ADVANCE CARE PLANNING

Elderly patients' preferences and practices in long-term care

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ACADEMIC DISSERTATION

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APPENDICES

LIST OF ABBREVIATIONS

ACP	advance care planning
AD	advance directive
ADL	activities for daily living
AP	advance planning
BMA	British Medical Association
CPR	cardiopulmonary resuscitation
CPS	Cognitive Performance Scale
15D	15D instrument of health-related quality of life
DEBATE	Drugs and Evidence Based Medicine in the Elderly (Study)
DM	decision-making
DNH	do-not-hospitalize
DNR	do-not-resuscitate
DPAHC	durable power of attorney for health care
ETENE	National Advisory Board on Health Care Ethics
HELP	Hospitalized Elderly Longitudinal Project
ICU	intensive care unit
LST	life-sustaining treatment
LTC	long-term care
LW	living will
MDS	minimum data set
MMSE	Mini Mental State Examination
NYHA	New York Heart Association's classification for organic heart disease
OR	odds ratio
PACE	Program of All-Inclusive Care for the Elderly
POLST	Physician Orders for Life-Sustaining Treatments
PSDA	Patient Self-Determination Act (1990) in the US
RAI	Resident Assessment Instrument
SD	standard deviation
STAKES	National Research and Development Centre for Welfare and Health
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments
WHO	World Health Organization

DEFINITIONS

These definitions have been used in this thesis and they are also presented in Figure 1.

Advance care planning (ACP)	A process of planning future medical care by discussions and team building between health care professionals, patients and families aimed at preserving quality of care at the end of life (Emanuel, 2000).
Advance directive (AD)	A description of one's future preferences for medical treatment that is provided in anticipation of a time when one may not be able to express these preferences because of serious illness or injury (Prendergast, 2001).
Advance planning (AP)	A process of reflection, discussion and communication of treatment preferences for end-of-life care that precedes and may lead to an advance directive (Miles et al., 1996).
Death	The very last moment of life, the moment of death and the following moment.
Dying	The time preceding death when it is obvious that the ongoing process will end in death.
End-of-life care	The care for a patient whose illness is progressive and incurable and for which prognosis-improving treatment is either unavailable or has been rejected by the patient; the patient's life expectance is short.
Life-sustaining treatments (LSTs)	Treatments that sustain life such as cardiopulmonary resuscitation, intubation, mechanical ventilation and antibiotics.
Palliative care	"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"(WHO 2002).

LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following original publications, which are referred to in the text by Roman numerals **I–V**. Some unpublished information is also presented.

I Laakkonen M-L, Pitkälä KH, Strandberg TE. Terminally ill elderly patient's experiences, attitudes, and needs: a qualitative study. OMEGA 2004;49:117–129.

II Laakkonen M-L, Pitkälä KH, Strandberg TE, Berglind S, Tilvis RS. Living will, resuscitation preferences, and attitudes towards life in an aged population. Gerontology 2004;50:247–254.

III Laakkonen M-L, Pitkälä KH, Strandberg TE, Tilvis RS. Physical and cognitive functioning and resuscitation preferences of aged patients. Journal of the American Geriatrics Society 2005;53:168–170.

IV Laakkonen M-L, Pitkälä KH, Strandberg TE, Berglind S, Tilvis RS. Older people's reasoning for resuscitation preferences and their role in the decision-making process. Resuscitation 2005, in press.

V Laakkonen M-L, Finne-Soveri UH, Noro A, Tilvis RS, Pitkälä KH. Advance orders to limit therapy in 67 long-term care facilities in Finland. Resuscitation 2004;61:333–339.

ABSTRACT

Background: Developments in life-sustaining medical technology and greater emphasis on medical care at the end of life have provoked interest in issues related to advance care planning (ACP). Little is known about elderly Finnish patients' opinions and wishes regarding ACP.

Objectives: Terminally ill elderly patients' perceptions of the end of life and their needs and wishes regarding care were evaluated. In addition, preferences for life-sustaining treatments (LSTs) and end-of-life care of home-dwelling elderly vascular patients and the factors associated with these preferences were determined. Finally, documentation for do-not-resuscitate (DNR) orders in long-term care (LTC) facilities and factors related to these orders were reviewed. This thesis comprises five studies (I–V) in three different settings.

Methods: Study I consists of interviews of 11 terminally ill elderly patients in an acute ward. The patients answered semi-structured questions in detail. Data were analysed by qualitative methods. Study II is a cross-sectional descriptive study of 378 home-dwelling elderly (age >75 years) vascular patients participating in a cardiovascular prevention study (DEBATE) in 2000. Participants were asked about whether they had prepared of a living will (LW), preferences for cardiopulmonary resuscitation (CPR) in their current health situation and their attitudes towards life. General health, physical and cognitive functioning, depression, and quality of life were also assessed. Studies III and IV examined the results of the two-year follow-up in the DEBATE study.

Study V is based on RAI data of 5654 subjects from three different levels of institutional LTC: chronic care hospitals (n=1989), nursing homes (n=3310) and assisted living (n=355) in 67 LTC facilities in 19 municipalities. Patients were assessed by MDS version 2.0.

Results: Terminally ill elderly patients were content with their daily care and symptom management but evaluated the care in light of the great workload of the nurses, forgiving them for not having time to talk to individual patients. These patients did not perceive themselves as dying and preferred to talk about treatments that could revive them and maintain their hope. The patients valued warm relationships between family members and friends.

Of the participants in the DEBATE study, 12% had a LW. However, having a LW did not decrease the preference for CPR; half of participants preferred CPR in their current health situation. In a logistic regression analysis where age, gender, cognitive impairment, quality of life, symptoms of depression and attitudes towards life were added as covariates, only attitudes towards life; (having zest for life and feeling needed) was independently associated with preference for CPR. Symptoms of depression were not significantly associated with CPR preference.

Three out of four participants in the two-year follow-up had a stabile CPR preference.

In a second logistic regression analysis, where age, gender, the variables significantly associated with resuscitation preference in 2002, NYHA class 3 or 4 in 2000 and having a living will in 2000 were used as covariates. The significant predictor for CPR preference was feeling needed (OR 1.80; 95% CI 1.03-3.14). The preference to forgo CPR was independently associated with having a cognitive impairment (OR 0.39; 95% CI 0.19-0.81) and an age of over 85 years (OR 0.52; 95% CI 0.29-0.93) Gender, physical functioning, having a living will, symptoms of depression or being widowed were not significant associates for CPR preference.

In Study IV, we investigated older patients' reasoning for resuscitation preference and the decision-making process. Participants described their resuscitation preferences, most often stressing meaningful life experiences or fulfillment, good interpersonal relationships with loved ones and presumed outcome of CPR. Four out of five of these patients thought that the patient's view should be taken into account when making decisions about LST at the end of life. However, we found that only a few had discussed issues related to ACP with a physician.

Of RAI subjects, 13% had a DNR order. We noted marked differences in the prevalence of DNR orders between caring units. Diseases and activities of daily living status were only weakly significant as background factors.

Conclusions: The caring culture in the acute wards did not have sufficient psychological space for terminally ill patients to elaborate on issues relevant to them regarding end-of-life care. Physicians should routinely assess elderly patients' willingness to discuss ACP and their preferences about LST specifically exploring patients' attitudes towards life, values and ethics. Open discussions and general guidelines about advance care planning, including DNR decisions, are needed to improve equality and self-empowerment among the elderly.

ABSTRACT IN FINNISH

ELÄMÄN LOPPUVAIHEEN HOIDON SUUNNITTELU
– Iäkkäiden potilaiden toiveet ja pitkäaikaishoidon hoitokäytännöt

Taustaa: Lääketieteen ja teknologian kehitys sekä elämää ylläpitävien hoitojen mahdollinen käyttö lähellä kuolemaa on herättänyt yleistä keskustelua ja luonut ihmisille tarpeita ja mahdollisuuksia ennakoivasti ilmaista toiveitaan elämänsä loppuvaiheiden hoidoista.

Tutkimuksen tarkoitus: Tämän tutkimuksen tarkoitus oli selvittää sekä iäkkäiden sairaalahoidossa olevien vaikeasti sairaiden potilaiden, että iäkkäiden kotona asuvien hyväkuntoisten potilaiden hoitotoiveita liittyen elämää uhkaaviin tilanteisiin. Heidän hoitotoiveitaan tiedusteltiin nykyisessä terveyden tilassa ja lähestyvän kuoleman tilanteessa. Tarkoituksemme oli myös selvittää laitoshoidossa olevien iäkkäiden potilaiden ei-elvytystä eli DNR -merkintöjen yleisyyttä sairauskertomuksissa ja tutkia mitkä tekijät DNR -merkintöihin liittyvät. Tutkimus sisältää viisi osatyötä (I–V).

Menetelmät: I tutkimuksessa haastateltiin puolistrukturoiduin kysymyksin 11 vaikeasti sairasta iäkästä potilasta terveyskeskuksen akuutilla osastolla. Äänitenauhat litteroitiin kirjalliseen muotoon. Aineisto analysoitiin laadullisin menetelmin.

II tutkimus oli kuvaileva poikittaistutkimus, jossa kysyttiin 378:lta yli 75-vuotiaalta kotona asuvalta verisuonitautipotilaalta heidän elämänsä loppuvaiheen hoitotoiveita. Potilaat osallistuivat samanaikaisesti sydän- ja verisuonitautien hoito- ja ehkäisytutkimukseen (DEBATE). Tutkimushoitaja haastatteli potilaita puolistrukturoiduin kysymyksin. Hoitaja tiedusteli oliko potilailla kirjallinen hoitotahto ja minkälaiset elämän asenteet heillä oli. Hoitaja tiedusteli myös heidän kannanottoaan elvytykseen nykyisessä terveydentilassa äkillisen sydänpysähdyksen varalta. Potilaiden mieliala arvioitiin Zung- depressiomittarilla, elämän laatua arvioitiin 15D- mittarilla ja kognitiivista toimintakykyä MMSE- mittarilla. Heidän fyysistä toimintakykyään arvioitiin päivittäisellä ulkoilulla ja toisen henkilön avun tarpeella.

III ja IV tutkimus selvittivät kyseessä olevien potilaiden kaksivuotisen seurannan tuloksia.

V tutkimuksessa selvitettiin DNR -merkintöjen yleisyyttä. Tutkimuksen aineisto perustui 5654 henkilön RAI -tietokannan tietoihin kolmelta laitoshoidon tasolta: Sairaalan pitkäaikaishoidosta (n= 1989), vanhainkodeista (n=3310) ja palvelutaloista (n=355), 67 eri laitoksesta 19 kunnan alueelta vuonna 2002. Potilaat arvioitiin MDS 2.0 versiolla.

Tulokset: I tutkimuksessa vaikeasti sairaat potilaat eivät mieltäneet itseään kuoleviksi potilaiksi. He puhuivat mielellään hoidoista, jotka helpottaisivat vointia. Siten he ylläpitivät toivoa elämänsä jatkumisesta. Vaikeasti sairaat potilaat kokivat saaneensa hyvää oirehoitoa. He arvioivat kuitenkin hoitoaan tuoden samanaikaisesti esille ymmärrystään hoitajien kiireestä ja ilmaisten siten tyydyttymättömiä tarpeita keskustelulle hoitohenkilökunnan kanssa. Haastattelujen valossa näyttää siltä, että akuuttihoidossa on liian vähän mahdollisuuksia huomioida kuolevien potilaiden eksistentiaalisia ja emotionaalisia tarpeita. Potilaat arvostivat suuresti omais- ja ystävyyssuhteitaan.

II tutkimuksessa kotona asuvilla DEBATE -tutkimukseen osallistuvilla iäkkäillä potilailla 12 %:lla oli hoitotahto. He toivoivat elvytystä nykyisessä terveydentilassaan yhtä usein kuin potilaat, joilla ei ollut hoitotahtoa. Noin puolet kaikista DEBATE tutkimuksen potilasta toivoi elvytystä nykyisessä terveydentilassaan. Logistisessa regressioanalyysissä, missä ikä, sukupuoli, kognitio, elämän laatu, masentuneisuus ja elämän asenteet olivat mukana, ainoastaan elämän asenteet tilastollisesti merkitsevästi liittyivät elvytystoiveisiin. Tässä mallissa masentuneisuus ei tilastollisesti merkitsevästi liittynyt elvytystoiveisiin.

Kahden vuoden seurannassa elvytystoive säilyi samana kolmella neljästä. III tutkimuksessa selvitettäessä eri muuttujien ennustemerkitystä elvytystoiveille otettiin logistiseen analyysiin mukaan elvytystoiveisiin vuonna 2002 liittyvät tilastollisesti merkitsevät muuttujat, jotka olivat ikä, sukupuoli, leskeys, kognition heikentyminen, masennusoireet, liikuntakyky ja vuoden 2000 tarpeellisuuden tunne. Lisämuuttujiksi analyysiin otettiin vuoden 2000 NYHA luokka 3–4 ja hoitotahto. Tässä analyysissä tunne tarpeellisuudesta vuonna 2000 ennusti elvytystoivetta. Kognition heikkeneminen ja yli 85 vuoden ikä liittyivät tilastollisesti merkitsevästi toiveeseen pidättäytyä elvytyksestä.

IV tutkimuksessa selvitettiin potilaiden perusteluja elvytysvalinnoilleen ja päätöksentekoon liittyviä asioita. Potilaiden elvytysvalinnat pohjautuivat etiikkaa ja arvoja korostaviin näkökohtiin. Myös korkea ikä ja potilaan arvio elvytyksen heikosta lopputuloksesta vaikuttivat elvytysvalintoihin. Neljä viidestä potilaasta arvioi, että potilaan pitäisi olla mukana päätöksen teossa päätettäessä elämän loppuvaiheen hoidoista. Vain muutamat potilaat olivat keskustelleet lääkärinsä kanssa hoitotoiveista mahdollisen henkeä uhkaavan tilanteen varalta.

V tutkimuksessa RAI tietoihin perustuen selvitettiin, että 13 %:lla laitoksissa asuvista iäkkäistä henkilöistä oli DNR -merkintä sairauskertomuksessa. Hoitavien yksiköiden välillä oli suuria eroja DNR -merkintöjen yleisyydessä. Paikallinen hoitokulttuuri muodostui tilastollisesti merkitsevimmäksi DNR -merkintöjä selittäväksi tekijäksi. Sairaudet ja fyysinen toimintakyky selittivät vain vähän DNR -merkintöjen käyttöä.

Johtopäätökset: Akuuttiosasto-olosuhteissa hoitohenkilöstöllä ei ollut mahdollisuuksia luoda kuoleville potilaille ilmapiiriä, missä emotionaaliset ja eksistentiaaliset tarpeet olisivat tulleet riittävästi huomioiduiksi. Tutkimuksen perusteella voidaan suositella, että lääkärit selvittäisivät iäkkäiden potilaidensa halun keskustella hoitotoiveistaan liittyen elämän loppuvaiheisiin. Toiveet tulisi selvittää laaja-alaisesti huomioiden potilaan elämän asenteet, arvot ja eettiset näkökohdat. Toiveet tulisi selvittää toistetusti huomioiden potilaan muuttunut sairaudentila tai elämäntilanne, ennen kuin lääkärit kirjaavat potilaan toiveet ja/tai hoitopäätökset sairauskertomukseen. Avointa keskustelua, yleisiä ohjeita ja tutkimusta DNR -päätösten tarkoituksenmukaisuudesta tarvitaan parantamaan iäkkäiden potilaiden oikeuksia ja autonomiaa.

1. INTRODUCTION

At the beginning of the 20th century, individuals faced the dying of their loved ones more frequently than do people today. Technical and medical developments and overall improvements in living conditions in Western societies have raised life expectancies of later cohorts. In European countries, about half of dying persons are aged 80 years or over, and for many of them, death appears as a gradual decline from chronic illnesses, such as cardiovascular diseases, dementias and malignancies, and in about one-third of deaths as an acute exacerbation of a significant disease (van der Heide et al., 2003). People in their last year of life, are estimated to account for 22% of all hospital bed days (Seale and Cartwright, 1994).

Advances in medicine have greatly improved the possibilities of treating seriously ill patients and prolonging life. With this development has also come the need for medical decision-making at the end of life to improve the quality of life of patients and their families by prevention and relief of suffering. In 2001, the proportion of deaths with any preceding end-of-life decision varied between 20 % and 50 % in different Europe countries (van der Heide et al., 2003). In the US, where the practice of advance care planning (ACP) is stressed, 71% of the deceased in 2000 had written advance directives (ADs) (Teno et al., 2004). Despite developments in ACP, progress of the hospice movement and general advances in palliative care, the care available for terminally ill people is still far from satisfactory for a large segment of our society, namely, the elderly who do not have cancer, those with heart disease and those with dementia (Neuberger, 2003).

In 2002, 49 418 Finns died (www.stat.fi). The mean age of the deceased was 70.2 years for men and 79.5 years for women. Of all deceased, about 20% (10 000) died of cancer and every third person died of cardiovascular diseases (www.stat.fi). The main caring places for the elderly dying patients are acute or long-term care (LTC) units. In 2002, nearly 23 000 older persons (77% of all deaths of persons > 75 years) died in nursing homes, service housing with 24-hour assistance or hospital wards. Of these, some 11 000 (36% of all deaths of persons >75 years) were LTC patients (Official Statistics of Finland (SVT) Social Security 2003:1). The average time spent in LTC before dying was 2.3 years, and patients' mean age at death was 86 years in 2002 (Noro, 2003).

According to the literature, reliable and detailed statistics exist on life expectancy, age, death and place and cause of death, but we know little about how patients, especially elderly individuals, perceive the end of life and dying (Hallberg, 2004), although this patient group is rapidly growing. Many studies have inquired about these issues from close relatives and health care providers, yielding useful information (Lynn et al., 1997, Miettinen and Tilvis, 1999, Teno et al., 2004). However, some investigators believe that family caregivers and professionals may not accurately interpret the experience of those dying (Higginson, 1994, Hinton, 1996). Neither families nor health care providers have adequate understanding of older adults' preferences for such end-of-life interventions as resuscitation (Uhlmann et al., 1988, Morgan et al., 1994, Hamel et al., 2000). Moe and Schroll (1997) showed that the greatest degree of disagreement of whether to accept curative treatments were between relatives of incompetent residents and staff members in nursing homes; curative treatment was significantly more often preferred by the relatives.

When making these difficult decisions about treatments and care, the elderly patient's own preference would be helpful. However, often acutely or seriously ill elderly patients are unable to discuss or describe their wishes about treatment. The living will (LW) could provide an answer to this dilemma, but many elderly individuals might not have a LW and may not discuss their thoughts and preferences related to the end of life and dying with their relatives or their physicians.

While planning this study, we thought that, in addition to elderly terminally ill patients, the adults over 75 years of age with chronic diseases and higher mortality rates than younger age groups would be an optimal participant group to answer these questions. The opinions of both of these patient groups were anticipated to yield valuable information to practitioners on how to approach older people, especially those in the terminal phase about death and dying, and how to provide them with high-quality care.

A few studies exist about preferences for life-sustaining treatments (LSTs) among the elderly in Europe, and several are available from the US, but no large-scale studies have been published from Finland. In this study, terminally ill elderly patients in the acute wards and home-dwelling cardiovascular patients were interviewed about their preferences related to LSTs and end-of-life care and the degree to which they wished to be involved in the decision-making process. In the section to follow, the context and cultural development of ACP and end-of-life care, and the different values and viewpoints of older patients, family members and health care professionals are described.

2. REVIEW OF THE LITERATURE

The number of articles related on dying and decision-making about end-of-life treatments is enormous. Searching from Medline with the key words dying and elderly or aged yielded 4600 articles, with the key words decision-making and elderly or aged about 8000 articles and with resuscitation and elderly or aged about 7000 articles. The abstracts of these articles were read and mainly only the largest studies were included. Further study selection criteria comprised the research describing important findings to clarify end-of-life care of elderly patients or patients' preferences related to end-of-life care. However, the medical literature contains scant information about very old (> 80 years) people's perceptions of the end of life.

For historical and cultural reasons most of the studies have been performed in the US or Canada, where interest to study ACP and quality of end-of-life care has been most pronounced. In Europe, while much fewer studies exist, interest in the topic is growing. The most relevant Finnish studies have also been included in this review.

Studies were included in the tables based on their methods or special interests.
Many studies included information from several viewpoints and are therefore cited many times. These studies are included in the tables according to their main findings. When the study is in the text and also presented in a table, the study has a superscripted index number following the citation that indicates the table in which it can be find, e.g. (Tsevat et al., 1998 [4]). This system is used in all sections of this thesis.

2.1. HISTORY OF END-OF-LIFE CARE AND ADVANCE CARE PLANNING

2.1.1. Developments in end-of-life care

Kouwenhoven and colleagues published the description of "closed-chest cardiac massage" in 1960. Closed-chest heart massage was then combined with artificial ventilation and became known as cardiopulmonary resuscitation (CPR). Resuscitation provided new possibilities for prolonging life and awakened public discussion about the limits of medicine and the medicalization of dying. Traditionally, medical care has been articulated as having two mutually exclusive goals: either to cure disease and prolong life or to provide comfort. Given this dichotomy, the decision relieve suffering is often made only after life-prolonging treatment has proven ineffective and death is imminent (Morrison and Meier, 2004).

Concerns and discussions about end-of-life care began on both sides of the Atlantic Ocean during the 1950s. Attention focused on the medical "neglect" of dying people in Great Britain. In the US futile treatments in the face of suffering and inevitable death were discussed. The main historical steps of palliative and end-of-life care since the 1950s in North America and Europe are presented in Table 1.

New views of dying, such as the concepts of dignity and meaning, and the disclosure of terminal illness to patients, began to emerge in the 1950s and 1960s. An active approach in caring for the dying was promoted. Resignation of the physician ("there is nothing more we can do") was supplanted by a determination to find novel and imaginative ways of continuing care to the very end of life. Mental and physical distress was recognized to have an interdependency, leading to a more embodied notion of suffering (Clark, 2002). Alleviating and palliating multidimensional suffering was a new goal for caring for dying persons, and it led to the hospice movement in Great

Table 1. History of palliative and end-of-life care since the 1950s in North America and Europe.

Period	USA/Canada	Examples from European countries	Situation in Finland
1950–1969	**Kouwenhoven et al. discovered "closed-chest cardiac massage" in 1960 *** • Concerns and discussions of futile treatments led to the "Right to Die" movement • "Living will" was described by Luis Kutner in 1969	• Discussions and concerns of medical "neglect" of dying people (UK) • Cicely Sounders developed hospice movement in 1959 (UK)	• Discussions and concerns of medical "neglect" of dying people
1970–1989	• The focus of public discussions was on patients' autonomy in medical decisions • "Palliative care" term was first proposed by Canadian surgeon Balfour Mount in 1974 • American Medical Association 1989: "Current Opinions of the Council on Ethical and Judicial Affairs" (legislation of patients' autonomy) • Medical Directive by Emanuel and Emanuel in 1989	• Dutch State Commission on euthanasia was established in 1985 • Palliative medicine was recognized as a medical speciality in 1987 (UK) • **Word Medical Association Declaration of Lisbon on the Rights of Patients, 1981, (up-dated in 1995)***	• National Health Board published guidelines for terminal care in 1982 • First hospices established in Tampere and Helsinki in 1988
1990–1999	• In the US, the Patient Self-Determination Act (PSDA) in 1990 • **WHO's report: Cancer Pain Relief and Palliative Care, 1990*** • The number of hospice and palliative care services was 3200 in 1997 in North America	• British Medical Association published guidelines of advance statements about medical treatments in 1995 • Patients' self-determination law was passed in Denmark in 1998, including concept of living will • British Medical Association published guidelines of withholding and withdrawing life-prolonging medical treatment in 1999 • The number of hospice and palliative care services in the UK and Ireland was 730, and in the rest of Europe 600 in 1997	• The Finnish Parliament passed the law "Act on the Status and Rights of Patients, 785/1992" • First living will form developed • The Chair in palliative medicine elected at the University of Tampere in 1999
2000–2004	• **WHO's report: National cancer control programmes: policies and managerial guidelines, 2002*** • EPEC Project: Education on Palliative and End-of-life Care, 2004	• Articles of the European Convention on Human Rights Act (2000) state that patients have the right to authorize or refuse life-sustaining medical treatments • British Medical Association published guidelines of decisions related to cardiopulmonary resuscitation in 2001 • Law of Euthanasia was passed in the Netherlands and Belgium in 2002	• Finnish Medical Association gave the current ethical guidelines for physicians for end-of-life decisions in 2000 • Federal recommendations for quality of end-of-life care for the elderly published in 2002 • National Advisory Broad on Health Care Ethics (ETENE) published guidelines for end-of-life care in 2003 • The Chair in pain management was elected at the University of Helsinki in 2004.

* These events have had an influence world wide

Britain (Sounders 1959). In 1967, Cicely Sounders founded St. Christopher's Hospice, and it quickly became a source of inspiration to others (Table 1). Within a decade, it was accepted that the principles of hospice care could be practised in many settings: in free-standing hospices as well as at home or in day care services.

In 1974, the term "palliative care" was first proposed by Canadian surgeon Balfour Mount to implement a new way of thinking about dying in the acute wards of hospitals (Clark, 2002). In 1975, the first Palliative Care Service was opened in Montreal, Quebec. The World Health Organization (WHO) initially defined palliative care in 1990, later updating in their report "National cancer control programmes: policies and managerial guidelines" (2002) as: "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." According to definition, WHO supports the principles of palliative care being applied as early as possible in the course of any chronic, ultimately fatal illness. Palliative care is described as the teamwork of physicians, nurses, social workers and volunteers.

Palliative medicine has roots in Great Britain, where it was recognized as a medical speciality in 1987. Palliative medicine has been defined as " the study and management of patients with active, progressive, far-advanced disease for whom the prognosis is limited and the focus of care is quality of life" (Doyle et al., 1998).

Hospice and palliative care is largely a phenomenon of the English-speaking world, with the exception of Northern European countries. In 1997, the number of hospice and palliative care services in North America was about 3200, in the UK and Ireland about 730, in the rest of Europe about 600, in Australia 160, in Asia 75, in Africa 60, and in Latin America 15 (Seale, 1998).

History of end-of-life care in Finland

In 1982, the National Health Board in Finland published the guidelines for terminal care and arranged public education on modern hospice practice. The first hospices were established in Tampere and Helsinki in 1988. At present, we have four hospices in Finland. The Act on the Status and Rights of Patients (1992, www.finlex.fi) also produced guidelines for the care of dying patients. The current physicians' ethical guidelines for end-of-life decisions were published in 2000 (Finnish Medical Association). The National Advisory Board on Health Care Ethics (ETENE) published "Ethical issues related to death in health care" in 2002 and "End-of-life care – memorandum of the National Advisory Board on Health Care Ethics" in 2003 containing guidelines for end-of-life care (see Table 2). In addition, Federal recommendations for quality of end-of-life care for the elderly were published in 2002 (Voutilainen et al., 2002).

The Anglo-Saxon terms and definitions: "palliative care" (palliatiivinen hoito) and "palliative medicine" (palliatiivinen lääketiede) (Vainio et al., 2004) are used in Finland. Competence to manage pain was established in 1998, but palliative medicine has not achieved its own speciality. However, the first Chair in palliative medicine was elected at the University of Tampere in 1999, and the Chair in pain management at the University of Helsinki in 2004. The Societies for Palliative Care (1995), Pain Research (1996) and Palliative Medicine (2003) have organized education and research in palliative care.

The term "end-of-life care" (saattohoito) is understood in Finland as active care for patients whose illness is progressive and incurable, or for whom prognosis-improving treatment is either not available or has been rejected by the patient; the patient's life expectancy is considered to be short. End-of-life care as such is independent of the patient's diagnosis (ETENE, 2003). The definition for "end-of-life care decision" (saattohoitopäätös) according to ETENE (2003) is "a medical decision made by physician in full consultation with the patient or the patient's representative. It can be a single decision concerning the line of treatment or the final result of a long process during which it has become clear that the patient's illness cannot be cured". The old term "terminal care" (terminaalihoito) is seldom used nowadays and then as a meaning for end-of-life care that directly precedes death (ETENE, 2003).

2.1.2. Developments in advance care planning

Modern medical technology and improved possibilities for medical care at the end of life have provoked considerable interest in ACP. In the US discussions about the limits of medicine developed into the "Right to Die" movement, and the "living will"(LW) was first proposed by Kutner in 1969. During the 1970s and 1980s patients' autonomy in medical decisions was much debated. Patients' autonomy was legitimized during 1980-2000 in many Western countries. Patients now have the right to authorize or refuse medical treatments, even life-sustaining measures. Many medical associations in the US (American Medical Association, 1989), UK (British Medical Association (BMA), 1995) and Finland (Finnish Medical Association, 2000) have given guidelines or recommendations on how to implement legislation for patients' care (Table 1).

