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WITHHOLD OR WITHDRAW FUTILE TREATMENT IN INTENSIVE CARE.

Arguments supported by physicians and the general public

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“For every ailment under the sun
There is a remedy, or there is none;
If there be one, try to find it;
If there be none, never mind it.”

W. W. Bartley, III 1934 - 1990

To my children
Helena and Olof

Abstract

Background: Since the 60s and with increasing intensity a discussion have continued about balance between useful and useless/harmful treatment. Different attempts have been done to create sustainable criteria and recommendations to manage the situations of futile treatment near the end of life. Obviously, to be able to withhold (WH) or withdraw (WD) treatment which is no longer appropriate or even harmful and burdensome for the patient, other processes than strict medical (or physiological) assessments are necessary.

Aim. To shed light on the arguments regarding to WH or WD futile treatment we performed two studies of physicians' and the general populations' choice and prioritized arguments in the treatment of a 72-year-old woman suffering from a large intra-cerebral bleeding with bad prognosis (Papers I and II) and a new born boy with postpartum anoxic brain damage (Papers III and IV).

Methods. Postal questionnaires based on two cases presented above involving severely ill patients were used. Arguments for and against to WH or WD treatment, and providing treatment that might hasten death were presented. The respondents evaluated and prioritized arguments for and against withholding neurosurgery, withdrawing life-sustaining treatment and providing drugs to alleviate pain and distress. We also asked what would happen to physicians' own trust if they took the action described, and what the physician estimated would happen to the general publics' trust in health services (Paper IV).

Results. Approximately 70% of the physicians and 46% of the general public responded in both surveys. The 72-year-old woman: A majority of doctors (82.3%) stated that they would withhold treatment, whereas a minority of the general public (40.2%) would do so; the arguments forwarded and considerations regarding quality of life differed significantly between the two groups. Quality-of-life aspects were stressed as an important argument by the majority of both neurosurgeons and ICU-physicians (76.8% vs. 54.0%); however, significantly more neurosurgeons regarded this argument as the most important. A minority in both groups, although more ICU-physicians, supported a patient's previously expressed wish of not ending in a persistent vegetative state as the most important argument. As the case clinically progressed, a consensus evolved regarding the arguments for decision making.

The new born child: A majority of both physicians [56 % (CI 50–62)] and the general population [53 % (CI 49–58)] supported arguments for withdrawing ventilator treatment. A large majority in both groups supported arguments for alleviating the patient's symptoms even if the treatment hastened death, but the two groups display significantly different views on whether or not to provide drugs with the additional intention of hastening death, although the difference

disappeared when we compared subgroups of those who were for or against euthanasia-like actions.

Conclusions. There are indeed considerable differences in how physicians and the general public assess and reason in critical care situations, but the more hopelessly ill the patient became the more the groups' assessments tended to converge, although they prioritized different arguments. In order to avoid unnecessary dispute and miscommunication, it is important that health care providers are aware of the public's views, expectations, and preferences. Our hypothesis—physicians' estimations of others' opinions are influenced by their own opinions—was corroborated. This might have implications in research as well as in clinical decision-making.

Keywords. Withdrawal life-sustaining treatment, Futility, Neonatal intensive care, Intentions, Hastening Death, Value-based medicine, Evidence-based medicine, Decision-making , Personal values

List of papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals.

I Rydvall A, Bergenheim T, Lynöe N. Decision making in a life-threatening cerebral condition: a comparative study of the ethical reasoning of intensive care unit physicians and neurosurgeons. *Acta Anaesthesiol Scand,* 2007 Nov;51(10):1338–43.

II Rydvall A, Lynöe N. Withholding and withdrawing life-sustaining treatment: a comparative study of the ethical reasoning of physicians and the general public. *Crit Care,* 2008;12(1):R13.

III Rydvall A, Juth N, Sandlund M, Domellöf M, Lynöe N. To treat or not to treat a newborn child with severe brain damage? A cross-sectional study of physicians' and the general population's perceptions of intentions. *Med Health Care Philos,* 2014 Feb;17(1):81–8.

IV Rydvall A, Juth N, Sandlund M, Lynöe N. Are physicians' estimations of future events value-impregnated? Cross-sectional study of double intentions when providing treatment that shortens a dying patient"s life. *Med Health Care Philos. Springer Netherlands,* 2014 Aug;17(3):397–402.

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List of Terms and Abbreviations

A	autonomy 21, 31, 32
ACDHD	Act concerning Criteria for Determination of Human Death 17
ANH	Artificial Nutrition and Hydration 18, 19, 21, 25
APACHE	Acute Physiologic and Chronic Health Evaluation 22
ARDS	Acute Respiratory Distress Syndrome 24
AV	Artificial Ventilation 16
BD	Brain Death 17
CCI	Chronic Critically Ill 23
COPD	Chronic Obstructive Pulmonary Disease 24
CPR	Cardio Pulmonary Resuscitation 16, 25
CT	Computerized Tomografi 25, 45
DDE	Doctrine of Double Effect 30, 33–35
DER	Double-Effect Reasoning 34
DNR	Do Not Resuscitate 18, 26
ECMO	Extra Corporeal Membrane Oxygenation 19
EOL	End-Of-Life 17, 18, 24, 28, 34–36, 39, 64, 69
IC	Intensive Care 13, 15–19, 24, 26, 34, 36
ICP	Intensive Care Physician 17, 37, 46
ICU	Intensive Care Unit 13, 15, 25, 26, 28
IG	The Instrument of Government 37
LOS	Length of Stay 39
LPT	Compulsory Psychiatric Care Act 32, 39
LST	Life-Sustaining Treatment 13, 15–18, 21–23, 25, 26, 45, 47, 52, 65
MF	Medical Futility 26
MOHSA	Ministry of Health and Social Affairs 39
MRI	Magnetic Resonance Imaging 25, 46
MV	Mechanical Ventilation 16–19, 27, 51, 52, 55

NBH The Swedish National Board of Health 17
NBHW The Swedish National Board of Health and Welfare 13, 17, 18
NM non-maleficence 30

PDE Principle of Double Effect 33
PVS Persistent Vegetative State 18, 21, 25, 49, 51, 52, 68

QOL Quality of Life 36, 46, 68

RDE Rule of Double Effect 33
RRDE Reinvented Rule of Double Effect 34
RRT Renal Replacement Therapy 19, 24, 27

SAPS Simplified Acute Physiologic Score 22, 23
SFAI Swedish Society of Anaesthesiology and Intensive Care 18
SIR Swedish Intensive Care Registry 23, 67
SOFA Sequential Organ Failure Assessment 23, 24
SOU Official Report of the Swedish Government 17, 33
SPC Swedish Penal Code 37
SSEP Somatic Sensory Evoked Potential 25

TBI Total Brain Infarction 17, 18

WD withdraw 13, 16, 17, 19, 22, 23, 26–28, 36, 49
WH withhold 13, 16, 17, 19, 22, 23, 26–28, 36

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Part I:
Introduction and Overview

1. Prologue

1.1 Birth of this thesis

It can be said to have begun during my first contact,1969-71, with health care as a help nurse in intensive care. There was no overt discussion about prognosis, every patient was fully treated until the last heartbeat. I saw a couple of times resuscitation of patients I later understood must have been brain dead. Of course I had, at that time, no power and no experience to question the strategies. But, I can remember that I felt it was awfully wrong with some patients. Later on I became a specialist in Anaesthesiology and Intensive Care (IC) 1982. Over time it became more and more obvious to me that many of our patients were far behind all life-saving treatment but there was almost no discussion about any other strategy than to do everything possible. Still, in the 1990s, the physician who tried to challenge the treatment strategies could get the epithet of "Dr Dead". Other invectives used to close discussion was accusation of performing euthanasia.

Becoming head of the Intensive Care Unit (ICU) in 1993 I took as one of the most important challenges to focus on the over-treatment problems. The regulation 1992 [1] from The Swedish National Board of Health and Welfare (NBHW) gave for the first time support for withhold (WH) and withdraw (WD) which was also described as ethically equivalent. However, few read the regulation and even fewer were prepared to really work in the direction of limiting Life-Sustaining Treatment in futile situations. Against a lot of resistance from the physicians but support from nurses we managed to significantly change attitudes and regular ethical discussions on individual patients became more common in the years of the late 1990s.

In 1997 the author succeeded to initiate the first ethics committee in Umeå University Hospital. The work in the ethics committee, thereby meeting one of my supervisors (Niels Lynøe) became the starting point for the research behind the thesis.

2. Introduction

2.1 Intensive Care

Intensive Care (IC) is a young discipline. Machines for artificial ventilation (ventilator) came into common use with the epidemics of poliomyelitis around 1948-50, many patients were either mechanically or manually artificially ventilated over long time. IC at that time was mostly respiratory care and many of the polio victims were rescued [2]. The county hospital of Borås opened the first 24/7 ICU-ward in Sweden in 1960.

IC of today is a broad medical field. It differs from most other specialties in medicine in that the interventions are about to monitor and protect, to support or replace vital organ function *awaiting therapeutic effect against the underlying illness or injury* [3]. One, of many, is the septicaemia with septic chock where it nowadays often is possible to bridge over the most critical passage of illness in stead of, lacking IC resources, a much higher mortality and morbidity is likely to occur. This is Life-Sustaining Treatment (LST) in its positive meaning though that term in the literature often is used in conjunction with the question of futile treatment [4, 5, 6].

> *From Marshall et al 2016:What is an intensive care unit? A report of the task force of the World Federation of Societies of Intensive and Critical Care* [3].
> An ICU is an organized system for the provision of care to critically ill patients that provides intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of acute organ system insufficiency. Although an ICU is based in a defined geographic area of a hospital, its activities often extend beyond the walls of the physical space to include the emergency department, hospital ward, and follow-up clinic.

Criteria for Initiation – reevaluation – limiting of IC

Adapted from [7] citing British National Health Services

- ICU is a service for patients with potentially recoverable conditions who can benefit from more detailed observation and invasive treatment than can safely be provided in general wards or high dependency areas.
- ICU should have clear operational policies based on multidisciplinary care, effective communication and consultant to consultant referral when possible.
- Since IC may serve only to delay death rather than reverse the underlying pathology, the appropriateness of admissions should be considered in the light of such reversibility, associated co-morbidity and the patient's stated or written preference against intensive care.

- Once admitted, the appropriateness of continuing care should be made as soon as practicable after full discussion within the intensive care team, with the referring team and the patient and/or family.
- A decision to limit treatment generates alternative options such as discharging of the patient, making the patient comfortable or withdrawal of ventilatory support.

2.2 End-of-life in Intensive Care

GR Dunstan was a priest who had another and maybe more realistic view than many doctors who, at that time, really regarded each death as a medical failure. His more than 30 year old statement makes sense.

> The success of intensive care is not to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by the quality of the dying of those in whose interest it is to die; and by the quality of human relationships involved in each death.
>
> –GR Dunstan, University of London, 1984 (cited by [6])

The development of advanced therapies, especially Mechanical Ventilation (MV), have changed the conditions for life and death. A patient who, before the era of Artificial Ventilation (AV), suffered an injury to the brain stem stopped breathing and died. In today's health care the MV goes on and the professionals have to make an active decision about continuing or withdraw treatment. In the context of "most is possible" and "as long there is life there is hope" in health care there is obvious risk to forget the limitations of medicine. Youngner, 1994, stated that medical advances give patients the "illusion of control" over life and death [8]. All care is not good care, sometimes it is even harmful and burdensome for the patient, the relatives and the staff. The problems with over treatment/inappropriate medical treatment/futile treatment is by no means limited to Intensive Care (IC). However IC contains invasive therapeutic measures, MV, where interruption often is followed by the patients death in a short time frame. To lower the goals for Life-Sustaining Treatment can not be concealed, rather it will be obvious and therefore must be communicated. When bringing up the issue of WH or WD, communication seems to be one of the largest problems.

Swedish History of End of Life in ICU

Still in the early 1970s there were no general regulations or routines targeting the problem of futile treatment. The enthusiasm of being able to save lives with modern technical devices and absence of routines and open discussion about the patients possibilities to survive sometimes led to inappropriate treatment or over-treatments. Sometimes Cardio Pulmonary Resuscitation (CPR)

was initiated to patients who later on would have been declared dead because of Total Brain Infarction (TBI). The description of that state and its fatal consequences was in place since long time even if there was a lack of accepted routines to manage the situations. Because of the fear of being accused of murder or manslaughter WH and WD of life-sustaining treatment was very uncommon though a few Intensive Care Physicians (ICPs) were said to do it behind closed doors by successively decreasing the ventilation until death.

In 1965 a Consultant Physician stopped iv fluids[1] to an 80-year-old woman, since months deeply unconscious, after a large stroke. The doctor was prosecuted after report from The Swedish National Board of Health (NBH) declaring that it is wrong to withdraw life-sustaining treatment but since the patient was dying and had a short life expectancy the court found the physician's act defensible [9].

The first Swedish official document regulating WD of treatment was published in 1973 [10] and authorized the discontinuation of all treatment including MV when the whole brain had lost its function – TBI. The definition and the investigations were basically identical with actual procedures for declaring death in accordance with direct criteria, Brain Death (BD) stated by the Act concerning Criteria for Determination of Human Death (ACDHD) valid since Jan1, 1988. Although a step forward the 1973 regulation broadly was perceived to describe the only situation where withdrawal of Intensive Care was permissible. In Official Report of the Swedish Government (SOU) [11] "The physician and the severely ill patient", 1978, the investigators reasoned around the possible limitation of LST near the End-Of-Life (EOL) and concluded that only when death was imminent it could be permissible to withdraw treatment. Moreover, there is a case description where a tetraplegic patient demands his physician to stop the Mechanical Ventilation to let him die. The following discussion concludes that this would be deemed to be manslaughter or murder thereby completely overruling a competent patient's right to decide over his own life (the negative right to demand withdrawal of Life-Sustaining Treatment. *Please see 2.4.3 on page 33).*

In 1987 NBHW again reported a physician to prosecutor because of letting a 3 year old child, who was in a vegetative state after near drowning, die by withdrawal of tube feeding. The argument for reporting was that the boy was not brain dead. The prosecutor abstained, however, to prosecute the physician [12].

Still in the 1990s aortocerebral angiography was repeated, sometimes more than once, to confirm totally ceased cerebral circulation in a patient with absent cranial nerve function and only minimal residual cerebral circulation on the first angiography, demonstrating that no survival was possible. The reason why it was performed in this manner is due to the fact that Total Brain In-

[1] giving sugar and salt containing fluids through a cannula inserted in a vein to substitute for the fluid a comatose patient cannot drink

farction (TBI) was regarded necessary to permit withdrawal of LST. Patients, after resuscitation from cardiac arrest, in a bad neurological state and a with pessimistic prognosis regularly became tracheotomized and thereby survived for a long time. Distinct Do Not Resuscitate (DNR)-orders were uncommon. You might often recognize different secret codes for DNR-orders in the different departments' documentation or you might find no documentation at all [13]. It might be described as some type of taboo to decide DNR and accordingly the do not resuscitate decision was not regularly communicated to either patients or relatives.

Finally in 1992 the The Swedish National Board of Health and Welfare (NBHW) published a guiding document about withholding or withdrawing life-sustaining treatment when this is futile. ("Life-sustaining treatment near the end of life") [14]. It was now stated that there are situations where Life-Sustaining Treatment (LST) could be discontinued. Ethically, WH and WD were explicitly regarded equivalent. Importantly this paper from the NBHW was rather weak – referred to as recommendations from NBHW ("Socialstyrelsens allmänna råd"). It lasted almost 20 years until the next paper arrived from the NBHW, SOSFS 2011:7, "Life-sustaining treatment" ("Livsuppehållande behandling") [15]. At this time the board presented detailed instructions for decision-making when treatment is not any longer in accordance with "science and proven experience" or when the patient himself requests withholding or withdrawing of LST. An update of a consensus document about treatment strategies in intensive care from Swedish Society of Anaesthesiology and Intensive Care (SFAI) was adopted to this legal document and published in 2012 (Treatment strategies for Life Support in Intensive Care) [16].

