



HEIKKI HINKKA

# Decision-Making in End-of-Life Care

## Influence of Physician's Training, Experience and Personal Characteristics



ACADEMIC DISSERTATION

To be presented, with the permission of  
the Faculty of Medicine of the University of Tampere,  
for public discussion in the auditorium of Finn-Medi,  
Lenkkeilijänkatu 6, Tampere, on December 1st, 2001, at 12 o'clock.

*Acta Universitatis Tamperensis 839*  
*University of Tampere*  
*Tampere 2001*

## ACADEMIC DISSERTATION

University of Tampere, Medical School,  
Departments of General Practice and Oncology  
Tampere University Hospital  
Finland

### Supervised by

Professor Pirkko-Liisa Kellokumpu-Lehtinen  
University of Tampere  
Docent Elise Kosunen  
University of Tampere

### Reviewed by

Docent Päivi Hietanen  
University of Helsinki  
Docent Olli-Pekka Rynnänen  
University of Kuopio

### Distribution



University of Tampere  
Sales Office  
P.O. Box 617  
33014 University of Tampere  
Finland

Tel. +358 3 215 6055  
Fax +358 3 215 7685  
taju@uta.fi  
<http://granum.uta.fi>

Cover design by  
Juha Siro

Printed dissertation  
Acta Universitatis Tamperensis 839  
ISBN 951-44-5178-3  
ISSN 1455-1616

Electronic dissertation  
Acta Electronica Universitatis Tamperensis 134  
ISBN 951-44-5179-1  
ISSN 1456-954X  
<http://acta.uta.fi>

Tampereen yliopistopaino Oy Juvenes Print  
Tampere 2001

*To Marja,*

*Lassi, Anni and Inkeri*

*The patient suffering from an incurable disease, and knowing the nearness of death, has a tremendous need to rely on the attending physician. It is of great importance to be able to trust in the physician's competence to relieve pain in a wide context and to make treatment decisions, which are morally and legally right and primarily for the patient's benefit. This trust should never be undermined by fear that the physician's personal attitudes or lack of training might lead to treatment not in line with the patient's will.*

## CONTENTS

LIST OF ORIGINAL PUBLICATIONS I-V	7
ABBREVIATIONS	8
1. Introduction	9
2. Review of the literature	11
2.1 End-of-life care	11
2.1.1 Definition of end-of-life care	11
2.1.2 Ethical issues in end-of-life care	13
2.1.3 Symptom control in palliative care	22
2.1.3.1 Pain control in palliative care	22
2.1.4 Education in palliative care	24
2.2 Decision-making in end-of-life care	26
2.2.1 Legislation, ethical guidelines and directives	26
2.2.1.1 Legislation and guidelines	26
2.2.1.2 Advance directives	27
2.2.1.3 Do-not-resuscitate orders	29
2.2.2 End-of-life decision-making by physicians	30
2.3 Euthanasia and assisted suicide	39
2.3.1 History, practices and legislation	39
2.3.2 Physicians' attitudes to euthanasia	41
3. Aims of the present study	43
4. Material and methods	44
4.1 Questionnaire study	44
4.1.1 Participants	44
4.1.2 Questionnaire	44
4.1.3 Statistical analysis	45
4.2 Education project	46
4.2.1 Participants	46
4.2.2 Questionnaire	46
4.2.3 Statistical analysis	47

4.3	Quality of terminal cancer pain control	47
4.3.1	Patients in the study	47
4.3.2	Statistical analysis	48
5.	Results	50
5.1	Influence of physicians' training and personal back ground factors on their end-of-life decisions (I-III)	50
5.2	Influence of one year's interactive internet-based training on GPs' attitudes and ethical decisions in end-of-life care (IV)	60
5.3	Assessment of pain control in cancer patients during the last week of life. Comparison of health center wards and a hospice (V)	61
6.	Discussion	63
6.1	General findings	63
6.2	Methodological considerations	63
6.3	Factors behind physician's end-of-life decisions	65
6.4	Evaluation of the palliative care education project	69
6.5	Quality of terminal cancer pain control	70
7.	Summary and conclusions	73
8.	Acknowledgements	76
9.	References	79
10.	Appendix	91
	ORIGINAL ARTICLES	97

## LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following original publications, referred to as I-V in the text. In addition, some previously unpublished information is also presented.

- I Hinkka H, Kosunen E, Metsänoja R, Puustelli A, Lammi U-K, Kellokumpu-Lehtinen P-L (2001): Decision-making in terminal care: a survey of Finnish doctors' treatment decisions in end-of-life scenarios involving a terminal cancer and a terminal dementia patient. Accepted for publication in Palliative Medicine.
- II Hinkka H, Kosunen E, Metsänoja R, Lammi U-K, Kellokumpu-Lehtinen, P-L (2001): Factors affecting physicians' decisions to forgo life-sustaining treatments in terminal care. Accepted for publication in Journal of Medical Ethics.
- III Hinkka H, Kosunen E, Metsänoja R, Lammi U-K, Kellokumpu-Lehtinen P-L (2001): To resuscitate or not: a dilemma in terminal cancer care. Resuscitation 49: 289-297.
- IV Hinkka H, Kosunen E, Metsänoja R, Lammi U-K, Kellokumpu-Lehtinen, P-L (2001): Does one year's interactive internet-based training make a change in GPs' attitudes and ethical decisions in end-of-life care? A controlled study. Accepted for publication in Journal of Cancer Education.
- V Hinkka H, Kosunen E, Kellokumpu-Lehtinen P-L, Lammi U-K (2001): Assessment of pain control in cancer patients during the last week of life: comparison of health centre wards and a hospice. Support Care Cancer 9:428-434.

## ABBREVIATIONS

ANOVA	analysis of variance
APM	all pain medication
CG	control group
CI	confidence interval
CPR	cardiopulmonary resuscitation
DDD	defined daily dose
DNR	do-not-resuscitate
EG	education group
GP	general practitioner
HC1	health center of Kangasala
HC2	health center of Virrat
ICU	intensive care unit
IV	intra venous
LST	life-sustaining treatment
NSAID	nonsteroidal anti-inflammatory drug
OR	Odds Ratio
PC	palliative care
PM	palliative medicine
SO	strong opioid
VAS	Visual analogue scale
WHO	World Health Organization
WO	weak opioid



## 1. Introduction

Modern medical science and technology have given rise to more and more conflicts of interest in the care of terminally ill patients. The resources of the health care system are limited and the consequences of modern treatments for terminal patients might prove problematic. Physicians who treat patients approaching the end of life often face moral, ethical and legal issues involving decision-making, futility, the right to forgo medical treatment, euthanasia and physician-assisted suicide.

Respect for the autonomy of the patient is the leading principle in Western ethical consideration. Finland was the first country in the world to introduce legislation on the patient's right to self-determination in 1993 (Pahlman 1997). There patient autonomy is defined to mean that the patient's consent is required as a precondition for treatment to be lawful and that the patient has the right to refuse any intended treatment or procedure or to discontinue any treatment already started. The patient's refusal also applies to treatments whose withdrawal may lead to death, disability or severe illness. It is also generally accepted that there is neither an ethical nor a legal difference in withholding a life-sustaining treatment or withdrawing such treatment formerly started (British Medical Association 1999).

Active euthanasia and assisted suicide are legally prohibited in almost all countries, although attitudes to them vary greatly both internationally and nationally among physicians, lawyers and laymen (Suarez-Almazor et al.1997). In a survey conducted in Finland most laymen were in favour of euthanasia in a scenario involving a terminally ill patient suffering from severe pain, whereas most doctors were against it (Ryynänen O-P and Myllykangas M, unpublished). The very recent decision of the parliament in the Netherlands to approve euthanasia in certain cases of terminal illness has again provoked an intense debate on the subject, especially in the media (Weber 2000).

Palliative medicine and the hospice movement from the 1960's can be considered to be the key to a new way of thinking among doctors working with patients with an incurable

disease (WHO 1990). Instead of hopeless curative efforts it seeks to achieve the best possible quality of life for patients and their families. Increasing research and education in palliative care has also dealt with ethical problems, inspiring critical discussion on the futility of active curative care in the care of dying patients (Pijnenborg, van der Maas et al. 1995, Youngner 1996, Council on Ethical and Judicial Affairs 1999, Walker 1999, Zuckerman and Wollner 1999, Fins and Nilson 2000).

For end-of-life decisions doctors have ethical guidelines and orders (British Medical Association 1999, Suomen Lääkäriliitto 2000). When practising with severely ill patients, however, the doctor often faces ethical dilemmas, for which no easy answers exist. The case is even more difficult if there is no longer a possibility to discuss matters with the patient and no advance directive exists. Previous international studies suggest that in such cases doctors make decisions according to their training and personal background; their own life-values and concepts of a good life may serve here as guidelines (Molloy et al. 1991, Christakis and Asch 1995, Waddel et al. 1996, Mebane et al. 1999). The family's appeal is also known to have great influence on the doctor's decisions (Perkins et al. 1990, Vincent 1990, Vincent 1999).

This present study sought to elucidate the decision-making process in end-of-life situations, where it can be considered to be an important quality factor of care. Special emphasis is laid on questions of terminal cancer care. Physicians' decisions were studied by cross-sectional and prospective questionnaire surveys and by a prospective clinical study. In the surveys, presenting scenarios entailing ethical dilemmas in terminal care this study was intended to clarify the impact of physicians' personal background factors and education on their decisions. In the prospective study, the decisions and clinical practice in pain treatment were the focus of interest. This involved comparison of the quality of terminal cancer pain control between two different levels of health care.

## 2. Review of the literature

### 2.1 End-of-life care

#### 2.1.1 Definition of end-of-life care

Up to the 19<sup>th</sup> century, most medical care related to the amelioration of symptoms while the natural history of the disease took its course toward either recovery or death. During the last century medicine was largely orientated to a search for root causes and ultimate cure, while therapy directed at symptoms was denigrated and dismissed as merely symptomatic. During recent decades, the hospice movement can be seen as one reaction against this trend. Misery and suffering call for immediate attention while the long-term search for basic cures proceeds. Both old methods of care and the best of modern medicine had to be addressed to the task of new study and therapy of pain. The concept “pain” is thus today interpreted to denote a whole spectrum of suffering (Wall 1986).

Expressions for end-of-life care have varied during the last decades. The term **hospice care** is widely used for the work in hospices in the “Hospice Movement”, which began in the late 19<sup>th</sup> century. The modern hospice movement has its model in St. Christopher’s Hospice in London, established by Cicely Saunders in 1967. Characteristic of hospice care was originally that care was administered in separate buildings, not in hospitals. The hospice care approach spread out of inpatient units first in North America, where home care units were introduced, with team work and volunteer help. The term “**hospice medicine**” is also often used for medical care in the hospices (Saunders 1998).

The term **terminal care** has also been widely used during the last decades, and many consider it a euphemism for hospice care or the care of the dying. In Finland the first guidelines for physicians were given in 1982 using this term: “Guidelines on terminal care”. Also in the Oxford Textbook of Medicine 1983, a chapter dealing with end-of-life care was titled “Terminal care “ by Cicely Saunders. This term has, however, recently been criticized for its vagueness and ambiguity. Does it refer to the last days, weeks or even months of life?

Could it possibly be applied to the time when goals changed from cure to care? Many also think that there is a still greater problem in the implied negativism and passivity of the term. “Terminal” suggests to many that all is finished, there is neither time nor possibility to do more. This association is one important reason why the latest books on end-of-life care prefer term “palliative” to “terminal” (Doyle et al. 1998).

In 1975 the Palliative Care Service in The Royal Victoria Hospital, was opened in Montreal. It was the first center to use the term “palliative”, and to start practising in hospital settings. Subsequently **palliative medicine** has expanded rapidly; today palliative units are attached to an increasing number of modern university hospitals. According to the *Oxford English Dictionary* to “palliate” means, amongst other things, to mitigate, to alleviate, to lessen pain, to give temporary relief. A useful definition for palliative medicine is that adopted in Great Britain in 1987, when palliative medicine was recognized there as a medical speciality. Accordingly “palliative medicine is the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is the quality of life (Doyle et al. 1998). This definition applies to palliative medicine as practised by doctors. When describing the care offered by a team of doctors, nurses, social workers and volunteers it is more correct to refer to **palliative care**, a useful definition of which has been suggested by the WHO (1990): “The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anticancer treatment.”

### *End-of-life care in Finland*

In Finland one important mile stone was the publication of guidelines for terminal care by the National Health Board in 1982. The first hospice in Finland (and in Scandinavia) was founded in 1987 in Tampere. The first Chair in palliative medicine in Finland was donated to the University of Tampere in 1999. Special competence in pain management was

established in 1998, but palliative medicine has not achieved a separate speciality position. The establishment of Societies for Palliative Medicine (1995) and Pain Research (1996) have both made for increased education and research in palliative care and palliative medicine. In Finland primary health care is organized by a comprehensive health center system. Most health centers have GP-managed wards, which take much of the responsibility for end-of-life care, especially for the elderly.

### **2.1.2 Ethical issues in end-of-life care**

Ethical issues in the end-of-life phase are focused on the decisions, which will enable doctors and other professionals to satisfy the criteria for a peaceful death, dignified and assisted by a helpful society well qualified to discharge this duty. In moral questions religion formerly had the predominant role in most cultures, and what was right or wrong was more easily found. Currently we live in secular and constantly changing societies with little absolutism. The field of bioethics is also influenced by an explosive growth of information giving an extraordinary range of options in situations where previously few existed. “Now moral decision may seem less secure as new perspectives on medicine appear and new options to interfere with the life cycle have taken place” (Roy and MacDonald 1998).

The perspectives in palliative care ethical issues have been categorized by MacDonald as follows (MacDonald 1994):

- \*competence
- \*communication with health professionals
- \*confidentiality
- \*cultural sensitivity
- \*dual ethical standards
- \*education of health professionals
- \*euthanasia and physician-assisted suicide
- \*life-prolonging therapy
- \*research
- \*responsibilities of health professionals
- \*resource allocation
- \*standards of care
- \*withholding or withdrawing of therapy
- \*unorthodox therapies

The terminal patient has a right to assume that the care he or she is receiving is **competent**; this is of prime importance in the case of symptom control and ethical decision-making. However, recent surveys, using pain as an index problem, indicate defects in physicians' basic knowledge of pain, in pain education and in pain treatment (Von Roenn et al. 1993, Cleeland et al. 1994, Larue et al. 1995, Vainio 1995). The professional's competence in palliative care is also considered to consist relevant attitudes to end-of-life care. To ensure competence, **education of health professionals** in palliative medicine at all levels of medical training is fundamental. A central component in a competent care is adequate assessment of symptoms and evidence-based treatments, but also knowledge of ethical aspects and jurisdiction. Publication of guidelines also serve this goal (MacDonald 1993, Snyder and Swartz 1993, MacDonald 1994, British Medical Association 1999).

**Clinical ethics** is an issue involving questions of the doctor's clinical everyday bedside work and decisions. Knowledge of the patient's body and biography constitutes the basis for clinical ethical decision-making. The essential point is consideration of the patient as a person like any other; this can be regarded as the main principle in personal care (Fried 1974). The thesis that clinical ethics is a doctor's business does not mean that the doctor alone decides what is best for the patient. On the contrary, a clinician must seek contributions from team members, patients, and families. This implies that health care professionals should have adequate **communication** skills to inform and discuss the patients and families, so that they are able to make logical choices (Buckman 1998). Good communication also entails good access to all available information for the patient and family.

*“What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about”*

*Oath of Hippocrates*

The oath of Hippocrates remains relevant in today's ethical thinking on **confidentiality**. Modern medical ethical principles and Western trends of thought value highly the principle of autonomy. The duty to protect confidentiality binds not only the physician in charge of the treatment of the patient; this duty extends to all other members of the clinical team. Confidentiality also extends to research, where the patient should be always asked for informed consent. The right to privacy and confidentiality of information should be respected in clinical trials (Gostin et al. 1993).

**Cultural differences**, including religion, have great influence on the attitudes of patients and physicians end-of-life questions (Neuberger 1998). In an American survey of four different ethnic groups (n=800), people of European-American background were least ready to accept life support compared to African-Americans, Mexican-Americans and Korean-Americans (Blackhall et al. 1999). Japanese doctors tend to make more decisions to continue life-sustaining treatments for terminal patients than do American doctors (Asai et

al. 1995; Asai et al. 1999). Chinese doctors for their part adhere more to family's wishes compared to American doctors (Feldman et al. 1999), this also reflecting differences in culture. On the other hand, American doctors evince a higher level of legal defensiveness than Danish doctors (Van MacCrary and Swanson 1999). Catholics (Vincent 1990, Vincent 1999) and blacks (Mebane et al. 1999) are generally more in favour of continuing life-prolonging treatments in the terminal phase. Cultural sensitivity should be respected in end-of-life decision-making, and is also a great challenge for communication skills.

The concept **dual ethical standards** includes problems such as confrontation of business and medicine (MacDonald 1994). For example medical companies may have opposite goals for drug use to those of cancer patients, their families and care-givers. Such may be the case with the recently introduced cytotoxic drugs for palliative treatment in advanced cancer; a dilemma can be seen in the contradiction between the advantages of a few extra months of life and the huge costs and extra suffering caused by the treatments.

On the other hand, should hospital and health care institutions be expected to demonstrate that they maintain an acceptable **standard of care** and competence? Has a dying patient the right to expect care on a commonly accepted level? The clinical and organizational audit in palliative care aims to improve care for patients and families by assessing whether we are doing the right thing the right way (Higginson 1998). This also includes the problem of **unorthodox therapies**. On the one side, recognition of the patient's autonomy and free will supports the idea of receiving the treatment he or she wants, even against the physicians' advice. But has the physician the right to abandon a patient who does not follow the academic medical path? On the other side, where is the limit to ethically accepting charlatans who exploit the patient's ignorance and look for their own advantage?

This leads to the question of the **responsibilities of health care professionals**. In the past it was clearly a health professional's responsibility to treat the needs of the patient as the highest priority, while other responsibilities were clearly secondary. In today's complex society these responsibilities raise questions; what are the responsibilities of the health



professional to family, institution of work, society at large, this including economical responsibility, and finally to the care giver's own family?

**Research on dying patients** involves specific factors to be taken into account. In research where the objective is to improve the patient's quality-of-life, the risk of causing harm is low (Kodish et al. 1992). If however the patient is asked to participate in a trial of a new drug, e.g. to establish the tolerable dose, the chance of benefit for the patient is small. In such cases ethical dilemmas arise, since in many cases patients do not fully understand the rationale of the trial (Daugherty et al. 1995). The vulnerability, both physical and mental, of this patient group is also one justification for special concern; special protection by the care givers is needed. The competence of patients to give informed consent is a matter of particular concern at the end of life. The incidence of dementia and delirium is increased, producing defects in cognitive function (Bruera et al. 1993). Generally the clinical instability of physical and mental condition, decreased performance status and increased age set their limits for clinical studies, too (Roy and MacDonald 1998). Questioning research in terminal care has also been criticized in that it adds burdens of its own, conflicting with the aims of care and the doctor-patient relationship and even constituting an affront to the dignity of people who are terminally ill (Cassell 1991).

In support of research in palliative care it is often mentioned that the purpose is one key in ethical discussion. If the investigator's main purpose is to produce generalizable knowledge, then secondary benefits potentially accruing to investigator are ethically acceptable. Informed consent, if freely offered, resolves many ethical problems. Here the patient is given a possibility to make a contribution to the common good.

Most people accept the principle that interventions to relieve human suffering are to be given priority in medicine (Hadorn 1991). However, **resource allocation** is seen to fail to match this moral principle. One explanation for this is that substantial funds are already being spent on dying patients. The costs of treating patients are heavily concentrated towards the last year of life, with much of the expenditure devoted to institutional care (Lubitz and Riley 1993). Another explanation may be that being formally a relatively new

area medicine it may wrongly be considered to be no more than another special advocacy interest.

Many physicians addressing end-of-life questions consider that programmes in palliative care would even reduce total costs of health care by cutting down expensive futile treatments and on the other hand increasing the ratio of quality of care achieved by the money spent. However, evidence for these conclusions is still awaited (Emanuel 1996).

