the physicians' interpretation of the term.

## MATERIALS AND METHODS

An extensive research program on physicians' health and working conditions has been running in Norway over the last 10 years (Aasland et al., 1997). As part of this study a representative reference panel of Norwegian physicians has been surveyed on a regular basis. This group of 1605 Norwegian physicians was sent an 11-page questionnaire in June 2002 (with one reminder in August), including two questions regarding end of life. They were asked to indicate in weeks a response to the question: "When a patient is labeled 'terminal,' approximately how many weeks should the patient have left to live, in your opinion?" On a 4-point scale (*not at all, 1–4 times, 5–10 times, more than 10 times*) they were asked to indicate how many times during the previous year they had answered the following question: "How long do I have left to live?"

The 43 specialties and subspecialties were merged into eight clinical relevant categories: general practice, laboratory medicine, internal medicine, surgical specialties, gynecology, anesthesiology, psychiatry, and public health. Specialists in training were categorized according to their future specialty. Some of the physicians did not give information regarding specialty and were not included in the analyses on specialties.

## Statistical Analyses

Between-group differences were computed by using *t* tests or one-way analysis of variance (ANOVA) for continuous dependent variables and  $\chi^2$  tests for categorical variables (analyses for comparison between responders and nonresponders). Where appropriate, differences between groups were further analyzed by post hoc analyses of the least significant differences. Because of skewed data, the dependent variable "weeks" was log-transformed to attain a normal distribution. Data were analyzed with the statistical package SPSS (version 12).

## RESULTS

### Respondents

A total of 968 physicians responded to the question on the interpretation of "terminal," yielding a response rate of 60.3%. The response rate was significantly lower among women (52.1%) and in the specialties of psychiatry (55.2%) and laboratory medicine (54.7%) compared to the respectively relevant subgroups, whereas the explanatory variable age showed no significant relation to nonresponse.

The distribution of responders and nonresponders according to gender, age, and specialty is shown in Table 1.

Mean ( $\pm$  *SD*) age of the respondents was  $48.5 \pm 10.9$  years old, with a range from 28 to 78 years. The female physicians were significantly younger than their male colleagues (44.4 vs. 50.9 years old)  $t = -11.4, p < .0001$ . The mean age for the different specialties varied from 47.7 years old (anesthesiology) to 51.1 years old (public health). Gender was associated with specialty ( $\chi^2 = 43.3, df = 8, p = .0003$ ), with pairwise comparisons showing significantly more male physicians among the surgeons whereas the female physicians more often were psychiatrists.

### The Interpretation of Being "Terminal"

The distribution of "terminal" defined in weeks left to live is displayed in Figure 1. The answers ranged from 0 to 26 weeks with a mean ( $\pm$  *SD*) of  $3.6 \pm 3.5$  weeks and a median equal to 2 weeks. Overall the physicians split into three groups, with considerable reduction in the number after 4 and 12 weeks. Thus 83.5% held the opinion that "terminal" means less than 5 weeks left to live, 15.0% that it means 5 to 12 weeks left to live, and 1.5% that is more than 12 weeks. The view that "terminal" designates a survival of less than 1 week to live was held by 8 (0.8%) physicians.

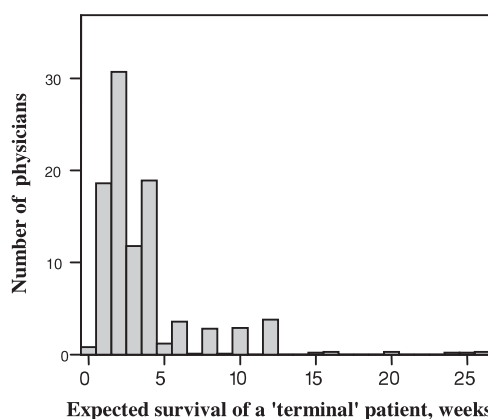


Fig. 1. Norwegian physicians' interpretation of "terminal" in weeks left to live.

Table 2 displays how the physicians define "terminal," taking gender, age, and exposure to end of life prognostication into account.

Bivariate analysis showed no statistically significant effect of gender on the interpretation of "terminal" in weeks ( $F = 0.760, df = 1, p = .383$ ), a finding that maintained when controlling for age and exposure to end of life prognostication ( $F = 0.054, df = 1, p = .816$ ). Examining the effect of age

Table 1. Main characteristics of the responders compared to non-responders

	Responders <sup>a</sup> ( <i>n</i> = 968)	Non-responders <sup>a</sup> ( <i>n</i> = 637)	<i>P</i> value
Gender			
Women	261 (52.1%)	240 (47.9%)	<i>p</i> = 0.0007
Men	659 (63.9%)	392 (36.1%)	
Age			
25–39 years	220 (62.9%)	130 (37.1%)	n.s. <sup>b</sup> ( <i>p</i> = .059)
40–49 years	300 (60.1%)	199 (39.9%)	
50–59 years	279 (65.5%)	147 (34.5%)	
60–69 years	119 (56.4%)	92 (43.6%)	
70+ years	34 (50.7%)	33 (49.3%)	
Specialty			
General practice	215 (72.1%)	83 (27.9%)	<i>p</i> = .0003
Internal med.	206 (67.3%)	100 (32.7%)	
Surgical spec.	93 (74.4%)	32 (25.6%)	
Gynecology	31 (68.9%)	14 (31.1%)	
Anesthesiology	39 (70.9%)	16 (29.1%)	
Laboratory med.	52 (54.9%)	43 (45.3%)	
Public health	49 (80.3%)	12 (19.7%)	
Psychiatry	69 (55.2%)	56 (44.8%)	

<sup>a</sup>Due to some missing data on gender, age, and specialty the total number differs somewhat. Total number of invited participants = 1605.

<sup>b</sup>Not significant.

**Table 2.** Definition of "terminal" by a sample of Norwegian physicians by gender, age, and exposure to end of life prognostication

	<i>N</i>	Mean	<i>SD</i>
Gender			
Women	261	3.3	2.8
Men	695	3.7	3.7
Age			
25–39 years	220	2.8	2.6
40–49 years	300	3.8	3.8
50–59 years	279	3.9	3.5
60–69 years	119	3.9	4.2
70+ years	34	3.7	2.7
Exposure to end of life prognostication			
Not exposed last year	438	3.8	3.9
1–4 times last year	335	3.6	3.1
5–10 times last year	105	3.2	2.8
>10 times last year	77	3.0	3.1

(five subgroups) showed a statistically significant difference ( $F = 5.787$ ,  $df = 4$ ,  $p = .0001$ ) that was unaffected when controlling for gender and exposure to end of life prognostication. A post hoc analysis revealed significant differences between the youngest physicians (25–39 years old) and all the other age subgroups, with the youngest applying a shorter time frame, whereas no significant differences were found among those other subgroups.