International History of End of Life in ICU

Forgoing treatment in IC near the EOL is first mentioned in the international medical literature during the mid 1970s related to the "Karen Ann Quinlan case", a young woman from the US living in a Persistent Vegetative State (PVS) after intoxication, circulatory arrest and thereby global hypoxic brain damage. Her parents asked for termination of ventilator treatment to give Karen the chance to die. The attending physicians, however, feared accusation of murder or manslaughter. The case was passed all the way to New Jersey Supreme Court. The verdict allowed withdrawal of Mechanical Ventilation (MV) and relieved the physicians from the risk of being prosecuted if interrupting LST. The MV was withdrawn. Karen had, surprising to those who were around, adequate spontaneous breathing which in fact should have been expected in a state of PVS. According to the parents the ventilator was "the bad guy", the burden. Artificial Nutrition and Hydration (ANH) via a gastrostomi was not regarded as a burden, thus this was continued until Karen died in a pneumonia 10 years later [17, 18].

US Supreme Court, in 1990, acknowledged the patents' right to forgo any treatment:

> Once the quality of life for a person in a persistent vegetative state is considered, the result is apparent: life-sustaining treatment must be terminated [19].

Life Sustaining Treatment, Mechanical ventilation and tube-feeding
When the issue was withholding or withdrawing life-sustaining treatment, the topics most focused on are the Mechanical Ventilation, Renal Replacement Therapy, Extra Corporeal Membrane Oxygenation and other advanced therapies where withdrawal results in the patients death within a short timeframe to the WD. With an increasing acceptance for WD of medical futile therapy there is sometimes still disagreement about other sustenance therapies like Artificial Nutrition and Hydration. Some have included antibiotics in this category. Reasoning on what really are the differences have included arguments of high cost vs. low cost and more invasive vs. less invasive interventions as well as estimation whether or not it is burdensome for the patient. Although there might be psychological differences between different life-sustaining treatment it is more difficult to identify ethical differences regarding differences in time between withdrawing the treatment and final death. Present Swedish guidelines do not identify ethical differences between WH and WD or between extraordinary measures and ordinary measures [20, chapter 5, p. 162-64] [16, 21].

2.2.1 Futility

The term "futility" was introduced during the 1970s as an argument in the discussion of forgoing medically meaningless treatment. Futile comes from latin "futilis" meaning "that easily pours out" or "leaky" (from Merriam-Webster dictionary). Searching medline in November 2016 (Pubmed) for "medical futility" the first hit of totally 3233 is "The futility of liver therapy in blood loss anaemia", today a curiosity, published in 1950 [22]. Until 1990 there were only few papers on medical futility, but after that hundreds a year and steadily 30–40 a year concerning futility and Intensive Care. *See figure 2.1 on page 22*.

The Swedish philosopher Anders Wedberg (1951) discussed meaningless treatment, here referred by Löfmark, Nilstun [23, 24, 25].

> *What makes a measure futile*
> If a person or a group of persons (physician, nurse, patient, and/or relative) is of the opinion that a (diagnostic, therapeutic, and/or nursing) measure aiming at a particular (physiological, life-prolonging, and/or quality of life) goal will probably not be achieved, then the measure is futile.
> *Consequences of a futile measure*
> If the measure is futile, then, the health care professionals (physician or nurse) may, ought or should withhold or withdraw the measure, with or without communicating (to the patient, the family or others) the different options, and the physician, (and not the patient, the family and/or others) will be responsible for the decision to forgo the measure.

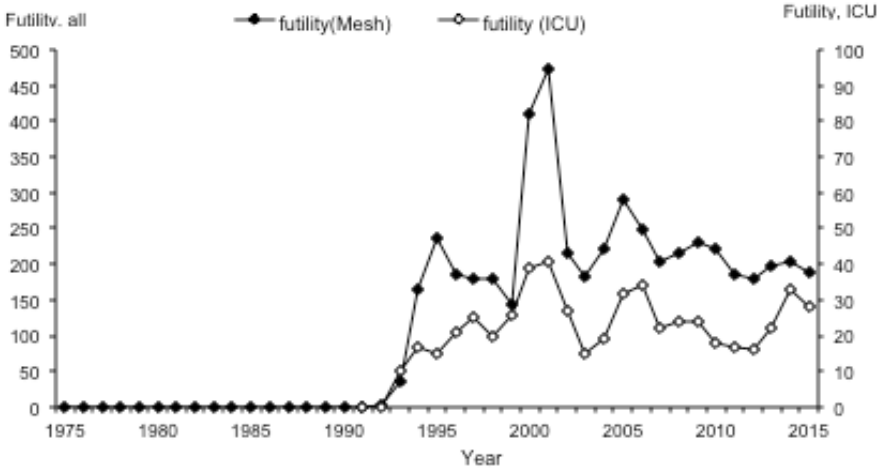


Figure 2.1. Frequency of hits for the term 'Medical futility (MeSh)' and 'Medical futility AND intensive care (MeSh)' for each year 1975–2015.

> "If a certain medical measure is not useful to the patient, it is meaningless"
> "If a certain medical measure is meaningless then the doctor could/should abstain from using that measure."
> Reducing the "equation" by the word "meaningless" gives us:
> *If a certain medical measure is not useful to the patient,then the doctor could/should abstain from that measure*

Principles of Need

Discussing prioritisation in health care Juth lines out the principles of need and defines two distributive questions about resource allocation:

> " - if a principle of need is to function as a principle for priority settings within health care, it must be able to answer two distributive questions: (1) when do we have sufficient more precisely, that is, when do further claims to health care lack normative force (or cease to be legitimate)? And (2) how should we prioritise among those who do not yet have a sufficiency? I would say that the fundamental challenge to any principle of need is to give as plausible an answer as possible to these two questions" [26, page 76].

The health care system is entitled to offer care for the patient to get a minimally acceptable good life or health. Resources should be distributed according to the principles of greatest need but only to the threshold of minimal needs. The therapy introduced must be meaningful for the patient, i.e. futile treatment cannot do the patient any good and therefore there is no need for futile treatment. However, the same patient may have need for other treatments, e.g. the palliative care [26, 27].

Schneiderman

Schneiderman in 1990 [28] caught up on previous discussion in the literature about the concept of "medical futility" and its possible usefulness in the process of forgoing life sustaining treatment. Futility has both quantitative and qualitative aspects. Quantitative as the probability of success, qualitative as the question whether success is of enough value. Schneiderman refers to Plato and Hippocrates and reminds us that as far back as during the ancient times there was an understanding of the limits of medicine.

> Whenever therefore a man suffers from an illness which is too strong for the means at the disposal of medicine, he surely must not even expect that it can be overcome by medicine.
> *from Hippocrates: The Art*

According to Schneiderman, futile in the sense of futile care must be evaluated in terms of usefulness (benefit) and of value for the patient. To influence a certain physiologic effect, although without gain for the patient, is still futile. An example is the patient in a Persistent Vegetative State who has no benefit of continued Artificial Nutrition and Hydration via gastrostomi though the treatment fulfills the physiologic effect of keeping the body from malnutrition. It is also in agreement with the principles of need which are no longer present when the action is of no use for the patient [26].

The Rise And Fall of The Futility Movement. [29]

According to the authors of this paper the interest for the futility issue appeared to have decreased. The reason was interpreted to be the failure to obtain consensus for a concept giving the physicians possibility to unilaterally decide about withholding or withdrawing Life-Sustaining Treatment. It was concluded that although there are sharp data for predicting mortality, medical futility also have value aspects which have to be negotiated and managed in collaboration with patients and/or surrogates in the case where the patient's autonomy is reduced

However, the interest in the issue of medical futility had not diminished at all, on the contrary, the publications and debate is manifold during the years from 2000 until today.

Paul E Marik [30] brings to life the problem with inappropriate intensive care treatment with a case description of an elderly severely ill patient undergoing major vascular surgery resulting in 6 weeks of advanced intensive care treatment, due to multiple organ dysfunction, before the patient died. The author claims that every effort past the two first weeks was futile but the caregivers could not reach consensus with the relatives about the treatment strategy.

Among patients aged > 85 years Biston [31] found in ICU-patients (n=1679) a mortality rate of 92% (after 6 months) and 96% (after 12 months) among patients aged 85 or more. Mortality is near 100 % among the elderly in ICU with

dysfunction in more than two vital organ systems. According to Biston and others both health care providers and the general public's expectations about what health care can achieve are unrealistic and often lead to inappropriate care in the end of life [31, 32].

2.2.2 Medical futility – physiologic assessment

The crucial question is if it is possible to predict death and thereby guide decisions on WH or WD futile treatment in the end of life. A second question is how this should be done.
Different scoring systems have been used to predict mortality risk in Intensive Care with different aims. The first presented scoring system was Acute Physiologic and Chronic Health Evaluation (APACHE), followed by APACHE II and APACHE III, and were developed by Knaus et al during 1981–1991 [33, 34, 35, 36, 37, 38].

Acute Physiologic and Chronic Health Evaluation (APACHE)
With APACHE in 1981 it could be possible to describe and compare ICU admissions, case mix and mortality and there was a prospect to be able to follow up and compare mortality between institutions. APACHE II, published in 1985, was described as "a severity of disease classification system". It consists of APS (acute physiologic score), twelve easily collected acute physiologic parameter scores and evaluation of chronic disease and age. Mortality risk is also related to different conditions which are presented as coefficients. The results were highly reliable on the group level with good correlation to the points of severity.The authors opened up for the future possibility of prediction on the individual level. Chang used trending of APACHE II physiologic scoring and organ failure scores and found near 100% specificity and about 50% predictive value for the risk to die. [39, 40, 41, 42]. The authors point out that the data were not aimed for actual decision making apart from one case where the attending physician considered withdrawal of treatment, the scoring points indicated chance of survival and, the patient actually survived!
The next refinement of scoring system by Knaus, APACHE III, with coefficients for 78 disease categories produced risk estimates in the range of 3% of actual mortality. Even with daily updated scoring, the first day APACHE III scoring predicts the majority of variation in death rates. Still the authors stress that APACHE III on an individual basis can be used only as one part in the decision making of LST [33].

Simplified Acute Physiologic Score (SAPS)
APACHE was based on patients from the United States. SAPS, SAPS II and SAPS III were developed in Europe and published in 1984 by de Gall [43]. SAPS takes into account similar data and also has similar prediction perfor-

mance [44, 45, 46, 47]. SAPS is now widely used, e.g. in the Swedish Intensive Care Registry (SIR).

Organ Failure Score

There have also been developed scores for Multiple Organ Dysfunction which were presented by Marchall 1995 and a task force under European Society of Critical Care Medicine (ECICM) who in 1996 developed the Sequential Organ Failure Assessment (SOFA) scoring system [48, 49]. They both assess the function in six organ systems from 0-4 points which gives in total 24 points as the worst score, which means 100% mortality, unless it is only obtained once during the first 24 hours, or as a series of measurements during subsequent ICU days.

ProVent score

This scoring system predicts one-year mortality for Chronic Critically Ill (CCI) patients who have been ventilator dependent for 14 or 21 days. Based upon the variables Age 50–64 or >65, Platelet count <100 * 10^9, vasopressor, dialysis and non-trauma. Prediction of one-year mortality is between 85 and 100% in different studies [50, 51, 52, 53, 54]. The authors think that the strong prediction could facilitate the communication with patients and especially with relatives about limitation of LST. *See also Figure 2.2 on page 25* .

Categorical variable	n (%)	OR (95% CI)	points
Age, ≥65 years	144 (29)	6.5 (3.8 - 11.2)	2
Age, 50-64 years	162 (33)	2.7 (1.6 - 4.4)	1
Platelets ≤ 100x10^9/L	63 (13)	3.0 (1.5 - 6.1)	1
Vasopressors	78 (16)	3.8 (2.0 - 72.0)	1
Hemodialysis	51 (10)	2.5 (1.1 - 5.4)	1
Non trauma	373 (76)	2.6 (1.5 - 4.6)	1

OR = Odds ratios are for one-year mortality

Figure 2.2. Model in Development Cohort With Categorized Risk Variables to Derive Simplified Scoring Rule (ProVent 14 Score) adopted from Hough 2015 [50].

To conclude regarding the use of scoring systems

On group level there are a couple of validated systems to predict mortality of Intensive Care patients related to a fine grained definition of different diagnoses and symptoms.

Common agreement to make decisions about WH or WD Life-Sustaining Treatment (LST) in the individual situation, based on scoring of physiologic

criteria, is still lacking although it can give additional information to the decision-making process and thereby facilitate communication between the stakeholders (patients, relatives, surrogates and health care staff) [55, 56].

2.2.3 Medical futility – the qualitative assessment

It appears that physiologic assessment or objective facts alone will never give the final answers in the deliberations of treatment strategies in the End-Of-Life (EOL) in Intensive Care (IC). In the last step of decision-making there remains the value-based arguments [57]. Sprung and others have reported different aspects of EOL situations from the ETHICUS study [58, 59, 60, 61, 62, 63].

"Reasons, considerations, difficulties and documentation of end-of-life decisions", reasons to withhold treatment in Intensive Care are reported [58]. Main reasons were "Good medical practice"(66%) and "Unresponsive to treatment" (50%) followed by "neurological reasons" (20%) and "Multiple Organ failure" (10%). Other reasons, rarely mentioned, were cost efficacy, living will, social and family pressures, legal concerns, legal principles and need for an ICU bed. Only a few (11%) reported experience of significant difficulties in dealing with the end-of-life decisions. A possible explanation was that death in many cases was imminent and the decisions therefore were self-evident. No systematic, as Sequential Organ Failure Assessment (SOFA), or other physiologic evaluation was mentioned.

In another dataset from the European ETHICUS study influences of religion, religiosity or only affiliation to a religion on attitudes to DNR-policies, end-of-life treatment, respect for patient's autonomy and euthanasia in the case of severe suffering, were examined. Religiously affiliated professionals as well as patients and patients' families wanted more extensive treatment than those who had no religious affiliation. No difference in the approach to autonomy between religious or non-affiliated health care professionals was found [64].

2.2.4 Some examples of medical futility

Acute abdominal aorta repair to an old patient

80-year-old man, until 5 years ago a heavy smoker. He is diagnosed with Chronic Obstructive Pulmonary Disease (COPD) of moderate severity. He had a myocardial infarction 5 years ago and had been successfully treated with coronary by-pass surgery. The patient is now suffering from a ruptured abdominal aortic aneurysm and two weeks after a technically successful repair there is a situation with Acute Respiratory Distress Syndrome (ARDS), renal failure necessitating Renal Replacement Therapy (RRT) and also circulatory failure with inotropic support. The patient has now become deeply unconscious and the clinical examination gave suspicion of right-sided hemiparesis.

Computerized Tomografi (CT) of the brain reveals a left-sided expansive cerebral infarction with 1 cm mid-line shift.

> The patient has a background with severe cardiovascular and pulmonary disease before the actual event. The present situation with multiple organ failure is associated with a very high mortality. No effective treatment is available for the stroke which would, if he survives, make rehabilitation impossible.