### *Withdrawing and withholding LST*

The core principles in medical ethics date from Antiquity and are commonly called “beneficence” and “nonmaleficence”. In end-of-life situations the physician should be able to weigh the benefits of treatments, planned or already started, in a wide context; in the light of the patient’s overall good. Decisions to withhold or withdraw a treatment have been made since the times of Hippocrates, who acknowledged the limitations of the art of medicine. Treatment must sometimes be forgone to avoid harm (*primum non nocere*). The World Medical Association states that it is right to let the natural process of death follow its course in the terminal phase of sickness (See 2.3.1 p. 39). “Although saving lives always has been, and will ever remain, a primary goal of clinical practice, life-prolonging procedures may result in little more than a stretching out of the dying curve or the extension of an unbearable and miserable life. Over the last decades there has been growing debate on the right of medical care to extend life to the bitter, biological end” (Roy and MacDonald 1998).

In this consideration the point lies, not in aiming to end patient’s life but in aiming to end futile treatment. Particularly this consideration is relevant if such treatments mean that the patient finds the physical, emotional and personal costs involved hardly bearable. A trend has developed over the last decades away from the ethic of prolonging life at all costs towards an ethic of emphasizing the quality of life and of dying when it is the “natural” time. This strong preference for the quality of the final days instead of their number in end-of-life decision-making is still not uniform and no consensus has yet been reached (Council

on Ethical and Judicial Affairs of American Medical Association 1992, British Medical Association 1999). Numerous court cases, often called “right-to-die”, and wide professional and public discussion on the subject have, however, gradually processed the common opinion to change the treatment pattern in a more conservative direction.

Certain important principles are prominent in the debate on this item. **The patient’s autonomy** is mostly considered to be the leading principle. “The will of the patient, not the health of the patient, should be the supreme law” governing decisions on initiating or discontinuing life-prolongation measures (Cassem 1980). There are, however, significant cultural differences of attitude to this issue. American doctors are more willing to issue DNR orders according to the patient’s consent than do their British colleagues (Mello et al 1998). In Japan the family’s, not the patient’s, will often dictates decisions (Asai et al. 1997). Chinese physicians are considerably more prone than their American colleagues to prefer the family’s will than the patient’s (Feldman et al 1999). In clinical practice it is not always easy to obey the principle of autonomy. People can generally agree on the justification of abandoning life-prolonging procedures when the patient is irreversibly unconscious. If the patient is conscious, intelligent and lucid, however, discontinuing respiratory support, antibiotics or parenteral nutrition is much more difficult.

One other important argument is that **benefits should be proportionate to burdens** (Cassem 1980), the basic idea in medical ethics. There is also general agreement that patients are not obliged to undergo and physicians are not obliged to offer, begin or maintain, treatments which are futile (The Hastings Center 1987, Stanley 1992).

**Futility of treatment should be assessed according to its clinical goals.** For example, antibiotics may treat pneumonia in an irreversibly unconscious patient. If the goal of the treatment is to restore the patient to an even slightly better intellectual capacity, the treatment is indeed futile. Thus treatment may be futile for the objectives of care even if it has clear medical effects. A treatment can also be futile in having no more evident effect in the terminal situation (e.g. chemotherapy in the late metastatic stage of a disease) (Roy and MacDonald 1998). On the other hand, the concept of futility of care has lately been

criticized as too easily constituting justification for unilateral withholding or withdrawal of treatment of marginal benefit (Council of Ethical and Judicial Affairs 1999, Dunphy 2000). Futility of care cannot be assessed by categorized terms but needs evaluation of great number of aspects in each individual situation.

Although emotionally it may be easier to withhold than to withdraw treatment which has been started, there are neither legal, nor according to most bioethicists, morally relevant differences between the two actions (Force 1991, Snyder and Swartz 1993, British Medical Association 1999). However, many doctors maintain that, compared to withholding a treatment, withdrawing a treatment already introduced is more often wrong both ethically and legally (Solomon et al. 1993). In a prospective study by Ferrand and associates in France (2001) to 7309 ICU patients it was found that 53% of deaths were preceded by a decision to withhold or withdraw life-support therapies. A major difference was found in the outcomes of patients according to the type of decision taken; withholding without withdrawal of life-support therapies was associated with mortality of only 56%, compared to a mortality of more than 90% after withdrawal decisions. This difference was explained by the fact that the group for whom withdrawal decision were taken were in more severe conditions. Withdrawal decisions are known to be undertaken less often than withholding (Faber-Langendoen and Bartels 1992, Vincent 1999).

Wide variation has been found in the attitudes of physicians in respect of specific types of treatments to be forgone. In a survey by Chirstakis and Asch (1993) for internists (n=481) the life-sustaining treatments most probably forgone were blood products and hemodialysis, the least probably tube feeding and IV fluids. A prospective study (n=211) by Asch and colleagues (1999) proved that this ranking also takes place in clinical practice. Physicians are known to withdraw forms of therapy supporting organs which have failed for natural rather than iatrogenic reasons, and also more often recently instituted rather than longstanding interventions (Christakis and Asch 1993). Of specific treatments, intravenous hydration is known to be one least readily withdrawn (Christakis and Asch 1993, Pijnenborg et al. 1995, British Medical Association 1999), probably because it is emotionally difficult to “let the patient thirst”. In a study by Burge, 52 terminally ill palliative care patients were

surveyed, and no association was found between severity of thirst and fluid intake (Burge 1993). According to Sarhill and associates (2001) careful clinical assessment and laboratory tests are needed for an adequate decision as to the type and amount of hydration. However, these investigators conclude that ethical principles govern decision-making on terminal hydration at the end-of-life (Sarhill et al. 2001).

Oral nutrition forms part of basic care and should not be withdrawn (British Medical Association 1999), and in some cases also parenteral hydration, for instance in the form of hypodermochlysis, means significant relief of patients' symptoms and thus constitutes good palliative care (Huang and Ahronheim 2000). Overall, there is still little evidence to guide physicians in the matter of fluid provision for dying patients (Burge 1996).

Attitudes to withholding and withdrawal of life support have been shown to have changed towards greater approval during the last few years. In a retrospective chart review by McLean and group there was a significant increase in the proportion of doctors who had withdrawn life support in Canadian ICUs from 1988 to 1993; in hospital A from 43% to 66% and in hospital B from 46% to 80% (McLean et al. 2000). The difference between the hospitals was significant ( $p < 0.05$ ), also revealing the importance of regional difference in decisions.

#### *Guidelines and legislation on withdrawing LST in Finland*

The National Board of Health defined terminal care in 1982 as "treatment provided to a patient at a stage where it is no longer possible to improve the prognosis by using the methods or treatment available as well as treatment when death is nearing". It is devised to meet all the patient's physical, psychological, spiritual and social needs. According to the guidelines it is the duty of the physician in charge to decide, on the basis of professional expertise and experience, when to withdraw life-sustaining treatment and to proceed to symptomatic care of the terminally ill (National Board of Health 1982). The current ethical guidelines of the Finnish Medical Association (Suomen Lääkäriliitto 2000) underline that life-prolonging treatment can only be withdrawn when the patient's disease is incurable and

death is inevitable. On the other hand, it is clearly stated that a decision to withdraw intensive care can be made on the same criteria as a decision to withhold it.

In Finnish legislation on the patient's right to self-determination from the year 1993 the patient's autonomy is defined to mean that the patient's consent is required as a precondition for treatment to be lawful and that the patient has the right to refuse any intended treatment or procedure or to discontinue any treatment already started (Pahlman 1997). The patient's refusal also applies to treatments whose withdrawal may lead to death, disability or severe illness. This legislation would already seem to have greatly changed Finnish doctors' attitudes and practice patterns in ethical decisions.

### **2.1.3 Symptom control in palliative care**

In terminal care, most subjects suffer from pain, and there is also a high frequency of other symptoms such as fatigue, dyspnea, nausea, dryness of mouth and problems of skin. In a study by Walsh and colleagues (2000) analysis of one thousand patients with advanced cancer revealed that the median number of symptoms was 11 (range 1-27); pain was most common (84%) and proneness to fatigue, weakness, anorexia and lack of energy next (69%, 66%, 66%, and 61% respectively). Psychological distress and also spiritual anguish are well known and processed problems. The patient's expression "pain" is often found to be a combination of many of these symptoms. The concept "spiritual pain" is nowadays also often used. Symptom control in palliative care concentrates on assessing the symptoms and separating them from each other and giving the best possible relief to each.

#### **2.1.3.1 Pain control in palliative care**

Half of all cancer patients are known to report moderate or severe pain, even in palliative care centers (Zhukovsky et al. 1995, Vainio and Auvinen 1996). It is commonly accepted that the most important task of palliative medicine in the terminal stage is symptom control, relief of pain in particular. Frequent and comprehensive assessment of symptoms is an

integral part of the management of cancer pain (Portenoy and Lesage 1999). In addition to analgesic drugs, many other effective approaches are to be considered in planning for good pain control. Especially radiation therapy often affords simple, efficient and well tolerable pain control for long periods. No patient should have to endure intense pain unnecessarily, and this is especially true in the final stages of any disease.

The consumption of pain medication, particularly strong opioids, has often been considered to be one significant indicator of the quality of PM (Vuorinen et al. 1997). There is considerable national variation in total opioid use. Finland belongs to a group of countries where the consumption of strong opioids is relatively low. In a Scandinavian comparison, Finland ranks last; consumption here is only one-tenth of that in Denmark (International Narcotics Control Board 1998), for instance. The low consumption of opioids in many countries is often explained by reference to opiophobia, which has its origins in strict regulations on opioid administration (Vainio 1992, Mercadante 1999). Other factors possibly acting against adequate use of these drugs in many countries include fears among physicians of the well-known side-effects of opioids, including possible addiction problems and the double effects of morphine in the terminal stage (Vainio 1992, Solomon et al. 1993, Buchan and Tolle 1995). Negative attitudes among cancer patients and their families in the case of morphine and analogs as a “last resort” have no doubt also contributed, as well as the fear for losing self-control.

Recent research and education in PM has probably helped to allay some of these unnecessary fears: according to the International Narcotics Control Board, the legal consumption of morphine in most Western countries has increased up to seven-fold during the past two decades. This is mainly due to the increased use of morphine in chronic cancer pain (International Narcotics Control Board 1998). In a survey conducted among Finnish physicians, the mean daily dose of opioids suggested for severe terminal cancer pain expressed in corresponding intramuscular morphine doses rose from 39 mg (1985) to 72 mg (1995) for a similar patient case. (Vainio 1992, Kaasalainen et al. 1997). On the other hand, questionnaires may draw too optimistic a picture of the situation. In a retrospective study carried out in a Finnish general hospital in 1994, medical records showed that only 28 % of

patients received strong opioids during the last week of their life (Vuorinen et al. 1997). The mean administered dose was 43 mg parenteral morphine, much less than in the hypothetical scenarios.

The costs of health care are rising rapidly all over the world, and the question of expansive treatments in end-of-life care is one of the key topics in medical ethics (Chochinov and Kristjanson 1998, Weiss 1999). However, adequate pain management in terminal cancer is almost always possible by means of common and relatively cheap medication without expensive invasive procedures such as intraspinal routes or nerve blockades (Cherny et al. 1995). A study of Grant and associates (1995) examined the impact of a system of interventions focusing on pain management. The interventions involved a supportive care consultation team and a pain resource center for nurses and families. The researchers reported a reduction in admissions from 255/5772 patients (4.4%) to 121/4076 (3.0%), with estimated cost savings of \$2,720,000.

During recent years several new opioid preparates have been introduced, making administration easier and more comfortable for the patient, even though they are sometimes more expensive (Sloan et al. 1998b). They also allow greater freedom in switching from one opioid to another in the case of poor efficacy or treatment-limiting side-effects (opioid rotation) (de Stoutz et al. 1995, Donner et al. 1996). Even the new, “expensive” fentanyl patches can be considered good value in view of the ease of care and the potential reduction in hospitalization time.

#### **2.1.4 Education and training in palliative care**

Parallel to development of palliative medicine, the question of adequate training in this area has come to the fore (Doyle 1996). The need for both under-graduate and post-graduate training has been shown in a number of studies (Vainio 1988, Boisvert and Cohen 1995, Zech et al. 1995, Zhukovsky et al. 1995, Sloan et al. 1996, Kaasalainen et al. 1997, Oneschuk et al. 1997, Sloan et al. 1997). Much attention has been put on the fact that **pain control** of terminal cancer patients is still often insufficient and uneven. This is considered



to be due to inadequate assessment and management of cancer pain by physicians, regardless of years in practice. Also doctors' ability to assess **other symptoms** as well as the psychological and spiritual needs of the terminal cancer patient have been shown to vary greatly among physicians (Sloan et al. 1996, Grande et al. 1997).

The role of patient-doctor **communication** has been seen to be of utmost importance in the effort for good symptom control; patients and families have singled out good communication as the first aspect to be improved in terminal care (Hanson et al. 1997). Practising physicians have also self-evaluated their skill in PC as insufficient and expressed their need for continuous training (Wakefield et al. 1993, Lloyd-Williams and Lloyd-Williams 1996).

A number of studies have shown the benefit of training projects in promoting the knowledge and skills of physicians (Elsay and McIntyre 1996, Mercadante and Trizzino 1997, Oneschuk et al. 1997, Sloan et al. 1998a, Schuit et al. 1999). However, palliative care involves much more than specific skills and knowledge of symptom control. It is a unique branch of medicine with holistic challenges in the patient's quality of life (Doyle 1996). Educational attempts to develop the quality of palliative care should not ignore, that personal attitudes, life-values and beliefs have a marked influence on the physician's work in palliative care, especially on **ethical decision-making**. Post-graduate education in palliative care has proved to have a significant impact on the attitudes and decisions of physicians in terminal care. In a study by Linder and colleagues the attitude of physicians (n=139) to recommending hospice care, understanding the aims of palliative care and understanding the concerns of the dying patient were self-assessed to have improved markedly during the education ( $p < 0.001$ ) (Linder et al. 1999). In a prospective study of Sekkarie and Moss (1998) among nephrologists (n=27), education on ethics and legislation made for an increase in readiness to withdraw dialysis ( $p < 0.009$ ).

## **2.2 Decision-making in end-of-life care**

### **2.2.1 Legislation, ethical guidelines and directives**

#### **2.2.1.1 Legislation and guidelines**

Physicians' decisions in ethically complicated situations rest in first place on the law. Observance of a clear statement in law gives the doctor protection both legally and mentally in difficult situations. The most popular example here is legislation on euthanasia. In spite of doctors' various personal opinions on euthanasia the practices are predominantly according to law, with the well known exception of the Netherlands prior to the very recently reformed euthanasia legislation in the country (Weber 2000). However, compliance with legislation confirming the patient's rights in less dramatic contexts such as the right to information or the right to good quality health care (The Act on the Status and Rights of Patients, Finland 1993) may be more easily neglected. It has to be remembered that physicians' awareness of actual legislation varies, and legal myths about end-of-life care can undermine good management and ethical practice. Up-to-date knowledge of the legislation is crucial; for instance in the USA the physicians have to know the specific law of the state in which they practise (Meisel et al. 2000).

In many cases, however, end-of-life decisions cannot be made by obeying simple precepts of law. This applies especially to decisions to withhold or withdraw a treatment (British Medical Association 1999). It is more often a matter of obeying ethical and moral principles, choosing between two bad options the less harmful one. In such decisions guidelines are helpful. Guidelines are given both by international (WHO, World Medical Association) and national organisations (national medical associations, boards). The purpose of general guidelines is manifold. On one hand they give physicians written support on which to lean in ethical decisions, and on the other they give patients a better possibility to obtain appropriate treatments and decisions. Without clear guidance, the public may feel that different standards are being applied in similar cases, while doctors do not necessarily have any yardstick by which to audit their own decisions. General guidance can also

stimulate the development of local policies and guidelines as part of a wider network of safeguards for doctors and patients (British Medical Association 1999, Suomen Lääkäriliitto 2000). The recently published guidelines from the British Medical Association: “Withholding and Withdrawing Life-prolonging Medical Treatment, guidance for decision-making” is a good example of a compact, practical guide in everyday ethical problems. The guide-book first gives good definitions of issues which are important for the subject, for example the competence of the patient. It informs on the essential medical, legal and ethical factors to be considered. By using clinical examples the book keeps thinking on a very practical level. The importance of communication and support for the patient are handled as well as the importance of recording and reviewing decisions (British Medical Association 1999).

#### **2.2.1.2 Advance directives**

More patients are nowadays taking an active role in their own health care and have clear views on what treatment they would or would not wish to be given (British Medical Association 1999). Many people are afraid that once they are no longer capable of giving their opinion, life-prolonging treatment might be continued long after it can result in any recovery. Commonly advance directives consist specifically in advance refusals of treatment, including life-prolonging treatment. These directives are often presented as formalized written documents, but it is not legally necessary for refusals to be in writing in order to be valid. On the other hand, for an advance refusal to be valid the patient must have been competent when the directive was made, acting free from pressure and having been offered sufficient, accurate information to make an informed decision. A valid advance directive has the same legal authority as a contemporaneous refusal and legal action could be taken against a doctor who provides treatment in the face of a valid refusal (British Medical Association 1999, Suomen Lääkäriliitto 2000).

Doctors’ attitudes to advance directives are known to vary. In a study by Mebane and colleagues (1999), the race and age of the doctor (n=502) were predictors of attitude. One third of doctors reported that they had themselves carried out an advance directive, white

and old physicians significantly more often ( $p < 0.05$ ). In general, attitudes supporting advance directives for patients were less often positive among older black physicians (54%) than among young black physicians (66%) or white physicians of any age ( $p < 0.05$ ). In a retrospective study of Hanson and Rodgman (1996) of data on 16678 decendants 10% were found to have had a living will. Deceased persons with living wills did forgo specific treatments such as cardiopulmonary resuscitation or ventilatory support almost two times more often, but remained intensive users of routine medical services. They were more often users of hospice services (20% vs 8%,  $p < 0.001$ ). In contrast, a prospective study of Danis and associates (1991) in a nursing home ( $n = 126$  residents), showed the effectiveness of written advance directives to be limited because of inattention to them and of decisions to place priority on considerations other than the patient's autonomy. An extensive controlled prospective study to improve care for seriously ill hospitalized patients (SUPPORT) ( $n = 4804$ ) in the US, in which an intervention took place to facilitate advance care planning, revealed a lack of effect of advance directives on decision-making (The SUPPORT Principal Investigators 1995). In a subsequent study of Teno and group (1997) in the same population it was found that advance directives often did not guide medical decision-making beyond naming a health care proxy or documenting general preferences in a standard living will format. Even if specific instructions were present, care was potentially inconsistent in half of the cases. When comparison was made of patients' and health care professionals' attitudes (Blondeau et al. 1998) physicians were found to have less positive attitudes towards advance directives than patients. Physicians were also least ready to consider advance directives important in expressing the patient's autonomy. Criticism has been addressed to advance directives in the claim that they impose an additional control which is not useful in terms of medical practice. In interfering with professional action they can call the physician's judgements in question (Zinberg 1989). However, in a qualitative study of Pfeifer and colleagues (1994) among primary care physicians ( $n = 43$ ), most physicians regarded advance directives as "icebreakers" for starting discussions, even if of limited utility otherwise.

### *Advance directives in Finland*

In spite of the existing guidelines and legislation, Finnish authorities have seen a need to produce a standard form on which patients can record their advance wishes, certified by two witnesses. Patients are not, however, obligated to use this form but can record their wishes in any way they please.

The former concept of “living will” (hoitotestamentti) has increasingly given way to the narrower concept of “advance directive” (hoitotahto), the latter term being used to refer to a person’s (written) expression of will with regard to his or her future, hypothetical treatment and/or general line of treatment. The concept has its legal foundation in the right of a competent person (as understood in the Patients’ Rights Act) who exercises his or her right of autonomy, to refuse all intended or ongoing treatment upon receiving adequate information or refusing to take in this information.

The directives are legally binding upon doctors and other health care professionals (Pahlman 1997), and they always take precedence over the views and opinions of the patient’s legal representative, relative or close friend. So far there have been no appeals or court cases in Finland in which the validity of an advance directive has been put to the test.

The Finnish Medical Association’s ethical guidelines regarding the validity of advance directives are based on the Act on the Status and Rights of Patients (Suomen Lääkäriliitto 2000). The guidelines state that according to this enactment, patients’ written directives regarding medical treatment can be regarded as binding documents.