No statistically significant association was found between exposure to end of life prognostication and interpretation of "terminal" in weeks using analysis of variance ( $F = 2.208$ ,  $df = 3$ ,  $p = .086$ ), either when controlling for age or gender.

Table 3 displays how Norwegian physicians in different specialties define "terminal" in weeks left to live.

Examining the effect of speciality on the definition of "terminal" in weeks showed a statistically significant difference ( $F = 4.168$ ,  $df = 7$ ,  $p = .0002$ ) that was affected somewhat when controlling for exposure to end of life prognostication ( $F = 3.373$ ,  $df = 7$ ,  $p = .001$ ), but not by gender and age. Post hoc analyses revealed significant differences between all three specialties, internal medicine, surgery, and anesthesiology, compared to general practice, public health, and psychiatry (Table 3), with the former applying a shorter definition than did the latter.

## DISCUSSION

Norwegian physicians' definition of the term "terminal" ranged from 0 to 26 weeks survival, al-

**Table 3.** Definition of "terminal" by a sample of Norwegian physicians by specialties

	<i>N</i>	Mean	<i>SD</i>
General practice	215	4.0	3.5
Internal med. <sup>a</sup>	206	3.2	3.6
Surgical spec. <sup>a</sup>	93	3.0	2.3
Gynecology	31	3.1	2.3
Anesthesiology <sup>a</sup>	39	3.1	3.5
Laboratory med.	52	4.0	3.7
Public health	49	4.6	4.4
Psychiatry	69	4.1	2.9

<sup>a</sup>Significantly lower mean values than general practice (internal medicine and surgery:  $p < .01$ ; anesthesiology:  $p < .05$ ), public health (internal medicine, surgery, and anesthesiology:  $p < .01$ ), and psychiatry (internal medicine, surgery, and anesthesiology:  $p < .01$ ).

though the majority would define survival among "terminal" patients to be somewhere between 0 and 5 weeks. There were significant differences between specialties. However, the relative homogeneity in the use of the term among internists, surgeons, and gynecologists indicates that it is primarily a hospital jargon. Physicians under 40 held a shorter definition of survival length than older, whereas no difference between genders or according to experience with end-of-life prognostication were observed.

The present study investigated a large, representative sample of a country's physician population, which enabled us to examine different subgroups. There were, however, some weaknesses. We examined the term "terminal" using one item only, with response categories in number of weeks, leaving no room for alternative ways of defining "terminal" and without giving indications of chance of surviving for a certain amount of time (Lynn et al., 1996). The response rate obtained was 60.3%. This was approximately 10% lower than the response rate obtained on the rest of the questionnaire. One might assume that some of the nonresponders found this issue more irrelevant for their own practice. This is supported by the finding that a better response rate was obtained among physicians from specialties such as surgery, internal medicine, anesthesiology, and general practice (67–74%), where the term "terminal" is used in clinical practice.

To our knowledge, only one previous study has examined physicians' definition of the term "terminal" (Christakis & Iwashyna, 1998). The present study investigated a cross section of physicians across all medical specialties, compared to internists (generalists and specialists) only in the former study. We were therefore able to describe differences that might have implications for the commu-

nication between different specialties. Physicians in general practice, psychiatry, laboratory medicine, or public health held a definition of longer survival, whereas physicians in internal medicine, surgery, anesthesiology, or gynecology applied a narrower time frame. There are several possible explanations for this, the most obvious being that the term is a jargon, used primarily in hospitals. General practitioners, for instance, see a different patient population and hence may have other connotations linked to the term "terminal" than do internists and surgeons. However, in communication between primary and secondary health care practitioners, such a difference in understanding of the term "terminal" can lead to misunderstanding and reduced quality of care toward the end of life (Higginson, Wade & McCarthy, 1990; Lecouturier et al., 1999; Lynn & Forlini, 2001).

Compared to our findings, Christakis and Iwashyna eight years earlier observed a much wider range (0 to 76 weeks, the majority labeling a "terminal" patient as having 16 weeks or less left to live) in their study among North American internists. A possible explanation can be differences in fund systems of health care in the two countries, with less than 6 months survival as a criterion for obtaining Medicare benefits such as hospice care in the United States compared to no such time limiting criterion in the Norwegian health insurance system. Other explanations for the observed discrepancy can be cultural differences between the two countries and changes in use of the term due to increased awareness of end-of-life care during the years between the two studies.

In line with Christakis' findings, no gender difference was observed in this study. Contrary to the Christakis study, however, no effect of experience with queries regarding life expectancy was observed, whereas an opposite effect of age/years of practice was found.

As the terms "terminal" and "terminally ill" are used without clear definitions (Lynn et al., 1996), efforts have been made to replace them with others such as "serious and complex illness" (Lynn & Forlini, 2001). In end-of-life care there is a need to focus specifically on the very last days of a patient's life, as symptoms such as dyspnea, constipation, or anxiety are managed differently if the patient has a life expectancy of a few days compared to 4–5 weeks or more (Adam, 1997; Ellershaw, 2002; Furst & Doyle, 2004). Similarly, appropriate planning of a patient's last few days regarding whether to stay in hospital or at home with the necessary health care support are dependent on every one involved understanding what is at stake. Unambiguous language defining the clinical situation is necessary

and has led to expressions such as "entering the actively dying phase of (a patient's) illness" (Bailey et al. 2005).

In conclusion, Norwegian physicians apply a narrower definition of the term "terminal" than do North American physicians, yet a substantially broader definition than recommended by experts in end-of-life care (Twycross & Lichter, 1998; Ellershaw & Ward, 2003). To reduce ambiguities in communication within the health care system we suggest that the term "terminal" should be used to describe a dying patient, with a short life expectancy of a few days to a week.

## ACKNOWLEDGMENTS

The study was funded by Eastern Norway Health Authority and was supported practically by Olaf Aasland at The Norwegian Medical association.