In the US, federal law was passed to improve care of older adults and to control health care costs. The Patient Self-Determination Act of 1990 (PSDA), which took effect in 1991, requires that patients or residents in facilities receiving Medicare or Medicaid funding be given the opportunity to express their wishes about life-sustaining treatments (LSTs) by drafting advance directives (ADs). Specifically, it requires each newly admitted patient or resident to a hospital, nursing home or home care to have state law related to treatment decisions explained and to have the written policies of the facility pertaining to end-of-life care discussed. It ensures compliance with state laws concerning ADs and legislates community and staff education about ADs (Hopp, 2000).

In the US, two types of ADs exist according to the legislation of each state (Pahlman, 2003, Lo and Steinbrook, 2004). One is an instruction type, a living will (LW), where persons specify in writing their preferences for medical care. Another type is a proxy directive, a durable power of attorney for health care (DPAHC). This is a legal document that allows an individual to designate a person to make medical decisions on his behalf should he be unable to make these decisions himself (Hopp, 2000). The designated person is referred to in the literature as a "medical power of attorney", " health care proxy" or "surrogate", and he/she should make decisions based on "substituted judgement" (the known or probable wishes of the patient) or "best interests" (the relative benefits and burdens of a given decision for the patient).

The articles of the European Convention on the Human Rights Act (2000), which are the recommendations for the legislation of nations in the European Union, stipulate that all treatments be based on the patient's informed consent and that the patient's opinion about his/her care be honoured (Pahlman, 2003, Stevart et al., 2003). In European countries, the concept of the AD is relatively new and still being developed. In the UK, an AD gives patients the legal right to grant or withhold consent for specific treatments prospectively. Guidelines on advance statements about medical treatment were published by the BMA in 1995. Nevertheless, in 1998, a survey of 214 general practitioners revealed that only 49% were aware that ADs carry legal force (Diggory and Judd, 2000). Of elderly inpatients, 82% had not heard about LWs or ADs, but many were interested in learning more (Schiff et al., 2000).

The legality of LWs varies between the Scandinavian countries; in Denmark (1992) and in Finland (1992) it is a legally binding document, but not in Sweden (Pahlman, 2003). In Finland, the 1992 legislation on patients' rights states that patients and/or the nearest family members should be heard in medical decisions, and a competent patient has the right to accept or refuse a treatment method, a treatment line or all treatments after he/she has received sufficient information about the care or he/she has refused to hear the information (Pahlman, 2003).

A living will becomes active when a patient as a consequence of a serious illness or accident loses his/her legal capacity. The Finnish LW form (Appendix 1) includes orders that all modes of treatment that artificially maintain the vital functions be refused unless compelling arguments can be made for the possibility of the patient's recovery. However, treatments may be applied for elimination or alleviation of symptoms. Intensive care, such as CPR, should be given only in the event that reasonable arguments exist for the possibility of the treatment yielding results better than merely a brief prolongation of life.

In Finland, people are not encouraged to appoint a proxy to make decisions about end-of- life care because the proxy directive is not legally valid. Instead, people are advised to define their own opinions about preferences in life-threatening situations by filling in a LW form containing statements as above. Alternatively, the preferences can be expressed freely by writing or verbally and then documented. Moreover, people are encouraged to discuss their preferences with their close relatives and to inform their family doctor about the existence of a LW. The possibility of appointing a proxy is now under discussion in the Finnish Ministry of Social Affairs and Health (www.stm.fi).

Physicians are encouraged to discuss the patient's preferences in life-threatening situations and to respect the patient's autonomy when confronted by a serious disease. Medical decisions should be based on these informed preferences of individual patients and on probable outcomes of the therapies of interest. For example, CPR after a heart arrest is effective in only one out of five patients (De Vos et al., 1999), and the figures are much lower for patients with serious conditions (Murphy et al., 1989). Although probable outcomes should be considered for all patients, they are especially relevant for patients with poor short-term prognoses, who may be more willing to limit the use of aggressive treatments such as resuscitation. CPR may be precluded when the patient's prognosis is poor and the estimated outcome of CPR is poor; physicians may assign the patient a do-not-resuscitate (DNR) order as a medical decision. Physician may assign a do-not-hospitalize (DNH) order for a terminally ill patient if palliative care can be ensured for him/her without acute hospitalization. In North America, resuscitation is performed unless prohibited by a specific order. A DNR order among American patients should therefore indicate that end-of-life decision-making has occurred (Hakim et al., 1996). Autonomy and self-determination of the patient is promoted in medicine more often in the US than in Europe, where patient-physician relationships are still somewhat paternalistic (Vincent, 1999, O'Keeffe, 2001, van der Heide et al., 2003).

DNR orders should be based on patient preferences, but studies have shown that patients, even when capable of communication, infrequently participate in decisions about resuscitation (Krumholz et al., 1998, Levin et al., 1999). Implementation of the Human Rights Act (2000) has provided new guidance for DNR decisions in the UK. The BMA's Decisions Relating to Cardiopulmonary Resuscitation (2001) recommends that decisions about whether to attempt resuscitation should be reached in a way that follows an individual patient's informed decision – either made at the time or in an AD – or reflects his/her best interests (Mayor, 2001). Doctors should be more aware of their obligations to ensure that medical decision-making is transparent. In Finland, Federal recommendations for quality end-of-life care for the elderly were published in 2002 (Voutilainen et al., 2002); these recommendations encourage the practice of transparent recording.

The original goal for ADs and ACP – from the perspective of ethicists and legal scholars – was to assist patients in making treatment decisions in the event of incapacity. However, from the patient’s perspective, the primary goal of ACP is more commonly to prepare for death and dying (Singer et al., 1998, Martin et al., 2000) by helping patients achieve a sense of control, relieving burdens on loved ones and strengthening or reaching closure in relationships with loved ones (Martin et al., 2000). Because medicine and society are faced with an ageing population that is slowly dying of chronic diseases, the question arises whether too much is spent on the dying. The key, policy-relevant hypothesis behind ADs proposes that if an intervention enhances a person’s right to choose, dying persons will not opt for technological and costly medical care, physicians will honour this choice, alternative palliative care will be less costly, and ethically defensible savings of squandered resources will result (Teno, 2000).

Legislation can have powerful effects on ACP. In the US, the Patient Self-Determination Act (PSDA 1990) had a pronounced effect on implementation of LWs and DNR orders in nursing homes; the prevalence of LWs increased from 4% to 13% and DNR orders from 30% to 50% between 1990 and 1993 (Teno et al., 1997). Half of the nursing home residents who were presented with and asked to sign an AD did so (Miles et al., 1996).

However, end-of-life medical decisions are very complex. Several patient and physician related factors have an influence on the decision-making process. In addition, family relations and social and cultural contexts affect these decisions. Advance treatment preferences have been shown to be difficult to form, communicate and implement (Miles et al., 1996). These problems have shifted the focus of research. It now seems more important to investigate elements of the ACP process, such as the patient-physician relationship and communication, and to explore the poorly understood values and motives behind the expressed preferences (Martin et al., 2000, Prendergast, 2001).

Today, AD forms are not the central or defining feature of advance care planning. ACP is seen as a process of communication and AD forms are best viewed as a tool embedded in the ACP process (Figure 1). Recent research suggests that preferences for care are not fixed but emerge in a clinical context from the process of discussion and feedback within the network of the patient’s most important relationships (Singer et al., 1998, Emanuel et al., 2000, Martin et al., 2000). Patients suffering from advanced illnesses may benefit most from care that combines life-prolonging treatment (when possible and appropriate), palliation of symptoms, rehabilitation, and support for caregivers (Morrison and Meier, 2004) (Figure 1). As the illness advances, discussions with the patient and, if the patient wishes, also with family caregivers should take place about the patient’s wishes and needs. Decisions about treatments and other forms of managements should be made on the basis of these discussions. This should be an ongoing process (Figure 1).

2.1.2.1. Developments in the advance directive documents

Designing AD documents that are sufficiently simple for patients to understand and complete but that provide future decision-makers with enough information to make decisions that accurately reflect the patient’s wishes is challenging. In the US, the initial AD documents were general, documenting refusal of heroic measures to prolong the dying process (by the Euthanasia Education Council, 1969), but they were difficult to apply in specific clinical situations (Malloy et al., 1992). More specific documents were then developed. They may ask patients to indicate which of the commonly used LSTs they would prefer in various types of illnesses, as in the Medical Directive by Emanuel and Emanuel (1989 [1]). In addition, specific illness scenarios and clinical vignettes with general statements about values have been developed (Malloy et al., 1992 [8], Schonwetter et al., 1996).

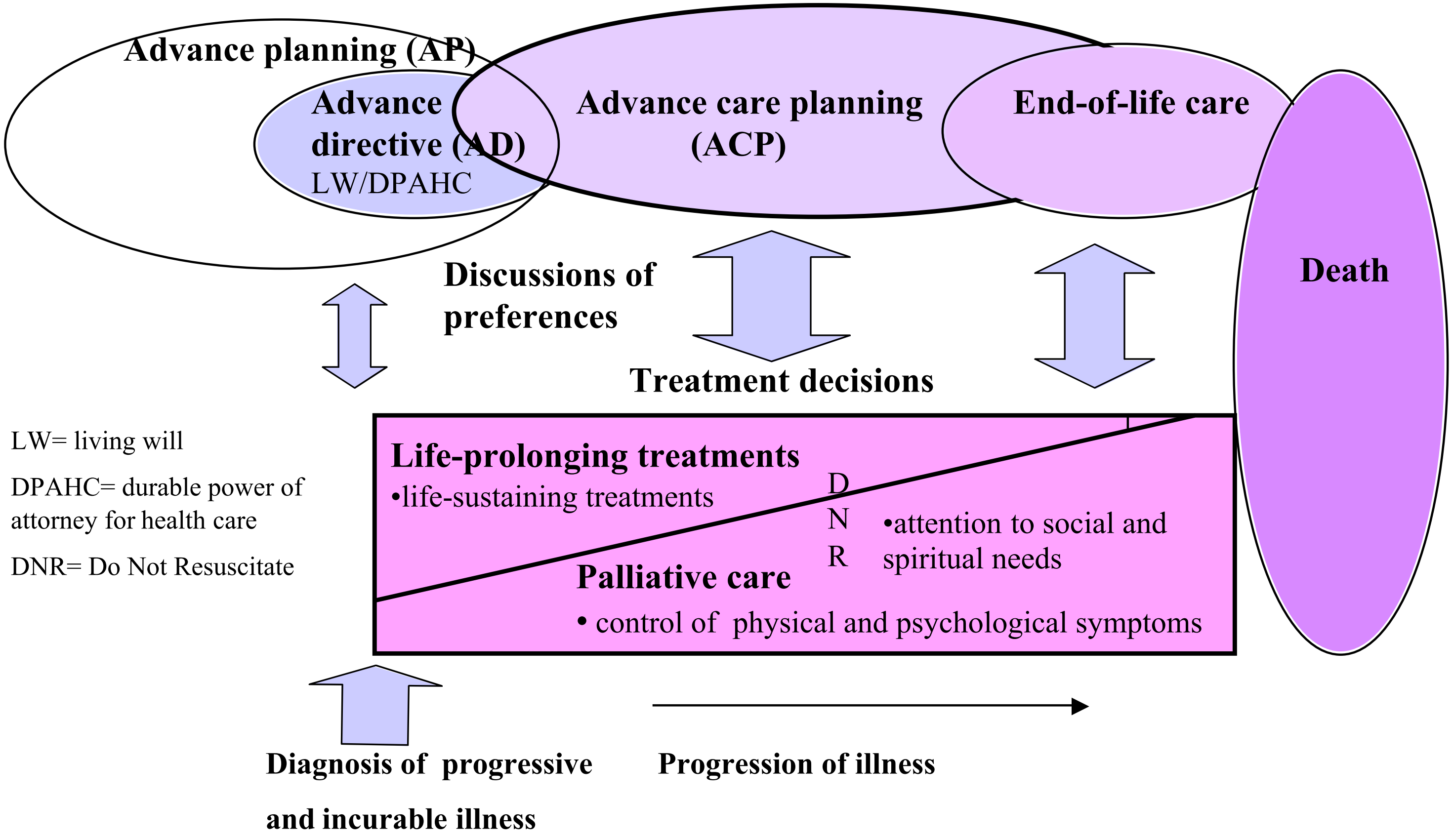
Despite extensive efforts to promote ADs, only a small proportion of outpatients have a written LW. More often patients have an AD to designate a proxy. These ADs contain limited information to guide the use of LSTs (Teno et al., 1997[7]).

To develop better AD documents, the PACE (a Program of All-Inclusive Care for the Elderly) programme was implemented in Oregon (Lee et al., 2000[7]). Pre-printed physician order forms known as Physician Orders for Life-Sustaining Treatment (POLST) were created. Emergency medical systems, hospitals and long-term care facilities in Oregon officially recognize a completed POLST as a legitimate basis for withholding specific treatments. Patients keep the original POLST with them in the event of an emergency. The POLST specifies what a physician can do in four medical treatment categories: 1) CPR, 2) medical intervention level (ranging from palliative care at home to intensive hospital treatments), 3) antibiotic use and 4) feeding tubes and intravenous fluids (long term or short term) (Lee et al., 2000). Studies of the use of POLST have found high consistency between the POLST instructions and the medical treatments given (Tolle et al., 1998, Lee et al., 2000 [7]).

The POLST form is more than an AD; it addresses patient preferences for limiting specific treatments, and it also implements the preferences by putting them into the form of doctors' orders to limit these treatments. This practice has benefits, but it also contains many problems. Physicians and all caring personnel must be very competent in geriatric and palliative medicine and have good communication abilities with frail elderly patients. Patients, physicians, medical professionals and family members need to have numerous conversations. Time and training are required to lead these ACP discussions and to implement good palliative care in nursing homes. The POLST system also demands standardization and institutional support (Cantor, 2000).

In Finland, the first living will form was developed in the 1990s (Appendix 1). Today, forms derived from this original form are available in pharmacies and hospitals and on the internet (Pahlman, 2003). In 2004, the Finnish Alzheimer Association published a LW form (www.alzheimer.fi). In this version, the individual is also asked to designate a person with whom medical treatments related to patient care should be discussed in case of advanced dementia. The respondent is also asked to give instructions about how he/she should be cared for in accordance with life attitudes and religious background, and where he/she wishes to be cared for in case of dementia. Whether the individual wishes to take part in research in case of incompetence can also be indicated.

Figure 1. **Advance care planning process**



LW= living will

DPAHC= durable power of attorney for health care

DNR= Do Not Resuscitate

2.2. END-OF-LIFE CARE

2.2.1. Comprehension of the dying process

Carers of dying patients must consider death and dying from many different perspectives, including cultural, spiritual, ethnic, social, religious, economic and medical contexts. One extension to think about dying, as stated by sociologist Clive Seale, is:

"Our bodies are the means by which we have life, vehicles for our communal sense of what it is to be human. But they also set material limits to our experiences, and ultimately dictate that our lives must end. As humans, we know these things, and this sets us apart from animals, who do not know they will die. We orient ourselves through our bodies, towards pleasure, emotions, libido, projects to create personal meaning and an individually fashioned sense of self-identity. Dying, and the sense of loss which death engenders, are episodes where the divide between nature and culture is seen in starkly clear terms. When studying the human approach to death we can see how we defend against threats to our basic security about being in the world, and construct lives of meaning, purpose and fulfilment."(Seale, 1998).

Terminal illness marks a time in people's lives when they experience many losses in, for example, physical strength, status as a family member and as a productive individual, control and independence and often life purpose (Miettinen, 2001). Several losses may occur together and some may not occur at all. Loneliness, isolation and grief awaken anger as a response to these losses (Faulkner and Maguire, 1994, Block, 2001). The care of dying patients often evokes feelings of guilt about the proper amount of medical care, giving too much active medical care or withholding that care too early. Feelings of inadequacy are frequent among family members and caring medical teams (Faulkner and Maguire, 1994, Mattila, 2002). Qualified medical and nursing care is needed to support patients and their families as they go through these feelings of anxiety (Block, 2001, Mattila, 2002).

In Western societies, values that underlie the care of seriously ill and dying people are based on the inherent worth, dignity and uniqueness of each person (Latimer, 1991). This view is based on the evolution of self through integration of life experiences, where each person has a unique background and is at a different point along the continuum between birth and death, not only in terms of time but also in terms of evolution of self. Through these unique life experiences, each person develops a balance between internal and external existence, a life style, a life meaning, a degree of self-knowledge and a personal philosophy (Latimer, 1991).

The disclosure of diagnosis, prognosis and treatment of terminal illnesses may differ dramatically among countries. Italy and Japan, for instance, offer complex biotechnology and advanced forms of treatments, but the disclosure of terminal cancer diagnosis and prognosis to the patient is largely considered to be cruel or to have the potential of leading to "social death" in these countries (Good, 1990, Elwyn et al., 2002). A preference for open awareness of dying is established in terminal care settings in the UK, US and other Anglophone countries (Seale et al., 1997), as well as in Finland.

Bad news is information that drastically and unpleasantly alters a patient's view of the future. How disclosure of diagnosis and prognosis is performed is very important to the patient (Faulkner and Maguire, 1994, Mattila, 2002, Twycross, 2003). Full disclosure is often neither possible nor seen as therapeutic. Controlling the amount of given information is essential and many physicians aim to maintain the patient's hope (Good, 1990, Kirk et al., 2004). Palliative care calls for excellence in professional care and the creation of a climate in which patients can strive to realize hopes and dreams to restore or maintain their sense of themselves as individuals and to come to terms with their impending death as far as they are able to or wish to (Latimer, 1991).

After the disclosure of diagnosis and prognosis, the process of accepting approaching death is long, unique and closely dependent on culture. Virtually all patients approaching the end of life are faced with physical, psychological, social and spiritual challenges. Personal coping responses may fall anywhere on a continuum, ranging from the exceptional or adaptive to the dysfunctional (Block, 2001). The pre-eminent coping task faced by a dying patient is dealing with loss. Grief is an intensely painful but normal psychological response to loss. Dying is associated with grief over both current and anticipated losses of health, future, physical abilities and roles and relationships (Block, 2001).

Clinicians use various constructs to describe and understand the grieving process. Kubler-Ross described in her classic study of 1970 the internal struggles involved in the living-dying process as individuals move through stages of shock, numbness, denial and bargaining towards eventual acceptance. Seale (1997) presented an adapted typology of awareness contexts (originally from Glaser and Strauss, work 1965), which ranges from closed awareness (knowledge of dying is denied by the dying person) to open awareness. Pattison (1977) outlined three phases of the living-dying interval, defining this as a period of time between the knowledge of one's impending death and death itself. The first phase is an acute crisis characterized by anxiety about dying that arises from primitive or immature coping mechanisms. This is followed by a chronic phase, where fears of the unknown and various losses might be resolved, and lastly, a terminal phase, which is associated with acceptance and withdrawal. The living-dying interval may last from days to years.

In 1990 in the UK, half of the people dying from cancer, but only one-fifth of those dying from other diseases knew that they were dying (Seale et al., 1997). The benefits of full and closed awareness were compared. Those dying in full awareness were more able to plan their dying so that they and their loved ones were more satisfied with the degree of choice over the place of death; they were less likely to die alone and were more likely to die in their own homes (Seale et al., 1997). In awareness of dying, practical and emotional matters may be set in order, loss anticipated and grieving begun by both those dying and those close to them (Seale et al., 1997). On the other hand, people rejecting awareness of impending death and continuing with their normal lives can still imbue dying with meaning (Seale, 1998). This approach enables secure projection of self-identity to be maintained, allowing social bonds to remain relatively intact up to the moment of death (Seale, 1998). This finding highlights the importance of sensitivity in disclosing a terminal prognosis. The manner of disclosure should take into account such factors as cultural and religious backgrounds and values.

Findings from recent studies suggest that awareness of dying is only moderate even among hospice patients and that both this awareness and the desire to live both tend to fluctuate over time (Chochinov et al., 1999, Hinton, 1999). In Hinton's 1999 study in the UK, hospice patients and relatives justified their acceptance, often giving more than one reason. The theme of factual inevitability, as " We all have a span of life", was frequently accompanied by religious faith and a sense of completion. When hospice patients were over 70 years old, caring relatives accepted dying more readily, but the patients themselves did not. While weakness did not affect a patient's acceptance, relatives became more accepting of the outcome. Imminent death usually appeared to be more acceptable if it could be contained within pre-existing concepts, beliefs, values or even habitual patterns of reacting.

2.2.2. Ethics in end-of-life care

Care for seriously ill and dying patients must have an ethical foundation. According to experienced hospice physician Elisabeth Latimer (1991), palliative care is based on a philosophy that acknowledges the inherent worth and dignity of each person in the framework of four ethical principles: autonomy ("itsemääräämisoikeus"), beneficence ("tee hyvää"), nonmaleficence ("alä vahingoita potilasta") and justice ("oikeudenmukaisuus"). In palliative care, it is important to understand that all patients should be regarded as unique persons with a right to compassion, gentle truth, autonomy in decision-making and excellence in physical and psychospiritual care (Latimer, 1991, Randall and Downie, 1998).

Respect for autonomy recognizes a person's right or ability to decide for himself or herself according to individual beliefs, values and life plan (Latimer, 1991). One's decisions are uniquely one's own and may be contrary to what is advised or deemed wise by others in a given situation. Respect for patient autonomy implies conveying accurate information gently, especially in the disclosure of the diagnosis and prognosis, and determining that it has been understood. The art of gentle truth-telling to the extent required and tolerated by the patient is important. Truth is fundamental to the patient-physician relationship. Decisions about life-sustaining treatments should be guided by this relationship, with decisions being made jointly by the patient and the physician. However, people vary in the degree to which they wish to be informed and to make decisions about their care (Latimer, 1991).

The principle of beneficence understands and seeks the patient's best interests; as stated by Beauchamps and Childress (1989): "One ought to prevent or remove evil or harm, and do or promote good". Beneficence requires the physician to provide benefits and avoid doing harm in the context of what medicine has to offer a particular patient (Knight, 1994). Beneficence obliges the physician to relieve suffering and enhance the patient's quality of life whenever possible. Nonmaleficence is embodied in the concept "one ought not to inflict evil or harm" (Beauchamps and Childress, 1989). This principle is violated when unnecessary physical or psychological pain or suffering is caused during tests or procedures, physical examinations, history-taking or communication of information (Latimer, 1991). Justice requires allocation of sufficient health care resources of the type necessary to provide high-quality care (Latimer, 1991). These principles also elicit the need for recurrent audits of clinical skills and evaluations of practices and outcomes for professional staff (Latimer, 1991).

2.2.3. Guidelines and recommendations for end-of-life care

Care for vulnerable elderly individuals and patients suffering from incurable diseases, many of whom may be near the end of life, has increasingly been scrutinized over in the past decade. Studies demonstrate an inadequate quality of care with regard to symptom control and poor matching the care with patient preferences and optimal resource use at the end of life (Mills et al., 1994 [4], SUPPORT 1995, Lynn et al., 1997 [4], Bernabei et al., 1998 [4], Miettinen et al., 1998 [4], Miettinen and Tilvis, 1999 [4], McCarthy et al., 2000 [4]). Within the past few years, guidelines and recommendations to improve end-of-life care have mainly been based on expert opinions (Institute of Medicine, 1997, Cassel and Foley, 1999), the experience of carers or the intuitions of dying patient's spouses and relatives. Selected publications and recommendations are shown in Table 2.

Patient-centred dying is the present focus of research. Qualitative studies (Singer et al., 1999[5], Steinhauser et al., 2000[3]) have shifted the aim of end-of-life care. By taking into consideration the

Table 2. Guidelines and recommendations for end-of-life care.

Authors	Basis of study	Recommendations
Emanuel and Emanuel, 1998, USA	A part of the Commonwealth-Cummings project on the quality of care at the end of life	A framework for a good death, emphasizing the multifaceted character of the experiences of dying patients and expanding considerations beyond physical and psychological symptoms to include economic demands and care-giving needs, social relationships, hopes and expectations and spiritual and existential beliefs
Teno et al., 2001, USA	Qualitative interviews of dying patients (data from Singer et al.1999, Steinhauser et al. 2000) and their families, structured reviews of professional guidelines and experts	A conceptual model of quality of end-of-life. Health care professionals should • ensure desired physical comfort and emotional support • promote shared decision-making • treat the dying person with respect • provide information and emotional support to family members • co-ordinate care across settings
Debate of the Age Health and Care Study Group, 1999, UK	Consensus of older people	• To know when death is coming and to understand what can be expected • To be able to retain control of what happens • To be afforded dignity and privacy • To have control over pain relief and other symptom control • To have choice and control over where death occurs (at home or elsewhere) • To have access to information and expertise of whatever kind is necessary • To have access to any spiritual and emotional support required • To have access to hospice care in any location, not only in hospital • To have control over who is present and who shares the end • To be able to issue advance directives which ensure wishes are respected • To have time to say goodbye, and to have control over other aspects of timing • To be able to leave when it is time to go and not to have life prolonged pointlessly
National Advisory Broad on Health Care Ethics (ETENE), 2003, Finland	Expert opinions	• The right to good and humane treatment even if no curative treatment exists • Patient's right to self-determination should be respected in end-of-life care. A patient's living will can only be ignored if the patient can be justifiably presumed to have changed his mind. • End-of-life care is based on a mutual understanding between the patient and caregivers. • To ensure continuity of care when treatment aims change and a patient is transferred from one unit to another. When the change is made from curative treatment to palliative care or end-of-life care, it is important to make as clear a plan as possible and record it in the patient's documents. The plan should be available for all persons participating in care. • Units providing end-of-life care should have sufficient resources (including staff, professional skills and equipment) to carry out the treatment plan made for a dying patient. • The patient has the right to die at home or in a place where family and friends are present. • Special attention should be given to persons who are not competent to decide about treatment, whether they are end-of-life care patients or their relatives • All dying patients have the right to good end-of-life care regardless of diagnosis.

patient’s emotional strengths, the physician together with other professionals can focus on the following goals, which many patients have identified as a “good death” (Emanuel and Emanuel, 1998[2]): optimizing physical comfort, maintaining a sense of continuity with one’s self, maintaining and enhancing relationships, making meaning of one’s life and death, achieving a sense of control and confronting and preparing for death.

2.2.4. Studies of older people’s views of death and dying

Older people’s views of death and dying may differ depending on whether or not a person is at the end-of-life phase (Teno et al., 2001, Hallberg, 2004). Studies describing older people’s views of death and dying before being at the end-of-life stage are presented in section 2.2.4.1. Different symptoms and problems related to the dying process are presented in sections 2.2.4.2. and 2.2.4.3. Studies related to care of advanced dementia patients are discussed in section 2.2.4.4. Advanced dementia patients have different illness and dying features than patients with advanced cancer or congestive heart disease.

2.2.4.1. Views of death and dying before being at the end-of-life stage

In a Finnish interview study, dying was described as a lifetime process where an experience of having led a full life promotes a “good” death (Nissilä, 1992). From childhood, people have faith in immortality, which many maintain by fantasies, beliefs and defences. By these means, a person facing death preserves hope that life will continue after death. Dying patients need to maintain their hope and a will to live amidst the many fears. While dying is a lifetime process (Nissilä, 1992), elderly persons can be assumed to be more aware of their mortality. Summaries of studies related to views of death and dying before being at the end-of-life stage can be seen in Table 3.

Some studies emphasize that older people view death and dying from a positive perspective of completion of the life cycle and the life span (Hallberg, 2004[3]). Molander (1999[3]) postulated that by reminiscing about their lives and telling stories, aged people try to find new, positive dimensions in their lives. However, not all old people review their life positively. Öberg (1997[3]) described in his study six ways of life, some of which were negative, producing a bitter life or a view of life as full of pitfalls. The experience of a negatively lived life was reflected in a “poor” death. These perspectives were supported by the findings of a meta-analysis (Fortner and Neimeyer, 1999[3]), where ego integrity was strongly related to low death anxiety.

The level of death anxiety in functionally impaired elderly living at home was reported to be low (Sullivan et al., 1998[3]) and significantly lower than in younger adults (Cicerelli, 2001[3]) In a review of death anxiety (Fortner and Neimeyer, 1999[3]), lower ego integrity, more physical problems and more psychological problems were suggested to be predictive of higher levels of death anxiety in elderly people.

Older people are concerned about pain during dying and issues such as knowledge of impending death or the presence of others during dying (Steinhouser et al., 2000[3], Vig et al., 2002[3]). Pinquart and Sörensen (2002[3]) found that aged people were more eager to discuss issues and consequences of death and were reluctant to prepare for the weakening and dying processes. This can be interpreted as elderly people being prepared for inevitable death but not perceiving themselves as dying persons. It was also interesting that no differences were observed in the preparations of the elderly between USA and Germany, despite these countries having dramatically different cultural backgrounds.

Table 3. Quantitative and qualitative studies of older people's views of death and dying prior to their reaching the end-of-life stage.