#### **2.2.1.3 Do-not-resuscitate orders**

In many countries orders to withhold cardio-pulmonary resuscitation (CPR) in a case of cardiac arrest do-not-resuscitate (DNR) orders have been given. The ethical basis for these rules is what is “in the best interests of the patient”. Many studies have shown that the outcomes of CPR are poor; especially with terminal cancer patients CPR nearly never leads

to survival for discharge from hospital (Faber-Langendoen 1991). A further justification for these orders lies in the fact that clinicians already make decisions to withhold resuscitation according to a range of personal principles, in which they have considerable discretion (Doyal and Wilsher 1993). The diagnosis of a patient has been shown to exert substantial influence on physicians' CPR decisions; patients with AIDS or cancer are much more likely to be the subject of DNR orders than patients with cirrhosis or severe congestive heart failure (Wachter et al. 1989).

DNR orders are considered to require clear evidence that a) the patient is irreversibly close to death in the short term or b) resuscitation involves an unacceptably high probability of death or severe brain damage if the procedure is successful (Doyal and Wilsher 1993). The order is in most countries submitted to a senior doctor's decision.

A study of Stern and Orłowski (1992) has shown that the introduction of DNR policies in an intensive care unit reduced the resuscitation attempts for hopelessly ill patients from 52% to only 3% of cases ( $p < 0.0001$ ).

There is no legislation for DNR orders in Finland. The general ethical guidelines of the Finnish Medical Association provide support for advance care planning together with the patient and family (Suomen Lääkäriliitto 2000). Accordingly some health care units have compiled their own guidelines to help physicians in planning end-of-life care, including CPR.

### **2.2.2 End-of-life decision-making by physicians**

In the literature the majority of studies concerning physicians' end-of-life decisions have focused on intensive care units (ICU), where the ethical questions frequently arise and involve serious problems in terms of futility of care, health care economics and prioritization of treatments (Smedira et al. 1990, Hanson and Danis 1991, Molloy et al. 1991, Asch et al. 1995, Prendergast and Luce 1997, Ferrand et al. 2001). See Table 1. However, ethical dilemmas at end-of-life also arise far beyond ICU settings. Patients in terminal condition

with of incurable diseases like cancer, dementia or stroke are treated in local hospitals, hospices, nursing homes and, most important, at home. The afore-mentioned retrospective study by Hanson showed that community physicians use few life-sustaining treatments for dying patients, the long-term primary care relationships and living wills having great influence on decisions (Hanson et al. 1999).

Studies of end-of-life decisions by physicians are mainly of four different types:

- 1) questionnaire surveys
- 2) prospective studies
- 3) retrospective studies
- 4) qualitative studies

These different approaches hold different advantages and disadvantages. Questionnaire studies need less economic resources and more easily reach great numbers of physicians, thereby increasing the reliability of results (Carter and Thomas 1997). On the other hand, their reliability can be criticized in that questionnaire studies involve limitations affecting the generalizability of their results. Especially postal surveys always involve the risk of selection in the responses obtained; response rates in studies among medical doctors are generally low (Asch et al. 1997). It is also important to bear in mind that responses to hypothetical scenarios may be different from actual physician behaviour. Furthermore, in contrast to real situations, respondents cannot ask questions and receive answers to those questions when presented with scenarios. On the other hand again, in a survey situation respondents can make clear their views as to what would be academically or philosophically right, free from the pressures of the real actual situation.

Prospective studies may be considered to give more reliable information on physician's actual decisions rather than theoretical attitudes. However, they entail problems of control, especially if the study time is long. Such studies are expensive and time-consuming, which is why the study size tends to be small, even if there are a few very large prospective studies on end-of-life decision making (Smedira et al. 1990, The SUPPORT Principal Investigators 1995, Ferrand et al. 2001).

Retrospective studies often evince weakness in the quality of information on predisposition, while the prime advantage is the quickness of results. Qualitative studies with in-depth studies or semistructured interviews carry the advantage of obtaining deep insight into complex problems difficult to study by quantitative measures; they are often used rather for hypothesis generation than for testing hypotheses (Carter and Thomas 1997). Studies carried out on physicians' decisions and attitudes on withdrawing and withholding life-sustaining therapy (LST) are collected in Table 1.

The ethical complexities of end-of-life care are known to be mentally stressing for doctors. In a qualitative study by Saunderson and Ridsdale (1999) 88% of general practitioners (n=25) had felt guilty about issues relating to the death of patient, and Gillick (1988) showed that there is also much uncertainty among physicians as to the legal consequences of end-of-life decisions. In a study by Solomon and group (1993, n=687) 70% of house officers and 34% of surgeons considered they had acted against their conscience in providing too active care to the terminally ill, because of the influence of technological solutions on care. Studies also show that in fear of legal or social consequences doctors tend to make more active decisions for the patients than they would do for themselves in a similar condition (Carmel 1999, Mebane et al. 1999). On the other hand, in serious and stressing end-of-life decisions doctors may have a tendency to treat themselves or the family of the patient instead of the patient (Gillick 1988).

For individual and thorough decision-making physicians need communication; they must listen to all relevant parties and thoroughly investigate all options. Medical, ethical, legal and psychological aspects are all to be considered in the decision-making process (British Medical Association 1999). The survey by Bruera and group (2000) to palliative care physicians (n=228) showed that **communication** is influenced greatly by culture. While 93% of Canadian physicians stated that at least 60% of their patients wanted to know about the terminal stage of illness, only 18% of South-American and 26% of European physicians reported thus ( $p<0.001$ ). Physicians do, however, underestimate patients' and families' willingness to end-of-life discussions. In a qualitative study of Pfeifer and associates (1994)



primary care patients (n=47) preferred end-of-life discussions earlier and with greater honesty than physicians perceived, and wanted more focus on outcomes. Primary care physicians (n=43) considered their roles in end-of-life discussions in five major categories: lifesaver, neutral scientist, guide, counsellor and intimate confidant (Pfeifer et al. 1994). In a survey by Johnston and Pfeifer (1998) (329 patients, 272 physicians) the patients preferred a more active role for physicians in both decision-making and discussion of end-of-life care than did physicians themselves.

**Guidelines** have been written to help physicians in the difficult dilemmas of end-of-life care (Snyder and Swartz 1993, British Medical Association 1999). However, these guidelines cannot give direct and simple advice for individual cases; often the doctor has to consider the situation by reflecting it against his or her own life-values and concepts of good life quality. Wider consultation, including second opinions, should be sought where the treating doctor has doubts about a proposed decision (British Medical Association 1999). However, decisions are often made in short time schedule and even in critical situations, without the possibility for consultation with a colleague or communication with the family. Especially in these cases personal characteristics of the doctor, for example age, race, gender, family status, life values, religiosity or experiences of severe illness in his or her own family, may play an important role in the decisions reached (Waddel et al. 1996, Mebane al. 1999).

Physicians are known to be greatly influenced by the **family's wishes and appeal** in their end-of-life decisions (Vincent 1990). In an evaluation of European intensive care physicians' end-of-life decisions (n=504) the family's strong appeal and wish "everything to be done" greatly changed treatment decisions in a more active direction in a scenario of a patient in postanoxic coma (Vincent 1999). This influence of family wish was greater if the physician was of religious disposition ( $p<0.05$ ). It also varied greatly between countries, physicians from the Mediterranean countries being most sensitive to the family's appeal ( $p<0.01$ ). The extremes were Greek physicians with 48% of doctors continuing full support in this case, and Scandinavian physicians with only 2% activity.

The **speciality** of the doctor has been found to exert a marked influence on physicians' end-of-life decisions. In an extensive nationwide retrospective study (n=5197) in the Netherlands general practitioners took fewer nontreatment decisions than hospital doctors and doctors in nursing homes (34%, 40%, and 56% of all dying patients, respectively)(Pijnenborg et al. 1994). In the same study there were significant differences (p<0.001) between specialists, cardiologists making fewest nontreatment decisions (28%) and surgeons the most (55%) (Pijnenborg et al. 1995). In a prospective study by Hanson and group (1996) physicians' (n=158) decisions to use or withhold life-sustaining treatments were analysed. Significant differences by speciality were seen; cardiologists were most willing to use life support, oncologists rarely. In a questionnaire study by a group under Waddell (1996) to Australian physicians (n=1588) there was also a significant difference by speciality in the attitude to active treatment in terminal illness. Active care was chosen by 58% of interns, 52% of GPs and palliative care doctors and by only 37% of other specialists (p<0.001). In the same study the **gender** of the physician also proved to be important, women being more active than men in choosing active therapy (51% versus 44%, p<0.01). Mebane and associates (1999) found that among US physicians (n=502) female doctors were also less willing to withhold tube-feeding (p<0.05). The influence of gender may be partly explained by life values; in a survey of Neittaanmäki and colleagues (1999) among Finnish doctors (n=1818) female doctors valued ideology as more important generally than male doctors. On the other hand, in a survey by Christakis and Asch (1995) among US internists (n=485) no gender difference was found in decisions on LST for critically ill patients. In this study the results for age were also opposite to those in the former study by Waddell; young doctors were more ready to withdraw life support. In the afore-mentioned survey by Mebane and group (1999), the **race** of the physician was also found to be a significant predictor of end-of-life decisions. Fifty-eight per cent of white physicians, compared to 28% of black physicians, agreed that tube-feeding in terminally ill cases is "heroic" (p<0.001).

Religion or religiosity is known to have a great influence on physicians' end-of-life decisions. Vincent (1999) found that European intensive care physicians (n=504) of

Catholic background were less likely to withhold ( $p<0.05$ ) or withdraw ( $p<0.01$ ) therapy than their Protestant or agnostic counterparts. Religious respondents were less likely than nonreligious to feel that they should sometimes administer drugs until death ensues ( $p<0.01$ ). Accordingly, in the above mentioned survey by Christakis and Asch (1995) physicians ( $n=485$ ) were less willing to withdraw life-support if they were Catholic ( $p<0.01$ ) or Jewish ( $p<0.05$ ), whereas in contrast religion had no significant influence on the decisions of physicians in an international survey of Molloy and group (1991).

Physicians' **age** and **experience** also have marked influences in end-of-life decisions and attitudes (Sjökvist et al. 1999). Experience in the physician's profession had a significant influence on end-of-life decisions in the survey by Waddell's group (1996) involving 1588 Australian physicians. Mainly supportive care for a patient in terminal illness was chosen by 62% of physicians qualified for over 21 years, compared with 48% of younger physicians ( $p<0.001$ ). On the other hand, according to Mebane's group (1999) younger physicians have more positive attitudes to advance care planning; scepticism toward future care discussion and documentation was significantly less common among young physicians ( $p<0.001$ ).

An interesting result was obtained in the prospective study by Kollef and Ward (1999) (501 patients, 113 physicians); private attending physicians made fewer decisions to forgo life-sustaining therapies in intensive care units than full-time critical care physicians. Also patients with underlying malignancies were less likely to undergo withdrawal if they had private attending physicians (32% vs 100%). These results can be explained partly by the greater experience of full-time critical care physicians in end-of-life questions; they are probably more comfortable in dealing with the issue of withholding and withdrawal of life support than physicians with less experience. However, the result also raises the question of the influence of economic factors on ethical decision-making; are rich people liable to receive more futile treatment and unnecessary suffering under the care of private doctors (Luce 1999)?

Table 1

**Studies on physicians' decisions and attitudes on withdrawing or withholding life-sustaining therapy (LST)**

<i>Author</i>	<i>Setting</i>	<i>Action studied</i>	<i>N</i>	<i>Main outcome</i>	<i>p</i>
<b>Prospective studies:</b>					
Smedira et al 1990	prospective, data of patients (USA)	forgoing LST in ICU	1719	45% of deaths preceded by decision to limit LST	
SUPPORT 1995	prospective intervention study (USA)	effect of enhanced patient-physician communication and better knowledge of prognoses on care of dying	4804	no significant changes in treatment outcomes	
Hanson et al 1996	prospective (USA)	influence of physician's speciality on using LST in end-stage diseases	158 (85%)	cardiologists were most active, oncologists most conservative	<0.001
Prendergast et al 1997	prospective (USA)	change in use of LST in ICUs	200/224	forgoing LST preceded death in ICUs: in 1987-1988 in 51%, in 1992-1992 in 90%	<0.001
Asch et al 1999	prospective, hospital patients (USA)	ranking of LST (willingness to forgo)	211	most likely: blood products, haemodialysis least likely: IV fluids, tube feeding	<0.0001
Kollef et al 1999	patients in ICU	influence of attending status of physician	501	private attending physicians less withdrawing LST	<0.001
Ferrand, E et al 2001	prospective, data of patients (France)	forgoing LST in ICU	7309	53% of deaths preceded by decision to limit LST	
<b>Retrospective studies:</b>					
Hanson et al 1991	retrospective, admissions to ICU (USA)	withholding of intensive care from elderly prior to death	9998	predictors: nursing home residence malignancy	<0.001 <0.01
Faber-Langendoen, K et al 1992	retrospective, data of patients (USA)	forgoing LST in ICU and hospital wards	70	74% of deaths preceded LST	
Ahronheim et al 1996	retrospective (USA)	hospital patients, died with diagnosis of dementia or cancer	164	more feeding tubes to dementia patients	0.02

McLean et al	medical chart review ICUs, 2 hospitals	withdrawal of LST in 1988 versus 1993	439	withdrawal of LST increase from 43-46% to 66-80%, difference between hospitals	p<0.05
<b>Questionnaire studies:</b>					
Molloy et al 1991	questionnaire, physicians (internat.)	activity of care in scenario of a terminal dementia patient	1160 (80%)	supportive treatment 8%, limited active care 42%, maximal care without ICU 32%, ICU 18%	
Christakis et al 1993	questionnaire, internists (USA)	ranking of LST (willingness to forgo)	481 (56%)	most likely: blood products, haemodialysis least likely: tube feeding, IV fluids	<0.0001
Solomon et al 1993	questionnaire, physicians (USA)	attitude to LST	687 (61%)	70% of house officers and 34% of surgeons considered having acted against conscience	<0.001
Pijnenborg et al 1994	death certificate study + questionnaire to physicians (Netherlands)	use of LST in deaths (all nonsudden)	5197 (76%)	GPs less for forgoing LST	
Asai et al 1995	questionnaire, physicians (Japanese, Japanese-American)	attitude on the use of LST in terminal cancer	213	Japanese more for continuing LST than Japanese-American (67% vs 33% for total parenteral nutrition for malnutrition)	<0.001
Asch et al 1995	questionnaire, ICU physicians (USA)	forgoing LST in ICU	879	34% continue LST against patient's or surrogates' wish, 83% unilaterally forgo LST	
Christakis et al 1995	questionnaire, physicians (USA)	physician characteristics associated with decisions to withdraw LST	485 (56%)	age, religion clinical experience, tertiary hospital	<0.05 <0.01
Pijnenborg et al 1995	death certificate study + questionnaire to physicians (Netherlands)	use of LST in deaths (all nonsudden)	5197 (76%)	nontreatment decision in 39% influenced by physician's speciality	<0.001
Waddell et al 1996	questionnaire, physicians (Austr.)	activity of care in scenarios	1588 (73%)	gender, religion, culture and speciality had all significant influence on decisions	
Asai et al 1999	questionnaire, physicians (Japanese)	attitude on LST for patients in persistent vegetative stage	200 (65%)	artificial nutrition and hydration forgone by 3% of physicians	

Carmel, S 1999	questionnaire, physicians (Israel)	use of LST in a metastatic cancer: practice for patients / wish for self	433 (78%)	less LST for selves than for old patients	<0.001
Feldman et al 1999	questionnaire, internists (internat.)	influence of culture on decisions on LST (US versus Chinese physicians)	40	Chinese physicians more often followed family's preferences than patient's (65% of Chinese, 5% of US physicians)	
Mebane et al 1999	questionnaire, physicians (USA)	tube feeding in terminally ill patients	502 (28%)	white more against than black (58% vs 28%) men more against than women (42% vs 29%)	<0.001 <0.05
Van McCrary et al 1999	questionnaire, physicians (internat.)	influence of law on decisions on LST (US versus Danish physicians)	363	less legal defensiveness by Danish physicians	p>0.001
Vincent 1999	questionnaire, European intensive care physicians	willingness to withhold or withdraw LST	504 (40%)	catholic physicians less willing to withhold catholic physicians less willing to withdraw (compared to protestants or agnostics)	<0.05 <0.01
Sjökvist et al 1999	questionnaire, physicians & nurses (Swedish ICUs)	attitude to the use of LST	850 (79%)	respondent characteristics affecting the level of care: years of ICU experience, the particular ICU in which the respondent worked	0.0001 0.0002
<b>Qualitative studies:</b>					
Asai et al 1997	focus group interview	attitudes to LST	7	Family's wish often overgo patient's benefit	
Pfeifer et al 1994	structured qualitative interviews	attitudes to end-o-life decision-making	43	Physicians' experienced roles: lifesaver, neutral scientist, guide, counselor, intimate confidant	
Mello et al 1998	interviews of physicians and nurses	decision making practices	34	British physicians made DNR decisions unilaterally American physicians sought more patients consent	

## 2.3 Euthanasia and assisted suicide

### 2.3.1 History, practices and legislation

The Ancient Greek philosophers Plato and Aristotle were strongly in favor of killing handicapped children, and terminally ill people were urged to commit suicide. Thomas More in his “Utopia” in 1518 advocated euthanasia in cases of chronic, incurable and painful diseases. In the 17<sup>th</sup> century the philosopher Francis Bacon stated that physicians should help their patients to get away easily in certain situations (Bacon 1958). At the beginning of the 19<sup>th</sup> century Carl Marx expressed criticism of physicians in his doctoral thesis “Medical Euthanasia”. In his opinion they were too much concerned with curing the disease and not the patient, and neglected him or her instead of doing something to help the dying. However, many of the acts Marx called “medical euthanasia” would today be called palliative medicine (Cane 1952, Roy and MacDonald 1998).

Adolf Hitler signed a secret document in 1939 which started an euthanasia project for the case of handicapped, disabled and mentally ill patients. Rumours about doctors being part of the project undermined trust in the whole profession, and even in today’s debate on euthanasia these burdens of medical history are often cited and probably still play a significant role in attitude formation (Roy and MacDonald 1998).

The World Medical Association and national associations express a strictly condemnatory attitude to euthanasia and doctor assisted suicide. The Declaration on Euthanasia: *“Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient’s own request or at the request of close relatives, is unethical. This does not prevent the physician from respecting the desire of a patient to allow the natural process of death to follow its course in the terminal phase of sickness”* (World Medical Association, 1987). The practice of euthanasia is illegal in most countries. One exception, widely known and discussed, is the Netherlands. Until the year 2000 euthanasia was there, too, still a criminal offence; the Dutch Supreme court in 1984 declared that euthanasia would be legally excusable if physicians found themselves in a conflict of duties involving a dilemma

between law and patient's request. The very recent decision of the parliament in the Netherlands (2000) to approve euthanasia in certain cases of terminal illness has again raised an intense debate on the subject (Weber 2000).

In Oregon in 1994 the Death with Dignity Act was approved by voters' support. There the doctor is not allowed to perform euthanasia directly, but by prescribing lethal medication to give help for terminal patients to advance their own deaths (Annas 1994). In Australia's Northern Territory voluntary euthanasia was legalized in 1995 (Ryan and Kaye 1996), but this was reversed in 1997.

### *Euthanasia in Finland*

There is no specific law on euthanasia in Finland, nor is the concept mentioned in any legislative enactment. The Criminal Code (revised in 1995) says: if a doctor were to kill a terminally ill and suffering patient who upon conscious and informed deliberation decided to ask to have his or her life taken, this act would in all likelihood constitute homicide (Kosunen et al. 2001). It would therefore carry a sentence of imprisonment. The ethical guidelines of the Finnish Medical Association likewise unambiguously condemn euthanasia. The Association does not accept active assistance under any circumstances, but says that "to kill a patient deliberately is in violation of medical ethics" (Suomen Lääkäriliitto 2000). The current act Concerning Health Care Professionals took effect in 1994. On the health care profession's ethical duties it stipulates: "Health care professionals shall commit themselves to maintaining and promoting health, preventing diseases, healing sick people and relieving their suffering".

Finnish legislation does not define assisting suicide as a punishable offence. In principle, a medical doctor can help a person commit suicide without legal consequences, but there is the obvious problem of how to distinguish between homicide on the one hand and assisted suicide on the other. Although the Criminal Code specifies no sanctions for assistance in suicide, the ethical guidelines for health care professionals take a different view: the Finnish Medical Association says in its guidelines that physicians must not help their patients to



commit suicide for instance by prescribing drugs for that purpose (Suomen Lääkäriliitto 2000).