## REFERENCES

- Aasland, O.G., Olff, M., Falkum, E., et al. (1997). Health complaints and job stress in Norwegian physicians: The use of an overlapping questionnaire design. *Social Science and Medicine*, 45, 1615–1629.
- Adam, J. (1997). ABC of palliative care. The last 48 hours. *British Medical Journal*, 315, 1600–1603.
- Bailey, F.A., Burgio, K.L., Woodby, L.L., et al. (2005). Improving processes of hospital care during the last hours of life. *Archives of Internal Medicine*, 165, 1722–1727.
- Brandt, H.E., Deliens, L., Ooms, M.E., et al. (2005). Symptoms, signs, problems, and diseases of terminally ill nursing home patients: A nationwide observational study in the Netherlands. *Archives of Internal Medicine*, 165, 314–320.
- Christakis, N.A. & Iwashyna, T.J. (1998). Attitude and self-reported practice regarding prognostication in a national sample of internists. *Archives of Internal Medicine*, 158, 2389–2395.
- Clayton, J.M., Butow, P.N., Arnold, R.M., et al. (2005). Discussing end-of-life issues with terminally ill cancer patients and their carers: A qualitative study. *Supportive Care in Cancer*, 13, 589–599.
- Ellershaw, J. (2002). Clinical pathways for care of the dying: An innovation to disseminate clinical excellence. *Journal of Palliative Medicine*, 5, 617–621.
- Ellershaw, J. & Ward, C. (2003). Care of the dying patient: The last hours or days of life. *British Medical Journal*, 326, 30–34.
- Emanuel, E.J., Fairclough, D.L., & Emanuel, L.L. (2000). Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. *JAMA*, 284, 2460–2468.
- Furst, C. & Doyle, D. (2004). The terminal phase. In *Oxford Textbook of Palliative Medicine*, Doyle, D., Hanks, G., Cherny, N., et al. (eds.), pp. 1119–1133. Oxford: Oxford University Press.
- Higginson, I., Wade, A., & McCarthy, M. (1990). Palliative care: Views of patients and their families. *British Medical Journal*, 301, 277–281.

- Hugel, H., Ellershaw, J.E., Cook, L., et al. (2004). The prevalence, key causes and management of insomnia in palliative care patients. *Journal of Pain and Symptom Management*, 27, 316–321.
- Kutner, J.S., Steiner, J.F., Corbett, K.K., et al. (1999). Information needs in terminal illness. *Social Science and Medicine*, 48, 1341–1352.
- Lecouturier, J., Jacoby, A., Bradshaw, C., et al. (1999). Lay carers' satisfaction with community palliative care: Results of a postal survey. South Tyneside MAAG Palliative Care Study Group. *Palliative Medicine*, 13, 275–283.
- Levorato, A., Stiefel, F., Mazzocato, C., et al. (2001). Communication with terminal cancer patients in palliative care: Are there differences between nurses and physicians? *Supportive Care in Cancer*, 9, 420–427.
- Llobera, J., Esteve, M., Rifa, J., et al. (2000). Terminal cancer: Duration and prediction of survival time. *European Journal of Cancer*, 36, 2036–2043.
- Lynn, J. & Forlini, J.H. (2001). "Serious and complex illness" in quality improvement and policy reform for end-of-life care. *Journal of General Internal Medicine*, 16, 315–319.
- Lynn, J., Harrell, F.E., Cohn, F., et al. (1996). Defining the "terminally ill": Insights from SUPPORT. *Duquesne Law Review*, 35, 311–336.
- Okie, S. (2005). Physician-assisted suicide—Oregon and beyond. *New England Journal of Medicine*, 352, 1627–1630.
- Saunders, C. (1961). Euthanasia. *Lancet*, 278, 548–549.
- Simpson, J.A. & Weiner, E.S.C., Eds. (2006). Oxford English Dictionary. Oxford: Oxford University Press. Available at: [http://dictionary.oed.com/cgi/entry/50249364?single=1&query\\_type=word&queryword=terminal&first=1&max\\_to\\_show=10](http://dictionary.oed.com/cgi/entry/50249364?single=1&query_type=word&queryword=terminal&first=1&max_to_show=10).
- The SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA*, 274, 1591–1598.
- Twycross, R. & Lichter, I. (1998). The terminal phase. In *Oxford Textbook of Palliative Medicine*, Doyle, D., Hanks, G., & MacDonald, N. (eds.), pp. 977–992. Oxford: Oxford University Press.
- Vig, E.K. & Pearlman, R.A. (2004). Good and bad dying from the perspective of terminally ill men. *Archives of Internal Medicine*, 164, 977–981.
- Weeks, J.C., Cook, E.F., O'Day, S.J., et al. (1998). Relationship between cancer patients' predictions of prognosis and their treatment preferences. *JAMA*, 279, 1709–1714.



This article is removed.





This article is removed.



This article is removed.

# Appendix



**Table 1 Overview of the studies in the thesis**

Study	Design	Paper	Number and type of subjects
<b>A</b>	Postal survey	I and II	1605 invited, 69.5 per cent responders. General physician population 3 groups
<b>B</b>	Focus group interview	III	6 oncologists in each group
<b>C</b>	Observational study	IV	231 consultations, 25 physicians, 142 patients



15. august 2002

Referansepanelet

Kjære kollega!

*Har du glemt oss?* Etter det vi kan se er du blant dem som ikke har svart på årets spørreskjema, men hvis du er sikker på at du har svart kan du se bort fra denne henvendelsen. Erfaringsmessig er det imidlertid alltid en del som trenger en påminnelse, og den kommer altså her. Hvis du av en eller annen grunn ikke ønsker å svare ber vi om at du likevel returnerer spørreskjemaet, gjerne med en påskrift om hvorfor det ikke er fylt ut.

Vi har stor nytte av data fra Referansepanelet i vår forskning på legers atferd og karrierer. En oppdatert oversikt over aktuelle publikasjoner finner du på [www.legeforeningen.no/index.db?id=4715](http://www.legeforeningen.no/index.db?id=4715)

Vi ønsker etter hvert å gi Referansepanelets medlemmer anledning til å svare på Internett, og spør hva dere mener om dette (sp. 1). Videre er vi særlig interessert i følgende tema: legen som portvakt for samfunnets ressurser (sp. 4 – 16), forholdet til legemiddelindustrien (sp. 17 – 23), om å forutsi sykdommers forløp (sp. 24), og legers misnøye generelt og i jobben (sp. 25 – 29). Dessuten er det som vanlig noen generelle spørsmål om spesialitet, jobbtype, familiesituasjon etc.

Ikke alle spørsmål passer like godt for alle leger. Vi ber deg likevel svare på alle (bortsett fra der hvor noen blir bedt om å hoppe videre). Dere som er pensjonister svarer ut fra siste arbeidsforhold, og skriver i marginen når det var.

Skjemaet returneres i vedlagte svarkonvolutt innen 15. september 2002.