Author(s)	Aims of study	Participants	Design /methods	Findings
Rao et al., 1997, UK	To assess the nature of thoughts regarding death and dying	125 randomly selected community residents. Mean age 86 y	Personal interview including assessments of cognition, depression	Only 10% expressed worries about the prospect of dying or thought about death often. Those who thought about death often had a lower mood and a poorer social network than others. Cognitive impairment reduced the frequency of thinking about death.
Öberg, 1997, Finland	To describe and understand how the life lived is reflected in and gives meaning to old age	37 strategically selected older men (n=14) and women (n=23) were interviewed. Age 73-83 y	Data analysis based on the grounded theory method	A list of six ways of life was presented: the bitter life, life as a trapping pit, life as a hurdle race, the devoted silent life, life as a career and the sweet life. Physical, psychological and social functional capacity were explained by circumstances in childhood, adolescence and adult life. Ageing must be seen as a continuation of a process, starting with an earlier life, where the life lived gives meaning to old age.
Sullivan et al., 1998, the Netherlands	To describe the views of the elderly about death, dying and hastening death. Prospective study	Functionally impaired elderly outpatients (n=643 in 1994, n=575 in 1995) Mean age 73 y	Personal interview at home and questionnaires focusing on fears and religious beliefs	Only a few had fear of death. Views and fears of death were stabile. Fears of death were most closely related to health status, especially to mental health. Views concerning hastening death were related to religious belief and affiliation.
Fortner and Neimeyer, 1999,USA	To review relationships between death anxiety, ego integrity, physical and psychological problems	49 studies: (mean age of subjects 73 y: mean number of subjects 92, range 16-293)	Literature search up to December 1996. Published and unpublished papers, meta-analysis	Higher levels of death anxiety were related to lower levels of ego integrity and more physical and psychological problems and may also be related to being institutionalized. Death anxiety tended to be higher elderly people residing in nursing homes than in elderly people living in more independent settings. Age, gender and religiosity were not reliable predictors of death anxiety.
Molander, 1999, Finland	To analyse life meanings of elderly persons > 80 y who describe their experiences of their life and imminent death	5 men and 5 women living at home. 5 had cancer	Personal interviews, life profiles. Grounded theory analysis	Subjects estimated their dying by intertwining their past life events and imminent death. By reminiscing about their lives and telling their stories, subjects tried to find new and positive dimensions to their lives. Confronting death seemed easier when mental images about death started to resemble the positive aspects of their earlier life. The importance of listening to elderly people's life stories and reinforcing the positive aspects of these was emphasized.
Steinhouser et al., 2000, USA	To explore experiences of deaths that the participants had confronted. What made those deaths good or bad?	Patients, family members, different health care providers (mean age 47 y, range 26-77)	12 focus-group interviews. Altogether 75 participants	Six major components of death were specified: pain and symptom management, clear decision- making, preparation for death, completion in life cycle, contributing to others, and affirmation of the whole person. Many participants feared dying in pain, and it and other symptoms could be reduced through clear communication and decision-making with physician. Participants expressed a need for greater preparation for the end of life, and they confirmed the deep importance of spirituality or meaningfulness at the end of life.

Cicerelli et al., 2001, USA	To assess the influence of age on meanings of death, comparing young and older adults	Groups of 78 younger adults (mean age 22 y) and 68 older adults (mean age 83 y)	The personal meaning of death scale and 4 fear-of-death subscales: fear of being destroyed, fear of significant others, fear of unknown, fear of dying process	Death meanings were different only for subscale motivator, indicating that these conceptions of death are stabile with age. Younger adults saw death as a force motivating towards achievement of certain goals. Younger adults had higher scores in all subscales of fear of death except being destroyed. Death meanings of what will happen after death had a closed relationship with fear of death; afterlife a lower fear of death and extinction a greater fear.
Vig et al., 2002, USA	To assess to clarify whether current values can be extended to preferences for end-of-life care	16 home-dwelling elderly (60-84 y) with non-terminal heart disease or cancer. 14 men, 2 women	Personal interviews regarding the most important things in subjects' lives right now	Current life values can not be extended to end-of-life care preferences. Heterogeneity was seen in views about the end of life. People were not only concerned with pain-free death, but also issues such as knowledge of impending death and the presence of others during dying.
Carrese et al., 2002, USA	To clarify how elderly patients think about their illnesses and approaching end of life	20 chronically ill: 16 women, 4 men. Mean age 86 y	Personal interviews regarding current/future illness and end-of life	16/20 did not think about the future and did not in general plan for the future. 19/20 were reluctant to think about, discuss or plan for serious future illnesses. Instead, they described "one day at a time" and "what will is to be will be" approaches.
Pinquart and Sörensen , 2002, Germany and USA	To investigate the relationship between preparation for death and future care needs	582 community care older adults from Germany and 593 from USA	Mailed questionnaires to assess preparation for death, preparation for future care needs, physical functioning and demographic variables	The majority of seniors had made preparations for death, more so than preparations for future care needs. Preparation for death was most extensive for older, more educated, widowed and more religious seniors, as well as for seniors living in USA as compared with Germany.
Hallberg, 2004, Sweden	To review older people's views of death and dying, whether in a terminal phase or not	33 publications	A stepwise literature search from data bases	Only a few studies examined the older person's views of death and dying. Common themes: 1) Emphasis on completion of the life cycle and life span perspective. These were mainly positive and comforting in the face of death, but also connected generations and were part of a higher life meaning; 2) The impact on and of the closest relatives and the fear of being a burden; 3) Death anxiety and fear of death and dying; 4) Strong evidence of older people's worries about dying and the end-of-life phase.

Elderly people are commonly considered to be more willing to talk about death (Rao et al., 1997 [3]), but Carrese et al. (2002 [3]) reported that chronically ill aged patients did not like to discuss future illnesses or dying. Personal conceptions of death and dying vary greatly, and in one study only 10% of home-dwellers aged over 80 years in the UK expressed worries over the prospect of dying or thought about death often (Rao et al., 1997 [3]) The elderly in the Netherlands had a stabile and low preoccupation with death (Sullivan et al., 1998 [3]).

2.2.4.2. Quantitative studies of end-of-life care

This section deals with quantitative studies describing different symptoms, needs and problems related to end-of-life care. A summary of the studies is presented in Table 4. The main findings of the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) and the Hospitalized Elderly Longitudinal Project (HELP) are outlined. SUPPORT was a large study with 9105 participants that described the care of seriously ill patients in acute wards in the US. The HELP study, which supplemented the SUPPORT study, comprised elderly patients of 80 years and over. These were the first broad studies in the US to explore care of dying patients. Previous studies of dying had mainly been performed in Europe. Many of these were carried out by researchers with sociology background (Hakanen, 1991 [5], Seale and Cartwright, 1994).

The SUPPORT study was a multicentred intervention trial to improve end-of-life decision-making and reduce the frequency of a mechanically supported, painful and prolonged process of dying. Phase I of that study (in 1989-1991) with 4301 severely ill patients confirmed barriers to optimal management and shortfalls in patient-physician communication and decision-making. Moderate to severe pain affected half of dying patients, and final hospitalizations of half of the patients included more than 8 days in the intensive care unit (ICU). Nearly half of do-not-resuscitate (DNR) orders were written in the last 2 days of life.

Phase II (in 1992–1994) included 4804 gravely ill patients, who were randomized into the intervention group (n=2652) or the control group (n=2152). In the intervention group, education was given to medical staff to increase understanding of prognoses and patients' preferences. On the basis of the observation phase, the investigators identified five major outcomes for the intervention phase: incidence and timing of DNR orders; patient-physician agreement on preferences for cardiopulmonary resuscitation (CPR); days in an ICU, in a coma, or on mechanical ventilation before death; presence of pain; and hospital resource use. The overall 6-month mortality rate in phases I and II was 47% (n=9105). Despite all efforts, the phase II intervention failed to improve care or patient outcomes (The SUPPORT Principal Investigators, 1995, Phillips et al., 2000). Although the outcome was negative, SUPPORT did provide the raw data to enable investigators to understand why advance directives (ADs) did not fulfil their early expectations (Prendergast, 2001) and also provided an enormous database for studies of end-of-life care in hospitals.

The median age of patients eligible for SUPPORT was lower than expected (65 years), with the median age for adults at death being nearly 15 years older. The investigators added a cohort of hospitalized patients 80 years of age or older to better understand the experiences of the very old. This supplemental project was named the Hospitalized Elderly Longitudinal Project, (HELP) and included 1266 patients with an unplanned hospitalization for 48 hours or more at one of four teaching hospitals in 1994 (Phillips et al., 2000). The HELP study produced numerous substudies (Lynn et al., 1997 [4], Tsevat et al., 1998 [4], Goodlin et al., 1999 [4], Puchalski et al., 2000 [10], Somogui-Zalud et al., 2000 [4], Teno et al., 2000 [10], Somodyi-Zalud et al., 2002) Over 100 articles describing end-of-life care among hospital patients have been published based on the SUPPORT and HELP databases.

Quantitative studies describing different symptoms and needs related to end-of-life care (Table 4) have shown many deficiencies in symptom management in acute hospitals but also in palliative settings. Most of these studies are from North America, but study findings from UK (Mills et al., 1994 [4], Murray et al., 2003 [5]) and Finland (Miettinen et al. 1998 [4], Miettinen and Tilvis, 1999 [4]) have revealed similar problems. However, some studies have demonstrated that good palliative care is possible with adequate monitoring and management of symptoms (McCann et al., 1994 [4], Chochinov et al., 2002 [4]). Other authors highlight the need for meeting emotional and spiritual needs (Chochinov et al., 1999 [4], Breitbart et al., 2000 [4]).

Studies of surrogates' opinions and end-of-life care support findings of other research describing poor symptom control among dying patients (Lynn et al., 1997 [4], Miettinen et al., 1998 [4], Miettinen and Tilvis, 1999 [4], Baker et al., 2000 [4], Teno et al., 2004 [4]). When comparing the different settings providing end-of- life care, family members – both in the US and in Finland – have more often been satisfied with the end-of-life care at home than in hospitals. Family members can better participate in the care at home and this care is more patient-centered. However, good professional knowledge is needed also in home care to treat difficult symptoms (Miettinen et al., 1998 [4], Teno et al., 2004 [4]).

On the other hand, relatives' retrospective reports of terminal illness may also be misleading and biased. While relatives' views of patients' awareness and acceptance of dying match patients' views well but relatives' retrospective reports of patients' pain and anxiety can be misleading or only moderately reliable (Higginson et al., 1994 [4], Hinton, 1996 [4]). Family members may overestimate (Higginson et al., 1994 [4], Hinton, 1996 [4]) or underestimate pain (Teno et al., 2004 [4]).

The SUPPORT study showed that aged persons are given less aggressive care than younger patients (Hamel et al., 2000 [4]). However, the survival disadvantage experienced by seriously ill elderly patients was not explained by the less aggressive treatment they received (Hamel et al., 1999 [4]). Interestingly, several studies have shown that older people opt for more active treatments than professionals or surrogates would estimate (Tsevat et al., 1998 [4], Hamel et al., 2000 [4])

In the HELP study, life seemed worth living even in hospital wards for hospitalized patients aged over 80 years (Tsevat et al., 1998 [4]). This suggests that health values should be ascertained directly from patients when ever possible. Cartwright (1993) found that those dying aged over 85 years had greater needs but received less support from relatives than people dying at younger ages. Sadly, older people were also not receiving more attention from medical staff in the last year of their lives. Findings from the HELP database indicated that 70% of dying elderly patients preferred care focused on comfort rather than prolonging life. However, many received LSTs (Somodyi-Zalud et al., 2002) and one out of four suffered pain during the last months of life (Somogyi-Zalud et al., 2000 [4]).

These studies show that elderly patients may have a will to live despite serious diseases or functional impairment. Age per se should not be a reason to withholding or withdrawing medical treatments, but if death is impending the goal should be to provide good palliative care, particularly when this is the patient's own wish.

Table 4. Quantitative studies describing symptoms of dying patients and problems related to care of these patients.

Author(s)	Aims of study	Participants	Design /methods	Findings
Higginson et al., 1994, UK	To compare retrospective assessments of surrogates with assessments of dying patients, surrogates and staff	Surrogates and palliative staff for 35 dying patients and 6 patients in two palliative care settings	Prospective assessments by staff, surrogates and patients + surrogate interviews 7 mo after patients' death	In pain control, other symptom control, family anxiety and patient anxiety there was little agreement. Comparison of surrogate ratings before death and 7 mo after suggested that surrogates alter their opinions during bereavement.
Mills et al.,1994, UK	To study the process of care of dying patients	50 dying patients in general hospitals: 29 had cancer, 21 other terminal illnesses. Mean age 66 y	Researcher made observations about the quantity and quality of care	Final period of hospitalization ranged from 6 h to 24 wks. Basic interventions to maintain patients' comfort were not provided: Oral hygiene was poor. Little assistance was given with eating. Contact between nurses and dying patients was minimal.
McCann et al., 1994, USA	To determine whether hunger and thirst could be palliated without forced feeding or hydration	32 mentally aware competent patients with terminal illness in long-term care. Mean age 75 y	Symptoms of hunger, thirst and dry mouth recorded and subjective level of comfort assessed by asking patients and families pain and other symptoms, fears and anxiety	20 patients (63%) never experienced hunger, and 20 patients experienced either no thirst or only initially during their terminal illness. In all patients, symptoms of hunger and thirst and dry mouth could be alleviated, with small amounts of food, fluid or ice chips and lip lubricant. Comfort care included use of narcotics in 94% of patients.
Hinton, 1996, UK	To assess the accuracy of surrogates' reports of patients' terminal illnesses with patients' interviews	71 surrogates of terminally ill patients and 77 dying patients in hospice care	Surrogate interviews few days before and 4 mo after patients died and patient interviews	Several symptoms showed poor agreement, notably pain, anorexia and depression, but vomiting, dyspnea and immobility ratings agreed moderately well. Awareness and acceptance of dying matched the surrogates' retrospective assessments moderately well
Lynn et al.,1997, USA	To characterize the experience of dying	3068 surrogates of SUPPORT I + II studies and 289 surrogates of HELP study. Mean age of dying patients was 67 y	Surrogates interviewed by phone 4 -10 wks after patients' death	55% of patients were conscious during the last 3 days of life: pain and dyspnea were common. 59% had preferred comfort care, but in 10% of cases care was not consistent with preference. Elderly patients died more often in nursing homes, younger in hospitals.
Bernabei et al., 1998, USA	To evaluate the adequacy of pain management in nursing homes	13 625 elderly and minority cancer patients. Mean age 81 y	RAI database, MDS. Daily pain was assessed	4003 patients (24%, 29%, and 38% of those aged >85 y, 75-84 y, and 65-74 y) respectively reported daily pain. 26% of patients with daily pain did not receive any analgesia. Patients older than 85 y were more likely to receive no analgesia.
Miettinen et al., 1998, Finland	To assess dying patients' symptoms and needs	371 surrogates of dying patients in home care, health center hospitals and district and university hospitals. Mean age of patients was 81 y	Surrogates interviewed by questionnaires	57% of patients had suffered moderate to severe pain, and for 22% of these pain relief was unsuccessful. Inadequate pain relief was associated with a feeling of helplessness in patients, unsatisfactory care of daily needs. Patients who died at home suffered pain less often, but more often had unsuccessful pain relief than patients dying in hospitals.

Tsevat et al., 1998, USA	To assess health values of older hospitalized patients	414/1266 patients from HELP study. Mean age 84 y (female 60%)	Time-trade-off utilities reflecting preferences for current health relative to a shorter but healthy life	On average, patients equated living 1 y in their current state of health with living 10 mo in excellent health. 30% rated their current quality of life as excellent, 69% were willing to give up at most 1 mo of 12 in exchange for excellent health. Surrogates underestimated patients’ time-trade-off score by 3 mo or more.
Chochinov et al., 1999, Canada	To assess dying patients’ desire to live	585 terminally ill patients in palliative care unit. Mean age 73 y	Measurements twice daily by self-report on a visual analogue scale	The four main variables decreasing patients’ will to live were depression, anxiety, shortness of breath and sense of well-being, with the prominence of these variables changing over time.
Miettinen and Tilvis, 1999, Finland	To investigate the occurrence of medical futility and its correlates	490 surrogates of patients who died at home or in acute or long-term care settings. Mean age of patients was 80 y.	A postal questionnaire sent to relatives 1 or 2 y after death	28% of patients were reported to suffer from medical futilities, most often from medications (21%) and unnecessary examinations (19%). Futilities were seldom reported for patients who died at home. Patients’ feelings of insecurity, male gender and poor atmosphere in caring place were independently associated with medical futilities.
Baker et al., 2000, USA	To examine factors associated with family satisfaction with end-of-life care	767/983 SUPPORT II surrogates’ interviews after patients’ deaths. Mean age of patients was 66 y	Satisfaction with patient comfort and decision-making	16% reported dissatisfaction with patient comfort and 30% dissatisfaction with communication and decision-making. Hospital site was related to both measurements of satisfaction.
Breitbart et al., 2000, USA	To determine the prevalence of desire to hasten death and associates of this desire	92 terminally ill cancer patients in a palliative care hospital. Mean age 66 y	Interviews including preference for hastened death, depression, hopelessness and social networks. Pain assessed with questionnaires	16% of patients suffered from clinical depression and 17% desired a hastened death. Depression and hopelessness were independent contributors to the desire for hastened death. No relationship existed between pain and desire for hastened death.
Hamel et al., 2000, USA	To evaluate how patient age influences patterns of care	SUPPORT data of 9105 patients. Mean age 65 y	Outcomes of patients’ preferences for active care, decision-making regarding CPR and other LST	Older patients (> 75 y) preferred less aggressive care than younger patients (CPR not preferred 38% vs. 28%), but many older patients also wanted CPR. Surrogates and health care providers underestimated older patients’ desire for active care. Older age was associated with lower hospital costs and higher rates of decisions to withhold LSTs.
McCarthy et al., 2000, USA	To characterize cancer patients’ experiences during the last 6 mo of life	SUPPORT patients: 316/520 with colon cancer and 747/939 lung cancer patients. Mean age 65 y	Retrospective analysis of data collected in four observational windows from patient and surrogate interviews and chart abstractions	Patients’ last 6 mo of life were characterized by poorly controlled severe pain and confusion. As death approached, patients favoured comfort measures over life extension, and about two-thirds wanted to forgo CPR within 3 days of death. Patients’ families incurred financial burdens.

Levenson et al., 2000, USA	To characterize experiences of patients during the last 6 months	SUPPORT patients with congestive heart failure, 539/1404 of whom died within 1 y. Mean age 70 y.	Retrospective analysis of questionnaire interviews with patients or their surrogates and chart abstractions	As death approached, illness became more severe, the experience of symptoms more frequent and patient preferred DNR more often. However, no significant impairment was present in quality of life. This reflected the unpredictable course of congestive heart failure during the last months of life.
Somogyi-Zalud et al., 2000, USA	To characterize experiences of patients during the last 6 months of life	417/1266 patients from HELP study. Mean age 86 y.	Chart reviews and interview data with patients and surrogates	Before hospitalization 2/3 patients reported fair quality of life. 70% preferred comfort care on the third day of hospitalization. During the last months of life 3 of 5 patients in hospital and 4 of 5 interviewed out of hospital preferred to forgo CPR. 25% of patients reported severe pain.
Chochinov et al., 2002, Canada	To identify the extent to which dying persons maintain their sense of integrity	213 terminally ill persons with cancer in palliative care unit. Mean age 69 y	Sense of dignity 0-7, desire to death, anxiety, hopelessness	8% reported loss of dignity as a great concern. They were far more likely than the rest of the cohort to report psychological distress, heightened dependency needs and loss of will to live.
Teno et al., 2004, USA	To evaluate experience of dying at home and in institutional settings in 2000	Surrogates for 1578 decedents used to estimate end-of-life care in 1.97 million deaths. Mean age of decedents 75 y	Patient interviews and family- centred end-of-life care outcomes	Of deaths, 67% occurred in institutions and 33% at home. 1of 4 of patients with pain or dyspnea were reported to not receive adequate treatment. 1of 4 reported concerns with physician communication. Over one-third reported insufficient emotional support in institutional care or home health agency. Nursing home residents were less likely to be treated with respect at the end of life. Family members of decedents who received care at home with hospice services were more likely to report a favourable dying experience.

2.2.4.3. Qualitative studies of end-of-life care

Qualitative studies describing the perceptions and preferences of dying elderly persons regarding end-of-life care are presented in Table 5. Similar to quantitative studies, these studies show problems in end-of-life care as well as in symptom management. The qualitative approach has also revealed new findings in this sensitive research area. For example, elderly long-term care patients in Canada estimated that the most important domains for end-of-life care were having a sense of control and avoiding inappropriate prolongation of dying (Singer et al., 1999 [5]). In addition, Murray et al. (2003 [5]) clearly demonstrated a difference between developed and undeveloped countries in facing dying and highlighted the importance of understanding cultural context when interpreting findings.

These qualitative studies show that it is essential to ask elderly patients directly about their preferences and values related to end-of-life care. Medical personnel more often discuss with these matters with surrogates or family members, neglecting to ascertain elderly patients' opinions and therefore misunderstanding patient's needs and wishes. These studies indicate the need to have discussions with patients, also as a way to increasing patients' awareness of dying. A literature review of Hallberg (2004) concluded that older people want to talk about death and dying. However, the life situation at the time of end-of-life discussions has a great influence on patients' preferences. Discussions should occur at different stages of the terminal illness. Patients especially highlight the need to receive respect for individual wishes in the communication process (Steinhauser et al., 2000 [3], Wenrich et al., 2001 [9], Vig and Pearlman, 2003 [5], Kirk et al., 2004 [9]). Some studies have shown that dying patients have rather small wishes and good end-of-life care can be arranged with quite small activities (Engle et al., 1998 [5], Singer et al., 1999 [5], Vig and Pearlman, 2003 [5]).

2.2.4.4. Studies of end-of-life care of patients with end-stage dementia

Few studies have described the care of end-stage dementia patients in Europe. About one thousand studies on this patient population have been conducted in the US, with many of these concentrating on feeding problems and creating guidelines for qualified good end-of-life care. Only few selected studies are presented in Table 6 describing the care of end-stage dementia patients in different settings.

Especially for patients who have reached the advanced stages of the illness, dementia should be considered a terminal condition similar to incurable cancer (Luchins and Hanrahan, 1993 [6]). A hospice treatment option that maintains patient comfort instead of preventing death at all costs should also be available to advanced dementia patients (Sachs et al., 1995, Volicer and Hurley, 1998, Mitchell et al., 2004). However, patients with dementia may live for many years longer than patients with most types of cancer. It is very difficult to predict when the patient has less than 6 months to live (Finne-Soveri and Tilvis, 1998, Mitchell et al., 2004), which has been the definition for terminal care or hospice care in the US. Less than 1% of US hospice enrollees have a primary diagnosis of dementia (Mitchell et al., 2004).

A "hospice approach" has been described for the care of patients with advanced dementia (Volicer, 1995, Volicer et al., 1998). In the US, the patient's proxy makes decisions about limiting a severely demented patient's treatment (Volicier, 1995). In a dementia care unit, the staff regularly share information with patients' families and make recommendations about the five levels of supportive care: 1) " Full care", 2) "DNR" but no other limits, 3) DNR plus " do not transfer to a hospital" (DNT), 4) DNR plus DNT plus " Do not work up fevers" (DNWU) and 5) comfort care only, which, in addition to the above limitations, also eliminates tube feeding. These treatment designations provide general guidance and are not intended to be followed rigidly. Achieving the goals of individual patients, such as maintenance of comfort, is the overriding aim (Volicer, 1995).

The recommendation of palliative care for end-stage patients (Luchins and Hanrahan, 1993 [6]) is difficult to interpret as it pertains to advanced dementia patients in the US (Ahronheim et al., 1996 [6], Morrison and Siu, 2000 [6], Mitchell et al., 2004 [6]). According to van der Steen et al. (2004 [6]), care for American nursing home residents with dementia is more aggressive than care for Dutch residents.

Decision-making for dementia patients is difficult. As one family caregiver in the US stated: ”Most of us assess quality of life in dementia patients more negatively than is justified, largely because we and our society hold cognitive skills in such high regard” (Post and Whitehouse, 1995). These findings of poor end-of-life care for elderly patients and difficulties in decision-making have promoted the practice of using ADs in the US. More studies are needed to evaluate the practices and end-of-life care of dementia patients.

Table 5. Qualitative studies related to end-of-life care in the elderly.

Author(s)	Aims of study	Participants	Design /methods	Findings
Hakanen, 1991, Finland	To describe and compare experiences of dying persons in university hospital, city hospital and hospice	18 terminally ill cancer patients age range: 38-82 y	Etological, socio-psychological approach	Quality end-of-life care could be arranged in a hospice setting, but not always in university or city hospitals. Quality end-of-life care was related to trouble in health care systems in co-ordinating care across settings. The balance between physical and emotional needs was explored.
Engle et al., 1998, USA	To describe and compare experiences, needs, priorities and concerns during the living-dying interval	13 nursing home residents: 6 women, 7 men (mean age 77 y, range 54-91; 8 black, 5 white).	Ethnographic, personal interviews ”How have things been for you?”, “What would make things better?”, ”What does dying mean to you?”	Dying was reflected in thinking of dying; having little or no fear of dying; finding comfort in religious faith. Pain: black people reported pain more often than white people. Nutrition: no appetite, swallowing difficulties, no pleasure in eating. Religion: religious activities as a source of comfort to reduce pain. Caregiving to other patients: identifying others worse off. Care receiving: staff doing extra activities, staff responding slowly to requests and residents unable to understand physicians. Coping: anger, withdrawal from situation, direct confrontation, humour and talking with staff.
Singer et al., 1999, Canada	To identify and describe quality of end-of-life care	3 patient groups; dialysis (n=48, mean age 48 y), HIV (n=40, mean age 40 y) and long-term care patients (n=38, mean age 76 y)	Personal interviews focusing on control of decision-making, personal preferences, views on withdrawal or termination of care	Long-term patients (n=38/126) estimated domains of end-of-life care: Avoiding inappropriate prolongation of dying (66%), Achieving a sense of control (47%), receiving adequate pain and symptom management (40%), reliving burden (34%), strengthening relationships with loved ones (32%)
Murray et al., 2003, Scotland and Kenya	To describe and compare experiences of illness and needs in a developed and an undeveloped country	Scotland: 20 cancer patients. Mean age 66 (range 48-87 y) Kenya: 24 cancer patients mean age 57 (range 41-80 y)	Personal interviews about the prospect of death and coping methods	Scotland vs. Kenya: Pain is unusual vs. analgesia unaffordable Anger in face of illness vs. acceptance “Just keep it to myself” vs. acceptance of community support Diagnosis: active treatment, then watching vs. signalled waiting for death Patients concerned about career in the future vs. patients concerned about being a physical and financial burden to the family.
Vig and Pearlman, 2003, USA	To characterize quality of life while dying	26 home-dwelling terminally ill men. Mean age 71 y (range 52-86 y)	Personal interviews: ”What are the most important things in your life right now? ”	They believed that death was near and were engaging in hobbies and enjoyable activities as an alternative to moving into the final stage of illness, in which they saw themselves as actively dying. New symptoms brought concerns about progression to active dying, They relieved anticipated burden on loved ones by engaging in new tasks.

Table 6. Studies related to end-of-life care in patients with end-stage dementia.

Authors	Aims of study	Participants	Design /methods	Findings
Luchins and Hanrahan, 1993, USA	To determine the appropriate health care for end-stage dementia patients	819 physicians, 1000 other professionals and 500 families of dementia patients	Level of care chosen from 5 alternatives from highly aggressive to palliative	61% of physicians, 55% of other professionals and 71% of families chose palliative care only. Increased age of the respondent and experience with terminal care choices were associated with choosing palliative care.
Ahronheim et al., 1996, USA	To compare treatments of dementia patients and cancer patients in acute hospital care	80 dementia patients (91%>75 y) 84 cancer patients (55% >75 y)	Charts of deceased patients were reviewed	47% of all patients received invasive non-palliative treatments. Dementia patients were more likely to receive feeding tubes. Resuscitation was attempted for 24% of each group. Overall, 88% received antibiotics; patients with dementia were more likely to receive antibiotics.
Morrison and Siu, 2000, USA	To compare survival and care for patients with end-stage dementia and those cognitively intact	Hip-fracture (59 intact + 38 demented) + pneumonia patients (39 intact + 80 demented) aged > 70y	Mortality, symptom care and aggressive care reviewed in cognitively intact vs. with end-stage dementia patients	6-mo mortality for dementia patients and pneumonia was 53%, compared with 13% for intact. 6-mo mortality for dementia and hip-fracture was 55% compared 12% with intact. Patients with dementia received as many burdensome procedures as intact patients and only 8/118 dementia patients had made decision to forgo LST other than CPR. 24% of dementia patients received a standing order for analgesics.
Mitchell et al., 2004, USA	To describe dying with advance dementia in the nursing home	Aged >65 years old persons (n=1609) who died with advance dementia within 1 year of admission	RAI data from MDS (1994-1997) from 643 New York states nursing homes. Assessment completed within 120 days of death.	Only 1% of residents with advanced dementia were perceived to have a life expectancy of less than 6 mo; however, 70% died within that period. Before death, 55% of demented residents had a DNR-order, and 1% had a DNH-order. Aggressive interventions happened: tube feeding (25 %), laboratory tests (50 %), restraints (10 %) and intravenous therapy (10 %). Distressing conditions included: pressure ulcers (15 %), constipation (15 %), pain (12 %), and shortness of breath (8 %).
van der Steen et al., 2004, the Netherlands and USA	To compare treatment of lower respiratory tract infection and care of dementia patients in the US and the Netherlands	36/701 dementia patients from USA and 61/551 from Netherlands living in nursing homes	Treatment and mortality, stratified for dementia severity	Treatment of lower respiratory tract infections in the US involved a larger number of antibiotics, more frequent hospitalizations and greater use of i.v. antibiotics and rehydration therapy than in Dutch residents at the same dementia stage. In both countries, treatments to relieve symptoms of respiratory infection were provided to only a minority of residents. Dutch mortality rates were higher overall.