Global hypoxic brain damage
A man, age 55, who is working full time as a physician. Unloading his car his wife thought it took too long. She went to find out why, and found him breathless and without pulse on the ground. Immediate emergency alarm was done and Cardio Pulmonary Resuscitation (CPR) was started. The ambulance arrived in 10 minutes, ventricular fibrillation was found. In 15 minutes after the alarm regular heart rhythm and adequate blood pressure could be restored. However the spouses had not met for 15-20 minutes, thus the duration of circulatory arrest may be more than 15 minutes.
On the fifth day in ICU, after optimal treatment including controlled normothermia, there was deep coma, but spontaneous breathing when testing. The corneal reflexes were absent and extension pattern was the best motor response. Pathologic Somatic Sensory Evoked Potential (SSEP) (stimulation in the periphery does not give signal to the cerebral cortex) and Computerized Tomografi (CT) of the brain showed totally extinguished cortical structure and widespread injuries of the cortex and mid-brain could also be seen in Magnetic Resonance Imaging (MRI). The typical picture of brain with global anoxic injury.

> The brain damage is widespread and all the signs put together tell us that recovery to any type of autonomous life is very unlikely and Life-Sustaining Treatment would in most cases like this be withdrawn [65] On the contrary, an active life-saving approach with tracheotomy, continued Artificial Nutrition and Hydration and antibiotics when needed may end up in years of survival in Persistent Vegetative State. This later path is hardly useful or meaningful for the patient and probably is against an hypothetical advance directive.

2.2.5 Turning point. Palliative Intensive Care

For patients in advanced state of incurable disease, e.g. malignancy, outside the ICU a growing experience of deliberation of the situation with breakpoint talk and turning to palliative care has evolved. The patients and the relatives are engaged in a process of information, support and often there are new goals for the medical care. Nowadays this process, in Sweden anyway, is fully transparent and it often takes some time and several visits with the care team to define and establish a therapy program [66, 67, 68].

Table 3. Criteria for clinical diagnosis of a vegetative state*

- No interaction with others or awareness of self when awake
- No comprehension or expression of language
- No sustained and reproducible voluntary or purposeful response to external stimuli
- Spastic limbs may move nonpurposively
- Noxious stimuli may cause reflex withdrawal
- Some emotive events may occur, such as smiles or grimaces, but not as a reproducible response to stimuli

*From reference 5.

Figure 2.3. Clinical characteristics after a global hypoxic damage to the brain. From Fine 2005 [17].

In the Western World most patients are dying at hospitals or in other institutions. In the US 70% of the deaths occur in hospital and out of them at least 15% in the ICU. As discussed below (*see 2.2.6, on page 28*) a majority of deaths in ICU is proceeded by WHs or WDs. The introduction of the concept of Medical Futility was, at least partly, an attempt from ICU-physicians to find arguments for unilateral decisions of forgoing Life-Sustaining Treatment [29, 69]. A lot of experience indicates that it is important that patients and relatives are part of the decision-making process in order to minimize misunderstanding and conflicts [70, 71, 72]. Consequences of bad communication regarding DNR–orders might be lawsuits and reports in media. This was reported from Great Britain [73]. At the end most stakeholders have one common goal when cure is no longer possible: The patient should not suffer [74, 75, 76, 77, 78].

2.2.6 Withdraw or withhold - what's the difference?

The oldest publications to be found on PubMed (november 2016) searching for "withdrawal of life sustaining treatment", "withdraw", "withhold" is from 1977 but after that time the number of papers have increased to 500 in 1990 and thereafter 400-500 are published each year. The number of papers published also related to Intensive Care have steadily been between 30 and 50 each year. *See figure 2.4 on page 29*.

Life sustaining treatment is withheld or withdrawn in 50-75% of all intensive care deaths including adults and children. WH is more common in adults

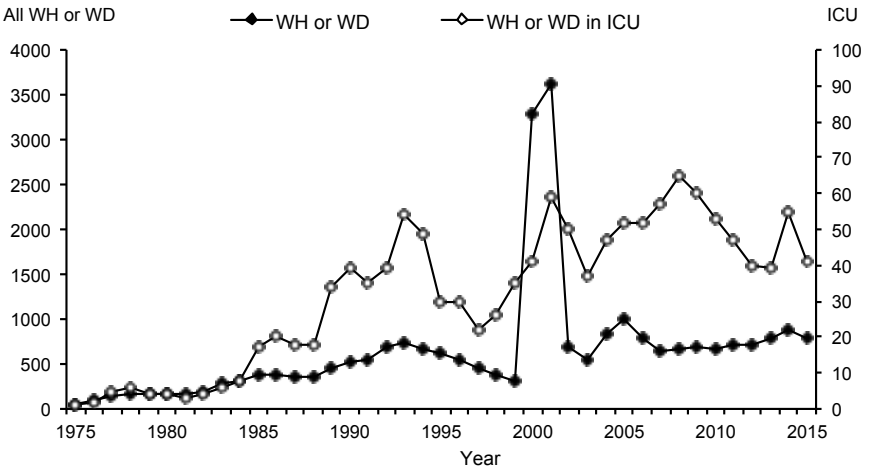


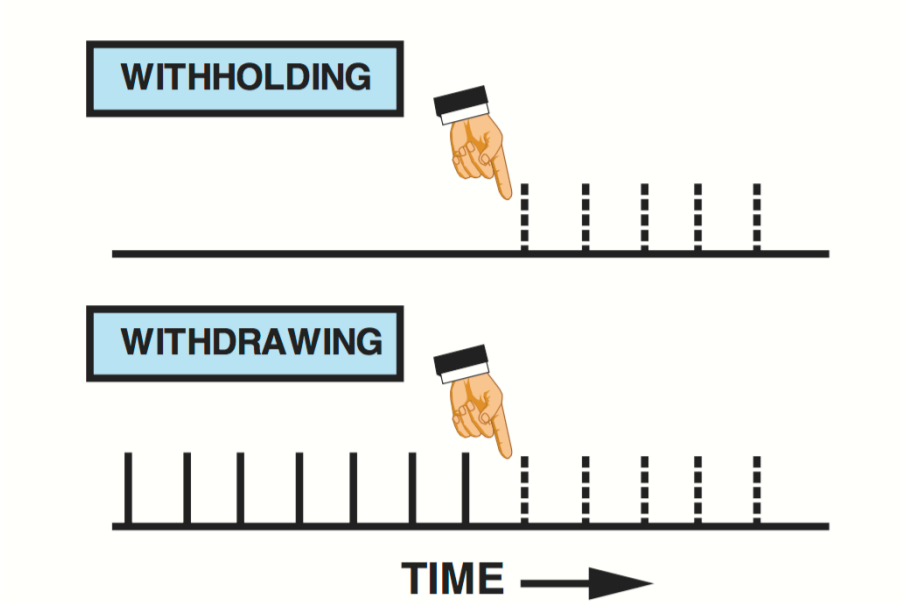
Figure 2.4. Frequency of hits from PubMed for the term (withholding treatment[MeSH Terms]) OR care, withdrawing[MeSH Terms] and '(((withholding treatment[MeSH Terms]) OR care, withdrawing[MeSH Terms])) AND intensive care[MeSH Terms] ' for each year 1975–2015.

and WD in children [63, 79, 80, 81, 82, 83, 84]. WH and WD is considered ethically equivalent [15, 16, 20, 85, 86]. However; therapeutic arguments could be in favor of a possibly more sound therapeutic strategy, not to WH, rather trying treatment and thereafter be well prepared for WD if the treatment trial has failed [20, 86]. There is a substantial increased mortality-rate among patient groups who have been deemed too ill for care but the survival-rate might have been higher if treatment had not been withheld [6, 15, 87, 88, 85].

A common standpoint among both professionals and families is that withholding is acceptable in a situation where the treatment is obviously futile whereas withdrawal is regarded as non-acceptable because of the sanctity of life arguments [89, 90, 91, 92], and even by some considered as illegal [93, 94, 95, 96, 97].

The Jewish tradition has been settled in Israelian law which forbids withdrawal of a continuously performed treatment like MV while intermittent treatment like Renal Replacement Therapy (RRT) can be finished and pointless treatment may thereby be withheld. In this manner a withdrawal procedure is transformed into a withholding procedure. A human is not allowed to act in a way that may hasten death or influence the time of death (termination of MV) which has resulted in timer equipped ventilators in Israel. The ventilator can thus be turned off without the action of a human hand [98, 99, 100].

A burden, an uncomfortable feeling for the professional, may be the fact that withdrawal of Mechanical Ventilation can be associated with almost immediate death. This seems to be an obstacle for this action, notwithstanding



Similarities between withholding and withdrawing mechanical ventilation at the end of life. Each mechanical breath is represented by a vertical line. Whether the patient is already receiving mechanical ventilation or not, the decision relates to whether to apply it from now (interrupted vertical lines), and the consequences of that decision will be the same.

Figure 2.5. From Vincent J-L. Withdrawing may be preferable to withholding. Crit Care. BioMed Central; 2005 Jun;9(3):226–9. .

the conviction that it would be the correct action [64, 58, 75, 63, 85, 94, 101, 102, 103, 104].

2.2.7 Who should decide?

In Europe the physicians take the major responsibility for decisions about forgoing treatment in the ICU while the relatives are presented with the facts and decisions [62]. Medical facts are the dominating arguments for WH or WD and a vast majority (90%) of physicians do not experience problems with patients' and relatives' acceptance of the decisions [59]. Among surgeons interviewed by Svantesson the process of making End-Of-Life decisions was described principally as a medical one, with few ethical reflections. Decision-making was mostly conducted in collaboration with other physicians. Patients, fam-

ilies and nurses did not seem to play a significant role in the process [105]. In a Swedish survey Sjökvist reported that a majority of physicians (87%) wanted to make the decision of withholding treatment themselves. It could be done alone or together with the patient or family. When the patient was autonomously incompetent, 73% of the general public and 70% of the nurses preferred a joint decision made by the family and the physician together. Among physicians (61%) regarded themselves as the only decision maker. This view was supported by 5% of the public and 20% of the nurses [106]. In the US the patient's autonomy and the surrogates substituting the autonomy of an incompetent patient seem to be more inclined to come in conflict with the physicians' views [107, 108, 109, 110].

Who should really decide? Probably it is not too difficult as long as the situation is distinct and the communication between the stakeholders remain sound. All of them should be given the possibility to see the facts which may lay ground for agreement. When agreement can not be reached the procedure into resolution differ between places. A hospital's ethics committee and also sometimes a civil court can be consulted [97, 106, 111, 112, 113].

2.3 Ethics

2.3.1 Normative ethics

Normative ethical theories attempt to identify norms (or principles) which challenge the question "Which general moral norms for the guidance and evaluation of conduct should be accepted and why?". In other words: How we ought to act and the reasons why [20].

Applied ethics

Applied ethics (or practical) ethics refers to use of norms applicable to problems, practices, policies and conduct in different professions. General norms as derived from normative ethics theories are usually only the starting point for the judgements necessarily executed in a clinical setting [20].

2.3.2 Non-normative ethics

Non-normative ethics could, according to Beauchamp&Childress, be *Meta-ethics* and *Descriptive Ethics*

Meta-ethics

Meta-ethics deals with analysis of language, concepts and methods of reasoning in normative ethics.

Descriptive Ethics
Descriptive ethics is the empirical investigation of moral beliefs, attitudes and actual acting (including decision-making) e.g. in clinical settings. The present thesis is based on investigations of how concerned physicians and the general public reason, argue and presumably would act in different situations in health care, particularly in intensive care. In this sense the present papers in the thesis are primarily descriptive [20, Chapter 1, p:1-3].

2.4 Ethical principles in healthcare

In order to make normative ethical reasoning applicable in health care (as well as in medical research) ethical principles with relevance for medicine have been introduced and developed by different scholars. Most well-known is the work of Beauchamp and Childress [20]. They have suggested the subsequent four principles as important and relevant principles for biomedical reasoning: non-maleficence, beneficence, autonomy and justice.

2.4.1 Principle of non-maleficence

Primum non nocere, "Above all, do not harm" is often referred to as the most important maxim in the Hippocratic tradition. But according to the Hippocratic tradition it might be understood as a balance between the attempt to do good and avoid or minimize the risk of harming the patient. The "Primum non nocere" maxim cannot easily be found in the Hippocratic texts and could rather be interpreted as "At least, do no harm" [114]. According to Lynöe [115] *Primum non nocere* maxim was founded in the 19th century in the paradigm shift between the humoral medicine tradition and the evolving scientific era of medicine and surgery as argument for "doing nothing" (expectation) in favor of "not doing potentially bad treatment" which, in the matter of e.g. exsanguination and other really dangerous "treatments", saved lives. The principle of non-maleficence should probably be understood in the Hippocratic sense when balancing an expected beneficial effect of a medical treatment with the risk of harming the patient with the same treatment. In an intensive care setting the non-maleficence principle might be relevant when discussing distinction between e.g. killing and letting die, intending and foreseeing harmful outcome (in combination with the Doctrine of Double Effect (DDE)). *See 2.4.6 on page 35*. Many of the discussions and decisions involving seriously ill and injured patients are about non-maleficence, often in the difficult balancing of which treatments are possibly beneficial, non beneficial or at worst harming in situations where curative treatment is futile. According to Beauchamp&Childress the principle of non-maleficence might be specified in the subsequent manner both in general and in a health care setting:

Rules specifying the principle of non-maleficence [20].

1. *Do not kill.* It may seem self-evident. However there is an ongoing process in several countries to legalize physician-assisted suicide. In Sweden killing is forbidden and regarded as murder even if it is demanded by the patient.
2. *Do not cause pain or suffering.* A lot of both diagnostic and therapeutic procedures in health care have the potential to cause pain and suffering although together with desired results. Thoughtful and prudent working in health care is vital to minimize pain and suffering.
3. *Do not incapacitate.*
4. *Do not cause offense*. The health care professionals should carefully consider the potentially asymmetric relation e.g. doctor–patient where the professionals have a certain responsibility for being humble and not cause offense or disrupt the communication.
5. *Do not deprive others of the goods of life.*

2.4.2 Principle of beneficence

As a physician and representative of the health care system as a whole the principle of beneficence tells us to offer and provide patients with preventive interventions and treatments against disease whenever there is a medical need [26]. When this is no longer possible, health care providers are supposed to offer help to alleviate pain and distress, and lastly, comforting care. The principle embraces the objectives for the health care system. Sometimes the principle is taken for granted because not following the principle would be understood as neglect according to the current health care legislation. Often one or more of the other prima facie principles (*see 2.4.5 on page 35*) put limits on the principle of beneficence, e.g. the non-maleficence principle [116, 117].

According to Beauchamp&Childress the principle of beneficence might be specified in the subsequent manner both in general and in a health care setting:

Specifying the Principle of beneficence. [20]

1. *Protect and defend the right of others.*
2. *Prevent harm from occurring to others.*
3. *Remove conditions that will cause harm to others.*
4. *Help persons with disabilities.*
5. *Rescue persons in dangers.*

2.4.3 Autonomy and the principle of autonomy

A person who can exercise her or his autonomy encompasses self-rule and is acting freely in accordance with a self-chosen plan. It involves three steps:

Three steps to realize autonomy[118]

- *The desire of the individual.* (presupposes a capacity to reason and express desires and wishes)
- *The decision* (presupposes adequate information and a capacity to understand the provided information as well as decision-making capacity)
- *The action* (presupposes capacity to exercise the decision made).

The ability to exert one's autonomy differs between individuals and is also situationally related. Factors that might influence e.g. decision competence are cognitive function, capacity to hear and see etc. An extreme case is total loss of ability to exert autonomy. According to the autonomy principle a person has the right to participate in decision-making regarding interventions and acts that concerns the actual person. The person/patient should be respected on the present level of autonomy [119]. As far as the decision solely affects herself/himself it seems morally correct to claim real self-rule. However, very few human beings are solitaires and the situations where no one else is influenced are probably uncommon which should, according to Hermeren [120], limit the person's ability to exert autonomy and hence his/her participation in decision-making. Generally, in Swedish health care, according to the Constitution (Instrument of Government) and the "The Patient Act" a competent person has the right to abstain from any health care intervention but cannot demand an intervention which is, by the professionals, deemed to be non beneficial or ineffective or simply not available. Accordingly, the patient has complete negative rights but no formal positive rights. There are, however, some exceptions. In Sweden there are positive rights, e.g. abortions and sterilization and there also are limitations of the negative rights e.g. regarding disease control. The Compulsory Psychiatric Care Act (LPT) also overrule a persons right to autonomy if her or his capacity to make decisions is seriously compromised due to serious psychiatric conditions.