Med vennlig hilsen

  
Olaf Gjerløy Aasland  
Instituttssjef

Vennligst oppgi vår ref. ved henvendelse

Postadresse	Telefon	Postgiro	E-post
Postboks 1152 sentrum, 0107 Oslo	23 10 90 00	0805 5114707	forskningsinstituttet@legeforeningen.no
Besøksadresse	Telefaks	Bankgiro	Internett:
Legenes hus, Akersgata 2, Oslo	23 10 90 60	5005 05 48802	<a href="http://www.legeforeningen.no/forskning/forsk.htm">http://www.legeforeningen.no/forskning/forsk.htm</a>



**1 Kunne du tenke deg å besvare spørsmålene fra Legeforeningens forskningsinstitutt til Referansepanelet på internett? Sett ring rundt ett tall.**

- 1 Ja, ubetinget
- 2 Ja, dersom anonymiteten ble sikret
- 3 Nei, ikke under noen omstendighet
- 4 Nei, jeg har ikke tilgang til Internett
- 5 Nei, jeg stoler uansett ikke på at anonymiteten sikres ved bruk av Internett
- 6 Nei, jeg behersker ikke teknologien godt nok
- 7 Annet, skriv: \_\_\_\_\_

**2 I en gjennomsnittlig arbeidsuke, omtrent hvor mange timer bruker du på**

pasientarbeid	<input type="text"/>	<input type="text"/>
møtevirksomhet	<input type="text"/>	<input type="text"/>
papirarbeid	<input type="text"/>	<input type="text"/>
telefoner etc.	<input type="text"/>	<input type="text"/>
Sum (samlet arbeidstid)	<input type="text"/>	<input type="text"/>

**3 På spørsmål 2, hva har du inkludert i begrepet pasientarbeid? Sett ring rundt ett tall.**

- 1 Kun ansikt-til-ansikt kontakt med pasienter
  - 2 All direkte kontakt med enkeltpasienter, inkl. telefoner, e-post m.m
  - 3 Alt arbeid direkte relatert til enkeltpasienter, også journalarbeid, telefoner og møter
  - 5 Annet, skriv
- \_\_\_\_\_

**4 Hender det at du tilleggser pasientens ønske om en bestemt undersøkelse eller behandling mer vekt enn ditt eget medisinske skjønn skulle tilsi? Sett ring rundt ett tall.**

- 1 Aldri
- 2 1-2 ganger per år
- 3 3-10 ganger per år
- 4 1-3 ganger per måned
- 5 Ukentlig eller hyppigere
- 6 Ikke aktuelt for meg

**5 Har du i legeerklæringer eller attester bevisst fremstilt pasientens situasjon slik at muligheten for å oppnå det uttalelsen dreide seg om ble best mulig? Sett ring rundt ett tall.**

- 1 Aldri (gå til spørsmål 7)
- 2 Ikke aktuelt for meg (gå til spørsmål 7)
- 3 Ja (spesifiser hva slags attest og hyppighet)

		1-2 per år	3-10 per år	1-3 per mnd.	≥ ukentlig
5.1	Henvisning	1	2	3	4
5.2	Sykmelding II	1	2	3	4
5.3	Erklæring om attføring eller uførepensjon	1	2	3	4
5.4	Førerkortattest	1	2	3	4
5.5	Attest til skole	1	2	3	4
5.6	Attest til reiseselskap	1	2	3	4
5.7	Forsikringsattest ved skade	1	2	3	4
5.8	Attest ved tegning av forsikring	1	2	3	4
5.9	Annet	1	2	3	4

**6 Hvilke begrunnelser vil du angi for slik strategisk attestskriving? Sett ring rundt ett eller flere tall.**

- 6.1 1 Raskere behandling for pasienten
- 6.2 2 Pasientens økonomi
- 6.3 3 For å sikre en rettferdig behandling
- 6.4 4 Hvis jeg ikke gjorde det, ville det gjøre pasientens livssituasjon mye vanskeligere
- 6.5 5 Noen pasienter trenger all mulig støtte og hjelp
- 6.6 6 Kravene (til denne ytelsen) er for strenge
- 6.7 7 Jeg slipper å diskutere med pasienten selv om jeg er uenig
- 6.8 8 Pasienten har rett til å bestemme
- 6.9 9 Det er vanskelig å skrive noe annet enn det pasienten mener er riktig
- 6.10 10 Noen pasienter trenger mer hjelp enn de innser selv
- 6.11 11 Hvis ikke jeg gjorde det, ville pasienten bare oppsøkt en annen lege
- 6.12 12 Noen pasientopplysninger er det ikke riktig å gi andre instanser del i
- 6.13 13 Annet, skriv: \_\_\_\_\_

**7 Hva er dine erfaringer som lege i forhold til utøvelse av kontroll- eller ressursforvaltningsfunksjoner? Skalaen går fra 1 (helt enig) til 5 (helt uenig). Sett ring rundt ett tall for hver påstand**

	Helt enig				Helt uenig
7.1 Kontrolloppgaver har ikke representert problemer for meg i legearbeidet	1	2	3	4	5
7.2 Jeg har ofte vært i tvil om mine beslutninger er i tråd med hensikten bak gjeldende regelverk	1	2	3	4	5
7.3 Er jeg i tvil, er det oftest pasientens syn som avgjør hva jeg skriver	1	2	3	4	5
7.4 Å ha kontrolloppgaver i egenskap av lege føles ofte som en personlig belastning	1	2	3	4	5
7.5 De gangene jeg har vært streng, har pasienten bare gått til en annen lege	1	2	3	4	5
7.6 Å ha kontrolloppgaver i egenskap av lege har vært meningsfylt medisinsk arbeid for meg	1	2	3	4	5
7.7 Jeg har ofte opplevd at pasienter holder tilbake opplysninger av betydning for min avgjørelse	1	2	3	4	5

**8 Arbeidet som lege kan ha gjort noe med ditt syn på mennesket og samfunnsspørsmål. Vi ber om din vurdering av eventuelle endringer siden du tok medisinsk embedseksamen. Sett ring rundt ett tall for hver av de fem påstandene**

8.1 Mitt generelle menneskesyn er	8.3 Min vurdering av folks ønsker og krav er
1 mer negativt	1 mer restriktiv
2 uendret	2 uendret
3 mer positivt	3 mindre restriktiv
8.2 Min tillit til pasienter jeg møter for første gang er	8.4 Mitt syn på ansvaret for sykkelighet
1 mindre	1 går mer i retning av individet
2 uendret	2 uendret
3 større	3 går mer i retning av samfunnet
8.5 Mitt politiske syn på trykdeordninger	
1 Går i retning av mindre generøse ordninger	
2 Uendret	
3 Går i retning av mer generøse ordninger	

**9 Omtrent hvor mange sykmeldinger skriver du per uke?**

Ca. 