2.3. ATTITUDES OF THE ELDERLY TOWARDS ADVANCE DIRECTIVES

Multiple studies related to ADs have been published in the US during the last decade. These studies have large heterogeneities; many studies were small with selected participant groups, different research questions were asked and cultural and legal backgrounds were different. These factors have made it difficult to generalize the results (Miles et al., 1996). Table 7 presents a few quantitative studies of elderly participants, illustrating their attitudes towards ADs and content and meaning of ADs in different settings.

One goal of AD is for individuals to prepare for dying from psychological and practical points of view. For many people, this goal may be frightening, thus inhibiting the use of ADs. From society's perspective, ADs should also reduce health care costs. AD use has been widely recommended in the US, especially among older people (Emanuel et al., 1991 [7], Sachs et al., 1992 [7], High, 1993, Virmani et al., 1994, Lee et al., 2000 [7], Molloy et al., 2000 [7], Teno et al., 2000 [10]).

Among hospitalized patients in different studies in the US, proportion of having an AD ranged from 1-40% in 1995 (Miles et al., 1996, Gross 1998 [7]), and in a population-based study of elderly outpatients, 9% had an AD in 1993–1994 (Gross 1998 [7], Hopp, 2000). Of 16 678 decedents in 1986, 10% had a LW and they were more likely to use hospices (20% vs. 8%) and half as likely to receive LSTs than decedents without a LW (Hanson and Rodgman, 1996). LWs were most often prepared by those dying of cancer and least often by those dying of diabetes or heart disease. In 2000, 56% of deceased patients in home care and 81% of those in hospices or nursing homes had a written AD in the US (Teno et al., 2004 [4]). However, LW completion has varied greatly among community-dwelling elderly people, and reasons for this are poorly understood (Sachs et al., 1992 [7], Prendergast, 2001).

In Europe, only a few studies have been published on LWs. In Denmark, 3% of nursing home residents had a LW (Moe and Schroll, 1997). In the UK, 82% of elderly inpatients had not even heard of LWs or ADs, but they were interested in the concepts (Schiff et al., 2000 [7]). In Finland, less than 5% of acute care hospital patients have a written LW (Hilden and Palo, 2000, Skrifvars et al., 2003 [10]).

In the US, people with ADs are better educated and come from higher socio-economic classes than persons with no LW (Miles et al. 1996, Hopp, 2000), and African Americans are less likely than Caucasians to complete an AD (Eleazer et al., 1996, Hanson and Rodgman, 1996, Kahana et al., 2004 [7]). Completion of ADs may reflect a better ability to complete the documents or having values in line with ADs (Eleazer et al., 1996, Miles et al., 1996, Hopp, 2000). People with ADs are less inclined to accept aggressive LSTs in terminal illnesses or permanent dependence of invasive life support (Walker et al., 1995 [8]). Completion of ADs is higher among persons in older age groups compared with younger age groups (Levin et al., 1999 [10]).

The stability of preferences has also been studied in the US. Of elderly outpatients, 85% had stabile preferences for a variety of LSTs in a two-year follow-up, and patients with a LW were less likely to change their wishes (Danis et al., 1994 [7]). In another study, 80% of patients had stable preferences for LSTs when asked at the end of their intensive care stay and one month later (Everhart and Pearlman, 1990). Of SUPPORT patients, 80% had stabile preferences over two months (Rosenfeld et al., 1996 [8]). Of patients initially preferring DNR, those with substantial improvements in depression scores were more likely to change their preference in favour of CPR (Rosenfeld et al., 1996 [8]). In a small study of nursing home residents' preferences regarding

LSTs, one in four changed over 12- and 24-month study periods. Changes in residents' cognitive status predicted changes in their decisions (McParland et al., 2003 [8]).

The reasoning behind AD completion has been the focus of abundant research. Most people are willing to give up some longevity for quality of life, thus regarding certain life situations as worse than death (Emanuel et al., 1991 [7], Gamble et al., 1991 [7], Walker et al., 1995 [8], Gross, 1998 [7], Schiff et al., 2000 [7]). Such reasons as wanting to preserve dignity, affirm religious beliefs, remain in control during disability, remain communicative and retain life savings have been reported (Pfeifer et al., 1994 [9], Miles et al., 1996, Schonwetter et al., 1996, Singer et al., 1998, Martin et al., 2000, Lo et al., 2002). Some people also want decisions of medical treatments to reflect altruistic values, such as refusing to burden loved ones and sparing family members from having to make difficult decisions (Everhart and Pearlman, 1990, Mead et al., 1995, Schonwetter et al., 1996, Schiff et al., 2000 [7]).

The reasons for AD completion vary according to the life situation and cultural context (Emmanuel et al., 1991 [7], Garrett et al., 1993, Singer et al., 1998). There are also large differences in AD policies in North America. One of the extremes is the POLST practice in Oregon (Lee et al., 2000 [7]) (for more details about POLST, see section 2.1.2.1). In a recent study from the US, only Caucasian race and number of hospitalizations predicted having an AD among the home-dwelling elderly (Kahana et al., 2004 [7]). Physical health, mental status or social relationships did not have predictive value (Kahana et al., 2004 [7]).

In one study, young patients (mean age 48 years) with a terminal disease emphasized that AD completion as a part of ACP facilitates reflective discussions of values, goals and preferences with loved ones in a non-crisis situation (Singer et al., 1998). However, some researchers have suggested that written ADs are not necessarily the desired outcome of ACP. Many patients may be more satisfied by a discussion about their wishes (Singer et al., 1998, Emanuel, 2000).

This is possibly why empirical research has shown that despite positive attitudes towards LWs patients seldom complete such forms (Lo et al., 1986 [10], Emanuel et al., 1991 [7], Gamble et al., 1991 [7], High, 1993, Teno et al., 1997 [7]). Research interventions may increase the use of AD forms, but only modestly (Miles et al., 1996). While attempts have been made to educate older outpatients about ADs (Sachs et al., 1992 [7]), these interventions have had little impact on AD use (Sachs et al., 1992 [7], High, 1993).

Elderly people discuss advance planning more often with family members and loved ones than with physicians (Lo et al., 1986 [10], Gamble et al., 1991 [7], High, 1993, Miles et al., 1996, Hopp, 2000, Schiff et al., 2000 [7], Kahana et al., 2004 [7]). Moreover, older people have a hierarchical and particular preference for support from spouses, when available, followed by children and other relatives when having discussions about preferences related to LSTs (Johnston et al., 1995 [10], Hopp, 2000, Kahana et al., 2004 [7]).

A qualitative study of the house-bound chronically ill elderly in the US showed that patients were reluctant to think about, discuss or plan for serious future illness (Carrese et al., 2002 [3]). Instead, they described a "one day at a time" or "what will be will be" approach to life, preferring to "cross that bridge" when they needed to. These elderly people considered end-of-life matters to be in the hands of God. The completed ADs were not well understood and were intended for use only when death was near and certain. Most of these patients seemed not to be interested in ACP and were confident that they could rely on others, particularly on family members, should the need arise (High, 1993).

Table 7. Quantitative studies of elderly people's attitudes towards advance directives (ADs) and of the content and meaning of ADs in different settings.

Author(s)	Participants	Aims of study	Findings
Emmanuel et al., 1991, USA	405 outpatients; 235 < 65 y, 170 > 65 y	Patients' opinions of ADs	93% of the patients were interested in ADs. The lack of physician initiative and the nature of the topic were barriers to AD completion. Patients<65 y wanted to complete ADs more often than patients >65y. Outpatients refused LSTs in 70% of cases in poor prognosis scenarios.
Gamble et al., 1991, USA	Ambulatory patients n=75, >60 y	To determine the prevalence of LWs and preferences in case of incapacity	None had signed a LW. 3% had discussed a LW with their physician, although 81% wanted to have this discussion. In case of incapacity, 86% preferred to receive basic medical care or comfort care and 93% wanted their family to make decisions about terminal care.
Sachs et al., 1992, USA,	131 outpatients > 65y without an AD	To compare a randomized, controlled trial of an educational intervention with the usual use of ADs	6 mo later, only 7/48 (15% vs. 10%) in the intervention group had an AD or a note of AD discussions with their physician in the medical chart. Participants stated that procrastination was a barrier to completing a legal AD document. Some expected their family to be available to make decisions on their behalf. Only a few cited discomfort with the topic or problems with the documents as reasons for not executing an AD.
Garrett et al., 1992, USA.	2536 outpatients, >65 y	To determine which patient characteristics are associated with the desire for LST in the event of terminal illness	53% of women and 43% of men chose less active treatment. High depression scores were associated with the desire for more active treatment. 16% had a LW. 84% stated, that religion has a very important influence on preferences.
Danis et al., 1994, USA	2536 primary care patients > 65 y, mean age 74 years	To determine participants health status, depression, social support, use of LW and desire for LSTs if they were to become terminally ill. Questions repeated 2 y later.	The choice to forgo treatment was twice as stabile as the choice to opt for treatment in a 2-y follow up. 85% of patients had stabile preferences for a variety of LSTs at final assessment. Patients with a LW were less likely to change their wishes (14%) than those without a LW (41%). Persons were more likely to opt for increased treatment at a later time if they had been hospitalized, had become more immobile or more depressed, or had received less social support. Patients with life-threatening illness had strong desires for LSTs.
Teno et al., 1997, USA	SUPPORT (n= 4804) acute care patients from 1992-1994, mean age 65 y	To evaluate the content of AD documents.	12% of inpatients had ADs, and of these 66% were DPAHC. Of patients with an AD, only 12% had talked with a physician when completing the document, and only 25% of physicians were aware of patients' ADs. Only 3% of ADs would have been applicable to the patient's current situation.
Gross, 1998, USA	8727 inpatients and 22966 outpatients in Illinois in 1994	To assess the prevalence and content of ADs	Of 8727 inpatients, 11% had an AD, and of 22966 outpatients 15% had an AD. Of 328 examined medical ADs, 26% were LWs and 64%were a power of attorney for health care forms. 7 did not specify any preference for their proxy to follow; 189 did not want LST if the burden of treatment outweighed the expected benefits, 14 wanted their lives to be prolonged unless they were in an irreversible coma. 32 were DNR orders of nursing home residents.

Lee et al., 2000, USA	58 deaths in Portland, Oregon	To evaluate how POLST instructions had been carried out	98% of all participants who died during the study period had completed a POLST. In the last 2 wks of their lives, care was consistent with POLST instructions regarding CPR for 91%, antibiotics for 86%, IV fluids for 84%, feeding tubes for 94% and level of medical intervention for 46%.
Molloy et al., 2000, Canada	527 residents from 6 nursing homes	To study the effect of systemically implemented ADs in nursing homes on patient and family satisfaction in decision-making and on health costs.	49% of competent residents and 78% of families of incompetent residents completed ADs. Satisfaction was not significantly different between intervention and control nursing homes. The main difference between the groups was a decreased use of resources in the intervention group without changes in mortality.
Schiff et al, 2000, UK	76 inpatients, mean age 81 y	To determine patients' knowledge of LWs and their health care choices	82% had not heard of a LW or AD. Most people chose relatives as a health care proxy. 24% had discussed issues surrounding medical care with their proposed proxies. Women were less likely than men to request active treatment options. The single condition most feared was advanced dementia. At the end stage of a terminal disease, 90% would refuse CPR, 86% i.v. fluids and 82% antibiotics. 74% expressed interest in a LW, because their views would be known and to relieve the burden of decisions on their family
Kahana et al., 2004, USA	231 primary care patients (mean age 80 y), 99 physicians, 127 family members	To examine the potential facilitators or deterrents to end-of-life planning for community-dwelling adults, including personal and social influences	65% had discussed end-of-life issues with family members or professionals, and 60% had an AD. The only predictors of having an AD were race and number of hospitalisations. Respondents in their 60s tended to have discussed wishes with others, the oldest adults (>90 y) had also largely expressed their wishes. Three-quarters of physicians did not know the end-of-life wishes of their patients having an AD, but 82% of the respective caregivers knew.

2.3.1. Resuscitation preferences

In the medical literature, studies of life-sustaining treatments have concentrated on cardiopulmonary resuscitation because this is life-saving medical intervention under appropriate circumstances. On the other hand, when indiscriminately applied, CPR for an older person may lead to undue suffering (Miller et al., 1992 [8]). Survival rates are lower in the elderly than in younger persons, although this probably reflects the effects of co-morbid illness rather than of age itself (Murphy et al., 1989, Ebell, 1992). Reports from the SUPPORT and HELP databases showed that 21% of subjects received CPR during their index hospitalisation; 64% died two days after CPR (Goodlin et al., 1999 [8]). Despite much knowledge about the prognostic variables that determine the medical effectiveness of CPR, a certain amount of medical uncertainty exists in individual cases.

Since many studies demonstrate that elderly patients wish to participate in decision-making for CPR (Shmerling et al., 1988 [8], Bruce-Jones et al., 1996 [8], Agard et al., 2000 [9]), these issues should be discussed with elderly individuals confronting serious diseases. Some important studies of elderly patients' CPR preferences are presented in Table 8.

2.3.1.1. CPR preferences in different settings

The preference for CPR among the elderly has varied markedly depending on the setting and context. Based on American studies, 75% to 20% of older outpatients would opt for CPR in their current state of health (Uhlmann et al., 1988 [8], Murphy et al., 1994 [8]). Of decisionally capable nursing home residents, 60% preferred CPR and 89% reported preferring to be hospitalized in the event of serious illness (O'Brien et al., 1995 [8]). Eighty-four per cent of frail patients (or their surrogates) in an acute geriatric unit favoured the use of CPR (Torian et al., 1992 [8]). The desire for CPR from the SUPPORT database was high, also among the patients 75 years of age or older; two-thirds of these patients opted for CPR (Hamel et al., 2000 [4]).

In the case of a serious disability, such as coma or a terminal illness, 20-45% of older people opt for CPR (Shmerling et al., 1988 [8], Danis et al., 1991 [7], Emmanuel et al., 1991 [7], Michelson et al., 1991 [8], Miller et al., 1992 [8], Morgan et al., 1994 [10], Schiff et al., 2000 [7]).

Considerably less studies in Europe have examined patients' preferences for resuscitation, comprising altogether under 1000 patients. Some noted that the majority of patients favoured CPR (Bruce-Jones et al., 1996 [8], Mead and Turnbull, 1996), while others indicated that the majority preferred to forgo CPR (O'Keefe et al., 1993, van Mil et al., 2000 [8]).

2.3.1.2. Factors associated with resuscitation preferences

The psychology behind the advance preferences for CPR among the elderly is poorly understood and many factors are probably involved. Certain demographic variables, knowledge of the CPR procedure, mood and cognitive status, the experienced quality of life and the degree of functional disability have been associated with resuscitation preferences. Some studies clarifying these associations are shown in Table 8.

Demographic variables
Certain demographic variables are related to the preference for CPR among the elderly. In the US and the UK, younger age (Malloy et al., 1992 [8], Bruce-Jones et al., 1996 [8], Hamel et al., 2000 [4]),

lower education (Malloy et al., 1992 [8]), male gender (Malloy et al., 1992 [8], Bruce-Jones et al., 1996 [8]), having a spouse (Bruce-Jones et al., 1996 [8]) and non-Caucasian ethnicity (O'Brien et al., 1995 [8]) have been associated with preference for CPR.

Information about the resuscitation procedure

Several studies have shown that older individuals overestimate their probability of survival after CPR by least 200% (Lo et al., 1986 [10], Miller et al., 1992 [8], Murphy et al., 1994 [8], Agard et al., 2000 [9], van Mil et al., 2000 [8]). The most common source of information about CPR is the television (Miller et al., 1992 [8], Bruce-Jones et al., 1996 [8]). Many patients appear not to understand what procedures constitute CPR (Shmerling et al., 1988 [8]). Different educational aspects have been studied extensively. For example, the wording of descriptions of LST interventions has been shown to be important (Malloy et al., 1992 [8]). Knowledge of CPR outcomes in outpatient studies has resulted in patients opting for CPR less frequently (Murphy et al., 1994 [8], O'Brien et al., 1995 [8], van Mil et al., 2000 [8]).

Mood

Many studies have demonstrated an association between resuscitation preferences and depression (Lee and Ganzini, 1992 [8], Ganzini et al, 1994 [8], Rosenfeld et al., 1996 [8], Eggar et al., 2002 [8]). Physicians have raised concerns about the ability of depressed persons to make autonomous decisions about LST. Symptoms of depression, such as apathy, hopelessness, pessimism, low self-esteem, paranoia or suicidality, may influence patients to refuse a medical therapy that they might accept if they were not depressed (Ganzini et al., 1994 [8], Menon et al., 2000 [8]).

The current literature provides conflicting evidence of the association of depression and preferences for LSTs. While some authors have demonstrated no effect of depression (Michelson et al., 1991 [8], McParland et al., 2003 [8]), others have even reported that persons were more likely to prefer increased treatment (Garrett et al., 1993, Danis et al., 1994 [7], Straton et al., 2004 [8]). Generally, though, studies have shown that subjects reporting depressive symptoms desired fewer life-saving treatments (Lee and Ganzini, 1992 [8], Ganzini et al., 1994 [8], Rosenfeld et al., 1996 [8], Eggar et al., 2002 [8]).

Hopelessness, defined as a system of negative expectancies concerning oneself and one's future life, reflects futility and pessimism (Menon et al., 2000 [8]). Subjects with high levels of hopelessness were at least five times more likely to refuse CPR if required during their current hospitalization (Menon et al., 2000 [8]). The effect of hopelessness seems to be independent of depression status.

Lee et al. (1990) describes several mechanisms by which depression may influence the capacity of patients to make choices about their treatment. Feelings of low self-esteem and worthlessness may lead patients to conclude that they do not deserve to be treated. Feelings of guilt may be associated with thoughts of having to suffer and endure punishment and pain, and depressed patients may refuse treatment as a form of passive suicide. On the other hand, Fortner and Meimeyer (1999 [3]) concluded in their review that lower ego integrity, more physical problems and more psychological problems were predictive of higher levels of death anxiety in elderly people. Death anxiety may be one reason why some depressed patients preferred more active treatment.

In one study from the UK, a lack of social contacts was associated with the preference to forgo CPR (Bruce-Jones et al., 1996 [8]). Another British study, also showed that those elderly outpatients who thought about death often had poorer social networks than others (Rao et al., 1997 [3]). Because poor social contacts may be related to low mood and depression, the association with resuscitation preferences can be understood.

Cognitive impairment

Depression is also associated with cognitive impairments, such as attention and concentration deficits, which may interfere with the patient's capacity to clearly consider different treatment options.

Elderly individuals who had cognitive impairment and were incapable of completing ADs were significantly more likely to opt for life-sustaining interventions (Fazel et al., 2000 [8]). Impairment in daily decision-making skills was associated with an increased likelihood to prefer CPR in an American nursing home study (O'Brien et al., 1995 [8]), and a change in cognitive functioning predicted changes in CPR preference in a two-year follow-up (McParland et al., 2003 [8]). These findings raise the question of a cognitively impaired patient's competence to participate in treatment decisions.

Quality of life

Some studies suggest that patients would give up life quantity for life quality (Phillips and Woodward, 1999, van Mil et al., 2000 [8]). A study based on the HELP database suggested a different preference (Tsevat et al., 1998 [4]). Subjects were asked if they were hypothetically willing to "trade off" years of their current health for years of excellent health. On average, seriously ill patients were willing to trade off one year of their current state of health for 8.8 months of living well. However, slightly more than one-third would not opt for any reduction in lifespan. In another study, by contrast, patients' perceived quality of life did not appear to be associated with their preferences for LSTs (Uhlmann and Pearlman, 1991).

Physical functioning

The current literature provides conflicting data on the association of physical functioning and preferences for LSTs. High self-reported physical mobility has been found to be associated with the preference to opt for CPR in American nursing home residents (O'Brien et al., 1995 [8]).

A decline in physical functioning resulted in an increased preference for treatment in two outpatient studies in the US (Danis et al., 1994 [7], Straton et al., 2000 [8]) and in one acute care setting in the UK (Bruce-Jones et al., 1996 [8]). Fortner and Meimeyer (1999 [3]) concluded in their review that fear of death may explain these findings. However, some smaller nursing home studies have shown no association between declining physical functioning and resuscitation preferences (Michelson et al., 1991 [8], McParland et al., 2003 [8]).

2.3.1.3. Reasoning for resuscitation preferences

A few studies have investigated the reasoning behind CPR preferences. Intensive care unit patients regarded their preference for LST as "the desire for continuation of interpersonal experiences with family and friends" and choices to forgo LST as "a fear of becoming a "caretaking burden"" or as a statement of "the natural time to die" (Everhart and Pearlman, 1990). "I do not want to be a burden on my family" was the most important factor cited by older patients for forgoing CPR in the UK (Mead et al., 1995). In focus group interviews of English participants (>50y), desire to live and quality of life were considered to be good reasons for preferring resuscitation, and advanced age and excessive cost of health care reasons for forgoing resuscitation (Phillips and Woodward, 1999). In a Swedish qualitative study, 36 of 40 cardiovascular patients opted for CPR stating that: "If there is a chance, I will take it", and researchers found patients considering a DNR order in their current health situation difficult to understand (Agard et al., 2000 [9]).

Christian patients and families may also provide religious justifications for opting aggressive medical care near the end of life. A recent study reports four reasons 1) hope for a miracle, 2) refusal to give up on the God of faith, 3) a conviction that every moment of life is a gift from God and is worth preserving at any cost and 4) a belief that suffering can have redemptive value (Brett and Jersild, 2003). An American study, found an association between religion and preference for LST; with Catholics being more willing to accept treatments than Protestants (Malloy et al., 1992). Some studies report that religious beliefs have no influence on resuscitation preferences (Ehman et al., 1999, Heeren et al., 2001 [8]).

Multiple factors may have an influence on resuscitation preferences among the elderly. Studies often contradict each other. Nevertheless, many elderly people wish to discuss their preferences and have definite opinions about application of CRP in different clinical situations. A large proportion of the elderly prefer resuscitation in their current health situation. However, the outcome of CPR is often overestimated. For many persons, the preference for CPR may mean the same as “a will to live”. Resuscitation preferences should be understood and interpreted in the broad context of the patient’s well-being, mood and values.

Table 8. *Quantitative studies of cardiopulmonary resuscitation (CPR) preferences of aged people in different settings.*

Author(s)	Participants	Aims of study	Findings
Shmerling et al.,1988, USA	78 ambulatory patients >65 y	To evaluate the preferences for CPR and usefulness of discussions about CPR by interviews	Only 7% had an accurate understanding of what CPR meant before hearing the description. 25% felt that CPR was indicated in the presence of irreversible coma, 28% in terminal cancer and 41% in irreversible heart failure. 87% thought discussions about CPR should take place routinely, but only 3% had previously discussed this issue with their physician. The majority of the elderly had clearly defined opinions about CPR and wished to discuss these with their physician.
Uhlmann et al., 1988, USA	258 outpatients >65y, 90 spouses and 105 physicians	To determine the preferences for CPR in a current, stroke and chronic lung disease situation, questionnaire	Up to 75% of patients preferred CPR in current health. Spouses overestimated CPR desire in all situations. Physicians underestimated patient's preferences for CPR in hypothetical scenarios and overestimated desire in current health situation.
Michelson et al., 1991, USA	44 nursing home residents, mean age 84 y	To evaluate by using case vignettes residents preferences for CPR	Residents' levels of depression, degree of independence or social isolation (number of outside visitors) was not associated with CPR preference.
Lee and Ganzini, 1992, USA	100 inpatients, >65 y	To evaluate by questionnaire about LST in current and hypothetical situation	Depressed and non-depressed patients were compared: Depressed patients desired fewer interventions in their current health situation and in the "good" prognosis scenarios. Subjects' assessment of quality of life was the most powerful predictor of desire for LST.
Malloy et al., 1992, USA	201 home-dwelling elderly, mean age 76 y	To determine whether the wording of descriptions of LSTs would affect choices	155/201 changed their minds at least once when given the same scenario but a different description of the intervention. Catholics preferred more treatments than Protestants (27% vs. 16%), younger more than older subjects (23% vs. 14%), males more than females (24% vs.18%), less educated more than over 16 y educated (26% vs. 17%).
Torian et al. 1992, USA.	141 frail elderly in acute geriatric unit, mean age 82 y	To evaluate patients' preferences for CPR after admission by a physician interview	84% of patients preferred CPR. Patients with DNR orders were more functionally dependent, more acutely and chronically ill and less likely to participate in decision regarding CPR. The majority of DNR orders were made by surrogates, while the majority of CPR directives were made by the patients themselves.
Miller et al., 1992, USA	248 outpatients, mean age 73 y	To assess knowledge about procedural and efficacy of in-hospital CPR	Older people overestimate the survival by nearly 300%. Most older people have definite opinions about the appropriate application of CRP for different clinical situations. Most believe that patients with advanced dementia or widespread cancer should not be resuscitated, while patients with depression or early dementia should.
Ganzini et al., 1994, USA	43 depressed inpatients, mean age 69y	To evaluate patients' preferences for LST by an interview in admission to unit and at discharge	After treatment of depression, the most severely depressed and the most hopeless (n=11, 26%) patients showed an increase in desire for LST. In mild or moderate depression, a patient's desire to forgo LST is unlikely to be altered by depression treatment.

Murphy et al., 1994, USA	371 ambulatory patients >65 y	To assess patients' preferences in acute or terminal illness. Clinicians gave prognostic information	Before information 41% and after it 22% opted for CPR in acute illness. Only 6 % of patients >86 y opted for CPR in acute illness after information.
Walker et al, 1995, USA.	>70 y home-dwelling elderly (n=105, 68 had a LW)	To assess preferences for CPR in 5 hypothetical scenarios. Description of CPR, then again same scenarios presented.	LW+ and LW- groups were compared: More discussions with physicians in LW+ group. In functional and cognitive decline scenarios, LW+ group declined CPR more often. No difference was presented between the groups preferring CPR in their current state before and after CPR description .
O'Brien et al. 1995, USA	421 residents in 49 nursing homes	To assess preferences regarding CPR, hospitalization and tube feeding, and individual factors associated with CRP preferences.	60% of decisionally capable individuals would opt for CPR, 89% would choose hospitalization if seriously ill and 33% would elect tube feeding. African-American ethnicity, high self-reported physical mobility, moderate to severe impairment in daily decision-making skills and not having a spouse were associated with an increased likelihood to prefer CPR. Only 12% had discussed preferences with health care providers. 14% changed their preference from pro CPR to against CPR after receiving additional information about CPR procedures.
Bruce-Jones et al., 1996. UK	214 patients in acute care, mean age 84	To assess preferences for CPR and relating factors. Questionnaire administered on admission and prior to discharge.	Resuscitation was preferred by 60%, particularly married and functionally independent patients and those who had not already considered it. Not wanting CPR was associated with lack of social contacts. 67% welcomed enquiry about their preferences and 78% wanted to participate in decisions, 43% as sole decision-maker. Wishing to choose oneself was associated with not wanting CPR, prior knowledge of CPR, and lack of a spouse. Patients' opinions remained stable during their admission.
Rosenfeld et al., 1996, USA.	SUPPORT database. n= 1590	To assess the stability of CPR preference over 2-mo period and it's relationship to depression	80% of patients had stabile preferences. Of patients initially preferring DNR, those with substantial improvements in depression scores were more likely to change to a preference for CPR at follow-up.
Goodlin et al., 1999, USA	SUPPORT + HELP database; patients who had experienced heart arrest n= 2505/10281 (mean age: received CRP (n=514) or not (n=1991): 65 y vs. 67 y)	To evaluate how demographic variables and resuscitation preferences are associated with resuscitation	21% received CPR and of these 18% survived the index hospitalization and 64% died after 2 days of CPR. Patient's or surrogate's preference to attempt CPR was associated with having CPR. 13% of patients who received CPR had preferred to forgo CPR, and 38% of patients who had wanted CPR or were unsure did not receive CPR at the end of life. Age, race, site of hospital, quality of life rating, disease and physician estimation of 2-mo survival were associated with received CPR.