About information to patients, and relatives, there has been a big change over the last decades from an approach where patients often, with the health care staff's intention to do good, were spared burdensome information, this is referred to as paternalism (if the patient in such situations actually is competent of making decisions the act is referred to as hard paternalism and if the patient is not competent soft paternalism). The attitude is currently to give full disclosure of the actual condition and there is also research implying that patients want to get honest information though the facts are unpleasant to hear [121, 122].

2.4.4 Justice (J)

The principle of justice, when applied to health care, states that patients with the same health problem should be offered the same service/treatment independently of sex, age, ethnicity, financial capacity, social position, degree of autonomy etc. In the context of scarce resources it might resemble daily problems in different fields of health care where both technical resources and staff

are limited. This might occur in intensive care units, neonatal intensive care units (and treatment with e.g. extra corporeal membrane oxygenation). The principle that equal cases should be treated equally (also referred to as human dignity principle) is, according to the Swedish ethical platform for priority-setting, the first and most important principle. The principle to allocate care according to patient's need is considered the second principle and, finally, when the two first principles are fulfilled, health care staff is supposed to also consider cost-benefit aspects (Official Report of the Swedish Government (SOU) 1995:5) (see *2.4.7 on p.37*). Sometimes; however, it might be a problem if the established procedures do not match with what intuitively would be correct. A patient with a fair chance to benefit from a life-sustaining treatment should have such a treatment in favour of a patient where the treatment is merely futile. There is however no medical need for a futile treatment and in this sense it is not an issue. But sometimes it is difficult to estimate whether or not a certain treatment is actually futile and accordingly whether or not there is a medical need [26].

> A Strategy that seeks to maximize the health benefits available from scarce ICU resources may therefore be justified in overriding the right of individuals to demand unlimited access to resources from which they are very unlikely to benefit [76].

2.4.5 Prima facie principles (PFP)

Do not harm, do good, autonomy and justice are usually considered as Prima Facie Principles. All principles are usually more or less relevant and should be aiming to fulfilment as much as possible. However, principles often concur, thus often the principles are not possible to fulfil concurrently. The goal is then to let the most relevant principle supervene the others – e.g. the beneficence principle might be overruled by the autonomy principle if a competent patient declines the offered medically relevant treatment [118]. Gillon proposes equalization of the four ethical principles in medicine, though autonomy on top. [123]

2.4.6 The Doctrine of Double Effect (DDE)

The concept of Doctrine of Double Effect (DDE), also known as Principle of Double Effect (PDE) and Rule of Double Effect (RDE) originating from the writings of Thomas Aquinas (1225–1274) concerns the example self-defense homicide. Interpreted by T. A. Cavanaugh [124], Thomas Aquinas statement was formulated as follows bellow:

1. The act is the least harmful capable of achieving the end (proportionatus fini[2]);

[2]Proportionality tells "no more harm than necessary to achieve the goal to parry the threat"

2. considered independently of the evil effect, the act is permissible;
3. the agent is more obliged to pursue the good than to avoid the evil (plus tenetur[3]) and
4. the agent intends the good and does not intend the evil as a means or as an end.

In other words the intention of an act is the most important (according to this reasoning), not the consequences. If the intention is benevolent the act is good (or acceptable) even though the foreseen consequence is bad. Similarly, if the intention is evil the act is bad even though the consequences is good/desirable.

A modern formulation of the requisites for Doctrine of Double Effect can be found in Principle of Biomedical Ethics (chap 5 pp164-166; [20])

1. *The nature of the act.* The act must be good, or at least morally neutral, independent of its consequences
2. *The agent's intentions.* The agent intends only the good effect, not the bad effect. The bad effect can be foreseen, tolerated and permitted, but it must not be unintended.
3. *The distinction between means and effects.* The bad effect must not be a means to the good effect. If the good effect was the causal result of the bad effect , the agent would intend the bad effect in pursuit of the good effect.
4. *Proportionality between the good effect and the bad effect* The good effect must outweigh the bad effect. That is, the bad effect is permissible only if a proportionate reason compensates for permitting the foreseen bad effect.

Situations often described in the Double-Effect Reasoning (within the Catholic Church) are from obstetrics, i.e. the saving of a woman's life by surgically removing an ectopic pregnancy from the fallopian tube and thereby killing the foetus. Many therapeutic and diagnostic interventions in medicine might be ethically defended by the rule of double effect. Especially advanced therapies like major surgery or chemotherapy where the likelihood of usefulness or survival for the patient is unclear.

In End-Of-Life (EOL) situations and not at least within Intensive Care (IC) common therapeutic interventions consists of administering potent analgetics and tranquillizing drugs like Opioids and Benzodiazephins to alleviate pain and distress. The bad effect is the risk of shortening life by the unintended effects of such drugs which in an isolated situation would be seen as killing but in the actual situations is regarded as morally acceptable.

Even though hastening death is not intended it might sometimes become an issue if the provided dose, by a later judgement, is considered too high. Since it is not possible for a prosecutor to look inside a physician's brain to observe her or his intentions (whether it is good or bad) the doctrine of double effect is of little help in such situations [125, 126]. The current version of the rule of double effect has been criticized by e.g. Sulmasy who has introduced the The

[3] more held

Reinvented Rule of Double Effect (RRDE) which in his opinion should make it morally possible to give continuous sedation in the end of life until death and at the same time avoid considering it as euthanasia [127]. This has been criticized and undermined by Lindblad et al [128].

While as many other rules and principles being not perfect, the Doctrine of Double Effect (DDE) gives professionals in health care a fundament for ethical deliberations in the EOL care. However, DDE has no legal impact.

> Clinicians have a medical obligation to ensure that patients are kept comfortable, an ethical obligation to avoid prolonging the dying process, and a legal obligation to avoid inappropriate shortening of the dying process [129].

2.4.7 To prioritize in health care

The county councils are responsible for Swedish health care. A part of financing is federal. The advanced and resource demanding investigations and treatment modalities increase with a rapidity with which the economy cannot keep pace. Limited resources force managers to choose between and limit the space allowed for different fields of operation. It could mean to choose expansion of primary health care at the expense of cancer care. This is known as *horizontal prioritization* opposite to distribution of resources to different tasks inside the same sphere of activities (e.g. inside the care of coronary disease) referred to as *vertical prioritization*. [20, Chapt 7, p279-81] [118]. The Intensive Care (IC) is another example of a medical discipline where vertical prioritization is done all the time and sometimes is quite dramatic and painful since beds are limited and almost impossible to expand in the short term. It can thus be a daunting task to create a bed for the next patient with a life threatening condition without putting another patient at unacceptable risk. This vertical prioritization is necessarily done by the responsible professional workers on the “shop floor” . Prioritization is finally a matter of distributive justice.

The difficult choice facing health services

The difficult choice (Vårdens svåra val) is the Official Report of the Swedish Government (SOU) and has since 1995 been the framework for prioritizing in the Swedish health care system. This framework contains an ethical platform for prioritation and three important principles are provided:

The three principles

The principle of **Human Dignity** is considered as the most important:. All human beings have the same value and the same rights irrespectively of personal qualities or roles in the society. In a concrete medical context this principle might be understood as equal cases should be treated equally.

The second important principle is that of **Need and Solidarity**. This principle implies that resources should be allocated to those with the largest need in mind even if those who are in need do not understand it themselves. It means that it is the medical need that counts and not a patient's financial capacity nor the patient's ability to make him or herself heard.

When the two first mentioned principles are fulfilled the third principle might be considered: The **Cost-benefit**-principle. There should be a fair relation between cost and effect on health, assessed as a better health or Quality of Life. This principle is supposed to be applied when comparing different alternative treatments concerning the same patient. It is not supposed to be applied between different patients or patient groups [130, 118].

The next step is to define rules for action in the clinical environment where the following directions were given:

Prioritization in clinical contexts [130]

I. A. Highest priority. Acute life-threatening conditions, treatment of disease where denied treatment would jeopardize life or cause disability.
B. Caring and treatment of severe chronic illness. Palliative care near the EOL. Care and treatment for those with reduced autonomy.

II. Individualized prevention. Habilitation and rehabilitation.

III. Treatment of less acute and less severe chronic diseases.

IV. Intermediate group.

V. Care and treatment not related to illness or injury.

In the real world there are obvious problems of prioritization every day. In those, e.g. in Intensive Care the above described rules give almost no guidance. However in the situations of EOL treatment and decisions on WH or WD, if and when, it inevitably comes to a question of distributive justice which is not endorsed by the official prioritization principles.

2.4.8 Official and unofficial values

The ethical principles, presented above, are more or less endorsed in Swedish health care law and regulations (presented below) and might accordingly be considered as official values. Health care providers are supposed to follow these values and the derived norms. If health care providers have their own personal values they are also supposed (at least in a Swedish setting) to keep them for themselves and not letting such values influence clinical decision-making. This is underlined by the fact that in Sweden there is no room for conscientious objection within health care [131]. Studies have, however, in-

dicated that Swedish health care providers' own personal values sometimes actually influence clinical decision-making [132]. Since such personal values are usually influencing decision-making in a tacit and uncontentious manner, personal values are not presented or declared openly. Hence, such values have been referred to as unofficial values. Usually when analyzing clinical decisions a first step is to focus on factual aspects and then the relevant ethical principles or official values. When these aspects have been scrutinized we focus on whether or not the decision or conclusion is reasonable – i.e. is following from the factual and ethical premises. The problem with unofficial values is that they are not considered as value-aspects – they are coming into the decision-making-process through the 'back-door' [133]. The personal values seem to tacitly influencing the presentation of factual aspects and are, accordingly, difficult to identify both for the health care provider and the patient or other persons concerned.

Factual aspects might be circumstances such as: a patient's or persons' trustworthiness [132], the estimation of whether or not there is a medical indication for a certain treatment [134], the estimation of whether or not a patient is decision-competent [133] or the estimation of future events [135]. A method for measuring value-impregnation of factual aspect will be discussed in connection with paper IV.

2.5 Laws and regulations in Sweden

The Swedish legislation contains few laws directly addressing situations in health care. Chapter 2 in The Instrument of Government (IG) or "the Constitution" (in Swedish 'Regeringsformen') is, however the base for fundamental rights and freedoms in Sweden and is thereby the foundation for patient autonomy. The Swedish Penal Code (SPC) has no special focus on health care, and likewise, no exceptions which would make euthanasia legal. That implies that an action (in health care)) with the intention to shorten life for an imminently dying patient is against the penal code and could result in a murder charge. This is rarely occurring but there has recently been a case where an Intensive Care Physician was prosecuted for manslaughter. The physician was accused of having provided a huge dose of an anesthetic drug to a dying baby. The physician was finally acquitted and the prosecutor abstained from appealing the verdict to a higher court [126].

In the following subsections some of the important legislations (with relevance for health care) are presented , and in figure *2.6 on page 42* there is a compilation of development of Swedish legislation for health care over time.

2.5.1 The Penal Code (Swedish: Brottsbalken) SFS 1962:700

Chapter 3 in the Swedish penal code deals with crimes against life and health. This includes both killing and injuring another person. The sections most relevant in the context of this thesis are:

Section 1: A person who takes the life of another shall be sentenced for murder to imprisonment for ten years or for life.

Section 2: If, in view of the circumstances that led to the act, or for other reasons, the crime referred to in Section 1 is considered to be less serious, imprisonment for manslaughter shall be imposed for at least six and at most ten years.

Section 5: A person who inflicts bodily injury, illness or pain upon another or renders him or her powerless or in a similar helpless state, shall be sentenced for assault to imprisonment for at most two years or, if the crime is petty, to a fine or imprisonment for at most six months. (Law 1998:393)

According to the above stated penal code every surgeon and many other doctors should be imprisoned because of inflicting bodily injury and pain. However as stated in Chapter 1, section 2 in the Penal Code, unless otherwise stated, an act shall be regarded as a crime only if it is committed intentionally. Therefore, If a patient dies during surgery which is performed according to accepted standards, this will (probably) not be considered a crime.

2.5.2 From The Instrument of Government (IG), SFS 1974:1525

2nd Chapter, Fundamental rights and freedoms
4§ There is no death penalty.
5§ Every citizen is protected from corporal punishment. No citizen should be subject for torture or medical compulsion to force disclosure or to hinder her/him from expressing an opinion.
6§ Every citizen is protected from forced corporal interference. Furthermore, the citizen is protected from visitation, searching somebody's home or similar infringement. Likewise everyone is protected against monitoring of personal circumstances such as personal messages, telephone calls etc.

2.5.3 The Health and Medical Service Act (HMSA), SFS 1982:763

The Swedish Health and medical service act (in Swedish:"Hälso och sjukvårdslagen") regulates the responsibilities of county councils and municipalities. It states that the residents should be provided good-quality health and medical care with the goal to obtain good health for the whole population. It also stresses that health care should be given with respect for the individuals'

autonomy and dignity. So even though patients have no right to health care the responsible county council has a duty to provide patients with health care when there is a medical need.

2.5.4 The Patient Act (PA) SFS 2014:821

This fairly new law covers more in detail the patients' rights. The right to achieve information is the basis for being able to participate in the decision-making process. Every patient has the right to choose between different medically adequate alternative treatments. It could, for the palliative patient, be the right to choose between continuous or intermittent palliative sedation. Also there is a right to a second opinion on the initiative of the patient. The patient has the right to abstain from any treatment with the exception of acute psychiatric conditions covered by Compulsory Psychiatric Care Act (LPT).

2.5.5 The still missing item, SOU 2015:80

Swedish law currently does not give any rules for a surrogate person replacing the autonomy of a decision-incompetent person. The Governmental inquiry about "Support and Help to Adults in decision making in Health care, care and service and research" has been reported to the Ministry of Health and Social Affairs but there is still no legislation. It contains suggestions implying power for e.g. a relative to make surrogate decisions. However, with the exception for the surrogate to decide in matters of life and death [136].

2.5.6 Health care economics and fees

Almost all hospital care in Sweden is financed by taxes. The professionals, including all physicians, have fixed monthly salaries not depending on specific procedures. There is in fact no economic incitements for the physician to recommend any certain treatment alternative prior to some other. However, other ways could possibly put strain on the operational part of the health care system. Some units use activity points influencing budget which may reward advanced or prolonged treatment irrespective of the patient's best.

In Sweden, unlike in many other countries, there should be a limited risk that the economic issues allocated to hospital care blur the decision making at the End-Of-Life.

Patient fees for hospital care are modest at 100SEK a day irrespective of type of care or procedure. It would be fair to claim that no relative should see the Length of Stay (LOS) as an economic burden for the patient or the people around him. Economic considerations are probably of minor importance for the patient and the relatives. Financial considerations are probably of minor importance when dealing with EOL issues.