--	--	--	--

	Aldri	Månedlig	Ukentlig	Daglig
10 Hvor ofte er du i tvil om du bør sykmelde en pasient?	1	2	3	4
11 Hvor ofte er du i tvil om en sykmeldings varighet?	1	2	3	4
12 Hvor ofte møter du pasienter som ikke vil sykmeldes, selv om du anbefaler det?	1	2	3	4

**13 Opplever du det som positivt eller negativt å skrive ut sykmeldinger?**

Positivt		Nøytralt		Negativt
1	2	3	4	5

**14 Opplever du det som meningsfylt å skrive ut sykmeldinger?**

Meningsfylt		Nøytralt		Ikke meningsfylt
1	2	3	4	5

**15 Ta stilling til følgende utsagn. Skalaen går fra 1 (helt enig) til 5 (helt uenig). Sett ring rundt ett tall for hvert utsagn.**

	Helt enig			Helt uenig	
15.1 Det bør bli tillatt å sykmelde pasienter på rent sosiale indikasjoner, for eksempel ved ektefelles sykdom	1	2	3	4	5
15.2 Pga. de spesielle problemer arbeidsledige pasienter har, bør leger sykmelde dem lettere enn andre	1	2	3	4	5
15.3 Pasienten skal undersøkes personlig av lege når en sykepengeattest skal fornyes	1	2	3	4	5
15.4 Telefonkonsultasjon vil nesten alltid være faglig forsvarlig ved utskriving av sykepengeattest	1	2	3	4	5
15.5 Pasientens ønske om sykmelding bør være det mest avgjørende når legen skriver sykmelding	1	2	3	4	5
15.6 Sykmelding er et viktig behandlingsalternativ	1	2	3	4	5
15.7 Avgjørelser om sykmelding gjør at jeg ofte føler at jeg kommer i konflikt med rollen som hjelper	1	2	3	4	5
15.8 Den forenklete funksjonsvurdering bygger helt og holdent på pasientens opplysninger	1	2	3	4	5
15.9 Sykmelding er en medisinsk oppgave	1	2	3	4	5
15.10 Sykmelding bør ikke kunne gis av annet helsepersonell enn leger	1	2	3	4	5
15.11 Hvis en pasient med kreft er arbeidsufør pga. depresjon, angst eller uro, foretrekker jeg å bruke kreftdiagnosen på sykmeldingen	1	2	3	4	5
15.12 Dersom jeg er i tvil om hvilken diagnose jeg skal skrive på en sykmelding, lar jeg pasienten avgjøre dette	1	2	3	4	5
15.13 Jeg kan for lite om klinisk undersøkelse av muskel-skjelettsystemet til å kunne stille korrekt diagnose	1	2	3	4	5
15.14 Jeg er ikke flink nok til å håndtere mennesker med psykiske eller sosiale problemer	1	2	3	4	5
15.15 Sykmelding er en moralsk oppgave	1	2	3	4	5
15.16 Sykefravær er en sak for arbeidslivet og det er unødvendig å involvere leger	1	2	3	4	5
15.17 Jeg er mindre streng i praksis enn det jeg egentlig synes jeg burde være når det er spørsmål om sykmelding	1	2	3	4	5

**16 Ansvarsfordeling mellom lege og pasient. Ta stilling til følgende utsagn:**

	Helt enig			Helt uenig	
	1	2	3	4	5
16.1 Legen er fagkyndig og bør velge for pasienten i de fleste kliniske situasjoner	1	2	3	4	5
16.2 Pasienten bør primært få den informasjonen som øker sjansen for at han godtar legens oppfatning om hva som bør gjøres	1	2	3	4	5
16.3 Fordi han vet for lite, vil pasientens selvbestemmelsesrett i mange situasjoner være en trussel mot hans helse	1	2	3	4	5
16.4 Etter en grundig informasjon fra legen bør pasienten selv kunne velge den behandlingen hun synes passer best ut fra egne verdier	1	2	3	4	5
16.5 Pasienten bør innenfor de gitte økonomiske og helsepolitiske rammene selv ha kontroll over viktige medisinske beslutninger	1	2	3	4	5
16.6 Økende krav om informasjon og pasientsamtykke gjør legegjerningen vanskeligere enn før	1	2	3	4	5

**17 Forholdet til legemiddelindustrien. Ta stilling til følgende utsagn:**

	Helt enig			Helt uenig	
	1	2	3	4	5
17.1 Reklame fra industrien påvirker ikke min forskrivning av legemidler	1	2	3	4	5
17.2 Informasjon fra industrien er avgjørende for min faglige oppdatering	1	2	3	4	5
17.3 Informasjon fra industrien er av høy faglig kvalitet	1	2	3	4	5
17.4 Industrien underslår ofte viktig kunnskap om legemidler	1	2	3	4	5
17.5 Industrien styrer for mye av medisinsk forskning i Norge	1	2	3	4	5
17.6 Noen av industriens forskningsprosjekter er kamouflert markedsføring	1	2	3	4	5
17.7 Legers arbeid påvirkes ofte av industrien	1	2	3	4	5
17.8 Noen spesialisters faglige råd er påvirket av sterke bånd til industrien	1	2	3	4	5
17.9 Legeforeningens holdning til at industrien skal finansiere kurs og seminarer er for streng	1	2	3	4	5
17.10 Legeforeningens holdning til industrifinansierte reiser er for streng	1	2	3	4	5
17.11 Ektefeller/samboere bør kunne få delta under seminarer finansiert av industrien hvis de betaler eget opphold	1	2	3	4	5
17.12 Det bør være mulig å kombinere industrifinansierte reiser og ferieopphold	1	2	3	4	5
17.13 Personlige bånd med enkelte legemiddelrepresentanter gjør meg positivt innstilt til dette firmaets produkter	1	2	3	4	5
17.14 Uten legemiddelindustrien, ville legers videre- og etterutdanning blitt dårligere	1	2	3	4	5
17.15 Industrien opererer i sin markedsføring med lister over viktige og mindre viktige leger	1	2	3	4	5
17.16 Forskningsprosjekter finansiert av industrien holder vanligvis høy kvalitet	1	2	3	4	5
17.17 Legene holder seg i for liten grad til Legeforeningens retningslinjer	1	2	3	4	5