Fazel S et al., 2000, UK	Home-dwelling elderly, 50 volunteers and 50 patients with moderate degrees of dementia >60 y.	To assess treatment preferences in three clinical vignettes	Subjects who opted for more LST had a lower MMSE score (22.6 vs. 26.1). Elderly individuals with cognitive impairment and who were incapable of completing ADs were significantly more likely to opt for LST.
Menon et al., 2000, USA	295 inpatient males in acute ward, > 60y (medically seriously ill were excluded)	To evaluate the influence of depression and hopelessness on LST preferences	Patients with major depression were compared with non-depressed patients. Patients with high levels of hopelessness desired less LST in their current illness; they were 5 times more likely to refuse CPR. The diagnosis of major depression did not significantly influence the desire for LST.
van Mil et al., 2000, The Netherlands	75 home-dwelling elderly and 45 inpatients >75 y	To study the effects of information, quality of life and hospitalization on CPR preferences	Chances of surviving CPR were overestimated. After CPR information 65% of participants preferred to forgo CPR; these were more often women than men. Men's CPR preferences were more associated with pain, whereas women's were more associated with being impaired in physical functioning. CRP preference in the current state of health did not differ between outpatients and inpatients. Only 6% had discussed CPR with their doctor, but 70% wanted routine CPR discussions and 61% preferred to make the final decision themselves
Heeren et al., 2001, USA	374 males, acute care patients Mean age 70	To determinate whether religiosity influenced choosing end-of-life treatments	90% were Christians, 24% of these were Catholics. Two-thirds considered themselves fairly religious and more than half found a great deal of strength and comfort in religion. Only tube feeding showed a significant relationship, with Catholics less willing to undergo this procedure than other Christians.
Eggar et al., 2002, UK	49 day or in patients with depression, 56% >65 y	To investigate patients decision to accept CPR before and after treatment for depression	The median follow-up period was 28 days. 44% received ECT. Depression was assessed by HDRS score. Median score changed from 17 to 8. After treatment, only one patient out of the original 17 continued to refuse CPR, with none of the 32 originally consenting patients changing to refusal.
McParland et al., 2003, USA	65 nursing home residents. 2y follow-up, mean age 85y	To assess the stability of CPR preferences	21 participants were missed during the follow-up. 74% had stabile preferences for CPR. Degree of change in cognitive status, but not status of depression or the change in functional level, predicted changes in decision.
Straton et al., 2004, USA	645 physicians>58y longitudinal cohort study	To assess the 6-y follow-up stability of LST preferences and its association with functional decline and depression	Physicians with significant functional decline were more likely (AOR=2.14; 1.18-3.88) to prefer LST. Physicians with declining functioning + worsening depression were more likely (AOR= 5.33; 1.60-17.8) to prefer LST than subjects without declining function or worsening depression

2.4. DECISIONS REGARDING LIFE-SUSTAINING TREATMENTS AMONG ELDERLY PATIENTS

The current literature about decision-making of life-sustaining treatments is abundant. This review focuses on studies of elderly patients. Table 9 shows qualitative and Table 10 quantitative studies related to LST decisions of elderly patients.

2.4.1. Informed consent

There is a consensus in Western countries that all medical treatments should be based on patient's informed consent. Legally, a person is not obliged to accept a recommended treatment, even if refusal may result in an earlier death. Doctors have, however, an obligation to discuss treatment options and their implications with patients. According to Doyal and Wilsher (1994), patients must meet five requirements to be legally or morally competent to consent to non-treatment. Patients must be able to:

1) understand a simple explanation of their condition, prognosis and proposed treatment or non-treatment
2) reason consistently about specific goals linked to their personal beliefs
3) choose to act on the basis of such reasoning
4) communicate the substance of their choice and the reasons for that choice
5) understand the practical consequences of their choice.

It is important to give clear and simple information when assessing a patient's competence to make specific decisions about the prolongation of their life. Patients may be confused and unable to manage their affairs in general but may still have the ability to competently say that they would rather die than receive LSTs or vice versa. The presumption should be that elderly patients are competent unless shown otherwise and the justification recorded in the notes. However, the term "autonomy" should be used with much caution, since even "freely made" decisions depend on the knowledge of the disease's consequences, possible and available help and society's view of what constitutes an adequate decision and behaviour (Staehelin, 2004).

Many debates have centred around the question of whether all elderly patients should be consulted about resuscitation (Higginson, 2003). Presenting the choice of resuscitation to those with virtually no chance of surviving resuscitation has been considered to be unfair because autonomy is enhanced only by offering viable options (O'Keeffe, 2001, Drought and Koenig, 2002). A recent study of medical inpatients in the UK showed that at least 40% of acute ward patients lacked the mental capacity to give consent, but clinicians tended not to recognize this (Raymont et al., 2004). This finding highlights the need to assess medically ill patients' capacity thoroughly.

If a patient lacks capacity to give or withhold consent, a doctor's obligation is to treat in what he perceives as the patient's best interests (Finnish Medical Association, 2000). Many patients, e.g. patients with advanced dementia, may be unable to make autonomous decisions about LST. For these patients, it is recommended that clinicians establish and take into consideration the presumed wishes of the patients (Lo et al., 1986[10], Volicier, 1995). The manner in which the patient has thought and acted previously plays an important role in decision-making (DM). Information should be obtained from representatives specifically named by the patient or from close relatives. However, many studies show incongruence between patients and family members

Table 9. Qualitative studies of decision-making (DM) related to life-sustaining treatments.

Author(s)	Participants	Aims of study	Findings
Pfeifer et al., 1994, USA	47 outpatients and 43 primary care physicians 16/47 of patients (35%) were >61 y	To identify outpatients' and physicians' attitudes, preferences and expectations regarding discussions of end-of-life medical care.	Patients expressed strong feelings about having end-of-life discussions early enough in their medical course that they were still competent. Patients desired information that focused more on expected outcomes than on medical processes. They also wanted their physicians to play central roles in these discussions, and they were less concerned than physicians about losing hope. Physicians considered LWs excellent "icebreakers" for starting discussions but of limited utility otherwise.
Tulsky et al., 1998, USA	56 tape-recorded outpatient (>65 y) discussions	To describe how physicians discuss ADs with patients	American physicians spoke twice as much as they listened. In 91% of cases, physicians discussed irreversible scenarios in which most patients would not want to be treated, and only 48% asked patients about their preferences in reversible scenarios. Physicians were unlikely to elicit or explore patients' values. In 88% of cases, physicians discussed surrogate DM and documents to aid AP.
Rosenfeld et al., 2000, USA	21 elderly (81% women) persons representing a spectrum of functional status, mean age 83 y	To identify the desired features of end-of-life medical DM. Personal interviews focusing on narratives of serious illness	Persons were concerned with the outcomes of serious illness rather than with medical interventions. They defined treatments as desirable to the extent that they return to their valued life activities. Advanced age was relevant in treatment considerations, guided by concerns about personal losses and having lived a "full life". Decision-making authority: given to both physicians and families based on their respective areas of expertise. Physician's skills in treating serious illness and prognosticating outcomes were critical to DM authority. When functional recovery was not possible; precedence to families for that they can provide care for a loved one. Caring during serious illness; not burden to loved ones.
Agard et al., 2000, Sweden	40 chronic heart failure patients: 25 men and 15 women, mean age 75 y	To study patients' knowledge about CPR and their experiences and preferences regarding involvement in DM	Many lacked fundamental knowledge of CPR. The majority opted for CPR no matter how small their chances of survival were. The issue had not earlier engaged their thoughts, much less been discussed with physicians. Patients would like the physician to bring up the question of resuscitation. Patients relied on the physician's ability to judge whether CPR would be a beneficial
Wenrich et al., 2001, USA	137 patients with chronic or terminal illness, family members, professionals	To assess by focus groups interviews of aspects of communication between patients and physicians in end-of-life care	Six areas of high importance were found: Talking to patients in a honest and straightforward way, being willing to talk about dying, giving bad news in a sensitive way, listening to patients, encouraging questions from patients and being sensitive to when patients are ready to talk about death. Patients had a need to achieve a balance between being honest and straightforward and not discouraging hope.
Sainio et al., 2001, Finland	25 cancer outpatients, mean age 50 y, range 30-70	To explore patients' experiences about participation in DM	Promoting factors to participate in DM were the patient's activity, presence of a primary nurse/physician, encouragement of nurses and physicians to participate, treatment of patients as equals and nurses and physicians having enough time for patients. Hindering factors to participate in DM were patient ignorance, active illness and patient's shyness. Other obstacles to participate in DM were the nurses' and physicians' tendency to treat patients as objects, to fall into a routine, problems with information dissemination and lack of time.
Kirk et al., 2004, Canada and Australia	72 patients + relatives, 12 patients were 21-50 y, 41 patients were 51-70 y and 19 were >71 y	To explore experiences of patients receiving palliative care and experiences of their relatives regards the disclosure process	All patients wanted information about their illness and wanted it fully shared with relatives. In information-sharing, the process is as important as the content. The timing, management and delivery of information and perceived attitude of practitioners were critical to the process. This applied to information interactions at all stages of the illness. Main content areas mentioned related to prognosis and hope.

about what the patient would want regarding end-of-life care (Uhlmann et al., 1988 [8], Morgan et al., 1994 [10], Moe and Schroll, 1997, Tsevat et al., 1998 [4]). Patients' family physicians can also be a valuable source of information about patients' values and preferences.

There are problems with the concept of giving informed consent. Informed consent at the end of life is particularly complicated because of the emotional overlay which always accompanies awareness of a threat to one's life (Drought and Koenig, 2002). Some researchers have pointed out that the consent should not be the only focus of discussion (Singer et al. 1999 [5], Rosenfeld et al., 2000 [9]). Emphasizing consent for specific procedures may be a way to avoid confronting the larger issues of death and discussing the patient's dying. Physicians may use discussions about informed consent as a way of approaching the issues of values and dying. The primary focus of discussions about the use of LSTs should be on realistic and achievable goals of care (Singer et al., 1999 [5]).

2.4.2. Participation in decision-making

Finnish cancer patients aged between 30 and 70 years defined participation in DM as an opportunity to ask questions, to obtain or provide information and to choose from various treatment alternatives (Sainio et al., 2001 [9]).

Many studies demonstrate that also elderly out- and inpatients wish to participate in DM about LSTs, particularly CPR (Lo et al., 1986 [10], Shmerling et al., 1988 [8], Morgan et al., 1994 [10], Agard et al., 2000 [9]). Patients would like physicians to initiate the discussion about resuscitation (Lo et al., 1986 [10], Morgan et al., 1994 [10], Agard et al., 2000 [9]), preferably while patients are still healthy (Shmerling et al., 1988 [8], Johnston et al., 1995 [10]). While many studies show that patients feel comfortable discussing CPR (Lo et al., 1986 [10], Agard et al., 2000 [9]), some studies indicate that elderly patients are not interested in discussions related to future illnesses and end of life (Carrese et al., 2002 [3]). The majority of patients interviewed had not talked about LST with their doctors (Lo et al., 1986 [10], Emanuel et al., 1991 [7], Gamble et al., 1991 [7], Agard et al., 2000 [9]). Patients desire information on expected outcomes and prefer honest DM discussions (Pfeifer et al., 1994 [9], Rosenfeld et al., 2000 [9], Kirk et al., 2004 [9]).

A large proportion of patients estimated that shared DM would be the best way to decide about LSTs (Shmerling et al., 1988 [8]). Several studies have noted that many people also express the desire that physicians' or family members' wishes be paramount in the event that they become too cognitively impaired to decide for themselves (Lo et al., 1986 [10], Ende et al., 1988, Mead and Turnbull, 1996, Hopp, 2000), even if this results in conflict with the patient's prior expressed wishes (Puchalski et al., 2000 [10]).

Some researchers have found that older patients have less desire than younger patients to make decisions and to be informed (Ende et al., 1989, Singer et al., 1998, Puchalski et al., 2000 [10]). They suggest that patients' desire for autonomy seems to decline with severity of illness and advancing age. Patients may be distressed or overwhelmed by the DM process and may trust their physician's or surrogate's judgement more than their own.

Patients' opinions about their roles and those of others may change over the course of hospital admission and with severity of illness (Puchalski et al., 2000 [10], Kirk et al., 2004 [9]). Some studies also report that ethnicity may explain differences in the desire of autonomy in DM (Blackhall et al., 1995, Singer and Bowman, 2002, Murray et al., 2003 [5]).

Table 10. Quantitative studies of decision-making (DM) related to life-sustaining treatments (LSTs) among elderly patients in different settings.

Author(s)	Participants	Aims of study	Findings
Lo et al., 1986, USA	28 < 65 y and 69 >65 y patients with severe chronic illness, and 55 >65 y patients without severe chronic illness	To evaluate elderly patients' thoughts about ADs, and decision-making (DM) if they became severely demented	66% had thought quite a lot or a moderate amount about whom they would want to make decisions in the case on incompetence. Of these, 80% wanted relatives to make decisions and 13% preferred their physician. 73% would refuse intensive care, 70% would refuse CPR, 75% would refuse a feeding tube and 53% would refuse antibiotics in the care of severe dementia. Most patients felt positive emotion when discussing these matters: 71% felt control over things, 53% felt relieved and cared for. Some expressed negative emotions: 22% were nervous, 6% felt as giving up.
Morgan et al., 1994, UK	100 patients and their legal next of kin. Patients mean age 80 y	To evaluate patients' and their next of kins' opinions about DM of CRP after the CPR procedure explained	Most patients and relatives (89 and 88) thought that doctors should discuss plans for CPR with them.34 patients felt that discussion on their CPR status should be limited to themselves, while 37 relatives thought that this should involve them but not the patient. 8 preferred CPR and 35 preferred to forgo CPR. In 63 cases, the patient and relative together preferred that physician should make the final decision of CPR.
Johnston et al.,1995, USA	329 outpatients (mean age 51 y), 282 resident physicians and 272 practicing physicians	To study patients' and physicians' opinions on timing, content and situation of discussions about ADs	91% of patients thought that ADs should be discussed before patients become extremely ill and 84% believed, that the discussion should occur when the patient is healthy. 60% of physicians believed that the discussions should occur when a fatal disease is diagnosed. The majority of patients and physicians agreed it is the responsibility of the physician to initiate the discussion of ADs.
Wenger et al., 1995, USA	14008 hospitalised Medicare patients, mean age 79 y	To evaluate the relationship between DNR orders and patients' characteristics	DNR orders were assigned to 12%. Patients with greater sickness at admission and functional impairment received more DNR orders, but even among patients in the sickest quartile only 31% received DNR orders. DNR orders were assigned more often to women and patients with dementia or incontinence and were assigned less often to black patients and patients in rural hospitals.
Hakim et al., 1996, USA	6802 patients from SUPPORT-database, mean age 65 y	To evaluate the relationship between patient's CRP preferences and the frequency and timing of DNR orders	55% of the patients or surrogates preferred to have CPR in the event of cardiopulmonary arrest, and 29% preferred to forgo CPR. Of these, DNR orders were written in 52% of cases. DNR order was predicted by: patient's preference for CPR, patient's probability to survive for 2 mo, poor quality of life and impaired functional status before hospitalization, hospital site and physician's speciality. DNR were written more frequently for older patients regardless of prognosis.
Bradley et al., 1998, USA	600 nursing home residents, mean age 83 y, retrospective cohort study.	To measure the frequency with which nursing home residents and their surrogates discuss future treatments with clinician	72% of residents had no discussion of future treatment wishes documented. Most discussions in nursing homes focused on life-support systems, with less attention paid to preferences regarding pain management, hospitalization or proxy DM. Cognitive impairment and poor functional status were associated with increased likelihood of having at least one discussion, mainly with patient's relatives; in less than 30% of discussions were residents themselves involved.
Eliasson et al , 1999, USA	Medical records of discharged patients and physician interviews	To determine the reasons for physicians not writing DNR orders for dying patients	DNR orders were indicated for 149/613 patients (24%). In 88 (59%) of these, DNR orders were absent. Explanations for not writing DNR orders included the belief that the patient was not in imminent danger of death (56%), belief that primary physician should discuss DNR issues (49%) and lack of an appropriate opportunity to discuss DNR issues (43%).
Hamel et al., 1999, USA	9105 patients in SUPPORT study, mean age 65 y	Is age associated with less aggressive treatment?	Physicians were less likely to want life-extending care if in patients' situation when patients were older.
Levin et al, 1999, USA	Interviews and chart reviews of 413 nursing home residents mean age 84 y	To evaluate whether residents and their families discuss LSTs with their physicians	Chart orders to limit therapy were common (DNR in 74%), but physician-resident discussions about LST were not; discussions mostly occurred with family members. 32% had ADs, 29% of residents reported discussions about LST.

Puchalski et al., 2000, USA	646 SUPPORT (mean age 63 y) and 513 HELP (mean age 84 y) patients	To determine the extent to which older, seriously ill inpatients would prefer to have their family and physician make LST decisions	71% of HELP patients would prefer to have their family and physician make decisions for them. The predictors of preference for family and physician DM included preference to forgo CPR and having a surrogate decision-maker. These patients would not want their stated DNR preferences to be binding were they to lose the capacity to make their own decisions.
Wenger et al., 2000, USA	5055 patients in SUPPORT study, mean age 65 y	To evaluate physician's understanding of patient CPR preference	Physician understood 86% of patients' preferences for CPR, but only 46% of patients' preferences to forgo CPR. Patients whose physician understood their preference to forgo CPR more often received DNR orders, received them earlier and were significantly less likely to undergo CPR.
Teno et al., 2000, USA	SUPPORT (n= 9105) Mean age 65 y	The frequency of discussions about LSTs	Fewer than 40% of patients (or surrogates) reported that their physician had talked with them about their prognosis or preference for LST. Among patients who preferred palliative care, only 29% thought that their care was consistent with that aim. Those who discussed their care preferences with a physician were 1.9 times more likely to believe that treatment was in accord with their preferences.
Vetsch et al., 2002, Switzerland.	882 chart review (mean age 63 y) and 174 dying patients (mean age 70 y)	To investigate the prevalence, manner of application and appropriateness of DNR orders in acute hospitals	5% of "ordinary" patients aged <70 y, 20% 70-80 y, 46% >80 y and 72% > 90 y had DNR orders. 15% of patients in chart review (group 1) and 54% of dying patients (group 2) had DNR orders at admission and 22% vs. 93% (gr 1 vs. gr 2) had DNR orders at end of hospital period. 6% of patients or their families were involved in DM concerning potential CPR. Physical functioning was the most important dependent factor for DNR in group 1.
van der Heide et al. 2003, the Netherlands.	20480 deaths in six European countries.	By mailed questionnaire physicians estimated the medical DM that had preceded the death of patient.	Death happened unexpectedly in about a third of cases in all countries. The proportion of deaths that were preceded by any end-of-life decision ranged between 23% (Italy) to 51% (Switzerland). Decision was discussed with the patient when competent most frequently in the Netherlands (92%) and less frequently in Italy (42%) and Sweden (38%).
Skrifvars et al. 2003, Finland.	1486 in-hospital cardiac arrests in four acute hospitals.	To assess the prevalence and implementation of DNR orders among patients suffering in-hospital cardiac arrest in whom CPR was not initiated.	85% of these patients had a DNR order. Prevalence of DNR orders differed between participating hospitals. In the majority of the cases the ward physician had made the DNR order decision. Only in 5% of cases a relative had been consulted. 59% of the DNR orders were noted in patient's medical records and in all other cases it was found in the nursing records. Living wills were uncommon, only 1.5%.
Hilden et al. 2004, Finland.	Postal questionnaire for nurses. N= 408.	To explore the nurses' experiences and views on end-of-life DM and compare them with physicians views.	48% thought that a DNR order implies only withholding resuscitation and 44% believed that it meant a change from curative to palliative care. 56% of the nurses reported that a DNR decision was discussed always or often with a patient who was able to communicate; physicians were more positive in this respect.
Hilden et al. 2004, Finland.	Postal questionnaire for physicians. N= 436 of 800	To explore physicians' experiences of decisions concerning living wills (LW) and DNR orders and their view on the role of patients and family members in these decisions.	13% of physicians had a LW (60% orally and 40% in written form). 92% had a positive attitude toward and 86% respect for LW. One fifth of the physicians reported to have enough time to discuss the content of a LW with patients before its activation. DNR orders were interpreted in two ways: resuscitation forbidden (70%) or only palliative care required (30%). 72% discussed DNR decisions always or often with patients able to communicate, and even 76% discussed with the family members of patients unable to communicate.

2.4.3. Prevalence of DNR orders in different care settings and related factors

DNR orders are the result of complex treatment decisions. In the US, hospital policies usually require CPR unless a DNR order has been authorized by the patient or a surrogate decision-maker or there is an AD. In Europe, the usual approach is that the consultant, after whatever consultation he or she chooses with medical and nursing staff and family (but rarely the patient), decides whether or not a patient should be resuscitated (O'Keeffe, 2001).

Most often orders to limit therapy are issued in acute care settings. A decision to limit medical therapy is made for 70%-80% of patients who die in American hospitals (Ganzini et al., 1994 [8], Somogyi-Zalud et al., 2002), but in many European countries the practice of making end-of-life decisions happens more rarely, in 23% (Italy) to 51% of cases (Switzerland) (van der Heide et al., 2003 [10]). However, in a recent Finnish study, over 80% of patients who died in four secondary hospitals had a DNR order (Skrifvars et al., 2003 [10]).

DNR orders in acute care

The elderly are more likely than the young to be recipients of DNR orders (Wenger et al., 1995 [10], Hakim et al., 1996 [10], Goodlin et al., 1999 [8], Hamel et al., 1999 [10], Vetsch et al., 2002 [10], Skrifvars et al., 2003 [10]). Of 14 008 hospitalized Medicare patients in the US, 1625 (12%) were assigned DNR orders (Wenger et al.,1995 [10]). More often DNR was assigned to women, patients with dementia or incontinence and sicker patients. DNR was assigned less often to black patients.

There are much fewer studies from Europe reporting on these issues. The policy to assign orders to limit therapy varies among European countries (van der Heide et al, 2003 [10]). In Switzerland, DNR orders were written for more than 40% of hospitalized patients aged over 80 years (Vetsch et al., 2002 [10]).

DNR orders in long-term care

In the US, ACP including the medical DM, is considered important in the nursing home setting because of the high probability of development of serious illnesses in this frail, very old population. Each year in the US, more than 25% of nursing home residents are transferred to acute care hospitals, and as many as 30% of residents die within the first six months (Gillick et al., 1999).

The Patient Self-Determination Act in the US (1990), had a pronounced effect on implementation of LW and DNR orders in nursing homes. By the end of the 1990s, the prevalence of DNR orders had soared to 74% (Mark et al., 1995, Levin et al., 1999 [10]). Old age, impaired functioning, cognitive impairment, lengthy stay in a nursing home, physician-family member discussion and the presence of an AD have been found to be associated with DNR orders in nursing homes in USA (Batchelor et al., 1992, Terry and Zweig, 1994, Levin et al., 1999 [10]).

Social and cultural differences are important when studying factors related to ADs. For instance, Japanese residents of an Asian nursing home were more likely to be “no code” than Chinese residents (Vaughn et al., 2000), and black nursing home residents were five times as likely to want CPR as white residents (O'Brien et al., 1995 [8]). In Europe, by contrast, only a few studies of ACP have been carried out in long-term care. In Denmark, less than 3% of nursing home residents had a LW, fewer than 2% had a DNR order and only 1% had a do-not-hospitalize (DNH) order (Moe and Schroll, 1997).

Policies and the caring culture of nursing homes have a great influence on the practices to assign DNR orders; the prevalence of DNR orders varied (4-63%) in eight central Missouri nursing homes with demographically similar resident populations (Terry and Zweig, 1994).

Unfortunately, evidence suggests that DM in end-of-life issues in the US, including decisions about CPR, is not often discussed with nursing home residents, not even with those who are competent (O’Brien et al., 1995 [8], Bradley et al., 1998 [10], Levin et al., 1999 [10]). The findings from nursing home studies are consistent with research in acute care settings, which have concluded that poor heath status and poor prognosis are associated with ACP discussions.

Additional meaning of DNR orders

Physicians might interpret the DNR order in a broader manner than intended by the patient (Asplund and Britton, 1990, Beach and Morrison, 2002). The meaning of a DNR order for Finnish nurses was not initiating resuscitation, but also giving the patient good basic care (Hilden et al., 2004 [10]). In a recent study (Hilden et al., 2004 [10]), Finnish physicians interpreted DNR orders in two ways: resuscitation forbidden (70%) or only palliative (symptom-oriented) care required (30%). These findings are alarming because confusion about patient care policies can exist between health professionals, resulting patients being treated inadequately (Hilden et al., 2004 [10]).

CPR and DNR orders have great symbolic importance. Even though relatively few patients receive CPR in long-term care, writing a DNR order may actually impede care. It may stigmatize the patient, inappropriately limiting care and lessening respect for the person in the eyes of nursing home staff and family members (Zweig, 1997). Hospital policies should distinguish DNR status from palliative care and explicitly restrict the scope of interpretation of a DNR order (Beach and Morrison, 2002).

2.4.4. Influence of physicians’ characteristics on decision-making

The characteristics of physicians may also have an influence on decisions to limit therapy. Physicians’ decisions regarding LST may depend on their own racial background, status or area of speciality (Feldman et al., 1999, Hanson et al., 1999, Mebane et al., 1999, Hinkka, 2001). In a Finnish study, the physician’s age, experience with terminal patients, area of speciality and the value the physician sets on ADs affected the decisions (Hinkka, 2001). Female and young physicians chose active treatments for dying patients more often and were also more influenced by the family’s appeal for more active treatment (Hinkka, 2001).

Physicians’ religious affiliation and cultural differences seem to have an influence on DM in end-of-life care. In a study of different European countries, withdrawal of LST occurred more often if the physician was Protestant (44%), Catholic (41%) or had no religious affiliation (36%) than if the physician was Greek Orthodox (13%), Jewish (16%) or Moslem (24%) (Sprung et al., 2003). Physicians in southern Europe were less likely than those in the north to apply DNR orders, withhold treatment or discuss such issues with the patient (Vincent, 1999). In comparing European and American DNR practices and DM, European physicians more often made DNR decisions unilaterally than American physicians (Mello and Jenkinson, 1998).

The setting of DM also affects on decisions. Community physicians used fewer LSTs for dying patients. Their long-term primary care relationships and LWs had a great influence on their decisions (Hanson et al., 1999). In an other study, primary care physicians considered their older outpatients’ quality of life to be worse than did the patients themselves, and these physicians’ estimates of quality of life were significantly associated with their opinions of LST for their patients (Uhlmann and Pearlman, 1991) Future treatment preferences of physicians themselves also had an impact on their decisions (Mebane et al., 1999).

Despite patients’ interest, their willingness to participate in discussions about LST tended to be passive (Johnston et al., 1995 [10]). Physicians often fail to initiate discussion, and this failure is the most common barrier to discussions (Virmani et al., 1994). Reasons for physicians not discussing resuscitation were discomfort with talking about CPR, the belief that they already understood the patient's opinions and lack of time (Layson et al., 1994, Eliasson et al., 1999 [10]). Ninety per cent of physicians favoured discussing CPR when they believed the patient should not be resuscitated, but only 61% when they believed the patient should be resuscitated (Reilly et al., 1994). The discussions about AP consisted of only completion of an AD, with the values behind ADs not elaborated (Tulsky et al., 1998 [9]). When comparing patients' and health care professionals' attitudes, physicians were found to have less positive attitudes towards ADs than patients (Blondeau et al., 1998). Physicians were also less ready to consider importance of ADs in expressing the patient's autonomy.

Most physicians desired patient participation in the DM process (Bedell and Delbanco, 1984, Ebell et al., 1991), but they seldom discussed end-of-life issues with patients except in special contexts, e.g. with terminally ill patients (Reilly et al., 1994, Virmani et al., 1994, Johnston et al., 1995 [10], Bradley et al., 1998 [10], Eliasson et al., 1999 [10]).

According to American studies, physicians and family members are often unaware of patient preferences for end-of-life care (Teno et al., 1997 [7], 2000 [10], Wenger et al., 2000 [10], Kahana et al. 2004 [7]). Only 12% of patients with an AD had talked with a physician when completing the document, and only 25% of physicians were aware of patients' ADs (Teno et al., 1997 [7]). The descriptions, language and outcomes of treatments have an influence on patients' DM about LSTs (Malloy et al., 1992 [8], Miller et al., 1992 [8], Murphy et al., 1994 [8], Walker et al., 1995 [8], Teno et al., 1997 [7]). Physician's views, values and personal preferences often decisively influence patients' preferences (Miles et al., 1996).