### **2.3.2 Physicians' attitudes to euthanasia**

Euthanasia has been a topic of wide debate in medical ethics over recent decades. The subject is mostly a matter of principles and also often highly emotional. Religious tenets are among the most frequently used arguments against euthanasia, comparing euthanasia directly to murder. Euthanasia is less favoured by Catholic physicians compared to their Protestant colleagues (Di Mola et al. 1996, Emanuel et al. 1996). It is also less favoured by physicians practising in palliative care. In a survey of Di Mola and associates (1996) among Italian palliative care physicians only 6 % were for active euthanasia, compared with about 30% reported by studies on medical populations in general. Most palliative care professionals consider that good control of pain and other symptoms as well as caring for the patient's deepest needs in a holistic way make discussion of euthanasia unnecessary (Roy and MacDonald 1998).

Euthanasia also has strong advocates. One of the main justifications is the autonomy of the patient, which implies the right to decide when it is no longer tolerable to live. In endless suffering euthanasia constitutes the only solution. Empathy with the patient is also an important argument, as is doubt as to the possibilities of palliative care to relieve utmost suffering. It is also often mentioned that without the influence of modern medicine and medical technology, most suffering patients would die quickly without suffering (Brock 1992, Truog and Berde 1993).

Physicians of various medical specialities, nurses and the general public have been surveyed in several studies on their attitudes towards euthanasia (Davis et al. 1993, Kinsella and Verhoef 1993, Paume and O'Malley 1994, Stevens and Hassan 1994). In an inquiry among oncologists (n=355) and cancer patients (n=155) in the USA in 1996, the oncologists were markedly less in favour of euthanasia in a scenario of a terminally ill cancer patient with uncontrolled pain (23% versus 68%) (Emanuel et al. 1996). Both oncologists and patients

considered euthanasia most acceptable in the case of uncontrolled pain, least in the case of patients with controlled pain but having lost meaning for life. Being older, religious, especially Catholic, meant less ready acceptance of euthanasia. One notable result was that patients who had considered euthanasia for themselves were mostly depressive. Patients suffering pain were less for euthanasia or assisted suicide. This is parallel to the results of a study in the Netherlands; in only 10% of cases of euthanasia was pain the only reason (van der Maas et al. 1991).

### *Finnish opinions on euthanasia, assisted suicide and withdrawing LST*

In Finland the first survey on physicians' attitudes to euthanasia was made in 1993 with a postal survey involving a random sample of 500 doctors. The results showed that 5 % were in favour of legalisation with no reservations, 25 % in favour with some reservations. Almost one third were firmly against euthanasia and one fifth against euthanasia with some reservations.

In 1998 a major survey was carried out to compare the views and opinions of doctors, nurses and citizens. Five imaginary case reports were presented, attitudes to active euthanasia, passive euthanasia (withdrawing life-sustaining treatment) and assisted suicide were asked. In all cases, the population showed a more positive attitude towards euthanasia and assisted suicide than health care professionals. Negative attitudes were most frequently reported among doctors, who on the other hand accepted passive euthanasia clearly more often than other groups (Ryynänen OP, Myllykangas M, unpublished).

### 3. Aims of the present study

The aim of this study was to evaluate the influence of physicians' training, experience and personal characteristics on their opinions concerning end-of-life decisions, and to assess the quality of pain control in palliative care

The specific aims were:

- A) To assess the influence of physicians' training, experience and personal characteristics
  - 1) on ethical decision-making in terminal care between active and palliative treatment policies in general,
  - 2) on the choice between continuing and withholding or withdrawing specific life-sustaining treatments and
  - 3) on the choice between starting or withholding cardiopulmonary resuscitation in the case of a terminal cancer patient
- B) To assess the influence of a one-year interactive internet-based post-graduate course on physicians' decision-making and attitudes in terminal care,
- C) and to evaluate the quality of pain control, quantity and costs of pain medication in terminal cancer care, and compare this between health center wards and a hospice

## **4. Material and methods**

### **4.1 Questionnaire study (I-III)**

#### **4.1.1 Participants**

In May 1999 a questionnaire was sent to a stratified sample of 1100 Finnish physicians in the register of the Finnish Medical Association. The sample consisted of 300 surgeons, 300 internists and 500 GPs. In addition, the questionnaire went out to all Finnish oncologists (n=82). Reminders were sent in June and September. The final acceptable response rate was 63 % for GPs, 61 % for specialists in medicine, 58 % for surgeons and 68 % for oncologists. The mean response rate was 62 %, which is above the average for surveys among physicians (Asch et al. 1997). 59% of the responders were male. Altogether 730 acceptable questionnaires were included in the present study.

#### **4.1.2 Questionnaire**

A 12-page (40 questions, 119 variables) questionnaire was designed to study doctors' treatment decisions in ethically complicated situations in terminal care. Seven hypothetical patient scenarios based on clinical cases were presented, six of them terminal cancer patients and one a terminal dementia patient (Appendix). After each scenario the doctors were asked to choose from given treatment options. The influence of a treatment complication, family's appeal and advance directive on the decision was evaluated in two scenarios by giving alternative settings for the original scenario. Four scenarios (1,2,6 and 7) in the questionnaire are the topic of this study; the other three scenarios will be a topic for further studies.

In two scenarios, after asking the treatment decisions, a Likert-type scale was presented to evaluate the influence of different factors (patient's benefit, family's benefit, physician's legal protection, ethical concerns, patient age, cost of treatment, patient's social status) on the decision (from 1 very little effect to 5 enormous effect).

After the patient scenarios, the questionnaire continued with items concerning the physician's fear of death (set of 11 questions, Likert 1-5). A fear-of-death index was calculated by summing up the responses to four questions which were found to be most closely associated with the decisions (range 4-20, cut point 16). The fear-of-death query and its validation process are presented in Appendix. Attitudes to several moral and ethical aspects were assessed with a 10-cm visual analogue scale (VAS from definitely disagree to definitely agree), the statements concerning euthanasia, palliative care, role of religion in ethical decisions, advance care directives, health care economics, physicians' satisfaction with own health and salary and sense of burn out. Next, a previously used (Neittaanmäki et al. 1999) four-step Likert scale was applied to assess physician's personal conceptions of professional status, own health, family life, religion, nature and standard of living. Finally, sociodemographic data were inquired.

The questionnaire was tested in a pilot study in January 1999. It was sent to 45 physicians (health center practitioners and specialists) twice at a two-weeks interval in order to test the reliability of the responses to patient scenarios and the questions on attitudes and values. Thirty physicians returned two acceptable questionnaires. The value of the kappa coefficient for an acceptable scenario or question was determined to be more than 0.40, which is a commonly accepted limit for reliability.

#### **4.1.3 Statistical analysis**

Gender, age distribution and physicians' speciality were cross-tabulated with sociodemographic parameters, life-values, medical training and treatment decisions. Statistical significance was tested using Pearson's Chi-square test. The relationships of physicians' decisions, gender, age categories and speciality with variables indicating attitudes (VAS) were examined by Student's t-test (I,III), one-way analysis of variance (ANOVA, I) and Kruskal-Wallis test (II). Statistical significance of difference between decisions in alternative scenarios was studied by Friedman's test. Forward stepwise logistic regression (Hosmer and Lemeshow 1989) was used to create models explaining the

importance of background variables in the treatment decisions. The independent variables in the analysis were: attitudes and life values (22 variables), training and experience (8), demographics (4), existence of own advance directive (1), experience of severe illness in own family (1) and fear-of-death index (1), altogether 37 variables.

Forward stepwise logistic regression was also used to create a model explaining the justifications for treatment options.

Data analysis in was carried out by using SPSS/Win (Version 9.0).

## **4.2 Education project (IV)**

### **4.2.1 Participants**

A one-year, internet-mediated educational project in palliative care for general practitioners was awarded, planned and accomplished by the Finnish Cancer Foundation in 1999-2000. A total of 79 health center doctors registered in the project, coming from all parts of Finland. A questionnaire was delivered to the participants in the project at the beginning of the opening symposium in February 1999 (Time 1). The questionnaire was also mailed to a control group (CG) of 100 health center doctors randomly picked from the Finnish Medical Associations register. The same questionnaire was sent to both groups a year later when the education project was complete, in March 2000 (Time 2). The GPs in the education (EG) group were also sent an evaluating form.

### **4.2.2 Questionnaire**

The questionnaire used in this study was similar to that in studies 1-3, with the exception of an additional set of questions concerning the responders' conception of the importance of education for physicians in several areas of palliative medicine. The attitude was asked on a five-step Likert scale "not at all important – extremely important".

### **4.2.3 Statistical analysis**

Statistical significance of differences in treatment decisions in scenarios between the education and control groups was tested by Pearson's Chi-square test, as well as in cross-tabulation of answers on life-values and opinions on palliative care education. Change in answers to all the above between Time 1 (beginning of the education project) and Time 2 (after the education project) was analysed by kappa coefficient. The relationships of the medians of the variables indicating attitudes and opinions (VAS) were tested by Wilcoxon's Signed Ranks Test both between EG and CG and between Time 1 and Time 2. Data analysis in was carried out by using SPSS/Win (Version 9.0).

## **4.3. Quality of terminal cancer pain control (V)**

### **4.3.1 Patients in the study**

The study formed part of a prospective research project on the quality of terminal care in two Finnish health center hospital wards and one hospice (Lammi et al. 2000). In the health centers (Kangasala and Virrat) the study group consisted of all consecutive patients admitted for the treatment of cancer and giving their informed consent during a 12-month period in 1998 (Kangasala, N=20 and Virrat, N=16). Nine patients refused. In Pirkanmaa Hospice, by reason of the greater number of patients, not all but the first three consecutive patients who gave their informed consent in each month of 1998 were included in the study group (the annual number of patients in Pirkanmaa Hospice in 1998 was 239). The number of participants was 36 (out of 55 who were asked 19 refused). The most common reasons for refusal in all units were tiredness, weakness and lack of interest; many of those who refused died during the following week. During the study, 21 participants in health centers and 32 in the hospice died. Three of these were excluded from the analysis due to insufficient information on medication, in consequence of transfer to other health care units. A total of 20 patients were included in the present study in health centers and 30 in the hospice (Table 2).

Table 2  
**Patients in the study (V)**

	Health centers	Pirkanmaa Hospice
Eligible patients	45	55
Refused	9	19
Evaluable patients	36	36
Died during the study	21	32
Insufficient data	1	2
Included in the study	20	30

Demographic data, diagnosis and medication were recorded by a nurse upon admission. Pain was measured using a 0-10 cm visual analogy scale (VAS) (Miller and Ferris 1993), the extremes on scale being “no pain at all” and “intolerable pain”. The patients received instruction from a nurse on how to use the scale. If a patient was too weak to manage help was given by the nurse. The pain score was recorded every other day. The mean pain scores (VAS) for the last and the second last week of life were calculated for each patient. The patients’ medication on the seventh from last and the last day of life (regular medication, rescue doses, routes of administration) was recorded from medical charts.

#### **4.3.2 Statistical analysis**

The use of pain medication was analysed according to the WHO analgesic ladder model (World Health Organization 1986). To compare the efficiency of pain management in individual patients and on different wards, defined daily doses (DDD) of pain medication were calculated for strong opioids (SOs), weak opioids (WOs) and all pain medication (APM, including NSAIDs) for each patient on the seventh day before death and during the last 24 hours of life (designated below as last day of life). The daily cost of medication for each patient on the seventh from last and the last day of life was analysed.



Statistical significance was assessed by Chi-square tests in cross-tabulation of categorical variables and Student's t-test for numerical variables.

Data analysis in was carried out by using SPSS/Win (Version 9.0).

## 5. Results

### *5.1 Influence of physicians' training, experience and personal background factors on their end-of-life decisions (I-III)*

In the case of a terminal cancer patient (Scenario 1, I) 17% and in the case of a dementia patient (Scenario 2, I) 43% of all the doctors chose active treatment (Fig.1). The decision in the former scenario was different in alternatives for the scenario: iatrogenic gastro-intestinal bleeding increased the proportion of the active treatment option to 47%, family member's appeal to 55% and patient's spiritual need to 47%. The alternative with an advance directive cut down the choice of active treatment option to 11%.

In another scenario (Scenario 7) envisaging a terminal cancer patient (II) decisions to withdraw or withhold specific treatments were asked. A high proportion of doctors chose to forgo blood transfusion, thrombosis prophylaxis, mechanical ventilation and antibiotic treatment (82%, 81%, 79% and 60%, respectively), but only a minority of doctors were for withdrawing intravenous hydration and supplemental oxygen (29% and 13%, respectively). Family's appeal and demand "everything to be done" significantly increased choices of an active option in all the treatments asked. In the scenario of a young terminal cancer patient suddenly dying (Scenario 6, III) 16% of the doctors would have started cardiopulmonary resuscitation (CPR).

#### *Attitudes and life values*

Attitudes to active euthanasia were largely reprehensive, more so among female physicians ( $p < 0.001$ , Fig 2A). Attitudes towards assisted suicide were even more condemnatory and here no gender variation was found (Fig.2B). In contrast, attitudes to withdrawing LST were mostly permissive (Fig 2C). Paradoxically older doctors held less tolerant views on withdrawal of LST, even if they generally chose more forgoing of treatments in the scenarios. Oncologists and older doctors more often agreed on the statement "Terminal care is satisfying work" ( $p < 0.001$  and  $p = 0.007$ , respectively, Fig 2D).