Category	Law, regulation or common advices	Consequence, comment
R	**MF 1973:26**	
	Proclamation about prognosis and treatment when there has arozen a situation of total and irreversible loss of all brain function	Regulates solely the situation "total brain infarction(TBI). If TBI the treatment may be discontinued
SOU	**SOU 1978:82**	
	"The Physician and the patient:" About the end of life.	
	An example from the report deals with a patient who has got stuck in ventilator traetment for a long time because of advanced and not treatable respiratory failure. He demands to be aloud to die by terminating the ventilator treatment. Conclusion was that this would be an unrealistic and illegal action.	Still there is no option to withhold/withdraw lifesustaining treament notwithstanding the fact that the prognosis is futile if the death is not imminent.
R	**SOSFS(M) 1982**	
	Proclamation about changes in MF1973:26 about prognosis and treatment when there there has arozen a situation of total and irreversible loss of all brain function	This document clarifies some moments of the examination routines for verifying the diagnosis of Total Brain Infarction
L	**SFS 1987:269** Law about criteria defining human death. It was legally valid from jan1 1988 and onwards.	Organ donation with maintained circulation possible. Make transplants of other organs than kidneys possible
	1. A human being is dead when all brain functions are irreversibly lost **2.** Physician should determine death according to scientific knowledge and accepted medicial standards **a.** death is declared if breathing and circulation have ceased for enough long time for the brain to completely and irreveribly lose its function **b.** If breathing and circulation are maintained by artificial means the death should be declared if the investigation of the brain shows that its function completely and irreveribly has been lost. **3**. After declaration of death medcial maesures may be continued for maximum 24 hours to make it possible to perform organ donation or to deliver a foetus with capacity to survive.	
A	**1992:2** General advices regarding life sustaining treatment near the end of life	It became finally possible to question futile treatment and in such situations withhold and withdraw treatment.
	The first document from swedish authorities to acknowledge that there are situations, apart from total brain infarction, where it would be medically and ethically appropriate to withhold and/or withdraw life sustaining treatment	
R	**SOSFS 2011:7** Life sustaining treatment. This regulation defines several mandatory procedures in association with decisions near the end of life	There are now well defined rules which, if followed, gives both patients and physicians confidence in well thought through procedures.
	1. A patient near the end of life should be provided with a firm contact of care who is responsible for defining and reevaluation of the care on a regular basis.	

Figure 2.6. Development of Laws and regulations in Sweden with special relevance to health care system. SOU=”Swedish Government Official Reports”; R=Regulations from the National board of Health and Welfare ; L=Swedish law; A=Advice from the National board of Health and Welfare

3. Aims of this thesis

From the tradition of Hippocrates physicians have developed virtues, ideals, values, attitudes, rules and strategies which define or influence the physicians' professional praxis. The values and attitudes being expressed by physicians in health-care praxis may not be in concordance with those of the patients which can result in conflicts of value and loyalty also among different medical specialties [137, 138, 139]. To reduce the risk of misunderstanding and disputes it is important to increase the physicians' knowledge of the patients' expectations and values. Likewise, it is of interest to understand how the general population reason about ethical issues in medicine [137, 138, 139].

There were, at the time for carrying out the actual studies, several publications about physicians, nurses and the general public's attitudes concerning withholding or withdrawing treatment to a terminally ill patient [137, 138, 139, 140, 141, 142] but few focusing on which arguments would be most relevant for the decisions made [142].

To shed light on the prioritization of different arguments we planned and realized two studies of physicians' and the general public's preferences and how they prioritized arguments regarding the treatment of a 72-year-old woman suffering from a large intra-cerebral bleeding with bad prognosis. Similarly another study was conducted regarding a newborn boy with postpartum anoxic brain damage. For details about the cases, *see appendices beginning at page 78*, and the applied methods *see chapter 4, page 47*.

The aim of this thesis is to investigate the arguments used to underpin the position taken by the different groups of physicians and the general public

Main research questions were

1. Which arguments are relevant and considered most important by physicians and the general public in the decision of surgery or not on an earlier healthy 72-year-old woman with intra-cerebral bleeding and bad prognosis?
2. Are there differences between physicians from different specialties (anaesthesiologists and neurosurgeons) regarding which arguments are considered the most important for or against withdrawing ventilator treatment?
3. When the treatment becomes even more obviously unsuccessful, which arguments are considered most important for or against withdrawing ventilator treatment?
4. How may a physician relieve a patient's discomfort after withdrawal of the ventilator treatment? Is it even acceptable to give sedatives and opioids in doses aimed to shorten the dying process?

5. Which arguments are relevant and considered most important by physicians and the general public in the decision of continuing or withdrawing the ventilator treatment to a severely brain-injured child?
6. Are there differences between Critical Care Physicians and Paediatricians in the arguments for continuing or withdrawing the ventilator treatment to a severely brain injured child?
7. Are there differences between the physicians and the general public in the arguments for continuing or withdrawing the ventilator treatment to a severely brain injured child?
8. How may a physician relieve a child's discomfort after withdrawal of the ventilator treatment? Is it even acceptable to give sedatives and opioids in doses aimed to shorten the child's dying process?
9. The vignette also contained questions regarding how trust in health care may be influenced by different standpoints in the surveys. How do the physicians' own estimations of future events influence the understanding of other people's values?

Part II:
The investigations

4. Materials and Methods

4.1 Surveys

Data in this thesis included two surveys (cross-sectional studies), each based on vignettes regarding: 1) an older patient suffering from a life-threatening disease and 2) a newborn baby also suffering from a life threatening condition. The first survey (paper I and II) was sent to a random sample of anaesthesiologists (n=298), neurosurgeons (n=112) and a random sample of the general public (n=989) in Västerbotten county, Sweden. The second survey (Paper III and IV) included random samples of anaesthesiologists/ICU-physicians (n=299) and paediatricians (n=329) as well as all neonatologists (n=112) plus a random representative sample of the general public (n=585) in Västerbotten county, Sweden. The physicians were randomly selected from the commercial database Cegedim/Stockholm including all physicians and their specialties in Sweden. The random sample of the general population was drawn by a company associated with the Swedish tax authorities. The questionnaires were sent by mail with prepaid return envelopes. Two reminders, including the questionnaires, were sent with two weeks intervals.

4.1.1 Survey 1: a 72-year-old woman with intra-cerebral haemorrhage

The first survey was conducted in the autumn of 2004 and was based on a vignette in which a previously healthy seventy-two year old woman had been stricken by a severe intra-cerebral hemorrhage. The vignette was presented in three different steps: In the first situation, A, pre-fixed arguments for and against surgery were presented. The response-options were 'agree entirely or mostly' or 'disagree mostly or entirely'. The responders were asked to prioritize between the arguments and to estimate which of the arguments they considered the most important. In the next step and situation, it was described that the patient had had neurosurgery but that after ten days of intensive care, the patient had further deteriorated. A CT of the brain showed widespread ischemia. After having been shown this information the responders were asked to evaluate arguments for and against withdrawal of the provided Life-Sustaining Treatment (LST). The response-options were similar to those in the first step. Here also the responders were asked to prioritize between the arguments. Finally, in the last step, the treatment was withdrawn and in this palliative situation the responders were asked whether or not to provide alleviating treatment

with opioids and sedatives. Should it be given with the foreseen but not intended effect of hastening death or could it be given even in higher doses with the intention to shorten the dying process? The response-options were similar to those in the first and second steps. The responders were asked to prioritize between the arguments. Sex, age, and for the doctors, length of professional experience were recorded as background variables. Finally we evaluated the responders' experiences of health care as a patient or as a relative.

For a full description of the development of the case and the pre-fixed response-options, *see appendix A on page 78*.

The present survey was used to examine three different issues:

1. Compare and examine whether Neurosurgeons' and Intensive Care Physicians' response patterns differed or not, answering the question of performing or withholding neurosurgery where there was no evidence based knowledge about surgical intervention in such a condition.
2. To investigate whether or not Intensive Care Physician were more concerned about Quality of Life (QOL)-issues than neurosurgeons. and if possible differences represented different assessments of facts or moral values.
3. To investigate to which extent consensus exists between doctors and the general public regarding interpretation of factual and value aspects in the described situation with a critically ill patient.

…

4.1.2 Survey 2: Newborn boy with severe brain injury from perinatal hypoxia

The second survey also contained a vignette, this one describing a newborn infant with a severe hypoxic brain damage and different questions in relation to the treatment. The questionnaire was mailed to a random sample of intensivists/anaesthesiologists (n=299), paediatricians/neonatologists (n=329) and the general public in The County of Västerbotten (n=585). The vignette was developed in two steps: In the initial scenario, the baby was resuscitated, but displayed no spontaneous breathing and had no normal reflexes and was provided with ventilator support. The attending nurse argued that further life-sustaining treatment would be futile while the physician and the parents claimed that the treatment should continue for an additional week to have Magnetic Resonance Imaging (MRI) of the brain performed in line with local guidelines. Pre-fixed response-options were provided to which the responders could assess as "A very strong argument, A rather strong argument, A rather weak argument, No argument at all". *Please see appendix B on page 80*

In the second scenario, one week later, no improvement could be seen in the neurological condition. Magnetic Resonance Imaging (MRI) showed massive brain damage and additionally pneumonia and septicaemia had set in. Because

of the severe neurological injury and therefore the anticipation of very low quality of life, if the baby survived, the decision was made to withhold antibiotics and other treatment against the acute situation and also to withdraw current Life-Sustaining Treatment. After withdrawing the ventilator treatment the child suffered from respiratory distress and developed seizures and the question was whether or not it would be acceptable to alleviate the symptoms with effective drugs with foreseeable but not intended additional effect of precipitating the death, or to give the drugs in doses with the additional intention of also hastening death. The term euthanasia was used, in both the first and second scenario. *See appendix A, starting on page 78*.

Pre-fixed arguments for and against the present action were presented in terms of "Agree completely or to a large extent", or "Disagree to a large extent or completely". The responders were also asked to prioritize the arguments which made it possible to dichotomize the groups for or against the actual action. Sex, age, and for the doctors, length of professional experience were recorded as background-variables. In this second survey we asked the responders what would happen with their own trust in health care if the actual physician provided the effective alleviating drugs with additional intention to shorten the death process. The response-options regarding what would happen to own trust were: "Trust would decrease", "Not influenced" and "Increase". *See appendix B starting on page 80*.

In paper III the main results of this study was presented, and furthermore, in paper IV the issue regarding what would happen with the physicians' own trust was further developed. It was assumed that if a physician's own trust would decrease it would be corresponding to a negative attitude towards intentionally hastening death with effective drugs, meaning that the participant found the action bad. Similarly, increasing one's trust in health care might reflect a positive attitude towards the action, meaning that it is something good. Those who stated that their trust would increase or decrease were classified as value-influenced, an indication that they had passions in one or the other directions. Those who stated that their trust in health care would not be influenced were classified as value-neutral. This proxy measure for studying personal values among physicians has been used in other studies [135, 143] and a compilation of such studies indicate that the more controversial (in terms of e.g. conscientious objection or against health care law) an issue is the more passionate the physicians becomes and, accordingly, the more value-influenced the participants. The proportion of physicians classified as value-neutral participants tend to decrease the more controversial and passionate the physicians become. The reason for using this proxy-measure is that one can assume that a large majority of Swedish physicians understand themselves as value-neutral, meaning that they keep their own personal values (religious or philosophical) to themselves [132].

The physicians were also asked what they estimated would happen with the general public's trust in health care. The response-option were similar

compared to answering what would happen to own trust allowing to compare response-options and calculate inter-rater-agreement as an indication of whether or not the estimation of the general public's trust was influenced by what the physicians stated would happen with their own trust. *See appendix B, part 2B on page 81*

4.1.3 Statistics

In both surveys the results were merely presented as proportions of those who had agreed to a large extent or completely (or supported an argument). In order to see whether there were differences, 95% confidence intervals for proportions were calculated. It was assumed that confidence intervals not overlapping each other represented significant differences similar to conducting a hypothesis test (e.g. Chi-2 test) and obtaining a p-value <0.05. In paper I a hypothesis was presented and in this study p-values were calculated using Chi-2 test. As significant level p-values<0.05 was chosen. When calculating association Odds Ratios were used with 95% confidence intervals. Lastly, in paper IV inter-rater agreement was calculated using Cohens Kappa test where <0.20 is considered as poor agreement, 0.21- 0.40 is considered as fair agreement, 0.41-0.60 as moderate, 0.6 - 0.80 as good and 0.81-1.00 as very good.

4.1.4 Research ethics

The empirical parts of this thesis are built upon cross-sectional surveys. Postal self-administered questionnaires were sent to different samples as described in the *chapter 4, section 4.1 on page 47*. It was anticipated that some recipients might be worried and feel uncomfortable reading the vignettes, especially perhaps if they had own recent or traumatic experiences from ICU care and EOL-situations. We assume that this might be a reason for dropping out (that is: not returning the questionnaire). The voluntariness of participating in the surveys were stressed in the introductory letters to potential participants. Participants were also welcomed to contact the researchers for questions and discussions, which happened in only few cases. These contacts rather point at persons with hard and difficult to bear experiences felt it a relief to speak out about their experiences. During the planning of the study we judged the potential benefits from carrying out the study outweighed the potential harms. Our experiences after having concluded the project point in same directions. The surveys were approved by the Regional research ethics committee at Umeå University: Dnr 2010-105-31M.

5. Results

5.1 Main results paper I and II

Demographics for responders of the first survey about the 72-year-old woman including response rate for the first, second and third sending out are outlined in *figure 5.1 on page 52*. Ninety-four percent of responding neurosurgeons were men compared to 69% of the responding ICU-physicians which reflects the sex distribution within these specialties. Sex distribution among the general population was 50/50 (randomized selection). There was no difference regarding age, sex distribution or experience as a patient between early and late responders. Age distributions were similar among the physicians and the general public.

Because of the similar response pattern in the two groups of physicians they were merged into one group and contrasted to the general public. A larger part of the general public responded not until the second or third reminder but response patterns were similar for early and late responders also among the general population. This might indicate that if we had sent out additional reminders this would not have changed the response pattern. More members of the general population group compared to the physicians' had their own experience of health care, negative and positive. *Figure 5.1 on page 52*

The internal drop out (incompletely answered survey) was low and varied between questions asked. The first (surgery or not) was answered by 84% of the physicians and 86% of the general public, the second (withdraw (WD) the ventilator or not) was answered by 89% of the physicians and 87% of the general public, and the third step (giving sedatives and analgesics) was answered by 93% and 87% respectively. A few responders marked two arguments as most important, and in these cases both arguments were identified as being most important.

5.1.1 Should Neurosurgery be performed or not?

Neurosurgeons and ICU-physicians

The neurosurgeons (84%) and ICU-physicians (78%) agreed that the present patient should forgo surgery. Both groups of doctors considered the quality-of-life aspect to be the most important argument although more neurosurgeons than ICU-physicians emphasized this argument ($p<0.001$). A minority within both groups of physicians considered the patient's wish not to end up in a Persistent Vegetative State (PVS) as the most important, significantly more ICU-physicians gave precedence for this argument ($p<0.001$). The cost-benefit aspect and the son's request to do anything to save his mother's life were given

	Neurosurgeons n=70/112 62,5%	ICU-physicians n=219/298 73,5%	All physicians n=289/420 68,8%	Public 501/989 50,7%	P-value
Age	46,7	46,0	46,1	47,0	NS
Sex (man/woman)	66/4	152/87	218/71	245/256	<0.001
Duration of career (years)(mean)	15,2	15,1	15,2		
First responders(%)	54,3	66,7	64,1	50,8	
Second responders(%)	25,7	18,7	20,6	24,6	
Third responders(%)	20,0	14,6	15,3	24,6	<0.001
Experience of Health care(%)					<0.001
As Patient					
Positive	51,5	54,9	55,0	50,9	
Negative	5,2	1,4	1,4	2	
Both positive & negative	19,4	26,5	24,8	38,8	
No experience	23,9	17,2	18,8	8,2	
As a relative					NS
Positive	47,0	41,3	42,6	46,8	
Negative	1,5	4,2	3,6	3,8	
Both positive & negative	40,9	46,5	45,2	39,5	
No experience	10,6	8,0	8,6	9,9	

Figure 5.1. Demographics for the first survey, A previously healthy 72-year-old woman with a severe intra-cerebral bleeding

the lowest priority by both groups of physicians. Likewise, few regarded the arguments age or withholding surgery as a form of euthanasia as important. *Figure 5.2 on page 52*.