Physicians may wait too long before initiating discussions regarding preferences for end-of-life care, with patients often becoming so ill that they are unable to participate in the DM process (Bedell and Delbanco, 1984, Reilly et al., 1994, Virmani et al., 1994, Bradley et al., 1998 [10]). Family members are under stress of the impending death and decisions are hastily made and thus may not reflect the patient's preferences (Bedell and Delbanco, 1984, Hakim, et al., 1996 [10]). By contrast, patients who have discussed their preferences with physicians are more likely to receive treatment in accord with their preferences for palliation (Teno et al., 2000 [10], Wenger et al., 2000 [10]).

Physicians can overestimate the benefits of CPR or be overly pessimistic about the survival probability of older patients. Improved estimates of survival may encourage DM based on physiological rather than chronological age. Different methods are available to estimate the survival of resuscitation. One model estimating survival time has been developed from the HELP database by using a limited amount of clinical information available from the medical chart plus a brief interview with the patient or surrogate (Teno et al., 2000 [10]). The use of this kind of model can increase the knowledge for DM, but it should only be one component of the DM process. Measures of the physician's perception of patient's preferences for care and the physician's subjective estimates of prognosis are also required.

2.4.5. How and when physicians should address end-of-life issues

Advance directives were developed to meet legal challenges and the perceived needs of patients. SUPPORT study investigators have shown that the optimism about the Patient Self-Determination Act has not been realized. They found that ADs rest on mistrust based on a history of over-treatment arising from physician paternalism (Prendergast, 2001). A physician-centred solution that focuses on specific interventions might not address patients' own concerns. A patient-centred approach uncovered that many patients desired to retain control of decisions while they were capable of doing so; when they were no longer capable, they wanted those decisions made by their proxy (Singer et al., 1998). Singer and colleagues (1998) also presented an idea that patients may not want to talk to physicians because physicians have not met their needs. These findings have shifted the focus of research to examining the physician-patient relationship and communication skills.

In practice, end-of-life planning discussions tend to be open-ended, ill-defined, time-consuming and frequently emotionally draining. They force the clinician to acknowledge uncertainty to the patient or surrogate and to explore treatment compromises that are clinically defensible and meet the patient's personal needs (Prendergast, 2001). Without specific guidance in communication, physicians apparently have poor insights into their patients' wishes and may project their own values in DM (Bedell and Delbanco, 1984, Uhlmann et al., 1988 [8], Uhlmann and Pearlaman, 1991, Tulsky et al., 1998 [9]). Guidelines for protocols for communicating with patients about sensitive topics in palliative care have been developed (von Gunten et al., 2000, EPEC Project, 2004). Evidence indicates that when physicians conduct an open "patient-centred" interview (in which the emphasis is on empathy, openness and reassurance), rather than the traditional closed "physician-centered" interview, satisfaction improves on the part of patients and their families (Dowsett et al., 2000, Wenrich et al., 2001). There is also evidence that these communication skills may be improved by educational efforts (Fallowfield et al., 2002, Morrison and Meier, 2004).

The existing research does not provide guidance on the appropriate timing and circumstances for initiating discussions about LSTs. However, Quill (2000) has described a set of clinical situations that can be used to establish indications for initiating LST discussions. Urgent indications are imminent death, the patient's wish to talk about dying, enquires about hospice or palliative care, recent hospitalization for severe progressive illness and severe suffering and poor prognosis. When the physician estimates the patient's survival time to be less than 6-12 months, routine actions could be discussing prognosis, discussing treatment with low probability of success and discussing hope and fears. Initiating end-of-life discussions earlier and more systematically would allow patients to make more informed choices, achieve better palliation of symptoms and have more opportunities to work on issues of closure (Weeks et al., 1998, Quill, 2000).

Beach and Morrison (2002) suggest that physicians discuss with patient or their surrogates the broad goals of therapy, from which more specific decisions can be negotiated depending on their likelihood of reaching the patient's goals. These discussions should be noted in the chart, and the patient's goal, not simply their DNR status, should be communicated to all involved in the patient's care. Physicians should be educated in communication skills and encouraged to reflect on their own experiences with death. Some North-American researchers have proposed that ACP should be an ongoing process, with discussions about culturally shaped values and preferences, and that discussions of preferences should be focused away from rigid autonomy and towards personal relationships (Martin et al., 2000, Prendergast, 2001). These suggestions are supported by several qualitative studies (Singer et al., 1999 [5], Steinhauser et al., 2000 [3], Wenrich et al., 2001 [9]).

In end-of-life treatment decisions, physicians and families often have shared goals; both seek the best possible care for the patient, leading to recovery if possible, and most want to avoid over-treatment if recovery is not possible. These shared goals form the basis of a natural alliance that the skilled physician can build on to facilitate communication. Preferences for care emerge from the process of discussion and feedback within the network of the patient's most important relationships (Singer et al., 1998). Such decisions are inevitable embedded within a social context of family and loved ones. The physician repeatedly discussing these matters with the patient over time provides an opportunity to build trust. These meetings also create a new social context in which the physician plays an important role in the ongoing development of preferences for care. Other caring personnel also have an important role in this context. These conversations are instrumental in end-of-life DM. Patients seek decisions that make sense within their relationships. The ability to address specific decisions and their consequences encourages the family and surrogates to focus on the patient. The challenge to the physician is to recognize and acknowledge the importance of social and spiritual issues while providing expert biomedical care (Steinhauser et al., 2000 [3]).

2.4.6. Basis for this study

According to several studies, despite developments in palliative care, the quality of end-of-life care for many elderly patients is still poor. Studies have demonstrated that older people are more worried about the dying process than their inevitable death. This review, and the recent review of Hallberg (2004), showed a lack of research on very old (> 80 years) people's views of dying and death. Dying and death are strongly related to cultural context. Little is known about seriously ill elderly Finnish patients' attitudes and opinions related to end-of-life care.

Western bioethics has developed a set of practices to provide guidance when confronting decisions about medical care before death; these practices include informed consent, ADs; i.e. LWs and/or selecting a surrogate decision-maker, and orders to forgo LSTs such as resuscitation. These practices have been particularly emphasized in the US. Several American studies show that ADs are widely recommended, especially for the elderly. However, elderly patients seldom assign LWs, more often they just designate a proxy decision-maker. Elderly people also rarely discuss ADs with health care personnel. How relevant is the idea of ADs to elderly Finns? Are patients ready to discuss the issues related to dying? To what extent would patients prefer to be involved in decisions related to end-of-life care?

According to this review, the resuscitation preferences are related to many factors and studies clarifying these factors are abundant. However, only a few follow-up studies have been conducted on resuscitation preferences; none of these in Europe.

In the US, DNR orders are widely used in long-term care facilities as a part of ACP. According to both American and European studies, DNR orders are used in acute care more often for elderly patients than for younger patients. There is only one study from Denmark on the use of DNR orders in long-term care in Europe. What is the practice of DNR orders in long-term care settings in Finland?

This study was conducted to shed light on these questions.

3. AIMS OF THE STUDY

The general aim of this study was to investigate elderly patients' preferences for life-sustaining treatments and end-of-life care, and to evaluate advance order practices in long-term care facilities in Finland.

Specific aims were as follows:

1. To clarify how terminally ill elderly patients in acute wards perceive the end of life and what their needs and wishes regarding care are (I).
2. To investigate how resuscitation preferences, health condition, life attitudes and having a living will are related in home-dwelling elderly vascular patients (II).
3. To investigate the factors related to resuscitation preferences of aged vascular patients (II, III).
4. To investigate elderly vascular patients' reasoning for their resuscitation preferences (IV).
5. To clarify elderly patients' preferences in decision-making of life-sustaining treatments (II, IV).
6. To assess the documentation of do-not-resuscitate and do-not hospitalize orders in medical records and to determine factors related to these orders (V).

Figure 2

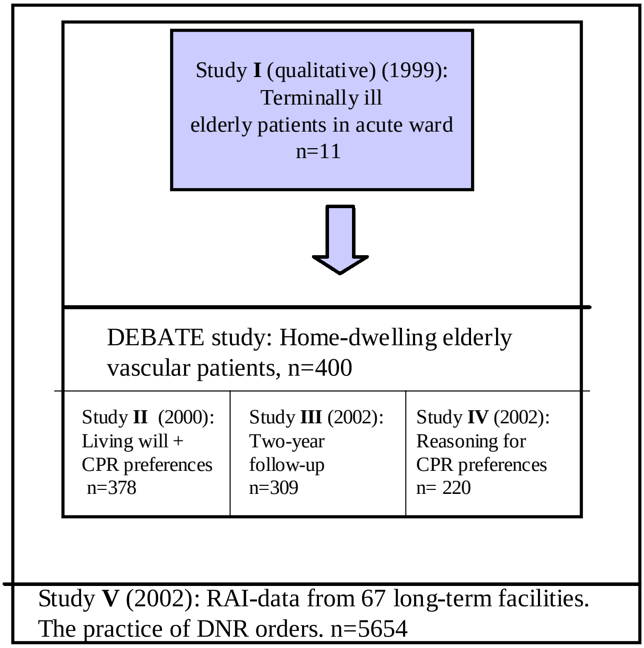
Study design
(studies I-V)

Studies I-V explored advance care planning of elderly patients in three different settings.

Study I also investigated the needs and wishes of dying elderly patients. Some of these findings generated questions to be answered by studies II-IV.

The DEBATE study examined factors associated with cardiopulmonary resuscitation (CPR) preferences.

From RAI data, factors related to do-not-resuscitate (DNR) orders were investigated.

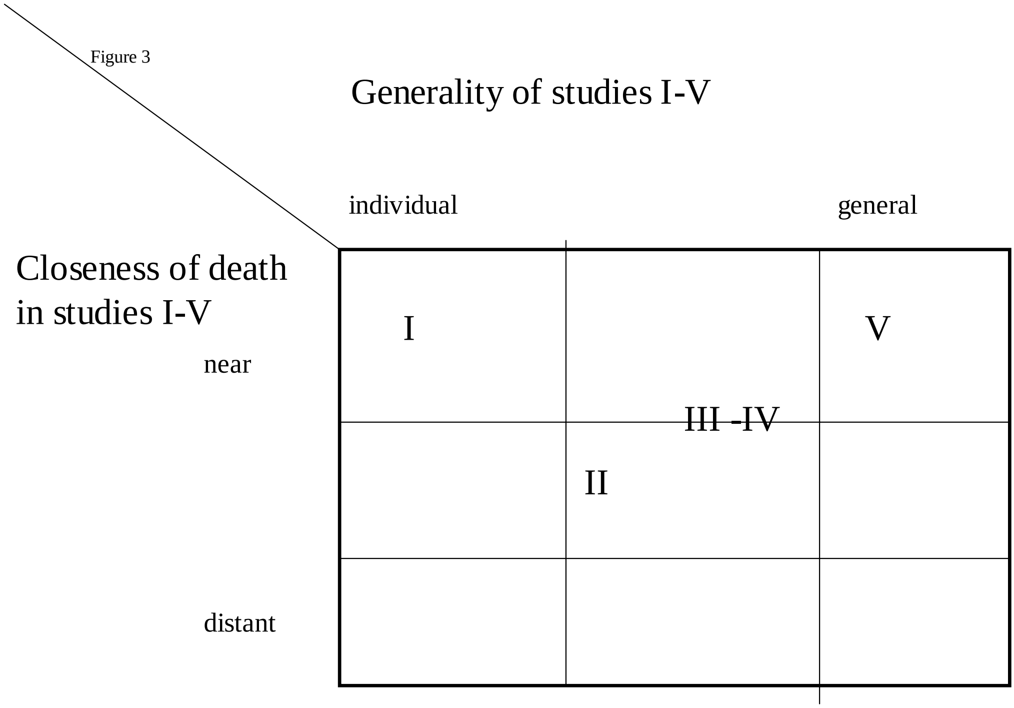


DEBATE= Drugs and Evidence Based Medicine in the Elderly

RAI= Resident Assessment Instrument

Figure 3

Generality of studies I-V



4. PARTICIPANTS AND METHODS

This study consists of three different phases with two different methods. Firstly, a qualitative study (I) was performed in which terminally ill elderly patients in acute wards were interviewed in depth. Secondly, quantitative studies (II–IV) where carried out in which community-living vascular patients of the Drugs and Evidence-Based Medicine in the Elderly (DEBATE) study were interviewed about their preferences for life-sustaining treatments (LSTs) and issues related to end-of-life care. Thirdly, a quantitative study (V) of the Resident Assessment Instrument (RAI) database, including assessments of residents at three different levels of institutional care, i.e. chronic care hospitals, nursing homes and assisted living, from 67 different facilities in Finland, was carried out. The study design is presented in Figure 2. Figure 3 depicts studies I–V in two-dimensionally; according to closeness of death and generality.

4.1. QUALITATIVE STUDY (I)

Participants

Participants were identified and recruited from three acute geriatric wards at Koskela, Helsinki City Hospital, over a seven-month period in 1999. Patients were selected by nurses with the aid of consulting physicians according to the following criteria: 1. terminal illness with an estimated prognosis of less than six months, 2. no cognitive impairment, 3. willingness to discussabout issues related to end-of-life care and dying and 4. performance status sufficient to tolerate an interview greater than one hour in duration.

Participants were selected to represent both genders (eight females, three males), different social backgrounds and different diseases with different end-stage trajectories. None were the researchers' patients. Participants' median age was 81 (range 64–89) years. Although 14 patients were approached to take part in the study, one patient refused and one was excluded due to unclear prognosis. After ten interviews, new issues no longer seemed to arise – a concept that qualitative researchers refer to as saturation (Eskola and Suoranta, 1998). However, we wanted to include more males to ensure that a wider range of views would be represented. Thus, one female patient was excluded at random and a male patient recruited instead. Eleven patients in total participated in this study.

They all needed acute hospital care at the time of their interview. Five were able to walk for a few metres, five needed assistance and a wheelchair in order to move and one was bedridden. Four patients were later discharged from the hospital; the remaining seven either died, remained in the hospital or were transferred to other institutions. Four patients died within one month, three within three months, and four were still alive after six months.

Interviews

One interviewer (MLL) conducted all interviews at the most convenient location for the patient. The interviews took one to two hours. Interviews were audiotaped and contained in-depth semi-structured questions, that were open-ended to allow patients to speak freely. Additional questions encouraged elaboration and clarification of emerging themes.

The interview usually started with the patient's background and experiences with the disease and its symptoms. The following topics were included in the in-depth interviews: 1. current illness and its symptoms, 2. opinions about advance directives, 3. attitudes about prognosis, 4. characteristics of a good quality of life, 5. relationships to relatives and friends and 6. views of a good death.

Analysis

The interviews were transcribed verbatim, and the transcripts were analysed by content analysis (Pope and Mays, 1999). The transcripts were read several times to identify emerging themes. Data were organized into codes and further into broader categories that would encompass these initial codes and provide insight into identified themes. Each item was compared with the rest of the data to establish analytical categories (constant comparison) (Pope and Mays, 1999). The entire reviewing and coding process was performed independently by two researchers (MLL, KHP). The researchers had discussions to reach a consensus for any differing concepts. This procedure was refined following a review of the transcripts in order to identify deviant cases and provide a new perspective on the results (Pope and Mays, 1999, Silverman, 2000).

Tabulations were used to determine how attitudes to particular concepts (e.g. resuscitation preferences) were distributed (Eskola and Suoranta, 1996).

4.2. DEBATE QUESTIONNAIRE AND INTERVIEW STUDIES (II–IV)

Participants

Studies of the second phase (II-IV) (Figure 2) were a part of the Drugs and Evidence-Based Medicine in the Elderly (DEBATE) study (Strandberg et al., 2001) investigating the effectiveness of cardiovascular disease prevention and treatment in vascular patients aged 75 years and older. Participants were recruited by mail in 1998–2000 out of a random sample of 75-, to 95-year-old individuals (n=4821) living in Helsinki, Finland, and who were born in 1924 or 1925 (n=1450), 1919 or 1920 (n=1450), 1914 or 1915 (n= 1000), 1909 or 1910 (n=774), 1904 or 1905 (n=147) (Figure 1, see Study II p. 249). All home-dwelling individuals with an atherosclerotic disease were considered eligible. They were contacted by telephone and were invited to visit the study nurse. During the first visit the atherosclerotic disease was confirmed, and the patients signed an informed consent. Participants were followed up for three years (2000–2003). Baseline data, collected before the prevention trial procedures, were used in Studies II and III, and data from the year 2002 in Studies III and IV.

In Study II, 22 participants were excluded from analyses: 11 for refusal, 10 for difficulties in answering questions about ACP and one (with a LW) for failing to answer all questions. The persons excluded were older than the rest of the subject pool (85 y (SD 4) vs. 80 y (SD 5)), but there were no significant differences in terms of gender, education, mood, general health or MMSE score. In 2000, the mean age of the subjects was 80 y (75 y, n=136 (36.0%); 80 y, n=131 (34.7%); 85 y, n=83 (22.0%) and 90 y, n=28 (7.4%)). Of the participants, 65.1% were females, 21.7% had an education over 9 years, 15.1% had symptoms of depression, 14.0% had cognitive impairment and 36.0% had excellent mobility according to the 15D scale in 2000.

Of the original subject pool (n=400) in 2000, 91 participants were excluded from analyses in 2002 (Study III): 31 had died, 28 withdrew from the study, 10 moved to long-term care, 11 refused to answer questions about resuscitation and LST and another 11 failed to answer some of the other questions (Figure 2, IV).

In 2002, of the available 309 persons, 220 (72%) took part in a comprehensive interview and 89 (28%) in a brief interview. The comprehensive interview was proposed to participants willing to answer questions related to resuscitation and without cognitive impairment (MMSE <24).

Materials and Measures

Mailed questionnaires

Information was collected at baseline and thereafter annually by questionnaires, which included items on demographic characteristics, health, diseases and current drug treatment. Depression was evaluated with the Zung depression scale (Zung, 1965). Quality of life was assessed with a standard health-related quality-of-life 15D instrument (Sintonen, 2001). Cardiovascular symptoms were evaluated at baseline with the New York Heart Association (NYHA) classification (Fisher, 1972). Also at baseline, physical functioning was evaluated by enquiring whether the participant goes out daily (yes/no) or needs another person's help daily (yes/no) (Pitkälä et al., 2001). In 2002, physical functioning was evaluated by enquiring about the amount of daily walking, with the following response alternatives provided: a) not at all, b) under 1 km, c) 1-2 km and d) over 3 km. In Study IV, physical functioning was defined as locomotion using a mobility scale (1-5) from 15D (Sintonen, 2001).

In 2000, attitudes towards life were determined by the following questions: 1) Are you satisfied with your life? (yes /no), 2) Do you have zest for life? (yes/no), 3) Do you feel needed? (yes/no), 4) Do you have plans for the future? (yes/no), 5) Do you suffer from loneliness? (never/sometimes/often) and 6) Do you feel depressed? (never/sometimes/often) (Pitkälä et al., 2001). In statistical analysis, the fifth and sixth questions were dichotomized as "never" =1 or "sometimes and often" = 0.

Annual visits by the study nurse

Participants underwent detailed assessments including cognitive function measurements with the Mini-Mental State Examination (MMSE) (Folstein et al., 1975). The study nurse discussed ACP, wishes concerning end-of-life care and the concept of LW with participants. The nurse explained the LW as a signed consent in which a person, who may later become unable to communicate as a consequence of a serious and incurable disease, gives permission in advance to forgo artificial LSTs.

Participants were then asked questions from the semi-structured questionnaire, e.g. " If you – in your current health situation – suddenly became ill and had a heart arrest, would you prefer to be resuscitated?"(yes/no). The semi-structured questionnaire was constructed based on previous studies (Shmerling et al., 1988 [8], Emanuel et al., 1991 [7], Gamble et al., 1991 [7], Danis et al. 1994 [7], Johnston et al., 1995 [10], Tsevat et al., 1998 [4]).

In 2002, if the participant was willing to answer resuscitation question and did not have any cognitive impairment, he/she was administered a comprehensive semi-structured questionnaire by the study nurse (Appendix 3)(Study IV). Participants were then also asked to justify their resuscitation preferences from optional statements given to them. These statements were derived from findings of Study I.

The interview contained open-ended questions. Subjects' responses were written down by the study nurse during the interview, and these transcripts were analysed using content analysis according to qualitative studies (Pope and Mays, 1999). The patients were asked an open-ended question: "What do you think your outcome would be after resuscitation in your current health state?" These answers were classified and then dichotomized as follows: good or moderate =1, poor =2 and do not know =3. Altogether 220 elderly justified their resuscitation preferences (Study IV).

At baseline, the following questions from Appendix 3 were asked: 1-7, 10, 21-35, 43 and 44. In 2002, participants with cognitive impairment (MMSE < 24) were asked the following questions from Appendix 3: 1-7, 10, 29, 34, 35, 43 and 44 in the brief interview (n=89); the comprehension interview (n=220) included all questions shown on the questionnaire (Appendix 3). In 2001 and 2003, only a few questions were asked from the baseline questionnaire. Only data from baseline and 2002 were used in this thesis.

Statistical analyses

The data were analysed with the NCSS statistical program (www.ncss.com). Differences in proportions between different groups were tested with a chi-square test, and continuous measurements with the Mann-Whitney U-test. Logistic regression models were used to determine which variables were independently associated to resuscitation preferences. Odds ratios with 95% confidence intervals were calculated. In all analyses, P-values <0.05 were considered statistically significant.

4.3. RAI DATABASE STUDY (V)

Data were drawn from the Resident Assessment Instrument (RAI) database (STAKES, National Research and Development Centre for Welfare and Health), which collects data twice a year in a project known as "Benchmarking and Implementation of RAI in Elderly Care in Finland". The data included assessments of 5654 residents in three different levels of institutional care; chronic care hospitals (n=1989), nursing homes (n=3310) and assisted living (n=355), from 19 municipalities and 67 facilities during January 1- June 30, 2002, in Finland. Three out of four participants were females, the mean age was 82.4 (SD 9.5) years and the mean length of stay in institutional care was 2.6 (SD 3.3) years. Of the subjects, 49.4% had an education of primary school or less (data missing 2326/5654) and 52.4% were widowed (data missing 555/5654).

The Finnish translation of the Minimum Data Set (MDS) version 2.0 for LTC facilities – an American standardized questionnaire used to assess health, functional capacity and psychosocial status – was used in data collection. Every resident was assessed by the staff working on the wards. The assessments were performed according to the MDS User's Manual (Morris et al., 1995), and the staff had been thoroughly trained in how to complete MDS assessment forms item-by-item (Bernabei et al., 1997).

Functional disability was measured by using the activities of daily living (ADL) score based on four items (locomotion in unit, toilet use, eating, personal hygiene). The ADL score ranges from 0 to 6, where zero represents being totally independent and six totally dependent (Morris et al., 1999) . The definition for cognitive impairment was derived from the Cognitive Performance Scale (CPS) embedded in the RAI instrument (Morris et al., 1994). The CPS scale ranges from 0 to 6 and is based on five MDS variables (presence of coma, short-term memory, cognitive skills for daily decision-making, being understood by others, self-performance in eating). Zero represents a cognitively intact person and five to six an individual with severely impaired cognition (Morris et al., 1994). The clinical diagnoses were taken from medical records. Diagnoses were only considered to be relevant if they affected the resident's current ADL status, cognitive status, mood or behavioural status, medical treatments or nurses' monitoring of risk of death (Morris et al., 1995).

The information collected for the ACP section was whether any of the following were explicitly noted in patients' medical records: a) a living will (LW), b) a do-not-resuscitate (DNR) order, intended to allow the patient to forgo resuscitation in the event of cardiopulmonary arrest and c) a do-not-hospitalize (DNH) order, intended to preclude referral to an acute care hospital. The concept of advance order to limit therapy, which was defined as documentation of a DNR order or a DNH order in the medical record, was used as a dependent variable.

Terminal prognosis, as recorded in MDS, must be estimated by an experienced senior physician together with the caregiving team and including either the patient or relatives, or both. Terminal prognosis was defined as a medical condition from which a patient was expected to die within six months (Finne-Soveri and Tilvis, 1998).

Statistical Analysis

Statistical analyses were performed using SAS for Windows 8.02 software (SAS Institute, Inc., Cary, NC, USA). The chi-square test was used to test for categorical variables, and two-tailed Student *t*-tests for continuous variables when comparing persons having an advance order to limit therapy with persons not having one.

A logistic regression model was created to determine the best set of independent characteristics to explain the presence of care-limiting orders. Age, gender and the variables significantly associated with the advance orders to limit therapy in bivariate analysis were added to the logistic regression model. Odds ratios with 95% confidence intervals were calculated.

R2-values were computed to determine the strongest explanatory value of these factors in different logistic models.

4.4. ETHICAL CONSIDERATIONS

In Study I, patients received oral and written information (Appendix 2) about the study before they gave their oral consent, followed by written informed consent. The study protocol was approved by the local ethics committee.

The interviewer (MLL) introduced herself to the participants both as a researcher and a physician. None of the participants were the researcher’s patients. Questions were open-ended to allow patients to speak freely. Additional questions encouraged elaboration and clarification of themes as they arose.

If a patient experienced a question as uncomfortable, the researcher could leave the subject, and if needed, return to it later in a different setting. The topic of the interview was very sensitive. The researcher tried to avoid negative anxiety-provoking emotions. Difficult emotions were handled at once, and all interviews ended peacefully. At the end of the interview, the researcher asked whether participants wanted their opinions about resuscitation or other wishes concerning care to be documented in the medical chart and whether further discussions were desired with the caring physician. Documentation was carried out accordingly. Participants were given the researcher’s phone number in case of questions, but no calls were made. Participants were generally happy with the discussions and had appreciated the interviews.

The research protocol of the DEBATE study had been approved by the local ethics committee. The same study nurse gave verbal information about the study and met the participants annually. The questions about ACP were made face-to-face, and if negative emotions emerged, these questions were skipped and emotions were elaborated by discussion. The study nurse was experienced in caring for cancer patients and in discussing matters related to end-of-life care.

The research protocol of the “Benchmarking and Implementation of RAI in Elderly Care in Finland” project was also approved by the local ethics committee.

5. RESULTS

5.1. TERMINALLY ILL ELDERLY PATIENTS' EXPERIENCES, ATTITUDES AND NEEDS IN THE ACUTE WARD (I)

Experience of treatment and wishes concerning care

Patients interviewed in Study I (n=11) declared themselves to be content with the nursing care that they had received. However, they judged their care with simultaneous consideration and understanding for the haste and great workload of their nurses. Only a few were (totally) content with doctors' treatment and care. Contact with the doctors had been at a distance. It was not easy to get the patients to talk about their daily needs since they considered it self-evident that their basic needs had been met, and their symptoms taken care of and relieved. The patients were very modest, even reluctant, about expressing, their needs and special wishes to nurses, doctors and relatives.

Patients' preferences concerning treatment and decision-making

The patients wanted to be treated actively. They considered symptom relief to be especially important. In case of hypothetical cardiac arrest during their present state, 4 preferred resuscitation, 3 expressed a preference to forgo resuscitation, 2 said that the physician should decide and 2 could not express an opinion. Participants did not perceive themselves as dying patients yet. In the hypothetical situation at the very end of life, patients were reluctant to express precise opinions of treatments. Many thought that they would rely on professionals' opinions. Most participants had not spoken and were reluctant to speak with their doctors and nurses about a poor prognosis or about dying. Nine of the 11 patients wanted to know facts about their illness. They preferred to hear issues related to hope such as further treatments. Most patients (8/11) did not feel a need for religious activities in the ward.

Valued things in life

The meaning of family members and friends was significant. The success and good life of those closest to them brought the patients happiness. Security and good care provided quality of life.

5.2. LIVING WILL AND RESUSCITATION PREFERENCES OF THE AGED POPULATION (II–IV)

Comparison of individuals with and without a LW in 2000 (n=378)

Of the 44 participants (12%) with a LW (Table 1, II), the proportions of female (82% vs. 63%, $p<0.02$), widowed (57% vs. 41%, $p<0.05$) and better-educated (34% vs. 20%, $p<0.04$) individuals were higher than among those without a LW. They also considered their subjective health to be poor less often than those without a LW (9.1% vs. 35%, $p<0.001$). No significant differences were present between the LW and non-LW groups in MMSE scores, depression scores, NYHA classifications, or physical functioning (Table 1, II). The LW and non-LW groups also did not differ from each other in their attitudes towards life (Table 2, II).

An important finding was that of individuals with a LW, 20 (46%) preferred CPR in their current health condition, a proportion not significantly different from the 58% of individuals without a LW. However, individuals with a LW preferred antibiotic treatment significantly less often (9%, 4/44 vs. 28%, 92/378) in a hypothetical end-stage illness situation than individuals without a LW. Individuals having a LW and preferring CPR had more often zest for life and plans for the future and they felt themselves more often needed than those having a LW and preferring to forgo CPR.