**18** Hvor ofte deltar du i arrangementer (bortsett fra lunsjbesk) som er støttet av industrien?

- 1 Aldri
- 2 1-2 ganger per år
- 3 3-10 ganger per år
- 4 1-3 ganger per måned
- 5 Ukentlig eller hyppigere
- 6 Ikke aktuelt for meg

**19** Hvor ofte har du besøk av legemiddelrepresentanter på din arbeidsplass?

- 1 Aldri
- 2 1-2 ganger per år
- 3 3-10 ganger per år
- 4 1-3 ganger per måned
- 5 Ukentlig eller hyppigere
- 6 Ikke aktuelt for meg

**20** Hvor ofte reiser du utenlands med støtte fra industrien?

- 1 Aldri
- 2 1-2 ganger per år
- 3 3 ganger per år eller hyppigere
- 4 Ikke aktuelt for meg

**21** Hvor mange forskningsprosjekter finansiert av industrien deltok du i i 2000-2001?

- 1 Ingen
- 2 1-2 prosjekter
- 3 3 eller flere prosjekter
- 4 Ikke aktuelt for meg

**22** Har du mottatt direkte betaling fra industrien når du har deltatt i forskningsprosjekter?

- 1 Nei
- 2 Ja. Angi beløp per pasient (gjennomsnitt) NOK 

--	--	--	--	--

**23** På din arbeidsplass, hva bestemmer om du deltar i industristøttede arrangementer?

	Ja	Nei
Det styrer jeg selv	1	2
Det forventes av overordnede	1	2
Det er en del av den sosiale kulturen	1	2
Det varierer	1	2
Tilfeldigheter	1	2
Annet, skriv _____		

## 24 Om å forutsi sykdommers forløp

	Helt enig	Delvis enig	Delvis uenig	Helt uenig
24.1 Leger bør unngå å være for spesifikke med hensyn til å forutsi et sykdomsforløp overfor pasientene	1	2	3	4
24.2 Leger bør som regel vente til de blir spurt før de uttaler seg til pasientene om et sykdomsforløp	1	2	3	4
24.3 Det er nyttig å ha en optimistisk holdning i diskusjoner med pasienter	1	2	3	4
24.4 Jeg finner det av og til nyttig å gi prognosen et positivt preg	1	2	3	4
24.5 Jeg finner det av og til nyttig å gi prognosen et negativt preg	1	2	3	4
24.6 Hvis pasienten er optimistisk med hensyn til prognosen, støtter jeg vanligvis en slik oppfatning	1	2	3	4
24.7 Hvis pasienten er pessimistisk med hensyn til prognosen, støtter jeg vanligvis en slik oppfatning	1	2	3	4
24.8 Hvis det faktiske sykdomsforløpet blir uventet dårlig, føler jeg meg forpliktet til å fortelle dette til pasienten	1	2	3	4
24.9 Hvis det faktiske sykdomsforløpet blir uventet godt, føler jeg meg forpliktet til å fortelle dette til pasienten	1	2	3	4
24.10 Jeg synes at jeg har for lite trening i å utarbeide prognoser	1	2	3	4
24.11 Det er stressende å utarbeide prognoser	1	2	3	4
24.12 Det er stressende å formidle prognoser	1	2	3	4
24.13 Det er vanskeligere å utarbeide en presis prognose enn å stille en riktig diagnose	1	2	3	4
24.14 Jeg vil kvie meg for å forutsi noe om et sykdomsforløp når den kliniske situasjonen er særlig usikker	1	2	3	4
24.15 Jeg synes at pasienter forventer for høy presisjon med hensyn på prognose	1	2	3	4
24.16 Hvis jeg stiller feil diagnose kan pasientene miste tillit til meg	1	2	3	4
24.17 Hvis jeg utarbeider feil prognose kan pasientene miste tillit til meg	1	2	3	4
24.18 Hvis jeg stiller feil diagnose kan mine kolleger miste tillit til meg	1	2	3	4
24.19 Hvis jeg utarbeider feil prognose kan mine kolleger miste tillit til meg	1	2	3	4
24.20 Hvis en kollega utarbeidet feil prognose ville jeg antakelig miste noe av min tillit til ham/henne	1	2	3	4

	Helt enig	Delvis enig	Delvis uenig	Helt uenig
24.21 Det er vanskelig å vite hvilke pasienter som ønsker informasjon om sin prognose	1	2	3	4
24.22 Jeg synes det er vanskelig å innlede en samtale om prognose med pasienter	1	2	3	4
24.23 De fleste pasienter kjenner ikke sin egen prognose	1	2	3	4
24.24 Det er viktigere å utarbeide prognose ved kroniske enn ved akutte sykdommer	1	2	3	4
24.25 Når en pasient er informert om en positiv prognose kan sykdomsforløpet påvirkes i positiv retning	1	2	3	4
24.26 Når en pasient er informert om en negativ prognose kan sykdomsforløpet påvirkes i negativ retning	1	2	3	4
	Ingen ganger	1-4 ganger	5-10 ganger	>10 ganger
24.27 I løpet av det siste året, hvor ofte har du fått spørsmålet "Hvor lenge har jeg igjen å leve?"	1	2	3	4
24.28 Når en pasient betegnes som "terminal", omtrent hvor mange uker vil en slik pasient etter din erfaring leve?	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div> <div style="border: 1px solid black; width: 30px; height: 30px; margin-right: 5px;"></div> <div style="margin-left: 10px;">uker</div> </div>			

**25 Angi på en skala fra 1 (svært misfornøyd) til 7 (svært fornøyd) i hvilken grad du er fornøyd med:**

	svært misfornøyd						svært fornøyd
25.1 Den ansvarsmengden du er blitt tildelt	1	2	3	4	5	6	7
25.2 Den variasjon i arbeidsoppgaver du har	1	2	3	4	5	6	7
25.3 Kollegene dine og de øvrige ansatte	1	2	3	4	5	6	7
25.4 Fysiske arbeidsforhold	1	2	3	4	5	6	7
25.5 Muligheten/anledningen til å bruke dine evner	1	2	3	4	5	6	7
25.6 Alt tatt i betraktning, hva synes du om jobben din	1	2	3	4	5	6	7
25.7 Frihet til å velge dine egne arbeidsmetoder	1	2	3	4	5	6	7
25.8 Anerkjennelse du får for godt utført arbeid	1	2	3	4	5	6	7
25.9 Lønnen din	1	2	3	4	5	6	7
25.10 Arbeidstiden din	1	2	3	4	5	6	7
25.11 Når du tenker på hvordan du har det for tiden, er du stort sett fornøyd med tilværelsen, eller er du stort sett misfornøyd?	1	2	3	4	5	6	7
25.12 Hvis du skulle svart på spørsmålet om å være fornøyd for fem år siden, hva ville du svart da?	1	2	3	4	5	6	7
25.13 Hvis du skal svare på spørsmålet om å være fornøyd om fem år, hva vil du svare da?	1	2	3	4	5	6	7