	Neurosurgeons priority %. (CI)	ICU-physicians priority %. (CI)
Surgery should be performed because		
health care's first task is to save lives	10.7 (2.6-18.8)	7.6 (3.9-11.3)
the neurosurgeon refers to experience of a successful case 2 years ago.	1.8 (0.0-5.3)	13.7 (8.9-18.5)
otherwise it might be interpreted as euthanasia	1.8 (0.0-5.3)	1.0 (0.0-2.4)
the son has asked the doctor to do anything he/she can do to save his mother's life	1.8 (0.0-5.3)	0
Surgery should be avoided because		
as the patient's quality of life would be greatly reduced	76.7 (65.7-87.1)	54.0 (47.1-60.9)*
of the age of the patient	3.6 (0.0-8.5)	1.0 (0.0-2.4)
of the cost and the uncertain result	0	1.0 (0.0-2.4)
of the patient's wish not to end up in a persistent vegetative state (PVS)	3.6 (0.0-8.5)	21.7 (16.0-27.4)*

*Figure 5.2. Responses of neurosurgeons and ICU-physicians to the question of whether or not to perform neurosurgery on a 72-year-old patient with a large haemorrhage in the left part of the brain. The responders were exposed to four arguments for and four arguments against. The proportions of neurosurgeons and ICU physicians who found the arguments most important are presented with the 95% confidence intervals (CI). * $p<0.001$*

All physicians and the general public

Most members of the general public supported arguments in favor of performing the neurosurgery (59,8%) while a majority of the physicians supported arguments against surgery (82,3%). "The primary task of health care is to save lives" was the most prominent value-based argument by the general public for doing surgery along with the argument "The personal experience of a neurosurgeon". Among empirically based arguments the physicians stressed the "quality of life" issue for not doing surgery. Few in both groups considered age of the patient, cost-benefit arguments or the son's wish as important for the decisions about surgery or not. *Figure 5.3 on page 53*.

Surgery should be performed because				
health care's first task is to save lives	12.9 (9.0-16.8)	4,5	78.3 (74,7-81.9) *	29.8
the neurosurgeon refers to experience of a successful case 2 years ago.	25.0 (20.0-30.0)	11,1	80.8 (77.3-84.3) *	23.6
otherwise it might be interpreted as euthanasia	5.6 (2.9-8.3)	1,2	55.4 (51.0-59.8) *	2.5
the son has asked the doctor to do anything he/she can do to save his mother's life	8.7 (5.4-12.0)	0,5	58.9 (54.5-63.3)	0,5
Surgery should be avoided because				
as the patient's quality of life would be greatly reduced	82.8 (78.5-87.1)	61,5	40.6 (36.3-44.9) *	12.5
of the age of the patient	18.8 (14.3-23.3)	1,6	18.2 (14.8-21.6)	2.8
of the cost and the uncertain result	15.8 (11.6-20.0)	0,8	15.7 (12.5-18.9)	2.3
of the patient's wish not to end up in a persistent vegetative state (PVS)	71.6 (66.3-76.9)	18,4	54.5 (50.1-58.9) *	22.6

* = P<0.001

Figure 5.3. This table shows the response pattern of the doctors and members of the general public who answered the question regarding whether neurosurgery should be performed in a formerly healthy 72-year-old patient suffering from a major haemorrhage in the left central part of the brain. The results are presented as proportions of those who agreed 'mostly' or 'entirely', with a 95% confidence interval (CI). The percentages of those who considered the argument to be the most important are also presented.

5.1.2 Should Life Sustaining Treatment be discontinued?

Neurosurgeons and ICU-physicians

A majority, more than 90% in both groups, supported arguments for withdrawing the Mechanical Ventilation, the dominating argument was: "it only prolongs the dying process" (>70%) and second in accordance with the patients wish "not to end up in a PVS" (appr 20%). About 7% of the neurosurgeons

and 5% of the ICU-physicians supported the argument that withdrawal of Life-Sustaining Treatment should be regarded as a type of euthanasia. *Figure 5.4 on page 54*.

	Neurosurgeons Percent, CI	ICU-physicians Percent, CI
The ventilator treatment should be continued because		
as discontinuation may be percieved as a kind of euthanasia	7.0 (0.4-13.6)	5.0 (2.0-8.0)
as a son is strongly against discontinuing ventilator treatment, thus treatment should be continued	0	0.5 (0.0-1.5)
The ventilator treatment should be discontinued because		
continuation only prolongs the dying process	75.5 (64.3-86.7)	72.4 (66.2-78.6)
it is in accordance with the wishes of the patient	17.5 (7.6-27.4)	22.1 (16.6-27.6)

Figure 5.4. Responses of neurosurgeons and intensive care unit (ICU) physicians to the question of whether or not to withdraw life-sustaining treatment in a terminally ill patient after unsuccessful neurosurgery. The responders were exposed to two arguments for and two arguments against. The proportions of neurosurgeons and ICU physicians who found the arguments most important are presented with the 95% confidence intervals (CI)

All physicians and the general public

Both most of the physicians (94%) and the general public (78%) concluded that the most important arguments were the arguments against continued Life-Sustaining Treatment (LST). The mostly supported argument in both groups was “It only prolongs the dying process”. However, a significantly higher proportion of physicians supported this argument. The second most embraced argument against continuing LST was “Not to end up in a Persistent Vegetative State” which was supported by 21% of the physicians and 35% of the general public ($p<0.001$). A minority of both groups regarded the withdrawal of MV as possible euthanasia. A significantly greater proportion of the general public prioritized that argument, $p<0.001$. *Figure 5.5 on page 55*.

5.1.3 Should potent sedatives and analgesics be administered?

Neurosurgeons and ICU-physicians

A large majority of physicians in both groups (Neurosurgeons 88.1%, ICU-physicians 96.2%) supported the use of analgetics and tranquillizers even though they may hasten death. A small proportion of both groups stated that this treatment should be given but without any risk of hastening death. Only few sup-

	Doctors Percent, CI	Priority (%)	Public Percent, CI	Priority (%)
The ventilator treatment should be continued because				
as discontinuation may be percieved as a kind of euthanasia	6.3 (3.5-9.1)	5,5	28.3 (24.3-32.3)	14,9
as a son is strongly against discontinuing ventilator treatment, thus treatment should be continued	10.1 (6.6-13.6)	0,4	35.2 (31.0-39.4)	7,4
The ventilator treatment should be discontinued because				
continuation only prolongs the dying process	91.9 (88.9-94.9)	73	72.4 (78.1-84.9)	42,5
it is in accordance with the wishes of the patient	83.9 (79.6-88.2)	21,1	76.2 (72.4-80.0)	35,2

Figure 5.5. This table shows the response pattern of the doctors and members of the general public who answered the question regarding whether to continue ventilator treatment in a terminally ill patient after unsuccessful neurosurgical treatment. The results are presented as proportions of those who agreed 'mostly' or 'entirely', with a 95% confidence interval (CI). The percentages of those who considered the argument to be the most important are also presented.

	Neurosurgeons Percent, CI	ICU-physicians Percent, CI
Tranquillizers and morphine should be provided		
in order to keep the patient free of symptoms, although they may hasten death	88.1 (79.8-96.4)	96.2 (93.6-98.8)
in order to shorten the dying process	3.4 (0.0-8.0)	0
but without risking the aceleration of death	3.4 (0.0-8.0)	1.4 (0.0-3.4)
Tranquillizers and morphine should not be provided		
if the purpose is to hasten the dying process	5.1 (0.0-10.7)	2.4 (0.3-4.5)

Figure 5.6. Responses of neurosurgeons and intensive care unit (ICU) physicians to the question of whether or not to provide tranquillizers and morphine to a terminally ill patient. The responders were exposed to two arguments for and two arguments against. The proportions of neurosurgeons and ICU physicians who found the arguments most important are presented with the 95% confidence intervals (CI).

ported an additional intent to give drugs in doses aiming to shorten the dying process. *Figure 5.6 on page 55*.

All physicians and the general public

Most physicians and members of the general public agreed that potent sedatives and analgesics should be given in the situation described in the actual case. (doctors 95% , general public 82%). *Figure 5.7 on page 56*.

	Doctors Percent, CI	Priority (%)	Public Percent, CI	Priority (%)
Tranquillizers and morphine should be provided				
in order to keep the patient free of symptoms, although they may hasten death	97.6 (95.8-99.4)	94,4	95.9 (94.2-97.6)	76,2
in order to shorten the dying process	9.9 (6.4-13.4)	0,7	45.7 (41.3-50.1)	5,8
but without risking the aceleration of death	29.6 (24.3-34.9)	1,9	49.2 (44.8-53.6)	12,2
Tranquillizers and morphine should not be provided				
if the purpose is to hasten the dying process	72.7 (66.5-77.9)	3,0	52.0 (47.6-56.4)	5,8

Figure 5.7. This table shows the response pattern of the doctors and members of the general public who answered the question regarding whether to provide tranquillizers and morphine to a terminally ill patient disconnected from life-sustaining ventilator treatment. The results are presented as proportions of those who agreed 'mostly' or 'entirely', with a 95% confidence interval (CI). The percentages of those who considered the argument to be the most important are also presented

	General population	Physicians
Number	267	418
% answers	46	67
Sex (man/woman)	132/135	277/141
Percent	49.4 / 50.6	66.3 / 33.7
Age group (numbers)		
20-30 years	50	0
31-40 years	45	50
41-50 years	50	104
51-60 years	57	124
61-70 years	63	96
>70 years	0	36
General trust		
High	92,8%	94,2%
Low	7,2%	5,8%

Figure 5.8. Demographics for the second survey, the newborn boy

5.2 Main results paper III

Demographics for responders of the second survey about a newborn boy are outlined in *figure 5.8 on page 56*. Of the answering physicians there were 40 intensivists, 155 anaesthesiologists, 137 paediatricians and 87 neonatologists resulting in a response rate of 67%. There was no identifiable difference in response pattern between the different groups of physicians. They were there-

fore merged into one group for comparison with the general public. Sixty-six percent of responding physicians were men which reflected the sex distribution in the sample. Sex distribution among the general population was 50/50 (randomized selection). There was no difference regarding age, sex distribution or experience as a patient between early and late responders. The sex distribution differs between the groups because of the random sample of the general public (50/50). The physicians targeted were specialists or near specialists in their respective sphere of activity. Age distribution differs, possibly because few physicians have reached that level of competence before the age of 30.

No difference in response patterns was found between early and late responders neither among the physicians nor among the general public. Both groups had high trust in health care (>90%).

5.2.1 Continue or discontinue ventilator treatment

A larger portion of the general public (58%] compared to the physicians (52%) held arguments for withdrawing of the ventilator treatment as the most important. To avoid "Very much suffering" was the dominating argument in both groups followed by "Poor quality of life". The dominating arguments for continued ventilator treatment were "Parents' strong wish to continue" (physicians 20%, general public 25%) and "Physicians primary task is to protect and preserve life" (physicians 14%, general public 14%). *See figure 5.9 on page 58*. Among both physicians [OR 4.7(CI 3-7.3)] and the general public [OR 5.5(CI 3.1-9.6)] there was an inverse relation between the "Protecting life argument" and the "Quality-of-life argument". Moreover, we found an inverse relation between the "Protecting life argument" and the "Further suffering argument" for the physicians [OR 5.7(CI 3.4-9.5)] and the general public [OR 4.7(CI 2.3-9.7)].

The only difference to be found between the different groups of physicians was whether or not to regard the parents' wish to continue. A larger proportion of paediatricians and neonatologists [74% (CI 68-80)] than aneasthesiologists and intensivists [57%(CI 51- 65)] supported this argument ($p<0.001$). No difference was found between paediatricians and neonatologists or between anaesthologists and intensivists.

5.2.2 Providing treatment which might even hasten death

As described in the vignette, after withdrawing the Mechanical Ventilation the baby develops convulsions. To relieve possible suffering, anticonvulsant drugs are administered which can have the (foreseen) side-effect of hastening death. The majority of physicians and the general public (96% vs 99%) supported and (94% vs 80%) prioritized that such treatment should be provided even

	Doctors (n=418) Percent, CI	Priority (%)	**Public (n=257)** Percent, CI	Priority (%)
The ventilator treatment should be continued because				
Physicians' primary task is to protect and preserve life	39 (34-44)	13,5	51 (45-57)*	14,4
The parents' strongly wish to continue	67 (62-72)	19,9	66 (60-72)	25,4
Otherwise it might be understood as euthanasia	15 (12-18)	0,7	21 (16-26)*	1,5
Other reasons (a)	32 (27-37)	12,3	22 (17-27)*	2,3
	Sum (%)	46,4		43,6
The ventilator treatment should be withdrawn because				
If the baby survives, its quality of life will be very poor	69 (64-74)	16,4	62 (56-68)	15,2
Otherwise it would result in very much suffering for the baby	78 (74-82)	34,3	80 (75-85)	37,5
Otherwise it would give the parents false expectations	*24 (20-28)*	2,0	44 (38-50)*	3,4
Other reasons (b)	9(6-12)	1,0	8 (5-11)	0,4
	Sum (%)	53,7		56,5

Figure 5.9. The first column shows, with a 95% CI, the proportions of those who evaluated the provided arguments as strong and rather strong for and against continuing life-sustaining treatment of a severely ill newborn baby. In the second column the percentages of those who prioritized a specific reason are presented.
** = Comparison of the two groups shows that p-value would have been less than 0.05.*
(a) Other reasons for continuing the treatment provided by physicians were that the clinical examination should be continued according to routines (n = 34) and allow the parents time (n = 5) and that the parents' trust should not be jeopardised. One pointed out that treatment should benefit the child—not the parents or health care
(b) Other reasons for discontinuing the treatment were...

considering the foreseen but not intended side-effect. *See figure 5.10 on page 59*.

Regarding the additional intention of hastening death 70% (CI 64-76) of the general public supported and 17% prioritized that action, whereas 23% (CI 19-27) of the physicians supported and 3% prioritized this argument ($p<0.001$).

5.2.3 How trust is influenced

The responders were also asked about how their trust in health care would be influenced if physicians abstained from active treatment against convulsions with the unintended side-effect to hasten death. Among the general public 61% (CI 55-67) and among the physicians 81% (CI 77-85), $p<0.001$, judged that trust in health care would decrease.

	Doctors (n=418) Percent, CI	Priority (%)	Public (n=257) Percent, CI	Priority (%)
Provide effective treatment				
To make sure that the boy is not suffering, the doctor should offer effective treatment which might unintentionally hasten death	96 (94-98)	94,0	99 (98-100)*	80.2
To minimise suffering, the doctor should offer effective treatment with the additional intention of hastening death	23 (19-27)	3.4	70 (64-76)*	16.7
Other reasons (a)	13 (10-17)	0.7	11 (7-15)	1.1
Provide no treatment				
In order to avoid hastening death, the doctor should not offer such treatment, even though it is effective against convulsions	4 (2-6)	1,0	7 (4-10)	0.9
Such treatment should not be offered if the doctor also intends to hasten death	48 (43-53)	0.2	26 (21-31)*	1.1
Other reasons (b)	10 (7-13)	0.2	7(4-10)	0.8

Figure 5.10. In the first column we have presented, with a 95% CI, the proportions (CI) of those who agreed completely or to a large extent providing or not providing a treatment that might hasten death. In the second column we have presented the percentage of those who prioritized the support for a specific reason
** = Comparison of the two groups shows that p value would have been less than 0.05*
(a) Other reasons given for providing the treatment were
(b) Other reasons for not providing the treatment were…

5.2.4 The euthanasia issue

On the question what would happen to the responders' trust in health care if doctors in such situations used alleviating drugs in higher doses with the additional intention to hasten death significantly fewer of the general public, 29% (CI 23-35) compared to the physicians, 62% (CI 3-7.3) stated that their trust would decrease. *Figure 5.11 on page 60*.