Of the whole sample, 192 participants (51%) had considered issues related to LWs and ACP. However, only 11 persons (3%) had discussed LW or other preferences related to medical care in life-threatening situations with their physician. Seven of these persons had a LW. No difference (49%, 21/44 vs. 42%, 140/334) existed between the groups with and without a LW in willingness to discuss these issues with their physician.

Individuals with a LW had discussed significantly more often (91%, 41/44 vs. 26%, 86/334) issues related to ACP with their close relatives and were also more willing (91%, 41/44 vs. 49%, 164/334) to discuss these issues with their close relatives than individuals without a LW.

Comparison according to resuscitation preferences in 2000

We also divided and compared the participants according to their CPR preferences (Table 3, II). Of the whole sample, 15 (4%) did not want to define their resuscitation preference and 149 (39%) preferred to forgo CPR. The latter group were older, more often female and widowed, and a greater proportion of them considered their quality of life to be poor. Persons preferring to forgo CPR also had lower mean MMSE scores. However, no significant differences were present between the groups in the proportions of cognitively impaired persons (MMSE points <24), or NYHA class and physical functioning.

Life attitudes of persons preferring to forgo CPR did differ significantly from those preferring CPR (Table 4, II), and there were more individuals who felt depressed or lonely and a smaller proportion that had zest for life, plans for the future or felt needed.

Participants preferring CPR in their current health situation favoured significantly more often (36%, 78/214 vs. 12%, 18/149) antibiotic treatment in a hypothetical end-stage illness situation than individuals preferring to forgo CPR.

In the logistic regression analysis where age, gender, cognitive impairment (MMSE points <24), 15D score, depression (Zung-scale points >44), and attitudes towards life were added as covariates, having a zest for life (OR 3.3, 95% CI 1.2-8.7) and feeling needed (OR 2.2, 95% CI 1.2-3.9) were independently associated with preference for resuscitation. In this model, having plans for the future (OR 1.2, 95% CI 0.7-2.0) and depression on the Zung scale (OR 1.1, 95% CI 0.5-2.2) were not significantly associated with CPR preference.

5.2.1. Results from a two-year follow-up

Of baseline participants (n=378), 82% (n=309) were followed for two years and 79% (n=297) were followed regarding resuscitation preference (Table 1/R). The number of participants with a LW increased from 44 (11.6%) to 53 (17.2%) during the two-year follow-up. There were 14 new persons with a LW.

Table 1/R. Stability of preferences at baseline and at the two-year follow-up.

Preference	Baseline	*(n=378)*→	Follow-up	*(n= 297)*
			Yes (n=140)	No (n=157)
		n	n	n
Resuscitation	Yes	214	123	
	Yes			54
	No	149	17	
	No			103

Of participants, 76% had stabile preferences for resuscitation. The preference to forgo CPR was the most stabile preference. One of four preferring CPR at baseline changed their preference to forgo CPR at the follow-up. Of all participants in 2002, 54% preferred to forgo resuscitation.

Fifty-four participants changed their resuscitation preference to forgo CPR during the two-year follow-up. During this time they developed significantly more often cognitive impairment (see Table 2/R) than participants consistently preferring CPR. They were also older and more often women, widowed and with less education, but these characteristics were not statistically significant.

Seventeen participants changed their preference to opt for CPR during the follow-up. They had significantly better cognitive functioning than participants consistently preferring to forgo CPR. They were also younger, had a better NYHA class and physical functioning in 2000 and were more seldom widowed, but these characteristics were not statistically significant.

Table 2/R. Characteristics of participants followed up from 2000 to 2002 by resuscitation preference in 2002.

Characteristic	Total, % (n=297)	Stabile CRP+, % (n=123)	Changed to forgo CPR, % (n=54)	Stabile CPR-, % (n=103)	Changed to CPR+, % (n=17)
Female	65.3	53.7	64.8	78.6	70.6
Age: 92 years	8.1	2.4	9.3	8.7	5.9
87 years	24.9	17.1	16.7	34.0	11.8
82 years	35.0	31.7	42.6	33.0	47.1
77 years	36.4	48.8	31.5	24.3	35.3
Widowed	43.8	35.0	42.6	55.3	41.2
Education >9 years	19.9	22.8	14.8	18.4	23.5
MMSE[1]<24 points in 2000	11.1	8.1	14.8	12.6	11.8
MMSE[1]<24 points in 2002	21.2	9.8	27.8**	34.0	5.9*
Developed cognitive impairment in 2-year period	10.4	6.5	16.7*	13.6	0
Depressive symptoms[2] in 2002	20.8	13.8	14.8	31.1	29.4
Developed depressive symptoms[2] in 2-year period	13.1	9.8	11.1	17.5	17.6
Daily walking over 1 km	49.8	53.7	46.3	46.6	52.9
NYHA[3] class 3-4 in 2000	27.6	22.0	29.6	34.0	23.5
Feeling needed in 2000	71.4	83.7	79.6	55.3	52.9
Having a living will in 2000	12.7	8.1	14.8	16.5	17.6
Having a living will in 2002	17.1	12.2	14.8	22.3	29.4
Preferring CPR after information in 2002	19.9	39.0	11.1	1.9	17.6
No answer to CPR question after information in 2002	48.5	37.4	48.1	63.1	41.2

Differences in proportions between two groups were tested with chi-square test (* P <0.05 and ** P <0.01).

[1] Cognitive impairment according to Mini-Mental State Examination (Folstein et al., 1975).

[2] Zung depression scale depression scale > 44 points (Zung, 1965).

[3] New York Heart Association's physical functioning scale for organic heart disease (Fischer, 1972).

We also used multivariate analysis to determine which characteristics independently predicted resuscitation preferences. In this analysis, the variables significantly associated with resuscitation preference in 2002 (Table 1/ III) were used. NYHA class 3 or 4 in 2000 and having a LW in 2000 were added as covariates in the logistic regression model. The significant predictor for resuscitation preference was feeling needed in 2000 (OR 1.80, 95% CI 1.03-3.14). Having a cognitive impairment (OR 0.39, 95% CI 0.19-0.81) and age over 85 years (OR 0.52, 95% CI 0.29-0.93) were independently associated with the preference to forgo resuscitation. Gender, physical functioning, having a living will, having symptoms of depression or being widowed were not significantly associated with resuscitation preference.

Comparison according to life attitudes

We also determined whether positive life orientation had an influence on different variables during the two-year follow-up. At baseline, 94 of all participants (25%) had a positive life orientation, as determined answering "yes" to all of the following items: being satisfied with life, having a zest for life, having plans for the future, feeling needed and seldom feeling lonely or depressed. Compared with others, participants with a positive life orientation were more often younger and men, had better education, more often preferred CPR (p<0.002), less often developed symptoms of depression (p<0.001), had better mobility function in 2000 (p<0.001) and less often had a decline in mobility (p=0.01). Moreover, at baseline, they had seldom had cognitive impairment (p<0.002), but in the two-year follow-up positive life orientation did not save them from cognitive impairment (Table 3/R). In conclusion, positive life orientation appears to predict better physical and mental functioning in these very old age groups.

Table 3/R. Characteristics of participants by life orientation in 2000.

Characteristic	Total, %	Positive life orientation, %	Non-positive life orientation, %	p-value[1]
	(n=378)	(n=94)	(n=284)	
	100%	24.9%	75.1%	
Female (n=246)	65.1	48.9	70.4	<0.001
Age: 90 years (n=28)	7.4	3.2	8.8	0.03[2]
85 years (n=83)	22.0	16.0	23.9	
80 years (n=131)	34.7	34.0	34.9	
75 years (n=136)	36.0	46.8	32.4	
Education >9 years (n=82)	21.7	34.0	17.6	<0.001
Depression[3] in 2000 (n=57)	15.1	2.1	19.4	<0.001
Developed depression[3] in 2-year follow-up (n=47)	12.4	2.1	15.8	<0.001
MMSE[4] <24 in 2000 (n=53)	14.0	4.2	17.3	<0.002
Developed MMSE[4] <24 in 2-year follow-up (n=36)	9.5	9.6	9.5	0.98
Mobility[5] grade 1 in 2000 (n=136)	36.0	50.0	31.1	<0.002
One grade or more mobility[5] decline in 2- year follow-up (n=70)	18.5	9.6	21.5	0.01
Prefer CPR in current health situation (n=214)	56.6	70.2	52.1	<0.002
Change CPR to DNR in 2-year follow-up (n=54)	14.3	19.1	12.7	0.12

[1] Differences in proportions between two groups were tested with chi-square test.

[2] P-value was calculated by analysis of equal variance t-test.

[3] Zung depression scale > 44 points (Zung, 1965).

[4] Cognitive impairment according to Mini-Mental State Examination (Folstein et al., 1975).

[5] Mobility scale from 15D health-related quality of life instrument (Sintonen, 2001).

5.2.2. Reasoning for resuscitation preferences and elderly patients' role in the decision-making process

Reasoning for resuscitation preferences

Individuals who preferred CPR (n=114/220) justified their view in the following ways (Table 2, IV): 1. "Life is precious and worth living for me" (92%), 2. "Maintaining life is a value of its own" (92%) and 3. "I feel needed by my family and my closest" (81%). Those who preferred to forgo CPR (n=106) justified their opinion as follows: 1. "I have already gained old age and led a full life" (88%) and 2. "People can not decide these things" (72%). Subjects, who stated that ”Life is not worth living" (13%) more often had signs of depression than those preferring to forgo CPR (Zung >44; 8/14 vs. 15/92, p<0.001). Subjects who reported that " My family does not need me anymore" (36%) also more often had signs of depression than those preferring to forgo CPR (Zung >44; 14/38 vs. 9/68, p< 0.005).

Of the whole sample, only a few 26/220 (12%) admitted that fear of death would have an influence on their preference, and of these 14/26 (54%) preferred CPR. They tended to more often be depressed than the rest of the sample, but the result was not statistically significant (Zung >44; 7/26 vs. 29/165, p=0.12).

Responses to the open-ended question regarding reasoning for resuscitation preferences

Of the 114 participants preferring CPR in the case of cardiac arrest in their current health situation, only one responded verbally in addition to the statements: ”*So I get time to discuss with my closest.*" In contrast, however, of the 106 participants preferring to forgo CPR, 21 (20%) responded verbally in addition to the statements. Ten of these participants expressed views like such as *"After resuscitation the health condition would probably be very poor"*. Seven of the participants explained their preference to forgo CPR as ”*That would be an easy way to go*”, and three estimated that their resuscitation would be ”*Useless work*”.

Aspects related to decision-making

Of the 220 participants, only 20 (9%) had discussed and 83 (38%) would like to discuss issues related to advance planning, including resuscitation and LST, with their physician in their current health condition (Table 3, IV). Most patients wished that the physician would initiate these discussions. However, 80% of patients wanted to be involved in the end-of-life care decision-making; 9% wanted to decide alone, 23% with a physician and 48% with a physician and a close relative.

Of the 220 participants after receiving information about resuscitation, 45 (20%) did not express any preference and 47 (21%) changed their preference. Of those who had preferred CPR, 39/114 (34%) changed their preference to forgo CPR. Of those who had preferred to forgo CPR, 8/106 (8%) changed their preference to opt for CPR.

Of the 220 participants, 164 (75%) stated that religion had a great or medium significance in their life. There was no difference in religious beliefs between the groups divided according to resuscitation preference.

5.3. ADVANCE ORDERS TO LIMIT THERAPY IN LONG-TERM CARE FACILITIES (V)

Of the subjects, 767/5654 (13.6%) had altogether 787 advance orders to limit therapy and 751/5654 (13.3%) had a DNR order (Table 1, V). These orders were present almost twice as often in chronic care hospitals (19.4%) than in nursing homes (10.9%) and 20 times more often in chronic care hospitals than in assisted living (1.1%, $p<0.001$). However, the variation of occurrence in DNR orders between individual LTC institutions was enormous: 0-92.4% in hospitals, 0-79.4% in nursing homes and 0-7.1% in assisted living. There were only a few DNH orders (36, 0.6%), and most of these were in nursing homes (31, 86.1%).

Table 4/R. Cross-tabulation of advance orders to limit therapy and living wills, n (%).

Type of advance order	DNR	DNH	LW
Do-not resuscitate (DNR)	751 (100)	20 (3)	41 (6)
Do-not hospitalize (DNH)	20 (56)	36 (100)	6 (17)
Living will (LW)	41 (24)	6 (4)	170 (100)

According to cross-tabulation, only a moderate concordance was present between these advance orders. Of persons with a LW (n=170), only 41 (24.1%) had a DNR order and 6 (3.5%) a DNH order. Of those with a DNH order, 20 (55.6%) also had a DNR order (Table 4/R).

Subjects with advance orders to limit therapy were more often treated in chronic care hospitals and had spent longer in institutional care (mean 3.1 years vs. 2.5 years, $p<0.001$) (Table 2, V). No statistical differences were found between the advance orders to limit therapy based on age, gender or marital status.

Of the residents with severe cognitive impairment (CPS score 5-6, n=2052), 429 (20.9%) had advance orders to limit resuscitation or hospitalization. Of the residents with nearly total or total dependence in ADL functioning (ADL score 5-6, n=2415), 537 (22.2%) had advance orders to limit therapy. Only 44 individuals (0.8%) in the entire sample (n=5654) had been given a terminal prognosis, and of these 10 (22.7%) had a DNR or DNH order.

Explanatory value (R^2) of significantly associated variables

A logistic regression model was created to examine the independent variables associated with advance orders to limit therapy (DNR or DNH order). When adjusted for age, gender, length of stay in institutional care and level of LTC, having a living will (OR 2.34, 95% CI 1.61–3.41), significant impairment in ADL (ADL score 5-6) (OR 2.93, 95% CI 2.44–3.51), severe cognitive impairment (CPS score 5-6) (OR 1.70, 95% CI 1.43–2.01), having pain (OR 1.12, 95% CI 1.02-1.23) and having certain diseases, such as stroke (OR 1.36, 95% CI 1.06–1.74) and pneumonia (OR 1.82, 95% CI 1.03–3.23), had independent predictive value for the advance orders to limit therapy.

However, variation between individual institutions produced the strongest explanatory value (49%) (Table 3, V); this did not increase by adjusting the model with the strongest factors associated with advance orders to limit therapy, nor was it affected by adding age or gender to the model. Impairment in ADL functioning ($R^2=0.11$), level of long-term care ($R^2=0.05$) and all diagnoses ($R^2=0.04$) were only weakly associated with presence of a DNR or DNH order.

6. DISCUSSION

Elderly Finnish patients seem to base their thinking on values of Western bioethics. They appreciate open disclosure of diagnosis and wish to participate in decision-making about medical treatments as long as they have strength to participate. However, only half of them wished to discuss these issues with their close relatives or with their physician, suggesting that open disclosure of prognosis is undesired by many, who prefer to maintain their hope until the very end. The terminally ill elderly patients in acute care wanted their physician to make end-of-life treatment decisions. Home-dwelling elderly patients preferred shared decision-making.

Of outpatients, 12% had a written LW. About half of elderly outpatients preferred resuscitation in case of cardiac arrest in their current health situation. Those with a LW preferred resuscitation as often as those without a LW. Resuscitation preference was associated more strongly with elderly patients' attitudes towards life than physical functioning or depression. In a two-year follow-up, the feeling of being needed predicted the preference for CPR; cognitive impairment and age over 85 years were independently associated with the preference to forgo CPR.

Marked differences were found in the use of DNR orders between caring units in long-term care in Finland. The roles of diagnosis, symptoms, functional capacity and poor prognosis remained modest compared with that of local practices.

Because of the medical and geriatric background of the author, the main emphasis of these studies was on medicine, specifically on the physician-patient relationship and the quality of medical care during dying or when preparing for death.

6.1. TERMINALLY ILL ELDERLY PATIENTS' EXPERIENCES, ATTITUDES AND NEEDS IN THE ACUTE WARD (I)

From terminally ill elderly patients' perspectives, the end-of-life care they received in acute wards was good in pain and symptom management, which is one of the main domains in quality end-of-life care (Emanuel and Emanuel, 1998 [2], Singer et al., 1999 [5], Steinhouser et al., 2000 [3], Teno et al., 2001 [2]). The other domains, including finding meaning in one's life and death, achieving a sense of control, confronting and preparing for death, and relieving the burden on and strengthening relationships with loved ones, were not successfully fulfilled.

Elderly terminally ill patients wished for active care strongly. Perhaps the diagnosis and prognosis have been revealed to these patients in an obscure manner, allowing them to have an incomplete understanding of the situation. Full disclosure should be considered a part of a complex and ongoing process, not a single event (Good Delveccio, 1990, Wenrich et al., 2001 [9], Kirk et al., 2004 [9]). However, in the Helsinki health care system, a seriously ill patient will meet often the same physician only once or twice during the illness process (Hakanen, 1991 [5]). Patients experienced the physicians as being distant, and hoped for more discussions with them. These findings are consistent with those of previous studies (Hakanen 1991 [5], Engle et al., 1998 [5], Steinhauser et al., 2000 [3], Baker et al., 2000 [4], Teno et al., 2004 [4]).

Patients described the patient-physician relationship as a traditional closed "physician-centred" approach (Morrison and Meier, 2004). Physicians had no possibilities to have open "patient-centred" interviews to explore the patient holistically, rather than as a set of medical symptoms. Needs were mainly explored by nurses, who were gentle but very busy. Patients were altruistically concerned about nurses' workload and therefore failed to disclose some of their daily needs. This same tendency was observed in the relationships between patients and their close relatives. A humble demeanour was commonly seen in this study. An earlier Finnish study revealed that patients try to behave like "good patients", which hinders them from expressing their wishes and needs (Hakanen, 1991 [5]). According to another Finnish study, nurses in acute wards seldom discuss about giving up tasks or family roles, questions related to religion or negative emotions with dying patients. Topics more often discussed include physical symptoms and depression (Muurinen and Raatikainen, 1999). According to nurses' interviews, the most difficult aspects of their work with dying patients are the setting of boundaries to one's own emotional involvement with the dying persons, and confronting the emotions of the relatives (Molander and Parviainen, 1996).

Aged patients hope for discussions while preparing for impending death (Hakanen, 1991 [5], Molander, 1999 [3], Wenrich et al., 2001 [9]). Health care providers should provide these discussions to assist terminally ill elderly patients in reaching an awareness and acceptance of death. Awareness and acceptance of dying develops in interaction (Glaser and Strauss, 1965, Butler 1968, Pattison 1977) and it enables life planning to proceed and offers the hope of achieving a degree of control over the manner and timing of death (Seale, 1997).

The importance of hope is consistent with other study findings (Delveccio Good et al., 1990, Latimer, 1998, Wenrich et al., 2001 [9], Kirk et al., 2004 [9]). Hope and need for hope were expressed in different ways. Health carers conveyed hopeful messages during many stages by providing functional and concrete aid.

The patients valued highly their relationships with family members and friends. Several studies corroborate this finding (Singer et al., 1999 [5], Steinhouser et al., 2000 [3], Teno et al., 2001 [2], Vig and Pearlman, 2003 [5]). Health care professionals should support and strengthen the relationships between patients and loved ones whenever possible. According to our patients, nurses were overloaded. More resources, especially educational efforts, are needed to develop the open patient-centred approach necessary to ensure that all domains of quality end-of-life care are achieved.

When studying sensitive issues, such as dying persons' experiences and needs, the qualitative research approach has been shown to be fundamental. Qualitative studies have produced new goals for medical treatment and updated guidelines of quality end-of-life care. Many previous qualitative studies (Tables 3, 5 and 9) were carried out in countries where AP and ACP have been used to achieve a "good" death (Emanuel and Emanuel, 1998 [2], Martin et al., 2000). Despite vast cultural differences, we made some consistent findings, such as the importance of hope, the high value of relationships with family and friends, difficulties in communication with physicians, which gives validity to our study. However, this study also produced concepts that are not necessarily generalizable. Some of these concepts were tested in a larger population in the DEBATE study (II, IV), where they were corroborated.

6.2. LIVING WILL AND RESUSCITATION PREFERENCES OF AGED PATIENTS (II–IV)

An important finding was that of elderly vascular patients with a LW 46% preferred CPR in their current health condition, a proportion not significantly different from the 58% of individuals without a LW. This finding highlights that an existing written LW does not free health professionals from thoroughly exploring the patients' current values and preferences. However, individuals with a LW preferred antibiotic treatment significantly less often (9%, vs. 28%) in a hypothetical end-stage illness than individuals without a LW. These findings are consistent with Walker et al. (1995 [8]). There is a trend towards participants with a LW opting for less aggressive treatment, and our study does not exclude the possibility that in a larger study with higher power the difference between the groups might be significant. However, our study shows that a notably large proportion of older people with a LW believe their chances of surviving from resuscitation are good and therefore would opt for CPR.

The proportion of persons with a LW in our study (12%) is similar to that in studies performed in the US at the beginning of the 1990s (Garrett et al., 1992 [7], Miles et al., 1996, Gross, 1998 [7], Hopp, 2000), but in USA today the prevalence of ADs is estimated to be about 25% (Lo and Steinbrook, 2004). Our proportion of persons with a LW is higher than in studies from other parts of Europe (Moe and Schroll, 1997, Schiff et al., 2000 [7]). The Finnish Act on the Status and Rights of Patients (1992) was taken into use, and this may have encouraged patients to complete a LW. Public discussions have also promoted LWs.

Of participants with a LW, 91% had discussed issues related to AP with close relatives, but only 16% had discussed these issues with a physician. In a recent American study, 48% of home-dwelling elderly had an AD and had shared their wishes with others, but only 25% of their physicians knew their end-of-life wishes (Kahana et al., 2004 [7]). Of our participants without a LW, 42% had discussed issues related to AP with close relatives, but only 1% had discussed these issues with their physicians, although 42% would have liked to. This finding is quite consistent with other studies from Europe (Agard et al., 2000 [9], Schiff et al., 2000 [7]).

These findings show that Finnish caring culture does not promote discussions about AP with home-dwelling elderly vascular patients. Most of the patients who had completed a LW document had done so without consulting any professionals but had discussed issues with their close relatives. LWs would be more useful if they emphasized ACP, particularly discussions of end-of-life care with physicians, rather than merely completing a legal document. Such discussions would result in more informed ACP (Singer et al., 1998, Emanuel 2000, Lo and Steinbrook, 2004).

6.2.1. Resuscitation preferences

Our studies are probably the first to demonstrate that general life attitudes are associated with resuscitation preferences. The feeling of being needed was particularly predictive of a preference for CPR. An age of over 85 years and declining cognitive function were independently associated with the preference to forgo CPR. Gender, physical function, having a LW, symptoms of depression or being widowed were not significantly associated with resuscitation preferences. Our findings are contrary to those of Fazel et al. (2000 [8]), who found cognitive impairment to be associated with the preference of opting for treatments. In their study, the level of cognitive impairment was, however, more severe than in ours. We also found in bivariate analyses that persons preferring to forgo CPR had symptoms of depression more often than persons preferring CPR. This finding is supported by many other studies (Lee and Ganzini, 1992 [8], Rosenfeld et al., 1996 [8]), although some researchers have presented conflicting results (Garrett et al., 1993 [7], Danis et al., 1994 [7], Straton et al., 2004 [8]). The changed life situation or having a greater fear of death might explain a depressed patient's preference to opt for more active treatments.

Of the home-dwelling elderly, one in four had a positive life orientation, and they more often preferred CPR than the other participants (70% vs. 52%). In the two-year follow-up, these persons less often developed mobility decline or symptoms of depression, but their life orientation did not save them from cognitive impairment. We found positive life orientation to be an independent factor that has multiple effects. This finding is supported by a previous Finnish study, where positive life orientation was independently associated with survival among older cohorts during a 10-year follow-up (Pitkälä et al., 2004), and by several American studies (Maruta et al., 2000, Ostir et al., 2000, Penninx et al., 2000).

In 2000, 57% of all participants preferred resuscitation. After the two- year follow-up, 45% preferred CPR. The preference for CPR was slightly lower than in an American study of outpatients (Uhlmann et al., 1988 [8]) or in a British study in an acute care setting (Bruce-Jones et al., 1996 [8]). Our DEBATE study participants were older and more often widowed than participants in Uhlmann et al.'s (1988) study. In the study in the UK, the participants were older, but the setting was different, and patients' functional capacity was poorer than in our study.

Seventy-six per cent of all participants maintained a stabile resuscitation preference. This finding is consistent with previous studies (Everhart and Pearlman, 1990, Danis et al., 1994 [7]).

In our two-year follow-up, those preferring to forgo CRP or changing their preference to forgo CPR more often had signs of depression or developed cognitive impairment than those who consistently preferred CPR. This finding suggests that depression and cognition should be assessed in patients preferring to forgo CPR. If the patient is suffering from a major depression, the resuscitation preference may change to opting for CPR after the depression is treated (Ganzini et al., 1994 [8], Eggar et al., 2002 [8]).

Resuscitation preferences of elderly vascular patients were often based on religious considerations and value-based thinking, findings also reported by earlier studies (Everhart and Pearlman, 1990, Mead et al., 1995). A meaningful life and a feeling of being needed and loved by someone were the justifications for many older individuals preferring CPR. Over half of these persons also grounded their preference on plans for the future. For many older individuals, the justification for forgoing resuscitation was perceiving their lives as positively and fully lived.

The justifications were derived from our qualitative study (I). Similar justifications have been reported for cancer patients in describing their progressive awareness and acceptance of dying (Hinton, 1999). Our DEBATE study (IV) findings validate the results of the qualitative study (I) and unite the question of resuscitation to the context of dying. Fear of impending death may result in a preference for treatments (Danis et al., 1994 [7], Straton et al., 2004 [8]). This concept was considered in light of terminally ill elderly patients' (I) hope for active treatments. However, vascular patients did not support this statement as a reason for their preference.

6.2.2. Opinions about participating in advance planning and decision-making

Approximately half of the participants in DEBATE study had considered issues related to advance planning. Patients more often preferred to discuss these issues with close relatives than with their physician. Only a few participants had discussed advance planning issues with their physician, and most hoped that the physician would take the initiative in these discussions. While this finding was in line with previous research, the willingness to discuss these issues with a physician in the current state of health was lower than in European (Phillips and Woodward, 1999, Agard et al., 2000 [9]) or Australian (Kerridge et al., 1998) studies. However, several reports support our finding of patients' reluctance to discuss issues related to weakening and dying (Carrese et al., 2002 [3], Salander, 2003).

After receiving information about the resuscitation procedure and prognosis following the procedure, one out of five patients had difficulty expressing their preferences, even though the description of the information was neutral, standardized and based on previous studies of the same research field in the US (Malloy et al., 1992 [8], Murphy et al., 1994 [8], Schonwetter et al., 1996). Participants may have been confused and overwhelmed by the information. In answering the question for the first time, in light of their feelings and values, the information overload and the emphasis on intellectual issues may have rendered patients mute. This finding shows how important it is to consider the individual when giving information and how difficult it is to study these sensitive issues by quantitative methods.

In Agard's et al.'s (2000) qualitative study, patients who preferred CPR had difficulties in understanding the question of who should make the DNR order and in choosing one of the alternatives. They relied on the physician's ability to judge whether CPR would be beneficial. When discussing resuscitation with an elderly patient and revealing its poor prognosis, physicians should be aware of the sensitivity of these matters.

The terminally ill elderly patients in Study I and half of the DEBATE study outpatients did not like to discuss poor prognosis or worsening related to dying. This can be understood as their not wanting to give up hope of survival. A Swedish study of patients with advanced cancer showed that, although patients wish to visit their physician and discuss cancer and treatment issues, they do not want to discuss their poor prognosis (Salander, 2003).

Four out of five patients thought that the patient's view should be taken into account when making decisions about LST at the end of life. Almost half of the patients considered that the physician together with the patient and a close relative would be the best team in the DM process. These findings contradict results of our qualitative study, where terminally ill patients preferred to rely on professionals' DM at the very end. One explanation for this discrepancy may lie in changed life and illness circumstances. The terminally ill patients might perceive the effort of participating in DM as too great as they become physically weaker, but in their current situation they would prefer to participate in DM. It may also be too demanding emotionally for patients to discuss these issues with relatives. These terminally ill patients had good symptom control, holstering their confidence in relying on the professionals. Some of them preferred that a close relative participate in DM at the very end, some did not. To conclude, most of the elderly patients wish to participate in DM related to their medical care for as long as their physical and mental strength allowed. This result is supported by earlier studies (Lo et al., 1986 [10], Ende et al., 1988, Mead et al., 1995, Agard et al., 2000 [9]).