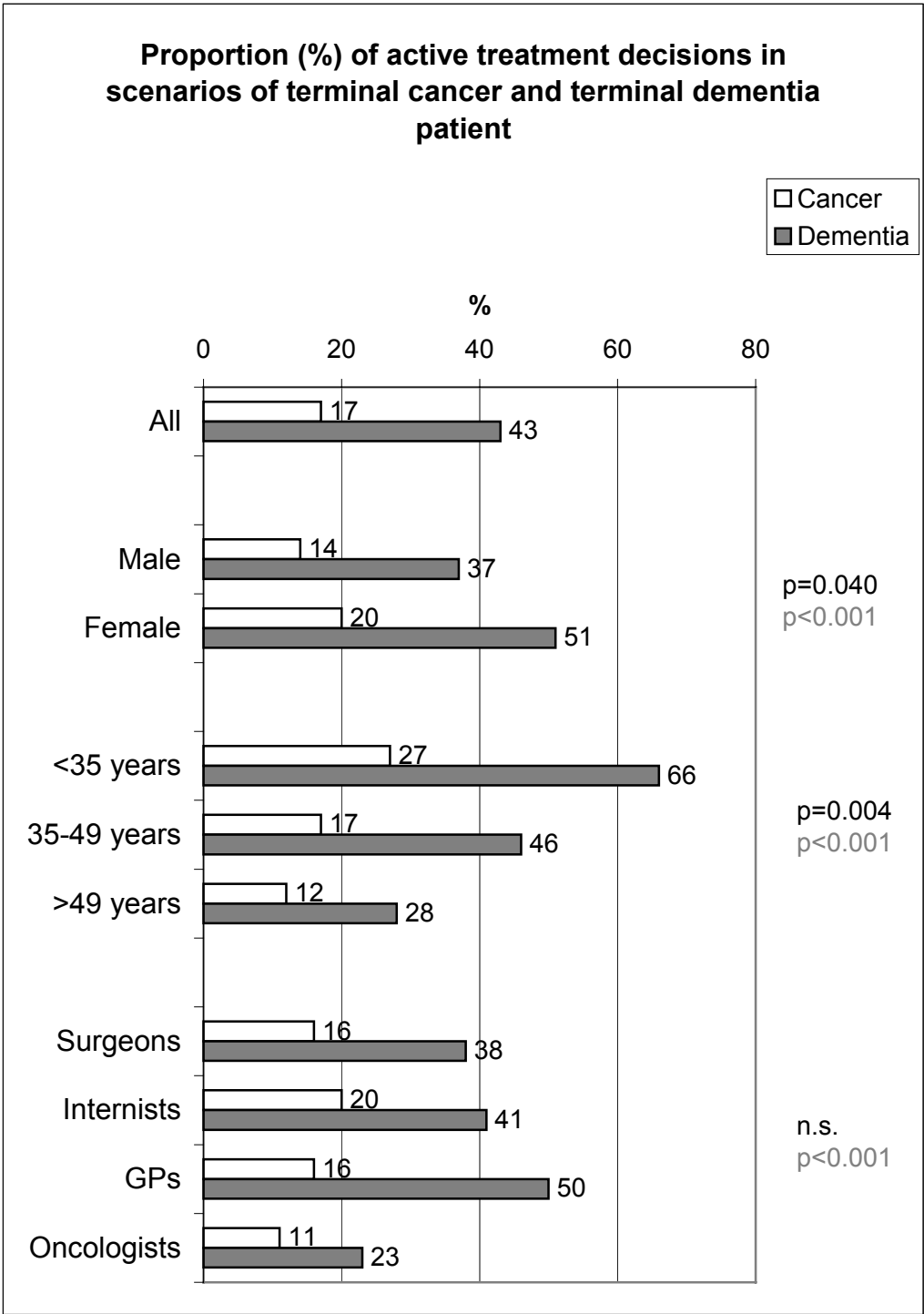


Fig. 1

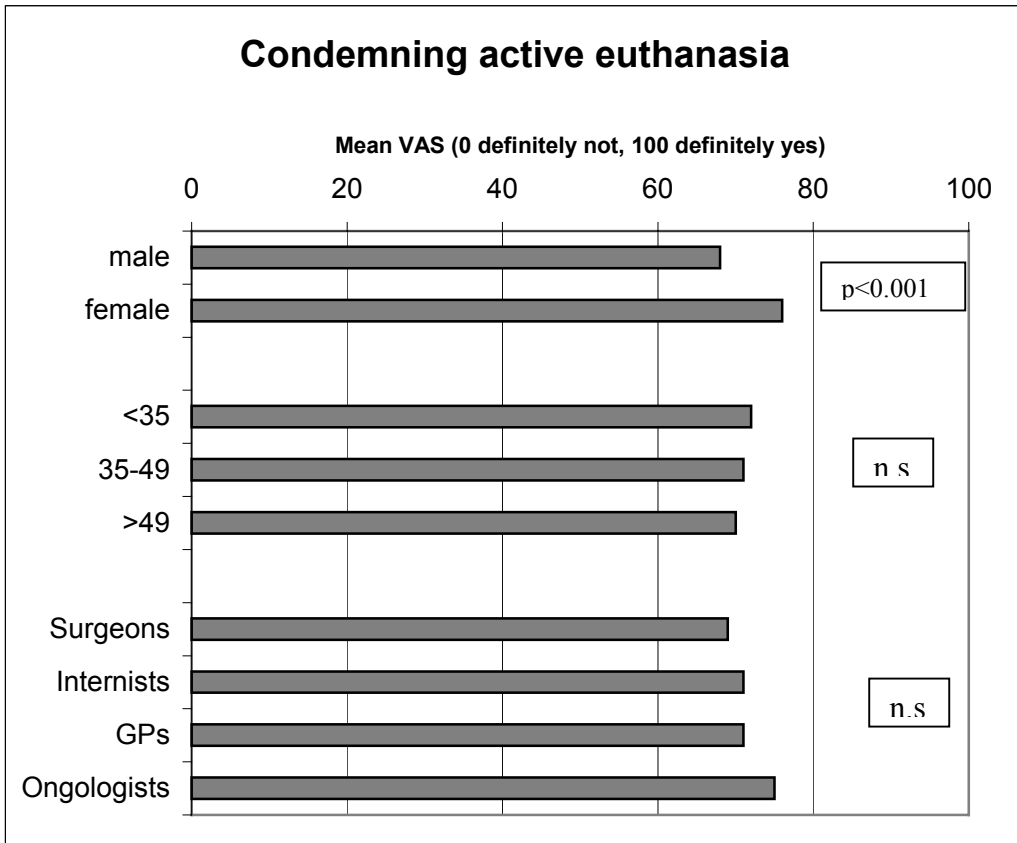


Fig. 2A

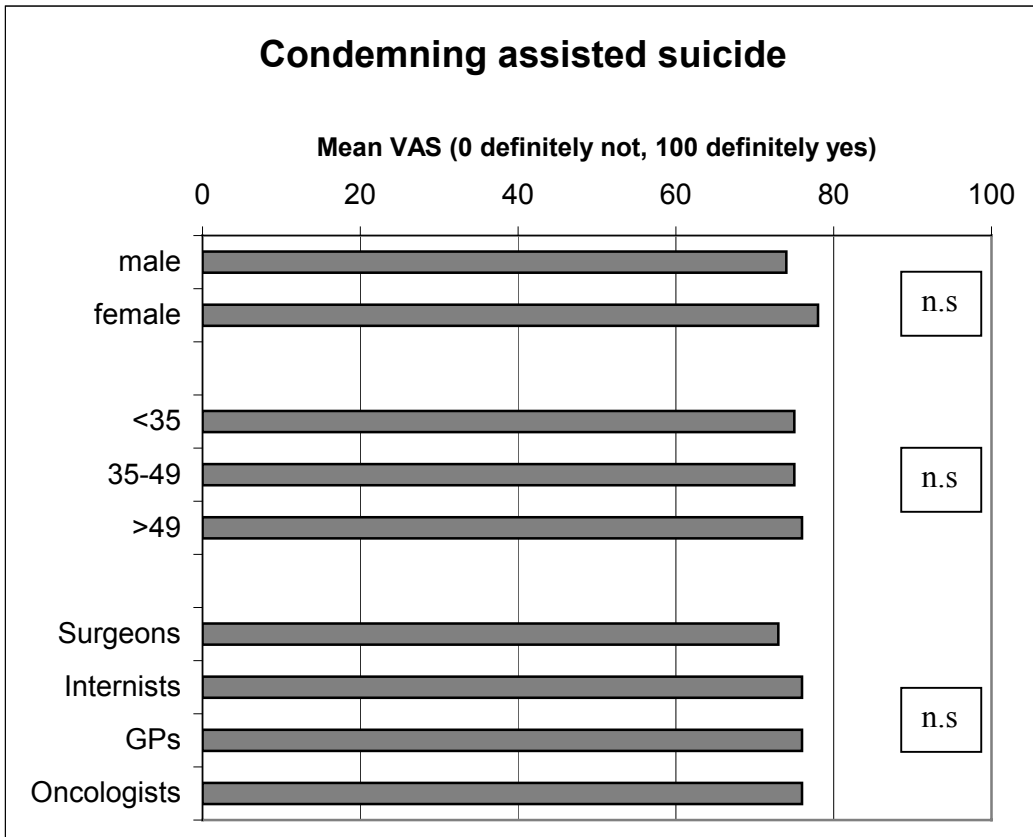


Fig. 2B

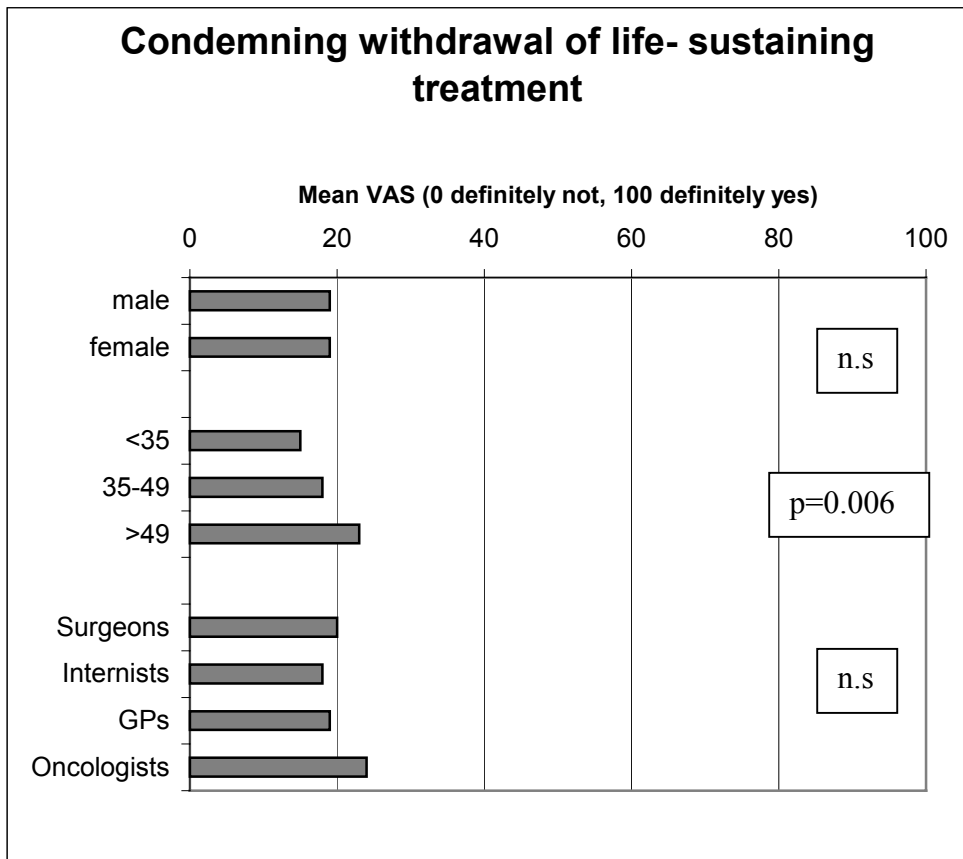


Fig. 2C

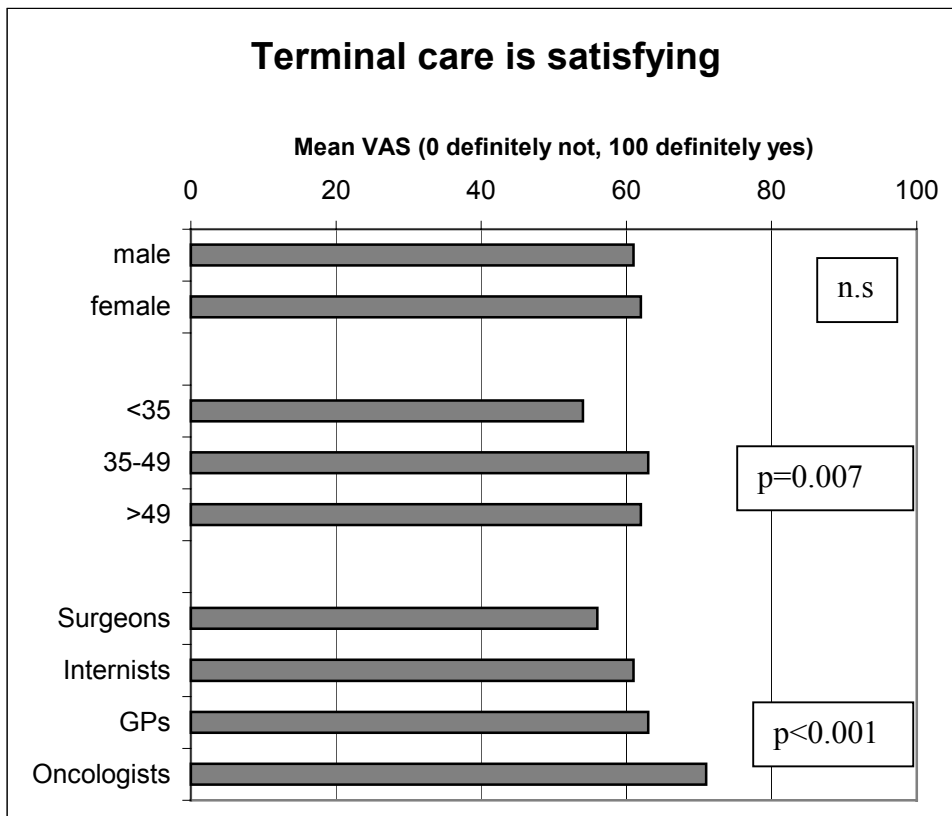


Fig. 2D

Length of life was a life-value rated as important more by the youngest doctors (66%, 63% and 50% in age groups, respectively,  $p=0.004$ ). A high standard of living was a life-value appreciated more by young doctors (57%, 54% and 40% in age groups, respectively,  $p=0.002$ ). Female physicians considered religion more important; 55% of female doctors considered faith in God important compared to only 44% of male doctors ( $p=0.003$ ).

### *Influence of gender and age on decisions*

Female physicians frequently chose an active treatment option for the terminal cancer patient (20% vs 14%,  $p=0.040$ ) and dementia patient (51% vs 37%,  $p<0.001$ , Fig.1). Among specific treatment options, women less often chose to withdraw thrombosis prophylaxis (76% vs 84%,  $p=0.022$ ) and supplemental oxygen (7% vs 17%,  $p<0.001$ , II). On the other hand, women were more willing to withhold laboratory tests (62% vs 57%,  $p=0.057$ ) or X-ray examinations (61% vs 58%,  $p=0.039$ ). Women were also more influenced by the family's appeal in most scenarios. In the case of the CPR decision no gender difference was seen (III).

Young doctors were also more active in their decisions in the case of a terminal cancer patient (Fig. 1, I). In age groups <35 years, 35-49 years and >49 years the proportions of physicians who would have chosen active treatment were 27%, 17% and 12%, respectively ( $p=0.004$ ). The corresponding figures in the case of the dementia scenario were 66%, 46% and 28%, respectively ( $p<0.001$ ). Young doctors also more often chose to continue antibiotics, thrombosis prophylaxis and supplemental oxygen ( $p=0.025$ ,  $p=0.006$  and  $p=0.004$ , respectively, II). Of doctors under 35 years 29% chose to start CPR compared to 13% of doctors over 49 years ( $p<0.001$ , III). The family's appeal had greatest influence on the decisions of the youngest doctors; readiness to withdraw antibiotics from a terminal cancer patient decreased from 51% to 24% ( $p<0.001$ ), while the corresponding figures among the oldest doctors were from 65% to 50% ( $p<0.001$ , III).

### *Influence of speciality on decisions*

Oncologists differed from other specialists. A trend emerged towards less active decisions in the scenarios of a cancer and a dementia patient (Fig. 1, I). They also least frequently chose the active treatment option for the cancer patient with an iatrogenic bleeding complication ( $p=0.017$ , I). Of the specific treatments, oncologists were least inclined to continue intravenous hydration, nasogastric tube, thrombosis prophylaxis, mechanical ventilation and supplemental oxygen ( $p<0.001$ ,  $p=0.008$ ,  $p=0.002$ ,  $p=0.017$  and  $p=0.034$ , respectively, II). In the case of intravenous hydration the difference was most striking: 60% of oncologists would withdraw it compared to 21-31% of other doctors ( $p<0.001$ ). They also most often withheld laboratory tests ( $p=0.019$ ) and thorax X-ray examination ( $p=0.011$ , II). However, there was no statistically significant difference in the CPR decisions by speciality (III). Although oncologists were the speciality group most ready to forgo active treatments, they were still greatly influenced by family appeal. After the family's strong request their willingness to withdraw antibiotics decreased from 68% to 36% ( $p<0.001$ ), the corresponding figures among surgeons being from 67% to 54% ( $p<0.001$ , II).

### *Regression analysis*

Stepwise logistic regression analysis revealed that different variables predicted decisions in different scenarios. However, physician's age and the attitude to withdrawing LST were the two factors found to predict decisions in all the regression analyses performed (cancer patient, dementia patient, antibiotic treatment, intravenous hydration, CPR decision). The probability of the physicians in the oldest age group, compared to the youngest, commencing active treatment was significantly lower in the case of both the cancer patient (OR 0.36, I) and the dementia patient (OR 0.17, I). The more the physicians considered withdrawing LST to be wrong, the more they chose an active treatment option: a 1-cm increase on the 10-cm visual analogue scale measuring this attitude (0 - forgoing LST is definitely to be accepted, 10 - forgoing LST is definitely to be condemned) resulted in an OR 1.24 for a more active decision in the case of the cancer patient and OR 1.08 in case of the dementia patient (I). Other factors which entered many models explaining these end-of-

life decisions were: experience of terminal patients in practice, speciality of the doctor and the value the physician set on advance directives in practice (Tables 3-6, I; Tables 4,6, III; Table 5).

Table 3

**Odds Ratios for Decisions to Withdraw Antibiotic Treatment (Original Scenario) by Independent Significant Variables Included in the Model (N=424)**

Variable		N	OR	95%CI
<b>Life value:</b>				
Considering length of life	not important	169	ref.	
	important	255	0.47	0.26-0.85
<b>Attitudes and opinions (VAS):</b>				
Withdrawing life-sustaining treatment is reprehensible		424	0.88*	0.79-0.97
Assisted suicide is reprehensible		424	0.89*	0.79-1.01
I feel burn out, tired to work		424	0.89*	0.80-0.99
Good palliative care enables good death		424	1.12*	0.98-1.28
<b>Training and experience:</b>				
Taking care of terminal patients in practice	yes	338	ref.	
	no	86	0.53	0.29-0.98
<b>Demographics:</b>				
Physician's age	<35	55	ref.	
	35-49	239	2.58	1.30-5.09
	>49	130	5.10	2.20-11.80

OR, Odds Ratio; 95%CI, confidence interval 95%; VAS, visual analogy scale measurement of attitude ( 0 = definitely disagree, 10 = definitely agree).

Analysis between decisions to continue treatment (Likert 1-2) and to withdraw treatment (Likert 4-5).

\*, the influence of one unit (=1 cm on VAS) increase in attitude to the probability to withdraw treatment



Table 4

**Odds Ratios for Decisions to Withdraw Intravenous Hydration (Original Scenario) by Independent Significant Variables Included in the Model (N=398)**

Variable		N	OR	95%CI
<b>Attitudes and opinions (VAS):</b>				
Withdrawing life-sustaining treatment is reprehensible		398	0.89*	0.80-0.98
<b>Training and experience:</b>				
Speciality of the physician	surgeon	108	ref.	
	internist	93	1.37	0.75-2.52
	GP	167	2.91	1.68-5.01
	oncologist	30	18.51	5.80-59.03
<b>Demographics:</b>				
Physician's age	<35	53	ref.	
	35-49	217	2.23	1.11-4.48
	>49	128	3.25	1.53-6.88

OR, Odds Ratio; 95%CI, confidence interval 95%; VAS, visual analogy scale measurement of attitude ( 0 = definitely disagree, 10 = definitely agree).

Analysis between decisions to continue treatment (Likert 1-2) and to withdraw treatment (Likert 4-5).

\*, the influence of one unit (=1 cm on VAS) increase in attitude to the probability to withdraw treatment

Table 5

**Odds Ratios for Decisions to Withdraw Antibiotic Treatment (Scenario A1: Family's appeal) by Independent Significant Variables Included in the Model (N=406)**

Variable	N	OR	95%CI
<b>Attitudes and opinions (VAS):</b>			
Withdrawing life-sustaining treatment is reprehensible	406	0.90*	0.82-0.98
I feel burn out, tired to work	406	0.91*	0.83-0.99
Advance directives have been helpful in my decisions	406	0.92*	0.86-0.99
<b>Demographics:</b>			
Physician's age	<35	54	ref.
	35-49	229	2.64 1.38-5.05
	>49	123	5.49 2.69-11.20

OR, Odds Ratio; 95%CI, confidence interval 95%; VAS, visual analogy scale measurement of attitude ( 0 = definitely disagree, 10 = definitely agree).

Analysis between decisions to continue treatment (Likert 1-2) and to withdraw treatment (Likert 4-5).

\*, the influence of one unit (=1 cm on VAS) increase in attitude to the probability to withdraw treatment

Table 6

**Odds Ratios for Decisions to Withdraw Intravenous Hydration (A1: Family's appeal) by Independent Significant Variables Included in the Model (N=443)**

Variable		N	OR	95%CI
<b>Life value:</b>				
Succes in career	not important	45	ref.	
	important	398	0.49	0.23-1.03
<b>Attitudes and opinions (VAS):</b>				
Withdrawing life-sustaining treatment is reprehensible		443	0.88*	0.78-0.99
Physician's profession is satisfying		443	1.30*	1.10-1.53
Advance directives have been helpful in my decisions		443	0.89*	0.83-0.97
<b>Training and experience:</b>				
Speciality of the physician	surgeon	111	ref.	
	internist	102	1.42	0.70-2.86
	GP	202	1.98	1.04-3.76
	oncologist	28	6.55	2.41-17.78
<b>Demographics:</b>				
Gender	male	269	ref.	
	female	174	0.57	0.33-0.99
Marital status	married	343	ref.	
	single	29	0.61	0.17-2.23
	divorced	28	1.16	0.44-3.05
	widow	5	2.12	0.30-15.15
	common law marriage	38	2.99	1.29-6.94
Physician's age	<35	61	ref.	
	35-49	253	1.85	0.73-4.71
	>49	129	2.94	1.08-8.00

OR, Odds Ratio; 95%CI, confidence interval 95%; VAS, visual analogy scale measurement of attitude ( 0 = definitely disagree, 10 = definitely agree).

Analysis between decisions to continue treatment (Likert 1-2) and to withdraw treatment (Likert 4-5).

\*, the influence of one unit (=1 cm on VAS) increase in attitude to the probability to withdraw treatment

## **5.2 Influence of one year's interactive internet-based training on GPs' attitudes and ethical decisions in end-of-life care (IV)**

The quality of the education project was considered “good” by 59% of the doctors in the education group (EG) and “excellent” by 41%; 93% of doctors in EG and 29% in control group (CG) had previously participated in postgraduate training in palliative care. A greater proportion of EG doctors had a specialist degree in general practice (60% vs 26%,  $p=0.006$ ) and they also reported having terminal patients in practice more often than controls (95% vs 79%,  $p=0.029$ ). EG doctors also reported higher voluntary activity in palliative care: 80% of them were members of some palliative care-associated society, compared to 10% of the control group ( $p<0.001$ ).

In the scenarios of a terminal cancer patient and a dementia patient doctors in EG and CG showed uniform activity (IV; Table2). When more specific treatment decisions were asked, there was a marked trend for doctors in EG to choose a less active treatment policy. Almost all (93%) doctors in EG would have withheld cardiopulmonary resuscitation (CPR), whereas one third (33%) of doctors in CG would start CPR ( $p=0.004$ , IV; Table 2). Doctors in EG also chose more to withdraw antibiotics (70% vs 45%,  $p=0.023$ ) and intravenous hydration (50% vs 24%,  $p=0.014$ ) and to withhold blood transfusion (95% vs 74%,  $p=0.009$ ) and laboratory examinations (88% vs 48%,  $p<0.001$ ) from a terminally ill cancer patient. The family's appeal “everything to be done” markedly influenced both groups in the case of withdrawing antibiotics and iv-hydration, somewhat less in the case of withholding blood transfusion and examinations (IV; Table 3).

The attitudes towards active euthanasia were highly negative in both groups. There was some tendency for an even more condemnatory attitude among doctors in EG (median 9.0 vs 8.3 on VAS scale 0-10,  $p=0.069$ ). Attitudes to withdrawing LST in terminal care were similar and mainly approving in both groups (median 0.9 vs 1.2 on VAS scale 0-10, n.s.). Also other measured attitudes and opinions were very similar. However, EG physicians agreed significantly more often on the statement “Terminal care is satisfying work” than

CG physicians (median 8.3 vs 6.4 on VAS scale 0-10,  $p=0.001$ ). No significant differences were found in the studied life-values between the groups.

In general, treatment decisions or attitudes did not change significantly in either group during the year, but a trend towards a decrease in differences between the groups was seen (IV; Table 4). Nonetheless, a few significant changes in attitudes were seen during the year. The opinion “I feel burn out” had decreased in EG doctors (median from 2.4 to 1.3 on VAS 0-10,  $p=0.015$ ), and in contrast among CG doctors satisfaction with the physicians profession and own health had decreased  $p=0.037$  and  $p=0.004$ , respectively).

### **5.3 Assessment of pain control in cancer patients during the last week of life.**

#### **Comparison of health center wards and a hospice. (V)**

In all, the mean consumption of strong opioids (SO) was 1.39 ( $\pm 1.95$ ) DDD per patient seven days before death, equivalent to 139mg oral morphine. By the last day of life this increased to 1.91( $\pm 2.13$ ) DDD, equivalent to 191mg oral morphine. No statistically significant difference in SO doses was found between the two units (V; Table 2). The proportion of patients receiving SOs was smaller in the hospice 7 days before death (80% vs 53%,  $p=0.050$ ), but was found to be on the same level as in health center wards during the last day of life (90% vs 83%, n.s., V; Table 4). Weak opioids (WOs), by contrast, were used to a greater extent in the hospice 7 days before death (43% vs 15%,  $p=0.034$ ), but also this difference evened out during the last week of life (30% vs 20%, n.s.). NSAIDs were used for more than half of the patients in health center wards 7 days before death, whereas their use was minimal in the hospice (60% vs 17%,  $p=0.002$ , V; Table 4). During the last day of life the NSAIDs were used for a minority of patients in both units (30% vs 20%, n.s.).