We finally identified the responders who supported the arguments that the physician, in order to minimize the total suffering, should provide drugs with the additional intention to hasten death. Among them, rather few, 15% (CI 10-20) of the general public and 19% (CI 11-27) of the physicians thought that such an action would decrease trust in health care. In the two group of responders who were against acting with the additional intention to hasten death the majority considered that trust would be reduced [general public 62% (CI 51-73) and physicians 74% (69-79), p=0.06]. *Figure 5.11 on page 60*.

5.3 Main results paper IV

We analyzed the answers of what would happen to physicians' own trust and their estimation of the influence on the trust of the general public, if physicians would treat a dying patient with alleviating drugs in doses that also intentionally hastened death. A moderate inter-rater agreement (Weighted kappa

		Doctors (n=418) Percent, CI	Public (n=257) Percent, CI
a.	*My trust in healthcare would decrease if doctors in such cases used effective drugs in order to also intentionally hasten death (n = 75/259)*	62 (57-67)	29 (23-35)*
b.	*My trust in healthcare would decrease if doctors in such cases used effective drugs in order to also intentionally hasten death—among those who answered yes to euthanasia (n = 180/94)*	19 (11-27)	15 (10-20)
c.	*My trust in healthcare would decrease if doctors in such cases used effective drugs in order to also intentionally hasten death—among those who answered no euthanasia (n = 76/322)*	74 (69-79)	62 (51-73)*

Figure 5.11. Proportions of the responders whose trust would decrease if doctors used effective drugs in order to also intentionally hasten death among
(a) the two groups in general and among those who
(b) answered yes as to a euthanasia-like action and
(c) those who answered no to a euthanasia-like action. The results are presented as proportions with a 95% CI.
** Comparison of the two groups shows that p-value would have been less than 0.05*
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= 0,552) was found. *See figure 5.12 on page 61*. Those whose own trust would decrease, 58,7% (CI 52.6-64.8), estimated that the general publics' trust also would decrease. Among those whose own trust would be uninfluenced, 16.2% (CI 9.8-22.6) estimated that the general publics' trust would be uninfluenced. Among those physicians whose own trust would increase, 3% (CI 0-9.6) assessed that the general publics' trust would increase.

After subgrouping we have analyzed the responders' estimations of whether or not trust would be influenced in relation to the responders' own opinions in the matter of treating a dying patient's symptoms effectively with drugs that can hasten death and additionally administer drugs in doses with the intention to hasten death. A majority of those who were against this action, 84,2% (95% CI 31.6-51.6) regarded that the general publics' trust would decrease whereas those being pro the action estimated 41.6 % (95% CI 31.6-51.6) decrease in general publics trust in health care. The difference is significant. *See figure 5.13 on page 62*.

There were also differences in the estimation of own trust in relation to being pro or contra the action. *See figure 5.14 on page 62*. Of those being pro the action 19.2% (95% CI 11.2 -27.2) thought that their trust would decrease while the corresponding proportion of those being against the action was 73.6% (95% CI 68.8-78.4). A comparison between those whose own trust would either decrease or increase and relating that to being pro or contra the action resulted in OR 79 (95% CI 24.5-252.5).

		Physicians´ estimations of the general populations' trust		
		Decrease (%)	Not influenced (%)	Increase (%)
Physicians´own trust would	Decrease (n=250)	58,7	3,0	0,5
	Not influenced (n=126)	14,2	16,2	1,0
	Increase (n=26)	1,7	1,7	3,0

Figure 5.12. Displays answers to the question 'what would happen to your trust in health care if physicians provided effective drugs against convulsions to an imminently dying patient with the additional intention of hastening death?'

The physicians were also asked what they estimated would happen to the general population's trust. The strength of the inter-rater agreement is considered as moderate (Weighted Kappa-value = 0.552). The table also illustrates that the asymmetry is due to the 14.2% of the physicians whose own trust would not be influenced and who estimated that the general publics' trust would decrease

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A majority, 55% (95% CI 49-61) of the general public stated that their trust in health care would be unaffected, 29% (95% CI 23-35) that it would decrease and 16% (95% CI 12-20) that it would increase if physicians had double intentions when using treatment that may hasten death. Among those against (n=76) such actions 62% (95% CI 51-73) thought that their trust would decrease, 34% (95% CI23-45) that it would be uninfluenced and 4% (95% CI 0-8) that it would increase. Of those positive (n=180) to double intentions, 63% (95% CI 56-70) stated that their trust would not be influenced, 22% (95% CI 16-28) that it would increase and 15% (95% CI 10-20) that it would decrease.

	Physicians´ estimations of the trust of the general population		
	Decrease (%)	Not influenced (%)	Increase (%)
Pro the action (n=89)	41,6	43,8	14,6
Contra the action (n=311)	84,2	14,2	1,6

Figure 5.13. The response-pattern of those being pro or contra actions with double-intentions regarding the physicians' estimations of "what would happen to the general publics' trust in health care if physicians provided effective drugs against convulsions to an imminently dying patient with the additional intention of hastening death?"

The difference in response-pattern was significant (Chi2 = 72.2, df = 2 and p<0.001)

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	Physicians´ own trust would		
	Decrease (%)	Not influenced (%)	Increase (%)
Pro the action (n=94)	19,2	55,3	25,5
Contra the action (n=322)	73,6	25,2	1,2

Figure 5.14. The response-pattern of those being pro and contra actions with double intentions regarding 'what would happen to your trust in health care if physicians provided effective drugs against convulsions to an imminently dying patient with the additional intention of hastening death?'

The difference in response-pattern was significant (Chi2 = 119.7, df = 2 and p<0.001)

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Part III:
Discussion, conclusions, acknowledgements appendices, Swedish summary

6. General discussion

The discussion about the balance between useful and useless/harmful treatment has with increasing intensity been present since around 1960. Different attempts have been done to create sustainable criteria, national and international recommendations to manage the situations of futile treatment near the end of life. A couple of scoring systems, APACHE, SAPS, SOFA, ProVent all have good validity to predict mortality in intensive care on the group level. In case of very high Organ Failure (SOFA) and ProVent scores mortality can be predicted even on the individual level[50, 49, 144] Nevertheless, there is an abundance of reports on continued advanced life-sustaining treatment deemed clearly medically futile by the attending physicians [58, 64, 70, 145, 146]. To be able to withhold or withdraw treatment which is no longer appropriate or even harmful and burdensome to the patient, other processes than strict medical (or physiological) assessments obviously are necessary. The concept of "Non-beneficial treatments in hospital at the end of life" is yet another and maybe better, less provocative and more patient-centered description of meaningless treatment [70].

In general, physicians are trusted for their professional judgments in medical situations [97, 112, 147]. But physicians are not seen to be entitled to make unilateral decisions. Reports from different countries point at preferences for the process of refraining from life-sustaining treatment as an open process where the patient, or more often in intensive care, the closely related persons, must be fully informed and invited to participate [75, 105, 106, 148, 149, 150, 151, 152].

Obstacles to communication

One may ask what factors are obstacles to good communication and collaboration with relatives and other surrogates in end of life situations. Legislation and "soft rules" may contribute to a climate of communication. In the US as well as in many other countries there is a tradition connected to an interpretation of the principle of autonomy that gives surrogates the power to decide even in situations where the professionals have come to an opposite judgment. There are also examples of lawsuits, however few [153], that give the patient (or the surrogate) a lot of power to decide whether to withhold or withdraw treatment [154].

In Sweden and in several other European countries there is no or a much weaker legislation about surrogates compared to the situation in the US. *See 2.5.5 on page 41.* In the Swedish situation, formally, the physician holds the

full medical responsibility hence she/he is the only person entitled to make a decision of e.g. withdrawing treatment. However, guidelines recommend communication and a consultation process with patients and relatives, but the decision stays with the doctor in charge. This might mean advantages as well as disadvantages. Relatives are spared the potential burden of guilt to have decided about "life and death" for their beloved ones. The physicians' own values, rather than an objective medical re-evaluation of the situation, might contribute to the decision in an unintended way. Also perceived risks for being accused for medical misconduct might influence doctors' decisions in a direction of continuing non-beneficial treatment.

Treatment of no use for the patient

The problem that treatment continues, although useless for the patient, is still present in Sweden as well as in other countries. Communication and a formalized consultation process with patients and relatives/surrogates might mean a way to alleviate this problem to some degree. Of course, physicians must be trained to be skilled in communication in EOL–situations. Obviously, this training must not be restricted to technical communicative skills, as a number of important value-based issues must be covered. Some examples of these kind of questions and issues important to discuss and reflect upon are mentioned here:

- Is it a failure not to have saved a patient although he/she was too ill or too injured to be saved already from the beginning? What is the root of the doctor's feelings of shame, sometimes obvious in these situations?
- Why do doctors sometimes conceal the honest information by not being available for communication with patients/relatives, or by using euphemisms or speaking in riddles? Is it because the physician presumes anger or opposition to her/his planning of the treatment?
- Does the ongoing development of sub- and super-specialists in medicine where "single organ doctors" are created mean that the holistic perspective is lost? Does this mean that physicians tend to embrace such a concept of successful treatment of one organ at a time (rather than the person) [69].
- The ethical reasoning regarding end-of-life treatment has progressed during the last decades, but has the fear for juridical litigation increased during that same period? No important changes in the legislation have taken place in Sweden in the last years. In the general Swedish debate, however an increasing criticism of the health care system can be noted. The critics deals with a variety of topics, e.g. limitations of the accessibility to health care, but also about concerns for the quality of care.
- The field of medical knowledge and technology is rapidly growing. Do doctors fear not to give the most optimal and up to date treatment to every patient, and are they afraid of criticism for not doing so?
- To decide and also execute decisions of withdrawal of Life-Sustaining-Treatment are tasks for the Intensive Care Physician. These decisions might mean that

the physician also decides about the time of death. Is this emotionally sometimes too demanding a task for the ICU doctor?
- Are arguments emphasizing "sanctity of life" still important in the decision-making about WH and WD? – If this is the case the reflections and discussions during training ought to contain dimensions of existential questions, conception of life.
- Are differences between representatives of different medical disciplines regarding their views on "Non-beneficial treatments in hospital at the end-of-life" sometimes a hindrance to act? In that case a multidisciplinary approach when training physicians might be helpful. The discussions must preferably not be restricted to physicians only – the participation of nurses and other staff categories has shown to be valuable [155]. *Please, see 6.3 on page 68* regarding different views of neurosurgeons and ICU-physicians.
- Is the delineation between the definitions of euthanasia and withdrawal of non-beneficial treatment a problem? In that case this also must be in focus, *please see 6.2 on page 68* for a short discussion of this topic.
- Are there risks for a slippery slope in the sense that practicing withholding or withdrawing of non-beneficial treatments might develop towards situations where patients are held back from being offered adequate treatments from reasons connected to e.g. scarce resources [85, 156]? *Please see 6.1 on page 67* for a discussion on distributive justice!

6.1 Distributive justice

It is a fact that the health care in high income countries gives a lot of inappropriate treatment. The problems exists at different levels: Over-treatment might in the end result in harming the patient, and should be avoided to avoid maleficence. But there are also arguments connected to distributive justice – to avoid to waste scarce resources (human as well as financial resources). In technically advanced fields of medicine such as ICU environments there is almost no possibilities to expand the number of beds in the short term. The consequences of prolonged non-beneficial treatment of certain patients are that other patients, with a fair chance of recovery if treated at an ICU, will be refused and suffer the risks of dying or having life-threatening complications [157, 85]. The process of withdrawing medically futile Life-Sustaining Treatment must be done controlled, respectfully and in a transparent way. It can not await the acute situation when the next patient knocks at the door. Re-evaluation of treatment at the ICU ought to be done on a regular basis. There is always an indication to start treatment, and if this indication is no longer present, the treatment should be stopped within a reasonable timeframe.

The Swedish priority rules do not allow prioritizing between different patients or patient groups. However, widely accepted ethics reasoning for Life-Sustaining Treatment situations and situations with Medical Futile treatment

thrive to avoid treatment for which there is no meaning and thereby no need [26, 27]. The risk not to be admitted to the ICU could be less if the reevaluation of treatment occurred on a more regular basis than present [85, 158].

6.2 Euthanasia – physician assisted suicide

ICU patients most often cannot communicate. Physician Assisted Suicide (PAS) can only be practiced in relation to a patient who can exert his/her autonomy – a decision-competent person. The concept of PAS is in that sense not applicable to most near the End-Of-Life situations in the ICU. The debate whether PAS should or should not be allowed is almost irrelevant to the issue on avoiding "Non-beneficial treatments in hospital at the end of life". To intentionally hasten death, even if this intention is combined with an ambition to alleviate pain and discomfort for the patient, must be seen as acting against the Penal Code and as morally problematic. This issue is however not unproblematic: – What if the doctor is hesitant to give the treatment really needed due to the fear of being litigated? The consequences could be improper palliative care.

6.3 Neurosurgeons and ICU-physicians

Our pre-assumption was that neurosurgeons would be more inclined to surgery than ICU-physicians, which showed not to be the case. The most chosen argument by the neurosurgeons for withholding surgery "Quality of life would be greatly reduced" has support in the first randomized study of surgical intervention of intracerebral hematoma, the "STICH study" published after the survey was performed [159]. The, until then, unsystematic experience not to operate on large intracerebral hematomas because of bad results seemed to be correct. The ICU-physicians regarded the patient's earlier wish, an autonomy argument, as the most important for withholding surgery. The described patient's condition deteriorates when the case evolves, thereby neutralizing the differences between the groups of doctors.

6.4 Methodological considerations

Response rate is always a pertinent matter when it comes to surveys. The response rate for the doctors were in both surveys similar to or higher than in other studies (70% and 66% respectively) [160, 161], whereas it was lower for the general public (51% and 46% respectively) which is in level with other studies [134]. The vignettes and the questions may have been complicated and technical for the general public despite normal Swedish language and ambitious explanation of facts. Some of the questions may even have been upsetting

for a non-professional. However there were no differences in response pattern between sex, age, or those who answered early and late and no demographical differences between those who answered and those who did not. Neither were there differences in experience of health care (Survey 1) or general trust in health care (Survey 2).

Vignettes

Vignette-based surveys have their strengths in the fact that certain situations can be described in detail and thereby clearly defined, and limited issues can be analysed [162]. The vignette-based survey can reach a large group with prefixed questions whereas the interview can give details from a few. The more clearly defined the description is, the higher the validity.

The vignette is not the real-life [162]. However, there are examples to validate vignette-based survey against documented real-life. Rousseau et al documented a series of Post Partum Bleedings and exposed the doctors anonymously for their own cases as vignettes. They found a fair to good inter-rater agreement and concluded that vignettes can reflect actual practices in emergency and are useful to assess quality of management in such situations [163].

6.5 Future perspectives

The question of withholding or withdrawing futile treatment has to be considered regularly, and has to be included in every day clinical practice. As an illustration of this statement , the Swedish Intensive Care Registry (SIR) has in its quality assurance points included that treatment strategy (level of care) should be defined and documented within 24 hours after admittance to an ICU, and thereafter reconsidered daily.