6.3. ADVANCE ORDERS TO LIMIT THERAPY IN LONG-TERM CARE FACILITIES (V)

DNR orders strongly depend on the local caring patterns of institutions where the decisions are made. Variation within the level of LTC was pronounced (DNR variation between chronic care hospitals 0-92% and between nursing homes 0-80%). This suggests that DM may be incidental or that large differences exist in documentation. Considerable institutional and practice variation has been reported in the early 1990s in American LTC facilities (Batchelor et al., 1992, Mark et al., 1995) and in Scandinavian acute care hospitals (Sjokvist et al., 1999, Skrifvars et al., 2003 [10]), but to a lesser degree than in our study.

Advance orders to limit therapy were more often based on functional status than on diagnoses, supporting results of studies in the US (Berlowitz et al., 1991, Wenger et al., 1995 [10]). The prevalence of terminal prognosis was very low in this study, only 0.8%. No significant association was found between a terminal prognosis and advance orders to limit therapy.

The prevalence of DNR orders (13%) in Finnish LTC is low compared with American nursing homes (up to 70%) (Terry et al., 1994, Mark et al., 1995, Levin et al., 1999 [10]), but is nine times higher than in a Danish study (Moe and Schroll, 1997). The large differences between the US and European countries can be understood by considering the vastly different historical and cultural backgrounds. Only a few of our patients had a DNH order.

The findings of Study V reveal that discussions and consensus about how to process ACP in LTC settings have largely been incidental and lack clear updated guidelines. Many DNR orders may be made orally or expressed in some way other than formal DNR documentation.

Overall, our subject pool included 19% of all LTC beds at three levels of care in Finland. The sample for the assisted-living group was small, but nursing homes and chronic care hospitals were represented in their actual proportions. Strengths of this study include the large sample size and the validated methods used.

6.4. PROMOTING BETTER END-OF-LIFE CARE FOR ELDERLY PATIENTS

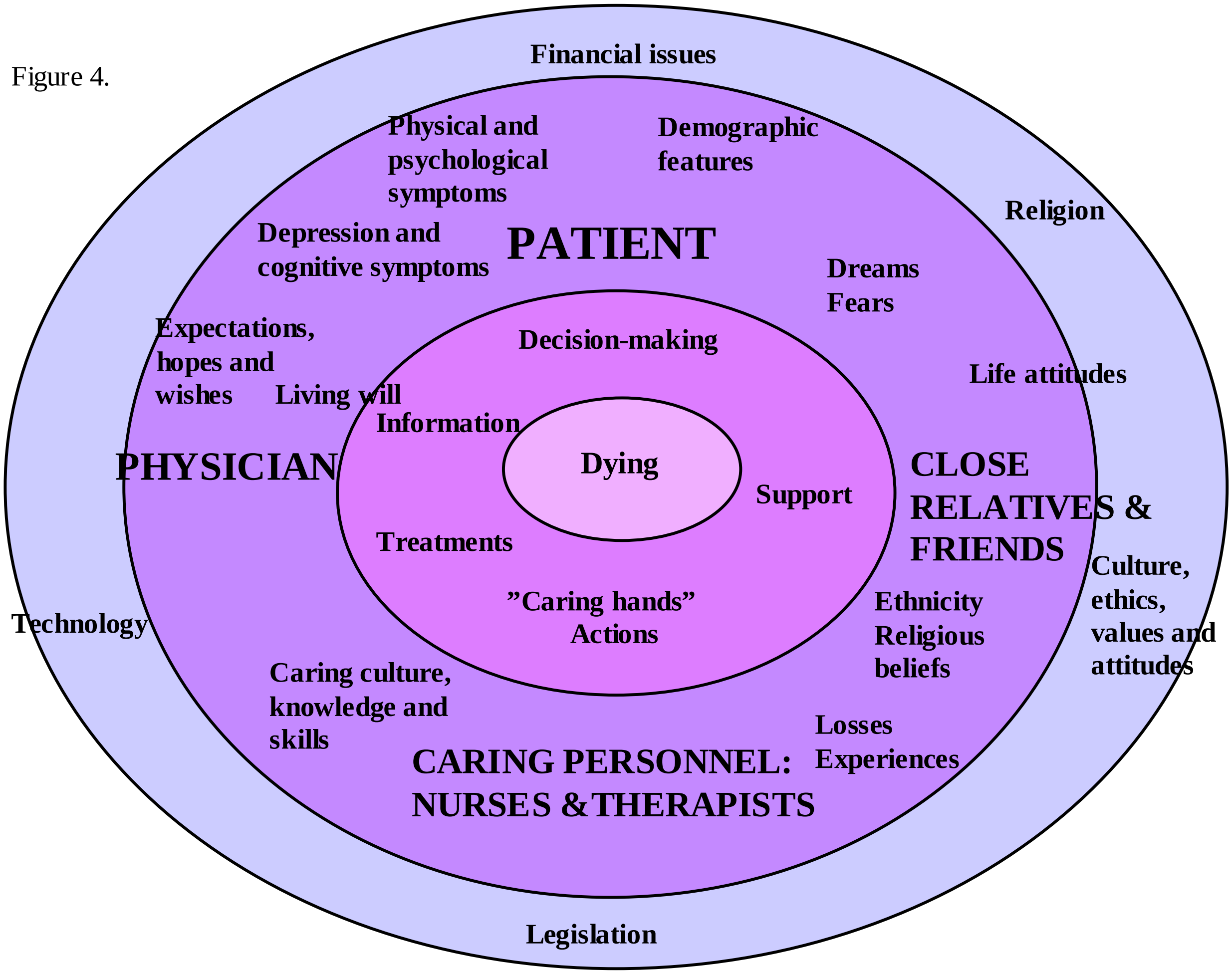
Some developmental issues may be integrated from the results of Studies I-V. Physicians need to improve their abilities to discuss issues related to end-of life care with patients (I) and should discuss these issues with patients more frequently (II-V). Resuscitation preferences and other preferences should be determined for patients suffering from incurable diseases, including vascular diseases, if the patient wishes to discuss these issues (Figure 1). The patient's awareness of presumed outcome and the patient's values and attitudes towards life should be sensitively explored. We should remember that from the patient's perspective the enquiry of resuscitation preference is related to the context of worsening, with the patient assuming that preparation for death and dying is imminent. Patients' values and preferences for treatment may change over the course of illness or in different life situations. Similar to physical care, the discussions should be understood as a process, not as a single event (Wenrich et al., 2001 [9], Kirk et al., 2004 [9]).

Figure 4 presents the components of end-of-life care. The structures of our society, including religion, legislation, economics, technology, culture and ethics, shape our attitudes, values and expectations of progressive illness and of death and dying. All of these dimensions have an influence on DM and quality of end-of-life care, and should be explored to some extent. There is a one central person in the framework, the patient. The role of the physician together with the caring personnel and close relatives and friends is to support the dying patient. The teamwork should increase as the illness progresses.

Physician should thus have the ability to communicate effectively with the patient and to discuss end-of-life care on an ongoing basis, taking the opportunity to gain the patient's trust. To handle this task, physicians, as well as other caring personnel, should receive more education about communication skills and palliative care. Greater resources should also be allocated to ensure adequate time for discussions and for exploring psychological needs as well.

The ACP process calls for institutions to actively co-ordinate better care across settings (Teno et al., 2001 [2]). The need for better communication between the patient and physician has been established in many countries. For the patient, it is the only way to ensure that care and treatment reflects, as closely as possible, patient's wishes and values (Singer et al., 1998, Emanuel, 2000, Martin et al., 2000, Lo and Steinbrook, 2004).

Figure 4.



Components of end-of-life care

7. CONCLUSIONS

1. In our qualitative study, terminally ill elderly patients' physical symptoms were attended to, but our caring culture failed to provide sufficient psychological space and time for these patients to elaborate on issues related to the dying process and their needs. A patient's need for information should be individually assessed, and caregivers should be willing to maintain their hope. Physicians should promote shared DM with elderly patients as long as patients have the strength and willingness to participate, but after these are exhausted, physicians should take responsibility for final treatment decisions. Physicians should encourage caring personnel and loved ones to strengthen their relationships with the patient. Because terminally ill elderly patients express their hopes and wishes very quietly, extra effort should be directed at identifying their wishes.

2. Of Finnish home-dwelling elderly vascular patients in the DEBATE study, half preferred CPR in their current health situation, and of these approximately 12% had a LW. Having a LW did not decrease the reported preference for CPR. CPR preferences are related to general life attitudes rather than to physical health status. After the two-year follow-up, the best predictor for opting for CPR was the feeling of being needed. Cognitive impairment and an age of over 85 years were significantly associated with the preference to forgo CPR. Physical functioning, having a living will and symptoms of depression were not predictors of resuscitation preference. Three out of four patients had a stabile resuscitation preference. Resuscitation preferences should be understood and enquired about in the broader context of the patient's well-being, mood and values.

3. Older vascular outpatients justify their resuscitation preferences by highlighting their experiences of a meaningful life or fulfillment in life, interpersonal relationships with family and friends, religious considerations and presumed outcome of CPR. Less than half of the patients wished to discuss end-of-life treatment preferences with their physician in their current health condition. However, four out of five patients thought that the patient's view should be taken into account when making decisions about LST at the end of life. In routine practice, physicians should assess patients' willingness to discuss ACP and their preferences about LST in detail, including an exploration of patients' values and ethics, as part of the comprehensive care plan.

4. The prevalence of DNR was 13% among institutionalized elderly persons in Finland. Marked differences were present in the use of DNR orders between caring units. However, the roles of diagnoses, symptoms, functional capacity and poor prognosis are modest compared with that of local practices. Open discussions, general guidelines, training and research on the adequacy of DNR decisions are needed to improve equality and self-empowerment of the elderly residing in institutions.

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APPENDIX 1.

SOSIAALI- JA TERVEYSHALLITUS

HOITOTESTAMENTTI

Täten minä

Nimi Syntymäaika

määrään, että jos minä vakavan sairauden tai onnettomuuden seurauksena menetän oikeustoimikelpoisuuteni, esimerkiksi tajuttomuuden tai vanhuudenheikkouden vuoksi, ei minua hoidettaessa saa käyttää keinotekoisesti elintoimintoja ylläpitäviä hoitomuotoja ellei tilani korjautumiseen ole selkeitä perusteita/. Vaikeitten oireitten poistamiseksi tai lieventämiseksi voidaan kuitenkin edellä mainittuja keinoja tilapäisesti käyttää.

Tehohoitoa voidaan minulle antaa vain, jos voidaan kohtuudella arvioida, että sen antaminen johtaa parempaan tulokseen kuin pelkästään lyhytaikaiseen elämän pitkittymiseen.

Jos toivorikkaana aloitettu hoito osoittautuu tuloksettomaksi, siitä on välittömästi luovuttava.

Paikka ja aika

Allekirjoitus (nimi, ammatti ja kotipaikka)

Vartavasten kutsuttuina ja samanaikaisesti saapuvilla olevina todistajina vakuutamme täten, että

Testamentin tekijän nimi

jonka hyvin tunnemme, on omakätisesti allekirjoittanut edellä olevan hoitotestamentin selittäen sen vakaaksi tahdokseen. Hän on tehnyt tämän hoitotestamentin terveellä ja täydellä ymmärryksellä, vapaasta tahdostaan ja käsittäen täysin sen merkityksen.

Paikka ja aika

Kaksi esteetöntä todistajaa

Allekirjoitus	Allekirjoitus
Ammatti	Ammatti
Kotipaikka	Kotipaikka

APPENDIX 2.

Hyvä Keskisen terveyskeskuksen potilas,

Olen tekemässä tutkimusta pitkäaikaissairaiden toiveista omasta hoidostaan ja toisaalta heidän mielipiteistään hoitotestamenttiasioissa. Olen kiinnostunut, saatteko riittävästi tietoa omasta terveydentilastanne ja koetteko, että mielipiteenne tulee riittävästi huomioonotetuksi Teitä koskevissa hoitoratkaisuissa. Olen kiinnostunut myös kuulemaan mielipiteitänne saamastanne hoidosta. Haluaisin myös kysyä Teiltä:

- Minkälaisia asioita arvostatte tällä hetkellä eniten elämässänne? Miten voisimme parhaalla mahdollisella tavalla edistää hoidolla näiden asioiden toteutumista?
- Minkälaisesta hoidosta koette hyötyvänne kaikkein eniten?
- Missä ja miten toivoisitte itseänne hoidettavan juuri nyt ja tulevaisuudessa?
- Oletteko miettinyt, mitä kuolema Teille merkitsee? Tulisiko potilaan vai lääkärin saada päättää hoitoratkaisuista lähellä kuolemaa? Kuinka paljon potilaan tulisi saada tietoa omasta ennusteestaan lähellä kuolemaa?
- Mitä toivoisitte tekevänne ennen kuolemaa?

Jos koette, että haluatte vastata edellä mainitun kaltaisiin kysymyksiin, tulen mielelläni haastattelemaan Teitä. Haastattelu kestää noin yhden tunnin. Haastattelu nauhoitetaan ja se kirjoitetaan myöhemmin kokonaisuudessaan papereille tutkimustarkoitusta varten. Tutkimuksen valmistumisen jälkeen haastattelunauhat hävitetään. Tutkimuksen avulla pyrin kehittämään hoitoa potilaiden toivomaan suuntaan.

Tutkimus on Teille täysin vapaaehtoinen ja Teidän mielipiteitänne käsitellään nimettömänä. Voitte kieltäytyä tai vetäytyä tutkimuksesta milloin tahansa sen vaikuttamatta millään tavoin hoitoonne.

Jos päätätte osallistua haastatteluun, annatte meille sen myötä mahdollisuuden kehittää työtämme edelleen. Mikäli Teillä on kysymyksiä, vastaan niihin mielelläni.

Helsingissä _____ / ______ 1999

Marja-Liisa Laakkonen
Geriatrian erikoislääkäri
Koskelan sairaala
p. xxx xxxxosasto N7 tai
p. xxx xxx koti

SUOSTUMUS:

Olen saanut riittävästi kirjallista ja suullista tietoa tutkimuksesta “Iäkkään vaikeasti sairaan potilaan toive omasta hoidostaan” ja haluan osallistua siihen. Olen tietoinen, että osallistuminen on vapaaehtoista ja että voin keskeyttää osallistumiseni milloin tahansa ilman että se mitenkään vaikuttaa vahingollisesti hoitooni / kohteluuni nyt tai vastaisuudessa.

Samalla annan suostumukseni siihen, että :

Tässä terveydenhuollon toimintayksikössä saamastani hoidosta, minulle tehdyistä tutkimuksista ja toimenpiteistä potilasasiakirjaan kirjattavia tietoja saa tarvittavilta osin käyttää hyväksi nyt tehtävässä lääketieteellisessä tutkimuksessa.	KYLLÄ _____ EI _____

Potilaan allekirjoitus:

Paikka ________________________________Aika ______ / ______ ___________

Allekirjoitus ____

Nimenselvennys ____

Syntymäaika /Sotu _________________ - ____________

Suostumuksen vastaanottaja:

Paikka ________________________________Aika ______ / ______ ___________

Allekirjoitus ____

Nimenselvennys ____

APPENDIX 3.

DEBATE – tutkimukseen osallistuvien kysymykset

Seuraavilla kysymyksillä haluaisimme selvittää iäkkäiden mielipiteitä hoidosta ja toiveista mahdollisen vaikean sairauden varalta ja kuolemaan liittyen. Haluaisimme kysyä näitä mielipiteitä erilaisissa elämäntilanteissa olevilta iäkkäiltä. Tämän vuoksi lähestymme näiden kysymysten kanssa myös Teitä.

Ensin kysyisimme Teidän näkemyksiänne hoitolinjoista mahdollisessa vaikean sairauden tilanteessa sekä mielipiteitänne liittyen kuolemaan?

Ensiksi kysymme Teiltä mielipiteitänne *hoitotahtoa* koskevista asioista. Hoitotahto-asiakirja (tai hoitotestamentti) on potilaan allekirjoittama tahdonilmaus, missä hän ennakolta antaa luvan elintoimintoja keinotekoisesti ylläpitävän hoidon lopettamiseen tilanteessa, missä parantavaa hoitoa ei enää ole eikä hän kykene enää itse ilmaisemaan tahtoaan.

1.Oletteko miettinyt aikaisemmin hoitotahtoasioita? Kyllä ☐ Ei ☐

2.Onko Teillä kirjallinen hoitotahto-asiakirja (hoitotestamentti)? Kyllä ☐ Ei ☐

3.Oletteko keskustellut siitä tai muuten hoitotoiveistanne mahdollisen henkeä uhkaavan tilanteen varalta Teitä hoitavan lääkärinne kanssa? Kyllä ☐ Ei ☐

4.Haluaisitteko keskustella näistä asioista lääkärinne kanssa? Kyllä ☐ Ei ☐

5.Oletteko keskustellut hoitotahto asioista omaisenne kanssa ? Kyllä ☐ Ei ☐

6.Haluaisitteko keskustella omaisenne kanssa näistä asioista? Kyllä ☐ Ei ☐

7.Mikäli nykyisessä terveydentilassanne sairastuisitte äkillisesti ja saisitte sydänpysähdykseen, haluaisitteko, että Teitä elvytetään? Kyllä ☐ Ei ☐

8.Miksi haluatte itseänne elvytettävän?
a. Elämä on minulle kallisarvoista ja elämisenarvoista Kyllä ☐ Ei ☐
b. Omaiseni ja ystäväni tarvitsevat vielä minua Kyllä ☐ Ei ☐
c. Minulla on vielä paljon tärkeitä ja keskeneräisiä asioita elämässä Kyllä ☐ Ei ☐
d. Elämä ja sen ylläpitäminen ovat arvoja sinänsä Kyllä ☐ Ei ☐
e. Pelkään kuolemaa Kyllä ☐ Ei ☐
f. Muu syy, mikä? ____

9.Miksi ette halua itseänne elvytettävän?
a. En usko, että minulla olisi mahdollisuuksia selviytyä siitä Kyllä ☐ Ei ☐
b. Olen jo iäkäs ja riittävän täydesti elänyt Kyllä ☐ Ei ☐
c. Elämä ei ole elämisenarvoista Kyllä ☐ Ei ☐
d. Nämä asiat eivät ole ihmisten päätettävissä Kyllä ☐ Ei ☐
e. Omaiseni eivät tarvitse minua enää Kyllä ☐ Ei ☐
f. En pelkää kuolemaa Kyllä ☐ Ei ☐
g. Pelkään elvytyksen aiheuttavan minulle kärsimystä Kyllä ☐ Ei ☐
e. Muu syy, mikä? ____

____

10.
Mikäli sairastuisitte hyvin vakavasti, esimerkiksi pitkälle edenneeseen syöpään tai vaikeaan dementiaan,
a. – ja tällöin saisitte äkillisen sydänpysähdyksen, niin haluaisitteko,
että Teitä elvytetään? Kyllä ☐ Ei ☐
b. – tai tällöin sairastuisitte vaikeaan keuhkokuumeeseen, niin haluaisitteko,
että Teille annettaisiin antibioottia? Kyllä ☐ Ei ☐

11.Miten ymmärrätte tai kuvaisitte sydämen elvyttämistä?
____

____

____

12.Minkälaiseksi arvioitte mahdollisen sydämen elvytyksen jälkeisen ennusteen nykyisessä terveydentilassanne ?

____

Kerron nyt Teille kuvauksen sydämen elvytyksestä.
Sydämen elvytyksessä käytetään useita toimenpiteitä, joiden pyrkimyksenä saada sydän lyömään ja ylläpitämään hengitys ja verenkierto tilanteessa, missä henkilön sydän tai hengitys on pysähtynyt. Elvytys voi sisältää suusta suuhun hengitystä tai hengitysputken asettamista keuhkoputkeen ja rintakehän painelua sydämen käynnistämiseksi. Se voi myös sisältää sähköisen iskun rintakehälle sydämen rytmin palauttamiseksi. Se voi sisältää lääkkeiden antoa henkilön laskimoverenkiertoon tai hengityskoneeseen kytkemisen tai mekaanisen hengityksen ylläpidon.

Elvytyksen ennuste riippuu monista tekijöistä: mm mikä syy on aiheuttanut sydänpysähdyksen, henkilön muut sairaudet ja kuinka nopeasti elvytystilanne on havaittu. Tutkimusten mukaan kaikista elvytetyistä alle kaksi kymmenestä saadaan elpymään ja he palaavat vielä sairaalasta kotiin. Yli 70-vuotiaista alle yksi kymmenestä palaa elvytyksen jälkeen kotiin. Heistäkin useilla on toimintakyvyn heikentyminenstä joka estää normaaleja päivittäisiä toimintoja.

Tiedustelisin vielä uudelleen mielipidettänne edeltäviin hoitotahto kysymyksiin.

13. Mikäli nykyisessä terveydentilassanne sairastuisitte äkillisesti ja saisitte sydänpysähdykseen, haluaisitteko, että Teitä elvytetään? Kyllä ☐ Ei ☐

14. Mikäli sairastuisitte hyvin vakavasti, esimerkiksi pitkälle edenneeseen syöpään tai vaikeaan dementiaan,
a)- ja tällöin saisitte äkillisen sydänpysähdyksen, niin haluaisitteko, että Teitä elvytetään? Kyllä ☐ Ei ☐
b)- tai tällöin sairastuisitte vaikeaan keuhkokuumeeseen, niin haluaisitteko, että Teille annettaisiin antibioottia? Kyllä ☐ Ei ☐

15. Haluaisitteko keskustella elvytysasioista lääkärinne kanssa? Kyllä ☐ Ei ☐

16. Haluaisitteko keskustella hoitotahto asioista lääkärinne kanssa? Kyllä ☐ Ei ☐
Jos kyllä, niin milloin hoitotahto asioista tulisi mielestänne keskustella?
a) Terveenä ollessa
b) Vakavan sairauden/toimenpiteen uhatessa
c) Kun tiedossa on vakava sairaus/toimenpide
d) Milloin?

17. Kenen tulisi tehdä aloite keskustelulle?
a) Lääkärin
b) Potilaan
c) Omaisen
d) jonkun muun, kenen? ________________________________

18. Osaisitteko sanoa miksi potilas ja lääkäri keskustelevat keskenään harvoin hoitotahto tai elvytysasioista?
a) Lääkärillä ei ole aikaa keskustella asiasta, vaikka molemmat haluaisivat puhua Kyllä ☐ Ei ☐
b) Potilas ei halua keskustella asiasta Kyllä ☐ Ei ☐
c) Lääkäri ei halua keskustella asiasta Kyllä ☐ Ei ☐
d) Potilas arvioisi ennusteensa heikoksi, jos lääkäri ottaisi asian esille Kyllä ☐ Ei ☐
e) Potilas ja lääkäri molemmat pelkäävät keskustella asiasta Kyllä ☐ Ei ☐
f) Asiasta ei kannata keskustella, koska asia ei ole ihmisten päätettävissä Kyllä ☐ Ei ☐
g) jokin muu syy? Mikä?

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19. Miksi Teillä **ei** ole hoitotahtoa?
a) En halua ajatella asioita seikkaperäisesti eteenpäin Kyllä ☐ Ei ☐
b) En pidä asiaa ajankohtaisena Kyllä ☐ Ei ☐
c) Koen, että minulla ei ole riittävästi tietoa laatia kirjallista hoitotahtoasiakirjaa yksin Kyllä ☐ Ei ☐
d) En ymmärrä riittävästi hoitotahdon merkitystä Kyllä ☐ Ei ☐
e) Pelkään, että hoitotahtoasiakirja ymmärretään väärin Kyllä ☐ Ei ☐
f) Kirjallinen hoitotahtoasiakirja luo ahdistusta, ikään kuin ennakoisin tulevaisuutta Kyllä ☐ Ei ☐
g) Toivoisin lääkärin päättävän elämän loppuvaiheiden hoidosta Kyllä ☐ Ei ☐
h) En pysty ajattelemaan kaikkia vaihtoehtoisia tilanteita mitä sairaudet voisivat tuoda tullessaan enkä voi tietää mitä niissä tilanteissa ajattelisin Kyllä ☐ Ei ☐

i) Toivoisin lääkärin ja omaisen päättävän yhdessä elämän loppuvaiheiden hoitolinjoista Kyllä ☐ Ei ☐
j) Nämä asiat eivät ole ihmisten päätettävissä Kyllä ☐ Ei ☐
k) Jokin muu syy. Mikä? ____

____

20. Miksi Teillä on hoitotahtoasiakirja? Ympyröikää vain *yksi* seuraavista vaihtoehdoista
a) Arvostan elämänlaatua
a) Haluan itse osallistua hoitoratkaisujen päätöksiin
b) Toivon sen helpottavan omaisteni asemaa
c) Jokin muu syy. Mikä? ____

____

21. Jos sairastuisitte huonoennusteiseen sairauteen, esim. dementiaan, haluaisitteko, että lääkäri kertoo
a) Teille suoraan tästä sairaudesta Kyllä ☐ Ei ☐
b) entä elinennusteesta? Kyllä ☐ Ei ☐

22. Jos sairastuisitte huonoennusteiseen syöpään, haluaisitteko, että lääkäri kertoo
a) Teille suoraan tästä sairaudesta Kyllä ☐ Ei ☐
b) entä elinennusteesta? Kyllä ☐ Ei ☐

23. Kenen tai keiden mielestänne tulee tehdä päätös elämän loppuvaiheiden hoitolinjoista ?
Ympyröikää vain *yksi* seuraavista vaihtoehdoista*:*
a) lääkäri
b) potilas
c) potilas ja potilas yhdessä
d) lääkäri ja omainen yhdessä
e) lääkäri, potilas ja omainen yhdessä
f) joku muu, kuka tai ketkä?
____

____

24. Entä, oletteko keskustellut kuolemaan liittyvistä asioista oman lääkärinne tai hoitajanne kanssa?

25. Haluaisitteko keskustella ? Kyllä ☐ Ei ☐

26. Oletteko keskustellut läheistenne kanssa omaan kuolemaanne liittyvistä asioista? Kyllä ☐ Ei ☐
Haluaisitteko keskustella ? Kyllä ☐ Ei ☐

27. Oletteko keskustellut papin kanssa kuolemaan liittyvistä asioista? Kyllä ☐ Ei ☐
28. Haluaisitteko keskustella ? Kyllä ☐ Ei ☐

29. Missä toivoisitte kuolevanne ?
a) kotona
b) sairaalassa
c) nykyisessä hoitopaikassani
d) saattokodissa

30. Oletteko yleensä saanut riittävästi tietoa sairauteenne liittyvistä asioista?
– lääkäreiltä? Kyllä ☐ Ei ☐

31. Koetteko, että Teidän näkemyksenne sairautenne hoidossa on riittävästi huomioitu hoidossanne? Kyllä ☐ Ei ☐

32. Onko omaisenne keskustellut lääkärin kanssa hoitoonne liittyvistä asioista? Kyllä ☐ Ei ☐

33. Haluatteko, että omaisenne osallistuisi näihin keskusteluihin ? Kyllä ☐ Ei ☐

Kysyisimme vielä miten näette ja suhteutatte nykyisen terveytenne ja sen suoman elämänlaadun suhteessa elinaikaan.

34. Kuinka monta kuukautta yhdestä vuodesta *nykyisessä terveydentilassanne* antaisitte **enintään** elinajastanne pois, jos vastaavasti saisitte lyhyemmän, mutta täysin terveen ja toimintakykyisen, elämän?

Antaisin pois elinajastani __________ kuukautta, jotta voisin elää __________ kuukautta täysin terveenä ja toimintakykyisenä. (Kuukausien summa 12 eli yksi vuosi)

35. Kuinka monta vuotta toivoisitte saavanne vielä elää? _______________ vuotta
(Jos vähemmän kuin vuosi: kuinka monta kuukautta: _____ kuukautta)

36. Onko Teillä uskonnollista vakaumusta? Kyllä ☐ Ei ☐

37. Jos kyllä, niin kuulutteko johonkin seurakuntaan tai uskonnolliseen yhteisöön? Kyllä ☐ Ei ☐

38. Jos kyllä, niin mihin kuulutte? ____________________________________

39. Minkälainen merkitys uskonnolla on elämän asenteisiinne?
a) suuri merkitys
b) kohtalainen merkitys
c) pieni merkitys
d) ei merkitystä

Seuraavaksi vielä muutama kysymys elämänasenteistanne

40. Mikä tai mitkä asiat elämässänne tuovat Teille turvallisuutta? ________________________________
____

41. Mitkä tai mitkä tekijät luovat turvattomuutta? ____

____

42. Miten luonnehtisitte turvallisuuden kokemustanne nykyisessä elämässänne?

X ____X
erittäin turvaton erittäin turvallinen

43. Mitä toivotte tulevaisuude ____

____

44. Mikä tuo Teille tämän hetkisessä elämäntilanteessanne elämänlaatua ja mielihyvää?

____

____

45. Miten luonnehtisitte yleistä elämän asennettanne?

X ____X
erittäin pessimistinen erittäin optimistinen

Sydämellinen kiitos vaivannäöstänne!