The mean costs of pain medication did not differ significantly between the two health care units (V; Table 6). There was, however, a slight trend towards more expensive pain medication in health center wards; the mean cost of all pain medication during the last day of life was 3.65 ( $\pm 3.23$ ) euros in health centers and 2.39 ( $\pm 2.05$ ) euros in the hospice. This

was primarily due to more frequent use of the more expensive transdermal fentanyl in health center wards.

The mean self-reported pain scores (VAS 0-10) for the two last weeks indicated no variation in the two health care units (3.01 in health centers, 3.19 in the hospice). Neither were there any signs in either of the centers of an acceleration in the scores towards the end of life (V; Table 7).

## **6. Discussion**

### **6.1 General findings**

Great variation was seen in Finnish doctors' end-of-life decisions in this largest survey on ethical decision-making ever carried out in Finland. Doctors' decisions differed significantly according to gender, age, training, experience and personal attitudes. Being young or female often predicted more active treatment decisions and being an oncologist meant more willingness to forgo life-sustaining treatment. Experience in terminal care and acceptance of limiting life support in general were significant predictors for forgoing treatment decisions. The volunteering GPs in the one-year interactive education project in palliative care were revealed to have markedly wider former experience in palliative care than controls. Consequently they also had greatly different, mostly less active attitudes in ethical end-of-life decisions. During the year decision-making and ethical attitudes were not altered. However, attitudes evincing exhaustion by work-load decreased among the GPs in the project. The quality of terminal care, when the levels of pain medication and pain measurement scores were used as index, was found to be on a good level in the two different units of the Finnish health care system for terminal cancer patients. The costs of terminal cancer pain medication were relatively low.

### **6.2 Methodological considerations**

In the major study the respondents were doctors from four specialities: surgeons, internists, GPs and oncologists. These specialities were chosen as being known to be engaged with cancer patients in all stages of disease. A good response rate (62%) was achieved in this major study. The response rate in the survey of education project participants was lower (51%) but average for surveys among medical doctors. The number of patients in the prospective study for pain control was relatively small (50), by reason of many practical, psychological and ethical problems involved in doing research with dying patients.

Clinical scenarios have been used to evaluate a variety of physicians' behaviors (Kirwan et al. 1983, Longstreth 1987, Holmes et al. 1989, Liberati et al. 1991). Standardized clinical scenarios have several advantages: they can control for patient and clinical characteristics, they are easy to self-administer, and they can be collected from large populations (Jones et al. 1990). However, research on decision-making by this means has certain limitations. The reliability of the scenario can be insufficient; physicians' answers can vary because of factors not measured. Hence testing of reliability is important. In this study the questionnaire was tested in a pilot study at a two weeks' interval and the reliability was found to be sufficient, kappa coefficient 0.40 or more. Also, there is a risk that responses to hypothetical scenarios may be different from actual physician behaviour. Furthermore, in contrast to real situations, physicians cannot ask questions and obtain answers to them when presented with scenarios. Actual practice patterns may be influenced by other factors not directly reflected in a written scenario, for example patient-physician interaction, social desirability response (Morrell and Romano 1990) and other biases of subconscious origin (Schulman et al. 1999). However, according to Moskowitz and associates (1988), keeping in mind the limitations mentioned, written simulations are an effective research instrument for elucidating the decision-making process. Christakis and Asch (1995) showed that the differences in physicians' personal end-of-life decisions expressed in hypothetical vignettes also applied in clinical practice. Physicians' decisions to forgo several life-supporting treatments reported in a questionnaire study by Christakis and Asch (1993) were also almost identical to the results obtained in clinical practice reported in a subsequent prospective study by Asch and colleagues (1999).

The Visual Analogue Scale (VAS) is a self-reporting device extensively used to measure subjective phenomena such as patient symptoms (pain, nausea, fatigue, dyspnea), affect (feelings, mood), function, and quality of life. Various aspects of life have been measured using this technique (Miller and Ferris 1993). The VAS is one of a group of measurement and scaling techniques known collectively as "graphic methods". The technique has been extensively studied and has proved reliable and valid in most circumstances (Aitken 1969, Scott and Huskisson 1976, Gift 1989). Its scale properties (ordinal, equal, interval, ratio) have been questioned, but most researchers are satisfied that parametric statistical



procedures applied to the VAS are appropriate (Miller and Ferris 1993). In the present study the special advantage of the method was its sensitivity in measuring attitudes and opinions, compared to fixed interval rating scales (Joyce et al. 1975). It also served as an easily understood measure of pain for severely ill cancer patients (Rees et al. 1998).

### **6.3 Factors behind physician's end-of-life decisions**

The findings in this study of the influence of age on decisions are very much in line with the results of a survey of Australian physicians (Waddel et al. 1996) and one international study (Molloy et al. 1991) which used one same scenario as in this study (Scenario 2): the greater the number of years in practice, the less active the treatments. In a study by Varon and associates (1998) American medical students requested resuscitation significantly more often than qualified and experienced physicians and nurses in a hypothetical case of metastatic cancer (N=234,  $p<0.005$ ). Also in a nationwide study in the Netherlands, most physicians felt that over the years they had been inclined to move increasingly from life-prolonging treatments towards non-treatment decisions (Pijnenborg et al. 1995). The reason for young doctors being more often inclined to continue treatments for a terminal patient is probably a matter of less experience and greater fear of legal consequences. Such a conception is supported by the finding that young doctors were most appreciative of advance directives and that they were found to value more the length of life. Young doctors were also more concerned about the physician's legal protection. The finding that young doctors were least persuaded that terminal care is satisfying for the doctor, may be interpreted to mean that end-of-life decision-making was also most stressing for them. In a stressing situation young doctors are probably prone to make more "safe" and "formally right" decisions, to lighten the personal responsibility in the decision.

The findings of this study are also in line with the results obtained by a group under Waddel (1996), who showed that female physicians were more likely than men (49% versus 40%,  $p<0.01$ ) to favour active treatment for a severely demented Alzheimer patient. This gender difference in decision-making may be influenced by different life-values and attitudes among male and female doctors. In this study women doctors, who were often

more active in their decisions, also showed parallel general attitudes. They expressed more ready condemnation of euthanasia (Fig 2A), and they were more concerned about the physician's legal protection (I); they also were more religious (I; Table 3A). Part of the gender difference in decisions may be due to bias; female doctors may be more conscientious and feel more responsibility in completing a questionnaire. However, several earlier studies support the present finding of the significance of gender in physicians' thinking and practice. Neittaanmäki and colleagues (1999) studied Finnish doctors' life values; women doctors rated close friends, health and the importance of ideology in general as more important compared to men. Hall and Roter (1998) showed differences in communication patterns between male and female physicians; female physicians focused more often on patients' emotional and psychosocial concerns. Surgeons also differ by gender in decision-making; in the case of breast cancer male surgeons make more radical treatment decisions (mastectomy) while female physicians are more for breast-conserving surgery (Mandelplatt et al. 2001). These results imply that a gender difference in "soft" life-values, and in both emotional and psychosocial aspects, seems to result in different decisions in ethical end-of-life dilemmas. However, contradictory results have also been reported. In a study by Lawrence and Clark (1987) American female doctors chose resuscitation (CPR) less often for terminal patients than did men ( $n=182$ ,  $p=0.02$ ), which conflicts with the finding of no gender difference in the CPR decision in the current study. Also unlike the results of this paper, in the study by Christakis and Asch (1995) of 862 American internists gender had no role in decisions for hypothetical vignettes of terminal patients. These divergencies suggest that other factors like cultural and educational differences also exert significant influences on decisions, and these may overgo gender variation.

In the above mentioned survey by Lawrence and Clark (1987) American physicians ( $n=182$ ) were asked to make a CPR decision in a hypothetical patient scenario. In this the doctor's speciality showed a significant association with the decision taken. Specialists in cardiology and pulmonology showed a less active approach to CPR of a cancer patient than all other specialities. This is in line with the findings here, which indicates a trend for specialists in internal medicine to be less inclined to start CPR than GPs. One possible explanation for

these differences in CPR decisions is the more frequent involvement of patients with an unsuccessful outcome from resuscitation on hospital wards for internal medicine, adding some scepticism to this speciality group. The prospective study by Pijnenborg and group (1995) in the Netherlands collected information on 2257 deaths and showed that in 39 % of all non-sudden deaths, a non-treatment decision was made. The percentage varied greatly by speciality, being lowest (28%) among cardiologists and highest (55%) among surgeons. This would support the conception that differences by speciality also prevail in real clinical practice.

In this study oncologists were significantly less active in their decisions in most scenarios. The most outstanding difference from other specialities was seen in their opinions on continuing iv-hydration (II; Table 1). This is in line with the survey by Waddell and colleagues (1996) to 2172 Australian physicians; in a scenario of a young metastatic terminal cancer patient only 20% of palliative care physicians chose intensive care compared to 29% of specialists and 35% of general practitioners ( $p < 0.001$ ). Oncologists here were also the speciality to be most influenced by family's appeal (II; Table 1 and 2). Reasons for this can be found in the attitudes oncologists evinced in this study: they expressed most the view that terminal care is satisfying. They also had most supervision and post-graduate training in terminal care, and had self-evidently most experience in treating terminal patients. These results suggest that the reason for oncologists' less active decisions lay in greater experience and in a more balanced attitude to end-of-life questions. Oncologists' greater experience in terminal care and familiarity with ethical decision-making also explains why they were the speciality group to set least value on advance directives. Their decisions were probably initially largely parallel with the directives.

In the analysis of attitudes acceptance of withdrawing LST was found to be the most frequently appearing variable predicting decisions. Withdrawing LST was formerly often called "passive euthanasia". Nowadays many experts do not accept this expression, because of the possibility of wrongly linking the concept to active euthanasia. It is important that professionals and the public make a clear distinction between euthanasia and the withholding of futile life-supporting treatments, the two being clinically, ethically and

legally totally different. If the difference is not clear, even efficient pain therapy may be considered to be some form of euthanasia (Roy and MacDonald 1998, p.123). Results of the regression analysis suggest that many physicians still hold that withdrawing life support is close to euthanasia and rather make active treatment decisions than involve themselves in this “passive euthanasia”.

Among the specific treatments iv-hydration is a good example of the way various background factors, including attitudes, influence decisions (Table 4 and 6). Speciality and age of physician were greatly predictive of this decision; the oncologists made significantly fewer active decisions than others, and young physicians more. These factors reflect the importance of experience in having the courage to make withdrawing decisions. Probably doctors with experience of terminal care are better aware of research results on the subject; for the most part iv-hydration does not give better life quality to a dying patient (Huang and Ahronheim 2000). In this study male doctors also decided more often to withdraw iv-hydration. This probably reflects a more “masculine” courage to make “radical” decisions. Male doctors’ greater acceptance of euthanasia (Fig 2A) may reflect the same gender difference. On the other hand, being female may be taken to mean more “empathic” attitudes to family’s appeal and to lead to continuation of treatment “for the family’s best”. According to the regression analysis “soft and positive” attitudes, success in career not so important” and “physician’s profession is satisfying” run parallel to more decisions to withdraw iv-hydration (Tables 4 and 6). These attitudes probably also reflect overall human and holistic thinking and appreciating the patient’s and family’s overall well-being.

According to previous international studies religion has a marked role in physicians’ ethical decision-making. (Vincent 1990, Christakis and Asch 1995, Vincent 1999). Here, however, religiousness did not show much influence on the end-of-life decisions, although 55% of female physicians and 44% of male physicians considered faith in God important. Religion did not emerge as a significant independent variable for physicians’ decisions in any of the scenarios. One possible explanation lies in the relatively uniform religious and ethical education of Finnish doctors compared to many other, more heterogeneous populations:

about 90% of Finnish people belong to the Lutheran Church. This may also explain the fact that decisions did not tally with the fear-of-death index, either.

#### **6.4 Evaluation of the palliative care education project**

It emerged here that end-of-life decision-making and attitudes varied greatly between the GPs who volunteered for the one-year interactive palliative care project and the controls. One explanation lies in the markedly wider experience in palliative care among the participants in the education group. This is in line with the above-mentioned findings of Waddel and group (1996): physicians with more experience in palliative care chose intensive care less often for a terminal cancer patient. Previous participation in relevant education may also explain some of the difference: in the present study 93% of doctors in EG and only 29% in CG had previously participated in postgraduate training in PC. In the Netherlands, post-graduate palliative care education was shown both to increase GPs knowledge of palliative care and change attitudes to end-of-life decisions (Schuit et al. 1999).

The observation that treatment decisions or attitudes were not significantly altered in the education group during the year does not mean that the education project had failed in its goal to give training also in ethical decision-making; rather it suggests that the participants were already experienced and dedicated to this area and hence the changes were not significant. An important conclusion has to be drawn: to achieve the goals of education in PC the most difficult target group, the “silent majority” of doctors should be reached. This is especially important in countries like Finland, where terminal care will be carried out more and more in primary health care by family physicians with no specialization in the field.

The results here showed a significant decrease in expressions of exhaustion by work-load among the GPs in the project. This would imply that an interactive education project like this can be considered to partly fulfill the task of supervision.

## 6.5 Quality of terminal cancer pain control

It was important for the aims of the study to evaluate the quality of pain control in palliative care and variation in decision-making also in actual clinical situations. Decisions on pain medication during the last week of cancer patients' life served this purpose in the study. The general conclusion can be drawn that both in GP-managed health center wards and in the specialist-managed hospice the level of pain medication and quality of pain control were good, also in comparison to international figures.

In the light of the findings in a long-term survey of morphine use in cancer pain patients in a pain management unit in Germany the mean doses of strong opioids in this study were comparable. In the study referred to the average oral morphine dose for 550 patients was 82mg (Schug et al. 1992). The average initial dose was 61 mg and the average last dose 104 mg. The average last daily dose in DDD was 1.04, which is lower than in this study (1.29 DDD 7 days before death and 1.53 DDD during the last day of life). A clear trend was seen in both units to use more step-three (strong opioids) on WHO guidelines compared to earlier results in Finland (Vuorinen et al. 1997).

The results on mean opioid doses used for terminal cancer patients do not reflect any differences in pain management by a GP or a hospice specialist. However, differences were seen in the proportions to which strong opioids, weak opioids and NSAIDs were used and in types and in administration routes of strong opioids. Physicians in health centers had been more active in introducing transdermal fentanyl on the wards, possibly because of the "easiness of pain control" of which commercial agents have actively informed the GPs. Under the pressure of multiple and miscellaneous demands in geriatric wards such a simple means of pain therapy probably has been awaited. Specialists in hospices are probably more aware of the guidelines on using oral morphine as a basic tool as far as this route is usable (Cherny and Portenoy 1993). Hospices are also smaller units and economic factors conceivably play there a greater role in physician's decisions on medications. Pain control strategy in the hospice can be described as "keeping it simple", with mostly weak opioids or strong opioids used in monotherapy (V; Table 5), whereas the strategy in health center wards

would appear to go more according to the original WHO guidelines (World Health Organization 1986), by combining NSAIDs with opioids.

The costs of analgesic therapy per day showed a trend towards more expensive pain medication in health centers. This was due to the relatively high price of the transdermal fentanyl more in use there. The daily cost of pain medication of patients treated with the fentanyl patch was approximately double that among patients treated with oral morphine. The difference is quite conspicuous, but the significance of this result should be considered in a broader context. When it is taken into account that the mean analgesic cost of one day in health center wards represented only about 5 % of the total costs of a hospital day, and even less in the hospice, the price factor should not be given too much weight. More attention should be paid to other factors such as effectiveness, low level of side-effects, and ease of administration. It has to be remembered that in only a minority of terminal cancer patients' pain management needs the special and often also expensive treatments of a special clinic (Cherny et al. 1995). However, according to Mercadante (1999) costs are still often a barrier to good cancer pain management, even where "simple" analgesic therapy is concerned. One of the great tasks of palliative medicine is to identify and show the existing problems of resource allocation to the public and to those responsible for the health economics.

In a recent meta-analysis by Collins and associates (1997) the mean score in VAS (0-10 cm) for moderate pain was 4.9 and for severe pain 7.5. In this light the present results (mean 3.11-3.05) indicate relatively good pain control in terminal cancer patients at two levels of the Finnish health care system. It has to be considered that patients in the hospice were younger, and younger age has been found to be associated with a greater need for analgesics (Mercadante and Dardadoni 1997, Mercadante et al. 2000). In spite of this the hospice achieved equal pain control with health center wards with less frequent use of strong opioids, less frequent use of parenteral morphine and an overall tendency towards smaller mean doses of pain medication. Psychological distress factors are known to be associated with poor pain relief (Mercadante and Dardadoni 1997). A homely and welcoming

atmosphere and holistic care provide at least one explanation for the good pain control achieved with less medication in the hospice compared to health center wards.



## 7. Summary and conclusions

The purpose of this study was to evaluate the influence of physicians' training and personal background factors on their ethical treatment decisions in end-of-life care and to assess the level of pain control in two different units for terminal cancer patients in Finland. A stratified sample (1180) of Finnish physicians were sent a questionnaire presenting scenarios involving terminal cases. The doctors were asked to choose from among treatment options. These decisions were analysed according to physicians' training factors, experience, attitudes, life values and demographic data. The general practitioners (79) participating in an interactive internet-based education project in palliative care and 100 controls were surveyed with the same questionnaire before and after the project. Pain medication, self-assessed pain and costs of pain treatment were evaluated in terminal cancer patients during their last week of life in general practitioner-managed health center wards (n=20) and in a specialist-managed hospice (n=30).

1) Finnish doctors' attitudes to active euthanasia and assisted suicide were very uniformly condemnatory. On the other hand, physician's attitudes to the rightness of withdrawing life-sustaining treatment in general varied and most often predicted end-of-life decisions. Views on the proposition that terminal care is satisfying for the doctor also differed greatly; a more positive attitude meant less active treatment decisions. Of the life-values asked valuing the length of life was the most important predictor for treatment decisions; greater appreciation of long life meant logically more use of active therapy. From these results it may be concluded that professional supervision would be very important especially for less experienced doctors to make difficult end-of-life decisions more objective and less dependent on physicians' own life-values.

2) Oncologists made less active treatment decisions for terminal patients compared to surgeons, internists and general practitioners. In general, experience of terminal care in practice influenced towards less active end-of-life decisions among all physicians. It may thus be concluded that training and experience give a wider view of the patient's real best in a terminal situation, and often leads to a decision to forgo futile treatments. These results

underline the importance of post-graduate education, especially in ethical decision-making, for all physicians working in terminal care.

3) Female and young doctors chose active treatment options for dying patients more often. They also were more influenced by the family's appeal for more active treatment. In the case of gender it may be concluded that it is partly a matter of gender-related difference in empathy and human thinking and also in women doctors' different life-values and attitudes; women doctors were more apt to condemn active euthanasia and they were more religious. One important factor was greater concern for the physician's legal protection among young and female doctors. The conclusion is that better knowledge of legislation and ethical guidelines would lead to more uniform decisions by doctors. More frequent advance planning of end-of-life care, for instance with the help of advance directives, would probably be of great benefit especially for less experienced doctors.

4) The diagnosis of the patient and the treatment considered had a great influence on the decision physicians made in terminal situations. The terminal dementia patient was treated in a more active way than terminal cancer patient by all speciality groups, all age groups and both genders of doctors. In the scenario of a terminal cancer patient thrombosis prophylaxis and mechanical ventilation would be withdrawn by almost all physicians, whereas intravenous hydration and supplementary oxygen only by a small minority of physicians. Wide variation was seen in physicians' attitudes to withdrawing specific life-prolonging treatments; greatest variation was found in physicians' decisions to use intravenous hydration. The conclusion is that research and education aiming at a better knowledge of prognoses and the real efficacy of treatments in future would probably lead to end-of-life decision-making, which better reaches the goals of care.