26 Hvor fornøyd er du med jobben din sammenlignet med hva du tror folk i andre yrker er?

		Mindre fornøyd	Like fornøyd	Mer fornøyd
26.1	Advokater	1	2	3
26.2	Prester	1	2	3
26.3	Lærere	1	2	3
26.4	Flyvere	1	2	3
26.5	Psykologer	1	2	3
26.6	Sykepleiere	1	2	3
26.7	Håndverkere	1	2	3
26.8	Bønder	1	2	3
26.9	Politifolk	1	2	3

27 Hvis du var ung i dag og skulle velge yrke, hvilket yrke ville du valgt?

28 Forskning viser at følgende forhold kan redusere arbeidsgleden for leger. Hvordan stemmer dette for deg? Sett ring rundt ett tall for hver påstand.

		Stemmer ikke	Stemmer litt	Stemmer helt
28.1	Jobbe i team, særlig tverrfaglige	1	2	3
28.2	Dokumentere alt du gjør og hvorfor (accountability)	1	2	3
28.3	Ta stadig mer hensyn til pasienter og pårørende	1	2	3
28.4	Forholde seg til stadig flere kliniske retningslinjer og standardiserte prosedyrer	1	2	3
28.5	Et stadig økende krav om å være produktiv	1	2	3
28.6	Media som er stadig mer pågående og kritisk	1	2	3
28.7	En familie som krever at du skal være hjemme oftere	1	2	3
28.8	Myndigheter som har en økende skepsis til leger og deres profesjonelle autonomi	1	2	3

**29 Eysencks personlighetsinventorium. Sett ring rundt ett tall for hvert spørsmål.**

	Ja	Nei
29.1 Har du mange forskjellige hobbyer?	1	2
29.2 Har du vekslende humør?	1	2
29.3 Er du en pratsom person?	1	2
29.4 Er du forholdsvis livlig?	1	2
29.5 Bekymrer du deg ofte over ting du ikke skulle sagt eller gjort?	1	2
29.6 Liker du å treffe nye mennesker?	1	2
29.7 Blir dine følelser lett såret?	1	2
29.8 Hender det ofte at du går "trøtt"?	1	2
29.9 Plages du ofte av skyldfølelse?	1	2
29.10 Bekymrer du deg for at fryktelige ting kan skje?	1	2
29.11 Tar du vanligvis selv initiativet for å få nye venner?	1	2
29.12 Er du stort sett stille og tilbakeholden når du er sammen med andre?	1	2
29.13 Greier du vanligvis å skape liv i et heller kjedelig selskap?	1	2
29.14 Liker du å fortelle vitser og gode historier til dine venner?	1	2
29.15 Har du ofte følt deg trøtt og likeglad uten grunn?	1	2
29.16 Liker du å gjøre ting som krever at du handler raskt?	1	2
29.17 Har du noen gang ønsket at du var død?	1	2
29.18 Plages du av "nerver"?	1	2
29.19 Blir du lett såret når folk finner feil ved deg eller arbeidet du gjør?	1	2
29.20 Liker du å ha masse liv og røre rundt deg?	1	2

**30 Hvor vil du plassere deg selv politisk på en skala fra 1 (konservativ) til 5 (radikal)?**

(Skriv et tall mellom 1 og 5)

### 31 Bakgrunnsopplysninger

#### 31.1 Bosted (helseregion)

- 1 Østfold, Akershus, Oslo, Hedmark, Oppland
- 2 Buskerud, Vestfold, Telemark, Aust-Agder, Vest-Agder
- 3 Rogaland, Hordaland, Sogn og Fjordane
- 4 Møre og Romsdal, Sør-Trøndelag, Nord-Trøndelag
- 5 Nordland, Troms, Finnmark

#### 31.2 Hva er din sivilstand nå?

- 1 Enslig
- 2 Samboende
- 3 Gift
- 4 Separert
- 5 Skilt
- 6 Enke/enkemann

#### 31.3 Er du blitt alderspensjonist siden 1. januar 2000?

- 1 Ja
- 2 Nei

#### 31.4 Nåværende hovedstilling (skriv)

\_\_\_\_\_

#### 31.5 Angi prosent (100% er full stilling)

--	--	--	--

#### 31.6 Når begynte du i denne stillingen?

Måned 

--	--

 År 

--	--	--	--	--

#### 31.7 Hvis du har fått spesialistgodkjenning etter 1. januar 2000 skriv spesialiteten her:

\_\_\_\_\_

#### 31.8 Er du fastlege?

- 1 Nei
- 2 Jeg er fastlege
- 3 Jeg er vikar for fastlege

Antall pasienter på listen:

--	--	--	--	--

**Takk for hjelpen!**

## **Intervjuguide**

### **Gruppeintervju – onkologer**

#### **Introduksjon**

Presentasjon av Lotte

Presentasjon av Victoria

Presentasjon av prosjektet, målsetting, prosjektets ulike deler

Spørreskjemaundersøkelse av tverrsnitt av norske leger

Gruppeintervju 3-4 grupper

Evt en observasjonsstudie blant hematologer og revmatologer

Formålet med prosjektet er å få en bedre forståelse for hva som ligger bak legers håndtering av formidling av prognoser. Slik informasjon er viktig for pasienter, vi vet f.eks at de fleste klagesaker dreier seg om informasjon og kommunikasjon. De siste 10-20 årene har det skjedd store endringer når det gjelder forventning om kommunikasjon mellom pasient og lege, med økende krav til kommunikasjonsferdigheter hos leger. Kunnskap fra denne studien vil kunne brukes for bedret kommunikasjonsundervisning når det gjelder prognoseformidling, i grunnutdanningen og i spesialistutdanningen, også når det gjelder mestring av denne potensielt belastende delen av legejobben.

Litt om gangen i dagens intervju

Vi bruker båndopptaker for å sikre oss at vi får med alt. Påminnelse til de som vet de har en stemme som bærer dårlig.