7. Conclusions

Conclusions with numbering corresponding to "Aims" on page 43

1. A majority of the doctors consider withholding surgery for an earlier healthy 72 years old woman with intra-cerebral bleeding and bad prognosis with the prioritized argument that the Quality of Life would be greatly reduced, and second argument that the patient's wish not to end up in a Persistent Vegetative State. A majority of the general public want surgery with the dominating arguments that "First task is to save lives" and that there is an "example of a similar case which was successfully operated".
2. The only difference found between anaesthesiologists' and neurosurgeons' arguments for or against withdrawing ventilator treatment was the former's focus on "patient's wish not to end up in a Persistent Vegetative State" and the latter's focus on "the Quality of Life-question"
3. When the treatment becomes even more unsuccessful, a majority of both doctors and the general public regard that ventilator treatment should be withdrawn, but 15% of the general public prioritize continuing because of regarding withdrawing as euthanasia.
4. Alleviating medication after withdrawal of the ventilator treatment should be given in order to keep the patient free from symptoms even if it may hasten death. There is a small (6%) part of the general public tolerating medication with the additional intent to shorten the dying process but almost no doctors supported this argument.
5. The majority of both physicians and the general public regard that the Ventilator treatment should be withdrawn to a severely brain injured child with the dominating argument "otherwise very much suffering" followed by the "poor quality of life" argument. Of those who would continue the ventilator treatment the "Parents' strong wish to continue" and "Primary task to protect and preserve life" were the most prioritized arguments.
6. The paediatricians and neonatologists are significantly more inclined to meet the parents' wish to continue the ventilator treatment than anaesthesiologists and intensive care physicians.
7. A larger proportion of the general public than of the doctors considered that the ventilator treatment should be continued because of "Primary task to protect and preserve life" and "It might be understood as euthanasia". Of those in the general public who preferred withdrawing the ventilator therapy

a larger proportion supported the argument of "Otherwise it would give the parents false expectations".

8. The large majority of both groups support that the doctor should offer effective treatment to relieve discomfort after withdrawal of the ventilator treatment even if it might unintentionally hasten death. A significantly larger proportion of the general public supports the additional intent to shorten the dying process.
9. The physicians' estimations of the general publics' trust in health care is clearly influenced by their own trust related to the action with double intentions. The concept used to describe this is value-impregnation.

7.1 Main conclusions

I. Physicians of different specialties have similar main values about non-beneficial treatment.
II. The general public have trust in the physicians professional skill and ability to make adequate medical judgments, including judgements near the End-Of-Life.
III. A common opinion, among health care professionals, that those closely related and surrogates want "everything to be done" irrespective of meaninglessness, is not true.
IV. In order to avoid unnecessary dispute and miscommunication, it is important that health care providers are aware of the public's views, expectations, and preferences.
V. Applying more systematic evaluation of treatment effects and patient prognosis and also taking the consequences of the result could lead to less suffering for the hopelessly ill patient, less work load on the intensive care units and thereby increased availability for the patients who really could take benefit of the ICU-care.

8. Acknowledgements

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9. Populärvetenskaplig sammanfattning på svenska

Syfte och mål

1. Att undersöka vilka argument som överväger för och emot att avstå/avbryta behandling inom vuxenintensivvård och nyföddhetsintensivvård där patientens prognos är mycket dålig.
2. Att undersöka eventuella skillnader mellan läkargrupper, narkosläkare/IVA-läkare, barnläkare/specialister i nyföddhetsvård och neurokirurger.
3. Undersöka huruvida det föreligger skillnader i värderingar och bedömningar mellan läkare och befolkning

Områdesöversikt

Inom intensivvård i Sverige på 1970-talet fanns inga rutiner för att undvika en förlängd vård hos intensivvårdspatienter, som man sannolikt förstod, var utom all räddning. Patienter som vi idag bedömer ha misstänkt total hjärninfarkt (TH) och där det idag görs diagnostik av död utifrån hjärnrelaterade kriterier blev föremål för hjärtlungräddning när de, på grund av sina utslagna autonoma funktioner, fick cirkulationssvikt och hjärtstillestånd.

Från 1980-talet har diskussionerna fortsatt om hur man ska kunna avväga terapin för att undvika överbehandling med samtidigt vidmakthållande av adekvat behandling. Ett flertal ansatser har gjorts för att med hjälp av scoringsystem (skattningssystem) välja – välja bort patienter för uppstart av intensivvård respektive finna kriterier för att avstå eller avbryta livsuppehållande terapi. APACHE II, APACHE III, med flera undersökningar har, trots goda förutsägelser, inte kunnat visa vägen för strategin vad gäller avstående eller avslutande av meningslös behandling.

Hur befolkningen och olika professionella i vården ser på beslutsprocessen har undersökts av bland annat Sjökvist [141] som funnit att det finns skilda uppfattningar mellan allmänhetens önskan att vara delaktig i beslut om att avbryta intensivvårdsbehandling och läkarnas uppfattning att sjukvården bör fatta beslut. Kan det vara så att otillräcklig information ger detta resultat? Andra studier talar för att en stor del av sådana beslut fattas utan fullständig och öppen information. Varför? Är det skam eller vanmakt doktorn känner för att han/hon inte kunnat rädda patienten? Löfmark [122] har i studier av mycket svårt sjuka medicinpatienter undersökt attityderna till information om beslut om att avstå från hjärt-lungräddning och funnit att patienterna upplevt det mycket positivt att få fullständigt ärlig information även om budskapet är plågsamt.

Projektbeskrivning

Det finns en del studier av doktorers, sjuksköterskors och allmänhetens attityder till att avstå från att behandla en svårt och terminalt sjuk patient, men det finns få studier där man fokuserat på vilka argument som är relevanta och viktigast då beslut ska fattas. Vi har mot den bakgrunden genomfört en enkätbaserad studie av neurokirurgers, narkos- och intensivvårdsläkares och befolkningens val av argument för och emot att göra ett neurokirurgiskt ingrepp på en 72 årig patient med en stor hjärnblödning och där prognosen var oviss (delstudie I och II).

Vi har också genomfört en likaledes enkätbaserad undersökning vad gäller narkos- och intensivvårdsläkares, barnläkares/specialister i nyföddhetsvårds argument för och emot att avbryta behandlingen hos ett nyfött barn med mycket omfattande hjärnskada på grund av syrebrist vid förlossningen. Vidare har vi studerat argument för och emot, att vid avbrytande av den livsuppehållande behandlingen, ge tillräcklig lindrande behandling med morfin och lugnande medel samt huruvida det är acceptabelt att ge morfin och lugnande medel i sådan dos att döendet påskyndas (delstudie III och IV).

Resultat, första enkäten

Från den första enkäten, som jämförde neurokirurgers, narkos- och intensivvårdsläkares och allmänhetens argument för och emot aktiv behandling (operation) av en äldre kvinna med mycket stor hjärnblödning och dåligt kliniskt tillstånd fann vi att: Neurokirurger och narkos- och intensivvårdsläkare prioriterade starkast argumentet ”livskvalitet” medan narkos- och intensivvårdsläkare även framhöll betydelsen av patientens tidigare viljeyttringar. Vid jämförelse mellan läkare och allmänheten fanns stora skillnader vid ställningstagandet till operation. Läkare bedömde att avstå i 82% mot befolkningen 40%. När fallet utvecklades till allt mera hopplöst sjuk patient blev bedömningarna alltmera eniga men med olika prioriterade argument.

Resultat, andra enkäten

Den andra enkäten rörde ett svårt hjärnskadat nyfött barn. Vi undersökte argument för ställningstagande för eller emot fortsatt respiratorbehandling, huruvida det är accetabelt att ge lugnande och smärtstillande medel i tillräcklig dos för att lindra respektive ge en dos som också syftar till att påskynda döendet. Majoriteten av såväl läkare som allmänhet stödde argument för att avbryta behandlingen. En stor majoritet stödde också argument för att lindra/ta bort symtom även om detta skulle påskynda döendet. När intensionen också är att påskynda det oundvikliga dödsfallet visar sig allmänheten betydligt mera benägen att acceptera ett sådant handlande än doktorerna.

I den enkäten undersöktes också hur läkares bedömning av andras värderingar blir påverkad av den egna uppfattningen, här kallat värdeimpregnering. Detta ingick sedan när vi studerade argumenten för eller emot frågan

om dubbla intentioner, det vill säga att enbart lindra eller att också avsiktligt påskynda döendet. Vi fann en stor skillnad i bedömningen av allmänhetens förtroende för sjukvården beroende på om läkaren var för eller emot dubbla intentioner. Vi kunde bekräfta tidigare undersökningsfynd att läkares bedömning/uppskattning av andras värderingar påverkas av läkarens egna värderingar.

Slutsats

Mina data visar att det är stora skillnader mellan hur läkare och allmänhet värderar och ser på situationen med en svårt sjuk patient på IVA. Med ökande svårighetsgrad av sjukdomen tenderar läkares och allmänhetens syn på vårdens inriktning att sammanfalla, dock ibland baserat på olika argument. För att undvika missförstånd och kommunikationsproblem är det viktigt att vårdgivare beaktar och har kännedom om anhörigas uppfattning, förväntningar och prioriteringar och upprätthåller en miljö där information är ärlig och ändamålsenlig och kommunikationen öppen.

Appendices

A. A 72-years-old woman with a severe intracerebral haemorrhage

Situation A

A previously healthy 72-year-old woman is brought to the emergency room in a deep coma for what is believed to be a stroke with a right-sided hemiplegia. In order to conduct a CT scan and to secure respiratory function, it is necessary to intubate and mechanically ventilate the patient. The CT scan shows a large haemorrhage in the left central part of the brain. A surgical evacuation in this delicate area is considered undesirable. However, without neurosurgery, intracranial pressure will probably increase, and a herniation of the brain will occur. Accordingly, without treatment, the patient is presumed fated to die within a few days.

In favour of surgery

- Surgery should be performed because it is the first task of health care to safe lives.
- A neurosurgeon refers to experience from a successful case 2 years ago; thus, the surgery should be performed.
- Surgery should be performed because otherwise it might be interpreted as a kind of euthanasia.
- Surgery should be performed because a son has asked the doctor to do everything to save his mother's life.

Against surgery

- Surgery should be avoided because the patient's quality of life would be greatly reduced.
- Surgery should be avoided because of the age of the patient.
- Surgery should be avoided because of the cost and uncertain result.
- Surgery should be avoided because of the patient's wish not to end up in a persistent vegetative state (PVS).

Situation B

Neurosurgery has been performed and the patient is transferred to the intensive care unit. After 2 days the patient is still on the ventilator, no improvement has been observed and the patient is still deeply unconscious. After 10 days a new CT scan is conducted, which indicates that a large area of the brain is incarcerated. The patient is no longer able to breathe without a ventilator, and the physicians discuss whether to continue the treatment.

In favour of continuation of ventilation

- Ventilator treatment should be continued because discontinuing it might be perceived as a kind of euthanasia.
- The patient's son is strongly against discontinuing ventilator treatment, thus, treatment should be continued.

Against continuation of ventilation

- The treatment should be discontinued because it only prolongs the dying process.
- The treatment should be discontinued because it is in accordance with the wishes of the patient.

Situation C

The physicians have now decided to withdraw ventilator treatment and inform the relatives. After 12 hours of breathing unaided, the patient develops convulsions and forced breathing. The condition looks painful and stressful. In order to alleviate the patient's symptoms, morphine and tranquillizers may be provided. However, these drugs might also affect the respiratory centre in the brain and accordingly hasten death.

In favour of morphine and tranquillizers

- Tranquillizers and morphine should be provided in order to keep the patient free from symptoms even though they might hasten death.
- Tranquillizers and morphine should be provided in order to shorten the dying process.

Against morphine and tranquillizers

- Tranquillizers and morphine should be provided but without risking acceleration of death.
- Tranquillizers and morphine should not be provided if the purpose is to hasten the dying process.

B. Newborn boy with severe hypoxic brainingjury

Part 1

In the present case, we described a 29 years old first time pregnant woman who delivered a boy with a birth weight of 3,500 g who suffered severe oxygen deprivation at the delivery. The baby was not breathing spontaneously, and immediately received ventilator treatment, cooling and additional intensive care. After 2 days of ventilator treatment, the baby is still not able to breathe spontaneously and lacks normal reflexes. The electrical activity of the brain is minimal. The boy might eventually be able to survive without a ventilator but, if so, he would most likely suffer from severe disabilities with widespread paralysis and severe mental retardation. Discontinuation of ventilator treatment at this moment would bring about the death of the baby.

An experienced nurse maintains that continuation of the intensive care is futile, as it would only prolong suffering. The treating physician suggests, as do the parents, that the intensive care should continue for an additional week in order to have a brain MRI performed, in accordance with local guidelines.

Based on this information, the participants are asked to consider the subsequent arguments and to mark which of the response-options best reflects the responders' view:

1. The ventilator treatment should be continued because physicians' primary task is to protect and preserve life:
   A very strong argument, A rather strong argument, A rather weak argument, No argument at all
2. The ventilator treatment should be continued because the parents' strongly wish this to continue:
   A very strong argument, A rather strong argument, A rather weak argument, No argument at all
3. The ventilator treatment should be continued because the opposite might be construed as euthanasia:
   A very strong argument, A rather strong argument, A rather weak argument, No argument at all
4. Other reasons for continuing the ventilator treatment:
5. The ventilator treatment should be withdrawn because if the baby survives, its quality of life will be very poor:
   A very strong argument, A rather strong argument, A rather weak argument, No argument at all

6. The ventilator treatment should be withdrawn because the opposite would result in very much suffering for the baby:
   A very strong argument, A rather strong argument, A rather weak argument, No argument at all
7. The ventilator treatment should be withdrawn because the opposite would give the parents false expectations: *A very strong argument, A rather strong argument, A rather weak argument, No argument at all*
8. Other reasons for withdrawing the ventilator treatment
9. The responders are now asked to prioritize between the stated arguments and to select only one point

Part 2

Additional information about the case is now added: The MRI showed severe and widespread brain damage. The following day, the child also develops pneumonia and blood infection. It is determined that without antibiotics and ventilator treatment, the child would die. After having discussed the situation with the parents, a decision is made to withhold antibiotics and also to withdraw the ventilator treatment.

Accordingly the ventilator is withdrawn. To a certain degree, the child is able to breathe, but slowly, superficially and forced. Shortly after, the child develops generalized seizures. Even though there is only a small risk that the child is suffering, it is difficult for the relatives and the staff to watch the seizures. Accordingly, the treating physician promptly administers an antiepileptic drug. The drug is provided in a normal dose but might nevertheless affect the respiratory centre and consequently hasten the death process. Shortly after, the child dies, probably considerably earlier than if the drug had not been provided.

Based on this information, the participants are asked to consider the subsequent statements and mark which of the response options best reflect the respondents' opinion:

10. In order to be quite sure that the child does not suffer, the physician ought to provide the drug in question even though the death process may be unintentionally hastened:
    Agree completely, Agree to a large extent, Disagree to a large extent, Disagree completely
11. In order to minimize the child's total suffering, the physician ought to provide the drug in question with the intention of thereby hastening the death process:
    Agree completely, Agree to a large extent, Disagree to a large extent, Disagree completely
12. Other reasons to provide the drug in the present situation.
13. In order not to hasten the death process, the physician ought not to administer the drug in question, even though this will mean that the

seizures will not be treated promptly:
Agree completely, Agree to a large extent, Disagree to a large extent, Disagree completely

14. The physician ought not to administer the drug in question if there is an intent to hasten the death process:
Agree completely, Agree to a large extent, Disagree to a large extent, Disagree completely
15. Other reasons not to provide the drug in the present situation.
16. Afterwards the responders are asked to prioritize among the provided statements and select only one.

Finally the participants are asked to state:

17. What would happen to your own trust in the healthcare system if physicians in this kind of situation abstained from providing effective drugs that unintentionally would hasten death. *Trust would decrease, Trust would increase, Trust would not be affected*
18. What would happen to your own trust in the healthcare system if physicians in this kind of situation provided effective drugs with the intention also being to hasten the death process: *Trust would decrease, Trust would increase, Trust would not be affected*

Physicians (not the general population) were also asked to assess what they think would happen to the general populations' trust in the two sets of circumstances described and with the same response options. At the end of the questionnaire we asked about age and sex and the participants' general trust in the healthcare system: *Very high, rather high, rather low and very low.*
Physicians were asked to specify their specialties.

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