5) The internet-based education project in palliative care was rated satisfactory by most participants. Ethical end-of-life decision-making did not change much during the one-year project, this mainly due to the former interest, experience and education of this voluntary education group. Nonetheless, this project was shown to have a marked role in relieving work-linked stress among the participants. One of the most difficult tasks in fulfilling the

aims of this kind of post-graduate education project is to reach the “silent majority” of doctors.

6) Pain control was on a good level in the two different health care units for terminal cancer patients in Finland. However, some differences were found in the use of pain medication between general practitioner-managed health center wards and a specialist-managed hospice. Costs of pain medication did not differ and were very reasonable. According to this study GP-managed health care wards seem to give qualified pain management for elderly cancer patients.

## 8. Acknowledgements

This study was carried out at the Departments of General Practice and Oncology, in the Medical School of the University of Tampere, and in Tampere University Hospital, Finland. The three-year most intensive research period in my life, which brought this thesis to harvest, was greatly inspiring and worth all the trouble. I discovered the basic hypotheses for this research in my work in the Kangasala Health Center Wards. I owe profoundest thanks to all my colleagues and other personnel in there for the countless discussions on medical ethical dilemmas, which finally encouraged me in my mature years to set out on this project which “had been there waiting for me”.

I express my deepest gratitude to my enthusiastic and widely knowledgeable supervisors, Professor Pirkko-Liisa Kellokumpu-Lehtinen, M.D., and Docent Elise Kosunen, Ph.D., M.D., of the Medical School in the University of Tampere. You each had very different and markedly personal ways of guiding me from the first steps of this study. You complemented each other perfectly. I thank you for both the maternal patience and the stringent criticism, both of which motivated me to face my challenges more and more persistently. I wonder that you could manage with the e-mail chaos I addressed to you in moments of highest inspiration. My long-time colleague in Kangasala Health Center, Ulla-Kaija Lammi, M.D., Ph.D. also played an invaluable role in our research team. Apart from everything else, you have the honour of being the initial booster for this project. I am profoundly grateful.

I wish to express my sincere gratitude to Professor Kari Mattila, M.D., Head of the Department of General Practice, University of Tampere, for his encouraging support and flexibility in providing me with ideal facilities to carry out the studies.

I warmly thank Riina Metsänoja, M.Sc., School of Public Health, University of Tampere, for teaching and helping me with the statistics. Our co-operation was smooth and flexible. I am also pleased to thank Professor Pekka Laippala, D.Sc., School of Public Health, University of Tampere, for much advice in statistics. My gratitude also goes to Anne Puustelli, B.Sc., for the demanding work she undertook in data analysis. I am deeply

grateful to Ms. Arja Salomaa in the Department of General Practice in the Medical School of Tampere for the thorough technical conduct of the postal surveys. I am also pleased to thank Ms. Ella Taisto, my secretary in Kangasala Health Center, for her high-quality technical support during the study. Juha Hänninen, M.D, head of the Terho Hospice in Helsinki, afforded great assistance in carrying out the survey of GPs in the education project. Thank you very much. Kaija Holli, M.D., Ph.D., Professor of Palliative Medicine in the Medical School of Tampere University deserves the warmest thanks for much important advice during this study.

I owe special thanks to my collaborators in the study of terminal cancer pain. The personnel in the Pirkanmaa Hospice under the lead of Timo Leino, M.D., in the Health Center of Kangasala, headed by Toivo Rintamäki, M.D., and in the Health Center of Virrat under Kalevi Saloranta, M.D. deserve all gratitude for their unprejudiced attitude and perseverance in helping to carry out this demanding prospective study. Most of all I owe respectful thanks to all the patients who during the last days of their lives were unselfishly willing to participate in the study for the benefit of future patients.

I wish to express my gratitude to the official reviewers of this study, Docent Päivi Hietanen, M.D., Ph.D. of Helsinki University Hospital, and Professor Olli-Pekka Ryyänen, M.D., Ph.D. from the University of Kuopio, for their careful review and constructive comments, which helped me to improve the manuscript. The language was revised by David Kivinen, Diploma in Translation, and Robert MacGilleon, M.A., to whom I am grateful.

I thank my numerous friends for conversations enjoyed in my traditional smoke-sauna, and for the moments of quiet by camp-fires, and for the not so quiet moments in our jazz-gospel band. All this has given me intelligent, relaxing and spiritual atmosphere, which has enriched my thinking and kept me in touch with other perspectives of life.

My family has offered me love, respect and patience, all invaluable for my life and for this study. I thank my beloved wife, Marja, for her endless and unselfish support and care. I am

deeply grateful to my children Lassi, Anni and Inkeri for all the joy you have given to my life. Above all, I thank God for the privilege of being father in this lovely family.

In this research I cooperated in the “European Network of Teaching Cancer Care in General Practice”. The co-ordination of this network is done by the Department of General Practice/ Family Medicine, Division Public Health, Academic Medical Center/ University of Amsterdam, The Netherlands. The whole project was financially supported by the EU Europe Against Cancer Program. The Medical Research Fund of Tampere University Hospital, the Pirkanmaa Cancer Society, The Finnish Medical Association and The Research Institute of The Evangelical Lutheran Church of Finland also supported this work.

## 9. References

Aitken R (1969): Measurement of feelings using visual analogue scales. *Proc Roy Soc Med* 62:17-24.

Annas G (1994): Death by prescription. The Oregon Initiative. *N Engl J Med* 331:1240-1243.

Asai A, Fukuhara S and Lo B (1995): Attitudes of Japanese and Japanese-American physicians towards life-sustaining treatment. *Lancet* 346:356-359.

Asai A, Fukuhara S, Inoshita O, Miura Y, Tanabe N and Kurokawa K (1997): Medical decisions concerning the end-of-life: a discussion with Japanese physicians. *J of Med Ethics* 23:323-327.

Asai A, Maekawa M, Akiguchi I, Fukui T, Miura Y, Tanabe N and Fukuhara S (1999): Survey of Japanese physicians' attitudes towards the care of adult patients in persistent vegetative state. *J Med Ethics* 25:302-308.

Asch D, Hansen-Flaschen J and Lancken P (1995): Decisions to limit or continue life-sustaining treatment by critical care physicians in the United States: conflicts between physicians' practices and patients' wishes. *Am J Respir Crit Care Med* 151:288-292.

Asch DA, Jedrzejewski MK and Christakis NA (1997): Response rates to mail surveys published in medical journals. *J Clin Epidemiol* 50:1129-1136.

Asch D, Faber-Langendoen K, Shea J and Christakis N (1999): The sequence of withdrawing life-sustaining treatment from patients. *Am J Med* 107:153-156.

Bacon F (1958). *The Advancement of Learning*. J.M.Dent., London.

Blackhall L, Frank G, Murphy S, Michael V, Palmer J and Azen S (1999): Ethnicity and attitudes towards life sustaining technology. *Soc Sci Med* 48:1779-1789.

Blondeau D, Valois P, Keyserlingk EW, Hebert M and Lavoie M (1998): Comparison of patients' and health care professionals' attitudes towards advance directives. *J Med Ethics* 24:328-335.

Boisvert M and Cohen SR (1995): Opioid Use in Advanced Malignant Disease: Why Do Different Centers Use Vastly Different Doses? A Plea for Standardized Reporting. *J Pain Symptom Manage* 10:632-638.

British Medical Association (1999). *Withholding and Withdrawing Life-prolonging Medical Treatment*. BMJ Books, London.

Brock D (1992): Euthanasia. *The Yale Journal of Biology and Medicine* 65:121-129.

Bruera E, Spachynski K, MacEachern T and Hanson J (1993): Cognitive failure in cancer patients in clinical trials (Letter). *Lancet* 341:247-248.

Bruera E, Neumann C, Mazzocato C, Stiefel F and Sala R (2000): Attitudes and beliefs of palliative care physicians regarding communication with terminally ill cancer patients. *Palliat Med* 14:287-298.

Buchan ML and Tolle SW (1995): Pain relief for dying persons: dealing with physicians' fears and concerns. *J Clin Ethics* 6:53-61.

Buckman R (1998). Communication in palliative care: a practical guide. In: *Oxford Textbook of Palliative Medicine*, pp. 139-156. Eds. D. Doyle, G. Hanks and N. MacDonald, Oxford University Press, Oxford.

Burge FI (1993): Dehydration symptoms of palliative care cancer patients. *J Pain Symptom Manage* 8:454-464.

Burge F (1996): Dehydration and provision of fluids in palliative care. What is evidence? *Can Fam Physician* 42:2383-2388.

Cane W (1952): Medical euthanasia. *Journal of the History of Medicine and Allied Sciences* VII:401-416.

Carmel S (1999): Life-sustaining treatments: what doctors do, what they want for themselves and what elderly persons want. *Soc Sci Med* 49:1401-1408.

Carter Y and Thomas C (1997): *Research Methods in Primary Care*. Radcliffe Medical Press, Oxford and New York.

Cassell E (1991): *Nature of Suffering and the Goals of Medicine*. Oxford University Press, Oxford.

Cassem N (1980): When illness is judged irreversible: imperative and elective treatments. *Man and Medicine* 5:154-166.

Cherny NI and Portenoy RK (1993): Cancer pain management. Current strategy. *Cancer* 72:3393-3415.

Cherny NJ, Chang V, Frager G, Ingham JM and Tiseo PJ (1995): Opioid pharmacotherapy in the management of cancer pain. *Cancer* 76:1288-93.

Chochinov HM and Kristjanson L (1998): Dying to pay: the cost of end-of-life care. *J Palliat Care* 14:5-15.



Christakis NA and Asch DA (1993): Biases in how physicians choose to withdraw life support. *Lancet* 342:642-646.

Christakis NA and Asch DA (1995): Physician characteristics associated with decisions to withdraw life support. *Am J Public Health* 85:367-372.

Cleeland C, Gonin R, Hatfield A, Edmonson J, Blum R, Stewart J and Pandya K (1994): Pain and its treatment in outpatients with metastatic cancer. *N Engl J Med* 330:592-596.

Collins S, Moore R and McQuay H (1997): The visual analogue pain intensity scale: what is moderate pain in millimetres? *Pain* 72:95-7.

Council on Ethical and Judicial Affairs of American Medical Association (1992): Decisions near the end of life. *JAMA* 267:2229-2233.

Council on Ethical and Judicial Affairs of American Medical Association (1999): Medical futility in end-of-life care. *JAMA* 281:937-941.

Danis M, Southerland L, Garret JM and Smith JL (1991): A prospective study of advance directives for life-sustaining care. *N Engl J Med* 324:882-888.

Daugherty C, Ratain M, Grochowski E, Stocking C, Kodish E, Mick R and Siegler M (1995): Perceptions of cancer patients and their physicians involved in Phase I trials. *J Clin Oncol* 13:1062-1072.

Davis A, Davidson B, Hirschfield M, Lauri S, Lin J, Nordberg A, Phillips L, Pitman E, Shen C and van der Laan R (1993): An international perspective of active euthanasia: attitudes of nurses in seven countries. *Int J Nurs Stud* 30:301-310.

de Stoutz ND, Bruera E and Suarez-Almazor M (1995): Opioid toxicity reduction in terminal cancer patients. *J Pain Symptom Manage* 10:378-84.

Di Mola G, Borsellino P, Brunelli C, Gallucci M, Gamba A, Lusignani M, Regazzo C, Santosuosso A, Tamburini M and Toscani F (1996): Attitudes toward euthanasia of physician members of the Italian Society for Palliative Care. *Annals of Oncology* 7:907-911.

Donner B, Zenz M, Tryba M and Strumpf M (1996): Direct conversion from morphine to transdermal fentanyl: a multicenter study in patients with cancer pain. *Pain* 64:527-34.

Doyal L and Wilsher D (1993): Withholding cardiopulmonary resuscitation: proposals for formal guidelines. *BMJ* 306:1593-6.

Doyle D (1996): Education in palliative medicine. *Palliat Med* 10:91-92.

Doyle D, Hanks G and MacDonald N (1998). Introduction. In: Oxford Textbook of Palliative Medicine, pp. 1-8. Eds. D. Doyle, G. Hanks and N. MacDonald, Oxford University Press, Oxford.

Dunphy K (2000): Futilitarianism: knowing how much is enough in end-of-life health care. *Palliat Med* 14:313-322.

Elsey B and McIntyre J (1996): Assessing a support and learning network for palliative care workers in a country area of South Australia. *Australian Journal of Rural Health* 4:159-64.

Emanuel E (1996): Cost savings at the end of life. What do the data show? *JAMA* 275:1907-1914.

Emanuel EJ, Fairclough DL, Daniels ER and Clarridge BR (1996): Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 347:1805-1810.

Faber-Langendoen K (1991): Resuscitation of patients with metastatic cancer. Is transient benefit still futile? *Ann Intern Med* 151:235-239.

Faber-Langendoen K and Bartels DM (1992): Process of forgoing life-sustaining treatment in a university hospital: An empirical study. *Crit Care Med* 20:570-577.

Feldman M, Zhang J and Cummings S (1999): Chinese and U.S. internists adhere to different ethical standards. *J Gen Intern Med* 14:469-473.

Ferrand E, Robert R, Ingrand P and Lemaire F (2001): Withholding and withdrawal of life support in intensive-care units in France: a prospective study. *Lancet* 357:9-14.

Fins J and Nilson E (2000): An approach to educating residents about palliative care and clinical ethics. *Acad Med* 75:662-665.

Force ATSBT (1991): Withholding and withdrawing life-sustaining therapy. *Am Rev Respir Dis* 144:726-731.

Fried C (1974): *Medical Experimentation, Personal Integrity and Social Policy*, pp 101-105. North-Holland Publishing Company, Amsterdam, Oxford.

Gift A (1989): Visual analogue scales: measurement of subjective phenomena. *Nurs Res* 38:286-288.

Gillick MR (1988): Limiting medical care: physicians' beliefs, physicians' behavior. *J Am Geriatr Soc* 36:747-752.

Gostin L, Turek-Brezina J and Powers M (1993): Privacy and security of personal information in a new health care system. *JAMA* 270:2487-2493.

Grande GE, Barclay SI and Todd CJ (1997): Difficulty of symptom control and general practitioners' knowledge of patients' symptoms. *Palliat Med* 11:399-406.

Hadorn D (1991): The Oregon priority-setting exercise: quality of life and public policy. *Hasting Center Report* May-June:11-16.

Hall J and Roter D (1998): Medical communication and gender: a summary of research. *J Gen Specif Med* 1:39-42.

Hanson LC and Danis M (1991): Use of life-sustaining care for the elderly. *J Am Geriatr Soc* 39:772-777.

Hanson LC and Rodgman E (1996): The use of living wills at the end of life. *Arch Intern Med* 156:1018-1022.

Hanson L, Danis M, Garrett J and Mutran E (1996): Who decides? Physicians' willingness to use life-sustaining treatment. *Arch Intern Med* 156:785-789.

Hanson LC, Danis M and Garrett J (1997): What is wrong with end-of-life care? Opinions of bereaved family members. *J Am Geriatr Soc* 45:1339-1344.

Hanson L, Earp J, Garrett J, Menon M and Danis M (1999): Community physicians who provide terminal care. *Arch Intern Med* 159:1133-1138.

Higginson I (1998): Clinical and organizational audit in palliative care. In: *Oxford Textbook of Palliative Medicine*, pp. 67-81. Eds. D. Doyle, G. Hanks and N. MacDonald, Oxford University Press, Oxford.

Holmes M, Rovner D and Rothert M (1989): Methods of analyzing physician practice patterns in hypertension. *Med Care* 27:59-68.

Hosmer DW and Lemeshow S (1989): *Applied Logistic Regression*. John Wiley & Sons, New York.

Huang Z and Ahronheim J (2000): Nutrition and hydration in terminally ill patients. *Clinics in Geriatric Medicine* 16:313-325.

International Narcotics Control Board (1998): *Narcotic drugs, estimated world requirements for 1998, statistics for 1996*. United Nations, New York.

Johnston S and Pfeifer M (1998): Patient and physician roles in end-of-life decision-making. *J Gen Intern Med* 13:43-45.

Jones T, Gerrity M and Earp J (1990): Written case simulations: Do they predict physicians' behavior? *J Clin Epidemiol* 43:805-815.

Joyce C, Zutshi D, Hrubes V and Mason R (1975): Comparison of fixed interval and visual analogue scales for rating chronic pain. *Eur J Clin Pharmacol* 8:415-420.

Kaasalainen V, Vainio A and Ali-Melkkilä T (1997): Developments in the treatment of cancer pain in Finland: the third nation-wide survey. *Pain* 70:175-183.

Kinsella T and Verhoef M (1993): Alberta euthanasia survey: Physicians opinions about the morality and legalization of active euthanasia. *Canadian Medical Association Journal* 148:1921-1926.

Kirwan J, Bellamy N and Condon H (1983): Judging "current disease activity" in rheumatoid arthritis: An international comparison. *J Rheumatol* 10:901-905.

Kodish E, Stocking C, Ratain M, Kohrman A and Siegler M (1992): Ethical issues in Phase I oncology research: a comparison investigators and institutional review board chairpersons. *J Clin Oncol* 10:1810-1816.

Kollef M and Ward S (1999): The influence of access to a private attending physician on the withdrawal of life-sustaining therapies in the intensive care unit. *Crit Care Med* 27:2125-2132.

Kosunen E, Pahlman I and Louhiala P (2001): Euthanasia in Finland. In: *Euthanasia in Europe - National laws, medical guidelines, ethical aspects*. Eds. Sohn W, Zenz M, Schattauer, Stuttgart and New York.

Lammi U-K, Kosunen E and Kellokumpu-Lehtinen P (2000): Palliative cancer care in two health centres and one hospice in Finland. *Support Care Cancer* 1:1-11.

Larue F, Colleau S, Brasseur L and Cleeland C (1995): Multicentre study of cancer pain and its treatment in France. *BMJ* 310:1034-1037.

Lawrence VA and Clark GM (1987): Cancer and resuscitation. Does the diagnosis affect the decision? *Arch Intern Med* 147:1637-1640.

Liberati A, Apolone G and Nicolucci A (1991): The role of attitudes, beliefs, and personal characteristics of Italian physicians in the surgical treatment of early breast cancer. *Am J Public Health* 81:38-42.

Linder J, Blais J, Enders S, Melberg S and Meyers F (1999): Palliative education: a didactic and experiential approach to teaching end-of-life care. *J Cancer Educ* 14:154-160.

Lloyd-Williams M and Lloyd-Williams F (1996): Palliative care teaching and today's general practitioners- is it adequate? *Eur J Cancer Care* 5:242-245.

Longstreth G (1987): Detecting colorectal neoplasms: Assessment based on hypothetical cases. *J Clin Gastroenterol* 9:331-336.

Lubitz J and Riley G (1993): Trends in medicare payments in the last year of life. *N Engl J Med* 328:1092-1096.

Luce J (1999): Physician variability in limiting life-sustaining treatment. *Crit Care Med* 27:2291-2292.

MacDonald N (1993): Priorities in education and research in palliative care. *Palliat Med* 7:65-76.

MacDonald N (1994): From the front lines. *J Palliat Care* 10:44-47.

Mandelplatt J, Berg C, Meropol N, Edge S, Gold K, Hwang Y and Hadley J (2001): Measuring and predicting surgeons' practice styles for breast cancer treatment in older women. *Med Care* 39:228-242.

McLean R, Tarshis J, Mazer C and Szalai J (2000): Death in two Canadian intensive care units: institutional difference and changes over time. *Crit Care Med* 28:100-103.

Mebane EW, Oman RF, Kroonen LT and Goldstein MK (1999): The influence of physician race, age, and gender on physician attitudes toward advance care directives and preferences for end-of-life decision-making. *J Am Geriatr Soc* 47:579-591.

Meisel A, Snyder L and Quill T (2000): Seven legal barriers to end-of-life care: myths, realities, and grains of truth. *JAMA* 284:2495-2501.

Mercadante S (1999): Pain treatment and outcomes for patients with advanced cancer who receive follow-up care at home. *Cancer* 85:1849-58.

Mercadante S, Casuccio A, Pumo S and Fulfaro F (2000): Factors influencing the opioid response in advanced cancer patients with pain followed at home: the effects of age and gender. *Support Care Cancer* 8:123-130.

Mercadante S and Dardadoni G (1997): Monitoring of Opioid Therapy in Advanced Cancer Pain Patients. *J Pain Symptom Manage* 13:204-212.

Mercadante S and Trizzino G (1997): The SAMOT supportive programme in southern Italy. *Support Care Cancer* 5:5-8.