Anonymitet. Materialet vil bli behandlet konfidensielt (dere vil få tilsendt utkast til artikler med mulighet til kommentarer). Opptakene vil kun bli avspilt for dataanalysen og bare av de 3-4 forskerne som er i gruppen (Akre, Graugaard og Rogg, samt en ikke fastsatt til). Opptakene slettes etter at dataanalysen er avsluttet.

Vi begynner med en presentasjonsrunde.

Selve intervjuet vil være todelt.

Den første og største delen vil bestå av drøfting av noen kliniske problemstillinger der prognoseformidling kommer opp.

Så vil vi snakke om mer generelle problemstillinger i forbindelse med prognoseformidling.

Litt generelt om hensikten med gruppeintervjuer: få fram variasjon i synspunkter og dermed få tilgang til mer informasjon enn om man hadde gjort individuelle intervjuer. Hvis dere er uenige med hverandre, kom med det, det er nettopp slik variasjon i synspunkter vi ønsker å få fram! Snakk først og fremst til hverandre, ikke til oss. Har dere kommentarer, hvis dere er enige eller uenige i det de andre sier, så kom med det. Ikke vent på å få ordet. Kom veldig gjerne med konkrete eksempler.

Hvis det ikke er noen spørsmål til det som er sagt så langt tror jeg vi skal begynne

#### **Intervju**

a)

*Presentasjonsrunde – husk navneskilt.*

Kan dere fortelle kort om hva dere jobber med, hva arbeidet går ut på, og hvor lenge dere har jobbet her? Hvor jobbet dere før?

**ca 10 minutter på dette**

b)

*Kliniske problemstillinger*

Ha som utgangspunkt deres egen arbeidssituasjon, enten på poliklinikken, eller sengepost.

1) Dere skal snakke med en pasient (med f.eks ca mammae) som har vært til en rgt undersøkelse. Dessverre viser denne den første metastasen (lever), dvs at sykdommen går fra å ha en kurativ intensjon til en livsforlengende/palliativ intensjon. Pasienten er spent på resultatet. Hva sier dere?

Kan dere huske en slik konsultasjon som var vellykket? Hva gjorde dere da?

Hva var det som gjorde det vellykket?

Eller ikke så vellykket? Hva gjorde dere da?

Er det karaktertrekk ved pasienten som er medbestemmende for hva du sier?

2) Det finnes ulike måter en pasient eller familie kan prøve å takle det å få uhelbredelig kreft. Hvordan svarer dere til en relativt ung (45-50år) pasient med avansert sykdom (f.eks ca pulm) som spør om hun kan leve med sykdommen i 10 år?

Har dere eksempler på ganger dere har håndtert et så stort sprik i forventning på en god måte?

Hva gjorde dere da?

Eller ikke fått det så bra til?

Hva gjorde dere da?

Hva hvis hun i stedet ikke vil vite noe som helst om sykdomsutbredelse eller prognose, men gjerne vil ha all tilgjengelig behandling? Hvordan håndterer dere det i forhold til plikt til å informere versus behov for at pasienten kan gi informert samtykke?

Eller

Hva hvis hennes pårørende ikke vil at hun skal vite noe?

Eller

Hva hvis hun ikke vil fortelle sine voksne barn noe som helst, selv om det nå er klart at livet går mot en ende?

Eller

Hva hvis barna er små, bor hos henne og hun har svært dårlig kontakt med den fraskilte barnefaren, og hun ikke vil fortelle noe til dem eller til eksmannen?

Bruker dere KRONISK for å beskrive mer stabile, men uhelbredelige kreftsykdommer? Hvorfor/hvorfor ikke, hva oppnås med å gjøre det?

3) Av og til får vi spørsmål fra pasienter eller pårørende som: skal jeg dø nå?/kommer han til å dø nå? Hvis denne pasienten nå er i en terminal fase (få dager igjen å leve) hvordan svarer dere? Har dere en metode dere ofte bruker? (evt kom med ex om å nærmest se seg selv litt utenfra, hvis det ikke kommer noe).

Hva med informasjon rundt RECUSITERING MINUS?

Nå har dere snakket om ulike årsaker til at disse konsultasjonene kan være vanskelige, utfordringer i relasjonen mellom dere og pasient/pårørende. Men hva med rammebetingelsene? Har dere tid nok, får dere være i fred med pasient og familie, i et egnet rom, uten avbrytelser

Evt

Dere har nevnt rammebetingelsene som en årsak til at ikke alt går så godt som dere ønsker, kan dere si noe mer om det?

Ca 1 time på dette

c) *Begreper* (glidende overgang)

Dere har snakket om erfaringene deres, at man må vurdere hva som er det riktige for den enkelte pasient, ikke bare utfra faktorer som alder, kjønn, sykdomsstadium, men hva som føles riktig for denne pasienten. En slags intuisjon. **Stikkord som går på det som er sagt**

Hvordan har dere lært dere det dere bruker/gjør?

Fast struktur med felles visittgang? I økonomisk pressede situasjoner/mest mulig ”effektiv bruk av leger”

I hvilken grad er det mulig i den daglige virksomheten å observere ”mestere” på avdelingen eller poliklinikken? Kan slike ferdigheter læres?

Vi har jo tenkt at kunnskap fra denne forskningen skal lede til bedret

kommunikasjonsundervisning i grunnutd. og spesialistutd. (Tror dere det er mulig?)

(Håp er et begrep man kan sette i sammenheng med prognose)

Evt: Håp har vært framme i diskusjonen. Hvordan tenker dere rundt håp i forbindelse med prognoseformidling?

Er det noe som ligger i bakhodet når dere snakker om pasienten om prognosen?

Jeg vil gjerne få noen kommentarer fra dere på begrepet prognose. Jeg har brukt prognosebegrepet helt unyansert i spørreskjemaundersøkelsen, og har et tolkningsproblem pga det nå. Begrepet er utydelig og gjør at det er vanskeligere å tolke dataene. Hvordan forstår dere det begrepet? Hva snakker dere om når dere snakker om prognose?

Hva synes dere om denne delen av jobben? Er det belastende?

For eksempel slik at dere tar den med hjem eller gruer dere for slike konsultasjoner?

Kan dere beskrive en typisk situasjon som får dere til å tenke at dere er fornøyde med å ha valgt akkurat denne spesialiteten?

Hva med det omvendte? (en situasjon som får dere til å tenke at dere er lite fornøyde med valg av spesialitet?)

Til slutt, har dere noen spørsmål rundt der vi har snakket om?

Er det noe dere vil tilføye?

Tusen takk for hjelpen!

ca 30-45 minutter på dette