Miller MD and Ferris DG (1993): Measurement of subjective phenomena in primary care research: the Visual Analogue Scale. *Family Practice Research Journal* 13:15-24.

Molloy DW, Guyatt GH, Alemayehu E and McIlroy W (1991): Factors affecting physicians' decisions on caring for an incompetent elderly patient: an international study. *Can Med Assoc J* 145:947-952.

Morrell D and Romano P (1990): Analysis of referral behaviour: Responses to simulated case histories may not reflect real clinical behaviour. *Br J Gen Pract* 40:182-185.

Moskowitz A, Kuipers B and Kassirer J (1988): Dealing with uncertainty, risks, and trade offs in clinical decisions: a cognitive science approach. *Ann Intern Med* 108:435-449.

Neittaanmäki L, Gross E, Virjo I, Hyppölä H and Kumpusalo E (1999): Personal values of male and female doctors: gender aspects. *Soc Sci Med* 48:559-568.

Neuberger J (1998): Cultural issues in palliative care. In: *Oxford Textbook of Palliative Medicine*, pp 775-785. Eds. D. Doyle, G. Hanks and N. MacDonald, Oxford University Press, Oxford.

Oneschuk D, Fainsinger R, Hanson J and Bruera E (1997): Assessment and knowledge in palliative care in second year family medicine residents. *J Pain Symptom Manage* 14:265-73.

Pahlman I (1997): Potilaan itsemääräämisoikeus ja hoitotestamentti (Patient's right of self-determination and living will). *Lakimies* 95:815-835.

Paume P and O'Malley E (1994): Euthanasia: attitudes and practices of medical practitioners. *Medical Journal of Austria* 161:137-144.

Perkins HS, Bauer RL, Hazuda HP and Schoolfield JD (1990): Impact of legal liability, family wishes, and other "external factors" on physicians' life-support decisions. *Am J Med* 89:185-194.

Pfeifer M, Sidorov J, Smith A, Boero J, Evans A and Settle M (1994): The discussion of end-of-life medical care by primary care patients and physicians: a multicenter study using structured qualitative interviews. The EOL Study Group. *J Gen Intern Med* 9:82-88.

Pijnenborg L, van Delden J, Kardaun J, Glerum J and van der Maas P (1994): Nationwide study of decisions concerning the end of life in general practice in the Netherlands. *BMJ* 309:1209-1212.

Pijnenborg L, van der Maas PJ, Kardaun JWPF and Glerum JJ (1995): Withdrawal or withholding of treatment at the end of life. Results of a nationwide study. *Arch Intern Med* 155:286-292.

Portenoy RK and Lesage P (1999): Management of cancer pain. *Lancet* 353:1695-1700.

Prendergast T and Luce J (1997): Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 155:15-20.

Rees E, Hardy J, Ling J, Broadley K and A'Hern R (1998): The use of the Edmonton Symptom Assessment Scale (ESAS) within a palliative care unit in the UK. *Palliat Med* 12:75-82.

Roy D and MacDonald N (1998): Ethical issues in palliative care. In: *Oxford Textbook of Palliative Medicine*, pp. 95-138. Eds. D. Doyle, G. Hanks and N. MacDonald, Oxford University Press, Oxford.

Ryan C and Kaye M (1996): Euthanasia in Australia - The Northern Territory rights of the terminally ill act. *N Engl J Med* 334:326-328.

Sarhill N, Walsh D, Nelson K and Davis M (2001): Evaluation and treatment of cancer-related fluid deficits: volume depletion and dehydration. *Support Care Cancer* (Online 10 July 2001).

Saunders C (1998). Foreword. In: *Oxford Textbook of Palliative Medicine*. Eds. D. Doyle, G. Hanks and N. MacDonald, Oxford University Press, Oxford.

Saunderson EM and Ridsdale L (1999): General practitioners' beliefs and attitudes about how to respond to death and bereavement: qualitative study. *BMJ* 319:293-296.

Schug SA, Zech D, Grond S, Jung H and Meuser T (1992): A long-term survey of morphine in cancer pain patients. *J Pain Symptom Manage* 7:259-266.

Schuit K, Bender W, Meijler W, Otter R, Meyboom B and Sleijfer D (1999): Learning effects of a workshop in palliative cancer care for general practitioners. *J Cancer Educ* 14:18-22.

Schulman K, Berlin J and Harless W (1999): The effect of race and sex on physicians' recommendations for cardiac catheterization. *N Engl J Med* 340:618-626.

Scott J and Huskisson E (1976): Graphic representation of pain. *Pain* 2:175-184.

Sjökvist P, Berggren L and Cook D (1999): Attitudes of Swedish physicians and nurses towards the use of life-sustaining treatment. *Acta Anaesthesiol Scand* 43:167-172.

Sloan PA, Donnelly MB, Schwartz RW and Sloan DA (1996): Cancer pain assessment and management by housestaff. *Pain* 67:475-81.

Sloan PA, Donnelly MB, Vanderveer B, Delomas M, W SR and Sloan DA (1997): Cancer pain education among family physicians. *J Pain Symptom Manage* 14:74-81.

Sloan PA, Montgomery C and Musick D (1998a): Medical student knowledge of morphine for the management of cancer pain. *J Pain Symptom Manage* 15:359-364.

Sloan PA, Moulin DE and Hays H (1998b): A clinical evaluation of transdermal therapeutic system fentanyl for the treatment of cancer pain. *J Pain Symptom Manage* 16:102-111.

Smedira NG, Evans BH, Grais LS and Cohen NH (1990): Withholding and withdrawal of life support from the critically ill. *N Engl J Med* 322:309-315.

Snyder J and Swartz M (1993): Deciding to terminate treatment: a practical guide for physicians. *J Crit Care* 8:177-185.

Solomon MZ, O'Donnell L, Jennings B and Guilfooy V (1993): Decisions near the end of life: professional views on life-sustaining treatments. *Am J Public Health* 83:14-23.

Stern SG and Orlowski JP (1992): DNR or CPR - the choice is ours. *Crit Care Med* 20:1263-1272.

Stevens CA and Hassan R (1994): Management of death, dying and euthanasia: attitudes and practices of medical practitioners in South Australia. *J Med Ethics* 20:41-46.

Suarez-Almazor M, Belzile M and Bruera E (1997): Euthanasia and physician-assisted suicide: a comparative survey of physicians, terminally ill cancer patients, and the general population. *J Clin Oncol* 15:418-427.

Suomen Lääkäriliitto (2000): Lääkärin etiikka (Medical Ethics). Suomen Lääkäriliitto, Forssa.

Teno J, Licks S, Lynn J, Wenger N, Connors A, Phillips R, O'Connor M and Murphy D (1997): Do advance directives provide instructions that direct care? *J Am Geriatr Soc* 45:508-512.

The SUPPORT Principal Investigators (1995): A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 274:1591-1598.

Truog R and Berde C (1993): Pain, euthanasia and anesthesiologists. *Anesthesiology* 78:353-360.

Wachter RM, Luce JM, Hearst N and Lo B (1989): Decisions about resuscitation: inequities among patients with different diseases but similar prognoses. *Ann Intern Med* 111:525-532.

Waddel C, Clarnette RM, Smith M, Oldham L and Kellehear A (1996): Treatment decision-making at the end of life: a survey of Australian doctor's attitudes towards patient's wishes and euthanasia. *MJA* 165:540-544.



Vainio A (1988): Treatment of terminal cancer pain in Finland. A questionnaire survey. *Acta Anaesthesiol Scand* 32:260-265.

Vainio A (1992): Treatment of terminal cancer pain in Finland: a second look. *Acta Anaesthesiol Scand* 36:89-95.

Vainio A (1995): Treatment of terminal cancer pain in France: a questionnaire study. *Pain* 62:155-162.

Vainio A and Auvinen A (1996): Prevalence of symptoms among patients with advanced cancer: an international collaborative study. *J Pain Symptom Manage* 12:3-10.

Wakefield M, Beilby J and Ashby M (1993): General practitioners and palliative care. *Palliat Med* 7:117-126.

Wall P (1986): Editorial - 25 volumes of pain. *Pain* 25:1-4.

van der Maas P, van Delden J, Pijnenborg L and Looman C (1991): Euthanasia and other medical decisions concerning the end of life. *Lancet* 338:669-674.

van MacCrary S and Swansosn J (1999): Physicians' legal defensiveness and knowledge of medical law: comparing Denmark and the USA. *Scand J Public Health* 27:18-21.

Varon J, Walsh GL, Marik PE and Fromm RE (1998): Should a cancer patient be resuscitated following an in-hospital cardiac arrest? *Resuscitation* 36:165-168.

Weber W (2000): Netherlands proposal for comprehensive euthanasia legislation. *Lancet* 356:1666.

Weiss SC (1999): Economics, ethics, and end-of-life care. *JAMA* 282:2076.

Vincent JL (1990): European attitudes towards ethical problems in intensive care medicine: results of an ethical questionnaire. *Intensive Care Med* 16:256-264.

Vincent JL (1999): Forgoing life support in western European intensive units: the results of an ethical questionnaire. *Crit Care Med* 27:1626-1633.

VonRoenn J, Cleeland C, Gonin R, Hatfield A and Pandya K (1993): Physician attitudes and practice in cancer pain management. A survey from the Eastern Cooperative Oncology Group. *Ann Intern Med* 119:121-126.

World Health Organization (1986): *Cancer pain relief*, WHO, Geneva.

World Health Organization (1990): *Cancer Pain Relief and Palliative Care*, WHO, Geneva.

World Medical Association (1987): Declaration on Euthanasia.

Vuorinen E, Vainio A and Reponen A (1997): Backlash in the treatment of cancer pain: use of opioid analgesics in a Finnish general hospital in 1987, 1991, and 1994. *J Pain Symptom Manage* 14:286-291.

Youngner S (1996): Medical futility. *Crit Care Clin* 12:165-178.

Zech DFJ, Grond S, Lynch J, Hertel D and Lehmann KA (1995): Validation of World Health Organization Guidelines for cancer pain relief: a 10-year prospective study. *Pain* 63:65-76.

Zhukovsky DS, Gorowski E, Hausdorff J, Napolitano B and Lesser M (1995): Unmet Analgesic Needs in Cancer Patients. *J Pain Symptom Manage* 10:113-119.

Zinberg J (1989): Decisions for the dying: an empirical study of physicians' responses to advance directives. *Vermont Law Review* 13:445-491.

Zuckerman C and Wollner D (1999): End of life care and decision making: how far we have come, how far we have to go. *Hosp J* 14:85-107.

## 10. Appendix

### Questionnaire (studies I-IV):

Answer the questions based on the following patient scenarios in the given order. Choose one of the three treatment options given (palliative, active, intensive). Circle the right option. Do not change your answer once decided.

**Palliative care** - good nursing, sufficient medication for pain and other symptoms, intravenous hydration only when it provides relief for the patient's symptoms

**Active care** – use of antibiotics, intravenous hydration or blood transfusions aimed at saving the patient's life in a life-threatening condition

**Intensive care** - referring the patient to the intensive care unit (ICU)

Scenario 1: An 82-year-old retired forest worker was diagnosed with prostatic cancer 3 years ago. During the past year he has received treatments for bone metastases. He has now been in hospital for a month, almost totally bedridden, and needs help with all functions. His mental condition has been normal. His general condition has weakened during the past week, he is now totally bedridden and has received large doses of pain medication. Today he became comatose. His haemoglobin count has decreased to 68 g/l, the week before it was 118 g/l. His blood pressure is 80/40 mm Hg. There is no verbal or written advance directive. The patient's wife has previously said she expects the doctor to make all treatment decisions according to his/her best understanding. Is your treatment decision

a) palliative care    b) active care    c) intensive care

The following four hypothetical situations complement this scenario:

A) You are told by a nurse that today the patient's faeces have been black. You remember having started ketoprofen medication for pain one week ago. Is your treatment decision

a) palliative care    b) active care    c) intensive care

B) You are told by a nurse that the patient's son is coming from the US the day after tomorrow to see his father still alive. Is your treatment decision

a) palliative care    b) active care    c) intensive care

C) You are told by a nurse that the patient has been in a spiritual crisis, and he has an appointment tomorrow with a congregation minister to receive Holy Communion. Is your treatment decision

a) palliative care    b) active care    c) intensive care

D) You are told by a family member that there is a written advance directive in which the patient wishes any active treatments to be withheld when there is no hope of recovery.

Is your treatment decision

a) palliative care    b) active care    c) intensive care

Evaluate the influence of the following factors on your decision on a scale 1-5

	very little influence					very much influence
patient's benefit	1	2	3	4	5	
family's benefit	1	2	3	4	5	
patient's legal protection	1	2	3	4	5	
doctor's legal protection	1	2	3	4	5	
ethical norms	1	2	3	4	5	
patient's age	1	2	3	4	5	
costs of care	1	2	3	4	5	
patient's social status	1	2	3	4	5	

Scenario 2: An 82-year-old man has suffered from progressive dementia for three years. He has been diagnosed as suffering from Alzheimer's disease. He is brought to the emergency department at 2 am with life-threatening gastrointestinal bleeding. He lives in a nursing home, has urinary and faecal incontinence, needs help washing and dressing and does not recognize his daughter. His blood pressure is 70/40 mm Hg and his heart rate 120 beats/min. The patient cannot communicate, and his family and physician cannot be reached. The nurse's aide who accompanied him to the emergency department is not familiar with the patient. There is no information available as to his wishes or those of his family concerning treatment in this situation. Is your treatment decision

- a) palliative care    b) active care    c) intensive care

Evaluate the influence of the following factors on your decision on a scale 1-5

	very little influence					very much influence
patient's benefit	1	2	3	4	5	
family's benefit	1	2	3	4	5	
patient's legal protection	1	2	3	4	5	
doctor's legal protection	1	2	3	4	5	
ethical norms	1	2	3	4	5	
patient's age	1	2	3	4	5	
level of dementia	1	2	3	4	5	
costs of care	1	2	3	4	5	
patient's social status	1	2	3	4	5	

Scenario 3: A 45-year-old woman suffers from pancreatic cancer with multiple metastases in the liver. There are no possibilities for active treatment. In three months she has become caecetic. Now she is in your wards in terminal care. Her friends are planning to take her to another city (distance 300 km) to consult a private doctor to get immunization treatment. The patient and her friends have expressed criticism of the official medical treatment and made accusations of a delay in diagnosis. As the doctor responsible for her care you

- a) accept the plan (as the last glimmer of hope) without criticizing it, because there is no medical treatment which you can order her
- b) you have a negative attitude to the plan and tell this the patient properly and justify your opinion with medical facts
- c) I don't know
- d) other.....

The same patient is in any case in your wards and is receiving immunization therapy ordered by an other physician. The therapy includes a special diet, which incurs about 20 ecus additional cost per day.

- a) you refuse to carry through the diet
- b) the patient can have the diet, but she has to pay the extra costs
- c) the patient can have the diet, because her presumed life expectation is very short
- d) other decision.....

Scenario 4: A 68-year-old patient suffers from breast cancer with bone metastases. She is bed-ridden and her general condition has rapidly collapsed. She is in health center ward and is receiving adequate pain treatment with which she is pleased. She is depressed and says she wants to get to a transfer to a hospice for her last days. She says she feels the atmosphere on the wards very restless and “institutional”. You have the right to issue a voucher for the costs (180 ecus per day) to be paid by the health center. The costs would be about double those in the health center and the chief doctor has advised you to use great discretion in issuing vouchers. Your solution:

- a) to accept the transfer
- b) to accept the transfer, provided that the patient pays the extra costs herself
- c) not to accept, because according to normal practice the patient’s care belongs to the health center wards and there are no special problems in her care
- d) I don’t know
- e) other.....

Scenario 5: A 60-year-old patient suffers from prostatic cancer with metastases. Because of a metastasis in the thoracic spine he has suffered from a total paraparesis for a month. There is no hope of improvement. The patient is well oriented to situation but he has totally lost his will to live. When you are alone together, he asks you for a morphine dose high enough to “get away”. You have refused overdoses, telling him that it is against your ethical principles. During the following days you notice that the patient is asking daily to double the morphine dose because of unbearable pain. As the anti-inflammatory pain medication is maximal you suspect the reality of the pain. You assess that such a rapid raising of the morphine dose would lead to the death of the patient. Your decision:

- a) to accept the raising of the morphine dose, because the patient in this terminal situation has the right to receive adequate pain treatment
- b) you try to help the patient’s situation by other therapy, i.e. antidepressants. You go on with the morphine doses given in guidelines.
- c) I don’t know
- d) other.....

Scenario 6: A 32-year-old female patient is brought by ambulance to the emergency department. She is accompanied by her husband who says his wife has inoperable brain cancer. She has been receiving maximum radiotherapy, but this has been discontinued three weeks previously. Her condition has deteriorated considerably during the past week. The patient has now had an epileptic seizure and has been unconscious since the attack. After 20 minutes at the department, the patient stops breathing and there is no pulse. Is your treatment decision

- a) to start CPR
- b) to withhold CPR

Scenario 7: A 62 –year-old male patient with pulmonary cancer and metastases is under your care in a hospital ward. He has high-dose morphine medication. Due to asphyxia he became comatose last night. He also suffers from severe anaemia, has abundant pleural exudation and fever. Which of the following treatments already started (\*) or planned would you withhold or withdraw. There is no possibility to discuss the situation with the family and there is no advance directive.

Would you withhold or withdraw any of the following treatment modes; express your decision on the scale 1-5

	I definitely would not					Yes I definitely would				
a) antibiotics (*)	1	2	3	4	5					
b) mechanical ventilation (*)	1	2	3	4	5					
c) blood transfusion	1	2	3	4	5					
d) pleural centesis	1	2	3	4	5					
e) thorax X-ray examination	1	2	3	4	5					
f) laboratory examination	1	2	3	4	5					
g) iv hydration (*)	1	2	3	4	5					
h) naso-gastric tube (*)	1	2	3	4	5					
i) thrombosis prophylaxy (*)	1	2	3	4	5					
j) supplementary oxygen (*)	1	2	3	4	5					

In the following two alternatives extra information on the same patient scenario:

A1) The patient’s daughters come distressed and crying to you, expressing their hope that everything possible be done to save their father’s life. Which of the following treatments already started (\*) or planned would you withhold or withdraw in this situation? (Same alternatives as above given)

A2) There is in any case a written advance directive in the patient’s medical chart. In this he expresses his wish that all active treatment should be withdrawn if there is no hope of recovery. Which of the following treatments already started (\*) or planned would you withhold or withdraw in this situation? (Same alternatives as above given)

Fear-of-death query:

8) Here some opinions and views on death are presented. Choose the alternative that is closest to your own thinking.

	Definitely agree	Agree to some extent	I don't know	I don't quite agree	Definitely disagree
A) Death is like a long dream	1	2	3	4	5
B) Dying means suffering	1	2	3	4	5
C) Dying is not tragic for the one dying but for those who remain	1	2	3	4	5
D) Death always comes too soon	1	2	3	4	5
E) Our existence does not end at death	1	2	3	4	5
F) Death is always in "higher hands"	1	2	3	4	5
G) I fear death	1	2	3	4	5
H) I fear that someone in my family will die	1	2	3	4	5
I) I worry about the sadness brought to my family by my own death	1	2	3	4	5
J) Sometimes I imagine what it would be like at my own funeral	1	2	3	4	5
K) I am distressed to think that some day I shall not exist	1	2	3	4	5

The validation of the fear-of-death index was following:

Originally a set of 13 questions concerning fear-of death was presented to 506 doctors (random sample from Finnish Medical Association's register), 580 nurses (random sample from the register of Finnish Association of Nurses) and 587 people (over 18 years) derived randomly from Finnish General Public Register. A factor analysis was carried out to find the questions that best defined the responder's anxiety concerning death. A reliability analysis was carried out (SPSS). This gave 4 questions that best related to anxiety caused by fear of death.

A test-retest was carried out first in a group of 50 nursing students, who completed the questionnaire and did it again after 2 weeks. After reformulating the questionnaire according to results of reliability analysis, a new test-retest procedure was carried out, with an interval of 2 weeks, in a group of 70 nursing students. In this reliability test the Kappa value for the questions was 0.4-1.0, indicating good reliability of the questionnaire. (Ryynänen, OP, Myllykangas, M, University of Kuopio, Finland 2001, unpublished)





## ORIGINAL ARTICLES